

University of Southampton
Faculty of Health Sciences

**Children and Young People's Experience of Source and Protective
Isolation While in Hospital**

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Submitted for the Degree of Doctor of Philosophy

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Abstract

Single room isolation is an essential part of transmission-based precautions for the purpose of infection prevention. Literature demonstrates that adults subjected to isolation precautions can experience loneliness, depression, feelings of stigma and confinement. The paediatric literature regarding the experience of isolation focuses on the parental perspective, or children with specific conditions, thereby having limited transferability to the general paediatric ward.

This study explored the experiences of children and young people in single room isolation whilst in hospital. Social constructivism was the underpinning philosophy, using a narrative inquiry method. Within this thesis the experiences of children in isolation were explored from the perspectives of the child (n=8), parents (n=11) and staff (n=21), recruiting participants from wards in a children's hospital in the UK. Data were collected between 2011 and 2015 using retrospective interviews and video diaries. This timeframe allowed for adaptation of data collection methods in response to slow recruitment of children to the study.

The data were analysed using narrative analysis, with findings contributing important insights into the child's experience of isolation whilst in hospital. Three themes were identified: control, community and coping. Control refers to the child's feelings of control in relation to their illness and the environment of the isolation room, both of which varied according to familiarity with the ward and with being hospitalised. The theme of community encompasses the times when in isolation the child wanted social interaction or time away from the community of the hospital ward, and also the social contact of their family and peers outside of the hospital for distraction and alleviation of boredom. Coping denotes the ways in which the children understood their need for isolation and how they managed their time in isolation through distraction, parental presence and control of the space in the isolation room. This research makes a unique contribution to the field, in relation to the topic of the child's experience of isolation, and also through the incidental findings regarding data collection methods in research studied with children within hospital. Although this study cannot give one structured approach to providing care for children in isolation, it encourages practitioners to consider the children's narratives from this study within their own clinical setting and individualise care according to their needs.

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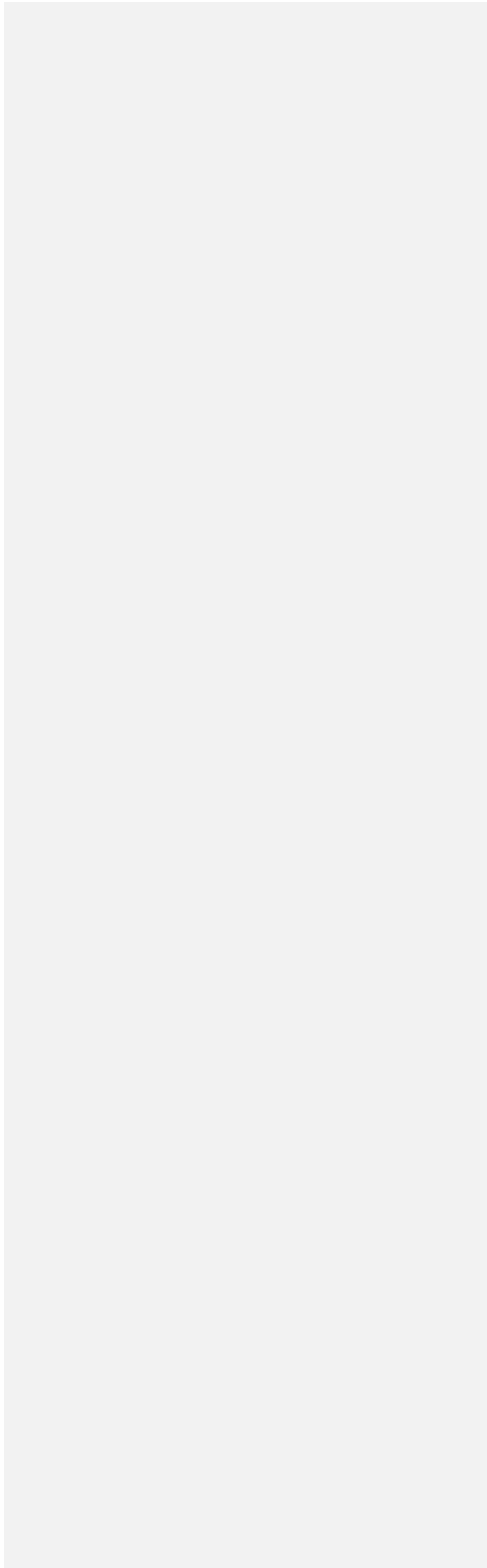
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Declaration of Authorship

I declare that this is entirely my own work and that I have not knowingly copied (plagiarised) the work of others. I confirm that this thesis is my own work. It has not been submitted for examination at any other university for any other award.

Disseminated Findings

Oral presentations

Austin, D. (2012) 'Children and young people's experiences of source and protective isolation'. Oral Presentation at *RCN Joint Children and Young People Conference*, Met Hotel, Leeds, 12-13th October 2012.

Austin, D. (2017) 'Children and young people's experiences of source and protective isolation'. Oral Presentation at *RCN International Research Conference*, Oxford University, Oxford, 5th April 2017.

Poster presentations

Austin, D., Prieto, J.A., Rushforth, H.E. (2011) 'The lived experience of isolation while in hospital: video diaries and researching children'. Poster presentation at *RCN International Research Conference*, Harrogate International Centre, 16th May 2011.

Austin, D., Prieto, J.A., Rushforth, H.E. (2011) 'The lived experience of isolation while in hospital: video diaries and researching children'. Poster presentation at *Faculty of Health Sciences Conference*, University of Southampton, Southampton, 17th June 2011. Prize Awarded.

Austin, D., Prieto, J.A., Rushforth, H. E. (2012) 'The lived experience of isolation while in hospital: video diaries and researching with children'. Poster presentation at *Postgraduate Showcase*, University of Southampton, 3rd May 2012. Silver Prize Awarded.

Austin, D., Prieto, J. A., Rushforth, H. E. (2019) Children and Young People's Experiences of Single Room Isolation. Poster presentation at *PIER Conference 2019*, Grand Harbour Hotel Southampton, 14th - 15th October 2019.

Publications

Austin, D., Prieto, J. A., Rushforth H. E. (2013) 'The child's experience of single room isolation: a literature review', *Nursing Children and Young People*, 25 (3) pp 18-24.

Glossary of terms

Anonymity - Anonymity in research is described when respondents remain unknown to the researcher (Polit & Beck, 2017).

Child - The term child will be used to encompass all children and young people aged 0 to 17 years in accordance with UN Convention of the Rights of the Child (Office of the United Nations High Commissioner for Human Rights, 1989).

Child Centred Care – Child-centred care acknowledges that children and their interests are recognised to be at the centre of thinking and practice when caring for children and families (Shields, 2015).

Community - A group of people with particular characteristics, attitudes and interests in common (McMillan & Chavis, 1986).

Control - Control is bringing the environment into line with one's wishes and bringing oneself in line with the environment (Rothbaum et al, 1982).

Coping - Coping is directed at dealing with or resolving or mitigating a problematic situation or difficulty (Ray et al, 1982).

Emotional Contagion - The theory of emotional contagion purports that there can be stress contagion between parents and infants. It has long been noted that emotions appear contagious (Darwin, 1872; Reik, 1948), and that individuals infer their emotional state from the emotional expressions and behaviours of another (Bem, 1972; Laird, 1974).

Family – Family is defined as a group of people responsible for the development and socialisation of children. It is accepted that family model is fluid, and varies according to social, financial, and cultural norms (Tillman & Nam, 2008).

Family Centred Care - Family-centred care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/young person, in which all the family members are recognised as care recipients (Shields et al, 2007).

Healthcare Associated Infection (HCAI) - An infection caused by any infectious agent acquired as a result of a healthcare intervention (DH, 2008).

Isolation – Isolation precautions are used for patients who are either known or suspected to have an infectious disease, are colonised or infected with a multidrug resistant organism or who are particularly susceptible to infection (Weston et al, 2016).

Parent - The term parent will be used to encompass parents, legal guardians and primary caregivers. Primary caregivers can be defined as any individual who attends predominantly to the needs of the child e.g. foster carer, grandparents.

Pathogen – An agent capable of causing disease to its host (Weston et al, 2016)

Protective Isolation -Single room isolation used by those who are at increased susceptibility to infection due to being immunocompromised, in order to protect them from exposure to infection (Siegel et al, 2007).

Social Context – The sociocultural environment or social setting where people live or in which something develops (Gergen, 1999).

Social Constructivism - A sociological theory that focuses on how people develop knowledge that allows them to construct and apply knowledge in different social contexts (Thomas et al, 2014).

Social Construct - An idea that has been created and accepted by the people in a society, based on their knowledge and understanding (Gergen, 2001).

Shared Care – Care provided between a local district hospital and a regional specialist centre

Source Isolation–Segregation, usually in a single room, of patients with an infectious condition in order to minimise the risk of spread to others who may be at risk from exposure to it (Siegel et al, 2007).

Stigma – A mark of disgrace associated with a particular circumstance, quality or person (Dovido et al, 2000).

Standard Precautions – A set of precautions used for infection prevention for all patients regardless of their diagnosis or infection status. These precautions are designed to reduce the risk of transmission of pathogens from both recognised and unrecognised sources of infection in hospital (Weston et al, 2016).

Transmission-Based Precautions– A set of precautions used in addition to standard precautions for patients with a known or suspected infectious disease or condition (Weston et al, 2016).

Abbreviations

AML – Acute Myeloid Leukaemia

BMT – Bone Marrow Transplant

CDC – Center for Disease Control

CF – Cystic Fibrosis

DH – Department of Health

GMC – General Medical Council

HCAI - Healthcare Associated Infection

HIV – Human Immunodeficiency Virus

LAF – Laminar Air Flow

MDRO – Multidrug resistant organisms

MRSA – Methicillin-resistant *Staphylococcus aureus*

MRSA PVL – Methicillin-resistant *Staphylococcus aureus* Pantón-Valentine Leukocidin

NHS – National Health Service

NSF – National Service Framework

PICU – Paediatric Intensive Care Unit

PPE – Personal Protective Equipment

RSV - Respiratory Syncytial Virus

SARS - Severe Acute Respiratory Syndrome

SCID – Severe Combined Immunodeficiency

UK – United Kingdom

UN – United Nations

USA – United States of America

VRE – Vancomycin Resistant Enterococci

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Chapter 1 Introduction

1.1 Introduction

Children experience hospital differently to adults as a result of their development, their age, their comprehension of illness and contagion. In addition, children are normally accompanied by their parents, whereas adults rarely have a member of their family resident with them whilst in hospital. There are differences in the reasons that children and adults need to be hospitalised; specifically the differing aetiology of diseases between these two groups. Historically, adult research [has](#) been translated into paediatric settings and accepted by practitioners as the best available evidence. However, since the introduction of the Children Act (1989) and the subsequent reconceptualisation of children's rights within the United Kingdom (UK), there has been a greater need to understand the child's experience and use relevant evidence in practice to ensure the child and their family's needs are met in hospital. Despite this desire to understand children's experiences, research with children is still fraught with many ethical and practical issues and there remains a paucity of paediatric-specific, clinically relevant research. Moreover, research with children has frequently focused on proxy perspectives which has resulted in underrepresentation of the child's voice within research.

Hospitalisation is a challenging time, and the available literature attests that being in isolation whilst in hospital further compounds this experience (Curtis & Northcott, 2017; Knowles, 1993). Transmission-based precautions, including single room isolation, are used to minimise the risk of spread of infection in hospitals for the protection of patients and staff. Although single room isolation is a cornerstone of transmission-based precautions, the experience of being nursed in isolation for adults is not fully understood. Furthermore, the limited paediatric research that describes the child's experience of isolation suggests that isolation places an additional burden onto the child and family, over and above the documented effects of hospitalisation (Russo et al, 2006).

Since 2001, the Department of Health (DH) has recommended that the proportion of single rooms in new hospital developments should aim to be 50% or more for both adults and

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children. This is because there is an increasing need within the National Health Service (NHS) to protect the vulnerable and accommodate those with potentially infectious conditions. Worldwide, there are an increasing number of multidrug resistant organisms (MDRO) (Ventola, 2015), which the Center for Disease Control (CDC, 2013) have declared as a crisis due to antibiotic resistance. This crisis reflects the worldwide overuse of antibiotics and denotes that antibiotic resistant infections must be isolated to reduce any risk of cross infection and spread of MDROs. The evolution of knowledge regarding mode and route of transmission has resulted in more targeted use of infection prevention measures including single room isolation (Antonovics et al, 2017; Sintchenko & Holmes, 2015). Based on the increased knowledge and higher level of surveillance of MDRO, there is an increased need for single room accommodation in hospital (Bryant et al, 2016). This is of particular importance with children due to their developing immune system and the increased number of communicable diseases of childhood such as respiratory syncytial virus (RSV) and varicella (Milstone et al 2010). Furthermore, there are an increasing number of children in the community with complex health care needs, often with indwelling devices and who access respite and healthcare settings, increasing the chance of them acquiring a MDRO and potentially requiring hospitalisation for management (Sandora, 2010). These issues within paediatrics, in addition to the worldwide concern over the increasing number of MDRO, indicate the need for increased number of isolation facilities compared to adult wards (Rubin et al, 2018). Thus, since the turn of 21st century, the increased provision of single rooms in newly built and renovated UK hospitals has improved the facilities for patients who required isolation due to infection, and by 2008 single rooms accounted for 28% of NHS hospital beds (National Nursing Research Unit, 2008).

It is evident that isolation facilities are in demand (Antonovics et al, 2017). Consequently, it is imperative that the experience is understood to ensure that care is based on the patients' needs. Children are major healthcare users, however they are rarely consulted for their perspectives in research about healthcare (Clark et al, 2013; Greig et al, 2013; Lambert et al, 2014a; Lambert et al, 2014b). The current aim of the UK government to make the NHS a more accountable and quality-conscious service has enhanced the importance of infection prevention amongst the media, public and healthcare providers (Pollock & Roderick, 2018), yet the patient

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experience of isolation precautions while in hospital has received limited focus in the literature. It is vital that isolation is fully understood in the context of those experiencing it so that the clinical care meets the needs of the children and their families.

Exploring children and young people's experience of being nursed in isolation while in hospital was the focus of this study. Within the background of this study lies my career trajectory and my belief that children have valuable contributions which need to be explored to inform care provision. From my own experience working as a researcher and paediatric nurse in acute care, I have become increasingly aware of how important it is that research must be relevant to practice, and the research question addressed in this thesis was founded on observing patient behaviour and working clinically with families in isolation. Children should have a voice within their care (Patterson Kelly et al, 2016) and through this research I based my decisions and actions in practice on this viewpoint, to influence the care that they receive whilst in hospital. This study served to address one research area where there was a significant lack of contemporary research that can be applied in paediatric wards of different specialities.

This chapter provides an introduction to the study as a whole. Firstly, the child's voice in research will be discussed which provided the foundations to many of the decisions made throughout the study. Secondly, infection prevention measures, focusing on isolation care will be explored, to distinguish the key issues of relevance to children and to compare these with adult care. This chapter culminates in the rationale for this study from a personal and professional perspective.

Chapter Two will provide an in-depth analysis of the literature pertaining to the care of children and adults nursed in single room isolation, and the experience for staff providing isolation as part of infection prevention. Chapter Two concludes with a justification for the research question for this study. Chapter Three will present the methodology, data collection methods, introduces the data analysis method, and the rationale for selecting this approach. Chapter Four reviews the data analysis methods including examples using the data from this study. The findings will be discussed in themes in Chapter Five and Six. Chapter Seven presents the discussion and theoretical preposition for the study. Conclusions will be drawn

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together in view of the knowledge that is added as a consequence of this study, with limitations acknowledged in Chapter Eight.

Throughout this thesis the term “child” will be used to encompass all children and young people aged birth up to 18 years in accordance with UN Convention of the Rights of the Child (Office of the United Nations High Commissioner for Human Rights, 1989).

1.2 Clinical Academic Role

As a paediatric nurse for the past 12 years, I have had the privilege to care for children and their families daily in a variety of settings, throughout their illness trajectories. This PhD began as part of clinical academic pathway, where the vision was to answer a research question that was derived from clinical practice. Having worked in paediatric intensive care, paediatric general and specialist wards and paediatric community, one key area of interest for me was the different experience that children requiring isolation precautions had, from their peers who were hospitalised, but not in isolation. When working clinically, I often heard the stories that the children shared about their experiences of isolation, and I felt that this area warranted further research and thus this formed the basis of this study. I worked within the children’s wards during this study and thus I was part of their social context albeit not with any of the patients that participated. Despite this clinical experience, I never truly lived the isolation experience as a child and therefore the children’s stories are essential to understand this experience.

During the process of this PhD I have also been a parent of a child in isolation and subsequently I have lived the journey of isolation which has added another lens to my interpretation of the data collected within this study. Whilst my episodes in isolation were unremarkable, it did elicit the feeling of not wanting to leave my son alone without anyone to watch him. Although he was not old enough to want interaction with other children, I could empathise that if he were old enough it was a lonely place to be in a single room, with no distractions of observing other people. These experiences have impacted upon the care that I now give to families being cared for in isolation. Both the personal and professional side of learning during this PhD journey has impacted my understanding and immersion within the world of children in isolation. In this thesis I aim to share this construction of the experience

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of isolation. I aim to share this knowledge with readers so that they may seek to provide the best possible level of individualised care to all children and families in isolation whilst in hospital.

In the clinical academic role, it was impossible to bracket my experience as a nurse. Therefore, it was essential that I present my clinical role and personal experience of isolation, for readers to consider my role as a practitioner throughout the findings. It was necessary for me to acknowledge my nursing role throughout the PhD journey, as my clinical knowledge, inherent understanding of the clinical research setting and experience of working with children through my role as a paediatric nurse, is intertwined with the knowledge that I gained through conducting this research. It is imperative to make this transparent, as if a researcher without the clinical knowledge approached this study the findings may be subtly different, as there are some parts of knowledge that are embedded as part of the practitioner role. From the beginning of this research journey I felt it necessary to establish a theoretical viewpoint to be able to justify the theoretical underpinning, and ontological and epistemological foundations of the study, in order to make my position as a nurse, parent and researcher transparent.

1.3 Children's Voices in Research

The rationale for researching children's perspectives has been advanced significantly, driven by social, political and theoretical forces, particularly the United Nations (UN) Convention of the Rights of the Child (1989) and the Children Act (1989) (Clavering & McLaughlin, 2010). Despite this, there are certain circumstances where a parental perspective or other proxy perspectives are used to understand a subject under study. Researchers continue to show that this proxy perspective can be compared with the child's perspective, however there are differences in their understanding and perception of experiences (Nilsson et al, 2013; Tay-Lim & Lim, 2013). As a clinical academic paediatric nurse, I had a strong conviction that research about paediatric healthcare must include children's voices, and that their contributions do not become tokenistic or diluted in data from proxy perspectives. It was with this viewpoint that the research was approached, to truly understand the child's world.

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Since the 1980s, there has been a move from a paternalistic approach, where research was conducted *on* children, to an approach where children are actively involved in the research process and their opinion is sought (Clark et al, 2013; Pope et al, 2017). Unlike other members of society, children have relied on adult advocates to enable their voices to be heard (Phelan & Kinsella, 2013). Historically, there was a belief that children may not have valuable, reliable, or significant contributions to make to research, and often children's views have been represented via parents/carers, or considered in context of their developmental capacity (Engel, 1999; Greene & Hill, 2005; Kirk, 2007). The reconceptualisation of the philosophy underpinning the involvement of children in research was formalised by the publication of legislation, and international conventions proposed to protect and assert the rights of children (Mazzoni & Harcourt, 2014), most notably in the UK in the form of the Children Act (1989) and National Service Framework (NSF): Children, Young People and Maternity Services (DH, 2004), and internationally via the United Nations (UN) Convention on the Rights of the Child (Office of the United Nations High Commissioner for Human Rights, 1989).

Following the international and national recognition of children's rights, there has been a growing concern to incorporate children as active participants in research, in order to effectively develop services based on the child's perspective (Balen et al, 2006; Kirk, 2007; Angell, 2009; Nilsson et al, 2013). However, even in 2010, it was noted by Coyne (2010a) that proxy perspectives were often included in healthcare research rather than directly including the child in the study. Yet within educational settings and voluntary organisations, the child's voice is commonly used in research (Kellet, 2010; Tay-Lim & Lim, 2013). Within the UK, DFES (2003) stated that listening to children protects them from harm and poor clinical practice, which reflects this new theoretical movement of valuing children's perceptions, however this is often not translated into research practice. Internationally, these standards are described as fundamental in Every Child's Right to be Heard document produced by Unicef (1989) and Save the Children (Lansdown, 2011) in addition to the UN Convention for Rights of Children (1989). The mismatch between international policy and healthcare research reliance on proxy perspectives may be due to difficulties in gaining ethical approval in paediatric research, the need to protect children who are ill and in hospital, the additional challenges associated with gaining data from children, most notably the ethical issues such as

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competence, consent, power, confidentiality, and fundamentally, whether the research is in the best interest of the child (Dixit, 2016; Fargas-Malet et al, 2010; Groundwater-Smith et al, 2015). Alternatively, for some there may simply be a lack of value attributed to the child's perspectives. Despite this lack of child perspective in health research, social scientists view children as active in the construction and determination of their own lives and those around them in society (Engel, 1999; Burr, 2015). Within any social construction will be a group of people who have their understanding and knowledge influenced by values and experiences of those within the construct. Therefore, children and parents' perceptions of an experience, although individual from one another will be intertwined and cannot be parted from one another.

The inclusion of children's voices in research is hindered by the belief that children cannot participate based on their cognitive and developmental capabilities. This introduces the concept of child development. Despite the seminal work regarding child development (Bowlby, 1969; Freud, 1951; Piaget, 1965; Robertson & Robertson, 1971; Vygotsky, 1978), Sameroff (2010) purports that development is an interconnectedness between context and the individual and cannot be described by ages. This supports the argument that any child may be developmentally ready to participate in research, regardless of age, dependent upon their social construct and life experiences. Whilst younger children may not be able to share their experiences for the purposes of research in the analytical manner that researchers desire, according to Greig et al (2013) their contribution in whatever format can provide some insight into their experience; seen through their eyes. Furthermore, an overreliance upon the excuse of child development being insufficient to participate in research does elicit the question of whether the lack of use of children voices within research is protective or oppressive? Different authors align to different theoretical perspectives on this matter. Interestingly some parents that were approached for participation in this study were reflective of these opposing viewpoints, as discussed in the Section 7.3.7.1, in Chapter Seven. For me, as a paediatric nurse working with children in the clinical research setting, it is oppressive of society to not explore the child's perspective and it can be argued that practice cannot be truly reflective of the needs of the child without the inclusion of children's voices, in accordance with the freedom of expression in the UN Convention (1989).

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The caveat to including children's voices within this study was the need to collect the data in an age-appropriate, engaging manner and the use of adjunctive data from alternative sources to support the children's perspective. This allowed the child's voice to be central to a study within the wider social construct of their family and society, through the inclusion of other perspectives. This study combined the need to hear children's voices with the need to protect children, using appropriate ethical considerations regarding recruitment and consent as described by Modi et al (2014) and through data collection methods such as video diaries or interviews that are deemed appropriate for the inclusion of children in research (Coad et al, 2009; Greene & Hill, 2005; Mukherji & Albon, 2010; Punch, 2002). Considering both the child's voice and the child's perspective by proxy in any one study supports the need for the child's voice to be heard, and enhances the trustworthiness of the data due to the diversity of perspectives (Coyne & Harder, 2011; Dockett et al 2011; Greene & Hill, 2005).

Clinically, in the UK there is often inclusion of the child's voice within practice, for example gaining their insight and participation in their treatment, however this tends to be with children with chronic conditions (Alderson, 2018). Often in acute clinical presentations the parents take the lead in discussing care with the clinicians as the child is not clinically well (Ocloo & Matthews, 2016). However, Sharkey et al (2014) report that there has been an increase in the number of international studies including children as informants in research. The reasons reported in the literature for this reliance on adult responses in care were barriers in communication, lack of therapeutic relationship with the child and asymmetric relationships between professionals and the child (Coyne et al, 2016; Sharkey et al, 2014).

Within UK society there is strong support to allow children to make decisions and assert their opinions, yet within healthcare there remains an overreliance on parental perspective particularly those in acute presentations to hospital (Foster et al, 2010). Similarly, in adult health services, in an acute presentation it is suggested that the professionals tend to behave paternalistically to make decisions in their best interest, yet as the adult gets back to health, they can make decisions of their own (Delaney, 2018). By contrast in paediatric care, the parent of the child tends to adopt this role (Sjostrand et al, 2013). With this paternalistic

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approach in mind it is possible to comprehend how the child's voice is often diluted in care decisions due to the role of the healthcare professionals and the parents. It was found by Sharkey et al (2014) that children and parents' perspectives on care were different, further reiterating the need to seek the perceptions of the child as well as that of their parents. Although the child's best interests are paramount to any paediatric healthcare provider, as part of paediatric practice, we are required to look at the whole family not just the child's perspective in isolation (Rigby, 2016). Furthermore, children are the experts in how they feel and how they experience a situation or care episode (Paul, 2016).

There are some exceptions in terms of participation within paediatric research in terms of the children who are nonverbal, where there has to be a reliance upon a proxy perspective (Clark, 2017). However, even this remains controversial as nonverbal children may have a contribution to research (Pernille, 2018), yet it remains inconclusive in the literature how this perspective is elucidated in a rigorous manner (Duncan & Fiske, 2015; Tisdall, 2012). Furthermore, due to developmental differences within children, age as an organising framework for participation in care or research is potentially inadequate and other means to seek information need to be considered, to incorporate the child's rights fully in care (Alderson, 2018; Coad & Evans, 2008; Coyne, 2005). Therefore, I approached this research with the understanding that every child has the right to express their feelings and perceptions of isolation, and that an inclusive, participatory data collection method would need to be employed to ensure that as many children as possible were able to participate.

1.4 Family Centred Care

Family centred care is described in the literature as a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/young person, and in which all the family members are recognised as care recipients (Shields et al, 2007). There are varying definitions within the international literature of family centred care, which has generated challenges in interpretation and implementation of family centred care in practice (Ford et al, 2018). However, Shields (2010) described family centred care as a central part of children's nursing, to incorporate parents in their child's hospital admission. Although family centred care has been adopted in practice in

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a manner of different ways worldwide, within the UK, the government responded to the needs of children in hospital through encouraging parents to be resident and through the employment of specially trained paediatric nurses (Livesley, 2010). Through these initiatives and Casey's Model of Partnership in Care (1988), partnership-working and family centred care has been embedded within the education and psyche of paediatric nurses since the 1980s (Savage & Callery, 2000, Jolley & Shields, 2009). It is acknowledged in the literature that the heart of family centred care is the notion to involve parents in their child's care in hospital, whilst acknowledging for some parents this cannot be achieved (Blower & Morgan, 2000; Callery, 1997; Coyne, 2015; Shields et al, 2006). Since the introduction of family centred care, most children resident in hospital will have a family member present with them for much of their stay, however the level of care that a parent can provide varies based on the parents' wishes, and the way the healthcare team and family work in partnership (Callery, 1997; Casey, 1995; Lee, 2007; Power & Franck, 2008; Shields et al, 2012).

The inclusion of family centred care in practice necessitates an understanding of what constitutes a family. Family is defined as a group of people responsible for the development and socialisation of children (Tillman & Nam, 2008). It is accepted that the family model is fluid, and varies according to social, financial, and cultural norms (Tillman & Nam, 2008). It is widely acknowledged in the literature that family structure is varied worldwide, but even within the UK. Thus, the interpretation of family centred care is likely to be interpreted and implemented differently according to the practitioner's understanding of family.

The level of participation that a parent has within their child's care should be discussed between the parents and staff to negotiate their level of participation in care and ensure that the parents and child's needs are met (Coleman et al, 2003). This is reflective of the NHS movement to a consumer-led service that seeks to provide care based on the needs of the service-users. However, in my clinical experience, there is rarely negotiation of roles or level of participation between parents and staff. This is corroborated with the evidence which suggests that family centred care and paediatric ward practice are not synonymous, and that different practitioners interpret the use of family centred care in different ways, leading to

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varying practices as described by Ford et al (2018) and Livesley (2010). There is in fact a presumption now within the UK that parents will stay with their child and will continue to adopt their same level of parental care whilst in hospital (Shields et al, 2012). Structural and material factors such as availability of parents and an insufficient number of staff are key factors within the provision of family centred care (Livesley & Long, 2013). This means that although parents are meant to determine their level of involvement in their child's care, often they are relied on to provide care without negotiation (Rosenbaum et al, 1998). The application of family centred care is complex in nature, and without clear definition, it has been interpreted differently and can result in inconsistencies for parents and nurses, which according to the literature, affects the child's experience (Hutchfield, 1999; MacKean et al, 2005; Shields, 2015).

Parental presence in hospital is fundamental to the child's experience and this could not be more evident in isolation where the child is not interacting with other children on the ward (Curtis and Northcott, 2017). The amount of care provision provided by the family may differ in isolation due to the physical barrier of the room, which also may impact on the experience for both the child and the family (Corlett & Twycross, 2006). There is a wealth of literature to support the theories of emotional contagion and mirroring behaviour between parents and children (Dezecache et al, 2015; Jacobsen et al, 1990; Prochazkova & Kret, 2017; Whelan & Kirkby, 2000). The theory of emotional contagion purports that there can be stress contagion between parents and infants (Dezecache et al, 2015). Therefore, not only the parents' presence, but also the parents' experience may impact upon the child's experience of hospitalisation and more specifically isolation, which is discussed in Chapter Seven. There are less studies in the past ten years which research parental presence whilst in hospital, and this may be because it is an embedded part of current UK practice for parents to be resident, that it does not warrant further research. Another consideration is the cultural evolution of the use of technological devices and social media within the 2010s and beyond, that Strasburger et al (2013) suggests have made it possible to communicate with family even without their physical presence in hospital. This may contribute to the reasons for the lack of research regarding parental presence in hospital within the past decade.

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Parental presence will be perceived differently throughout an international audience. Within some cultures it is expected that parents are resident, and their society would support this, in terms of carers' leave for parents and social supportive means to mitigate for the financial and other burdens of being resident as a parent in hospital (Mikkelsen & Frederiksen, 2011). In UK practice, although these additional burdens are likely to be considered by the healthcare team, Mumford et al (2018) states that they are not explicitly discussed with families on admission to negotiate their level of participation in care. Russo et al (2006) found that isolation places an additional burden for the parents, as the child is not only in hospital, but there are no other people to talk to within the ward, making the parents feel more inclined to stay. Additionally, in an Australian study, nursing staff shortages place an additional burden on families to stay to provide this care, meaning the control within this decision-making process of family centred care is moved to the professionals which negates the original concept of family centred care (Arabiat et al, 2018). The concept of family-centred care is incontrovertible, however the application of it in practice is often inconsistent, thus impacting on the child's experience of hospitalisation.

1.5 Children in Hospital

Children in isolation are a subset of all children in hospital. In order to understand the experience of isolation, it is important to look to the literature on hospitalisation to facilitate a comparison between the experiences. Hospitalisation is a uniquely stressful event for every child who is admitted, and the experience is complex as it rests on a number of inter-related, contextual factors (Forsner et al, 2009; Lines et al, 2015). Coyne (2006) describes that each child may have a different response to being in hospital, a response which is based on previous life experiences, therefore this necessitates their story being put into the context of their own social construct.

During the first part of the 20th century, there were strong restrictions on visiting children in hospital, often some hospitals completely banned parent visiting. In 1951, Bowlby published a World Health Organisation (WHO) document which suggested adverse effects on personality development as a consequence of inadequate maternal care (Bowlby, 1953). This was the beginning of Bowlby's theories on attachment. Bowlby collaborated with Robertson and

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together they went on to construct the stages of separation anxiety (Robertson, 1970). Following these seminal pieces of work, the Platt Report (1959) was published which advocated for better care for children in hospital, however it took many years for this to become a reality, which is reflected in the children's hospitalisation literature in 1960s-1970s where children experienced detrimental effects due to restricted visitation and lack of exploration of the child's experience of their care (Connell & Bradley, 2000). Although the change was gradual, Platt (1959) was a turning point in relation to paediatric health care, and particularly relevant here is that hospitals took steps to reduce separation of children and their parents by instituting unrestricted visiting, providing parental accommodation and avoiding admission to hospital where possible.

Attachment figures are described to be usually the child's caregivers and the person with whom they have an emotional bond (Koller et al, 2006b). Children will seek out their attachment figures when they are anxious, fearful or frightened, in particular when they are exposed to unfamiliar people or places (Bowlby, 1969, Howe, 2005). Admission to hospital confronts all of these aspects, which is why attachment plays an important role within the child's experience of hospital, and more specifically, isolation. Understanding the relationship between the child and their attachment figure is essential to understanding their attachment behaviours, even more so in hospital when they are removed from all the other aspects of their normal social context (Koller et al, 2006b; Roberts, 2010). Attachment is also important to consider in terms of how children form attachments to a familiar ward environment and staff in the absence of their usual attachment figure (Field, 1996). Sroufe (1988) explained that children's experiences of relationships with attachment figures can exert a powerful influence on their concept of self and the relationships with others within their social context. This reconciles with the work of Vygotsky (1978) which recognised that children are social agents and heavily influenced by their environment. Bowlby's theory of attachment (1969, 1973) and Vygotsky's theories of development (1978) in terms of their social construct, are determinants that suggest that parental presence is key to the experience of hospitalisation and that staff can impact upon this in parental absence.

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Children's comprehension of why they are in hospital and the understanding of contagion may impact on the experience of hospitalisation. Seminal research by Goffman et al (1957) inferred that children often perceived that the reason for hospitalisation was for punishment, rejection, abandonment and death, which may have been associated with the fact that the children were separated from their parents. The theory of immanent justice was presented by Piaget (1932, cited in Piaget, 1965) which considered that children thought that illness and injury were a punishment. A study by Kister & Patterson (1980) demonstrated that children of all ages used this concept of immanent justice more commonly with illness, than accidents, and it was inversely correlated to their understanding of contagion. However, there is evidence which supports the theory that children understand the concept of contagion (albeit in a developmentally appropriate manner) and do not attribute illness to punishment (Blackler & LoBue, 2016; Springer, 1994). The understanding of separation from the others to protect from risk of contagion in adults was shown by Currie et al (2018) to improve the response to isolation.

With an increased understanding of contagion and greater parental presence in hospital over the past few decades, research about children's experiences of hospitalisation has demonstrated more diverse findings than have been presented in this section. Children recall hospitalisation as being separated from family and their peer group, experiencing alteration in daily routine and surroundings and often going through some unpleasant treatments (Bonn, 1994; Crnkovic et al, 2009; Linder & Seitz, 2016). The literature attests that other stressors of hospitalisation are falling behind in peer groups and school work (Clift et al, 2007; Coyne, 2006), being in an unfamiliar environment with unacquainted people (Lamontagne et al, 1997), the physical environment and personal space (Coad & Coad, 2008; Lambert et al, 2014a; Linder & Seitz, 2016), being bored (Coyne & Conlon, 2007), fear of investigations and treatment (Forsner et al, 2009) and loss of control and fear of their imaginations of what will happen (Carnevale, 1997). Farias et al (2017) suggested that the experience of hospitalisation is impacted by the perception of their disease, the family support network and the entertainment strategies. This is reflective of the movement to the digital age, where previous studies did not mention entertainment, yet with the evolution of technology Stalberg et al (2018) describes that there is a need to continue the use of communication and technology in

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hospital as it would be at home. Although this literature provides an overview of the effects of hospitalisation on the child, many of these studies have focused on specific conditions or ages, or the negative aspects of the experience (Carnevale, 1997; Clift et al, 2007), which does not allow for transferability to all children's wards. It is essential to highlight here that the findings may be a consequence of different research methods or the environment of care in general, therefore, the findings need to be considered in context. Furthermore, as noted by Crisp et al (1996), the child's frequency of hospital admissions, and therefore exposure to hospital routine can influence not only their experience of hospitalisation, but also isolation.

Although it has been purported in this thesis thus far that the child's voice is central to understanding the child's experience, parents do play a part in creating the child's social viewpoint and construct. Therefore, it is important to consider the parental experience of having a child in hospital. Coyne (2005) found that parents perceived their child's experience of hospital as being shaped by being involved in the decision-making processes, which increased their self-esteem and self-regard. Findings from Kristensson-Hallstrom & Elander (1997) suggested that parents required strategies to help them cope, including relinquishing care of the children to nursing staff, but only after developing trust in their capabilities. The theme of trust transcends a number of the studies exploring the parental perspective of being in hospital with their child, with the development of trust being secured with time, evaluating the care team's skills and provision (Coyne, 2005; Diaz-Caneja et al, 2005; Thompson et al, 2004). The development of trust was demonstrated by Diaz-Caneja et al (2005) with good communication between the medical team and the family, and opportunities for the family to participate in care, which reduced their overall stress. In Battrick & Glasper (2004), parents were positive and complimentary about the care that their child received, yet children were more candid in their views. This suggests that children and parent's interpretations of their experiences may be different. The community of the hospital ward was described in Darbyshire (1994) and Russo et al (2006), with parents feeling a responsibility to help unaccompanied children whilst in hospital.

The experience of hospitalisation for children and parents is impacted by a number of factors. Being in a single room whilst in hospital generates different experiences. Within this study it

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was anticipated that some of the findings would be relevant to hospitalisation. However, these are not teased out in Chapters Five and Six as findings, because the purpose of this study was to seek out the findings relevant to isolation rather than hospitalisation. Therefore, through presenting this literature here, it is hoped to provide an overview of the hospitalisation literature within which to situate the findings from this study.

1.5.1 Children Nursed in Single Rooms

Children may be nursed in a single room for a variety of reasons other than the need for isolation precautions, for example privacy and dignity, for child protection reasons or simply bed availability. This study was not set up to explore the experience of single rooms for reasons other than infection prevention, therefore any children who were not subjected to isolation precautions were not included. Often it is not possible to offer a choice for children in hospital as they need isolation to protect them from potential pathogens or to isolate a pathogen they may be hosting. Isolation rooms are not freely available on paediatric wards in the UK as there is such demand for them (Mitchell et al, 2017). Single rooms offer maximum privacy and flexibility in routine, and Curtis & Northcott (2017) described a drive to increase the number of single rooms on children's wards internationally. There is limited research on the experience of single room occupancy without the requirement for isolation precautions. According to Langley et al (1994) and Vayalumkai et al (2007) there is greater demand than availability for single rooms for the number of children that require isolation for infection prevention. There are however no studies which document the experience of being subjected to isolation precautions, whilst receiving cohort care with multiple children with the same infectious pathogen, nursed in one ward area separated from other children on the ward. In a feasibility study by Morgan (2010), which was conducted in Boston, USA, it was established that an appropriate workforce was needed to cope with single room occupancy to minimise risk of social isolation and to support safeguarding guidelines. The design of the single isolation rooms within paediatric units may also impact on ability to enable clinical observation and facilitate family centred care where the parent can be resident as described by Chaudhury et al (2005), Mooney (2008) and Young & Yarandipur (2007).

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There are a small number of paediatric studies that compare the experience of isolation and hospitalisation which demonstrate differences in children's opinions (Bishop, 2008; Miller et al, 1998; Morgan, 2010). In an Australian study, Bishop (2008) reported that there was equal preference between single rooms and bays. Conversely, Miller et al (1998) and Morgan (2010) demonstrate that adolescents preferred shared rooms. However, in an adult study by Lau et al (2016), it was found that isolated and non-isolated patients had a similar length of stay, satisfaction, depression and anxiety scores when compared with patients hospitalised on the main ward. There are very few adult comparative studies exploring the experiences of people in isolation compared with hospitalisation, and the literature that are available do not provide conclusive evidence on which environment adults prefer, let alone children. This may be due to a number of contextual factors which could have influenced the data such as number of staff, facilities available and the reason for isolation (Gammon, 1998). The literature is sparse and cannot give much weight to demonstrate whether children prefer isolation or a shared bay.

This overview of children in hospital highlights that paediatric practice has evolved over time to incorporate family centred care within hospitalisation. Despite the parental presence and the inclusion of modern technology, hospitalisation remains a stressful, unfamiliar and for some an unpleasant experience which impacts upon the child and their parents.

1.6 Infection Prevention

This study aimed to understand the experience of children undergoing infection prevention measures specifically, isolation care. Isolation within the context of healthcare is the process of separating an infectious pathogen from the wider population through the use of a single room (source isolation), or the process of separating a person vulnerable to acquiring infection from potentially transmissible pathogens (protective isolation) (Siegel et al, 2007). Infection prevention within healthcare encompasses any measure taken to prevent the transmission of pathogens in any clinical setting. DH (2015) describe two tiers of infection prevention precautions applied in healthcare settings; standard precautions and transmission-based precautions. Standard precautions are based on the principle that any bodily fluids or substances may contain transmissible infectious pathogens, therefore they are employed for all patients (Haynes & Khardori, 2014). Standard precautions include hand hygiene, the use of personal protective equipment (PPE), safe injection practices and appropriate decontamination

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of equipment and linen. Transmission based precautions are recommended when standard precautions alone would not prevent the spread of pathogens (Weston et al, 2016). In the hospital environment, single room isolation is a key component of transmission-based precautions for many infectious conditions as a means of segregating patients with an infectious condition from others (Gasink & Brennan, 2009). This is known as ‘source isolation’. Single room isolation is also used by those who are at increased susceptibility to infection due to being immunocompromised, in order to protect them from exposure to infection (Koutlakis-Barron & Hayden, 2016). This is known as ‘protective isolation’.

1.6.1 Isolation Care

The availability of isolation facilities varies between hospitals and wards. Isolation precautions may be implemented in single rooms on wards, designated isolation wards or purpose-built isolation units with single rooms. Isolation rooms can be designed to have either positive or negative air pressure flows to prevent the transmission of airborne pathogens (Weston et al, 2016). Some isolation facilities have an anteroom attached to the isolation room, to allow for decontamination prior to entry into or exit from the isolation room. And the application and removal of PPE. Even if the air filtration or anteroom facilities are not available, isolation in a single room serves as a physical barrier and also a psychological cue to healthcare workers to practice good infection prevention measures as described in studies by Andrade et al (2017), Kilpatrick et al (2008) and Swoboda et al (2007).

The rationale for isolation care stems from historical practices of quarantine (Parker, 1999). Although infection prevention and more specifically isolation care has since been studied, it remains a relative ‘newcomer’ to the research field (Parker, 1999). In a systematic review by Cooper et al (2003), it was purported that there was little evidence to suggest that isolation measures at the time were effective. It would be unethical to conduct studies to test whether measures such as isolation were necessary, as there is sufficient evidence to suggest that based on our understanding of transmission of pathogens isolation is effective. As a consequence, Dancer (2016) described that many of the practices within infection prevention and isolation care are based on the best available evidence, together with evidence-based guidelines and conventional wisdom, rather than robust research. In order to accommodate for the lack of robust research in this field, many local guidelines are based on the work of the Center for

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Disease Control (CDC) who published an extensive guideline on isolation care (Siegel et al, 2007). It is worth noting at this point that although Siegel et al (2007) may appear dated, it has a strong form of evidence presented in these guidelines based on empirical evidence, not solely expert opinion. Furthermore, these guidelines are updated by the CDC, and are reviewed relatively frequently compared with other infection prevention and control guidelines, demonstrating their use of robust research to formulate the guidelines.

The practice of isolation care is needed to prevent transmission of pathogens, by creating a barrier (Koutlakos-Barron & Hayden, 2016). The modes of transmission vary according to the organism and some may be transmitted by more than one route; the routes of pathogen transmission (contact [direct or indirect], droplet, airborne and vector) are not entirely understood (Dancer, 2016). Direct transmission occurs when microorganisms are transferred between two people without a contaminated object or person as the intermediate (Siegel et al, 2007). Indirect transmission occurs when there is an intermediate object or person to cause the transmission (Groundwater-Smith et al, 2016). These are common types of transmission in paediatric patients, due to the proximity that children have to one another in school, home and social settings (Koutlakos-Barra & Hayden, 2016). Droplet transmission is when infectious pathogens are transmitted from an infectious individual to a susceptible mucosal surface of a recipient (Siegel et al, 2007), generally over short distances when a person coughs, laughs or sneezes. It is argued that droplet transmission could technically be a form of contact transmission, and to further compound this debate some pathogens within droplet transmission are transmissible by the contact route (Posfay-Barbe, 2008, Siegel et al, 2007). Droplet size and dynamics are other variables in the literature that differentiate between droplet and airborne transmission (Kutter et al, 2018; Shiu et al, 2019). Furthermore, according to Shiu et al (2019) there remains controversy around airborne and droplet transmission, specifically with respiratory viruses. Traditionally, a droplet has been defined as being $>5\mu\text{m}$ in size and will not remain suspended in air (Weston et al, 2016). By contrast, airborne transmission is fine respirable particles that can remain infective over time and can transmit infection over a long distance (Jones & Brosseau, 2015).

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It is essential to understand the background of transmission of pathogens as it is the basis of allocation of isolation rooms on wards. The evidence supporting airborne transmission is well documented and advocates that single isolation rooms are always recommended for airborne pathogens, preferably with air handling and ventilation capacity (Siegel et al, 2007). However there remains a lack of concordance on respiratory viruses in terms of mode of transmission, specifically in paediatrics where there is limited research regarding mode of transmission with respiratory viruses (Kutter et al, 2018). Droplet transmission warrants single room facilities, however due to the fact that the pathogens do not remain infectious over long distances, special air handling and ventilation are not required (Siegel et al, 2007). Single patient rooms are preferred for patients who require contact precautions, however if this is not possible there are other placement options such as cohorting patients or placement on wards with large spatial separation between beds and strict use of transmission-based precautions (Gould, 2009; Siegel et al, 2007, Weston et al, 2016). These decisions are made locally with consultation from the infection prevention team. However, these choices for the staff allocating isolation rooms and making decisions regarding transmission-based precautions have been shown to cause confusion and stress (Cassidy, 2006; Farquharson & Baguley, 2003). Due to the lack of easy to translate guidance, the differences in practice between UK wards and institutions can lead to different experiences for those in isolation, meaning the experience of isolation can be context specific (Dadd et al, 2003). Literature purports that the confusion and stress surrounding allocation of isolation rooms for the staff may be witnessed or observed by the parent and child, causing misunderstanding regarding the isolation precautions needed and ambiguity in reasons for isolation (Cole & Lai, 2009; Corley et al, 2010; Eames et al, 2009).

1.6.2 Reasons for Isolation

In England, the DH tend to focus on adult guidance on isolation care (DH, 2008; DH, 2010, DH 2015) and there is limited specific guidance on care of children in isolation. DH guidance is generally organism-specific, which can cause confusion for staff as they cannot prioritise which patient requires isolation, when faced with greater demand than availability (Cassidy, 2006). In England there are no national guidelines on isolation precautions for children or adults and there is reliance on CDC clinical guidelines (Siegel et al, 2007). DH documents are not clinical policies; therefore, they are not required to be translated directly into practice; they are clinical guidance papers which can be employed with local consideration to the Hospital

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Trust's requirements. The most comprehensive, up-to-date clinical guidance on isolation precautions are from the CDC (Siegel et al, 2007). Although it is over 10 years old, the guidance is comprehensive, transferable and has evolved to help healthcare workers worldwide prioritise those who need isolation and has received amendments in accordance with new knowledge of pathogens. The paediatric guidance in this guideline is not comprehensive, however there are limited differences in how to manage the pathogens that transcend adults and paediatric practice. This guidance, along with local policies are utilised to prioritise the need for isolation for children in hospital in the UK, particularly when demand exceeds supply of rooms.

1.6.3 Experience of Isolation

Children nursed in isolation in the UK usually have a bed for themselves, a parent's bed, a cabinet and a sink. Most isolation rooms have windows with external and internal views. Isolation rooms should have ensuite bathroom facilities (DH, 2015), however not all rooms have this facility. The level of entertainment available to the children such as television, toys and electronic devices is dependent upon the ward. Since completion of data collection for this study, there has been an increased number of personal electronic devices and phones being brought into hospital on admission, and the availability of wireless internet throughout the Hospital Trust has increased. Therefore, it is essential to consider the findings of this study within the context of the time of data collection (2011-2015). Children in isolation experience healthcare workers donning personal protective equipment (PPE) in accordance with transmission-based precautions. The physical differences in the environment of being nursed in isolation, when compared with a hospital ward, highlight how the experience may differ for children in these two environments. Moreover, children may experience isolation differently according to whether they are in source or protective isolation, which will now be explored.

1.6.4 Protective Isolation

Protective isolation is used as a method of segregating a child who has an immunocompromising condition, either directly due to their illness or due to the nature of their treatment; for example, those who are immunocompromised as a result of chemotherapy (Koutlakis- Barron & Hayden, 2016). Other reasons for protective isolation include, unimmunised infants, or children who have an immunocompromising condition such as

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Human Immunodeficiency Virus (HIV), aplastic anaemia or congenital conditions e.g. Severe Combined Immunodeficiency Disease (SCID) (Posfay-Barbe et al, 2008). The simplest form of protective isolation is the use of a single room and PPE. According to Siegel et al (2007), the degree of vulnerability of the child to acquiring infections will dictate the need for more advanced forms of air filtration in the room and specific PPE.

1.6.5 Source Isolation

Source isolation is used to segregate children with contagious pathogens in order to prevent the spread of infection to others, for example RSV, methicillin resistant *staphylococcus aureus* (MRSA) (Weston et al, 2016). The procedures that are required for source isolation are transmission-based precautions specific to the infectious agent and sometimes a restriction on the number of visitors (Siegel et al, 2007). Negative pressure ventilation rooms are used where possible for children who have a particularly contagious pathogen. For example, infections transmitted by the airborne route e.g. tuberculosis or chickenpox (Koutlakis-Barron & Hayden, 2016).

1.6.6 Cystic Fibrosis

Patients with cystic fibrosis (CF) are unique as they are a common patient on a paediatric ward, and they straddle both categories of isolation care. Patients with CF are commonly carriers of *Burkholderia cepacia* complex, *Pseudomonas aeruginosa* and *Staphylococcus aureus*, including antimicrobial resistant strains (Saiman et al, 2014). As a consequence of these pathogens, the patients need to be subjected to source isolation. However, for the patients with CF that do not have these pathogens, they require protective isolation from such infections, as these pathogens can affect their prognosis (Saiman et al, 2014). Furthermore, the respiratory secretions of all patients with CF potentially harbour clinically and epidemiologically important pathogens, even if they have not yet been detected in sputum cultures, and therefore isolation precautions should always be instigated for this group of patients.

1.7 Infection Prevention in Paediatrics

Adult literature has often been transferred into paediatric settings however as a paediatric nurse, I am keen that evidence used in practice is the best available and therefore specific to children. Children are a subset of the entire population of patients in hospital, and paediatric

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wards have a number of fundamental differences to adult wards (Sadeghi et al, 2012). In addition, children in isolation are a subset of the group of children in hospital who will have a different experience due to the precautions which are placed upon them (Curtis & Northcott, 2017).

Paediatric healthcare settings present unique challenges in terms of infection prevention due to children's dependency on others and their immunological naivety. Children, in particular unimmunised infants, are likely to acquire infections that they have been previously unexposed to, or are not yet immunised against (Koutlakis-Barron & Hayden, 2016). Congenital anomalies can make children vulnerable to acquiring infection (Posfay-Barbe, 2008). Furthermore, due to at least some of the care needs being met by parents or carers, there is an increased risk of pathogen transmission through direct contact (Rubin et al, 2015; Weston et al, 2016).

Healthcare associated infections (HCAIs) are infections that arise as an undesired consequence of healthcare treatment (Siegel et al, 2007). Unlike adult medicine, paediatric HCAIs can more commonly be subdivided into two groups; transmission of community acquired infections within the hospital setting (e.g. rotavirus, influenza or any of the common communicable diseases of childhood such as chickenpox), and transmission of infections originating in healthcare settings (e.g. device associated infections, surgical site infections) (Simon et al, 2016). The literature suggests that paediatric HCAIs are commonly community-acquired infections that are transmitted once a child is hospitalised (Health Protection Agency, 2012; Smyth et al, 2008; Wongsawat, 2008). As with adults, children with chronic conditions or suppressed immunological status who are frequently hospitalised, are at an increased risk of acquiring these HCAIs (Koutlakis-Barron & Hayden, 2016). Similar to adults, children in long term chronic care facilities, special education schools or respite facilities may have increased risk of acquiring infections, and may be sources of introduction of multi-drug resistant organisms to an acute setting (Murray et al, 2014; Siegel, 2002). Viral infections are the most common HCAI amongst children and commonly there are seasonal epidemics of such infections (Richet, 2012; Siegel et al, 2007). Alongside pathophysiological differences for the reason for isolation, the social, psychological and developmental differences may result in

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different experiences of isolation between adults and children. Therefore, child-specific research is necessary to truly understand what isolation is like for children in hospital.

1.8 Rationale for the Study

As a clinical academic nurse, I had a keen interest in promoting children's voices within research and hearing their stories, thus this study was conceptualised. Clinical academic roles were developed in line with the need for more clinically relevant research and to respond to the needs of an organisation. As a clinical academic nurse, I was issued the remit of infection prevention in paediatrics as a research area by the Hospital Trust and the University. Having been fully immersed within the Hospital Trust where the research would take place, I identified many areas that warranted further research. An area that was of specific interest was that isolation appeared to cause boredom, loneliness and feelings of social isolation amongst the children. Once the study concept had been devised from clinical practice, the literature was reviewed to ascertain if there was a need for such a study. Having conducted a literature review it was evident that there was a dearth of literature pertaining to the child's experience of isolation. Therefore, this study was designed to address these gaps in current literature and to inform children's isolation care incorporating children's own experiences.

It is important to highlight here that the research and developing knowledge did not follow the linear path that this thesis presentation suggests. The research, due to some challenges on the journey, was a consequence of constant interplay between the literature review, method development and analysis to ensure the findings met the research aims. For example, until I spent time with the children as part of this study exploring what they thought about being in isolation, some of the literature did not have the same pertinence in the literature review. Spending time with the children in this study allowed me to understand beyond the clinical role, to understand the construction of childhood and to comprehend that being a child is fluid and subject to context influence and reproduction based on place, time, culture, space and environment. Furthermore, the methods were adapted in accordance with feedback from the children and their response to recruitment. These challenges are critically discussed further throughout the thesis.

1.9 Conclusions

Children in hospital and more specifically in isolation, have a varied context-specific experience. Isolation care is an essential part of hospital infection prevention to maintain safety and minimise the risk of infection transmission, yet its implementation presents challenges, particularly within paediatrics. Children will experience isolation differently to adults due to different psychosocial priorities. Furthermore, for children there are different pathophysiological reasons for isolation when compared with adults and it is not appropriate to transfer adult data into paediatric settings. Therefore, a child-specific study was necessary to ensure that best practice is based on evidence from paediatric settings. A literature review of the pertinent paediatric evidence is presented in Chapter Two; this will highlight gaps in contemporary knowledge regarding the child's experience of isolation and will justify the research question for this study.

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Chapter 2 Literature Review

2.1 Introduction

This chapter presents the background literature relevant to this thesis. There will be a thematic review of the adult literature concerning experiences of isolation care, followed by a thematic analysis of the limited literature available pertaining to the child's experience of isolation care in paediatric healthcare. Finally, the staff perspectives on isolation will be reviewed. The chapter will conclude with a summary of presuppositions gained from the literature detailing current gaps in knowledge, which informed the development of the research question for this study.

2.2 Literature Review of Adult Experiences of Isolation Care

The adult and paediatric literature were searched separately. The paediatric literature was searched first, but due to the limited papers matching the search criteria, adult papers were reviewed. The adult review has been presented first in this thesis, as it is more extensive and orientates the study within the field of isolation care, before focusing on the unique challenges for children in isolation. Christenson & Prout (2002) and Kanner et al (2004) describe that where paediatric-specific literature is sparse, adult research studies may provide an insight into some of the potential experiences of children in a similar situation, and thus the adult literature was used to inform the design of this study, due to the paucity of child-specific literature (for Paediatric Literature Review see Section 2.4). Following a review of the adult and paediatric literature, the studies pertaining to the staff experience of caring for patients in isolation were reviewed and presented in Section 2.5.

2.2.1 Search Strategy

An integrative approach to the search was used as I wanted to include studies with different methodologies so that the maximum sources of research-based information were available for this review. The same search strategy was employed for the adult, paediatric and staff literature searches, although the search terms were different. The search terms used in the adult literature search used were synonyms and variations of 'isolation' and 'experience' (see Appendix 1). Literature was found through a combination of electronic database searches, incremental searching and manual hand searches. The electronic databases searched were The Cochrane Library, Allied and Complementary Medicine

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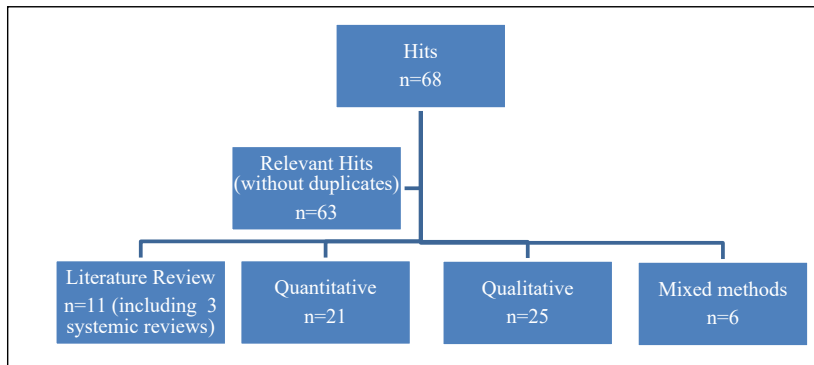
Database (AMED), Applied Social Sciences Indexes and Abstracts (ASSIA), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Excerpta Medica Database (EMBASE), OVID Medline, PsychINFO and Web of Knowledge. The electronic searches were conducted periodically between 2008 and 2019. Incremental searching is the use of references from one piece of literature to find other relevant papers (Crookes & Davies, 2004), this did not identify any further studies. Manual searches of relevant journals (Journal of Infection Prevention and Nursing Children and Young People) were conducted between 2007-2017 to ensure that the search was comprehensive and to account for any papers overlooked by electronic searching. Hand searching went back to 2007, as this was deemed acceptable for pragmatic reasons, however this did not yield any additional studies in this search. Inclusion and exclusion criteria were applied to determine relevant hits (see Table 2.1 below).

Table 2.1 Inclusion/Exclusion Criteria for Adult literature

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">• Full text• Printed in English• 1970-2019• Primary data sources	<ul style="list-style-type: none">• Abstract only• Any studies requiring translation• Pre 1970• Secondary sources of data, e.g. audit or service evaluation

The adult literature searches included studies from 1970-2019. The results from the adult literature search are presented in Figure 2.1.

Figure 2.1 Results from Adult Literature Search using Electronic Databases



After each search had been undertaken, and inclusion or exclusion criteria had been applied, the selected relevant papers were critically appraised. Critical appraisal of all papers; adult, paediatric and staff literature were critically appraised using the relevant Critical Appraisal Skills Programme (CASP) tools (CASP, 2018a; CASP, 2018b; CASP, 2018c; CASP, 2018d), in conjunction with Greenhalgh's tool for critical appraisal (2014). These tools were selected for ease and facilitated comparison between a diverse array of methodological approaches to a research question. The main determinants of quality of the study were concerned with reviewing the study design, the ethical considerations, sample, reviewing rigour, bias and analysis methods congruent with the research methodology (Greenhalgh, 2014).

The adult literature search produced a heterogenous sample of research papers, which had different research methodologies and different demographic groups that were isolated in hospital for different pathophysiological reasons. The studies were of varying quality, some with single cases, others with multiple participants, multi-centre, robust qualitative and quantitative methodologies. A summarising table of the adult literature can be found in Appendix 2. The adult literature was thematically analysed, as there were clear themes within the data: 'coping', 'emotional response', 'physical environment', 'social isolation', 'PPE' and 'privacy'. This summary of the adult literature serves as a background orientation to the experiences of patients in isolation which provided context to review the paediatric literature in Section 2.3. The methods used and sample sizes within the adult

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literature afford greater rigour than the paediatric literature presented in the Section 2.3, and therefore provide more validity, which is why it was necessary to present the adult literature within this chapter.

2.2.2 Coping

Coping was a word that was utilised widely in the literature with regards to both the participants' illness and their episode of isolation. Participants in the studies had distinctive strategies to cope with the situation; which were identified as distraction (Annibali et al, 2017; Collins et al, 1989; Knowles, 1993; Madeo & Owen, 2002), prior preparation and familiarity (Barratt et al, 2011; Bennett, 1983; Cava et al, 2005; Collins et al, 1989; Dunn et al, 2016; Gaskill et al, 1997; Pacheco & Spyropoulos, 2010), religious affiliations (Campbell, 1999; Gaskill et al, 1997), "switching off" (Campbell, 1999) and support networks (Gaskill et al, 1997; Holland et al, 1977). Vottero & Rittenmeyer (2012) and Barratt et al (2011) state that adaptation is fundamental to coping with isolation, and there are many factors that aid the process of adaptation. Lee et al (2011) purported using cognitive mechanisms and adequate external support were fundamental to coping with isolation whilst in hospital as part of their oncological therapy. However, Stajduhar et al (2000) described participants as comprehending their illness more rapidly in isolation and struggling to cope with this due to lack of social contact. Furthermore, Dunleavy (1996) purported that the degree to which isolation is enforced was comparable with the ability to cope. In many of these studies it was challenging to distinguish the experiences of coping from the experiences of illness and hospitalisation, from the experience of being in isolation. With the exception of Vottero & Rittenmeyer (2012) which was a systematic review, and Barratt et al (2011) which was a literature review, all of the studies within this section were small sample sizes, based on one ward, or with specific reasons for infection such as a specific pathogen. Thus, reducing the transferability of the findings beyond the context of the studies and this may account for some of the divergent findings within this theme.

Considering the wider context, isolation in society can occur as a consequence of a physical barrier (enforced isolation for protection or punishment) or as a personal choice to isolate themselves from society (Taylor et al, 2018), in which the responses align with the hospital isolation literature presented here. In hospital, isolation does not come as a choice

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and therefore it is possible to understand that the need for single room isolation may provoke challenges in terms of coping with enforced segregation from the wider ward and society. Gerst-Emerson & Jayawardhana (2015) state that social isolation can impact a person psychologically, physically and socially.

2.2.3 Emotional Response

Participants displayed an array of emotional responses to isolation; anxiety and depression (Abad et al, 2010; Catalano et al, 2003; Criddle & Potter, 2006; Davies & Rees, 2000; Day et al, 2013; Gammon, 1998; Gordon, 1975; Ibert et al, 2017; Knowles, 1993; Kohle et al, 1971; Lewis et al, 1999; Morgan et al, 2009; Rees et al, 2000; Sasaki et al, 2000; Tarzi et al, 2001; Tecchio et al, 2013; Wilkins et al, 1988; Zerbe et al, 1994), stress (Annibali et al, 2017; Mackellaig, 1987), feeling shunned (Mayho, 1999), feeling vulnerable (Skyman et al, 2010), onset of psychological symptoms (Denton, 1986; Sasaki et al, 2000), loneliness (Florey et al, 2009; Knowles, 1993; Madeo & Owen, 2002; Oldman, 1998), anger (Abad et al, 2010; Kennedy & Hamilton, 1997) and low mood (Kelly-Rossini et al, 1996; Kennedy & Hamilton, 1997; Davies & Rees, 2000; Rees et al, 2000), yet some felt positive emotions such as having time for reflection (Barratt et al, 2010; Oldman-Pritchard, 2003). Rees et al (2000) highlighted the difference in depression scores when patients scored themselves, compared with staff scoring, where staff underestimated depression scores in patients. This identified the importance of knowing who is providing the data as some of the older papers used observational data only, without patient involvement.

Overall the hospital experience was reported less favourably by patients in isolation as described in Gammon & Hunt (2018), Gasink et al (2008), Gordon (1975) Livorsi et al (2015), Lupion-Medozza (2015) and Siddiqui et al (2018). However, these studies all collected quantitative data and did not explore the reasons for the less favourable experience, therefore some of these findings may have been attributable to disease process rather than isolation itself. Holland et al (1977) did not demonstrate a difference in anxiety and depression scores between isolation and hospitalisation on a main ward. These differences may be attributed to the differences in data collection methods and ability to report their feelings, different reasons for isolation or simply the date of data collection. This demonstrates the heterogeneity of the studies within this literature review. Lewis et al (1999) identified that there is a lack of understanding of the experience of isolation,

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specifically the emotional response, which challenges practitioners to provide evidence-based care to patients, as there is such variation in responses and the research available is small scale, limited to certain conditions and much of it is dated.

Within the more recent literature is a study by Wassenburg et al (2010) where patients were only in short term, source isolation, and there was no noted impact on anxiety and depression levels. However for oncology patients, where isolation can be for a prolonged period, the solitude of a single room caused increased stress as they had more time to confront their mortality without the distraction of the rest of the ward (Biagoli et al, 2017; Dunn et al, 2016; Kohle et al, 1971), demonstrating the differences between source and protective isolation and the condition-specific and context-specific nature of these studies. Biagoli et al (2016a) and Biagoli et al (2016b) stated that isolation affords the patient privacy to display their emotions, yet the person cannot truly close the door to the outside world. This was demonstrated in the participants' internal struggle for social contact and privacy to aid their emotional response to isolation. Furthermore, this demonstrates the challenge to separate the intertwined nature of the emotional impact of illness and the emotional impact of isolation, thereby, calling into question the generalisability of these findings to other isolation settings. This may account for the single disease nature of the research presented thus far, and the need for heterogenous sample to be explored.

The loss of independence, loss of control and enforced passivity caused by isolation was described as frustrating and anxiety evoking by patients (Barratt et al, 2010; Criddle & Potter, 2006; Kohle et al, 1971; Gammon 1998; Gammon, 1999; Gaskill et al, 1997; Mayho, 1999; Mehrotra et al, 2013; Oldman-Pritchard, 2003; Tarzi et al, 2001; Thain & Gibbon, 1996; Vottero & Rittenmeyer, 2012). In a systematic review, Abad et al (2010) concluded that isolation had a negative effect on wellbeing and behaviour. Conversely, the freedom that isolation provided was preferred by some participants (Newton et al, 2001; Oldman, 1998). Dunleavy (1996) proposed that the degree to which the rules were enforced in isolation affected the overall patient isolation experience. Moreover, the differences in response to isolation could also be attributed to the type of isolation or patient personality type. Many of the studies did not provide this level of detail about their participants, or were single case studies (Mayho, 1999; Oldman-Pritchard, 2003) meaning that these findings must be considered judiciously.

2.2.4 Physical Environment

The physical environment of isolation was described as “a prison cell for the contagious disease patient” (Bennett, 1983), a prison (Thain & Gibbon, 1996), claustrophobic (Gaskill et al, 1997; Gordon, 1975), “living within four walls” (Barratt et al, 2010) and confined (Barratt et al, 2011; Campbell, 1999; Cava et al, 2005; Knowles, 1993; Lewis et al, 1999; Mackellaig et al, 1987; Skyman et al, 2010; Thain & Gibbon, 1996). The design of the room impacted the overall experience of isolation (Barratt et al, 2011; Van de Glind et al, 2007). For the rehabilitation patients in Kennedy & Hamilton (1997), Oldman-Pritchard (2003) and Skyman et al (2010), the space restriction impacted upon their exercise programme and subsequently their overall recovery. The view outside gave participants a connection to the world (Collins et al, 1989; Kennedy & Hamilton, 1997; Skyman et al, 2010; Ward, 2000). Madeo (2003) suggesting that the environment impacted upon their experience as they were confined to the four walls, therefore there was no distraction from external sources. The walls of the isolation room created a barrier to relationships (Barratt et al, 2010), activity (Ward, 2000), education and knowledge (Gasink et al, 2008) and other senses (Gaskill et al, 1997). Biagoli et al (2017) described the physical barrier as a positive aspect of care as it provided a defence for the participants to defend their loved ones and a defence from expressing their suffering. Similarly, Kelly (1999) described patients restricting visitation to isolate themselves and protect others. This highlights the differences between source and protective isolation, and the need to protect others from disease compared with protecting the patient emotionally.

Sensory deprivation was a theme in five studies (Denton, 1986; Gammon, 1999; Kohle et al, 1971; Oldman-Pritchard, 2003), with some participants describing heightened sensory perceptions to sounds and smells when coming out of isolation (Gaskill et al, 1997). Collins et al (1989) highlighted the need for more “extensions to the world” to allow for the social contact that they desired despite the physical barrier. The impact on sensory processing has only been reported in papers where patients were isolated for longer periods of time, for both source and protective reasons. It aligns with the need for social contact to relieve the symptoms of sensory deprivation. In light of modern technology there are now increased methods of providing this social contact to relieve the incidences of sensory deprivation. Malhotra et al (2018) explored the effects of using a “Red Box” (a room outside the single room with a phone into the single room to aid communication without

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the direct physical contact, but the patient can visualise the person using the red box) to improve communication with people in isolation, and they noted that there was an improvement in communication between staff and patients, and family and patients. However, the “Red Box” did not remove the need for physical contact, touch and smell of their loved ones. This presents the issue that although there is social contact in one form, whether that is via social media or through a “Red Box”, this cannot replace the human need for social and physical contact (Gupta, 2018). Humans are social beings and they exhibit a pervasive need for others (Gerber, 1997). Modern technology may partially or fully substitute this need for others whilst in isolation, or certainly support the removal of sensory deprivation, yet it does not remove this fundamental need of humans for contact.

2.2.5 Social Isolation

A lack of social contact appeared to be one of the strongest sources of stress as a consequence of isolation. Participants expressed feelings such as loneliness and seclusion (Abad et al, 2010; Barratt et al, 2011; Bennett, 1983; Biagoli et al, 2016a; Biagoli et al, 2016b; Campbell, 1999; Cava et al, 2005; Gammon, 1999; Gammon & Hunt, 2018; Knowles, 1993; Madeo, 2003), lack of “emotional warmth” (Holland et al, 1977), feeling “worlds apart” (Holland et al, 1977) and in a systematic review this theme was described as “fractured human connectivity” (Vottero & Rittenmeyer, 2012). Patients who had been in an open ward described others as a source of company and comfort whilst hospitalised and they missed this interaction with other patients when isolated (Campbell, 1999; Knowles, 1993; Ward, 2000). Kohle et al (1971) described a lack of community in isolation, where there was complete dependency on the staff. Solitude was valued by some participants as it rendered them free of responsibilities of being sociable (Biagoli et al, 2017; Campbell, 1999; Knowles, 1993; Madeo, 2003). However, in a systematic review by Vottero & Rittenmeyer (2012) this solitude was described as “enforced loneliness”. For some patients the period of isolation was part of their trajectory to wellness (e.g. post bone marrow transplant [BMT]), whereas for others isolation was an inconvenience as part of treatment (e.g. acquisition of HCAI). Therefore, the concept of enforced loneliness or solitude for reflection may be viewed considerably differently dependent upon the reason for isolation. Furthermore, at different points in their illness trajectory patients may seek or avoid social contact. Oncology patients in a study by Campbell (1999) said that isolation was easier to cope with when they felt unwell, as they wanted privacy during this time. As

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patients began to improve physiologically, they desired to be more active and the lack of space and social contact was a source of frustration (Collins et al, 1989; Kennedy & Hamilton, 1997).

The importance of visitors to alleviate loneliness and boredom was highlighted in a number of studies (Barratt et al, 2011; Collins et al, 1989; Criddle & Potter, 2006; Florey et al, 2009; Gaskill et al, 1997; Madeo, 2003; Madeo & Owen, 2002; Oldman, 1998; Oldman-Pritchard, 2003; Thain & Gibbon, 1996; Ward, 2000). In a number of the qualitative studies participants described relying on staff for interaction and socialisation (Campbell, 1999; Collins et al, 1989; Gaskill et al, 1997; Holland et al, 1977; Rossini et al, 1996; Thain & Gibbon, 1996). This acknowledges that time spent alone compared with time with company is a human variant, and a lifetime variant, and it is influenced by a person's need at that time for interaction or solitude. This would need to be explored by the staff with the patient, however this could differ in paediatrics, where there is usually a parent resident, and frequently acting as a proxy and a voice for the child. This demonstrates one area where this adult literature may not be entirely transferable to a paediatric population.

The literature also attested that there is an increased need for communication to reduce the psychosocial effects of isolation (Denton, 1986; Pacheco & Spyropoulos, 2010; Ward, 2000). Intriguingly, Abad et al (2010), Evans et al (2003) and Vinski et al (2012) highlighted that the frequency and length of visits from staff were considerably reduced when in isolation, which could have impacted the level of loneliness. Evans et al (2003) demonstrated that contact time in isolation was lower with staff, in addition to receiving half the number of contacts with health care providers compared with patients on the main ward. Although this study does not directly report the patients' experience of isolation, it has been included as the frequency and length of interaction with staff will impact the overall experience of isolation. This data also provides a baseline for comparison between the experience of hospitalisation and isolation. Barratt et al (2010) commented that isolation impacts upon the quality of care negatively. This is supported by supplementary literature that suggested that the frequency of staff visits in isolation was reduced and subsequently patient safety was an issue (Saint et al, 2003; Stelfox et al, 2003).

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2.2.6 PPE

PPE caused mixed responses from the participants in the literature, although it was not heavily represented in the data. Participants discussed that it became hard to recognise nurses due to PPE (Gaskill et al, 1997) and that there was a fear associated with staff wearing PPE (Gammon, 1999), describing that it was hard to develop relationships with staff when they donned PPE. In Knowles' paper (1993) PPE was described as an inconvenience with one participant stating "you can't have light or brief contact, you have to make an effort to get someone to come in and then they have to put the masks on, so you don't want to trouble them too much", which is echoed in the staff literature in Section 2.5. The challenges in the use of PPE may explain the reduced frequency of visits in isolation from staff described in Evans et al (2003) and Morgan et al (2009). In Chittick et al (2016), participants who responded to a Likert scale survey felt safer as a consequence of contact precautions including PPE, however as mentioned earlier, this may have been due to being in protective isolation and Chittick et al (2016) did not include participants in source isolation. Holland et al (1977) suggested that PPE caused a reduced ability of the staff to physically show emotional warmth to their patients and Roderick et al (2017) identified that there was a lack of recognition of healthcare workers when wearing PPE, which interfered with development of relationships with staff. Patients ranked the ability to identify health care workers role as important and when large stickers with name and role were applied to the gown the participants described an improved experience as it enhanced the familiarity of the staff to the patients (Roderick et al, 2017).

Stigma attached to PPE was highlighted in the literature as an issue for participants (Anderson et al, 2011; Cava et al, 2005; Gammon, 1999; Lewis et al, 1999; Mackelaig, 1987; Madeo, 2003; Madeo & Owen, 2002; Oldman, 1998; Rees et al, 2000). Skyman et al (2010) suggested that PPE highlighted the fact that a patient is contagious and that they were then labelled by other patients, which was demonstrated in the divergent findings between patients in source isolation who felt stigmatised (Anderson et al, 2011; Gammon, 1999, Rees et al, 2000), compared with patients in protective isolation who did not mind the use of PPE only that it reduced contact (Mackelaig, 1987; Stajduhar et al, 2000). Pacheco & Spyropoulous (2010) and Knowles (1993) described inconsistent practices between staff in terms of the use of PPE for patient interaction, which caused emotional

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distress and confusion, further demonstrating the context-specific nature of these findings due to the differences in clinical practice worldwide in terms of isolation care.

2.2.7 Privacy

Privacy was alluded to throughout the previous themes, however it appeared in many studies, thus warrants a theme of its own. In a case study by Oldman (1998), the participant found comfort in the time for reflection. For some, isolation afforded them privacy from being watched as they would be when on an open ward (Barratt et al, 2011; Biagoli et al, 2017; Florey et al, 2009), however this only had a moderate effect on their sleep, noise reduction and overall experience (Van de Glind et al, 2007). Gaskill et al (1997) mentioned the need for time alone, but also desiring company and socialisation as a motivator to getting back to normal health. The length of time in isolation is a factor that influenced the findings within other themes. In this theme Barratt et al (2011) and Florey et al (2009) explored the experiences of source isolation in district general hospitals for short periods, compared with Biagoli et al 2017 who reviewed the oncology patients experience of isolation following stem cell transplantation. Therefore, the need for privacy may not be associated with the length of isolation, but may be associated with the personality of the patient, their need for social contact or context-specific factors such as staffing levels and distraction available.

Oldman-Pritchard (2003) commented that although the room afforded privacy, often there was no respect for that privacy with people entering without knocking, or looking in as they passed the room. This highlights the need for patients to control their environment and their level of socialisation which is demonstrated in the literature (Gasink et al, 2008; Gaskill et al, 1997; Madeo & Owen, 2002). Kohle et al (1977) described this concept as the loss, and control, of autonomy. Van de Glind et al (2007) highlighted that control over the environment allowed for noise control and better sleep, improving the experience for the patient.

2.2.8 Understanding the Need for Isolation

Within the literature there are gaps in patients' and professionals' knowledge of infection transmission, and therefore misunderstanding regarding the appropriate use of PPE and isolation precautions necessary (Anderson et al, 2011; Beam et al 2015; Dramowski et al,

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2016). The professionals' lack of knowledge and confidence in their infection prevention knowledge relevant to isolation is described in Section 2.5.4. For patients, understanding the reason for isolation, did not make the experience any easier, but it did aid their compliance and ability to cope with the experience (Campbell, 1999; Gasink et al, 2008; Newton et al, 2001). However, the knowledge dissemination in terms of isolation precautions was variable to the patients within the studies (Campbell, 1999; Gasink et al, 2008; Newton et al, 2001). This is also noted in the staff literature in Section 2.5.4, due to different levels of knowledge in terms of infection prevention. Despite this, Chittick et al (2016) and Collins et al (1989) found that most participants understood their reason for isolation. Similarly, Gaskill et al (1997) found that participants had a strong understanding of their reason for isolation and therefore knowing what to expect eased their transition into isolation. Newton et al (2001) described that there were misunderstandings from patients regarding MRSA and the need to be isolated.

Understanding of the reason for isolation does not equate to compliance with isolation precautions, neither does it make it easier to cope with the experience of isolation (Carthey et al, 2011). In their systematic review, Vottero & Rittenmeyer (2012) commented on the impact of staff in having a significant contribution to the patient's experience in isolation, not only in explaining their reason for isolation, but the frequency of visits and communication whilst in isolation. Much of the adult patient literature pertaining to experience of isolation, does not ask about the understanding of isolation and this may be because the literature is predominantly quantitative, and therefore cannot deviate from a structured data collection tool. Whereas in qualitative studies (Anderson et al, 2011; Collins et al, 1989), the level of understanding was explored and contributed to their overall experience of isolation. This demonstrates that the paradigm of research and data collection tools employed within research can yield different results.

2.2.9 Conclusions from the Adult Literature

Many of the adult studies are dated, have small sample sizes and singular research settings. Much of the adult literature is condition-specific which again limited the generalisability even to other adult settings. The heterogeneity of the adult study design and populations studied proved challenging to reach conclusive findings, as a review would aim to do. Furthermore, the fundamental difficulty in using this evidence in the context of a paediatric

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study is the differences in aetiology of disease, the presence of a resident parent in the paediatric population and the psychosocial and developmental differences between adults and children. Yet in view of the lack of robust, large scale studies, the studies presented in this review are currently the best available adult evidence. Despite the flaws in the studies, the evidence base pertaining to adult experiences of isolation is more robust than the paediatric literature due to the number of confirmatory findings and marginally larger scale studies. Overall the experiences of isolation varied for adult patients depending on the type of isolation, their illness trajectory, personality differences, previous life experiences and support available, which may be true of the child's experience of isolation.

2.3 Children's Experiences of Single Room Isolation

The adult literature demonstrated some of the patient experiences of isolation, however as previously explored, children have different experiences and responses due to their psychosocial developmental differences. Therefore, despite the limited paediatric-specific research available, a comprehensive literature search was executed and is presented in Section 2.3.1.

2.3.1 Paediatric Literature Search

This study was founded from a need to answer a clinical question. On reviewing the literature regarding the experience of isolation for children, it was evident that the literature was sparse, dated and had limited transferability to contemporary practice within the NHS and thus this question warranted research. This prompted the literature search to be broadened, and to demonstrate a thorough search. Papers were reviewed back to the 1970s. It is acknowledged that literature from 1970-2019 is a vast time span, however the fundamentals of isolating patients in hospital for infection prevention has not changed significantly in this period. 1970 was selected as the earliest date as several databases do not predate 1970 and the main international isolation guidance was published in 1970 (CDC). Searches were repeated throughout the period of data collection (up to January 2015), and these papers are all presented in this literature review. No relevant studies after 2008 were found during this period. Subsequently, after data collection was completed and during the process of writing up the thesis, the literature searches were re-executed. There were some relevant paediatric studies retrieved during this period 2015-2019 (Curtis & Northcott, 2017, Moola, 2018, Vines et al, 2018), which have been included in this review.

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Literature was found using a combination of electronic bibliographic database searches, incremental searching and manual hand searches as described in Section 2.3.1. For the paediatric literature search the terms were broadened to synonyms of ‘isolation’, ‘experience’ and ‘children/families’ (see Appendix 3 for sample searches and search terms). The initial search did not include the search term ‘infant’. Subsequently with the inclusion of ‘infant’ to the literature search, no additional papers were retrieved. It is likely that the papers within this search were already captured through using the search terms ‘child’ or ‘neonate’. Furthermore, it is likely that the infants were nursed on children’s wards, thus the papers were already included in the searches including ‘child’ as a search term. Strict inclusion and exclusion criteria (See Table 2.2) were applied to the literature to ensure that the data were of the highest quality and relevant to the research question.

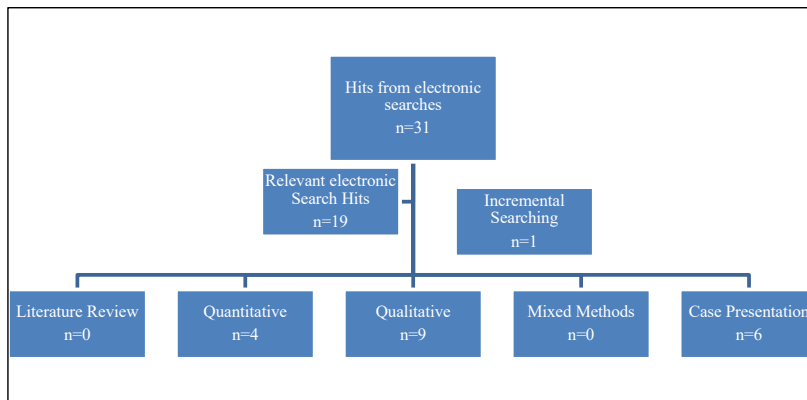
Table 2.2 Inclusion/Exclusion Criteria for Paediatric Literature Review

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">• Full text• Printed in English• 1970-2019• Infant/Child (0-17 years)/parent/healthcare provider perspective of the child’s experience of isolation• Primary data sources	<ul style="list-style-type: none">• Abstract only• Requiring translation• Pre 1970• Studies that explored the parents/staff perspective without consideration of the child’s perspective• Secondary sources of data; e.g. audit, service evaluation

The electronic database searches retrieved 18 relevant studies (Chan et al, 2007; Curtis & Northcott, 2017; Dalton, 1981; Drotar et al, 1976; Freedman et al, 1976; Koller et al, 2006a; Kronenberger et al, 1998; Kutsanellou-Meyer & Christ, 1978; Lazar et al, 1983, McKeever et al, 2002; Moola, 2018; Powazek et al, 1978; Rotegard & Sykepleievitenskap, 2007; Russo et al, 2006; Simons et al, 1973; Tamaroff et al, 1986; Vines et al, 2018; Wu et al, 2005). One further study was found by incremental searching (Broeder, 1985). No studies were retrieved using manual searching of Journal of Infection Prevention and Nursing Children and Young People (2007-2017). The search results are shown in Figure 2.2 below.

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Figure 2.2 Results from Paediatric Literature Search



There were 12 studies excluded (Cardim et al, 2008; Casey, 1989; Chan et al, 2006; Cohen et al, 2008; Dadd et al, 2003; Hall et al, 2007; Kellerman et al, 1976; Koller et al, 2006b, Lesko et al, 1984; Morgan, 2010; Rose & Blythe, 2009; Siegel, 2002) from the 31 yielded. These studies were excluded from this part of the review as they were commentary papers, service evaluations, related to single room accommodation not for isolation purposes, or they used staff perspectives about isolation without considering the child's perspective.

It is clear to distinguish at this point that there were multiple perspectives on isolation that have been presented in the paediatric literature review. The first was the experience of the staff or parents themselves, the second was the staff member/researcher or parents' perception of the child's experience and finally there was the child's voice giving their own perspective. All of these perspectives added to the understanding of the experience of isolation, however it was necessary to distinguish the person describing the experience so that the findings were considered in context. The final 19 papers within this literature review were critically appraised and analysed for common themes. A table of all the studies included in this literature review with their methods, sample sizes and key findings is available in Appendix 4. Although the papers in this literature review were not of high quality with small sample sizes, and mostly condition-specific samples, all the studies have sufficient strengths to make some contributions to this literature review.

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2.3.2 Historical Context to Paediatric Literature

Upon reading the studies presented within this paediatric literature review, it was evident that there were common themes throughout each decade and that the data collection methods altered during these decades. Therefore, Section 2.3.2. serves to provide an overview of the historical context of the paediatric literature.

The literature from the 1970s were all single centre case studies or case presentations of a single patient. Of these studies, one was a case study presentation of twins with immunodeficiency (Simons et al, 1973) and the other two were case study presentations of one child with SCID (Drotar et al, 1976; Freedman et al, 1976). The remaining two case studies in this period were observational in their nature. Kutsanellou-Meyer & Christ (1978) studied 11 patients and seven parents on an oncology ward and Powazek et al (1978) conducted a case study of 123 children and their mothers applying scoring systems to ascertain their levels of mood and depression. All the studies from the 1970s focused on protective isolation, specifically SCID (Drotar et al, 1976; Freedman et al, 1976; Kutsanellou-Meyer and Christ, 1978), Lymphohypogammaglobulinaemia (Simons et al, 1973) and oncology (Powazek et al, 1978). The interest in SCID isolation could be ascribed to the discovery of the molecular cause of human SCID in 1972 (Buckley, 2004). Due to the extended period of isolation required for SCID in the 1970s, many of the studies from this time investigated the effects of isolation on development (Drotar et al, 1976; Freedman et al, 1976; Simons et al, 1973). The limitation within the single case presentation and single centre case study method considerably reduces the transferability of the findings to general paediatric wards, particularly in current practice.

The literature from the 1980s was very similar to that of the 1970s; with the focus on developmental literature rather than experiential data. Four relevant studies were published during this decade. Of these studies two were single case study presentations of one child with SCID (Dalton, 1981; Lazar et al, 1983). One of the studies attempted to address some of the methodological flaws from the single case study method which predominated the studies in 1970s, by completing a case study of four children with SCID (Tamaroff et al, 1986). The fourth study of the 1980s, was the first study to explore source isolation in a general paediatric setting and it was completed in 1985 by Broeder; studying six children aged six-11 with brief, non-complicated illness. Although this was a single-ward study, it

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did incorporate children with different reasons for hospitalisation within the study, meaning that this study afforded greater generalisability to general paediatric wards.

In the 1980s there was a movement to increase children's rights within UK society, clinical practice and research (Casey, 1993). Family-centred care, although a development of the 1950s as a result of the work by Bowlby (1953) and Robertson & Robertson (1989) was not incorporated into research and practice greatly until the 1980s (Harrison, 2010; Lewis et al, 2007). By the 1980s there was greater understanding of children's rights and the need to incorporate their opinions into clinical practice (Harrison, 2010). Broeder (1985) used a child-centred methodology beyond its years, based on the 'draw and write technique'; to explore what six children aged six-nine years in source isolation thought about being in isolation. This is a method which is used in contemporary research with children as it is age-appropriate and can contribute to good memory recall (Kirk, 2007). Broeder's study used a child-centred methodology which allowed the child greater opportunity to truly tell their story. Despite the groundbreaking nature of this study, there were limitations of analysing data using the 'draw and write' methodology such as the risk of misinterpretation of the images, lack of confidence or enthusiasm for drawing from the children or lack of health to facilitate this method (Backett-Milburn & Mckie, 1999, McWhirter, 2014). Furthermore, draw and write method in latter years has received some criticism in terms of inconsistent methodology and analysis, and ethical issues in its use (Backett-Milburn & Mckie 1999; Hortsman et al, 2008; Sewell, 2011).

Between the 1970s and 1990s, the CDC produced further guidelines on isolation care. However, with increased knowledge of infection prevention, the guidelines had become increasingly complex due to being disease-specific, which led to challenges in the implementation of the guidelines (Parker, 1999), until the revised isolation care guidelines were published in 1996 (Garner, 1996). Despite the advances in isolation care, during the 1990s only one study was identified pertaining to the paediatric experience of single room isolation, and it focused on the parents' perspectives of isolation, not the child's perspective (Kronenberger et al, 1998). During the 1990s there was a dearth of literature pertaining to children in isolation. Although society had become less paternalistic and the 1989 Children Act advocated for including children in research, the ethical challenges of

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researching with children remained, which may account for a lack of paediatric specific literature during this period (Kirk, 2007).

In the 2000s there were studies exploring both source and protective isolation, however the majority continued to explore singular conditions. Nine relevant studies were retrieved for this decade. Of these studies, one was a quantitative study which sent out 51 parental questionnaires (53% response rate) to understand experiences following an admission for gastroenteritis or RSV to an isolation unit (Rotegard & Sykepleievitenskap, 2007). One was a mixed method study (Russo et al, 2006) which explored the experience of isolation as a consequence of CF through questionnaires to parents (192 sent, 43% return rate) and children (101 sent, 23% return rate). The other four studies in this time period were qualitative studies. Chan et al (2007) conducted interviews with seven parents following their child's admission with a diagnosis of suspected Severe Acute Respiratory Syndrome (SARS). Similarly, Koller et al (2006a) undertook 23 interviews with children, parents and healthcare workers to explore the experience of suspected SARS on an isolation unit. McKeever et al (2002) interviewed five mothers to understand the experience of isolation as a result of Severe Combined Immunodeficiency (SCID) (McKeever et al, 2002). Curtis & Northcott (2017) conducted an ethnographic study to explore the impact of single and shared rooms in hospital. The study consisted of observation and interviews with children, parents and staff. Moola (2018) and Vines et al (2018) interviewed children and young people with CF about their experience of isolation. The final study by Wu et al (2005) conducted interviews with 11 parents of children undergoing a BMT.

In 2003, there was the first recorded outbreak of SARS, worldwide there was widespread fear of contagion, most specifically in the country of origin (China). Two studies referred to the experience of isolation as a result of SARS (Chan et al, 2007; Koller et al, 2006a), however these data need to be considered with due caution as these findings may not be transferable to other settings or clinical conditions. Within the UK in this decade, there was increased concern to explore children's perspectives on account of documents such as Every Child Matters (Department for Education Services, 2003) and the National Service Framework (DH, 2004) which suggested that children have valuable perspectives that should be incorporated into practice. However, within this paediatric literature review, there remain three studies where the voice of the child is not included within the methods,

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and three studies which focus on parents' experience of isolation, not the child's experience.

In summary, by 2000-2018 the research became more varied in terms of methodology; encompassing parents and children's perspectives in addition to a wider variety of conditions. Despite the different reasons for isolation there were some common themes which will be presented in Section 2.4. Crucially, as a result of the lack of child-perspectives, child-friendly methods, larger sample sizes and variety of conditions, there are no studies which can be entirely transferable to a general paediatric ward caring for children of all ages and a variety of conditions in contemporary practice. The 1970s and 1980s literature often included staff/observer perspectives on isolation whereas the literature from 2000s tended to focus on the parent and child perspectives. The large number of qualitative studies within this literature search, demonstrate how explorative this research area is at present.

2.4 Thematic Analysis of Paediatric Literature

The paediatric literature papers found in the review were thematically analysed. The themes were: 'development', 'parental presence', 'anxiety', 'PPE', 'separation' and 'understanding the need for isolation'.

2.4.1 Development

Freedman et al (1976) showed delayed social development through the child's insular play activities in isolation, whereas Drotar et al (1976) described the social behaviour and maternal attachment as age-appropriate. Dalton (1981) demonstrated that his case had a preference for people as opposed to inanimate objects, however he did not discriminate among people and showed little affection. Dalton (1981) highlighted delays in development, however with intervention and time, development did proceed normally. As these are single case studies and therefore the external validity is limited, it is plausible that much of the observed behaviour of the children was attributable to the maturational process or personality alone, not isolation. The level of description in these studies highlighted a key flaw of the single case study method and a lack of description from the author regarding methods used and specific details that contextualise the findings.

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Description is vital in case studies to enable readers to make inferences to their own clinical area (Stake, 1995). Clinical practice has developed significantly from the 1970s, which may render some of the findings irrelevant to contemporary practice, specifically length of stay required for SCID. The findings related to social development were contrasting, and due to the limited explanation of the cases, it was difficult to draw any meaningful inferences for current practice from the findings of these studies.

Freedman et al (1976) described that cognitive and intellectual developmental proceeded normally and he did not demonstrate any form of sensory deprivation. The infant in Drotar et al (1976) had below average intellectual development at 12 months, however by 16.5 months his development met normal levels. In terms of motor development, Freedman et al (1976) demonstrated enhanced locomotor skills in their case. Dalton (1981) showed that motor development of his case was in line with normal developmental milestones. Tamaroff et al (1986) demonstrated differences between their four cases in terms of cognitive development and motor development. Despite Tamaroff et al (1986) using more cases to demonstrate commonalities in the findings, this study highlighted differences of development within the children studied and clearly larger samples were required for significance to be attributed to the findings. In Tamaroff et al (1986) there were delays in areas of development in two of the cases, yet the other two cases had no developmental or discernable psychological effects of isolation. This identified that there may be many other factors in addition to isolation which could have accounted for these findings. The main difference between the two sets of children in Tamaroff et al's study (1986) was the frequency of visiting from their parents. This could have indicated that the parents spent their time encouraging development when visiting, or that the children had more contact with people in general due to their parents being there, or simply that each child had differing levels of cognitive ability when they entered isolation. Without larger scale robust studies, it is impossible to attribute these findings to the consequence of isolation alone.

In terms of language development, Lazar et al (1983) showed their case had normal babbling aged nine months, however by 21 months he was still not talking, and even post-discharge he rarely initiated discourse even though he was capable of doing so. Dalton (1981) described deficits in language development and Drotar et al (1976) reported an initial delay in language and discourse development. This reflects the need for robust

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multi-case studies to be conducted, as with single cases it was impossible to distinguish the effects of isolation from the maturation process. Freedman et al (1976) showed a delay in desire to initiate interaction and language in their case. However once again, it is impossible to distinguish the effects of isolation from the normal maturational processes. Moreover, the level of input and interaction from staff and family is not discussed in these papers, which may be as a consequence of this study coming before the integration of family centred care into everyday paediatric practice.

Interestingly, none of the papers identified within this literature review that were published beyond 1980s explored the effect of isolation on development. This may be attributable to the length of isolation precautions for children in hospital in 1970s and 1980s and therefore, the noticeable differences in development. It could also be characteristic of the period of research, that development is no longer a key area of research unless executed longitudinally (Davies et al, 2014; Merrick, 2013). Despite this theme of research not being continued beyond 1980s, the notion of delayed development, in particular social development, being hindered by isolation transcends the following themes in terms of sensory deprivation and social isolation, albeit not pertaining to development, but related to the psychosocial sequelae of being isolated.

2.4.2 Parental Presence

Parental presence is highlighted as an issue that impacts upon the child's experience of isolation in a number of studies. In the studies post 1990 within this literature review, family centred care and a parent resident with their child was commonplace within practice, which may account for the fact that parental presence was not described in any of the pre-1990 literature. In Russo et al (2006) rather than wanting to be resident, the parents felt pressured to spend increasing amounts of time with their children whilst in hospital. Nurses in Curtis & Northcott (2017) noted that children in hospital require additional care beyond that which they require at home due to their illness. In children's nursing it is generally assumed that a parent will take on the additional role, whereas one nurse comments in her interview that in adult nursing the nurses would take on this care need. However, other nurses within this study (Curtis & Northcott, 2017) asserted that parents would be caring for their child at home and should continue this in hospital, without acknowledging any additional roles they may have to assume due to their child's illness, or

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the fact that they may have to continue their life outside of hospital potentially with other children (Wu et al, 2005). Additionally, children in hospital, but not in isolation can at least spend time playing with other children or engage in group activities thereby allowing parents to share some of the work involved in attending to play needs, which is not necessarily the case among children in isolation. The majority of parents in Curtis & Northcott (2017) were willing to continue this level of 'nursing' care, with one mother commenting that if they didn't have resident parents they would need many more nurses to carry out all the care required and the parents were very sensitive to the high nursing workload anyway, demonstrating the importance of parental presence on paediatric wards. Curtis & Northcott (2017) compared the experience of shared rooms and single rooms and found one restriction on a single room was that there was no community for the children, support or sociability, including relying on other parents to observe their child whilst a parent left the ward for a short period or social support which was also described in Wu et al (2005). Curtis & Northcott (2017) triangulated the data sources of child, parents and nursing staff, which provided an overview of the experience, yet through this method increased validity of the findings.

In addition to the pressures of leaving their children, parents in a number of studies commented on the pressure to manage their time between family at home and their child in isolation and along with the associated financial and workload burdens (Chan et al, 2007; McKeeever et al, 2002; Russo et al, 2006; Wu et al, 2005). Although this is a finding that is true of the hospitalised child literature (Hopla et al, 2005; McFeeters, 2016), the parents in Russo et al (2006) felt an increased financial and time burden as a result of their child being in isolation due to the increased need to visit their child to ensure that they were not lonely. In addition, in interviews in Koller et al (2006a) parents reported that children had lasting separation anxiety when discharged. Just five children were interviewed, and there was more focus placed upon the parental perspective and that of the staff, which may not have provided an accurate insight into the child's experience of isolation (Koller et al, 2006a). As this study was conducted on children with SARS, where strict isolation policies were implemented, this affects the potential transferability of the findings to general children's wards. Rotegard & Sykepleievitenskap (2007) desired more information regarding leaving isolation, as there was no clear guidance on how this process would occur and what the impact would be on their life at home.

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2.4.3 Anxiety

The experience of isolation was observed in the larger studies of Kutsanellou-Meyer & Christ (1978) (11 children and seven parents) and Powazek et al (1978) (123 children and their mothers). Separation was an issue presented in Powazek et al (1978), mainly for older children who were nursed in protective isolation. This study concluded through behavioural rating scales that older children scored higher than younger children in terms of experiencing anxiety. This study observed a large sample of 123 children and their mothers which is a key strength of the study. However, it did not distinguish between whether the anxiety recorded was caused by isolation or other factors (Powazek et al, 1978). Furthermore, the behavioural rating scales were described as one scale, which seems inappropriate when considering children of all ages as it did not factor in their developmental differences, which could question the validity and reliability of such a scale. In Curtis & Northcott (2017) nurses suggested that parental anxiety was due to leaving their child to go and get help from a nurse and being torn between leaving their child and the need to find someone, and not knowing the correct situations where it was appropriate to seek help.

Using standardised questionnaires and tests in a quantitative analysis, Kronenberger et al (1998) found that mothers had high depression and stress scores. This study only investigated the maternal scoring, and isolation was described as a stressor. Yet, the data from the tests did not differentiate between the stresses of illness and isolation. This study explored only the mothers' perspectives of isolation, therefore these findings may only be applicable to the mothers, not the children. In Wu et al (2005) parents described how their changes in moods were reflected in their child's behaviour. Considering the theory of emotional contagion, some of the heightened maternal stress scores in this study need to be considered in the context of the child and what they may have been coping with, as the maternal behaviours can unconsciously mirror onto the child, affecting the child's experience (Hatfield et al, 2009).

Anxiety was not heavily featured within the paediatric findings, mainly the parental experience in this literature review. To an extent, this reflects the fact that many of the studies pertain to long-term conditions (SCID, CF, oncology) and consequently, they were familiar with many of the hospital processes and procedures, therefore the use of isolation

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was not unfamiliar or anxiety provoking. In addition, the data collection methods used were limited, thereby limiting our understanding of anxiety as a phenomenon among children in isolation.

2.4.4 PPE

One main theme from Broeder's study (1985) was fear of PPE. The children found PPE scary as they could not see the nurses properly and their voices were muffled when wearing facial protection. One child in this study misunderstood the purpose of the PPE stating that they wear it so that "they can operate on you". Despite children reporting that PPE was scary and misconceiving its use, only two children depicted PPE in their drawings about their experience. PPE was mentioned in four studies as an issue that affected children's experiences of isolation. In McKeever et al (2002), mothers were required to wear PPE, and they described not eating and leaving the room in order to avoid repeating the entrance procedure of handwashing and gowning up. Mothers resented the PPE as they could not have skin to skin contact with their children, and one described "breaking the rules" to kiss their child (McKeever et al, 2002). This study was specific to SCID, which is extremely rare, and there are few other situations where parents are required to wear PPE, which limits the transferability of the findings, but it also highlights the significant impact this can have on normal family functions. In Koller et al (2006a), participants suggested that the masks impaired their ability to communicate or show emotion, which impaired the relationship between staff and the family. In Rotegard & Sykepleievitenskap (2007), parents wanted more information on the PPE that would be used, so that they could understand the process and avoid inconsistencies in practice. The inconsistencies were described as a source of stress for the parents.

The use of PPE in paediatric literature is not suggestive of any social stigma or feeling ostracised from the ward community as the adult patient literature had suggested (Anderson et al, 2011; Cava et al, 2005; Gammon, 1999; Lewis et al, 1999; Mackelaig, 1987; Madeo, 2003; Madeo & Owen, 2002; Oldman, 1998; Rees et al, 2000). This may be because the children, when isolated, are less aware of the rest of the ward and remained fixed within their social construct of their family and the isolation room, rather than being aware of what other people may think of them. Furthermore, the child's egocentricity in terms of their development may make them unaware that being in isolation had any

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different implications to a child on the main ward (Hoffman et al, 2013), and this may be reflected in the lack of child perspective within the literature within this theme.

2.4.5 Separation

Separation was an issue that came out of Broeder's study, with five out of six children drawing themselves alone in isolation. By the late 1980s it had become commonplace for parents to be resident with their child in hospital and have unrestricted visiting times (Davies, 2000). Therefore, research conducted after this may have significantly different findings due to their parents being present more of the time. Broeder (1985) does not describe the presence of parents on the ward in the paper.

Separation from family, home and peers was an issue highlighted in a number of the studies. Kutsannellou-Meyer & Christ (1978) suggested that children appeared more concerned with separation from their family and friends, than the possibility of acquiring an infection through not being in isolation. Mothers of infants with SCID in McKeever et al (2002) often felt depended upon for caregiving in order to lighten the nurses' workload, yet paradoxically they were not allowed to be resident. Therefore, mothers felt separated from their infant, but also separated from social contact when caring for their child (McKeever et al, 2002). Mothers in McKeever et al (2002) also suggested that when their child was recovering, they had less contact with staff and therefore felt more socially isolated prior to discharge.

During the SARS outbreak, parents in the studies within this review, were not allowed to be resident, which resulted in parents feeling guilt, pity, fear and that their normal roles were removed (Chan et al, 2007; Koller et al, 2006a). In Koller et al (2006a), children with SARS described feelings of separation and loneliness and missing their family. Despite the increased incorporation of family-centred care in practice, parents of children undergoing BMT in Taiwan were not allowed to be resident, and therefore described similar feelings of guilt that they could visit, but not touch or care for their child (Wu et al, 2005). This resulted in parents not sleeping or eating, and tension being generated between one another (Wu et al, 2005).

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In Russo et al (2006) the children were more concerned about being separated from their hospitalised peers. Vines et al (2018) described isolation as psychologically difficult, causing feelings of difference, separation, loneliness and consequently, sadness through limited social interaction particularly with staff. This could be because the children in Russo et al (2006) and Vines et al (2018) had CF – a chronic condition often requiring regular hospitalisation, which means that they may be used to being separated from their family. Russo et al (2006) explored children's experiences of isolation using questionnaires, however there was limited explanation of the questionnaire format. The key findings from this study were that the children disliked separation from their peers and subsequently wanted computers as a means of maintaining communication with their peers. Moola (2018) conducted their study with a similar population to Russo et al (2006), however due to the era of the research, there was greater use of online communication and this allowed them to create social opportunities to connect with their friends and also provide peer support within the CF community. However, this online interaction was not discussed within the CF population in Vines et al (2018) which may have been representative of the way in which the children were encouraged to interact within their clinic groups. The participants in Moola (2018) were older (10-24 years) compared with 10-17 years in Russo et al (2006) which may also account for greater use of social contact within an online forum.

In most UK clinical situations parents are allowed to be resident, however in the long-term context parents may not be able to stay for extended periods due to other commitments. This is reflected in Russo et al (2006), where parents felt pressure to be resident although it was not feasible for prolonged periods in hospital, which may affect the way the partnership of care between parents and healthcare providers was managed. Rotegard & Sykepleievitenskap (2007) did not comment on separation, however parents did feel that they needed more information on what nurses expected from them and the idea of partnership in care. Findings such as being left alone without parents, loneliness, and for the parents, guilt (Rotegard & Sykepleievitenskap, 2007; Wu et al, 2005) are comparable with the literature related to hospitalisation of children (Hopla et al, 2005; Shields et al, 2004). Without control subjects in these studies, it is difficult to attribute these findings to isolation alone. Although separation may be part of any hospitalisation experience, both

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the duration of treatment, and physical and psychosocial barriers of isolation may intensify effects of the experience.

2.4.6 Understanding of the Need for Isolation

Understanding the rationale for isolation aided coping mechanisms in three studies (McKeever et al, 2002, Rotegard & Sykepleievitenskap, 2007; Russo et al, 2006). In most of the studies there was an understanding and tone of acceptance amongst parents for the need for isolation. In McKeever et al (2002), mothers described isolation as a necessary ordeal which was vital for their child's survival. Parents and children in Russo et al (2006) and children in Vines et al (2018) understood the need for isolation to prevent transmission of infections, but they felt the social impact of this was unfair. Parents in Rotegard and Sykepleievitenskap's (2007) questionnaire study stated that they needed more information about why they were in isolation and what to expect in order to understand the situation better.

For children and adults with cystic fibrosis, they have grown up with the knowledge of cross contamination in terms of infection and therefore most participants had strong understanding (Moola, 2018). However, in response to this understanding participants were grouped into "rule followers" and others who were "questioning the rules" (Moola, 2018). This demonstrates that regardless of the level of understanding of reasons for isolation and subsequent risk to others and themselves, there remains a choice in response to that knowledge and for some they prefer to take the risk and socialise. This internal struggle is similarly represented in the interviews in Vines et al (2018) with adolescents who had CF describing the need to keep in mind the necessity of isolation alongside the desire to meet their own emotional and social needs. Contrary to Moola (2018) participants in Vines et al (2018) explained that on balance they found ways to comply with isolation procedures rather than questioning the rules. Despite their familiarity with the hospital environment and isolation procedures, children in Vines et al (2018) described their challenge in managing change and unfamiliarity in the routine in isolation. This demonstrates that for children who are unfamiliar with the hospital environment, there is a need for them to understand the significant impact that isolation may have, and the need to understand what will happen to them as a consequence of isolation.

2.4.7 Spatial Characteristics

Kutsanellou & Christ (1978) found that the adolescents in their study controlled their own environment by turning the lights off or shutting the curtains in an effort to have greater privacy. Curtis & Northcott (2017) found that although single rooms afforded the family privacy, it also inhibited the nurses providing surveillance to the child and decreased the level of interaction that the child and nursing team had. This demonstrates the enhanced validity of the triangulation of data sources. The difference in these two studies is the length of isolation; in Kutsanellou & Christ (1978) many of the participants were in protective isolation for months whereas in Curtis & Northcott (2017) the reasons for isolation were mainly acute and for short periods. Participants in Moola (2018) described being isolated in their day to day life due to not being able to interact with other children with CF for risk of transmission of infection, therefore they already recognised that isolation was detrimental to their wellbeing and mental health, and that isolation precautions in hospital further compounded these emotions. This resonates with the communication challenges that isolation created for the children and parents with SARS in Chan et al (2006). For children in Broeder (1985) there were feelings of deprivation voiced by the children that they wanted to go to the play room and see other people. Five out of the six participants in Broeder (1985) drew themselves alone in a single room, demonstrating the significance of this notion of being in a single room to them.

Participants in Vines et al (2018) described that they had a perceived disruption to their 'normal' sense of self due to the restrictions of being in a single room and made many comparisons in their interviews with the experiences of children in the main ward. This may be due to the proximity of the isolation rooms with the main wards, or simply that children in Vines et al (2018) have CF and therefore are familiar with the construct of the hospital. A participant in McKeever et al (2002) described the room as "everything.... That's where everything happens" and another mother stated "it's a space that's so isolated". These powerful words denote the all-encompassing nature of the isolation room on the experience for these participants. Although these infants were isolated for prolonged periods as a consequence of SCID, the all-encompassing nature of the room may have been felt in shorter periods of isolation.

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The spatial characteristics were not described with the same powerful linguistics that were used to describe single room isolation in the adult-patient literature. This may be the level of language that children have and their inability to describe an experience with the same level of conviction, or simply that they did not believe the room to be that detrimental to their experience in the way adult patients did. Children often have a parent resident with them most of the time. This may be a key factor on making the single room more familiar and more like home, which may also result in less powerful descriptors used here in this review.

2.4.8 Conclusions from Paediatric Literature

There are some key observations regarding the type of research with children that need to be highlighted at this point. Predominantly the papers published in the 1970s and 1980s investigated the experience through observation and professionals' perspectives. Latterly the studies shifted their focus to the child and parental perspective. The studies from 1970s investigated children in protective isolation, particularly those with congenital immunodeficiencies, whereas the more contemporary studies tended to focus on source isolation. This may have resulted from progression in knowledge in terms of infection prevention and subsequent earlier discharge of the children with immunodeficiencies, thereby meaning there was less research regarding the experience of isolation in protective isolation conducted. Furthermore, with increased surveillance of infections as described by Milstone et al (2010) and greater number of MDROs as recognised by Sandora (2010) in Section 1.1, this may account for the skew towards researching the child's experience of source isolation, ahead of protective isolation in the latter years. This contrasts the adult papers which were relatively evenly proportioned between the experiences in source and protective isolation.

From this paediatric literature review it was evident that source and protective isolation have the potential to impact upon the child's experience of being in hospital, although it is not always possible to distinguish the effect of being in isolation from the child's experience of hospitalisation or from their responses to their illness. It is also possible to say that parental presence impacts upon the patient experience. However the parenting role may alter due to being in isolation as proposed by Pineda et al (2012), who suggests that the normal parenting role is extended to take on a number of nursing roles. Furthermore, a

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number of the factors for causing emotional responses to isolation in this literature review were presented in Linder & Seitz (2016), which explored the child's experience of their oncology treatment and described loneliness, need for normalising their activities, the imposed burden of the illness and loneliness of a single room on the family of the child, which echo the findings of the experience of isolation. Linder & Seitz (2016) does not specify the proportion of time that the children in this study had in isolation and how much in the main ward, thus this reflects the intertwined nature of hospitalisation and isolation experiences, and the need to tease out the effects that are attributable to isolation alone.

The limitations in the methodologies of the literature in this review highlight that the studies mostly sit within the lowest forms of evidence as described in the traditional hierarchy of evidence (Greenhalgh, 2014), namely single case studies and small-scale qualitative research. However, it is argued by Evans (2003) and Dixon-Woods et al (2006) that regardless of the hierarchy, the research method must meet the need of the research, which means that some methods deemed weaker by the traditional hierarchy may be more appropriate to studies where research evidence is lacking. Therefore, due to limited research to date regarding the experience of isolation, it is likely that most studies would be exploratory in their nature and thus small-scale to gain understanding of the phenomena being studied, prior to launching into larger scale, multisite studies. Separate qualitative hierarchies have been proposed, which are usually topped by meta-synthesis or generalisable studies (Daly et al, 2007), which may be more appropriate to judge this literature within this review. However, in this literature review many of the studies have weak methodologies when assessed on the qualitative hierarchy of evidence, small sample sizes, poor response rates to questionnaires, ages not representative of the entire paediatric population, retrospective designs and samples specific to one condition. Only six studies included conditions which commonly present on general paediatric wards (Broeder, 1985; Curtis & Northcott, 2017; Moola, 2018; Russo et al, 2006; Rotegard & Sykepleievitenskap 2007; Vines et al, 2018). Additionally, many of the studies are dated. Therefore, the child's experience of isolation has shown itself to be an area that warrants considerable further research.

One of the key limitations of this literature review is that only eight studies actually researched the child's perspective and of these, only one study used a participatory

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method. Triangulation of data sources was evident in two studies using parent and child dyads and incorporating nursing staff (Curtis & Northcott, 2017; Koller et al 2006a), which enhanced the transferability of the findings. Triangulation of data from different participants is often necessary with children to enhance validity (Domanico et al, 2010), and also highlight differences in perceptions of an experience as demonstrated in Koller et al (2006a). Thus, when reviewing the data on children's experience of isolation as a whole it becomes clear that there is a considerable need for further research, with robust clinical studies that specifically gain the child's perspective on being in isolation in an age-appropriate manner, whilst seeking a heterogeneous sample that can be compared to current general paediatric wards.

Interestingly the themes between the literature pertaining to adults in isolation (presented in Section 2.2) and the paediatric literature in this section are different, with the exception of two (PPE and understanding the need for isolation). Although arguably, 'physical environment' and 'spatial characteristics' are similar, as are 'anxiety' and 'emotional response'; different terms have been selected based on how the participants within the themes described the concept of that theme. Despite the similarities, there are striking differences demonstrating the key differences relating specifically to paediatric care and family centred care within isolation ('development', 'parental presence' and 'separation'). The reasons for the differences in the themes are likely to be associated with the developmental difference psychosocially between the children and the adults in the studies. Furthermore, the nature of the diseases and subsequent psychological sequelae may be different. Children are regularly accompanied by their parents in isolation so other themes such as 'privacy' did not feature heavily in the paediatric data as this is not part of their care in isolation. This demonstrates that there are some fundamental differences and some more subtle differences between paediatric and adult isolation that need to be considered when using adult data in the context of the paediatric isolation experience.

2.5 Staff Perceptions of Single Room Isolation

The parent and children's experiences have shared some insight into the staff perceptions of single room isolation. Although this study was not designed to explore the staff perceptions of isolation, the staff, by their behaviours and interactions can significantly impact the experience that the child and their family may have in hospital (Maben et al,

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2015). However, there remain few empirical studies that explore how staff perceive isolation or focus specifically on the impact that staff can have on care in isolation. Staff are present throughout episodes of a patient journey in isolation and therefore can provide a valuable insight into this experience from their own viewpoint. Furthermore as demonstrated by Van de Glind et al (2007) staff perception of how the patient experiences isolation is similar to patient perception. Therefore, it was necessary to explore this lens of the experience of isolation within this review. There are limited data on the experience of staff when caring for children in isolation, thus the search terms were broadened to include 'staff', 'isolation', 'experience' and 'infection prevention'. For full search terms and an example literature search, see Appendix 5. The period of searching was limited to 1990-2019, as although the practice of isolating patients has not altered significantly over time, the attitudes and practices of staff may have changed with the evolution of knowledge as documented by Arli & Bakan (2017), Askarian et al (2007) and Ward (2012).

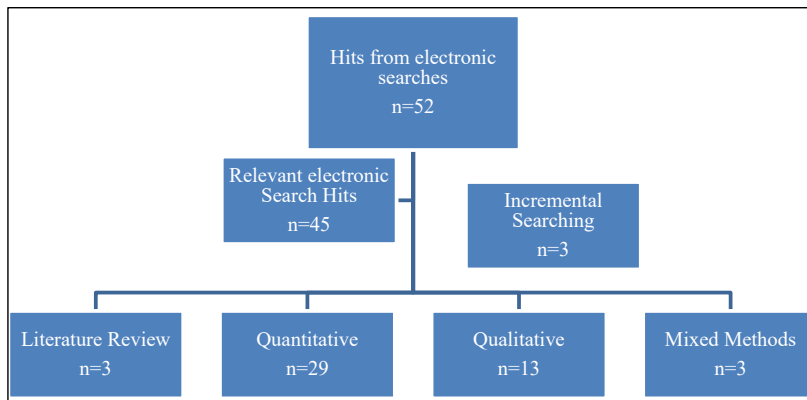
Literature was found using a combination of electronic bibliographic database searches, incremental searching and manual hand searches as described in Section 2.2.1. The inclusion and exclusion criteria (See Table 2.3) were applied to the literature.

Table 2.3 Inclusion/Exclusion Criteria for Staff Literature Review

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">• Full text• Printed in English• 1990-2019• Primary data sources	<ul style="list-style-type: none">• Abstract only• Requiring translation• Pre 1990• Secondary sources of data; e.g. audit, service evaluation

The electronic database searches retrieved 45 relevant studies. No studies were retrieved using manual searching of Journal of Infection Prevention and Nursing Children and Young People (2007-2017). Additionally, two studies were retrieved from two adult literature reviews (Morgan et al, 2009; Van de Glind et al, 2007), and where the adult studies had included staff perspectives, one study was included (Knowles, 1993). The search results are shown in Figure 2.3 below.

Figure 2.3 Results from Staff Literature Search



There were four studies excluded. These studies were excluded as they were concerned with infection data which were not relevant to patient care or staff experience such as the frequency that isolation rooms are used for infectious/non-infectious patients. The summary table of the staff data is presented in Appendix 6. The final papers within this literature review were critically appraised and analysed for common themes. The review of the literature led to the emergence of the following themes: ‘physical restrictions of the environment’, ‘frequency of patient contact’, ‘fear of contagion’, ‘infection transmission knowledge’ and ‘adherence’.

2.5.1 Physical Restrictions of the Environment

The physical environment impacts on a patient experience regardless of whether the patient is isolated as documented in the experience of hospitalisation literature (Lam et al, 2006; Sammut et al, 2015; Warren et al, 2000). In the adult literature and paediatric literature explored in Section 2.2.4 and 2.4.7, there are comments on the limitations that a single room has and the effects of that room on mood and experience. This concept was reported in some of the staff literature also. In a large comparative study where a hospital was rebuilt, the differences for adult nursing staff caring for patients in open bays in the old hospital and patients in 100% single rooms in the new hospital were explored (Maben et al, 2015). The findings highlighted that the staff found isolation challenging because of limited patient visibility and lack of co-worker access, which caused social isolation whilst

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at work for the healthcare team (Maben et al, 2015). This highlighted the personal and professional limitations for the staff whilst providing care to patients in isolation. Maben et al (2015) compared two clinical environments, their study was conducted opportunistically during the process of moving between a hospital with predominantly open wards to a hospital with majority single room facilities. The lack of studies comparing the experience of working between open bays and single room facilities for staff may account for the limited opportunities to conduct comparative studies such as this, as it is an exception to be rebuilding a hospital. Furthermore, globally the percentage of single room facilities vary (Sydnor & Perl, 2011), therefore the expected norm of the staff will be considered differently. Maben et al (2015) was a UK based study, thus the findings are transferable to other NHS settings.

Cassidy (2006) explored the student nurses' perspective of caring for adults in isolation and found that the imposed physical, psychological, social and emotional barriers of isolation significantly altered their caring experience. The students felt pressure to balance the need of individualised care with the need for isolation precautions, which lead to internal conflict of wanting to spend more time with patients but balancing this with the need for donning PPE each time they entered the room (Cassidy, 2006). This may not be entirely reflective of the nurse experience, due to the supernumerary status of students and subsequent lessened workload compared with qualified staff. However, the challenge in providing care for complex patients in isolation rooms was also identified in Chen et al (2016), reporting that being physically isolated from colleagues and providing or seeking support was challenging for them. These findings demonstrate the additional burden of providing care in isolation on staff, particularly in Maben et al's (2015) comparative study. Interestingly, one nurse in Knowles' paper (1993) described going into the isolation room to relieve her stress by being away from the ward environment. Despite Cassidy (2006), the other studies did not make comment on the seniority and experience of their nursing staff, which may considerably influence the level of personal conflict and difficulty in balancing the needs of the patient in isolation and the need for isolation precautions, thereby limiting the transferability of these findings.

The staff feeling isolated described in Cassidy (2006), Chen et al (2016) and Maben et al (2015) may have had limited impact upon the patient experience, however it could have

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impacted on the length of time the staff member wanted to spend in isolation without consulting colleagues. This is reflected in the literature regarding the number of staff visits and length of those visits to patients in isolation which is significantly reduced compared with patients on a ward (See Section 2.5.3) (Kirkland & Weinstein, 1999; Morgan et al, 2009; Saint et al, 2003). However, it could be argued that higher frequency and longer visits from staff may not reduce loneliness in patients, as it depends on the level of interaction between staff and patient at that visit, and also the relationship that they develop in that period (Trebbles et al, 2010). This may depend on staffing levels within the healthcare facility and this needs to be considered in context of all the staff literature, yet there is limited description of this within any of the staff papers. From a staff satisfaction perspective and thereby staff performance, staff who are happy in their decision-making processes and confident in their practice have greater resilience, ability to cope and longevity within the career of nursing, which may in turn affect the quality of care received for patients (Tzeng et al, 2002). Yet this is determined by experience, confidence and seniority of the staff member, which received limited description within these papers.

2.5.2 Frequency of Patient Contact

The frequency of patient contact does impact upon the experience of the patient in isolation. For nurses the location of the patients for whom they care, is fundamental to the amount to which they can interact and observe them (Kirkland & Weinstein, 1999). The physical presence of the nurse is visible to patients in a main bay whereas for patients in isolation they may not see a nurse as they will be walking past their room, unless one enters their room (Cassidy, 2006). Often nurses in the UK are required to care for people in isolation rooms and ward bays simultaneously, meaning that patients in the ward bays can be indirectly observed whilst they are caring for other patients within the main bay, however this is not true for a patient in isolation. This differs worldwide according to staffing ratios and the layout of the ward environment, differing considerably for the wards that are single room only, thus generalisability of the findings within this staff section is limited. Furthermore, the patient-nurse contact within the studies presented in this section of the review are all adult studies and therefore do not account for additional visitors. Whereas in the paediatric setting these would be further affected by the parental presence. Parental presence may necessitate a greater need for nursing interaction for reassurance, or lesser need as the parent takes on a number of nursing roles, however there is little data to

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support this proposition (Tandberg et al, 2018). Due to a lack of paediatric-specific research with staff experiences of isolation, there are limited transferable findings within this section to paediatric ward settings.

Kirkland & Weinstein (1999) found that healthcare workers were half as likely to enter patient rooms when they were subjected to contact isolation precautions. These findings were echoed in a literature review by Morgan et al (2009) and Saint et al (2003). Interestingly, Morgan et al (2009) and Saint et al (2003) were USA studies where there are predominantly single rooms, thus the adjustment between isolation and single room is associated with the use of PPE, which alters the frequency of contact rather than being in a single room compared with a main ward as described in Kirkland & Weinstein (1999). Farrington et al (2000) and Tiedkte et al (2018) explored the workload for staff when providing isolation precautions, they acknowledged that workload pressures rise, which may account for the reasons for less frequent patient visits. Farrington et al (2000) and Tiedkte et al (2018) do not comment on the impact upon the patients of the reduced presence of staff for the person in isolation as they solely explore the staff experience of caring for people in isolation. However within the adult literature, it is noted by participants that the reduced presence of staff has impact upon their overall experience of isolation (Campbell, 1999; Collins et al, 1989; Gaskill et al, 1997; Holland et al, 1977; Rossini et al, 1996; Thain & Gibbon, 1996). Conversely, Knowles (1993) presented six staff participants who described reduced contact with patients when in isolation, yet the participants felt this had little bearing on the overall experience, as if they needed the nursing care they would have it. However, this does not corroborate with the adult literature in Section 2.2.5, where patients described the need for contact with staff for interaction, not care (Evans et al, 2003). This demonstrates the different ways in which an experience can be interpreted by different people within that social context.

The studies within this theme provide sufficient detail on the clinical environment, but do not comment in detail on the nursing ratios to patients, additional support staff available and nursing tasks required to be completed within a shift, all of which would vary in the amount and intensity of care that the nursing staff could provide to the patients. Without this level of detail, it is challenging to determine the transferability of these findings, particularly to the NHS clinical environment, where nursing to patient ratios are varied to

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Northern America, where a number of these studies were published. Although the studies within this review acknowledge the reduced frequency and length of patient contact with staff in isolation, the impact of this for staff receives limited acknowledgement in the literature; an area which would be interesting to explore.

2.5.3 Fear of Contagion

The fear of contagion transcends other themes within the staff literature: frequency of contact and compliance in terms of the emotional response to their fear. The fear of contagion may not be described directly by staff, however it could be implicit in their responses to caring for someone in isolation, hence keeping this theme as its own entity, as this theme focuses on the studies where staff describe their fear of contagion or response to it. In Prieto & Macleod Clark's study (2005), participants were anxious about the risk to their own health from *Clostridium difficile* and MRSA, which influenced their infection prevention practices. One to one practice-based instruction influenced their practice to a much greater extent than tailor made guidelines, as this fear of contagion could be explored and the infection prevention measures were justified and explored with the staff, thereby rationalising their choice of PPE and associated fears. Although a dated study (thus excluded from the literature review), seminal paediatric work from Macqueen (1995) within a UK paediatric cardiac intensive care unit sought to explore the culture in terms of infection prevention. The study indicated that "germ theory" did not equate to nursing or medical practice, but that the culture of biomedicine may have interfered with infection prevention knowledge which caused conflict of understanding, which resulted in the overuse of PPE and overexaggerated infection prevention measures. This incongruence between knowledge, attitude and practice was also identified by Clock et al (2010), Faryad et al (2018), Landers et al (2010), Mohammadzadeh et al (2013), Sax et al (2005), Suliman et al (2018) and Wadhwa et al (2016); and it links with Section 2.5.4. This demonstrates that fear of contagion can precipitate irrational emotional responses, which led to overuse or underuse of PPE and, which is incongruent with the knowledge of infection prevention measures. To further complicate the link between fear of contagion, knowledge and practice, Knowles (1993) described that nurses reported that fear of infection was prevalent among other nurses, but no one reported it for themselves. This demonstrates that there is a lack of self-identification of fear of contagion, meaning that knowledge and practice may not be associated with fear of contagion in self-report studies.

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The need for self-protection and protection of their family, particularly when caring for patients with more complex or unknown infections (for example SARS) resulted in greater stress and anxiety from the staff in terms of fear of contagion (Chen et al, 2016; Koller et al 2006a; Nickell et al, 2004). In this study this often manifested in over-exaggerated responses to infection (Chen et al, 2016), which echoes the literature pertaining to emotional response and infection prevention knowledge in terms of fear of contagion (Branch-Elliman et al, 2015). In the face of epidemics, practice and fear of contagion reverts back to overuse of PPE (Chen et al, 2006). The fear of contagion will certainly have an impact on the way in which the patient perceives the experience of isolation according to the staff attitude, their use of PPE and their behaviours when caring for that patient, although this is not directly linked in the literature. Furthermore, staff are not always able to convey to patients and carers an accurate understanding of the isolation precautions as implemented (Prieto & Macleod Clark, 2005). Staff are often underconfident when it comes to explaining an infectious condition to patients and carers (Tiedtke et al, 2018). The fear of contagion aligns with the infection transmission knowledge, in that knowledge of infection transmission afforded a more rational approach to PPE. Staff may have the knowledge, but this can conflict with their beliefs. Individuals may not trust or believe the information imparted to them, or the knowledge that informs the practice guidelines that are available to them locally (Askarian et al, 2007). This exemplifies that improving knowledge may not be the entire answer in reducing irrational fear of contagion and compliance with practice.

The studies that described an emotional response from staff to providing care in isolation were in the majority related to a fear of contagion from SARS. SARS produced a level of anxiety and fear of contagion beyond that which would be attributed to many other infections as it was a relatively unknown entity at the point of outbreak (Lau et al, 2009). Cassidy (2006) and Kagan et al (2017) demonstrated that level of anxiety and subsequent job satisfaction correlated with perceived knowledge of infection, yet as presented earlier knowledge does not equate to compliance with protocol.

The literature pertaining to the SARS outbreak remains relevant, although context specific, it is not beyond the realms of possibility that some of the findings are transferable, or that

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another outbreak of different pathogen may trigger similar emotional response, hence including these studies within this literature review. Chen et al (2006) conducted self-report scoring for fear, depression and sleeping during the SARS outbreak with nursing subjects. Nursing staff anxiety and depression scores were high, along with poor sleep quality data initially, however after two weeks of SARS infection prevention teaching, these scores normalised, demonstrating that with knowledge and education, anxiety and the emotional response to infection transmission was reduced in this situation. These findings corroborate with Im et al (2018) and Nickell et al (2014) where nurses felt hopeless, cut-off, ashamed and overworked during an outbreak. The emotional response demonstrates their knowledge of infection transmission but also misinterpretation of the risk of transmission with appropriate PPE. Nickell et al (2014) conducted a larger scale study, with participants who were not all health providers, but health service users also, which may account for the emotional response, rather than the rationalised response based on knowledge of infection transmission. These studies pertain to SARS, which limits the transferability of the findings to UK settings without outbreaks, however useful to consider in context.

Although the emotional response to working with patients with infectious pathogens in isolation may not have a direct effect on the patient, it could do through the frequency they are visited based on staff fear of contagion as described in Kirkland & Weinstein (1999), and the overuse of PPE to protect themselves as highlighted by Macqueen (1995) and Prieto & Macleod-Clark (2005). This may also contribute to the fear of contagion for the patients through conflicting signs or information from the staff. Alternatively it may generate feelings of being stigmatised for having a potentially infectious infection for patients.

2.5.4. Infection Transmission Knowledge

The studies completed during the H1N1 flu outbreak (Wong et al 2011) and the SARS outbreak (Chan-Yeung 2004; Chen et al, 2006; Maunder et al, 2003; Nickell et al, 2014), found that staff felt insufficiently educated regarding infection prevention measures. However, staff also described an increased need for knowledge in Askaraian et al (2007), Chittick et al (2016) and Sax et al (2005), despite not being in the midst of an infection outbreak. The desire for more knowledge could present in staff as stress, anxiety and

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overuse of infection prevention measures as described in Section 2.5.3. Staff need for knowledge was reported to be high in staff caring for patients during these outbreaks, however there was no control in terms of their knowledge need when not caring for patients during an outbreak to compare with, thereby limiting the transferability of this finding. Furthermore, due to the infections being newly identified pathogens with limited knowledge of their mode of transmission, PPE was used to the maximum and therefore, the staff were all likely to want more knowledge to inform their practice. However, this is a rare situation and therefore the findings from these studies need to be considered in context. Additionally, due to the nature of the population, the samples are size-limited and context specific, which decreases their relevance to NHS practice. The implications of these findings will have impacted upon the staff's practice and thus may have affected the experience of the people for whom they were providing care which is described in Koller et al (2006a) and Maunder et al (2003). This demonstrates the benefit in using a triangulated data source approach as the impact of one person's responses to the situation can impact upon the others within that social situation, and thus provides a broader understanding of the overall experience.

Outside of the context of outbreaks such as SARS or H1N1 flu, there were studies that explore the need for education to improve understanding in the context of infection prevention to prevent fear of contagion. In Prieto & Macleod Clark (2005) nurses and healthcare assistants experienced huge confusion and conflict surrounding the issue of contact precautions. By contrast, in a study by Suliman et al (2018), using a self-reported questionnaire and observational checklist developed based on 2007 CDC guidelines, 90% of staff that participated reported good knowledge of isolation precautions. However, in the observational part of the study there was a low compliance with standard isolation practice and lack of use of isolation signs. This may demonstrate the challenges of using self-report questionnaires where participants are at risk of responding in the manner that they think they should respond, or respondent bias in that people with the knowledge responded, and those with insufficient knowledge did not respond as described by Greene (2015). In Knowles (1993) it was described that temporary staff were reluctant to care for patients with infections in isolation as they were unfamiliar with the ward, however another nursing participant commented that if barrier precautions are used then it does not matter who cares for the patient. This denotes the local "unwritten rules" that are present and the fear

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amongst nurses to do the wrong procedure, which lead to variations in practice as discussed in Sandgrem (2012). Faryad et al (2018), Peres et al (2016) and Zhang et al (2011) all demonstrated that the staff within their studies had a good knowledge of infection prevention, with different attitudes and compliance between the medical students in Peres et al (2016) and the nursing staff in Faryad et al (2018). This may highlight the differences between the knowledge from medical and nursing staff knowledge, which is described by Koutzavekiaris et al (2011) and Mathur et al (2011) in terms of medical staff having the theoretical knowledge and the nursing staff being stronger in the practical application of policy. These findings illuminate that knowledge and practice are not always synonymous, and that this may be because of external factors such as resources, staffing levels or context-specific factors, rather than knowledge. These external factors received limited commentary in these papers, thereby limiting external validity to a general paediatric setting. Furthermore, within these studies, many of the findings are context specific such as the level of education provided to staff, because they are single site studies, some with limited generalisability. The variations in the findings could also be attributed to the data collection methods.

2.5.5 Adherence

Adherence to isolation and infection prevention measures are essential for risk of transmission of infection, but also relate to the staff's perception of fear of contagion (Section 2.5.3) and transmission of infection (Section 2.5.4). In Dhar et al (2014), adherence with PPE use, specifically underuse of gowns and gloves, lack of hand hygiene was worse when in isolation and they concluded that this was associated with the increased burden of caring for patients in isolation. However, this study was conducted across USA in hospitals where there were a greater number of single rooms. The comparison between those in a single room for infection prevention reasons and those in single room for other reasons were equally poor in terms of adherence with use of PPE and hand hygiene. Due to the increased use of single rooms, the physical presence of walking into a single room might not have acted as a reminder to wear PPE and perform hand hygiene as is described in other studies (Prieto & Macleod Clark, 2005). Furthermore, availability of PPE was reported to be a factor in adherence (Cepeda et al, 2005; Chen et al, 2016).

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Clock et al (2010) reviewed their isolation precautions and found that signage to determine the use of PPE was present on only 85% of cubicle doors, gloves were only available 49-72% of times required and sinks or alcohol gel dispensers were available 91-95% for hand hygiene outside of room. This study explored isolation as a consequence of MRSA and VRE, both of which are not common reasons for isolation in paediatrics, as children are most frequently isolated for community acquired infections and droplet transmission was found to be the most common mode of pathogen-transmission in children (Vayalmukai et al, 2007). This may suggest that the findings from Clock et al (2010) have limited transferability to paediatric wards. However, the findings from Dhar et al (2014) were not specific to any infection/pathogen and therefore may be applicable to paediatric practice. Overall the availability of PPE and handwashing facilities, and education regarding its use, will impact upon compliance with infection prevention measures. In a literature review by Neo et al (2012), it was highlighted that the perception of colleagues and patients; intrinsic factors such as perceptions, risk appraisal, previous experience and risk-taking willingness, and professional education determined adherence to infection prevention measures (not specifically related to isolation) and impacted on nurses' motivations for complying with the use of PPE. This integrative review attempted to review qualitative studies in addition to quantitative to provide greater depth of understanding regarding non-compliance with infection prevention measures. However it has highlighted that there are a limited number of qualitative studies to support this acquisition of knowledge. The conflicting findings regarding availability of PPE and compliance may be context-specific and could be attributed to staff experience also.

There are inconsistencies in practice identified within this section that demonstrate a lack of adherence to isolation precautions identified by researchers in accordance with international guidance. In UK studies, Gould & Drey (2013) reported a lack of compliance using PPE in nurses as reported by student nurses. Slota et al (2001) demonstrated that compliance with gloving and gowning was 82%, and handwashing was 22% prior to their interventional study. Similarly, in international studies Beam et al (2015) and De Franca et al (2018) found variations in practices in the use of PPE and hand hygiene opportunities. The inconsistencies in practice are documented in mainly quantitative literature, and there is limited exploration using qualitative methods of these variations in practice, to comprehend the reasons for these. The one study that provides some qualitative data is

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Knowles (1993) which describes the challenges of having to don PPE, when already caring for multiple patients on a busy ward, just to attend to someone and the stress that puts on both the patient who may need something urgently and the staff member who is feeling stretched. Furthermore, there is a vast array of inconsistent terminology in isolation precautions which is demonstrated in these papers, which may also contribute to variations in practices (Zimrig et al, 2013).

There are a number of studies which are interventional and have looked at a measure to increase compliance in practice, such as coloured “safe zone” flooring (Johnson et al, 2018), standardised colour signs for the isolation door (Ghonim & Behnhuzzi, 2014), staff compliance contracts (Allen & Cronin, 2012; Johnson et al, 2018) and training (Anderson et al, 2015; Johnson et al, 2018). All of these studies reported positive outcomes in terms of adherence to isolation precautions. However, none of these studies were longitudinal and therefore cannot account for the improved practice over time, the findings are only reflective of the interventional period. Most of the studies within this section reported data from a multidisciplinary population, with the exception of Allen & Cronin (2012). Within this study (Allen & Cronin, 2012), there was no comment on education or contracts on visiting staff, medics or ancillary staff, who could all equally contribute to the transmission of pathogens without appropriate hand hygiene and use of PPE.

In 2010, Moore et al described a lack of single rooms to provide isolation care to meet the demand for patients requiring isolation. Thus they designed a study to assess the use of Smart Ideas Projects with screens, portable sinks and toilets in “portable cubicles”, where if a single room was not available and the patient was appropriately risk assessed, they could be nursed in this type of ‘isolation’ on the main ward. The findings from this interventional study demonstrated that for the 53 patients that were isolated using the Smart Ideas Project in this study, hand hygiene significantly improved, and only low levels of microbial contamination were present within the isolated bed spaces. This suggests that as an alternative to single room isolation, with appropriate risk assessment, the risk to the patient in isolation and those on the main ward was reduced in terms of risk of transmission of infection. The physical presence of the screens may have served as an aide memoire which could account for the increased prevalence of hand hygiene, which was also demonstrated by Prieto & Macleod-Clark (2005) in the single room isolation

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literature. It has to be considered however, with the knowledge of pathogen transmission that this would not be appropriate for all patients, or for all forms of transmission of pathogen. Furthermore, with added complexity, this could increase the risk of inappropriate allocation of isolation facilities, with greater decision making, and risk assessment regarding who is the most appropriate patient to be isolated in a single room, or most appropriate for using the Smart Ideas technology. Finally, this study does not explore the staff perception of this technology, and therefore it is impossible to comment if the staff felt more or less isolated from their colleagues as a consequence of this technology compared with a single room.

As demonstrated in this section, there have been a number of interventional studies to attempt to improve adherence amongst staff of isolation precautions and universal precautions to prevent the spread of infectious pathogens. Obviously without adherence to these isolation measures, patients' experiences may be affected due to acquiring infectious pathogens as a consequence of incorrect PPE. Furthermore, the staff want the satisfaction of being able to provide care within the care guidelines and in addition to correct infection prevention knowledge, this requires the correct facilities available, including sufficient staff to provide the highest possible care; all of which contribute to the reduced levels of compliance as demonstrated in this literature review, and described by Cimiotti et al (2012), Hall et al (2004) and Weinstein et al (2008).

2.5.6 Conclusions from Staff Literature

There are limited papers that explore the staff experience of isolation, or the staff interpretation of the patient's experience of isolation. Therefore, the literature presented here in Section 2.5 can only be considered in the context of the care that the patient receives which may impact their experience, rather than their own experience. In conclusion, the staff experience of providing care in isolation is multifaceted, and often context specific. It is clear that a number of the findings within this review will impact on the patients' experience, thereby suggesting the need for triangulation of data sources in future studies. Furthermore, in view of the limited evidence pertaining to the staff experience, particularly in a qualitative manner, more research is needed to explore the staff perceptions of isolation as they have a valuable insight into the experience for the patient. The studies presented in this literature review have limited transferability due to

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their single site study design, small samples and focus on the staff perspectives rather than the implication of this on the patients. The limited number of papers within this field, is interesting, and may be attributed to the fact that there is a greater need to understand the experience of being in isolation from the patients' point of view. However as demonstrated in this section, the staff have an impact on the patient's experience and therefore, it is necessary that the staff experience also needs to be explored further, to inform future care provision.

Despite the indirect nature of some of the findings within this literature review in context of the patient's experience of isolation, it is clear to see how the staff findings align with the adult isolation experience and to a lesser degree to the paediatric literature presented in this Section 2.3 and 2.4 in terms of compliance and understanding. It is clear also that the staff play a significant role in the patient's experience in isolation, thus identifying the importance of exploring their role within isolation care in greater detail.

2.6 Summary of the Literature

This literature review considered the adult, paediatric and staff perspectives of isolation care. The adult literature in this review provided some context on experiences in isolation and may be comparable to older children's experiences, or parental experiences of isolation. However paediatric-specific literature was critically analysed to understand the child's experience. The paediatric literature was sparse, condition specific and did not employ robust research methodologies with large, heterogenous samples. Despite these limitations in the paediatric research, the adult literature provided some key themes, some of which transcended into the paediatric literature; such as the use of PPE, separation and social isolation and the physical environment of isolation. Staff literature was reviewed, and the key findings were considered within the context of the adult and paediatric data and will be presented within this discussion. There were some findings that transcend all populations within this review and other findings that are specific to one certain group.

Overall the literature pertaining to children in isolation care is sparse, small scale and predominantly it sits within the lower forms of data within the hierarchy of evidence. Yet, the subject has received limited research, potentially due to the processes of infection

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prevention taking the priority. This subject area has received exploratory studies with most within the interpretative paradigm. This may lead to larger scale positivist studies in the future. However, the nature of the research question certainly lends itself to interpretative paradigm. The small sample may be in keeping with the research methodologies, or simply due to researching within a small population, a subset of whom will have participated in the studies. Despite this, there are findings that are useful to inform current practice and also which aided me to develop the data collection methods for this current study. The findings within this literature review are predominantly adult-focused, however even the paediatric ones are context-specific and therefore all the findings within this study must be considered judiciously and within the context of the clinical environment.

Paediatric care spans infants through to adulthood, and therefore within the context of any paediatric study, literature pertaining to adults and infants must be considered (Twycross et al, 2008). This potential for variety of findings as a consequence of the age range and development within paediatric research is both a challenge and an opportunity. For many researchers, particularly within this literature review (Broeder, 1985; Russo et al, 2006, Vines et al, 2018) the age range in the paediatric literature was maintained within a narrow window for comparison of the findings in terms of development, maturity and to allow for a comparison within a relatively small sample size. By comparison the adult literature were much larger samples and the opportunity for comparison across the population was more possible, than paediatric research due to a larger population from which to sample. This highlights that paediatric research is a niche area, and requires not only careful consideration of the methods and ethical decisions to make to conduct the research, but also the manner in which these early decisions implicate the way in which the findings can be used and interpreted.

Many of the paediatric studies, and also true of the adult and staff studies relate to one condition or one area of practice, limiting the heterogeneity of the study but allowing for easier comparison amongst the findings. Sampling within a more heterogenous population may have been limited by pragmatics or research methodology. Working within a general paediatric unit, the findings from this literature review, due to their limited heterogeneity have limited transferability for the social context within which I work and require judicious use.

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The striking finding within the paediatric literature, is the limited use of the child's voice and the lack of participatory methods to facilitate this. As discussed in Chapter One, children have the right to share their voice on experiences that they encounter and care needs to be based on this voice (Sartain et al, 2000). The paper that demonstrated the most innovative approach to data collection with children within this literature review, was actually produced in 1985 (Broeder, 1985). This could be reflective of the challenges in gaining ethical approval for studies that require greater intervention from a child, particularly seeking their experience in a "novel" manner, may have received some challenges from ethical committees, and in 1985, such strict ethical restrictions were not in place. Or simply that Broeder (1985) was proactive in seeking the child's voice. There has been some criticism of participatory methods and the flexibility and subsequent lack of rigour of these methods in the literature (Clark, 2010; Gallacher & Gallagher, 2008), particularly when multiple methods are employed to engage children of different ages to participate. This may have limited the use of participatory methods within healthcare research. Yet within social sciences research, the inclusion of the child's voice in a participatory manner is prioritised ahead of the methodological and ethical restrictions, as they want the child's voice to be central to their data (Engel, 1999). The differences between social sciences and healthcare research are likely to be attributed to the fact that in hospital the child is unwell, and therefore perceived as vulnerable, which may limit the degree to which they want, or their parents/carers want them, to be involved in research (Hullmann et al, 2010). This could be considered as protecting the child, or as preventing the child the opportunity to share their experience, depending on your epistemological viewpoint.

It is clear from the different findings between the different groups within this review, that children have a unique contribution to knowledge, which differs in the findings and outcomes from adults undergoing a similar isolation experience. The similarities presented in this literature were the environment and the isolation precautions that the children and adults as patients were subjected to. However the differences, between the child as patient and adult as patient are the ethos of nursing children (Crowley et al, 2011), the subsequent nursing-patient ratios (Crowley et al, 2011), the level of parental or family member participation in care (McDonagh & Viner, 2006), the communication (Bryon & Madge,

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2001), the pathogens requiring isolation (Crowley et al, 2011), the approach to researching with children (Carter & Ford, 2012), and a number of developmental and psychosocial differences (Bryon & Madge, 2001).

The paediatric research presented within this review, when compared with the adult literature does identify differences, for example in the adult literature a number of papers identify anxiety as an emotional response to isolation (Abad et al, 2010; Catalano et al, 2003; Criddle & Potter, 2006; Davies & Rees, 2000; Day et al, 2013; Gammon, 1998, Gordon, 1975; Ibert et al, 2017; Knowles, 1993; Kohle et al, 1971; Lewis et al, 1999; Morgan et al, 2009; Rees et al, 2000; Sasaki et al, 2000; Tarzi et al, 2001; Tecchio et al, 2013; Wilkins et al, 1988; Zerbe et al, 1994). However, within the paediatric literature, specifically the studies that explored the child's voice within their study there was no mention of anxiety. Within the parental literature there was anxiety mentioned, but by the parents not the children (Curtis and Northcott, 2017; Kronenberger et al, 1990; Powazek et al, 1978; Wu et al, 2005). The lack of anxiety being mentioned by the children, could be attributed to the fact that they did not experience anxiety. Alternatively, it could be that the data collection methods did not allow for this to be explored, or linguistically the children were unable to interpret or explain their understanding of anxiety. This again demonstrates the importance of using paediatric-focused, flexible methods that can be adapted in their terminology to ensure that children are able to contribute in a manner appropriate for them, using language that is familiar [to them](#). This introduces the concept of a multimethod approach to adapt to the needs of participants, to be able to facilitate their voice being heard without interfering with the rigour of high-quality research. This aligns with the work of bricolage researchers (Kincheloe, 2001; Warne et al, 2009), who suggest that increasing the methodological breadth and depth of a study, avoids the superficial nature of a contribution (such as that of a child), which may not be included otherwise.

Another key finding from this literature review is the differences in the experience of isolation between the child and the adult data and more interestingly the child and the parent experience. There were three studies that sought both child and parent perceptions and within these studies there were differences in the perceptions of the experience (Curtis & Northcott, 2017; Koller et al, 2006a; Russo et al, 2006), despite residing in the similar environment within the time of isolation. Within this, the staff perspective has another lens

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and sheds another light on the experience and was only represented in a triad in Koller et al (2006a). Russo et al (2006) demonstrated differences between the child and parent perspective on an experience with children wanting contact with their peers and missing out on social interaction, and parents not wanting to leave because they didn't want to leave their child alone. The children's main concerns were also regarding missing out on their social interaction whereas the parents were concerned with transmission of pathogen risk, which aligns with the adult literature (Russo et al, 2006). These differences are relevant here as they demonstrate the philosophical viewpoint of adults and children and how these differ, in that children are more egocentric and think about the immediate consequences of actions, whereas adults with greater interpretative thinking bring more consequential responses to questions as a result of psychosocial development as described by Mazzoni & Harcourt (2014). Furthermore, there are fundamental differences to children's nursing in terms of the parental presence, and use of family centred care which means that findings between adult and paediatric settings are often not comparable. Adult responses have no greater power or meaning than the child's, just simply that these responses are different and need to be considered alongside one another to truly understand an experience (Darbyshire et al, 2005). Furthermore, Moore et al (2008) suggest that as researchers, there needs to be greater use of the child's perspective, as adults will be less able to understand this viewpoint than another adult's perspective.

The literature review presented here has to be considered within the wider context of the hospitalisation literature, as there will likely be some comparisons. Isolation is a form of hospitalisation and many of the procedures, communication processes and cultures of the ward will transcend both isolation and hospitalisation. It was essential to review the isolation literature in the context of the literature on children in hospital to delineate differences and similarities in experiences between hospitalisation and isolation. As described in Section 1.5, there are some significant differences in hospitalisation and isolation for children. Many of the themes from the hospitalisation literature such as separation from friends and life at home, being in an unfamiliar environment, fear of investigations and treatment, being bored and loss of control may also be significant for children in isolation (Clift et al, 2007; Coyne, 2006; Coyne & Conlon, 2007; Forsner et al, 2009). However, due to the environment of isolation these feelings may be heightened. Conversely, the privacy and quietness of a single room may provide positive benefits, as

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has been reported in the adult literature about experiences of isolation (Barratt et al, 2010; Campbell, 1999). Isolation adds a very different perspective to the experience of hospitalisation for children and families due to the physical and psychosocial barriers created by being in an isolation room. Whilst a number of aspects of the child's experience of single room isolation may be attributable to the hospital experience itself, only by specifically studying the experience of children in single room isolation and where required, comparing these findings to the wider literature on the effects of hospitalisation, can we understand the experience of being in single room isolation. The staff literature highlighted fundamental differences in terms of their experience of care provision in isolation, describing the increased burden, anxiety and stress associated with the infection prevention knowledge and procedures that were required in isolation.

Many of the child, parent and staff studies pertaining to isolation, have findings that are congruent with the wider literature concerning social isolation as reported by Weiss (1979). Within the paediatric literature, the children reported missing peers, or parents if not resident and the parents described the challenge of feeling a burden to stay to stop the child feeling socially isolated and alleviate boredom. This difference in experience is described by Cacioppo & Hawkley (2009) as fuelled by cognitive development and awareness of the need for social contact. The adult and staff literature described the staff becoming the social contact and stimulation in addition to relying on visitors and resources available. The staff described the challenge to visit all patients to facilitate social interaction in addition to the other jobs required of them (Knowles, 1993).

A key finding here in the context of contemporary paediatric literature is that in an isolation environment, the concept of family centred care was not present within the literature (Koller et al, 2006a). From the paediatric literature presented within this chapter, it is evident that the care led very much by the parents, apart from the extreme cases such as SCID and SARS where parents were isolated from staying with their child and were required to wear the same PPE as the staff, thus limiting their ability to maintain their normal role as parent. Within the adult literature, there is a tone of the staff being able to provide care based on the individuals needs in isolation, which limits the ability to perform patient-centred care. The staff literature corroborates this with the expression that patients

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in isolation have limited interaction with staff and less frequent contact, limiting their ability to provide patient-centred care.

The final theme that transcended the adult, paediatric and staff literature was that of sensory deprivation. Within the longer periods of isolation particularly within the early paediatric research and some of the adult oncology studies (Biagoli et al, 2016; Gordon, 1975; Kohle et al, 1971; Knowles, 1993; Oldman-Pritchard, 2003), many of the subjects were found to experience sensory overload on coming out of isolation, felt depressed, or challenged through being removed from their usual ambience of the ward. Sensory deprivation within the modern culture may be considerably different to the level of sensory deprivation before many of the gadgets that allow social interaction through computers and mobile phones. In some studies staff identified that the lack of tools to facilitate electronic communication was a way in which patients struggled in isolation (Campbell, 1999; Knowles, 1993, Thain & Gibbon, 1996), however this would be considerably different in contemporary practice where electronic communication is more mainstream.

These findings in this literature review exemplify the manner in which society is reliant upon adult, parental and staff data to inform care practices about children, simply from the sheer volume of data that supports the practice of isolation from these perspectives. However, within the paediatric literature, there are some studies which demonstrate the power of using appropriate methods and gaining an insight into the care needs of children in isolation. The lack of paediatric data may have been limited by ethical challenges, and within contemporary society, with a greater respect for children's rights to share their voice on their care, it is essential that we look to seek this opinion. However, this does not negate the challenges of collecting data with young children and therefore using different perspectives to enhance the trustworthiness of the findings, and use different lenses on one experience could provide a rigorous data collection method to explore an experience.

This literature review has set the context for the current research. This chapter has highlighted a body of literature in relation to the experiences of children, adults and staff in isolation, which indicated that there were developmental differences and differences in practice according to paediatric and adult practice. This chapter emphasises the importance of hearing children's voices in research which is integral to an in-depth understanding of

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their isolation experiences, and the benefit of drawing on different perspectives within the context of isolation to provide a deep understanding of the experience of isolation.

2.7 Aims of the Study

From this literature review it is clear that the experience of children and young people nursed in isolation while in hospital is an under researched area. However, it is an area in which the potential adverse effects of isolation on the child may be considerable, which thus formed the mandate for the current study. This study aimed to overcome a number of the methodological criticisms presented in this literature review through a child centred philosophy. The methods used for this study presented in Chapter Three were used as a means to capture the child's experience from their own perspective using a rigorous, age-appropriate method, which was supported with the triangulated perspectives of the parents and healthcare providers.

Therefore, the research question for this study was:

What are children and young people's experiences of source and protective isolation while in hospital?

Further objectives from the research question are:

- To identify how children and young people feel about being in isolation
- To identify the parental perspective of their child being in isolation
- To understand the healthcare providers' perspective on how children experience isolation

2.8 Conclusions

In conclusion, there is limited of research pertaining to children's experiences of isolation, especially from the child's perspective. The isolation literature through the decades highlighted the move towards more robust methods, however the child-appropriate nature of the methods remains questionable. There are some common themes throughout the literature, although due to the inherent methodological weaknesses; there are limited areas for transferability into contemporary clinical paediatric practice. This study aimed to use an age-appropriate method with children of a variety of ages and conditions to explore their experiences of isolation from their own perspective and from the perspectives of their

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parents and healthcare providers. Chapter Three will describe and explain the methodological underpinnings and data collection methods of this study.

Chapter 3 Methodology and Data Collection Methods

3.1 Introduction

Chapter Two highlighted the dearth of literature pertaining to children in isolation, specifically exploring their perceptions of the experience of isolation. This research study set out to address the question of the experience of children in isolation. This research was not initially approached with a particular methodological framework in mind, but a need to explore a clinical question in the most relevant manner that would encourage children to participate. As a clinical academic researcher my key prerequisite for the study was to encourage child-participation and seek their story about their experience. Therefore, it was essential for this study that the data collection methods used elucidated the information from the children where possible, with other supporting data from participants who also understood the child's experience. It was also essential to conduct this research in manner that accounted for my tacit knowledge as a clinician, therefore viewing the experience, not as an insider, but also not as an outsider with no knowledge of the experience. Underpinning philosophies and theoretical frameworks were explored and the most suitable framework was employed. There were challenges in the recruitment of children to the study and these will be critically explored.

This chapter will begin by considering the postmodern view of children i.e. they are regarded as knowledgeable, useful members of society who can provide valuable perspectives. As a paediatric nurse, this is how I consider children in my care daily and how I seek their viewpoints in my clinical work, therefore it was the starting point for this study. The chapter will explore social constructivism and narrative research as the selected theoretical approach to the study. Finally, the chapter culminates with the methods used for sampling, recruitment and data collection. The methods used in the study were adapted to accommodate the challenges with recruitment and this is explained to demonstrate the critical thinking behind the decisions to explore this social construct. The merits and challenges of these data collection methods will be discussed in this chapter and reviewed in the context of the findings in Chapter Seven and Eight.

3.2 Philosophical View of Children

A crucial consideration for this study was the way in which children are viewed. Epistemology is the manner through which knowledge is acquired (Cruickshank, 2011),

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and in this study, the data were provided by children, or people who could provide a perspective on the child's experience. As a clinical academic researcher, I was keen to answer the question through the child 'telling their story' of isolation in hospital, where possible, which aligned to a qualitative data collection approach according to Holstein & Gubrium (2016). As a nurse who works daily with children and their families in clinical settings, I understood the importance of engaging with children and hearing their contributions, which drove the development of the data collection methods and the underpinning theoretical framework. The clinical academic role lends itself well to this need for tacit knowledge of how children were likely to respond to hospitalisation and potentially to the suggestion of participating in research. I regard children as knowledgeable, thinking and active members of society, which is why their opinions were sought in this study. It is widely purported that children are not mini-adults and their contributions must be valued (Clandinin et al, 2016; Coyne, 2006; Driessnack, 2005; Punch, 2002); therefore the way in which this research was conducted had to be age-appropriate and flexible in order that they provided honest and valuable data.

As highlighted in Chapter One, there is limited research in this area and children all have different perspectives and understandings based on their own social constructs, life experiences and their own health. Therefore, the data gained from this study were inductive in nature and warranted a qualitative approach. Children, as with adults, have their own conceptualisation of any setting, which are underpinned by life experiences and other influences. They develop their understanding of their world based on what they are exposed to, as with adults, however children have additional influences from peers and their parents, and now in the modern era, social media, which all influence how they perceive the world in which they live and experience. This is necessary to understand, as these aspects all underpinned the way in which the children interpreted their time in isolation and the narrative which they shared with me. Furthermore, as someone not within their clinical social construct, but someone who understands the clinical elements of this world, it must be acknowledged that children may have shared more with me, due to my understanding of their social construct, yet equally they may have disclosed less so as not to comment on the healthcare they received, due to my role as a clinician. Therefore, the study was approached with that premise that each child has his/her own perspective, but according to Greig et al (2013) their perspective is also socially determined, and that

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perceptions are inextricable from context or culture. My role as a researcher and nurse was explained to all participants and I used language that they would be familiar with from hospital, but without the use of jargon. This epistemological viewpoint of children and my own social construct drove the philosophical view, data collection methods and analysis of the data. As a paediatric nurse and researcher who worked with these children throughout the study, and for many other people who work with children daily, the thought that children have useful, valid contributions to research is a commonplace attitude. With this understanding, I contend that children's narratives are as important as those of the adults, however also with the acknowledgement that all these narratives are developed from within their own social construct.

3.3 Social Constructivism

Constructivism allows for individuals to seek understanding of the world in which they live and work in order to develop subjective meanings of their experiences (Appleton & King, 2002; Gergen, 1999). Social constructivism is a sociological theory that focuses on how people develop and apply knowledge in different social contexts (Thomas et al, 2014). This theory assumes the notion that any human develops knowledge based on experience (Vygotsky, 1978). A social context is a sociocultural environment or social setting where people live or experience their lives and in which their understanding of the world develops (Gergen, 1999), i.e. this could be the context of the hospital in this study. A social construct is an idea which has been created and accepted by a person or people within a society. This may be as an individual in a society or a wider social group (Gergen, 2001).

Social constructivism is based on three assumptions. Firstly, that knowledge can result from a person's interaction with the social context. Knowledge is constructed as a person makes sense of their experiences in the world and it is often context-specific. A social construct is not context-dependent and can therefore adapt to accommodate different contexts or influences within that social context. Social constructivism arises as a consequence of cognitive dissonance (Festinger, 1957), or the tension that comes from holding conflicting thoughts at the same time. It drives the mind to acquire new thoughts or modify beliefs in order to resolve a conflict and makes sense of a situation to reduce the internal conflict. The social environment, or context, plays a critical role in the development of knowledge (Thomas et al, 2011). Other people within that environment or the social etiquette from the context may serve to challenge the social constructivism of the

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individual, which in turn causes conflict and resolution through learning (Savery & Duffy, 1995).

Social constructivism is the overarching theory, that underpins this study as it acknowledges that a person's social construct develops based on their knowledge and understanding within their life experiences. However, social constructivism also accepts that a person's social construct can adapt as a consequence of an interaction within a new social context. This accepts that despite the fact that children, staff and families within this study had their own social construct, the clinical environment of the hospital and more specifically isolation may challenge and potentially develop their social construct. Therefore, social constructivism was deemed an appropriate theory to underpin this study.

Christenson & Prout (2002) suggest that children form their knowledge throughout their lifetime, and that this continues into adulthood. Children are individuals who are not replicas of their parents, because during their lifetime they construct their beliefs and knowledge from the whole of the society around them and this may change as they are exposed to different social contexts, settings and groups, and as they seek independence from their parents' thoughts and processes. This demonstrates why it is essential to explore the child's own perspective, not simply their parents/carers, which aligns with my social construct as a paediatric nurse.

Guba (1990) described social constructivism as problematic in that conceptual meanings can exist only in the context of a given mental framework. Thereby, any social construct will be shaped and limited by the values of the group they are within and those contributing to the construct. However, constantly evolving interactions and contestability lead to shifting constructions that can be destabilised. As part of a family within the hospital and considering the influence of the staff, the social construct of the child in isolation is influenced by many factors, including the social constructs of their parents and the staff around them, all of which will influence their experience. My understanding of this, is that these evolving constructions allow for and harness accommodation of new ideas (Kuhn, 1996).

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Throughout the process of this PhD journey, my social construct as a researcher and a nurse has evolved in accordance with the stories that the children, parents and staff have shared. Furthermore, through greater insight, my practice and manner in which I have approached the research has changed. These insights were documented in a reflective diary, for me to reflect upon during analysis and writing up stages. For me, what Guba (1990) considered a challenge to social constructivism, I consider a strength as it allows the study to be truly reflective of the social context, individual social constructs and accounts for the many interactions that alter people's perceptions of the experience through social constructivism.

Younger children are more dependent on their parents and therefore there is a journey of independent thought process development that increases with age (Greig et al, 2013), which has been considered within the analysis of this study. Although this poses the problem that perceptions of an experience are fluid and may change dependent upon their construct and context, weaving together the experiences of the children and people within their construct can produce an interwoven piece of research reflective of their social construct within the same theoretical position within isolation.

Social constructivism views reality as relative to those experiencing it (Gergen, 2001). Therefore, it allowed for the exploration of children's experiences of using multiple methods appropriate to the developmental needs of the children, and allowed for the differences in people's experiences (Denzin & Lincoln, 2008). Furthermore, social constructivism acknowledges that there are multiple realities due to participants' different life experiences, interactions and influences (Burr, 2015; Creswell, 2007; Gergen, 1999; Pope & Mays, 2000), and it aims to achieve some consensus of meaning, yet always allowing for new explanations and heterogeneity of findings (Appleton & King, 2002). The experience that a child has whilst in isolation is based on their ability to interpret and understand the meaning behind the experience. Alternative interpretations of the experience can also be revealed through an external view of the experience from parents and healthcare professionals, as has been used in other studies by Eiser & Morse (2001) and Sattoe et al (2012). Therefore, through using all perspectives, it was anticipated that the findings would reflect a rounded perspective of the child's experience of isolation in accordance with social constructivism.

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Burr (2015) suggests that a criticism of social constructivist research is that it is thought to focus on an individuals' viewpoint and not the views of the entire population. However, this criticism fails to understand the interaction in the population that helps the individual form their opinion, or the fact that multiple perspectives are often considered from a population to ensure that the data reflects the entire social construct, not just one perspective (Burr, 2015). Furthermore, studies into everyday life experiences such as this assume that there are multiple realities with differences that cannot always be resolved through increased data or rational processes (Gergen, 1999). Social constructivism seeks to show divergence between data and suggests that convergence will only occur as the interrelationships between all the elements are explored (Gergen, 1999). Moreover, it is wholly dependent upon the context which denotes that all the participants within any study are bound by complex interrelationships. This convergence was found through reflection on my role as the researcher, who at the beginning of this PhD journey was a relative outsider of the experience of isolation, only seeing it through my "nurses' eyes". However upon completion of this PhD I can now see it through the participants', parents', staff and my own perspective as a mother of a child in isolation. It is acknowledged that in this study, the experience of all children who are subjected to isolation procedures are not represented. However, it is anticipated that practitioners will be able to consider the findings in the social context of their patients, to provide individualised care according to the patient's own social construct.

3.4 Narrative Inquiry

A social constructivist approach has been adopted for this study. However the structure and principles of narrative research were used for the analysis method and to review the content of the children's stories, and therefore it is discussed in this section. This study is founded on the principle of children telling their story to be able to view the experience of isolation through the child's eyes. Squire et al (2014) describes a narrative as a set of signs, which usually involve verbal and nonverbal cues that convey meaning. Narrative inquiry seeks to adopt data collection methods that capture the truthful nature of the experience (Dibley, 2011). Truth is accepted to mean the perception of an event as understood by the person involved (Bailey & Tilley, 2002). Narratives are an embedded part of daily culture within a child's life and part of them developing their own social construct, they hear stories long before they can tell them, therefore many of the methods for describing

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experiences used by children are often in a story format (Engel, 1999). Narrative inquiry is reported to have been used in the 1970s initially, as it described that children organise knowledge of their lives in mental scripts of events (Engel, 1999). Nelson's script theory (1981) described that children often use stories to construct their dialogue with adults and relay information, which served as a useful tool to collect data. Furthermore, as an analysis framework, narrative research seeks value in participants' stories, which aligns itself with the epistemology of this study and social constructivism.

Narrative research inevitably leads to questions about the validity of the stories that the participants share, particularly whether or not they represent memory reconstruction or facts (Clandinin & Connolly, 2000; Holloway & Freshwater, 2007; Kim, 2016). However, considering my epistemological values and the philosophy of social constructivism that all narratives are carved within the history, biography and society of the person telling the story (Hunter, 2010), this conflicts with the theory of stories being reconstructed. According to Kim (2016), if a narrative does become reconstructed over time, this is due to the external influences and this forms a greater part of the narrative, to understand why it has changed, in the same way my narrative has evolved in this PhD process. Moreover, Bochner (2001) explained that narratives can be socially constructed and performative in nature, he stated this not as a criticism, but to demonstrate that the way knowledge is acquired is from within a person's social construct and the social context within which the narrative is formed. Furthermore, Polkinghorne (1988) theorised that a person's social construct is a continually evolving narrative. This aligns with a period of time in isolation where the child's perspective may change in context of what they are experiencing and the influences around them. This supports the use of narratives as a tool to collect data for children to describe their journey of time in isolation. For some participants, their isolation narrative describes a single experience, for others it was ongoing episodes within one experience of hospitalisation/isolation, and others it was a narrative of multiple admissions within a chronic health issue. Using a narrative inquiry form of data collection, it allowed for any of these differences and provided a rigorous analysis process to allow interpretation of the stories within their social context (Coffey & Atkinson, 1996). I wanted to collaborate with children, incorporate their unique insights to explore their true perceptions of single room isolation in hospital.

3.5 Research Design and Methods

As discussed throughout Chapter One and Two, children are not mini-adults and therefore the research design used when collecting data from children needed to be carefully considered to elucidate their narrative. Within this study children of different ages had different experiences to share and these needed to be captured in a manner that was not only appropriate, but also described as appealing to children (Hill et al, 2016; Punch, 2002). The literature attests to the use of methods that allow children to participate but also lead on research, allowing ethical symmetry between the child and the researcher (Christenson & Prout, 2002; Horgan, 2016; Mahon et al, 1996; Matutina, 2009; Robson, 2011). The literature also states that adult researchers may struggle to understand the world of the child even though they may have an insight into this world (Fine & Sandstrom, 1998; Punch, 2002; Solberg, 1996). However, through the clinical academic role and being within the child's construct as a nurse, and using participatory methods that allow the child to provide their narrative, it is possible to gain an insight into the insider view of the child's experience. The relationship between the participants and myself and the insider/outsider perspective were pertinent considerations in this piece of narrative inquiry in order that the temporality, sociality and place within the social context under study as described by Caine et al (2013) were considered.

Another key issue that emerged throughout the research study was the inclusion of the proxy perspectives, in this case through the participation of the parent(s) and the staff. Researchers working with children face challenges balancing the demands of ethical, rigorous data collection methods. One way in which this is reported to be managed in the literature is to augment the child's perspective with a proxy perspective (Iacono, 2009; Silva et al, 2014; Spriggs & Caldwell, 2011). With proxy perspectives there is a risk that the person participating would not provide information that represents the child's experience. The manner in which this was overcome was to keep the child's voice central to this study and triangulate this with additional data sources, to avoid the child's contribution becoming lost or tokenistic (Coyne, 2010b; Sattoe et al, 2012; Soderback et al, 2011). Pragmatically this was managed by the child being spoken to directly in their interview and not via the parent, and through the video diary the child was also telling their story. The use of proxy perspectives in this study were used to augment the data provided by the child and to see the contrasting and aligning stories regarding the child's experience

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of isolation. Throughout the rest of Section 3.5, the study design will be described with the underpinning literature to justify the decisions made in this research design.

3.5.1 Overview of Study Design

With the underpinning philosophy of children being at the centre of this research and social constructivism, it was essential to employ methods that allowed the child's voice to be heard in the data. The methods used were adapted throughout the data collection period February 2011- January 2015 (see Appendix 7 for detailed audit trail of data collection amendments).

- **Phase 1** used video diaries with children in isolation prospectively collecting their narrative, video stimulated recall interviews with children (February 2011-April 2012)
- **Phase 2** used video diaries with children in isolation or a retrospective interview with children who had been in isolation. Parents and staff providing care to children in isolation were also recruited to the study for retrospective interviews (May 2012-March 2013)
- **Phase 3** removed the option of the video diary element of the study (due to limited recruitment to the video diary method) (April 2013- January 2015)

An in-depth discussion of the study design methods has been presented in this chapter, to highlight the changes in methods that came about from feasibility of the initial approaches and feedback from the children.

3.5.2 Access

The hospital was purposively selected as the researcher was employed within this Trust and this is the social construct that I understand and I am familiar with, which aided some of the nuances of data collection and also data analysis and linguistics. The study hospital had a number of regional specialities within it, particularly within child health, which may enhance the transferability to other settings particularly district general hospitals which may cater for a number of these children within their wards. The setting will be described below to allow readers to ascertain whether the findings are transferable to their clinical settings and thus enhance dependability as suggested by Squire et al (2014).

3.5.3 Setting

The study recruited from nine paediatric wards which included general medicine, neurology, high dependency, intensive care, cardiology, oncology, orthopaedics, nephrology and surgery. Initially, only the medical unit and the oncology ward were selected to recruit from, however with limited recruitment it was decided to expand the selection to nine paediatric wards. The children in these wards varied in age from one day to 18 years old. Length of stay in isolation usually varied between less than 24 hours to two weeks. For the sample recruited in this study, the mean average length of stay was seven days. Time in isolation for children does not always account for their entire time in hospital, therefore for some of the children in the study, they were able to compare the experience of isolation and hospitalisation.

To understand the social context under study and some of the contextual impact, it is necessary to understand the hospital under study. The hospital is located within a culturally diverse city in the UK, which provided a heterogeneous sample from which to recruit. At the time of the study, the paediatric wards provided isolation care in designated single rooms. During the period of the study, there were no structural or decorative changes to the rooms. The oncology ward and cardiac ward had ensuite facilities, however the other isolation rooms were required to use a shared bathroom that had been designated for their use with a sign on the door. The isolation rooms in the oncology, cardiac and intensive care have air filtration systems. None of the wards had isolation rooms with anterooms. All the isolation rooms throughout the paediatric unit had a window facing onto the corridor, and most of the rooms had a window to an external view. The view from the outer facing window was variable according to the room location; often views onto the car park and other hospital buildings.

The rooms had an isolation sign displayed on the door, to indicate what infection prevention precautions were necessary for visitors and staff on entry to the room. All isolation rooms had curtains on both windows and a blind on the door. The facilities available inside the room were variable depending on whether the child was in isolation for source or protective reasons. In addition, some wards had charity funding for extra facilities such as games' consoles or computers in the rooms. At the time of the study, wireless internet was not available within the paediatric wards. Each room had capacity for

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a parent's bed, and normally accommodated a chair and a cabinet for storage. The décor was plain; light blue, cream or yellow on the walls, with occasional prints or paediatric-specific paintings to the walls.

In all the wards, it was promoted that one parent could be resident with the child, with the exceptions of intensive care and high dependency where parents were offered accommodation on hospital premises. At the time of the study, other than the parents' beds at the side of the patient and the parents' accommodation offered on the high dependency and intensive care, there were limited places for a second parent to be accommodated. Staffing throughout this study was always at national average levels. The management team was consistent throughout the study period. During the study period, patients were relocated from their speciality ward to another ward due to single room availability. For example, an oncology patient may have been nursed on a medical ward if there were insufficient beds or appropriate bed spaces on the oncology ward at the time of admission. It was vital to describe the moves between wards as some children within the study have been on different wards and therefore their social context, and thus potentially their social construct was altered within their isolation experience. The findings in this study provide commentary on different isolation experiences on different wards for these reasons.

The hospital under study is a specialist centre for some aspects of paediatric care; therefore the findings may not be transferable to all paediatric settings. Through this detailed description of the setting and a later description of the participants, it is anticipated that readers may find applicability to other clinical settings, thereby enhancing the dependability of the findings.

3.6 Sampling

In accordance with social constructivism and narrative inquiry, the selection of participants for this study was purposive. Gergen (2001) describes purposive sampling as selecting potential participants for the information that they could provide regarding the phenomenon under study, i.e. in this study children in isolation. This ensured that the sample was reflective of the population under study. Due to the recruitment challenges, having an open approach to sampling maximised the opportunities for recruitment. According to Denzin & Lincoln (2008) sample size must be driven by the need to fully explore and understand the multiple realities that exist, with the acceptance that there may

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be some convergence of findings amongst the population. Engel (1999) purports that within social constructivism, participants may all have different contexts within their data, therefore, although there may be similarities in the findings from their data, there will not be convergence of all findings and each story will present new findings. Data saturation is not entirely possible in social constructivism and narrative research (Squire et al, 2014). Therefore, it was essential to recruit sufficient participants so that their narrative represented many ages, conditions and reasons for isolation from a general paediatric ward, with the acknowledgement that this level of heterogeneity could have caused challenges in data analysis. The sample size and selection can have a profound effect on the overall quality and validity of the study (Coyne, 1997), thus much thought was attributed to the size of the sample that was selected for this study.

Sample size depends on successful recruitment, based on those who can provide necessary and useful data (Parahoo, 2014; Squire et al, 2014). Within the children's hospital, the wards that were selected all had isolation rooms, and within the wards under study there were 108 beds, of which 26% were isolation rooms. Initially the study aimed to recruit 12-18 children and parents to the video diary and follow up interview. The initial sample sizes were based on the adult literature sample sizes where larger scale studies have been conducted, combined with pragmatics of time for this study and the quality and volume of data yielded from each data set. Due to the recruitment challenges, Phase 2 used a different data collection method to increase the likelihood of reaching the target of 12-18 children. A total of eight children participated and 12 parents. Once the amendments to the recruitment strategy were made, the aim for staff recruitment was 10-20; this was achieved. The parental recruitment was also achieved. Although the initial sample size for children was not met, the paediatric data was triangulated with the staff data which increased the overall sample size. This enabled the study to be as rigorous as possible in terms of recruitment, despite it not being the original data collection methods or the sample required in the beginning. Consideration was taken of the fact that parents and staff may have been more willing to participate as they were more used to the research process. Despite the evolution of the data collection methods during this research study, and the recruitment challenges, it was fundamental to the researcher that the child's voice was central to the research study. This meant that recruitment had to continue until sufficient paediatric participants had been recruited, however this meant that the data collection

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period was longer than anticipated and the implications of this will be explored in the reflections on the study, in Chapter Eight.

3.6.1 Sampling Criteria for Children

There were three participant groups in this study; the child, their parent(s) and the staff. The following tables represent the recruitment criteria for all data collection methods in this study.

Table 3.1 - Sampling Criteria for Children

Inclusion Criteria	Exclusion Criteria
Children aged 6-17 years	Children who were younger than 6 years or people older than 17 years
Children under 16 who gave their own informed consent and also had parental consent, or aged 16-17 years and gave their own informed consent independent of their parents (parental consent was obtained in addition where possible)	Children (under 16 years at the time of consent) for whom parents did not consent to participate Children who were unable to/ did not want to provide assent/informed consent Children who were in anyway unsure about providing consent/assent, regardless of their parents' decision on consent
Children in either source or protective isolation	Children who were in isolation for any reason other than infection prevention
Children who were English speaking or could articulate their feeling in a manner that was comprehensible to the researcher	Children who communicated in a language/manner that required an interpreter or another person to interpret for the participant. This included any form of sign language
Children who were deemed well enough by their parents, healthcare professionals and the researcher	Children who were deemed too ill or in a vulnerable position by either their parents, healthcare professionals or the researcher
Children who were in isolation or had been in isolation in their hospital stay and met the other inclusion criteria, and had not been approached to participate in the video component of the study*	Children who were involved in the video diary element of the study

* The final criterion in this table applied only to Phase 2 and therefore did not apply when recruiting to the video diary part of the study.

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Every child needed to be competent to articulate their feelings and be able to comprehend the research. Utilising the theories of Piaget, Vygotsky and Erikson (cited in Rushforth, 2010) it was possible to suggest that competency to understand research and participate can be reached by the age of eight years old. However, with limited recruitment and the acknowledgement of the nursing staff that there were children who were younger than eight, but may have been competent to participate, I completed an amendment to the ethics committee to recruit children as young as six years. Each child was also individually assessed for competence by myself using my experience as a nurse and knowledge of children's competence, by getting the children to explain the purpose of the study and their involvement, in the presence of their parent. In the literature there is wide acceptance of interviewing children who are of school age as described by Greig et al (2013), however there is no literature that defines an age for participation in research of differing methods. Despite this, age remains the influential factor in determining children's competence to consent to participate in research. The age limitation for participation is generally based on the child's vulnerability, limited social power, reduced cognitive ability and limited life experience (Lambert & Glacken, 2011). From Alderson's (1993) seminal work examining children's ability to consent to surgery, it was contended that competence is not simply an individual skill growing over time through ages and stages of development. Rather competence is developed through experiences and relationships with others within their social context, and it is dependent on socio-cultural influences (Engel, 1999). Thus, irrespective of age, development or ability, in theory children have a right to be considered as competent participants in the research process (Lambert & Glacken, 2011), yet for the purpose of ethical submission there is a reliance on an age as a determining factor for children's participation in research (Fouka & Mantzourou, 2011).

In accordance with the Declaration of Helsinki, children under the age of 16 who were deemed competent could consent, however this was in addition to their parents' consent (WHO, 2008; General Medical Council [GMC], 2010). Children aged 16-17 were able to give their full consent to participate in research independently of their parents, however in accordance with best practice, parental consent was obtained in addition to the child's consent (GMC, 2010; Shaw et al, 2011). As the parent was given the information regarding the study prior to the child, I was never in a position where the parent would not consent, and the child wanted to participate. For children who were unable to give informed consent

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as deemed by myself and the parents, in accordance with their understanding of the study, their parents were asked to provide consent, and the child was asked to provide assent. If any child did not wish to participate, regardless of their parents' decision, their refusal to participate was respected (GMC, 2010). One parent's consent was adequate for participation of the child. When there was disagreement between parents as to whether a minor should participate in the research, it was suggested by the researcher that the child should not be included in the study as is described as best practice by GMC (2010). National Children's Bureau (2011) guidance on consent for children in research were used as this is the current UK guidance for consent for paediatric research.

In this study parents could participate without their child participating and vice versa, providing consent from the adult was obtained for their own and their child's participation. Children who were asked to participate in the video diary part of the study were not asked to participate in the retrospective interview part of the study, as it would have been unethical to ask children to participate twice into one study as described by Fargas-Malet (2010). If any children were missed during the recruitment period for the video diary element of the study, or they declined to participate the video diary, but they were happy to participate in the follow up interview, they were offered the opportunity to participate in the interview.

The experience of being in a single room for reasons other than infection prevention may have been different, therefore the findings would not have been comparable if children who were in a single room for other reasons participated. It was within the remit of my clinical academic role that the research that I conducted explored infection prevention and control, therefore this was the focus.

There was regrettably no funding for independent interpreters and there was a risk of inaccurate translation/interpretation from a parent. This meant that any child including those with learning disabilities could have participated providing they could communicate with the researcher without the need for anyone else to interpret. This limited the participation of children with special needs who are non-verbal, which is a regret as these children are regular healthcare users (Tisdall, 2012). Having reviewed the literature subsequently following this study, although there are studies which support a range of

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participatory methods within one study (Hill et al, 2016; Mayes, 2015), I have not found a single data collection method that would allow children who are non-verbal to participate in research that explores their experience in a manner that does not require a person familiar with them to interpret, which introduces a potential bias. This is why children who were non-verbal were excluded initially from the study. However, in the future it would be an interesting area to explore, as these are children that may have frequent hospitalisation and isolation.

The health of the child (as judged by the researcher, parents and the healthcare professionals) was the ultimate priority, which is why it was an exclusion criteria if the child was too ill to participate. Until a child was deemed “well enough” to participate by the researcher, health professionals caring for that child at the time, and ultimately the parent, the child was not approached to participate. This may have limited the child’s right to participation when they may have felt that they were able to, yet in order not to compromise their medical care and wellbeing it was necessary to put this safeguard in place.

3.6.2 Sampling Criteria for Parents

Table 3.2 demonstrates the sampling criteria for the parents in this study.

Table 3.2 Sampling Criteria for Parents

Inclusion Criteria	Exclusion Criteria
Parents of children who were aged 6-17 years who were in isolation as a consequence of infection prevention measures	Parents of children who were in isolation for other reasons or who were in hospitalised on the main ward
Parents who were able to provide informed consent	Parents who did not provide consent Parents who were unsure about providing consent
Parents who were English speaking,	Parents who were unable to communicate in a language/manner that required an interpreter, including sign language
*Parents of children who had been discharged at the time of recruitment and had not been approached to participate in the video component of the study	Parents of children who had been discharged home at the time of recruitment and must not have had the opportunity to participate in the video component of the study

*The final criterion in this table was added for Phase 2 and did not apply when recruiting to the video diary part of the study.

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Parents had to meet all criteria in Table 3.2 to participate in the study. For the purpose of the video diary part of the study, parent(s) were only recruited to the study if their child was participating in the study. Parents were recruited with/without their son or daughter being a participant to the retrospective interviews from Phase 2 onwards. It was considered whether the parent(s) could have made a video diary of their child's experience, however this was discounted as it would not have provided the child's narrative; their eyes and their voice on the experience.

Parents were required to provide informed consent for their own participation. Both parents could participate if they wished to do so. It would have been interesting to have yielded a greater number of fathers to participate as literature suggests that fathers have different insights into hospital experiences (Gower et al, 2016; Provenzi & Santoro, 2015). Pragmatically, it would have been more challenging to have both parents and the child available to participate in an interview at the same time, which may have hindered recruitment.

3.6.3 Sampling Criteria for Staff

Table 3.3 demonstrates the sampling criteria for the staff in this study.

Table 3.3 Sampling Criteria for Staff

Inclusion Criteria	Exclusion Criteria
Qualified healthcare professionals and staff who held a contract with the Hospital Trust, including healthcare support workers, play workers	Staff who did not hold a honorary or substantive contract with the Hospital Trust. This included students as they held a contract with the University
Staff who had cared for children in single room isolation as part of their job role	Any staff who had not cared for a child in isolation
Staff had to be prepared to undertake the interview in their own time	Staff who were not prepared to undertake the interview during their own time

Staff had to fulfil all criteria in Table 3.3 to participate in the retrospective interview. In order to provide data on how children experience isolation, the staff member participating in the study must have had experience of working with children in isolation. To ensure clinical care was not compromised, staff were required to participate within the study in

their own time. Staff were also required to hold a substantive contract with the Hospital Trust.

3.6.4 Accessing the Sample

The nature of recruiting children to this study required careful ethical consideration and negotiation with the Hospital Trust. The researcher met with the ward managers individually to explain the purpose of the study and the methods of recruitment. This discussion happened prior to recruitment and the study commencement. The consultants and matrons were also contacted prior to the start of the study with information and were given an opportunity to provide feedback or ask any questions. The way that I was introduced and presented in the clinical environment was essential for the credibility of the study. Being introduced as a clinical academic nurse who was exploring this research area in my own clinical field, enhanced the trust between the staff and myself which had implications in terms of the staff referring patients that were eligible for participation in the study, and for staff volunteering to participate as reported by Bulpitt & Martin (2010). There may also have been interest from staff to have research ongoing within their unit to promote the reputation of the unit and provide some evidence to support their care provision (Fouka & Mantzourou, 2011).

The ward managers were considered as “gatekeepers” and had to agree with the process of data collection on their ward prior to the study starting. Each ward had a poster displayed within the staff room to explain the purpose of the study to the ward staff. Further gatekeepers were considered to be the staff caring for the children and the parents. The pertinent issue here is that as the researcher, it was requested by the local ethics committee that I was not to approach the children directly. This was key in the interest of avoiding any risk of coercion. Although this level of safeguard was requested for the protection of the child, it could have potentially been a contributing factor in challenges in study recruitment, (Graham & Fitzgerald, 2010), and will be discussed later in Section 7.3.4. Within the UK at the time of the primary ethics submission (2010-2011), there was an increasing recognition of children’s capacity to participate in research, however there remained a need to protect children.

3.6.5 Contacting the Families

The process of contacting the families for recruitment to participation required careful consideration to ensure that there was no coercion and that families were allowed sufficient time to make their decision. Initially in the study protocol taken to the ethics committee, I asked to approach families directly about participation. This was declined and a compromise was taken that the staff would act as gatekeepers to give the information to the family about the study and I would visit the family later to discuss participation once they had read the information. For the video diary part of the study; children that met the inclusion criteria were identified when I visited the wards. If children met the inclusion criteria, an information leaflet and invitation was given to the nurse caring for them on that shift to give to the parents so that the nurse could act as the gatekeeper (see Appendix 8 for Recruitment Pack for Video Diary for Children and Appendix 9 for Recruitment Pack for Video Diary for Parents). Inside the parental information leaflet was an age appropriate leaflet for the child which the parent could pass on if they wished. For the video diary, families were given the information for a minimum of four hours before I returned to them, to allow them sufficient time to make an informed decision. Families would have been afforded more time if necessary, however all the families that met the inclusion criteria and were given information about the study had made their decision when I returned to them. It was accepted that 24 hours is reasonable as the minimum within Good Clinical Practice (National Institute for Health Research, 2016) to decide whether to participate or not in research. However, with some admissions being particularly short in isolation, and adult literature showing that an admission even as short as four hours to isolation can have psychosocial effects (Ward, 2000), it was necessary to gain consent rapidly to avoid missing data. Every family that received an invitation was documented in a log, to ensure that people were not repeatedly approached to participate.

The challenges with this method of recruitment to the video diary method was that as a sole researcher without a team, I was reliant upon referrals from staff (I received only one during the entire video diary data collection method period). The time-consuming nature of attending the wards daily to ascertain if any of the patients were eligible for participation and then to review later whether they wished to participate or not was challenging to facilitate around clinical duties. This method inevitably meant that some potential participants must have been missed. When wards were closed due to an outbreak such as

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rotavirus, only essential staff were allowed on to the wards, which limited my ability to recruit. Finally, on occasions there were admissions during a day after I had visited and due to short admissions, they may have been discharged by the next day when I visited.

Recruitment was dependent upon staff who did not know a lot about the study and also had less concern with the recruitment than I would have, if I were able to recruit in person. The challenge of not using face-to-face recruitment is described by Gates et al (2018). A limited number of staff referrals of potential participants meant that I was reliant upon my presence for recruitment. The lack of referrals could have been reflective of the busy nature of the wards. I publicised the study a number of times during the recruitment period with posters and my physical presence daily, however this did not seem to affect recruitment. It could also reflect the order of priority that recruitment to research studies has for clinical nurses on the wards as suggested by VanGeest & Johnson (2011). I did not provide education to medical staff for them to refer patients, which may have retrieved potential participants as they review patients daily and according to Siemens et al (2010) medical staff have a greater input in research regularly as part of their development. Therefore, in retrospect their inclusion within recruitment may have identified a greater number of potential participants to the prospective video diary data collection method.

Recruitment to the retrospective interviews with children and parents was conducted in two different ways. Firstly, the researcher reviewed the admissions book for each ward at minimum once a week, and identified children that met the recruitment criteria who had already been discharged. The parents of these children were posted an invitation and information leaflet, inside which was an age appropriate copy for the child if the parents wished to pass this on to them (see Appendix 10 for Recruitment Pack for Retrospective Interviews for Children and their Parents and Appendix 11 for Recruitment Pack for Retrospective Interview for Parents [when children were too young to participate]). Although this protected the child, it may have also denied them the opportunity to participate (Coyne, 2010a; Parsons et al, 2015; Turner & Almack, 2017). Conversely, with parents as the gatekeepers there was a risk that parents may have coerced them into participating. At interview, all child participants completed consent/assent forms and appeared keen to participate. The use of mail may have been a limiting factor as many

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people are more engaged with electronic media, such as delivering the information leaflet and invitation via email (Gates et al, 2018).

The alternative recruitment method was visiting the wards, I discussed with the nurse in charge and identified any potential participants who met the sampling criteria who were admitted on the ward at that time. If this was the case, I provided the invitation and information pack to the nurse (who acted as a gatekeeper) to give to the parents of the child at an appropriate time. In the same manner as with the posted invitation, inside the parents' copy there was a child's version that if the parent desired they could pass onto their child. For both methods of disseminating the invitation and information leaflets, the process of the family responding to express an interest in participation was the same. I did not directly contact the family to ask for participation as specified by the ethics committee. Attached to the invitation was a reply slip which the parents completed if they were interested in participation. This method aimed to provide no coercion at all, however it is acknowledged that there is a risk that potential participants ignored the invitation or forgot to respond and therefore there were missed opportunities for recruitment. Once the family returned their reply slip, I contacted them to arrange an interview date.

The challenges with recruitment led to a protracted period of recruitment beyond the expected time frame, however this does not impede the data quality as the ward structures, managerial staff and isolation practices did not change during this period. Therefore, the environment in which children experienced isolation was consistent throughout data collection.

3.6.6 Contacting the Staff

Staff were sampled using the criteria in Table 3.3. Purposive sampling was employed to ensure that the sample of 10-20 staff reflected as many members of the healthcare team as possible, thereby enhancing credibility and transferability of the findings. The aim of recruitment of staff was that each profession, and professionals of all grades that worked with the child in the social context of isolation would be represented in the sample.

Therefore, not every employee that met the inclusion criteria was invited as this may have yielded too many participants of one profession, or grade within profession. This demonstrates the additional level of selectivity employed within purposive sampling above

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that of recruiting the children and parents to the study, due to the increased population from which to sample.

The aim of recruitment of staff was to ensure each profession was proportionally represented, in terms of the total number of their profession within the child health unit for example nurses being the largest staffing group and therefore they represented the largest proportion of the sample. I accessed the number of nursing staff for each ward (including healthcare support worker staff and nurse specialists) from the nursing management, and other staff groups from their leads within the Trust, for example the medical lead for paediatrics, the head teacher and the play team leader. From the total number of employees for each staffing group, I was able to determine the number of participants for each group that would provide representative of that profession and this was the basis for the number to be recruited for each profession with a total recruitment of 20 staff. The recruitment strategy aimed to have staff from the following professions: nurses (including nurse specialists and healthcare support workers), doctors, play specialists, physiotherapists, clinical psychologists, school teachers and volunteers. Within each profession (nursing and medics), it was aimed to have different grades to represent different levels of experience and understanding of the child's experience of isolation. Clinical psychologists, school teachers and volunteers did not respond to their invitations to participation and therefore were not represented, which meant that the original estimations for ideal recruitment for each profession were fluid and adapted according to response to invitation to participation. The lack of participation from these professions may have been due to their workload, or presumption that they had less to contribute to this study. See Appendix 12 for Staff Recruitment Pack.

For nursing staff who are more visible on the wards, they were recruited in a similar manner to the parents. The nursing staff that cared for children in isolation were approached by the researcher on the wards when the researcher was visiting the wards to recruit children. The nursing staff that were approached were varied across the wards and the levels of nursing skills, to ensure a diverse sample. I varied the times of the visits in order to recruit nursing staff who work over the 24 hour work period. In accordance with the staff sampling strategy being purposive, it is accepted that there was an element of opportunism to this recruitment method with regards to the nursing care team that were

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working on the shifts when I visited. However, over the duration of the time of recruitment it is anticipated that a good variation of the nursing care team were approached to participate in this study until the total number of recruits were met. The process of nursing staff recruitment consisted of the researcher explaining the study to the staff member and through this discussion it was assessed whether or not they met the inclusion criteria. The staff that met the inclusion criteria were given an invitation which included a reply slip and a participant information leaflet, and they were logged in a record sheet to ensure that they were not repeatedly approached to participate. This method was used for nursing staff predominantly, however two of the junior doctors and two play specialists were recruited in this manner whilst I was on the wards recruiting children and their parents.

For the smaller staff groups, for example doctors, physiotherapists, play specialists, teachers, volunteers and specialist nurses, they were less likely to opportunistically be on the ward at the time of my visits. Therefore, I may have missed the opportunity to assess for eligibility to recruit, if I had not employed another recruitment strategy. This group were identified as eligible through my knowledge of the hospital and the teams that were likely to work with children in isolation. This highlights the value of the clinical academic role, working and researching in the same clinical unit meant that I had insider knowledge of the social context and was not starting without this knowledge which could have caused further challenge to recruitment, and would have relied upon the clinical staff to use elicit this knowledge. Furthermore, some staff members were identified as eligible by referral from other staff members using a “snowball” recruitment technique. The snowball technique happened when one staff member in the study identified another staff member who would be able to provide insight into the field of study; two participants were recruited in this manner. Within this approach, the same as the nursing recruitment method; an invitation and participant information leaflet were sent to the staff member who had to return a reply slip which was attached to the invitation to demonstrate their interest in the study and the researcher then contacted them to arrange an interview.

Staff recruitment occurred over two years, although more rapidly, and with more participation per invitation given than the child and parental recruitment. Siemens et al (2010) suggest that easier staff recruitment to research studies can be a consequence of the fact that staff have a continued engagement with research, and that professionals are

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required to participate in research as part of their job and clinical development.

Additionally, it may have been that the staff perceived the benefit from having such a research study conducted as proposed by VanGeest & Johnson (2011). Finally, there may have been a feeling of obligation to participate to support me as a nursing colleague, although friends and colleagues with whom I worked clinically were excluded. Throughout the recruitment for staff, it was more imperative than ever to ensure a non-coercive approach, hence explaining the study and leaving the information leaflet with them or sending it to them and allowing them to contact the researcher if they wished to participate.

3.7 Data Collection Methods

Data collection methods used during the study for children included video diaries, video stimulated recall interviews within Phase 1 and 2, and retrospective interviews for children, adults and staff were retrospective interviews in Phase 2 and 3. The Phases of the study are explored in greater detail in Section 3.7.4. Section 3.7 explores these methods and reviews some of the literature underpinning these methods.

3.7.1 Video Diary and Video Stimulated Recall Interview

Video diary (Section 3.7.1.1) and video stimulated recall (Section 3.7.1.2) methods were used concurrently in Phase 1 without other methods, and in combination with alternative methods in Phase 2 of the study. Video diary and video stimulated recall method was removed from Phase 3 due to limited recruitment.

3.7.1.1 Video Diary Method

Since the conceptualisation of this study, there has been an increase in the use of media, particularly the use of video data for communication and documentation, with blogging and online video sites which were common concepts and familiar to children (Barker & Weller, 2003). However, since the beginning of data collection and throughout the past five years, the use of media and technology including online video calls, vlogging and sharing of images and videos online via social media has become ubiquitous for children and young people (Wartella et al, 2016), and has been included in paediatric research in hospital (Karisalmi et al, 2018). At the commencement of this study the use of video diary was a novel concept with its use limited to children in education and children as outpatients or carers, not children as patients. The literature suggested that video diary data

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were comprehensive and robust (Buchwald et al, 2009; Iivari et al, 2014; Noyes, 2004; Pink, 2001; Rich & Patashnick, 2002; Robson, 2011; Rowe, 2009) and that videos can generate longitudinal data to research a fixed time period (Rich & Patashnick, 2002). Lomax and Casey (1998) and Rich et al (2000) suggest that video diary allowed for the minutia of everyday life to be recorded in a manner that cannot be replicated using other methods. Using the work of Pink (2001), the format of the video diary needed to be directed by the child to allow for maximum capture of their experience and social construct within the social context under study, and allow for the child to be creative. Furthermore, through giving the participant the video camera and leaving them alone, it was within their control what they choose to film, which would highlight what they perceived as the most important aspects within their social construct (Jones et al, 2015).

Gibson (2005) suggested that the “absent” researcher allowed for the participants to be creative and unrestricted in their data collection and that the process by which they make the video diary is equally as useful data as the content. Jones et al (2015) and Whiting et al (2018) extend this concept by suggesting that video diaries mediate the relationship between the researcher and the researched as they generate participant empowerment. In Gibson et al (2016) participants described using video diaries as a free means to express themselves, not to researchers or professionals, in a language that was comfortable to them, thus the data was thought to be more ‘natural’. However, in paediatrics it would be challenging to know if this would be entirely possible because of the presence of the parent. Moreover, Cherrington & Watson (2010) suggested that there is a balance between guidance and freedom in the production of video diaries, to ensure useful but creative data without restraints. The use of video diary did afford some opportunities to make the video diaries when their parents were present and of the two participants, the videos without the parents the data was more rich and analytical rather than descriptive of their daily activities. Video diaries allowed for children to have different competence levels with the technology, different means of verbal expression and variation of attention spans as described by Buchwald et al (2009). When considering video diary with other participatory research designs, video diary seemed inclusive whereas if faced with drawing an image or writing a story which were alternative study designs that were considered, some participants may have been embarrassed by a lack of ability as suggested in Haijes & van Thiel (2016), Harrison (2002) and Literat (2013). Furthermore, video diary appeared fun

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and engaging as a study design. This made video diary an attractive method for the study design, due to the innovative method and the use of a familiar means of communication to children.

There were some limitations to the use of video diary method that were acknowledged from the beginning of the study through reviewing the literature. Video diary method has previously been limited in research to educational settings, adult research in hospital and children in community healthcare settings, thus its use with sick children in hospital had not been documented in the literature. Additionally, with the use of an unrestricted and unstructured data collection method with the video camera, the literature suggested that there needed to be an anticipation that some of the data collected would not be relevant to the research question (Buchwald et al, 2009; Quadri & Bullen, 2007). However, in the interest of describing their social construct the ‘irrelevant’ data built on the knowledge of the child’s social construct and provided some context to their narrative. Finally, video diary data analysis was reported to be challenging as the researcher is not simply analysing the audio but also the visual (Buchwald et al, 2009). Goldman-Segall (1993) argued that video data cannot be comparable with transcripts from interviews as the data is so rich as a consequence of the visual elements. The data analysis for the purpose of this study is described in Section 3.10, which managed the video diary data in the same form as the interview data using it to illustrate their story of isolation, however in addition to the verbal transcript the analysis drew on the physical observations from the video. Despite these limitations and challenges to the video diary study design, the benefits of this innovative method drove the decision to use it as the first data collection method in this study.

Once consent was obtained from the family, the child was loaned a Flip Ultra HD ® video camera to make a video diary. Full instructions on the use and guidelines on what and what not to film were given to the child, with a parent present. Guidance was provided to the child concerning practical issues; issues to protect staff and other patients on the ward and to ensure that adequate material was captured on the video (for instructions for filming see Appendix 13). The video diaries were made from the day of consent for up to 7 days. Seven days of video data was selected as the maximum. This was a pragmatic decision based on the memory capacity of the video camera and the knowledge of the time that would be needed for analysis. The intention was to begin the diary as early as feasible in

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their admission to isolation. On day seven of data collection or sooner if the child was discharged earlier, the cameras were collected, decontaminated and data downloaded onto an encrypted hard drive. I visited the families every few days whilst the video diaries were being made, and I was available for technical difficulties at all times. The Flip Ultra HD® video camera was selected as it was small, appeared simple in design, child friendly in its appearance and silent in operation. The Flip Ultra HD® video camera was encased in a waterproof cover (used for appropriate decontamination in accordance with local infection prevention consultation and advice) which was also secured with a cable tie to ensure that the children could not access and subsequently contaminate the video camera itself.

The video diary data collection method yielded data beyond that which was capable in the retrospective interviews and allowed a greater insight into the child's social construct through viewing it as well as relying on their narrative as given at interview. Furthermore, collecting video diary data was prospective and therefore removed any need for the child to recall memory. It was with regret that this method didn't yield a greater number of participants.

Although the video diary did not recruit a sufficient sample and other data collection methods were employed, the reasons for this need to be considered in context of this research study, as it has been used successfully within other contexts as shown in the literature (Noyes, 2004; Pink, 2001, Rich et al, 2000), but not when children have been patients. Furthermore, it is not to say that this method may not be possible within this context now, due to the evolution of culture to be using more social media and video as part of youth culture (Karisalmi et al, 2018). The reasons for non- participation to the video diary are presented in Table 5.3 in Chapter Five. These data are presented [here](#) but will be discussed in greater detail in Chapter Eight, as although they are not direct findings from the research question, they do offer some significant contributions to the body of literature concerning data collection methods when researching with children.

3.7.1.2 Video Stimulated Recall Interview

Video stimulated recall interviews were used as part of Phase 1 and 2 of the study when children participated in video diaries, they were invited to participated in a follow up interview where the video was used to stimulate memory recall. In this study, the video stimulated recall interview was to be used only for the participants who had made a video

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diary, and of the two who made a video diary, only one participated in the interview. The other child declined participation in the interview, however was happy for their video diary data to be used in the study.

Video stimulated recall is the use of a video which is replayed during a research interview to stimulate discussion (Henry & Feters, 2012; Lyle, 2003; Morgan, 2007). According to Rowe (2009), video stimulated recall allows the participant to comment on matters of interest or confusion in the video and stimulate discussion during the interview. Paskins et al (2016) described how video stimulated recall allows the participant to get back into the moment and then they can recall the experience more clearly. The main limitation of this method in the literature was the concern that participants may not have wanted to recall the experience, and by replaying a video from that time it could have elicited negative emotions for the participant (Theobald, 2008). Although for the one participant to the video stimulated recall interview, the video did produce feelings of embarrassment watching the video, it allowed me to clarify and further elucidate sections of the video that appeared ambiguous or unclear, which simultaneously increased methodological robustness through respondent validation as described by Challen (2010), Sayre & Halling (2007) and Theobald (2008).

In the video stimulated recall interview the video diary was used to stimulate the memories of isolation and focus the child's thoughts at the beginning of the interview. The stimulated recall element of the interview occurred first, whereby the child was played excerpts of their video diary. The stimulated recall interview was conducted approximately two weeks after the child was discharged from hospital. For the child that participated in the video stimulated recall interview, it was decided to do the interview at the child's home. The parents did not want to participate and therefore the child completed the interview alone. As the video was not extensive (nine minutes in entirety), the entire video diary was shown to the child. Whilst watching the video excerpts the child was offered the opportunity to stop the video and discuss what they were viewing. Following the stimulated recall element of the interview, the interview schedule followed the same format as the interview schedule for the retrospective interviews as presented in Section 3.7.2, Table 3.4. The video stimulated recall interview was audiotaped and transcribed verbatim and was used as part of the bigger pool of audio interview data in terms of analysis.

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Video stimulated recall interviews compared with retrospective interviews are theoretically beneficial as they allow the participant to recall memories more specifically, not based on how those memories had been diluted or altered with the passing of time (Nguyen et al, 2013; Rowe, 2009). The use of stimulating memory recall can elicit positive response in that it stimulates memories for further clarification at interview, however it can also elicit negative emotions from the time that the video is showing and therefore provide stressful memories (Rowe, 2009). Fortunately the one participants to the video stimulated recall had no lasting stressful memories or negative impact and they were supported through the embarrassment of watching the videos. Participants were provided with contact details if they felt any lasting negative effect from any part of the research study.

3.7.2 Retrospective Interviews

In Phase Two of this study, retrospective interviews were offered as an option to children who did not want to participate in the video diary and interviews were the only data collection method used in Phase 3 of this study. Retrospective interviews are a means to gather information that has already occurred (Kortesluoma et al, 2003). This is with the acknowledgement that the story that they are telling may have altered by external influences or influences of other social contexts during that time (Engel, 1999). This is in keeping with social constructivism whereby the narratives are adapted and influenced by those around them, the social context and subsequent experiences (Gergen, 1999). The interview structure and format considered the participants and their capabilities as suggested by Graue & Walsh (1998) and Fargas-Malet et al (2010). For children it is argued that participatory methods are desirable as children do not have a long attention span or the ability to recall experiences like adults (Balén et al, 2000). However, when recruitment to the video diary method proved challenging, potential participants often commented that they did not want to participate as a consequence of the video diary method, however they would have done the follow up interview. Furthermore, if this research were completed today other participatory methods may have been considered in place of the retrospective interview. However, within the time period of data collection, one participatory method had not worked, therefore it was possible that another innovative method may not have worked. Although other methods such as draw and write technique, written diaries and observational methods were considered and discussed at research

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supervision, it was a pragmatic decision to use a data collection method that was well represented in the literature and had been widely used with children.

Retrospective interviews were not selected as part of the study design as a second-rate form of data collection, they were selected as a method to encourage participation. This was not without consideration that the desire was initially to collect prospective data. It would have been impossible to collect prospective interview data about the child's experience of their entire time in isolation and a two-week window of allowing the child and their family to resume normal home life was felt to be sufficient time for comfort, without the risk of losing the memories of their time in isolation. All the children were able to recall their time in isolation at interview, without any visual prompt, however that is not to say that visual prompts may not have elicited different responses. It was considered to take a picture of their isolation room with them to interview to elicit the memory recall, however many of the children were isolated in a number of wards and rooms, therefore pragmatically this would have been challenging. If there was one photograph of one ward, there could have been a risk that the child and family may have been inclined to focus the interview on that room in terms of their experience of isolation, not other isolation rooms. Furthermore, some participants shared experiences of being isolated in other hospitals, where photographs would be unobtainable. Through changing the data collection methods, it allowed for sufficient flexibility and adaptability of the method to allow children, parents and healthcare workers to participate and ensure the data were comparable, and dependable.

In congruence with social constructivism and narrative inquiry, children were encouraged to tell their story in the most appropriate manner possible. The interview needed to be semi-structured in format to allow for different age participants and the different experiences that were had. This aligned with narrative inquiry as the child could tell their story in the manner in which they felt appropriate, without interruption. This also enhanced the content validity as the findings were based on the participants' experiences of isolation, not an interview schedule wholly devised by the researcher. It allowed for flexibility and a fair account of the overall experience of the participant.

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Once participants (child and parent) had returned the reply slip from their invitation the researcher contacted them to arrange the timing and location of the interview. There was a high percentage of non-participation to the retrospective interview, similar to the video diary (only 13% participation for children and 20% participation for parents). However, because interviews were conducted retrospectively and recruitment was conducted via the post, no potential participants returned the reply slip with a justification for their non-participation and therefore, this area of non-participation cannot be given a rationale. The parents were given the option of where the interview would be conducted to allow them control over the situation, to support their child's needs, allow the family to feel comfortable in their environment and reduce any inconvenience for them. All the families apart from one had the interviews conducted at home. The other family had their interview conducted in a meeting room whilst at the hospital for an outpatient appointment. The date and timing of their interview was negotiated with the family to coincide with their schedules.

The child was offered the opportunity to do the retrospective interview separately from their parents, however all participants wanted to do a joint interview with parents present. Although there is concern of parents influencing the story that the child was telling, in this study it was often useful to have the parent present to be an aide memoire to their story and to allow the child to feel comfortable participating in an interview with a person they had only just met. Furthermore, as the parent is part of the influence on the child's social construct (particularly for the younger children who are more reliant upon their parents), conducting the child and parent interviews consecutively on the same day allowed for development of a shared construct.

For all parental interviews, the children did not interrupt the parents' narratives. Many parents did the interview without the child present. However, for the child participants there were many interruptions by the parent to the children's narrative, usually as a prompt or to rephrase something that either the child or the interviewer had said. The parents were guided not to lead the child's story, however as mentioned many did prompt their memory, usually when the child was deviating from the story or pausing. There were many episodes of data triangulation in the same family, where the child and parent independently initiated a discussion of an element of care from their story of isolation. The purpose of the

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interview was to explore the child's experience, through their eyes and through their parent's eyes and to discover their social construct whilst in isolation. Despite this, there were times when the parents focused on their own experience and this was inevitable as their narratives are intertwined and the parent's experiences and perceptions would have influenced the child's narrative. As a family unit, the experience impacted them all, and Greig et al (2013) described that a parents' experience may be mirrored onto the child and therefore affect the child's experience.

The interview schedule for both the video stimulated recall interview and retrospective interview was semi-structured, by using prompts which were discussed in any order to facilitate conversation (for interview schedule see Appendix 14). The themes from the literature review in Chapter Two were reviewed and broadly put into categories which informed some of the prompts of the interview schedule. Anecdotal experience informed further prompts. Finally, literature pertaining to children participating in interviews was considered in the context of this setting to ensure that the content, language and length of interview were appropriate for children (Greig et al, 2013). These measures were taken to ensure face, criterion and content validity of the interview schedule. The questions were worded as prompts/statements in the interview schedule, they were discussed in any order to allow for a natural flow of conversation and allow the child the control of the conversation. More often than not, the researcher allowed the participant to tell their story, interjecting only to clarify something or bring the story back to the time in isolation. With the parents, often it was necessary for the researcher to interject to ascertain whether the story they were telling was their own perspective or their interpretation of their child's perspective. The interaction between the researcher and participant was ongoing even when the researcher was not conversing through language, then body language was used such as nods and empathetic gestures. For the parent and staff interviews, the prompts were always emphasised as being in the context of their impressions of their child's perspective.

The interviews were audiotaped, and I did not take notes so that I could be fully engaged in the story that the participants were telling as suggested by Mack & Bernhardt (2009). The purpose of the audiotape was explained at the beginning of the interviews. It was a small audiotape to reduce the level of intrusion on the interviews, allowing the narrative to flow naturally (Engel, 1999). The child interviews lasted 7-15 minutes and the parental

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interviews lasted 15-50 minutes. All interviews were transcribed verbatim as soon as possible after interview. Table 3.4 illustrates the interview schedule.

Table 3.4 Interview Schedule

Children	Parents	Health Professional
A typical day in the room	A typical day in the room	A typical day in the room
The best and worst things about being in the isolation room	The best and worst things for the children about being in the isolation room	What the children consider the best and worst things about being in the isolation room
Aspects of isolation that could be improved	Aspects of isolation that could be improved/done differently	What the children/staff consider to be aspects of isolation that could be improved/done differently
Environment of the isolation room	Environment of the isolation room	Environment of the isolation room
The feelings associated with being in isolation	The feelings that the child associated with being in isolation	The feelings children associate with being in isolation
The level of understanding that the child has of their reason for being in isolation	The level of understanding that their child had of their reason for being in isolation.	The explanation given to children in isolation
How would the child describe to a friend at school what it was like in isolation	How would the child describe to a friend at school what it was like in isolation	The challenges for staff of caring for children in isolation The participants role in caring for children in isolation

Although the staff interview schedule is presented here in Table 3.4, staff interviews will be discussed in Section 3.7.3.

The consistency between the interviews was achieved through these prompts, which enhanced credibility. However, the techniques of interviewing were adapted and depended upon the sample group being interviewed. For example, when interviewing the children, if the child was sat on the floor playing, the interviewer would also sit on the floor and

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engage in playing whilst asking them to give their narrative. The credibility of the data collected was strengthened by the adoption of a number of other strategies; including the use of a familiar territory, avoiding tiredness, anxiety and illness by ensuring that the child had been home sufficient time to return to their normal routine, and responding with sensitivity throughout the interview to allow information to be disclosed, yet allowing the participant control over the information they shared in their narrative. This empathetic approach to the research was gleaned from my experience as a practitioner and understanding of the stresses for a family of a child who had recently been discharged from hospital.

It must be acknowledged that through prompting and directing the conversation, particularly as is more necessary with children, there is a risk that their story may be a joint narrative between the researcher and the researched, which Polkinghorne (1988) considers a key strength of narrative research. However for some, this is deemed a criticism, whereby the researcher has interrupted the natural flow of the person's narrative (Squire et al, 2014).

The interview (both retrospective and video stimulated) method was aided substantially by my knowledge and understanding of children in the hospital setting. The clinical academic role meant that I understood what they would have experienced clinically and could demonstrate empathy for this during the interviews. Linguistically, I was able to use and understand the clinical terminology that the participants used, which may have caused them to share more about the specific clinical implications of being in isolation. For example one of the parent participants was discussing the different times that they had been isolated, and I could appreciate the different isolation precautions they would have experienced in these three different experiences of isolation on different wards. This demonstrates a clear benefit to the inherent knowledge which allowed me to feel nearer to their understanding due to my clinical insight.

Retrospective interviews with children and parents yielded a detailed, interwoven narrative about their experiences within the social context of isolation. Therefore, even though it wasn't the preferred method initially for data collection methods with children, it did generate data that provided an entrance into the social construct of the children in isolation.

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The triangulation of the parental data supports the paediatric narratives and provided greater dependability in the findings.

3.7.3 Staff Interviews

Staff interviews were selected to be part of the study in Phase 2. Staff play such an important part within the social construct of children in hospital and specifically in isolation that I felt that their experience could not be ignored. Initially the staff perspective was excluded from Phase 1 of the study as it was anticipated that there would be extensive amount of data generated from the video diaries, therefore having staff data in addition would have been too much to process within the time constraints of this study. However, when Phase 1 yielded only two participants, the staff perspective of the child's experience of isolation was deemed vital to build the understanding of the child's social construct within the context of isolation.

The process of the staff interview was very similar to that of the child and parent. Once the staff member had returned the reply slip from the invitation, I contacted the participant to arrange a time and place for the interview. The staff interviews were conducted in the participant's own time to ensure that they were not taken away from clinical duties to participate in this research study. The location of the interview was always within the hospital to reduce inconvenience for the staff member, however it was off the ward in a meeting room to allow for the participant to focus on the interview without distraction. All interviews were audiotaped and then transcribed. The interviews followed a similar semi-structured approach as the child and parent interviews to facilitate the staff member telling their narrative and enhance consistency throughout the interviews as demonstrated in Table 3.4. Staff interviews lasted 20-55 minutes.

The challenge with staff interviews was to encourage the staff to focus on the impact on the child, rather than their own experiences of caring for children in isolation. On reviewing the data after each interview, I found that I became more efficient in keeping the interviews on track to explore the child's experience. Rapport was essential to allow the staff to open up and so a portion of the interview was allocated for this, so that the staff member trusted me, and they felt comfortable to disclose the information to me. In staff interviews Floyd & Arthur (2012) describe that there is a risk that participants will answer to colleagues with what they think the researcher wants to hear rather than their true

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perception of an experience, particularly if this contraindicates practice guidelines or best practice. At the beginning of the interviews I reiterated the confidentiality within the study and that the only aspects that would be disclosed were if there was an issue of patient safety or child protection that needed escalating to their managers. Otherwise it was established with the staff that all their insights were confidential. Developing this rapport early on and through knowledge of my clinical role appeared to be beneficial to obtaining honest, detailed narratives. Finally, due to the format of the interviews being structurally similar to the child and parent interview, it allowed for cross referencing of the data during analysis, rather than analysing the staff data as its own entity, thus enhancing dependability of the findings.

3.7.4 Overview of Recruitment

Phase 1 recruited two participants to the video diary, of which one participated in the video stimulated recall interview. Table 3.5 below demonstrates the low levels of recruitment of children and parents, in Phase 1 of the study.

Table 3.5 Sample of Children to Phase One

Type of data collection	Number invited to participate	Number participated
Video diary and video stimulated recall interview (Recruited February 2011-April 2012)	31 children and their parents	2 children (neither set of parents participated in follow up interview). One child participated in the video diary and interview, one participated only in the video diary.

Phase Two continued with recruitment to the video diary part of the study and retrospective interviews for children and their parents. During this time there was recruitment to the retrospective interviews, but no further recruitment to the video diary method.

Table 3.6 Sample of Children, Parents and Staff to Phase Two

Type of data collection	Number invited to participate	Number participated
Video diary and video stimulated recall interview (Recruited May 2012 – March 2013)	11 children and parents given invitations	0 participated
Retrospective interview (Recruited May 2012 – March 2013)	35 children invited 42 parents (some were joint invitations with the children above, the others were invitations where the child was too young to participate) 16 staff	3 children 2 parents 8 staff

Phase Three continued recruiting children, parents and staff to retrospective interviews, as shown in Table 3.7. It removed the video diary element of the study as it had recruited no further participants.

Table 3.7 Sample of Children, Parents and Staff to Phase Three

Type of data collection	Number invited to participate	Number participated
Retrospective interviews (Recruited April 2013-January 2015)	8 children invited 17 parents invited 20 staff invited	3 children 9 parents 12 staff

As is evident within these table, the number of invitations sent compared with the number of people successfully recruited to the study in the child group was considerably lower than the parental population. The staff were easier to recruit than the children and parents, for reasons as described earlier in Section 3.6.6. Table 3.8 shows the differences in recruitment across the different professions within the hospital.

Table 3.8 Recruitment of Staff

Type of data collection	Number invited to participate	Number participated
Staff retrospective interview	<ul style="list-style-type: none"> • 18 Nurses (Band 5-7, including newly qualified nurses) • 2 Nurse specialists • 3 Healthcare support workers • 4 Doctors • 4 Play specialists • 2 Physiotherapist • 1 Teacher • 2 Clinical psychologists • 2 Volunteers 	<ul style="list-style-type: none"> • 10 Nurses (Band 5-7 including newly qualified nurses) • 1 Nurse specialist • 1 Healthcare support worker • 4 Doctors • 3 Play specialists • 1 Physiotherapist • 0 Teacher • 0 Clinical psychologists • 0 Volunteers

3.8 Ethical Issues

The ethical issues in paediatric research are considerable. Within the UK there has been paediatric guidance on ethical research with children and specifically considering children as active research participants (DH, 2001; Graham et al, 2014; Kirby, 2004; Twycross et al, 2008). There is a constant balance between the philosophy that children are vulnerable and need protection from the burdens of research, and the belief that children have the right to participate in any research, so that care can be directed by children's voices and needs (Bos et al, 2013). Beauchamp & Childress (2009) provided a reasoning through difficult dilemmas, such as the issue of protectionism and children's rights associated with children's research. Beauchamp & Childress (2009) was used as a reference to consider the ethical decisions that were made within this study.

3.8.1 Ethical Approval of the Study

The study protocol was initially scrutinised by an internal university peer reviewer. It was assessed by the local paediatric research ethics committee and received favourable opinion. Finally, the study went through the Hospital Trust Research & Design approval process. Each of the four amendments to the original protocol were approved by the Local Ethics Committee (National Research Ethics Service, Southampton and South West Hampshire REC A) and the Hospital Trust R&D. The table of the amendments are summarised in Table 3.9 below. A detailed summary table of amendments within the research process and the decision making processes are presented in Appendix 7, with approval letters in this appendix also.

Table 3.9 Overview of Ethics Committee Submissions and Amendments

Date	Protocol Number	Amendment Number	Amendment
22/10/2010	1	Original protocol granted approval from local REC	Rec Number 10/H0502/83 IRAS ID 38367 Protocol Number RHM CHI0546
16/11/2011	2	1	Amendment to reduce inclusion age to 6 years from 8 years.
31/03/2012	3	2a	Amendment to include retrospective interviews in addition to prospective video diaries for participants that were missed in recruitment for the video diary. To include nurse interviews, for nurses that had cared for a child in the study only.
15/05/2012	3a	2b	Amendment as incorrect consent form included. Inclusion of correct consent form to include the fact that interviews were audiotaped on consent form.
21/11/12	4	4	Amendment to expand for inclusion of parents in interviews for children participating in the study, and for parents of children who weren't participating in either video diary or interview part of study, either due to age or declining participation. This amendment also sought to include retrospective interview with any staff involved in isolation, not just those specifically caring for participants within the study.
20/08/2014	5	5	Amendment to remove use of video diary data collection, as no further children recruited using this method. Amendment also proposed direct approach of recruitment by researcher to child and parent participants for the interview section of the study. Ethics committee agreed only to staff approaching the patient and parent to explain briefly who the researcher was and briefly about the study before the researcher approached.

Ethical and local Trust approval was completed for Phase One of the study in February 2011. Despite inviting 12 potential participants (who met the inclusion criteria) over the next eight months, only two agreed to participate. At this point, the decision was made to widen the age for potential participants (from eight-17 years to six-17 years) and the

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number of wards (from two to eight wards) to recruit from; which received ethical approval in November 2011. Even though a further 19 potential participants were invited, and the study was republished through posters and presentations to the paediatric unit, there were no further recruits to the study during Phase One. During this period, when visiting the wards to see if the children were keen to participate, I approached the staff initially and they provided reasons for non-participation, or allowed me to access to the family, at which point I visited the family, and when refusing participation, reasons for non-participation were offered. Although the reasons for non-participation were not sought out, it does provide some data to establish the reasons for non-participation in the video diary method of the study. The reasons for non-participation are presented in Chapter Five, Section 5.3 and discussed in Chapter Eight, Section 8.3.5.

The video diary method was often highlighted as the issue for non-participation; they felt burdened by the video diary when they felt unwell, and many families stated that they would be willing to participate in another form of data collection. Other reasons included not feeling that they were the appropriate people to provide data, or that they were in other studies. If it had been ethically approved that I could have approached the families directly with the invitation, it may have been possible to alleviate these concerns. However in the initial protocol, the ethics committee did not want me to directly contact the families prior to them expressing an interest in participating and therefore, it meant that families could not discuss their concerns with me prior to deciding if they wanted to participate. The study design was critically reviewed by the researcher, research supervisors and external experts to look for solutions to collect data from the child's perspective, using another method which could have recruited more participants.

The right to participate was debated extensively on deciding what age child should participate in this study. Initially the study began with recruitment of children aged eight-18 years. This age was selected based on the literature pertaining to video diaries and the competency to make a video diary and manage the technology independently. However, on discussion with ward staff it was felt that there were children admitted in isolation who met inclusion criteria (with exception of age), who were aged six-eight years, and who would have been competent to participate and had insights that would have been interesting to

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share. Further consultation of the literature (in non-hospital settings), research academics and the ethical committee, it was felt that the original age limit of eight years was conservative and was therefore amended to six years and above, with ethical approval.

Phase Two of the study began in May 2012 with the alternative study design, which was to include the option of retrospective interviews with children, their parents and staff, in addition to the video diary method. The inclusion of retrospective interviews was thought to alleviate the problem of people feeling burdened by being asked to do something when they were feeling unwell.

At this point the idea of including retrospective staff interview was first introduced. The initial idea was to recruit healthcare providers who had looked after the child and family during their isolation experience. The limiting factor with staff recruitment to these retrospective interviews, was that the children and families could not remember the names of the staff that had looked after them, or they had so many different people looking after them, that they wouldn't be able to share the child's experience specifically. This meant that no staff were recruited to this part of the study. Between May 2012 and October 2012, eight children were invited to participate to the video diary, 24 children and their parents were invited to participate in interviews; no children participated in the video diary and only one child and parent dyad participated in the retrospective interview.

In November 2012, it was decided that parents and children would continue to be recruited to the interviews. In addition, parents of children who were too young to participate in the study themselves, were recruited to share their child's experience, for which a further amendment was sought. Additionally, within the ethical amendment approved at this point was to include any staff who were known to care for children in isolation in general, rather than staff that were associated with the children within the study. These amendments were during the second part of Phase 2 of the study (November 2012-March 2013), during which three children were invited to participate in video diaries and 0 participated; 11 children, 18 parents and 16 staff were invited to participate in interviews and two children, two parents and eight staff participated.

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Phase three saw the final amendment to the study which was to remove the video diary part of the study and seek to recruit all children to the retrospective part of the study (April 2013 onwards). This was not a deviation from protocol as retrospective interviews were already part of the study protocol and therefore it was not until September 2014 that ethical approval was sought for the removal of video diary, in conjunction with another amendment that was planned. This additional amendment was to approach the participants (children and their parents) directly rather than using the nurse as gatekeeper. However, the ethics committee did not want me to approach the families directly until a nurse had introduced me and the project, without me present. This did not expand on my ability to recruit from the previous amendment to the protocol. Therefore Amendment 5 did not alter the recruitment process, only that the children were solely recruited to the retrospective interview, not the video diary.

Amendment 5 was part of Phase 3 of the study and was changed because it was concluded that since no further children had been recruited to the video diary data collection method, it would be unethical to continue to attempt to recruit using this method. Therefore, from April 2013-January 2015 children were only recruited to the retrospective interview; in this period eight children, 17 parents and 20 staff were invited; three children, nine parents and twelve staff participated. In January 2015, a pragmatic decision was made by myself and the research supervisory team that although continued recruitment may yield other perspectives in a very heterogenous sample, the circumstances of isolation and environment may change if the data collection period prolonged further. Therefore, despite not having achieved the desired original sample size with regards to the number of child participants, the sufficiency and richness of the data, lead to the pragmatic decision to cease data collection at this point.

This overview of ethical approval throughout this research journey, is designed to demonstrate the challenges that occurred during this period in recruiting children to a research study with a novel participatory method, and then using a more traditional data collection method of interviews. The use of both within this time period (2011-2015) and for use in the future will be discussed in the context of the data collected. This overview

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also demonstrates the restrictions put in place by ethical committees when trying to protect children from the burden of research in terms of how to approach the participants. The protective nature of ethical committees is essential to ensure that beneficence of children is balanced with non-maleficence (Beauchamp & Childress, 2009). However, the lack of interaction between the children and families, and myself prior to data collection may have impacted upon the recruitment, as it is reported in the literature that face to face recruitment had substantially better outcomes (Hammond & Cooper, 2011; Heiden et al, 2013; Namageyo-Funa et al, 2014). One reason for this restriction is the power imbalance between an adult researcher and a child, and the risk of coercion from a researcher. Despite the knowledge of my clinical role and responsibilities, it would be challenging for ethics committees to determine if there were a risk of coercion in a face to face approach to recruitment to the research study. However, a compromise to this is proposed by Hammond & Cooper (2011) who suggest that using a video in place of an invitation and participation information leaflet allows the potential participants to get to know a researcher more and therefore may be more inclined to participate. This may serve to reduce any power imbalances and allow the child to make a decision regarding participation independently. Anecdotal evidence and Karisalmi et al (2018) suggest that more recent ethical committee decisions for other studies permit direct approaches to children and families, thus were this study to be reattempted today, the viability of a such a study may have different outcomes.

3.8.2 Parental Presence

The parental presence in any paediatric research process needs to be considered; from recruitment to data collection. Parents can be influential in the consent phase, often responding on behalf of their child (Coyne et al, 2009; Turner & Almack, 2017). Despite the clear expectation in the participant information sheet that parents fully informed their children of the study prior to the family agreeing participation, it emerged at the point of consent/assent that some children were less aware of the reason for my visit than expected. This could be explained by the child having forgotten, or by parents perhaps protecting their children by not explaining the study to them as fully as intended, without realising that such protection might in fact be potentially detrimental rather than beneficial. However, by further explaining the study to the child myself at the start of the interview, and gaining their informed written consent or written assent as appropriate, I was able to

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ensure that all children were willing and happy to participate before commencing their interviews. This demonstrates the challenge in using parents as gatekeepers, that often their desire to protect their child in a similar manner to ethics committees, may negate the child's right to make decisions and share their voice (Graham & Fitzgerald, 2010; Holliday, 2001).

The second main issue surrounding the parental presence was at the interview. Gardner & Randall (2012) report that parental presence can impact the data that a child may provide during the interview. All retrospective interviews were conducted with parents present, at the families' decision. I offered the child and parent the opportunity to do the research independent of one another. Most parent interviews were conducted without the child as the parent would suggest that they continued playing or went elsewhere whilst I did their interview and then the child was asked back for their interview, or vice versa. This ensured that the child wasn't at risk in anyway whilst the parent was being interviewed, and that the parental presence did not influence on the child interview data itself.

This degree of flexibility in order of interviews and the parental presence was felt to be necessary to allow parents to be part of their child's interview and for the younger children this was necessary to allow for clarification and elucidation of detail. An example of this was in Hannah – the youngest participants' interview, where she was describing something she had made in isolation, which did not seem relevant to the study until the mum asked for her to say what else she had done, and what she liked doing at home. Following this elucidation from the mum, it became apparent that there was little for her to do in isolation, which is why she was describing making a hat with a vomit bowl as she was needing entertaining with very limited resources. This is described by Livesley (2010) as overcoming the linguistic ability that the child may find challenging in that setting.

Conversely, for the older participants, there was limited dialogue and responses were short in the presence of their parent. Obviously, there is no point of reference for comparison and these may have been the responses from the young people without the parental presence. However, the sole video stimulated recall interview was conducted without a parent, and the interview length was considerably longer and this participant explored their emotional perspective further. This may have been coincidence, however this is described by Gardner and Randall (2012) that teenagers may provide greater depth of data without

the parental presence, as it is seen in couple interviews with adults (Taylor & de Vocht, 2011).

3.8.3 Researcher-Researched Relationship

Within the literature, ethical issues that pertain to the relationship between the researcher and the researched are identified as power imbalances and representation of the child (Coyne et al, 2009; Phelan & Kinsella, 2013). Power balancing occurs with the development of trust in relationships (Cuevas et al, 2015). Therefore this was fundamental to me at interview, to allow the child and parent to open up and share their stories. The data collection method using the video diary was selected to remove the need for the child and I to interact, which according to Holliday (2001) would have reduced the power imbalance. However, there were less obvious ways to reduce the power imbalance in the retrospective interviews with the children.

For the parents, reducing a power imbalance was accomplished by allowing the parent to control the time and location of the interview and allowing them to dictate the order of the interviews. Furthermore, the interview schedule was flexible in that it was a series of prompts rather than a rigid structure, which meant that the parent controlled the format of the interview with limited direction from me. With the child, the power balance was not as easily removed and required my knowledge of working with children to aid the power balancing. In all of the children's interviews I spent time playing or interacting with them prior to the interview. With the use of the video diary at the beginning of the video stimulated recall interview, there was an immediate common ground to discuss. The goal of these approaches was to allow the children to open up and tell their story, without restriction, but the knowledge that I was there in a professional capacity. Kvale (1996) states that this negotiation of power balance may allow the interviewer and interviewee to interact and affect each other. This necessitated my reflective diary and documentation after each interaction with participants as the research process was evolving subtly after each interaction on ways to gain the story of isolation. The benefit to the nurse-researcher role was evident in the interviews in that I was able to negotiate the power imbalance, but also through answering any hospital- related questions they had so that I could be of benefit to them, again equilibrating the power balance (Richards & Emslie, 2000).

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As the main instrument for data collection, through the interviews, I have been gifted with years of working with children as a nurse in knowing how to approach them in age-appropriate language (specific to their condition and experience of hospital), which may have yielded a different conversation to another researcher who had less experience or no knowledge of the hospital environment. Eide & Kahn (2008) suggest that research interviews with practitioners can serve as sessions for reflection and counselling for the participants. Therefore, I had to be clear of my purpose in the visit, providing them with support and answering clinical questions within my capabilities, but providing them with alternative, long term sources of support as needed. Although none of the participants became overly emotional or worried during or after our conversations, I left them with both my contact details and a leaflet with sources of ongoing support that are available for all patients and families within the children's hospital.

3.8.4 Consent

Informed consent is a legal principle that regulates an individuals' ability to agree to or refuse an intervention which also includes the participation in research (Lambert & Glacken 2011). Consent in paediatric participants is a contentious issue and paediatric patients are often required to provide assent for their participation or treatment. Assent is grounded in the respect for autonomy and protection against harm and seeks to gain agreement from the child (Giesbertz et al, 2014). For this study younger children assented, and parents provided consent also. Children capable of providing consent were able to, in addition to their parents' consent and 16-17 year olds were able to provide consent independently of their parents, although within good practice, parental consent was also taken. At the point of gaining consent/assent, all participants were informed that if they wished to withdraw from the study at any point they could. This promoted the rights of the research participants, enhanced trust with the participants and the researcher, demonstrated the ethical principles of autonomy beneficence and thus, enhanced the credibility of the findings (Beauchamp & Childress, 2009).

Definitions for assent in the literature are vague and flexible (Bos et al, 2013, Lambert & Glacken, 2011), as it is not formally defined as consent is, therefore it is adapted by people to use within their research. Views vary considerably from not considering assent as a valid concept at all (Baines, 2011), through to a more pragmatic view that assent was

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mostly what was being aimed for at the start of research anyway by focusing on children's understanding about what they are being asked to do, in order that they feel comfortable and supported (Parsons et al, 2015). Although assent is not universally defined, it remains an important concept as it allows children to participate in research within the UK where parents are required in views of best practice to provide consent for any child under the age of 18 years, either in addition to their child's consent or assent. For this study, the inclusion of assent was to allow the children some control over their participation, even though their parents would have to consent, it made the process of the child's decision on participation in the study participatory.

Consent or assent was taken from all participants in written format in accordance with GMC guidelines (2010). If a child was 16-17 years they were deemed to be competent to consent, however their parents' consent was also requested. It would be unlikely that there would be discrepancies between the child and parents' desire to participate, as the parent had to pass the invitation and information leaflet to their child, after they read it. Therefore, if a parent was not keen for their child to participate, they would not give the child the information.

For the child under 16 years, it was assessed on a case by case basis if they were able to understand the study sufficiently and explain that back to me, prior to deciding if it was appropriate for them to provide written consent, or written assent. To ensure that all participation was voluntary, participants were asked to explain what they understood about the study and why they were signing the consent or assent form; this ensured that their decision was fully informed and there was no coercion (Tay-Lim & Lim, 2013; Twycross et al, 2008), if they were able to do this, then they signed the consent form. If they were unable to do this, but understood the process of the study and what they had to do they were able to provide written assent instead.

3.8.5 Anonymity

Anonymity in research is described when respondents remain unknown to the researcher (Polit & Beck, 2017). This is obviously not possible in most qualitative studies, specifically in this study, anonymity was not possible, nor was it guaranteed within the participant information sheet. The inability to provide anonymity within qualitative

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research may be a reason for non-participation as suggested by Tilley & Woodthorpe (2011), particularly in this study where some of the potential participants were children with chronic conditions who may have not wanted to declare their feelings in case it impacted upon future care as described in Saunders et al (2014). Furthermore, some participants may have not wanted to share their story face to face, but may have shared it in another, more anonymous form such as written diaries or any other manner that was less likely to be associated to themselves in the future. In attempting to maintain anonymity sufficiently within this study, there was the risk that the integrity of the data could be compromised as described by Saunders et al (2014). Therefore sufficient detail regarding the participants has been given to contextualise the data, allowing for rigorous analysis of the data, without compromising the confidentiality of the participants. Where anonymity is impossible, it is suggested by Morse and Field (1996) that it is essential for researchers to implement as many confidentiality measures as possible, as was the case in this study.

3.8.6 Confidentiality

Confidentiality refers to the assurance given by researchers that data collected as part of the research, will not be revealed to others who are not within the study team (Parahoo, 2014). The notion of confidentiality is underpinned by the principle of respect for autonomy and is taken to mean that identifiable information about participants collected for the purposes of research will not be disclosed without permission (Wiles et al, 2009). Confidentiality was employed in this study to ensure that participants could not be identified, which according to Kim (2016) is invariably more challenging in qualitative, and specifically narrative research where participants are sharing their story.

For this study, qualitative data posed challenges for maintaining confidentiality in that the study was conducted within one hospital and some of the conditions that the children have within this study were relatively rare. Confidentiality was maintained in all phases of the study, by assigning pseudonyms and removing any identifiable data. Pseudonyms were chosen by the children to assign to each data set. Furthermore, no dates of admission were included to remove any traceability of the patients. Staff were provided with participant numbers, and to enhance their confidentiality, minimal identifiable data of their qualifications and roles were declared in this study. The essential details regarding their professional roles were provided to contextualise the data that they provided. In addition,

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due to the prolonged data collection period (2011-2015) and the time of data collection being [five](#) years from publication of this PhD, this further enhances the guarantee of confidentiality and decreases the chances of traceability.

In paediatric studies there are risks to confidentiality that needed specific consideration. One of these considerations were any declarations in the interviews or videos or issues surrounding child protection or poor practice. Both of these issues were illuminated to participants in the participant information sheets, to ensure that they were aware that if any declarations were made that were of concern to myself, I had a duty as a registered nurse to declare these to the appropriate managers and authorities. It is noted in the literature that there are a number of risks to confidentiality within qualitative research, both anticipated and unanticipated and the moral compass of the researcher is essential to direct unanticipated issues to the correct authorities (Gibson et al, 2012). However, within this study, there were not any unanticipated issues that arose.

Within this study there was the added complexity of the video diary data. For this research to be approved at a local level and through the ethics committee, it was determined that the only person who had access to the videos was myself, therefore none of the video diary data could not be provided for publication, thereby protecting the participants' confidentiality. This was agreed with participants at point of consent and explained in their information leaflet. The video diary data was immediately transcribed into interview transcript format with annotations of the visual data and then left on an encrypted hard drive. The audio data from interviews were also transcribed by the researcher and then analysed. Therefore, the only person who could identify voices and images was the researcher; this allowed confidentiality to be maintained. It is proposed in a sociological domain that the use of video diaries to form a transcript removes the impact of the data and that it should be used in raw form to present the true story (Pink, 2001). However, in the interest of children's rights and the likelihood of gaining consent for the use of video diaries in their raw format, the use of transcripts was proposed and approved by the ethics committee. All data were stored on an encrypted hard drive separately from identifiable data, with one document linking the anonymised data to the original consent forms, which was stored in a locked office on a data encrypted hard drive. Any paper copies of data,

both identifiable and anonymised were stored separately in a locked filing cabinet, in a locked office throughout the study.

3.8.7 Ethics of Video Diary Data

The ethical implications of video data are a concern that is highlighted throughout the literature (Gibson et al, 2007; Harrison, 2002; Maunthner, 1997; Rich et al, 2000). The video diaries in this study only contained images and verbal data from people for whom consent was given, which in this study was limited to the immediate family of the participating child in the study. The parents were asked to complete names of any of their other children who may be filmed by the participant and consent for them to be filmed, in addition to the participant. The participant and their family were asked to agree that they would only film their immediate family and no one else, in accordance with the ethics committee. This decision was made as it could be potentially challenging to make a video diary in hospital where the patient is receiving care from multiple healthcare providers, and consent for each of them would need to be obtained. Thus, children were advised not to film any healthcare workers or any clinical practice. It was not outside the realms of possibility that the children may have still filmed clinical practice, and the healthcare providers were warned of this prior to the study starting. It was proposed in the study protocol that any video diaries that contained such sections would have been edited to remove clinical practice prior to data analysis, however this situation did not arise. In addition, as a source of reminder, each child participating in the study was issued with a poster that was displayed on the door to their isolation cubicle which informed entrants that they were part of the study.

Another issue related to filming in a clinical environment was the issue of documenting sub-standard practice. Through giving the children guidelines on filming, it was aimed that no clinical practice would be filmed so this issue could be avoided. However, each ward was informed at the beginning of the study that if any sub-standard practice was observed in the video diary it would be reported to the relevant managers. Similarly, if any issues of child protection were observed through the video diaries or similarly reported through the interviews, these would have been reported in accordance with my duty of care as a nurse (Nursing & Midwifery Council, 2018). Parents and children were informed of this in the participant information sheets. The children that participated in the video diary were

diligent in filming only themselves and their immediate family, for whom consent was obtained. Furthermore, no safeguarding concerns or substandard practice were identified in this study.

3.9 Reflexivity

Reflection involves reliving and revisiting what was done in a situation, the how, when where and why; it can lead to insight about something that was not immediately evident at the time (Darawsheh & Stanley, 2014). This was essential throughout the research study to ensure that the research processes were being driven by the research question and the desire to answer the question and inform clinical practice. However, within qualitative research and in particular social constructivism there is an increased tendency to utilise the concept of reflexivity to enhance the credibility of a study. Reflexivity as a term remains poorly defined and therefore there is discrepancy in how it is used within research (Dowling, 2006). Reflexivity is finding strategies to question our attitudes, values, assumptions, prejudices and habitual actions to strive to understand our complex roles in relation to others, and acknowledging that this all impacts on the study, in the same way that the study impacts upon on the researcher and their beliefs and values (Carolan, 2003). Reflexivity is also about focusing on one's own actions, values, and their effect on others, situations and social contexts (Finlay, 2002; Gergen & Gergen, 2000), which is essential in a study such as this where there is potential for a power imbalance with adults and children in interviews. It is essential as professionals that we go beyond reflection as practical problem solving and look to understand one's own actions on a situation.

In research, we can only seek to represent reality. Reflexivity acknowledges this and suggests the researcher and the researched will impact upon one another throughout the research journey. There is an acceptance that an exhaustive journey to the truth is unlikely to be possible, but that extending our understandings of the subject of our inquiry is a worthy ambition (Macbeth, 2001). Social constructivism suggests that through our interactions we adapt our thoughts, beliefs and social constructs and the notion of reflexivity also suggests this; that the meanings that we generate are an outcome of negotiation. In this context, it was therefore essential to demonstrate transparency in the data collection and analysis as I acknowledge that my understanding of the experience of isolation has changed since the beginning of this research journey, through interaction with those in isolation in the study, clinically and through being in isolation as a parent.

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Reflexivity, in accordance with social constructivism allows us as researchers not to freeze our positionality, but to embrace that this may be influenced through the research (Macbeth, 2001)₂ and to seek to explore where the change in positionality may have evolved from. Reflexivity will be revisited in Chapter Eight to demonstrate the processes of change in me as a researcher and practitioner.

3.9.1 Reflective Diary

Every meeting with a participant had the potential to be affected by the environment, the people present and the time delay after their isolation experience. My impact upon the participant and the level of power imbalance evident, despite my measures to reduce it₂ needed to be considered in the analysis of the data and thus these data were documented in the diary. Although the reflective diary was started with the intention of reflecting upon how the interview schedule was to be adapted to the needs of the participants, it became a journal to document the interactions between myself and the child participants and the role of the parent in the interviews₂. To conduct methodologically sound interviews the research process must be guided by reflection on relational issues on participants' reactions when answering the questions. These entries were completed immediately after the interview to ensure that no data were forgotten. These data were considered throughout the analysis and are presented as data in Chapter Five and Six, to ensure that any bias was considered in context and that the data were dependable (Parahoo, 2014). An example of the reflective diary is shown in Figure 3.1 below after an interview a reflective excerpt from the diary.

Figure 3.1 Excerpt from Reflective Diary

Following Nicholas' interview (age 12 years):

"His mum's presence was clearly impacting upon how he opened up... well I think that. He was very closed in his posture, and demeanour and just wanted to play on his computer game on his hand held device. He sat throughout the interview with his mum, not interjecting and not looking up. Nicholas' mum was sharing details of his admission to isolation where she challenged the staff as she did not initially feel that he needed isolation, but in a subsequent admission he did. Nicholas' mum proceeded to describe his stools, which may have been a source of embarrassment. After his mum had finished her interview, his mum sat watching Nicholas whilst we did his interview. The interview was in the hospital (albeit within a private office) but there was the fact that he wasn't comfortable possibly because he wasn't in his own environment. I did not probe him too much as the answers were short and not very analytical.....The reason he was reserved could also have been that that was his personality, or my presence in asking him about his feelings."

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This excerpt demonstrates the way in which I tried to review the interaction after each interview to consider all options for the way in which the interaction had occurred. Further excerpts are presented in Chapter Five and Chapter Six in boxes (to differentiate from data from participants).

Although the purpose of the reflective diary was to review the interviews and interactions with participants, to guide the process of the research, it also formed the beginning of the reflexive process. Through reviewing the reflective [diary](#), it was possible to see where my positionality on values and thoughts were evolving through interaction with the research process, the participants and clinically. Therefore, the reflective journal served the purpose of improving the research process, but also lending itself to support me in the reflexive process.

3.10 Rigour

Rigour is the means by which integrity and competence are demonstrated; it is about ethics and processes, regardless of the paradigm. Rigour is described by Morse and Field (1996) as necessary to prevent error within research and enhance quality. Demonstrating rigour in qualitative studies is essential so that the research findings have the integrity to make an impact on practice and policy (Tobin & Begley, 2004). Qualitative research has been criticised in the past for a lack of control over the validity and reliability of the data. For some researchers there is a debate over the language used in terms of rigour, and how terms such as reliability and validity translate into the rationalistic and naturalistic paradigms. There are many researchers who have moved to develop trustworthiness, rather than validity within qualitative research and the work of Lincoln and Guba (1985) highlights this. In the context of this study Lincoln and Guba (1985) were selected as they are ascribed to the underpinning philosophy of social constructivism and therefore using their measures of rigour to test against [demonstrated](#) internal consistency of the study. The main concerns throughout this study in terms of rigour was explaining the data collection methods in a manner that is repeatable and clear.

Trustworthiness and authenticity in narrative inquiry are focused on the original story told by the participants and the representation of this within a metanarrative for the purposes of the study. In selecting a narrative analysis method, I have considered that the children's

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stories will have been affected by their social construct and issues such as failing to remember certain intricacies of their time in isolation, or over-dramatising parts of the study. Considering my epistemological stance that children will present their stories in the way that they understand them, I acknowledged there are multiple realities of an experience according to the child's social construct. Therefore, every story was considered as authentic, valid and that their perspectives were worthy of being central to this study. The stories were entrusted to me as the researcher and therefore my aim was to represent these stories through the metanarrative.

Dependability is another element of ensuring consistency in qualitative research. Within this study the dependability and consistency were enhanced through the researcher being the research instrument and that the narrative analysis was conducted by myself through the research. Thus, the research itself and the analysis may not be wholly replicable as other researchers *would* draw on their own reflexivity. The issue of whether this study could be replicated at another point in time is problematic as children develop and in accordance with modern culture developing, it is unlikely that the social construct would remain consistent and therefore the findings would be altered accordingly. However, the findings within this study are hoped to be transferable to similar situations with similar children, hence the heterogeneity within the study which seeks to provide the most transferability possible to their clinical settings (Holloway & Freshwater, 2007; Lincoln & Guba, 1985).

3.11 Data Analysis Method

Qualitative data analysis seeks to explore meaning from everyday activities, exploring a phenomenon often in the natural environment and ultimately providing theories from the findings (Silverman, 2013). Qualitative research must be context-based and the researcher must be context-sensitive (Holloway & Galvin, 2016), which means that the analysis methods must reflect not only the data collected, but also the participants' data and the researcher's role. The process of qualitative data analysis varies between methodologies with some researchers emphasising a systematic, methodical approach, whilst others prefer to focus on the art of understanding which allows meaning to emerge (Green & Thorogood, 2013). Despite the different approaches to data analysis within qualitative data, Parahoo (2014) describes that the focus remains in seeking patterns within the data and

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finding explanations for the existence of the patterns. All forms of qualitative data analysis ascribe to being a pervasive activity throughout the life of the research process (Silverman, 2013).

In much of qualitative research, analysis begins when data collection commences (Chase, 2005; Squire et al, 2014). In terms of this study, data analysis actually began prior to data collection, as I was immersed as a nurse in the research setting prior to collecting data. Therefore, my prior understanding and thoughts were documented in the research reflective diary and were reflected upon throughout the study as more data were available, particularly during data analysis.

Qualitative research receives much criticism from the quantitative researchers, in terms of the rigour to the data analysis (Parahoo, 2014). Therefore, it was essential to present sufficient detail on the data analysis methods in this chapter to demonstrate a robust method, transparency of data analysis methods and therefore, validity of the findings. Furthermore, as a novice researcher with different types and sources of data, it was essential to have a structured analysis approach to ensure that the data were interpreted and presented appropriately, in congruence with the underpinning methodological viewpoints for this study.

Understanding an overview of qualitative data analysis as part of this study was essential to determine which pathway to take for data analysis. Cresswell (2007) describes the fundamental qualitative data analysis to be a process of generating codes, categories, patterns and ultimately themes. Saldana (2009) describes a code as a word or a short phrase that can be attributed to a portion of data, and this being the crude beginning to data interpretation and analysis. Different data analysis processes are akin to different methodologies, therefore, it was essential to select an analysis method that aligned with the underpinning philosophy of children in research, social constructivism and narrative inquiry.

3.11.1 Qualitative Data Analysis of Data from Children

Analysing data provided by children is a unique process as the data provided differs significantly from the data provided by adults (Engel, 1999). Adults provide detailed narratives of an experience, which often include not only descriptive narrative, but also

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some degree of interpretation of their experiences (Pasupathi & Wainryb, 2010). Children, particularly the younger ones tend to provide mainly descriptive data regarding an experience (Bird et al, 2013; Pasupathi & Wainryb, 2010). Children's conversations often change focus and require some direction as they are less likely to be free flowing in their story telling, and this often causes a jumbled sense of time and space, which often denotes that meaning dominates over chronology (Engel, 1999). Nelson's script theory poses a different viewpoint which suggests that the script is logical and sequential, however the order that is logical may be different for children and adults. This infers that for the person providing the narrative, it is sequential on its own terms. Therefore, more than ever with qualitative data analysis it is about being creative with analysis techniques, however without losing their congruence with narrative inquiry and social constructivism.

Triangulation of data sources was used to strengthen the stories, however this added complexity to the data analysis. The data sources from the child and the parent would be considerably different in their interpretation of their narrative, depending on the age and maturity. Therefore, the approach to data analysis needed to be flexible to accommodate descriptive and interpretive data forms and to allow both the voices of those narratives to be heard in the metanarrative presented in Chapter Six. This use of multiple methods in terms of analysis was described by Denzin & Lincoln (2008) as bricolage and the narrative inquirer as the bricoleur. Kim (2016) stated that narrative bricoleurs learn from differences and they are not chained to the same assumptions, due to the multiple genres within narrative inquiry and analysis. They are able to look through a kaleidoscope. It was unsurprising that narrative analysis is described in different manners, and disciplines within the literature as narrative is embedded in every aspect of our lives. This aligned with my philosophy of understanding the child, parents and staff perceptions of the experience with different views through the lens, but the kaleidoscope remains the same whoever is using it. The elements of the bricolage of data analysis will be explored throughout the end of this chapter with examples of how it was conducted in the context of this study. It was imperative that despite the bricolage of analysis methods, the analysis process was sensitive to the philosophical, epistemological and ontological differences.

3.11.2 Video Diary Data Analysis

Video diary data is often viewed as a deeper or more complex level of data compared to a transcript as it incorporates not just the audio but the visual data (Pink, 2001). The content

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of the visual video data is considered to be of equal importance and tells a story about the culture of that environment or situation and therefore is key to the analysis (Gibson et al, 2007). Video diary analysts often analyse the video as a whole, rather than separating the audio and visual. However, in order to analyse the data synergistically it was felt that putting the video into a transcript and analysing it with the audio data from the interviews was most appropriate. The videos were transcribed, initially for their audio. The transcripts were then annotated with all the visual aspects of significance and these were considered as much as the audio transcript in terms of the analysis. This allowed congruence throughout the paediatric data and adult data as it was all presented in transcript form.

3.11.3 Retrospective Interview Data Analysis

There are a multitude of methods that could have been employed for analysing the interview data generated from retrospective interviews with children, however most of these methods are more concerned with adult participants. Therefore, it was necessary to use a data analysis approach which incorporated the way children communicate and share their experiences, however also a method that could be adapted to analyse the parental and healthcare provider data. According to Engel (1999), children naturally tell stories to communicate information about themselves, share experiences, master emotions connected to those experiences and to solve puzzles, which aligns with the use of narrative analysis. Older children, and teenagers are more akin with the adult manner of describing and interpreting an experience. Maturity, experience and development affected the narrative the participants provided, therefore a data analysis method that could accommodate this was needed for this study. Furthermore, social contextual features of the child's world were considered in addition to the data from the reflective diary to aid in forming the understanding of the child's narrative. All data collected contained a story; whether that was a narrative of a single experience of isolation or multiple admissions in their hospital journey with a chronic illness. With all this considered, it was felt most appropriate to pursue a narrative analysis method.

3.11.4 Narrative Analysis

Narrative analysis seeks meaning not only in the story but in how the narrative was constructed in the context (Hunter, 2010), which allows itself to be used with both descriptive and interpretive narratives provided by the children and adults in this study. This was explained in Section 3.4. Narrative analysis allows for this difference in story

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content and context, whether it be over a period of days, weeks or months. For the staff, the narrative that they provided was often over years of healthcare experience, where the context of their care provision had been influenced by certain patients, experiences and care episodes. Narrative analysis lends itself with sufficient structure to analysing the narratives from all participants, allowing for the different formats that the child and adult data may take.

Polkinghorne (1988) suggests that the process of narrative data analysis is to analyse, interpret and seek narrative meaning in data; to understand human experience that is meaningful and the interactions that take place that make this meaningful. Narrative analysis has been documented by a number of researchers using slightly different methods, some of which have built on other's work but all of which have some limitations.

Polkinghorne (1995) posits that narrative inquiry requires two types of analysis; one is an analysis of narratives that relies on paradigmatic cognition and the other is narrative analysis which depends on narrative cognition. This denotes that there needs to be synchrony through the paradigm of research, data collection and analysis. Polkinghorne's analysis of narratives can be summarised as describing the categories of themes whilst paying attention to relationships within categories, uncovering commonalities that exist across multiple sources of data and producing general knowledge from a set of evidence (which underplays the unique aspect of each story) (1995). Secondly, Polkinghorne describes narrative analysis focusing on the events, actions and happenings to put them together in the plot of the narrative, this uses recursive movements from the parts of the narrative to the whole, seeks to fill in the gaps between events and actions, makes a range of disconnected data elements coherent in a way that appeals to the reader and makes a final story congruent with the data. The influences of Polkinghorne's analysis of narrative and narrative analysis as described here was considered a useful tool for this study, however other narrative analysis methods were considered.

Another key influence within narrative analysis is the work of Labov & Waletzky (1967) and Labov (1972). Labov & Waletzky's model of narrative data analysis (1967) focuses on what the "told" story is about. Labov & Waletzky focused on analysis of narratives connecting the elements of language, meaning and action. Many have described the work by Labov & Waletzky as more of a conceptual framework and have moved to incorporate

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this work within their own models (Mischler, 1986; Patterson, 2013; Riessman, 2008). Despite these adaptations, the fundamental concepts from Labov & Waletzky's work were to understand the person telling their story, ensuring the story line made sense, and also considers the use of inferring a story from non-verbal data. Additionally, as described by Halliday (1973) who succeeded the work of Labov & Waletzky, the meaning of what is said is not in content (ideational) alone, and therefore the analysis must consider how the narrative is spoken (textual), the context of the roles of speaker and researcher (interpersonal).

Riessman (1993) used influences from Polkinghorne (1988) and Labov & Waltesky (1967) to create a narrative analysis tool with structure and clarity, to ensure that no data are ignored in analysis and that findings presented are congruent and representative of the data collected. Riessman (1993) developed this model to overcome some of the previous criticism of narrative analysis such as the lack of rigour, structure and selectiveness of data (Squire et al, 2014). Riessman's (1993) structured approach to narrative analysis involves attending to experience, telling about experience, transcribing experience and analysing experience.

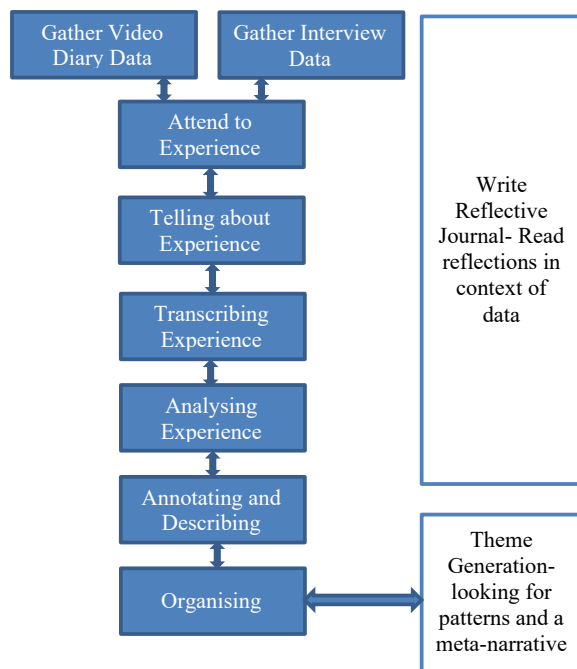
Narrative analysis has different approaches and for the purpose of this study it was useful to draw on these different methods to overcome the challenges of interpreting data from participants of different ages and different data sources, using a bricolage approach to the narrative analysis. Polkinghorne's (1988) description of the levels of interpretation (analysis of narrative and narrative analysis) allowed for the data from children to be less descriptive and use the parental data to "fill in the gaps" in terms of detail if necessary and analytical thinking, again where necessary. Furthermore, the work of Labov (1972) acknowledges the use of non-verbal data which was particularly useful in the interpretation of the paediatric data, specifically the video diaries. Finally, the structured approach to analysis of Riessman (1993) allowed the researcher to demonstrate consistency throughout the analysis of such a heterogeneous group of data. Therefore, to clarify, the approach that was taken for analysis was described by Riessman (1993) with the inclusion of Polkinghorne (1988) and Labov (1972).

3.12 Narrative Analysis Method

The narrative analysis method used in this study is presented in this section. The detail of each stage and examples of the analysis will be demonstrated in Chapter Four. Considering Polkinghorne's method of data analysis (1988), each transcript was individually analysed and then the data were brought together initially in groups (children, parents, healthcare professionals) and then viewed as a whole. Riessman's (1993) structure for narrative analysis is presented below; attending, telling, analysing and interpreting. However, throughout the analysis process, the work of Labov & Waletzky (1967), Labov (1972) and Polkinghorne (1988) were drawn upon as part of a bricolage. The data analysis processes including worked examples are presented in Chapter Four.

Figure 3.2 below demonstrates the fluid movement between stages within analysis that led towards the metanarrative, using the data analysis method.

Figure 3.2 The Process of Establishing a Metanarrative



3.13 Conclusion

This chapter has provided an account of the philosophy, research design and data collection and analysis methods used as part of this study. The central tenet of this study was the child's voice and their story of isolation and this is considered throughout this chapter in terms of underpinning philosophy, data collection methods and analysis methods selected, process of sampling and recruitment and the ethical considerations that were made. The data collection methods were selected and adapted in accordance with recruitment challenges, initially using a video diary data method and then latterly in the study period, a retrospective interview method. The information obtained from children, parents and staff members provided a triangulation of data on the experience of isolation throughout the paediatric wards in the hospital in the study. Ethical considerations were

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significant, as the study involved children. The data analysis method has been introduced, which is congruent with the chosen methodology and will be shown in Chapter Four with worked examples of the process of analysis, aiding transparency of the data collection method.

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4.1 Introduction

This chapter presents the data analysis methods used as part of this study. The use of narrative analysis was employed to explore the story within the data provided by the children, parents and staff, and felt to be the best way to present the child's experience of isolation as described in Chapter Three. Narrative analysis provided the process in which the meta-narrative of this study was produced. The process of analysis from raw data to metanarrative will be described in this chapter. Riessman's (1993) narrative analysis method: attending, telling, analysing and interpreting will be described in the beginning of this chapter with worked examples. The additional contribution of Labov & Waletzky (1967), Labov (1972) and Polkinghorne's (1988) analysis method were drawn upon during the analysis and have been acknowledged throughout this chapter. This chapter will demonstrate the process of analysis from raw data to final themes.

4.2 Riessman's Narrative Analysis

The following parts of Section 4.2 utilise the stages of data analysis as described by Riessman (1993). Riessman describes this version of narrative analysis as structural analysis. Social constructionists stress the local and situated nature of identity construction and are concerned with the analysis of 'small stories' within what may be perceived a mundane interaction, therefore looking for one overarching story was not the only purpose within these narratives, but how the individual narratives within the larger narrative were changed and adapted over time as they were influenced by their social context.

4.2.1 Attending to the Experience

Attending to the experience is the first stage of narrative analysis. Attending involves illuminating discrete features that would not normally be recognised, reflecting, remembering and recollecting them into observations (Riessman, 1993). Labov (1972) described this part of the analysis as presenting the context of the data. In this study, it was essential to recall the room that the child had been in, and specific features within this, the dynamics of the family, whether family members were resident and what isolation precautions they had placed upon them as shown in Figure 4.1 for Harriet's family. This

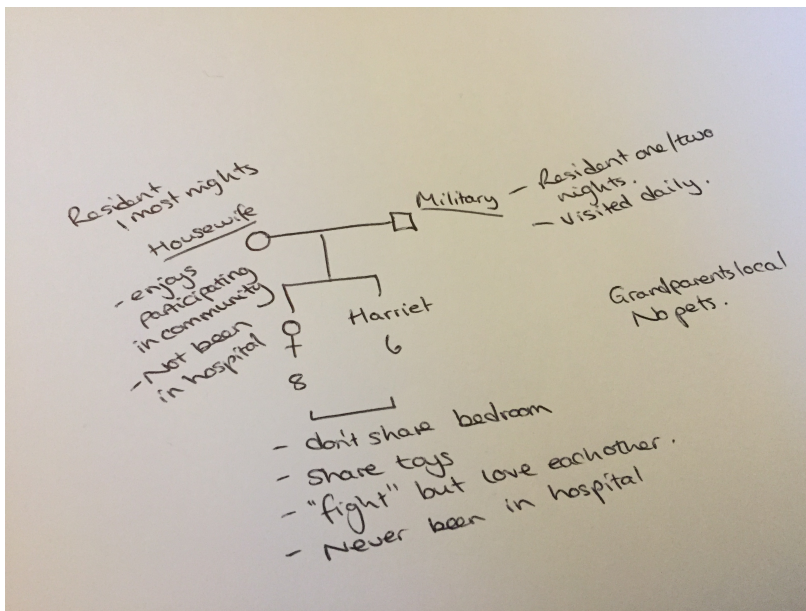
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was documented at the interview when having initial conversations with the family to put them at ease and gain some context to their social construct.

Polkinghorne (1995) describes this process as developing the context for the story, however for me it was about situating the narrative within the child's social construct:

- Description of the social context in which the narrative was constructed
- The nature of the person central to the story (the chief person(s) in the plot of the story)
- Identification of significant others affecting the choices and actions of the main character (people that would have influence within that social context)
- Choices and actions of the main character in pursuit of their goals (e.g. how the family found ways to cope with isolation)
- Attention to previous experiences in life, particularly associated with hospitalisation and isolation

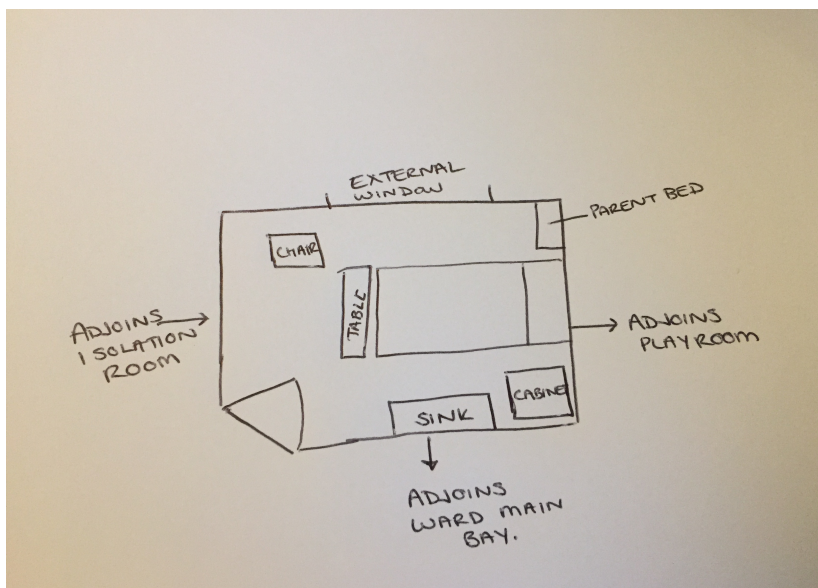
Figure 4.1 Documentation beginning the Understanding of the Social Construct



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Similarly, once I knew which room(s) the child was isolated in the hospital under study, I drew an image of the room to facilitate understanding the context of their narrative when analysing the data. An example of this is in Figure 4.2 below.

Figure 4.2 Sketch of the Isolation Room from Rachel's Admission



For the video diaries, these contextual data were recorded as part of the video diary, however for the retrospective interviews it required the researcher to explore this with the family. Extra contextual data were recorded on the contact summary form as show in Appendix 15. This level of context was vitally important to the data analysis, particularly the children's data. For example, James who shared a bedroom at home with his brother found the environment of an isolation room to be a considerable advantage and he viewed it as a privilege, which had significant impact to the tone of his narrative. Another example of this was Nurse 3 that participated, she had been in isolation herself with her son, which provided another dynamic to her data, which had to be considered in her analysis. These examples demonstrate the importance of this contextual data and attending to the experience in terms of analysis.

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The clinical academic role enhanced my ability to attend to the experience and contextualise the data as I had knowledge of staffing levels, the wards and their pressures at the time of data collection providing greater context to the stories provided by participants. All the wards within the study were adequately staffed during the study. These are all factors that are inherent knowledge for a nurse, however in the interests of accurately representing the findings from this study, need attending to in the analysis.

4.2.2 Telling about Experience

Telling about the experience is the manner in which data is obtained from the participants (Riessman, 1993). Telling considers not only the form of data collection but also the influences on that, from the participant, environment and also the researcher. This is the point when social constructivism was revisited as each child/family that participated needed to be considered within their own social construct before they were considered within the hospital isolation room context, as their home social construct influenced their experience in isolation and this had to be considered in the analysis (Engel, 2005). Family structures were documented before each interview, with detail such as friends and influences in their lives. In addition, this is where the power relationship between the child and the parent, and myself as the researcher were considered in terms of how the story was told. An example of where this extra context and detail impacted the findings was an interview with a boy with CF who had a friend with cerebral palsy that had been admitted to hospital multiple times a year in his lifetime. The participant with CF described himself lucky that he had been in hospital and isolation so few times in that year when compared with his friend. For this participant, telling their experience with this understanding of the social construct behind the child's experience, enhances understanding of the context of their story. Figure 4.3 presents an excerpt from the reflective diary which represents a manner in which the power balance was improved to allow for clear communication and these details were considered as part of the analysis.

Figure 4.3 Excerpt from Reflective Diary following Interaction with Imogen and Family

"Imogen was initially really quiet as her mum introduced me as a nurse when I entered the house. I think she thought that I was there to 'do something to her' rather than just an interview. Imogen is a young girl who is in her 2nd year of treatment following BMT, she is undergoing a new chemotherapy regime. Her mum offered me a cup of tea which I accepted and so I sat on the floor and played with her brother and her whilst her mum made the tea. I felt that this was a really useful time rather than making small talk with her mum. On the floor Imogen began chatting about her dolls and how they were going to have their hair done whilst combing it into different styles. She said how she couldn't wait to have hair again (Imogen had alopecia secondary to chemotherapy). She asked what I needed to do to her today whilst her mum was out of the room, I answered "nothing, I am just here to chat to you and your mum about what you think about being in hospital, especially when you are in the room on your own". She looked reflective and relieved and then said "oh good" and continued to play. Following this, she was happy to chat further.

Participant narratives were supported with additional questions in the form of the interview schedule, which allowed the researcher to redirect the narrative, or expand on certain aspects of the story to put it into the larger context. This required skill from the researcher to be listening to the narrative during the interview, whilst also listening actively to the data sufficiently at this point to seek out prompts or areas of clarification. Thus entering into the analysis of the data in a preliminary form through seeking clarification and elucidation of details within the story (Riessman, 1993).

Within telling the story there is a concern on the recall of the narrative, particularly given the delay between the experience and the telling of the story. For children, the literature attests that this may mean that their story be disjointed (Clandinin et al, 2016; Douglas et al, 2019; Engel, 1999). Similarly for adults, they can tell the story with a particular audience in mind and may emphasise certain areas to accommodate the listeners' needs (Greig et al, 2013). Narrative should therefore be considered a self-representation of what the person recalls at that time about the experience and how they want to present it to the listener (Goffman, 1959).

A large part of any qualitative analysis is the reflective role of the researcher. Silverman (2013) states that researchers must be methodologically versatile, interact skilfully with others to ensure that appropriate data is collected and then be sufficiently transparent

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throughout the analysis to ensure rigour in the data. As a clinical academic researcher, I have had a similar insight into the experience of isolation as that of the healthcare professionals, through clinical work on the wards where I have been able to observe behaviour and reactions to isolation. Similarly, through this research I have listened to intimate narratives from families regarding their time in isolation, therefore I have been privileged to witness a different side to isolation which not all healthcare professionals may witness. Furthermore, through my own experience of being a parent of a child in isolation during the process of data analysis and writing up, this has further influenced my understanding of the experience of isolation. I have not attempted to bracket this understanding, in accordance with narrative inquiry, but I have used this personal experience to inform my data analysis, through documenting my experiences in the reflective diary. In summary, I have considered my unique role and insight throughout the data analysis, and this is described in Chapter Seven as part of the discussion.

Peller (1987) states that it is not possible to be neutral and objective, to merely represent (as opposed to interpret) the world. This is acknowledged in qualitative research; however some analytical methods emphasise the researcher role and others do not consider it emphatically within their analysis. Therefore, considering the research philosophy of social constructivism, where my role as the researcher and a nurse could have impacted the findings and analysis, and the fact that as a nurse researcher I am within the research context, a data analysis method that strongly acknowledged the researcher role in interpretation needed to be employed in this study. The transcripts provided by the participants are not independent of their context and equally my experience within the clinical setting and paediatrics is not independent of the context of the analysis. In narrative analysis the researcher is viewed as part of the analysis and this is considered a strength of the process, providing sufficient transparency is presented. Transparency will be demonstrated for clarity by separating the findings in Chapter Five and Six and my reflections, with the reflections presented in text boxes, and my role within the study will be part of the reflection in Chapter Eight. Narrative analysis requires researchers to analyse and interpret findings concurrently. Josselson (2006) emphasises that narrative research is interpretive at every stage from conceptualisation to data collection, analysis and to writing up, demonstrating the importance of the researcher role within the data analysis and interpretation.

4.2.3 Transcribing Experience

Each interview was audiotaped and transcribed contemporaneously. In addition to the audiotapes, there were the two video diaries to include in the data set. The initial stage was listening to the audiotape/videotape multiple times, initially listening twice without making notes or transcribing, to allow full immersion and familiarity with the data. After each episode of listening, notes were made to document initial impressions of the transcript, such as key issues and areas that struck the researcher, which were included on the annotated transcripts. The process of transcribing each interview verbatim was conducted as soon as possible after the interview; this also allowed me to reflect on each transcript prior to doing the next interview. Furthermore, the video diaries were watched repeatedly after the transcript had been formed to document any non-verbal data or visual shots from the video that were relevant to the audio data. Using Simon's video diary as an example; the transcript from Simon's video diary was written after the third time of watching, it was written verbatim whilst watching the video. The transcript as demonstrated in the excerpt in Figure 4.4 below was annotated on subsequent viewings of the video. The different colours indicate different observations made on different times of viewing. Black denotes the first watch after transcription had occurred and been confirmed. Red was the second time of watching, blue third time and green fourth. Using the colours in this way, demonstrates how different things occurred to me at different stages when watching. This allowed me to understand what was most obvious when watching this video and which were the more subtle areas that I wanted to note when observing the child's interactions within their isolation room on the video camera.

Figure 4.4 Transcription and Annotation

<p>"I have been staying in this hospital for about 10 days now err.... (pause) and I would like to say that everything , staying in this isolation room is quite..... err quite nice, but sometimes and as the days go on and on and on and doctors are not seeing you and you are just waiting for your treatments and report it gets like quite boring you know..."</p>	<p>Looking directly at camera, then eyes divert to another person out of shot.</p> <p>Pans Camera around room- see mum on parents' bed next to his bed, eating food from a lunch box</p> <p>Pans back to face</p> <p>Television on but with no noise? like this so that he can use video camera or whether he had the noise down before.</p> <p>Able to hear noise of people talking outside in corridor.</p> <p>Lights off, dull day outside, dark in room</p> <p>Not smiling and sounding despondent in tone</p>
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This colour coding technique was also employed when transcribing the interviews, to reflect the tone, emotion and pauses associated with the spoken word. This allowed for some of the emotion and non-verbal data to be described in the transcript that may have been missed simply by transcribing the spoken words. The use of colours at this point was not related to coding but simply allowed me to see what I noted initially, and what was noted on subsequent times of listening. Therefore for the analysis, it became apparent to me the areas within the video diary that I deemed less obvious or illuminating on watching it back. Graham et al (2016) and Jones et al (2015) note that there is a level of detail from paediatric data in the non-verbal that may represent important data in the absence of the interpretive level of data that older children or adults were able to provide. Once the transcripts had been completed and the analysis process began, the audio and video data were continued to be used and listened to throughout analysis to ensure that the data were truly represented in the findings.

4.2.4 Analysing the Experience

The process of analysing the experience is the process of annotating and describing the transcript, organising it which leads to codes and themes being generated (Kim, 2016). Analysing data was the process in which I critically reviewed the verbatim transcripts with annotations, identified similarities and differences into summation and overarching themes, using the analysis format as described by Riessman (1993). The aim of the analysis was to create a metastory or metanarrative in which the individual narratives were used to

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represent the themes generated (Riessman, 1993), and to delineate between the different sources of child and parent dyad, and the staff (Lynch & Redpath, 2014). In this study as already mentioned, the processes of analysis were fluid and often codes were coming to mind when completing the interviews and also when transcribing, so these were documented in the reflective diary and reviewed at the point of coding formally beginning.

4.2.5 Annotating and Describing

The process of annotating and questioning was the process of familiarising with the data and trying to understand and interpret the data within the context [in](#) which it was given. Stories are not told in a vacuum, they are simultaneously situated within a particular context and within a wider social construct (Dibley, 2011). The process of annotation and preliminary coding and describing the transcripts happened soon after each data set were collected to allow for my accurate recall of events of the interview. Furthermore, following each interview I reviewed if there were specific questions that the data generated that could be reviewed in subsequent interviews. Given the length of data collection, each individual transcript was re-read prior to analysis of all the transcripts as a whole which occurred once the entire data set were collected. This ensured full re-immersion within the data and ensured that all data sources were recalled equally when reviewing the data as a whole.

Annotations/descriptions were made repeatedly as each time the data were listened to or read, new thoughts, memos or annotations were added to the transcript, until no further thoughts were apparent on listening to the transcript. In the interest of representing the true emotion behind the narrative, each time the data were reviewed, the original audiotape/videotape was played. This stage of analysis produced a fully annotated transcript having listened and viewed the audio/video tapes; descriptive of verbal and non-verbal data. This process of data analysis is descriptive, rather than theoretical; it is about describing the data, and these descriptions being shortened to codes of one word or a phrase used directly from the transcript. For me as a novice researcher, it was simply about describing what the participants have tried to convey in their narratives through further annotations on the transcript. Each description was given a word to summarise the description/annotation which became the code attributed to that piece of text. Finally, in accordance with Labov & Waletzky (1967), the language and meaning in the story were

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reviewed at this point to add to the annotation. Some of the codes were developed based on this search for language that described excerpts of the transcript.

For this study, each participant's transcript was reviewed in detail for codes, then analysed as parent and child duo to find where the codes and story overlap. The initial coding process began with literal codes that summarised an excerpt or paragraph from the transcript. Where possible the codes were chosen using the participant's words, to keep the codes as true to the original narrative as possible. An example of coding is shown below in Sophie's Transcript Table 4.1 below. This example transcript will be built upon throughout the rest of this chapter to demonstrate the journey from code to overarching theme. The codes have been given colours as shown in the right-hand column to distinguish codes that may be grouped together.

Table 4.1 Initial Coding of a Single Transcript

Transcript Verbatim	Code
Interviewer: <i>So tell me your experience of isolation Sophie. What was it like being in that single room?</i>	
PR11: <i>It was dull. Well it was dull but I guess it was better than being with lots of noisy babies and children. I needed more to do. I eventually got some school work sent to me as I was getting behind, but other than that there was the TV and my phone and the internet was in and out and there's no Wi-Fi. Ummm yeah.</i>	Boredom Disturbance/ Privacy Distraction Contact with outside world
Interviewer: <i>So what was the best thing about being in isolation?</i>	
PR11: <i>That I was away from a lot of noise I guess, but it was still quite noisy, like I could hear the people in the rooms next to me, especially if they were shouting or a baby was crying... The best bit was going home!</i>	Disturbance Need to get out
Interviewer: <i>And what was the worst bit for you?</i>	
PR11: <i>Well it was being away from people. I just had my phone and the TV in the room and Mum that was my only things to do or chat to. And I missed out on stuff, like stuff at school and with my friends and I would see it all on Facebook and be sad. It sucked being away from it all, so far away from it all... plus I was away from home and only had the stuff that we brought with us or the bits that Dad and the others brought up when they visited. It was a long boring time. I was happy to have school work brought to me 'cause it gave me something to do.</i>	Lack of social contact Missing out Distraction Boredom Parental Presence
Interviewer: <i>Wow! And if you had to describe that room to your friends at school how would you describe it?</i>	

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<p>PR11: <i>I would say... ummm... it was small, only just enough room for a bed and Mum's bed. Then there was a sink and a TV. It was a grey looking room and didn't look very modern, nothing really in it either.</i></p> <p>Interviewer: <i>and how did the room make you feel?</i></p> <p>PR11: <i>well not happy for sure... I mean I felt rubbish because everything was all a bit sore and then I had to be stuck in one room I couldn't even have a wander around when I felt like it. I mean sometimes I was so sleepy I didn't want to get up but other times it would have been nice to take a walk a little bit. hhhmmmm... It was quite miserable and I didn't like it. But I knew they were going to make it better, I mean make me better so it was like get it over with. I was glad to go home.</i></p> <p>Interviewer: <i>And what was the best bit about coming home?!</i></p> <p>PR11: <i>my bed! And my stuff and the fact that I could move around as I wanted as do what I want when I wanted. And my friends came to see me and... yeah I could have the internet all the time to chat to people. I was so happy to be home.</i></p> <p>Interviewer: <i>And did you have anyone come and see you when you were in hospital like visitors or staff?</i></p> <p>PR11: <i>well the nurses came in and to doing my medicines and taking my temperature and things, then the doctors came in in the morning normally and they decided what I needed and when I could leave..... Dad visited with my brother and sisters on the weekend. But no one else really.... Oh yeah there was the play person, she brought me a laptop thing, but I couldn't use that on the internet so it was a bit silly because I could only play games and I had better ones on my phone!</i></p> <p>Interviewer: <i>oh dear, so not lots to do in there?</i></p> <p>PR11: <i>no not really, but I had my phone so it was ok.</i></p> <p>Interviewer: <i>well at least you have some games and bits on there. So what do you think could be made better in those rooms for someone like you if they had to go into hospital?</i></p> <p>PR11: <i>hmmm I don't know really. It is a hospital so it can't be really flashy because they aren't like that, are they? But if there were things to do and it was quieter it would have been better. I just got bored with the doors slamming and screaming, like I would try and do something and there would be a noise so I wore headphones a lot. Ummmm I think having more space</i></p>	<p>Physical environment</p> <p>"Stuck in one room"</p> <p>Physical environment</p> <p>Isolation and the treatment were a necessary evil</p> <p>Need to get out</p> <p>Need to get out and independence/freedom</p> <p>Need for social contact with the people she selected</p> <p>Contact with outside world</p> <p>Distraction</p> <p>Disturbance</p> <p>Need to get out</p> <p>Distraction</p> <p>Contact with outside world and privacy from the outside world</p>
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<p>might have been nice, Mum and I were on top of each other at times and it got annoying a bit. I guess things like an iPad or the laptop to have Wi-Fi would have been good but it is a hospital so I'm not sure what you can have because stuff will get broken and things, so yeah... it's hard.</p>	<p>Contact with outside world</p> <p>Distraction</p>
<p>Interviewer: so if you could redecorate the room what would you like it look like?</p>	
<p>PR11: I would like it to be a bit cleaner looking... it's a bit hmmm not sure what to say drabby looking. I wouldn't want children's pictures everywhere, I'm not a toddler! But something a bit nicer than grey and blue.</p>	<p>Physical environment</p>
<p>Interviewer: yeah that's fair. You wouldn't want baby pictures or Peppa Pig on the wall!</p>	
<p>PR11: no but the grey... it's gross.</p>	
<p>Interviewer: yes. So if you had to describe that room to one of your friends, what would you say?</p>	
<p>PR11: I would say that it's small, a window to see a little bit of sky and occasionally the helicopter flew by and landed. There's a sink, a TV, and it's grey. I mean even the blankets are blue or grey. It just feels dull.</p>	<p>Physical environment and impact on mood</p>
<p>Interviewer: that's fair. And did you understand why you were in there rather than in the big ward bit?</p>	
<p>PR11: well I'm not sure where the big ward bit was on the ward... but I think they had to find me a room on my own because of my skin that it was something other people could catch, like Mum and me we had to be really careful and with my brother and sisters when they came in. The nurses had gloves on when they touched me.... Yeah because of me I suppose, but I don't know really.</p>	<p>Understanding of reason for isolation</p>
<p>Interviewer: and did anyone ever explain why you were in that room on your own?</p>	
<p>PR11: no... maybe they did... to Mum? But no don't think so... I didn't really ask because it was better to be away from other people.</p>	<p>Contact with outside world and privacy from the outside world</p>
<p>Interviewer: well thank you Sophie that was really helpful. Is there anything else that you want to add about being in a room on your own?</p>	
<p>PR11: no, don't think so.</p>	

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As demonstrated in Table 4.1 the codes were colour coded to denote similar concepts in the text. In this transcript, it can be observed that some of the codes are not exactly the same although they are the same colour, but are surrounding a similar area, which helped to develop the preliminary themes. This initial coding was done for each child individually, then reviewed across all the children to assess for commonalities and then preliminary themes were devised. Using the example of the green colour in Table 4.1, I will demonstrate in Table 4.2 how these codes were developed across the children's transcripts to develop the subthemes. The subthemes demonstrated within this transcript developed into the overarching theme of 'Community'. Table 4.2 shows all the codes for all the child participants that were similarly coded in green and associated with social contact, social interaction and missing out on this.

Table 4.2 Development of Preliminary Themes for Child Participants

Participant	Excerpt	Code
Sophie	"my phone and the internet was in and out and there's no Wi-Fi"	Contact with outside world
	"Well it was being away from people"	Lack of social contact, missing out
	"Mum, that was my only things to do or chat to. And I missed out on stuff, like stuff at school and with my friends and I would see it all on Facebook and be sad".	Missing out
	"It sucked being away from it all, so far away from it all"	Lack of social contact, missing out
	"Stuck in one room"	Stuck in one room
	(At home) "And my friends came to see me"	Need for social contact with the people she selected
	At home) "I could have the internet all the time to chat to people."	Need for social contact with the people she selected
	"well the nurses came in and to doing my medicines and taking my temperature and things, then the doctors came in in the morning normally and they decided what I needed and when I could leave..... Dad visited with my brother and sisters on the weekend. But no one else really.... Oh yeah there was the play person, she brought me a laptop thing, but I couldn't use that on the internet"	Contact with the outside world

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	so it was a bit silly because I could only play games and I had better ones on my phone."	
	"I just got bored with the doors slamming and screaming, like I would try and do something and there would be a noise so I wore headphones a lot"	Lack of contact with the outside world and privacy from the outside world
	"Mum and I were on top of each other at times and it got annoying a bit"	Contact with the outside world- not wanting the proximity of social contact
	"I didn't really ask because it was better to be away from other people"	Lack of contact, privacy from the outside world
Lara (from video diary)	"I am bored, cause there is nothing to do here"	Boredom, need for distraction
	"There aren't any screaming babies in here"	Privacy
	"That's the TV, the best bit of my room. Not much else to do, other than watch TV and sit around all day."	Boredom
	"I'm bored, bored, bored."	Boredom
	"I want to go to the gym for something to do"	Need for distraction
	"Today I've been to the gym. I went on the trainer. I think that I did quite well. More than I usually do. My aunty is coming round later, that should be fun."	Family visitation
	"This room is better than being in a room of loads of other children"	Privacy
Simon (from video diary)	No quotes verbatim, but multiple clips with all members of his family and extended family visiting. No clips from video diary were of Simon alone.	Importance of family visitation
Simon (from VSRD interview)	"After I did my biopsies and stuff like that, the frequency of doctors coming to see me everyday got less. The nurses used to come just to ask "do you need anything", and to check my temperature"	Contact with staff
	"There was this bed in there, so that my mother could sleep with me, I think that was really nice."	Parental presence for support
	"the worst bit... hmm... just staying in that one room"	Stuck in one room
	"Great that your parent could stay with you and you could do your own thing really...."	Family presence
	"Yeah, I had the curtains down just for privacy."	Privacy
	"I like the parents' bed, it is good because the person is there and they can give you like moral support. The person can stay"	Importance of parents staying for support

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	"They used to come in from time to time and ask "are you ok", "do you want anything?"	Limited social interaction with staff, mainly task-focused
	"Because at that time, I was, at that stage of my disease, when I came to the hospital the pain was severe and this hand was paining and the pus was dripping out and everything, so I think putting me in the isolation room was quite nice. I mean I think it was nice. If I was with other children I would think its ok, but when I was in that room we played our devotional song and religion and we could do our, you know, we Hindu people we chant.... If we were in that big room, we would have to consider other people too"	Privacy when unwell, but also to participate in religious devotions
	"I really like staying alone. But when I was sick I was searching for another person but after that it was a new experience of staying in another hospital."	Privacy and comfort of family at different points in illness trajectory
	"When I was in hospital, I got to know my mother nicely. Because I hadn't stayed lie that with her for years. I didn't know what my mother was"	Importance of family in hospital
Harriet	"A dog came to visit.... But it wasn't allowed in my room, but I don't know why though. But it wasn't allowed in my room."	Physical isolation from something sociable happening on ward
	"I watched a lot of Barbie DVDs which was good.... I made a bookmark for (SISTER) and a sick bowl hat"	Distraction in isolation
	"Sister came to visit me, grandma did too. Daddy came to visit me. Mummy came to visit me too. Once Mummy was sleeping with me and Daddy came to visit, then Daddy was staying with me and Mummy came to visit"	Importance of social contact with family
	"I saw a girl out the window, she had a tube up her nose as well"	Seeing other children in hospital, normalised the experience or her.
Eloise	"Being in a single room was a lot nicer, you had more privacy."	Privacy
	"These volunteers came round and they tried to come in but they just wanted to do colouring with you. I think that they could do different things with different age groups and adapt what they are doing to the children that are in, like I don't want to do some colouring. There are lots of other things that they could do."	Need for appropriate social contact
	"I would say that it was just a bit more privacy. It was a bit more quiet. It was just	Privacy Own space

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	<i>nicer to ummm have your own space rather than sharing it.</i>	
Imogen	<i>"The room on its own was a lot quieter and you got to look out the window!"</i>	Quiet of the single room- implied as a positive thing
	<i>"The room was lonely and boring, but you got a bigger TV"</i>	Social isolation
	<i>"I missed my friends" (reference to friends on the ward)</i>	Missed social interaction with wider ward
James	<i>"My Mummy is with me the whole time, in my room."</i>	Need for social interaction with people he trusts
Nicholas	<i>"It was quite loud, outside I mean, and the... the person next door was quite loud, and that was a bad and annoying thing."</i>	Despite being isolated, the outside world impacted upon him
	<i>"The best thing about it was that it was sort of lock out really from everyone else."</i>	Need for privacy
	<i>"I had my phone, so I didn't really miss anyone and the play people brought me stuff to do"</i>	Social contact with others via social media/phone
	<i>"It's kind of enclosed, I didn't really mind it tough... I'd rather have been at home."</i>	Enclosed from social interaction

4.2.6 Organising the Data to Form Preliminary Themes and Themes

The process of organisation of data was about collating the descriptive data (codes) as shown in Table 4.2 above in groups to begin to form preliminary sub themes. The codes were taken from the verbatim transcripts, and were tabulated according to the colour coded codes as show in Table 4.2. The codes were then grouped for the children to establish sub themes, as shown in Table 4.3 below. The subtheme was described in the table to ensure that the codes were appropriately attributed to that subtheme.

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Table 4.3 Sub Theme Development

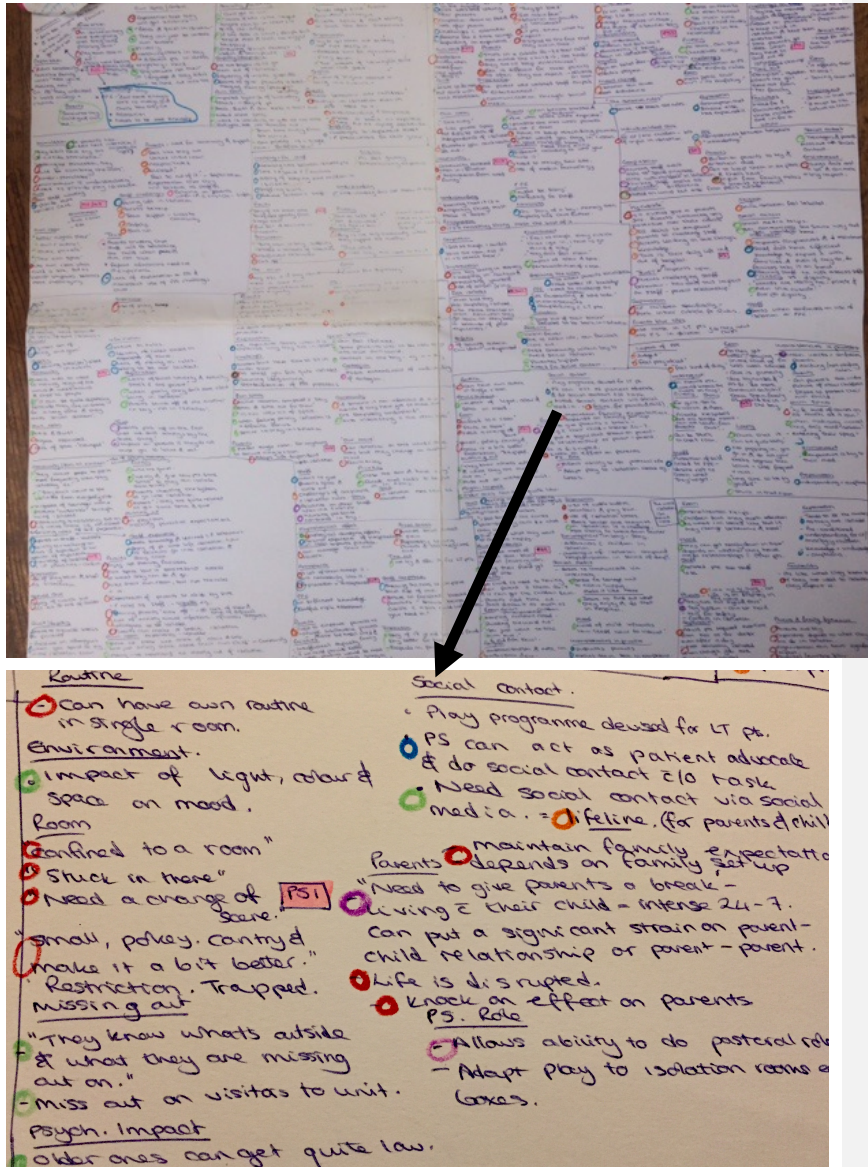
Codes from Children	Sub Theme	Sub Theme Description
<ul style="list-style-type: none"> • Contact with outside world • Lack of social contact • Need for social contact with the people she selected • Privacy from outside world • Not wanting interference from outside world (outside isolation room) • Family visitation • Contact with staff • Parental presence for support • Limited social interaction with staff, mainly task-focused • Privacy when unwell, but also to participate in religious devotions • Privacy and comfort of family at different points in illness trajectory • Seeing other children in hospital, normalised the experience for her. • Quiet of the single room- implied as a positive thing • Social isolation • Missed social interaction with wider ward • Social contact with others via social media/phone • Enclosed from social interaction 	Social Contact	Social contact includes description of lack of social contact, need for social contact, or when social contact is enforced upon them and need for privacy. Reasons for social interaction are also mentioned in this theme.
<ul style="list-style-type: none"> • Boredom • Need for distraction • Resident parents alleviated boredom • Physical isolation from something sociable happening on ward • Need for distraction 	Boredom	Boredom includes comments regarding being bored, need for distraction and ways in which distraction is provided
<ul style="list-style-type: none"> • Missing out • “Stuck in one room” • Contact with the outside world • Contact with staff • Importance of family presence • Seeing other children in hospital, normalised the experience for her. • Despite being isolated, the outside world impacted upon him 	Missing Out	Missing out includes any activities within the hospital or within the child’s life that they feel that they are missing out on as a consequence of the isolation room

This process of coding to subthemes was then completed for all the parents and staff transcripts to find overarching subthemes and eventually themes. Figure 4.5 below exemplifies the paper copy of how this process occurred. This shows how the codes were

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presented to ensure that there was a track back to which participant was included in which codes/subtheme, to ensure that the final themes were representative of all the data sets in the study. Figure 4.5 shows the presentation of the codes that were grouped together for PS1 (play specialist 1) and the colour coding to demonstrate how those codes align with other members of the staff. The child codes were actually created first and then the parent, followed by the staff, so that the child codes were leading the codes and subsequently preliminary themes. I was keen that the child voice led the data analysis and therefore their codes were created first and compared with the other data sources.

Figure 4.5 Example of Staff Overview of Codes



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Table 4.4 shows below shows how the subthemes from the children (as shown in Table 4.3) were amalgamated with the parental and staff subthemes. Where a parental or a staff code echoed a child code, this is denoted with an asterisk in Table 4.4 below. The asterisks were colour coded: parents were red, and staff were green. This demonstrates how the child data drove the analysis and kept the child central to the analysis process. Table 4.4 has colour coded codes: children are denoted in black, parents in red and staff in green.

Table 4.4 Subtheme Development from Codes

Codes	Sub Theme	Sub Theme Description
Children <ul style="list-style-type: none"> • Contact with outside world * * • Lack of social contact * * • Need for social contact with the people she selected • Privacy from outside world * * • Not wanting interference from outside world (outside isolation room) * • Family visitation * * • Contact with staff * • Parental presence for support * * • Limited social interaction with staff, mainly task-focused * • Privacy when unwell, but also to participate in religious devotions • Privacy and comfort of family at different points in illness trajectory * * • Seeing other children in hospital, normalised the experience for her. • Quiet of the single room- seen as a positive thing * • Social isolation * * • Missed social interaction with wider ward * • Social contact with others via social media/phone * • Enclosed from social interaction * 	Social Contact	Social contact includes description of lack of social contact, need for social contact, or when social contact is enforced upon them and need for privacy. Reasons for social interaction are also mentioned in this theme.
Parents <ul style="list-style-type: none"> • Reassurance that staff were with their child • Glad of the privacy for themselves • Lack of conversation with other children • Disturbed by other children around but couldn't see them • Lack of engagement with staff when in isolation • Negatives of having other children surrounding when ill • Desire for child to use social media to continue normality with peers outside hospital 		

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<p>Staff</p> <ul style="list-style-type: none"> Greater need for technology to aid communication with outside community 		
<p>Children</p> <ul style="list-style-type: none"> Boredom* * Need for distraction- age appropriate * Resident parents alleviated boredom* * Physical isolation from something sociable happening on ward* * Need for distraction* * <p>Parents</p> <ul style="list-style-type: none"> Input from play team improved boredom Preparation for stay improved boredom Felt responsibility to provide entertainment for child <p>Staff</p> <ul style="list-style-type: none"> Additional burden for families to try and keep child entertained in isolation Mood changes for teenagers and parents in isolation Need to distract Priority of distraction for children in isolation 	Boredom	Boredom includes comments regarding being bored, need for distraction and ways in which distraction is provided
<p>Children</p> <ul style="list-style-type: none"> Missing out* * “Stuck in one room” * Contact with the outside world* * Contact with staff* * Importance of family presence* * Seeing other children in hospital, normalised the experience for her Despite being isolated, the outside world impacted upon him * <p>Parents</p> <ul style="list-style-type: none"> Seeing activities going on outside without them for the children * Parents missing out on interacting * Missing out on social interactions/activities happening on the ward * Desire for own routine <p>Staff</p> <ul style="list-style-type: none"> Miss out on play room and resources on ward Physical confinement 	Missing Out	Missing out includes any activities within the hospital or within the child’s life that they feel that they are missing out on as a consequence of the isolation room

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Parents <ul style="list-style-type: none"> • Changed perceptions as a consequence of isolation • Different behaviours from staff observed * 	Stigma	A mark of disgrace associated with a particular circumstance, in this incidence isolation.
Staff <ul style="list-style-type: none"> • Parents felt stigmatised by sign on door • PPE • Unfamiliar with infection prevention precautions necessary • Lack of consistent information from colleagues • Inconsistent practice 		

The subtheme tables as exemplified in Table 4.4 were reviewed within academic supervision and with research colleagues to determine the final overarching themes. The raw data was continuously revisited to ensure that the final themes were representative of the narratives given by the participants and in particular were representative of the child's story of isolation. The final subthemes in Table 4.4 were combined according to the original colour coding, and overarching themes were identified. The final themes were Control, Community and Coping as shown below in Table 4.5.

Table 4.5 The Final Themes

Subthemes	Final Themes	Definition of theme
<ul style="list-style-type: none"> • Privacy • Familiarity with the Ward • Acceptance of Isolation • Merging of Parental/nurse role 	Control	<ul style="list-style-type: none"> • To have power over or directly influence over (Dictionary definition) • Control is bringing the environment into line with one's wishes and bringing oneself in line with the environment (Rothbaum et al, 1982).
<ul style="list-style-type: none"> • Missing out • Boredom • Social Contact • Stigma 	Community	<ul style="list-style-type: none"> • A group of people with particular characteristics, attitudes and interests in common (McMillan & Chavis, 1986)
<ul style="list-style-type: none"> • Understanding of isolation • Parental presence • Space • Need for time out 	Coping	<ul style="list-style-type: none"> • Coping is directed at dealing with or resolving or mitigating a problematic situation or difficulty (Ray et al, 1982)

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Having grouped the subthemes, I spent much time ensuring that the themes were appropriate and most of all representative of the stories that had been shared in the research process. The final themes were revisited also to separate out the themes with each subgroup (child, parent and staff) and ensure that they represented the story for all individuals within a subgroup, but also the dyads of parents/children. After mapping the themes out in many models, the best fit for the purpose of telling the metanarrative within the social construct of the individuals within the narrative was to present it as the three overarching themes as documented in Table 4.5. This process of final theme generation was revisited a number of times, having left it a period of time and also with different people to ensure that this was a rigorous process and enhance validity of the final themes. These themes represent a new understanding of the experience of children in isolation. Figure 4.6 and Figure 4.7 below show two reviews that I did at different time periods after analysis to ensure that the themes represented the raw data, in this process I reviewed the raw data and revisited the subthemes and themes.

Figure 4.6 The Final Themes Mapping

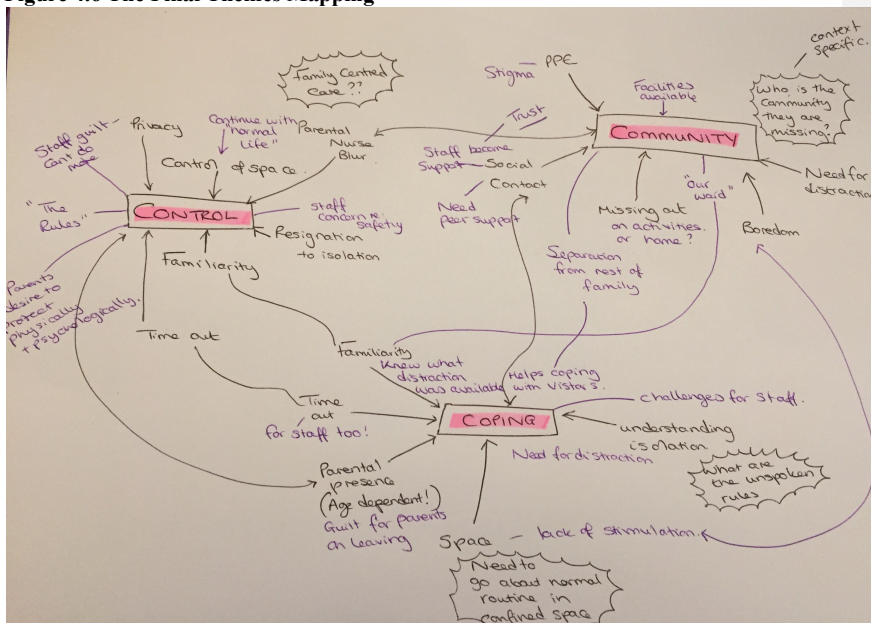
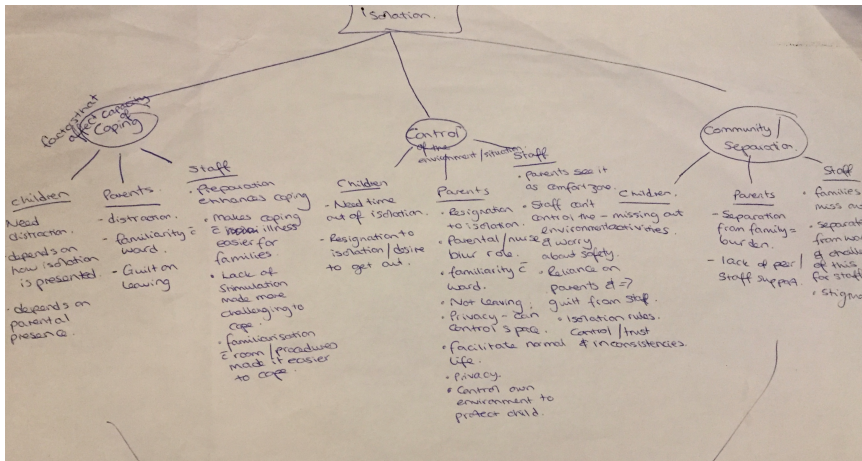


Figure 4.7 The Final Themes



This final theme mapping was revisited to affirm the themes. Figure 4.7 shows the subthemes subdivided into the different perspectives; the child, parent and staff. This is the beginning of how Chapter Five and Six were formed, with supporting parts of the original transcript to support their narratives and formulate the metanarrative. Reviewing the tables and the original paper copies of the codes, subthemes and themes throughout the research process aided the formation of the metastory or metanarrative, and demonstrates a rigorous analysis process.

I have made this analytical process transparent to ensure that the child's voice is clear throughout, but also to enhance the validity and provide a clear audit trail to towards the final metanarrative. In order to continue to demonstrate the transparency of these findings I have used verbatim data extracts throughout Chapter Five and Six. I have also included excerpts from the reflective diary to demonstrate the data that was generated from my observations and interactions. As a main data collection tool, I documented all interactions within the reflective diary, and this did form part of the analysis.

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4.2.7 Reading Experience

The final phase of narrative analysis is the representation as the reader encounters the story which is presented in Chapter Five and Chapter Six.

Polkinghorne (1988) described the use of looking for commonalities in the data sources to uncover the themes and this was the process that was undertaken at this point. The themes are ordered control, community and coping as this was format of many of the participants' narratives when they were describing their experience in isolation and thus forms the outline of the metanarrative that will be presented in Chapter Five and Six. The initial response to isolation was surrounded control whether that be control of the isolation room environment, or matters of control associated with their diagnosis or treatment. Secondly participants described a need to either seek or escape from the community of the ward and within their wider social context of home; for either support or avoidance from the situation depending on their response. Finally, the response was to display their coping mechanisms within the isolation room, which were individual ways to cope with the situation according to the participants' own social construct.

The metanarrative will provide the structure to the findings in the remainder of Chapter Five and Chapter Six. Chapter Five will explore the metanarrative for the children and parents, and Chapter Six will present the same metanarrative for the staff. In Chapter Five and Six, there will be some explanation of the narratives' underpinning story and how these relate to each theme, which will provide more construct to each theme. Chapter Five presents the dyad of data between the child and parents, and as such has been separated from the staff data in Chapter Six which is an overview of their understanding of the child's experience of isolation. Following analysis completion, the data were rereviewed to ensure that the themes were representative of all the individual narratives and are drawn together in a metanarrative in Section 6.4.

Bruner (1986) states that collaboration is inevitable because the reader is an agent of the text, which suggests that there is another layer of collaboration in the interpretation of the narrative, based on the readers preconceptions and thoughts. Readers of historical texts interpret the literature differently regularly (Bleicher, 1980). Based on this, the narrative presented in this thesis may be understood differently by number of readers who can use

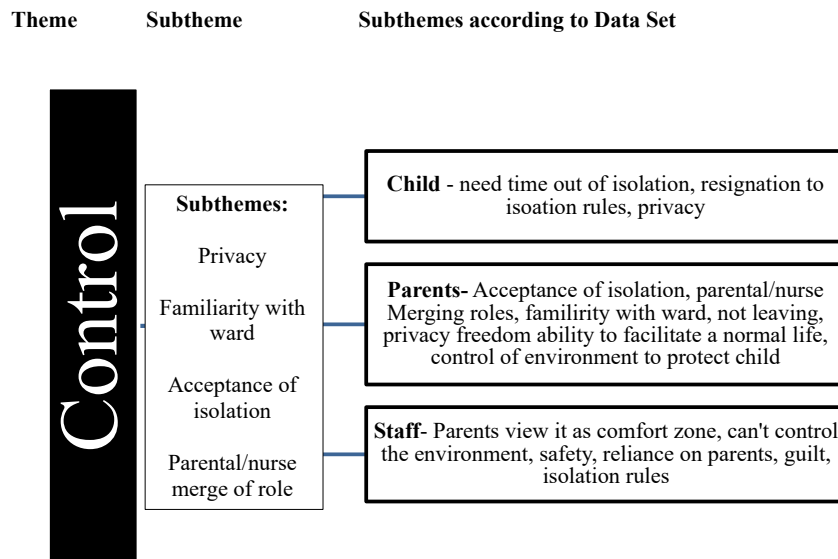
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the findings in a variety of different contexts. This is considered a strength of the presentation of the findings for narrative researchers, as it allows the participant to tell their story, for me to present the evidence and finally the person reading the story to use that in terms of their own practice by making their own judgement as to the relative validity within the context of their own environment (Polkinghorne, 2007). For some this may be viewed as a weakness of narrative analysis, as people will interpret the findings differently. However this thesis serves to be a depiction of the stories of the participants, their culture, psychological processes, social constructs and experiences at the time in which the data were collected, which will aim to provide sufficient background to allow the reader to explore the findings appropriately in the context of which they are using the findings (Riessman, 1993). This links with social constructivism, as the data here are presented within the context of the time and place in which they were collected. Similarly, it is hoped that readers will consider the findings within the context of their own environment, with acknowledgment of the time within which the data were collected (Feb 2011-Jan 2015) and the subsequent technology-driven culture evolution since data collection concluded.

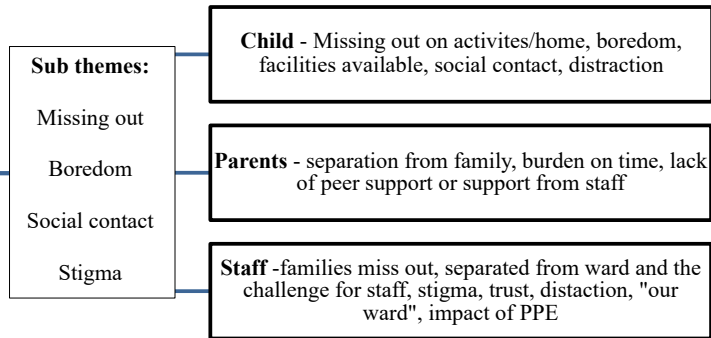
4.2.8 The Metanarrative

The metanarrative is the overarching story of isolation for the participants within this study which is represented in Figure 4.8.

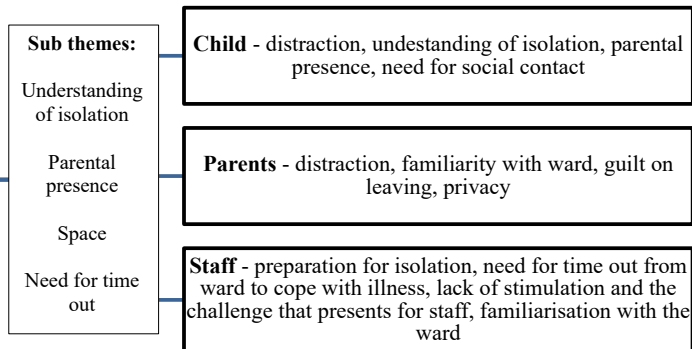
Figure 4.8 The Metanarrative



Community



Coping



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For any child admitted to isolation, whether that be for one episode of care only or on multiple occasions within a long-term health need, their story began with the reason for isolation and why they were “put” into isolation. This use of the word “put” was used by Imogen and her mum, but it echoes the manner in which other participants described being admitted to an isolation room, that it was beyond their control and was something that they had no decision within. This demonstrates the beginning theme within the metanarrative, the issue of control.

The next theme that will be explored in this [thesis](#) will be community. All participants by the nature of being in isolation were separated from the community. Whether they considered the community to be the other children, parents and staff on the ward or whether that be the wider social context at home [depended](#) upon their exposure to hospital and familiarity with the hospital, and these differences will be presented in this chapter.

The final theme presented is coping. All the children and parents within the study had different coping mechanisms again in accordance with their own social construct. Furthermore, there were aspects within the care provision that made it either easier or more challenging to cope with isolation, many of which were context-specific.

The themes within the metanarrative ([see](#) Figure 4.8) will form the subheadings, discussing each theme and their subthemes with excerpts from the transcripts. As the themes and subthemes are presented, each will be discussed using excerpts of the participant’s stories from the data to support the findings and underpinning narrative of the story of the experience of isolation. The themes have been ordered in this way to tell the metanarrative of the experience of isolation. The metanarrative is the underpinning storyline that represents all the findings from this study. Chapter Six will present the same themes with the staff findings.

4.3 Conclusions

Data analysis is a combination of science and art to search for patterns in the data and to find a means to explain those patterns. For this study, many data analysis methods were considered. [In](#) the context of social constructivism and the narrative approach to data collection, narrative analysis was deemed the most appropriate method to interpret all

Chapter 4 Data Analysis

forms of data in this study. The data analysis process is fully described and underpinned by literature in this chapter, and has been shown through the use of raw data which developed into the final themes which have been presented in this chapter. Chapter Five will present the findings for the children and parents within the study.

Chapter 5 Findings- Children and Parents

5.1 Introduction

This chapter serves to present the findings from the study, specifically the children and the parents. The previous chapter provided a description of the way in which the themes were derived from the findings, culminating with the metanarrative of the study. In this chapter the participants in the study; child and parents are introduced. The staff are introduced in Chapter Six where their findings are presented. The data that were generated from non-participation in the video diary data are presented in this chapter and discussed in detail Chapter Eight. The final part of Chapter Five presents the findings from the children and parent dyads.

The findings from Section 5.2 onwards are presented as a story to emulate the way in which the participants presented the experience of isolation in accordance with narrative inquiry to provide the story with a beginning, middle and end as described by Dibley (2011). The first theme 'control' is the presenting issue when admitted, then seeking out or removing themselves from 'community', which is the second theme within the metanarrative, and then 'coping' mechanisms are established, which is the final theme. Each story is unique, but there are interconnecting themes between stories, drawing these out may add to the evidence that brings new understandings. Findings that were solely attributable to hospitalisation have been excluded from exploration within Chapter Five and Six, as they are not relevant to the experience of isolation. However, there are a number of findings relevant to hospitalisation that may be heightened by the experience of isolation.

5.2 The Participants- Children and Parents

The participants need to be presented in detail, in order that the findings are understood in context (Squire et al, 2014). The families in this study demonstrated a clear sense of change in their lives as the 'world of isolation care' was imposed upon them and altered their social construct. Table 5.1 introduces the child participants.

Chapter 5 Findings from Children and Parents

Table 5.1 The Children

Name	Age	Diagnosis	Type of Isolation	Length of Isolation	Previous Isolation Experience	Who participated?
Lara	12	Pulmonary Ciliary Dyskinesia	Protective/Source	2 weeks	Hospitalised once before: 1 week in isolation.	Lara (in video diary and no follow up interview)
Simon	16	Spinal Tuberculosis	Initially in source isolation with suspected respiratory tuberculosis	2 weeks	No experience of hospitalisation or isolation.	Simon (in video diary and follow up interview)
Harriet	6	Haemolytic Uraemic Syndrome, presumed <i>Escherichia coli</i> (<i>E.coli</i>)	Source	7 days	No experience of hospitalisation or isolation.	Harriet and her mum
Eloise	17	Infective diarrhoea (Crohn's Disease)	Source	2 days	Hospitalised once before: nursed in a bay for 2 days.	Eloise and her mum
Imogen	9	Acute Myeloid Leukaemia (AML)	Source and protective at different times in three different hospitals	Multiple admissions to isolation ward, isolation rooms on oncology ward, isolation room on general wards - longest 6 weeks.	Hospitalised intermittently since diagnosis 9 months ago: protective isolation during BMT, source isolation for RSV, protective isolation when in shared care.	Imogen and her mum

Chapter 5 Findings from Children and Parents

John	6	Cystic Fibrosis	Source and protective	10 days	One previous admission at 6 months of age to protective isolation.	Mum
Erica	8 months	Mitochondrial Disorder, haemorrhagic hydrocephalus with VP shunt, hypertrophic cardiomyopathy, hypothyroidism, obstructive sleep apnoea and gastroesophageal reflux. RSV	Source	Has been admitted 5 times to 4 different wards, for up to 3 weeks; of these 3 times were in isolation up to 2 weeks at a time.	First 5 months of life in hospital in bays between 3 different hospitals and experience of isolation on different wards.	Mum
James	7	Cystic Fibrosis and <i>Pseudomonas aeruginosa</i>	Source and protective	7 days	4 previous episodes of hospitalisation-all in isolation.	James and his mum
Jessica	14 months	Bronchiolitis RSV	Source	4 days	3 previous episodes of hospitalisation – in isolation and main bay when cohorted with other children with RSV.	Mum
Rachel	2	EBV Encephalitis	Source	5 days	One previous experience of isolation for 8 days.	Mum
Freddie	2	Hand, foot and mouth – Enterovirus	Source	8 days	No previous experience of hospitalisation or isolation.	Mum and Dad
Nicholas	12	<i>Clostridium difficile</i> Crohns	Source	2 days	1 previous experience of hospitalisation on main ward.	Nicholas and his mum
Sophie	14	Cellulitis, Impetigo – <i>Staphylococcus aureus</i>	Source	5 days	No previous hospitalisation or isolation experience.	Sophie and her mum

Chapter 5 Findings from Children and Parents

The participating parents are presented in Table 5.2 below.

Table 5.2 The Parents

Name of Child	Participating parent	Other Children?	Experience of isolation	Occupation	Parent resident overnight?
Harriet	Mum	2 older siblings	No	Mum Housewife Dad in Navy	Dad stayed one night in hospital, Mum resident every night.
Eloise	Mum	1 older sibling	Previously stayed in a bay with Eloise	Office work	Mum resident some nights during admission. Single parent.
Imogen	Mum	1 younger half sibling	Multiple admissions with Imogen	Housewife	Mum and Dad separated. Dad is resident for half the hospital admission nights. Stepdad cares for other Son.
John	Mum	1 older sibling	No	Office work	Mum and Dad shared the nights in hospital.
Erica	Mum	1 older sibling	Multiple admissions with Erica	Mum Maternity leave	Mum stayed in the week. Dad stayed weekends and cared for other daughter in the week.
James	Mum	1 older sibling	1 previous admission with James	Mum works in a school	Mum resident in the week. Dad stayed with James at the weekend and cared for other son in the week.
Jessica	Mum	None	None	Mum on maternity leave, recently emigrated back from Australia.	Mum resident throughout. Dad did not stay but visited daily.
Rachel	Mum	1 older sibling	None	Mum doctor. Dad solicitor.	Mum resident throughout hospital stay. Dad stayed at home with other daughter.

Chapter 5 Findings from Children and Parents

Freddie	Mum and Dad	1 younger sibling	None	Mum on maternity leave	Mum resident throughout. Dad stayed at home to care for other daughter.
Nicholas	Mum	None	None	Mum office job	Single parent family, Mum stayed every night.
Sophie	Mum	2 younger siblings, 1 older	None	Mum nurse	Dad stayed at home with other children, Mum resident every night.

5.3 Reasons for Non-Participation to the Video Diary

Although the reasons for non-participation are incidental findings from this study, they are nonetheless findings, and essential to present to allow other researchers to review these data when considering using a video diary approach to data collection with children in hospital. The data are presented in this chapter in Table 5.3, however the discussion within the context of this study and future use of video diary research is in Chapter Eight.

Table 5.3 Reasons for non-participation to the video diary

Non-participant number	Age	Reason for Isolation	Reason for Non-Participation to the Video Diary Part of the Study
1	16	Protective	Participant did not feel confident enough to film herself.
2	7	Protective	Admitted to PICU prior to consent being obtained.
3	10	Protective	Researcher screened for MRSA PVL due to a contact during clinical role, therefore advised by the infection prevention team not to visit this participant, due to patient's immunodeficiency.
4	17	Protective	Researcher screened for MRSA PVL due to a contact during clinical role, therefore advised by the infection prevention team not to visit this participant, due to patient's vulnerability to infection.
5	12	Protective and source	Unable to obtain consent as ward closed due to outbreak of diarrhoea and vomiting.
6	12	Protective and source	Participant declined as due to be discharged the next day and did not feel able to participate for a short period.
7	16	Protective	Patient due to be discharged later that day.
8	12	Protective	Patient spends most of the time between intravenous medications at home, therefore his mother felt it wasn't "true isolation".
9	11	Protective	Patient is already in a number of studies and did not want to participate in another study.
10	11	Protective	Patient was unexpectedly due to be discharged later that day.
11	12	Protective	Unable to get consent as parents don't visit.
12	9	Source	Mother did not like the idea of filming her experience.
13	7	Protective	Transferred back to local hospital prior to consent being taken.
14	13	Protective	Unable to obtain consent as ward closed due to outbreak of diarrhoea and vomiting.
15	13	Source	Participant didn't want to participate in the video diary, but was happy to talk to me about her feelings about isolation.
16	13	Protective	Patient discharged prior to researcher approaching the family for consent.
17	10	Source	Patient declined as they were to be discharged later that day.
18	14	Source	Mother did not want her child to participate.
19	7	Protective	Mother did not want her child to participate.
20	6	Source	Mother declined as participant was "too shy" to do a video.
21	17	Protective and source	Participant did not want to explain their feelings on camera.
22	16	Protective	Participant too embarrassed to film herself as she looked at present.

Chapter 5 Findings from Children and Parents

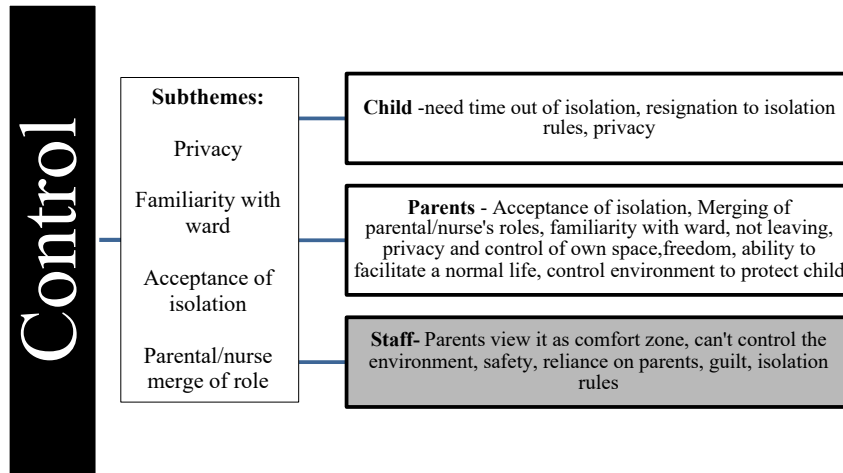
In total there were 39 children that declined participation to the video diary part of the study, although only 22 reasons for non-participation are presented in Table 5.3. The remaining 17 potential participants declined without reason, therefore they were not represented in this table. The researcher did not seek out reasons for non-participation, hence only when a reason for non-participation was offered was it documented in the table. The reasons presented (with the exceptions of logistics and clinical reasons) are mainly parental over-protection, embarrassment and shyness. Although these were findings for non-participation documented in this study, they were not reported in other social research using video diaries in educational settings (Harris et al, 2014; Noyes, 2004). Therefore, this may be attributed to the fact that the child was the patient and felt vulnerable at that point, or their parents were being paternalistic in their illness, or simply an issue of this era (2011-2015) and may subsequently be different today. It is my thought that with the knowledge of technological advancements now, understanding of children in practice today and reading the literature regarding video diary use, if I were to repeat the study with some recruitment strategy changes there may be greater uptake in this style of study, as other studies have demonstrated in hospital (Karisalmi et al, 2018).

The remainder of the chapter is allocated to presenting the findings from the parent and child dyads within the themes; control, community and coping.

5.4 Control

Control was a theme that was demonstrated throughout all the data sets, although with greater reference in the parent data, than the child. Control is defined as bringing the environment into line with one's wishes and bringing oneself in line with the environment (Rothbaum et al, 1982). Control is separated into the following subthemes as demonstrated in Figure 5.1.

Figure 5.1 Control



5.4.1 Privacy

Throughout the transcripts from the children, only three mentioned that isolation allowed privacy and control of their own space. However, this is widely mentioned amongst the parental data. The children that described the benefits of privacy and control over their isolation environment were Sophie, Eloise and Simon who were the oldest participants, which may account for their desire for privacy. For Sophie it was about being away from the noise. Eloise described having space to do her college work without disturbance. Simon liked the blinds down to the ward for privacy to allow for his own schedule and for him to practice his religion.

“ because at that time I was, at that stage of my disease when I came to the hospital the pain was severe and this hand was painning and the pus was dripping out and everything, so I think putting me in the isolation room was quite nice. I mean I think it was nice. If I was with other children I would think it's ok, but when I was in that room we played our devotional song and religion and we could do our, you know we Hindu people, we chant. I don't know why we do that. When my mother, when they took me to do the biopsy for cancer. My mother was saying, I need to chant, I don't know why, but it feels like, when we do that (chanting) it feels really nice inside, we get a bit mentally strong.” (Simon, 16 years)

Chapter 5 Findings from Children and Parents

The privacy allowed Simon some contentment and freedom to practice his religion which gave a positive lens to his experience of isolation. There was no mention of any other faith practices in the rest of the narratives.

For James, John and Lara there has been lifelong knowledge that they would be in isolation when in hospital and this led to the parents in these families making isolation part of the norm to enable isolation to be a positive hospital experience, as it enabled them to continue their normal routine within privacy. James' mum portrayed isolation as part of their life; making it seem fun by allowing special privileges. Some of these privileges such as "having breakfast in bed" could have been facilitated in the main bay, however through being in a single room it meant that James felt he was receiving special privileges of isolation that he enjoyed alone. Through James' mum being positive in her attitude, James was also positive in his tone and demeanour about isolation. James' mum felt that he probably valued the isolation room as it allowed him to do his physiotherapy treatments without embarrassment:

"It's our routine, its sleep and its things like getting dressed and actually doing his physio without him being embarrassed. We can shut the door and he can do his PEP mask and I have to do it and there is no crowd, because people do like to see what's going on, and it's not really fair for him to have to explain it all the time." (James' mum)

This highlighted that they valued privacy to conduct their own routine. James was quite a confident young man and his mum described him in the following way:

"He enjoys it (isolation), he genuinely enjoys it! Yes he enjoys the one to one with us, the attention he gets from the nurses. He is a bit of a comedian, so they sort of fuss over him. There is always someone popping in and saying hello. He enjoys the attention." (James' mum)

Privacy was mentioned by seven parents. For many of the parents the main positive aspect of privacy and controlling their environment in isolation was the benefit of sleep. Five of the parents commented on sleep deprivation and how this impacted upon them.

"I thought an isolation room was much better because it was a private space. And you could close that door and there weren't people around and we preferred that, it was better for both of us. Although it could get noisy outside of the room, it was obviously quieter than sleeping in the same room as other people." (Nicholas' mum)

Chapter 5 Findings from Children and Parents

This excerpt from Nicholas' mum demonstrated what many of the other parents had described. However, for Nicholas' mum the context which underpinned her rationale for this privacy was that Nicholas and his mum lived alone and were used to a quiet lifestyle. Nicholas' mum found being on the main ward overwhelming, and therefore when they were admitted to isolation and were allowed privacy, she valued this experience. Harriet's mum made a similar observation about privacy, however for Harriet the division of the walls and being able to hear people outside made Harriet more intrigued to see what was happening outside. This was challenging for Harriet's mum to explain to her young child why she must remain in the one room. For Jessica's mum, isolation rendered her free from the responsibility of interacting with others, and she was afforded privacy to have important conversations with the medical staff.

(With reference to the isolation room) *"I can't think of any negative aspects... I really can't! And actually, another positive was that they were really concerned about her at one point and the critical care lady came in and was able to have a chat to me and it was quite nice having a private conversation rather than a conversation in the middle of the ward with lots of people around."* (Jessica's mum)

This highlighted that privacy for conversations and time for reflection were possible in isolation. Conversely, Rachel's mum stated that being in isolation felt like there was a lack of consideration that a parent could be struggling, so although she wanted the privacy, she also wanted to be checked on by the staff, to ensure that she was coping. The context behind this narrative is important here; the mum had limited visitors whilst she was in hospital as her husband was caring for their other daughter and their extended family lived a distance away. Furthermore, she worked in the hospital as a doctor and therefore her levels of expectations from the staff may have been different to other parents, as she merges her narrative between that of a professional and a parent.

For the mums of Eloise, John and Imogen their commentary regarding privacy was related to the control of their environment. As explained by Eloise's mum and Imogen's mum wanted the control of the environment to facilitate sleep. This conflicts with the challenge for the nurses who are trying to observe the patients. Both Eloise and Imogen's mothers recalled experiences where in a shared room, they found that there were challenges with other families regarding bedtime, and timing of lights down and televisions being turned off, which may be why they recalled so positively about her experience in single rooms. Despite this, Imogen viewed isolation much less positively as shown below.

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“I mean the difference between being in a mixed ward and being in a single room... I think it was probably the second night in, the first night was just no sleep at all. Because of the activity and the noise, and the lights. But the second night in I felt that I am really not having this so I closed the curtains around the bed and I actually turned the ward bay lights off because there were other kids in there that couldn't sleep as well so I got back to bed and then the nurse would pull the curtains back and turned the lights on. So, I thought ok.... So I got out of bed, turned the lights off, closed the curtains again and then she came back in, didn't she? And she was really snotty with us..... It's ridiculous that we couldn't have the lights down to sleep. So, in isolation the removal of that situation was lovely”
(Eloise's mum)

John's mum also commented on the positive nature of controlling their own environment, routine and that they decorated the room as they wished. For most parents in this subtheme, there was a need to facilitate their normal routine and isolation aided them in doing this. In particular the families that had experienced shared accommodation in hospital, especially those who previously had a challenging experience, had a significant portion of their narrative dedicated to the challenges of sharing main wards in hospital, thus explaining their positivity regarding single room isolation.

5.4.2 Familiarity with Ward

Familiarity with the ward was not mentioned in the children's narratives. It was however, strongly mentioned in five parental narratives. These five children all moved wards during their time in the hospital, whereas the other participants may not have mentioned familiarity with one ward as they were consistently on one ward.

Imogen was cared for on different wards within the hospital, another children's hospital post BMT, and also her local hospital. Her mum described the need for familiarity below, within the context of being moved between isolation rooms on wards within the hospital under study, and she contrasted this with the state of the art oncology facility for BMT at another hospital. Despite the fact that another hospital was not their usual centre of care, it was made familiar.

“The best thing about the BMT hospital was that they said you are going to be in this room until you go home, which was a bit daunting but also brilliant. We will put up all posters, put up fairy lights and stuff, so it felt like home. We knew we were going to be in for a long time which made it much more friendly, even if we didn't know them on that ward.”
(Imogen's mum)

Chapter 5 Findings from Children and Parents

This exemplified that one ward where you are initially admitted or receive the majority of your treatment often becomes the baseline to which parents compare experiences. For Imogen's mum she did not like the other ward within the hospital under study and her experience there was significantly different to that on the oncology ward. However, she also commented on how a room can be made familiar with lights and home comforts.

Seven of the children in this study were patients who had previous experience of hospital, and for some isolation. For many of the parents of children who had previous experience of hospitalisation on a different ward, it was challenging to experience another ward as there was comparison between the experiences. In this study, isolation rooms and experiences were compared, normally within different wards. This subtheme has overlap into hospitalisation, however isolation did compound the issue of familiarity of the ward, as illuminated in the following section.

Freddie's parents' narrative below describes the experience of isolation on two different wards: one which was intensive care and one was a general medical ward:

(Describing experience in intensive care) *"Amazing nurses, and all quite young girls I would say, between twenty and thirty and they were so confident with what they were dealing with, actually I was just sat there a complete wreck and these people were switched on and switched on to us. You know, what we might be feeling and in terms of telling us (about care decisions regarding their son), you know that we might change our mind but you will always be kept informed, and you know we were."* (Freddie's dad)

"And because of that I think that you will always have an expectation that you will be treated like that everywhere and that there will always be a nurse available for you." (Freddie's mum)

"And that is probably why we feel a bit like this wasn't as good there..., they just weren't around in isolation (when transferred to the ward), it was just because you have come out of that. They were caring for our boy but they were kind of caring for us as well and that was different up there, they are just there then to care on a clinical basis for the child, if something goes wrong really. And I would say that is really different." (Freddie's dad)

This narrative was underpinned by the context that the parents were transferred from PICU, where they had a nurse at the bedside all the time when compared with an isolation room on a ward where the nurse cared for a number of other patients, which reduced the patient-nurse contact time. It is documented in the literature that families moving on or

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“stepping down” from PICU environments find the ward environment challenging and the less frequent access to nurses may contribute to the lessened trust between the staff on that ward and parents (Linton et al, 2008; Oxley, 2015; Suleman et al, 2016). Although this extract speaks of hospitalisation, the intensity of having a single nurse to care for your child in isolation in PICU, to a nurse caring for a number of children in isolation on the ward, will reduce the visibility of the nurse, which may affect the experience for the family. Therefore, when moving between a familiar ward to the unfamiliar, in addition to the reduction in the level of nursing care, the experience of isolation becomes more daunting for parents to provide the care for their child with lesser level of support.

The excerpt from Freddie’s parents was compared with Harriet’s mum’s narrative where she described that the mere presence of the nurse supported the parents and that developed trust which was altered when they had to move wards. Similarly, Harriet was also discharged from PICU to a ward isolation room. Interestingly, both Freddie and Harriet’s parents had not previously been in hospital, so this was their first experience of hospital, and also isolation. This suggested that in a short space of time, Harriet and Freddie’s parents developed an attachment and familiarity with the first ward they were admitted to, and then compared this to further wards; expecting the same standards in terms of care.

The familiarity with the ward varied between the children and parents who required hospitalisation frequently and for those who were in hospital for a first episode. As children and parents became more experienced in the hospital environment, they were less reliant on staff and often took on the role of carer. With time spent on the ward, came familiarity with the routine and the environment, which meant that the parents were able to take on some of the roles of the staff. However, in the beginning of hospitalisation, families needed a lot of support to gain that familiarity. This links to the literature surrounding the development of an expert parent (as discussed in Chapter Seven), where they acquire knowledge related to the care of their child, as Erica’s mum described:

“I suppose if I think back to kind of um... when we were first in the room and we didn’t know, well we didn’t feel confident, we hadn’t been trained in the rest of things, it was very early experiences, it was kind of wake up and umm get going. We did feel quite stuck in that room.....it wasn’t easy feeling that vulnerable. Even when she was in the side room when she was poorly, she wasn’t well enough to leave so you kind of felt trapped.”
(Erica’s mum)

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As Erica's journey in hospital evolved over the months, her parents became more confident in providing her care and being isolated was not considered such a problem, as they felt less vulnerable. However, there were also moments when they were moved again to another ward and that moved them backwards along the continuum of novice to expert as Erica's mum said:

"I remember actually [Erica's dad's name] and I having concerns when we were going back from HDU into a side room, that we had obviously gone from that one nurse to two patients as well as everyone knowing her, and kind of although they didn't know her quite that well at that stage, to a side room where you could go for hours without seeing anybody and you could go for hours without seeing anyone in the corridor even. So it was, it was, it did make us feel quite vulnerable, very vulnerable actually." (Erica's mum)

This exemplified where isolation can compound the experience of moving wards, particularly to an unfamiliar ward. Conversely, Rachel's mum who was familiar with the wards professionally as she worked as a doctor on the wards at the time of her daughter's admission to one of those wards, found that the familiarity did not help her in controlling the experience or coping with it. She felt that because staff knew she was also a doctor and therefore, familiar with the environment, it did not need to be explained to her many of the aspects of the ward routine which meant that she felt very vulnerable and alone.

"I think that if parents are given information about if ... you know why your child is in isolation, why you are in a side room, and if you need help you can do this, you can bring your child out of the room or you can't bring your child out of the room if you need help, or you need to push the buzzer, or you need to come out and leave your child in, or whatever because depending on the different situations, then that would probably empower people to know how best to seek the help that they need. Ummm.... You know and letting people know when the door needs can be left open and when the door needs to be closed or doesn't need to be closed but that doesn't mean we are not still here, you might not see us so if you need us press this button or come and find us. That means that people don't, no one ever said that to us about you know come and find us if you need us or anything like that, which I think it may have been because they assumed that I would do that anyway or that I would know what to do but if someone says that to you and they have openly invited you to ask them if you need something then you feel much more comfortable doing it." (Rachel's mum)

This excerpt also highlighted the difference in professional and personal experience of isolation. Rachel's mum had extensive experience of caring for children as a member of the medical team in isolation at the time of interview. However, when isolated with her child she did not feel able to access help and was not familiar with the routine of the ward, she described a degree of vulnerability. Although, Rachel's mum was a doctor within this

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context, when I was isolated as a parent with my Son, I could echo the feelings of Rachel's mum, as it was an unfamiliar environment even though it was within the same hospital in which I work. Therefore, profession becomes irrelevant, the familiarity with the informal unwritten rules or tacit knowledge of the ward, in addition to trust in the staff which also comes with familiarity as described by Freddie's parents, was what enabled families to feel familiar with a ward.

5.4.3 Acceptance of Isolation

The decision to isolate a patient is made on knowledge of their condition, diagnosis or symptoms. This decision is discussed with families prior to them being admitted to an isolation room. The resignation to isolation for some children came from their understanding of isolation. James exemplified this; his parents had the knowledge on diagnosis of CF that he would always require a cubicle on admission to hospital and therefore, they had prepared him for this:

"When I'm in hospital, I go into MY room!" (James, 7 years)

With preparation for isolation, James accepted being in isolation on every admission. For most of the children in this study, resignation to isolation was not mentioned, neither was an adverse reaction to being in isolation. This subtheme mainly emerged from the staff data, which concurred with James' experience, whereby prior preparation for isolation meant that James had neither positive or negative descriptors regarding his experience of isolation, but an acceptance of the need for isolation. James' mum stated she prepared for hospital, specifically isolation to be a positive place.

"He kind of treats it as a home away from home, possibly because he has always known he will be admitted to isolation at some point, but also because we have really tried to make hospital a fun place..... It's the only way it can be, it can't be any other way. It has to be a positive place for us, they are there to help us because he has been ill." (James' mum)

The acceptance of isolation was part of their life was echoed in John's mum's transcript. Again, John was a patient with CF and he had always known that when he was admitted he would be isolated. His mum described that going into isolation was his own little bit of space.

For Simon, the excerpt below described his acceptance of isolation.

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"I think when we had to stay in one single room, and umm, (clears throat) it was like, if you don't umm, how can you say it. If you have to stay in a room, there is nothing that you can do It is the rule. I mean we had to wait for doctors and we didn't know what, what's going on, what's happening next or when we will go home or.... So it was really you know..... We had to just stay in the room, 'cause its hospital and that's what we are there for, waiting for the decision to be made." (Simon, 16 years)

Simon described a level of understanding of isolation based on following rules of what the staff had told him, which demonstrates the impact of the staff in an isolation experience which will be described in Section 5.6.1.

In terms of the parents' narratives, Imogen's mum referred to the acceptance of isolation calling it a "necessary evil".

"It sucks but it's necessary, it is a necessary evil!" (Imogen's mum)

As the child-parent dyad provided limited data regarding this subtheme, limited overarching comments can be attributed to this subtheme and thus, concluding comments regarding this subtheme are presented in Section 6.3.3 in the context of the staff data.

5.4.4 Merging of Parental/Nurse Role

The merging of the role of the nurse and parent, and their responsibilities is common in paediatric practice. However, when isolated to a single room, it becomes more apparent as often the nurse is less visibly present than they would be on the ward as they may be in another isolation room. This subtheme was not recalled by any of the children, possibly because for a child, [their](#) mum becomes nurse when needed irrespective of context, particularly for children with long term conditions. In fact, throughout the narratives there was little mention of the role of the nurse in the children's transcripts, whereas in the parental narratives there was much more description of the role of the nurse.

Everything that happens with a child affects all family members, so nurses should also pay attention to the family and all care to the child should be planned around the family. This may be the case across all children in hospital, however the environmental and spatial limitations of [an](#) isolation room, limits the people from whom these parents can seek help, and they are reliant upon staff popping in or passing by.

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"Because we kind of feel as though we work in partnership with the team when we come in, I mean it's lovely, everybody knows Erica, everybody knows us. You just have a stream of people walking either poking their head in the door, waving or someone, you can see people going past doing a double take and then coming back and saying its Erica again! But again, I suppose that's also partly to do with the fact that we do care for her ourselves with little input now. And umm you can ask, because actually what we needed from them was a lot less. If we weren't able to do all that we could do then I don't know what parents do, nobody has ever been, at any point, negative with us but you just are very conscious that people are very busy and umm so we tend to just now say "oh when you're next passing can you just drop some syringes or Erica's meds are in an hour so can you just drop them in" ... We try not to be too demanding." (Erica's mum)

This narrative demonstrated the partnership in the role between the nurse and the family, and how the family were happy to continue their role from home where they were required to carry out full care for their daughter. I reflected on this interview in my reflective diary and considered the role of parents with acute and chronic health needs, as described below in Figure 5.2.

Figure 5.2 Excerpt from Reflective Diary

"Erica's mum described a unique experience of a mum of a child with chronic health needs who had had repeated hospital admissions. The balance for her might be completely different to that of a child who did not have chronic health care needs. The role blur here is considerable, with Erica's mum leading on care decisions and asking the staff to provide the resources for them. Over time she has developed this role, potentially out of necessity because the nursing team weren't available to provide that level of care, but also through exposure to the medical system. Parents of children with chronic health needs have different needs compared with children of acute health needs, based on the interview that I have conducted thus far."

By contrast, there were some families who were not used to the care that a chronically ill child needed when at home and therefore when they were required to take on the caring responsibilities in hospital, that was challenging and certainly for Eloise's mum, Sophie's mum, Rachel's mum and Imogen's mum there was a feeling that not only were they "left to it" but also they felt responsibility for the care as the nurses were not present continuously.

"You end up doing the care as much as you can... it's just easier that way, and you learn by trial and error whether you can do things or not on the ward. Like using the parents' kitchen I would just go out and see if anyone told me off, because no one ever explained what I was and wasn't allowed to do or where I could go. And I think, I don't know, I don't want to sound patronising but I think that there's a little bit of pastoral something that is missed a bit, because all the staff are so busy with their own job, doing medicines and

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observations, that everyone, the parents you are floundering going “I don’t know what I am doing””. (Sophie’s mum)

For Nicholas’ mum the role overlap came from her knowledge about decision making regarding isolation. Nicholas’ mum felt that he should have been isolated based on his presenting symptoms on a second admission. However, he was only isolated on his first admission and his mum suggested that the only reason they were put into a single room was because it was the only bed space available. Nicholas’ mum had strong feelings about when her son should be isolated and commented on how this could affect other children, however when admitted she did not speak up about this because she felt that the healthcare professionals knew best. Nicholas was later diagnosed with *C.Difficile* on return home, proving that his mum had been correct.

“On the second admission I don’t think that they connected his symptoms to being infectious and that he had clostridium and he came in with loose stools and it had a distinct odour, so symptoms that you would think cdiff. But they didn’t seem to pick that upbecause they hadn’t connected those symptoms to that possible infection which is really bad because he was having cdiff. It was bad for Nicholas because he had delayed treatment and it was bad for other children because they were potentially exposed and I didn’t say anything.” (Nicholas’ mum)

“Essentially, you’re in that, you’re within those four walls aren’t you, just with your parent. And then obviously the nurse popping in every so often. It was quite intensive for me, and the nurse would pop in every few hours for either a blood test or measure urine or give her a drink.” (Harriet’s mum)

This narrative described the nurse being task-focused and not spending time with Harriet to provide support. This may have been due to time pressures or simply that her mum was resident, therefore the mum could take on basic care as they would at home. Nicholas and Harriet’s mums described a level of vulnerability within these excerpts, based on the fact that they were in a single room and there were fewer opportunistic encounters with staff.

For Nicholas’ mum there was also an element of guilt in her tone, that she did not advocate for her son to be isolated on the first admission when she felt it would have been appropriate for him based on his symptoms. This guilt came from assuming that the healthcare professionals would know the best plan for her child. However, as parents become more familiar with the healthcare system it was apparent in the narratives that the parental-nurse role shifts further where the parent becomes the advocate for their child and

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leads on the care, an example of this is in the long term patients such as Erica, Imogen, James and John. This subtle movement from parent, to parent with additional nursing responsibilities needs was never explicitly mentioned in the narratives in the form of negotiation of roles as described by Casey (1995). From the tone of the parents' interviews, it was assumed by the staff that the parents would continue to conduct these roles whilst in isolation. This is not suggestive of the understanding of partnership of care and negotiation of family centred care as it is presented in the literature (Corlett & Twycross, 2006; Matziou et al, 2018; Mendes, 2016).

The level of responsibility felt by the resident parent and the feeling that the nurse was simply there to provide medicines and do tasks contrasted with the narrative of Jessica's mum. She was admitted with her baby and the father could not be there.

"I had a cry and the nurses were brilliant and they were like of course it is scary seeing her like this and they were brilliant, they sat with me for ages. So yeah I think that the nurses were fantastic". (Jessica's mum)

This excerpt described pastoral care provided by the nurses at a time when the support was really needed, particularly when isolated in a single room and with no additional sources of support as was the case for Jessica. In her transcript Jessica's mum described the nurses taking on all the care roles for Jessica, including feeding as she could not be orally fed. The situation where the nurse was carrying out all the care and providing support to the family is not described in any of the other narratives.

Interestingly, as the only father that participated in the study, Freddie's dad provided another perspective on the parent/nurse role.

"The day of his admission to the ward, it got to the evening and, they said to me that you have got to go home now. And I couldn't believe that, it's so unfair, what's that about because I've been involved in the whole thing and then just buuuffff you're out. And the lady said at the time, this will change. Things are different now, do you know what I mean? I care you know." (Freddie's dad)

This dad described a different experience compared with the mum's experience, in terms of his response to how to adapt his usual care for his son and the level of detail that he wanted in terms of protecting his son from further illness, whilst in hospital. It would have

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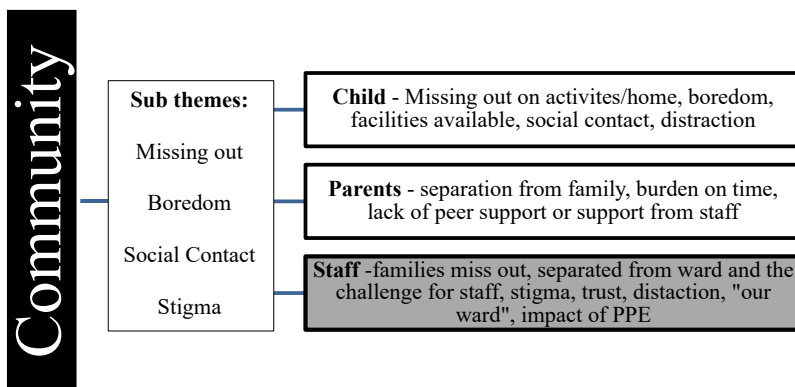
been interesting to collect more data from the fathers to ascertain whether there were commonalities in this respect or whether this was simply attributable to Freddie's dad. Across the parental narratives in this section, there are some commonalities in this parental role adaptation once admitted to isolation. This role change is also evident in the staff narratives.

Control transcends the subthemes of privacy, familiarity with the ward, acceptance of isolation and merging of parental/nurse role, with greater emphasis within this theme of the parental data than the child's voice regarding their experience. These findings describe the partnership in care and need for control over the situation of isolation in alignment with family centred care, which will be discussed in Chapter Seven.

5.5 Community

Community was a key theme that was demonstrated throughout all the data sets, although more commonly referred to directly in the child and parent data. Community is defined as a group of people with particular characteristics, attitudes and interests in common (McMillan & Chavis, 1986). Community is divided into the following subthemes as demonstrated in Figure 5.3 below.

Figure 5.3 Community



5.5.1 Missing Out

The subtheme of missing out was mentioned in five of the child narratives. For children who had only been isolated, their narratives rarely presented the notion of missing out. Whereas the children who have been hospitalised and in isolation when in hospital, were aware of what was available when they were on the main ward, and therefore what they were missing out on in isolation. Furthermore, some of the children were of the age where they wanted to be out of the room, active and interacting with others and therefore by being in an isolation room they felt left out of activities on the ward, exemplified here by Harriet:

Interviewer: "What can you remember about being in a room on your own in hospital?"

Harriet: "A dog came to visit me."

Interviewer: "Did it? That's exciting!"

Harriet: "But it wasn't allowed in my room, but I don't know why though. But it wasn't allowed in my hospital room." (Harriet, 6 years)

This was the opening of the interview, the first part of the narrative that she described was the dog and missing out on spending time with the animal. Her mum's account of this part of their narrative which she recalled independently is below.

"So during the week there was a lady that brought a dog, which was very exciting because she loves dogs but the dog was not allowed in, so she saw the dog and the curtain was open so she saw other children patting the dog. She wanted to touch the dog but the dog wasn't allowed into the room. It was like one of the worst things, you know. It is like dangling a carrot or a packet of sweeties in front of a child but saying actually you can't eat them." (Harriet's mum)

Similarly, Imogen and her mum recalled an experience of missing out on a Halloween party:

"The reasons for it (isolation) were explained very well but the practicalities were sometimes a bit... yeah I wasn't quite sure what to do, and there were certain times when I was like unsure of their rationale.... there was a particular time when there was a Halloween party in the play room and Imogen was absolutely desperate to go and she had been in isolation for three weeks and..." (Imogen's mum)

"I didn't even have an infection! I could go!" (Imogen, 9 years)

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"I understood 100% why kids need to be isolated but.... it is hard when there is stuff going on outside and they are very aware of it. And I think.... one of the play leaders or one of the nurses that had had a day off or had come in for another shift and they would say" Oh you're going to the Halloween party!" And it was like you know she can't. But everyone kept talking about it in her room. So, I think that when the kid is in isolation, it's almost a bit more helpful to keep them really isolated from all the social stuff. So that they don't know that they are missing out on stuff." (Imogen's mum)

This part of the narrative speaks of the confusion from staff in terms of knowledge of pathogen transmission and the need for isolation for length of time. This confusion regarding the "rules" specific to different pathogens is described in the staff narratives, but clearly it is demonstrated here how this confusion impacts upon the child's experience.

For Sophie, Nicholas and Lara it was about missing out, not on activities on the ward, but missing out on their social life and activities at home:

Sophie: "Well it was being away from people. I just had my phone and the TV in the room and mum that was my only things to do or chat to. And I missed out on stuff, like stuff at school and with my friends and I would see it all on Facebook and be sad. It sucked being away from it all, so far away from it all... plus I was away from home and only had the stuff that we brought with us or the bits that Dad and the others brought up when they visited. It was a long boring time. I was happy to have school work brought to me 'cause it gave me something to do!" (Sophie, 14 years)

"I was away from all of my stuff... I didn't mind it. Well, it was a bit annoying. I'd rather have been at home" (Nicholas, 12 years)

With the exception of Imogen's mum, no further parents described missing out on activities. This was a theme that as a parent of a baby in isolation I felt that I could empathise with as described in Figure 5.4 below.

Figure 5.4 Excerpt from Reflective Diary

After the interview with Sophie and her mum:

"Sophie and her mum described feelings of missing out of external aspects of their life. As the mum of a 5 month old, I found isolation really challenging, in that I wanted to spend time with my son and be there to undertake his care and be there for his feeds and nappies, but I struggled with the need to leave to do things, like getting bottles, or food for myself. Although I could leave the room, I didn't want to, which meant that I missed out on meals and had to wait for other visitors to come so that I could grab a shower. I can echo what Sophie's mum said and also the fact that Sophie missed out on her life outside... it was so hard to keep up to date with everything that was going on outside of the hospital as I had little phone signal and no internet. I struggled to even keep on top of messages to see how he was. I was only admitted with him for 48 hours, so I can really empathise how hard that must be for a week or more at a time."

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5.5.2 Boredom

Boredom was mentioned in six of the children's narratives. It was also mentioned in a number of the parental narratives. Throughout her video diary, Lara reiterates the word boring in every single entry. However, over the series of her video diaries she has received more interaction, and by the last video diary she speaks less about boredom but is talking about her sources of distraction such as leaving the isolation room to go to the physiotherapy gym.

Mum: "What did you... what have you done today?"

Lara: "Nothing"

Mum: "That's not true, what have you done today?"

Lara: "Nothing"

Mum: "What did we do together?"

Lara "ummmm"

Mum: "we played. We watched a film. We had a cuddle. What else did we do?"

Lara: "Don't know"

Mum: "Mummy has been waiting to see the doctor all day and now she can't come. So what would you like to be doing right now?"

Lara: "I want to go to the gym, for something to do and to get out." (Lara, 12 years)

Lara's mum did not stay whilst she was in hospital, therefore her only interaction was the staff and visitors, which made her construct of isolation very different from those children that had a resident parent. This narrative demonstrated that despite parents trying to provide sources of distraction sometimes it wasn't sufficient. Lara made no mention in her video diaries about the play team or school team coming to see her, and only when her mum probed her about activities did she identify some of the things that she had done in a day.

Similarly, Simon and Eloise both used the word boredom and monotony in their narratives. Nicholas' narratives highlights boredom as an issue, demonstrated also with the negative tone to the following excerpt.

"ummm, I took my phone in with me, yeah and the play people came and brought me stuff. It was boring though. Well, at first they did said like, do you want anything? But I didn't and I was fine, they had rubbish stuff. I wanted games and DVDs but not scratched ones like they give you and you can't watch them." (Nicholas, 12 years)

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Although Nicholas had this negative tone, his mum felt that isolation was probably better than being in the main bay, as he was used to a single room and that he wouldn't need the distraction of others, as he would not be bored on his own.

"I think that maybe younger children like other things going on around them and they like to see other people and the noise and the distractions. Whereas older children prefer the privacy and the solitude. Yeah and he is used to a room on his own at home and he is used to that space. (Nicholas' mum)

Rachel's mum echoed this boredom in the isolation room.

"We could go out of the cubicle at the end, so I did. This time (in hospital) it made me really think she was much keener quicker to get out of isolation and I think if we hadn't been allowed to get out that would have been really, really hard at the end. Ummmm I think that's because she was better, but also because she was a little bit older and kind of wanting to explore a bit more, getting a bit bored of being in those four walls with a TV that only worked for a certain length of time, yeah! That was great (laughs sarcastically)." (Rachel's mum)

The need for distraction was demonstrated in a number of other narratives; Sophie, Nicholas, Imogen and Simon and in a number of the parental transcripts. Simon refers to a moment in his time in isolation which provided distraction through watching the helicopter land, which he could see from his isolation room. For Sophie and Eloise, their boredom was alleviated by the distraction of school work which was brought in for them.

The parents described their children's boredom regularly in their narratives, often to illuminate the burden on their time in that they needed to be there to provide entertainment for their child.

"He was all on his own. Maybe if he had seen other children around, it would have been a bit more acceptable to him, "oh there is other people here, there is other children". Rather than I'm ill I'm stuck in a room, what's going on? Who's coming in? It, it did, his mood was really, really affected by what I am not quite sure but maybe seeing other kids kind of walking around or in their bed, may have helped him. Everyone other than us came into that room came in to see him or do something to him. Yes.... And that was both boring and scary for him." (Freddie's mum)

Imogen's mum suggested that distraction is not only necessary for the child, but also the parent:

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"If you are a way away from home then any distraction does make it easier." (Imogen's mum)

This demonstrates how the boredom transcends not just the child, but the parental experience and *that* this may be associated with the lack of stimulation or distraction, or alternatively the social isolation through the physical restrictions of the room. This reflects the theory of emotional contagion and how the mood from one another may be transmitted, particularly when isolated in a single room together (Dishion & Tipsord, 2011).

5.5.3 Social Contact

Social contact was described as the presence of staff, parents or other visitors. With modern technology and the era of electronic communication, there was commentary on the use of electronic communication in the form of social media to stay in touch with their home community, however this was probably used a lot less compared with today as a means of keeping in touch with the "outside world". Social contact is mentioned in four of the children's narratives and in most of the parental narratives.

In the interview with Imogen, she was asked what she thought about the isolation room and her simple answer was *"lonely and boring"*, this was with the presence of her mum or dad during her admission.

By contrast Harriet was content with the visits from her family, in addition to a parent present the whole time. However in the second excerpt below, Harriet talks of the day she was allowed out of isolation at the end of her admission and she was excited to meet other children on the ward.

Whilst in isolation: *"My sister came to visit me. Grandma did too. Daddy came to visit me. Mummy came to visit me too. 'cause once mummy was sleeping with me and mummy came to visit and then Daddy was staying with me and mummy came to visit."*

Out of isolation: *"I met a girl but I can't remember her name. She had a tube up her nose as well. And one little boy had a kidney thing, it was nice to play with them."* (Harriet, 6 years)

Harriet and Imogen, although too young to articulate that they found the experience socially isolating, described traits of social isolation in their narratives. Contrastingly the

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following two excerpts from Lara and Simon described positive aspects related to being isolated.

“I liked it because there were no screaming babies or children!” (Lara, 12 years)

For Simon who had been in another hospital on a main ward and witnessed other children having procedures, he found [that](#) the isolation room [allowed him](#) time to be reflective as he was removed from any social responsibilities.

“I saw parents crying. I saw babies, having all the things in them, like the cannulas and the things in the nose. I did not like watching that. I wanted to be away from it, but it made ummm.... a drastic change in me as to the way I see things, as to how I look at life. I could think on my own. Before this I was always complaining, I was always saying errm why am I so short and stuff like that, after that my thoughts changed, my attitude towards lots of people who I hated has changed, because I had time to think.” (Simon, 16 years)

Similarly, to Simon describing his attitude change for the positive through time in isolation, Sophie’s mum witnessed her daughter change in her level of confidence during her time in isolation.

“I think that being in isolation didn’t make it any worse, apart from not speaking with people. She is a chatty bubbly girl normally and not talking to people for a long period of time was quite hard, but if we were in the main bay and there were not kids that she wanted to talk to or they were too young or boys or whatever she may have really hated that more, so it’s tricky. She just needed to be able to chat to her friends more and with modern technology that’s possible, all depending on the quality of the internet signal..... But she wasn’t herself for that time, she lost herget up and go..... Her spark her zest... it was horrible to see it was like she went into herself.” (Sophie’s mum)

Freddie’s parents noted that by seeing other children it may have normalised the whole experience for him and that being isolated he lashed out more and displayed negative behaviour towards them. James and John’s mums did not describe any social isolation as they had a stream of visitors organised as their admissions were planned. The other parents that commented on the need for social contact, focused on their own need for social contact not their children’s. Harriet, Imogen and Erica’s mum all described varying levels of need for social contact and support from others.

“Even I became intrigued just to see who the other person was next door because you can hear voices and I ended up befriending the mother of another child that was suffering with EColi..... You sort of think to yourself, well, if I enjoy having that conversation with her,

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because I was able to walk out and make myself a cup of tea and enjoy those conversations, I dare say Harriet would have been able to enjoy that, but that is just not possible is it?" (Harriet's mum)

Similarly, Imogen missed her friends that she had met on the ward, rather than missing social contact of her friends at home. By contrast Erica's mum wanted to keep her social contact limited to her family and people she had known previously to this admission.

"I didn't really like the family room because you would go in there and people were comparing horror stories and that's not how I deal with things by talking about the negative things, I like to think of the positives" (Erica's mum)

Jessica's mum wanted the social support and contact and described in her narrative that she didn't feel able to leave the isolation room, so the staff became her support when she hadn't got her partner and extended family available. This experience is not exemplified in other transcripts and this may have been because of the other social constructs in that they had multiple sources of support aside from their partner, whereas Jessica didn't.

Alternatively, it could have been associated with the specific staff that were working on the unit at that time or the workload of the unit. It was necessary support for this mum at the time and without this social contact the experience would have been more challenging and Jessica's mum may have found it harder to cope with.

5.5.4 Stigma

Stigma is a staff driven theme predominantly. Stigma is defined as a mark of disgrace associated with a particular circumstance, quality or person (Dovido et al, 2000), which in this context is related to being in isolation and the pathological reasons for this. Stigma was particularly associated with PPE and was not mentioned in any of the children's narratives, and in fact it was only mentioned by one of the parents. Imogen's mum talked about how she didn't think her daughter was affected by the use of PPE, but for her it changed how she was perceived:

"She didn't mind it because she's 9, so it was explained but I think, whilst I don't think that she minded it, it's the atmosphere of the diseased..... When we had the regular nurses, you know that were on all the time, this one... particularly she would go "I've just got to put on all this stuff because you are diseased! And you are horrible and infectious!" in a jokey manner. And you know she would always stay a little bit longer and you know just chat to us after she had done and if we had someone from an agency or another ward they would be like "Oh god I've got to put on all of this stuff and check with someone" and

kind of just do the stuff and then go straight after... it made it much less fun for me or Imogen." (Imogen's mum)

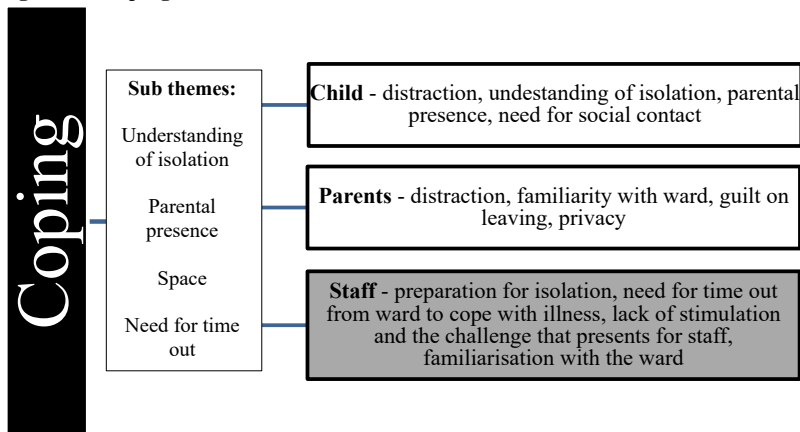
This demonstrated not only the challenges of using PPE for the interaction between the family and the staff, but also the importance of the way in which it was presented to this family made a difference to their interpretation of the PPE.

Community underpins the subthemes missing out, boredom, social contact and stigma. The subthemes suggest that children, parents and staff all have different experiences of isolation and that these different experiences are often a result of the type of isolation, their previous experience and such other factors. The subthemes within this theme demonstrate some alignment with the literature pertaining to social isolation, which will be explored in Chapter Seven.

5.6 Coping

Coping was a key theme that was demonstrated throughout all the data sets. Coping is described as dealing with, resolving or mitigating a problematic situation or difficulty (Ray et al, 1982). Coping is subdivided into the following subthemes as demonstrated in Figure 5.5.

Figure 5.5 Coping



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5.6.1 Understanding of Isolation

The subtheme of understanding the reasons for isolation and preparation for isolation were described mainly in the parental narratives. Lara, Simon, Sophie and Eloise all mentioned their reason for isolation and Eloise discussed preparing by bringing in her school work and laptop. Their understanding was clear as presented in these excerpts:

"I'm in here for my chest infection. They think its pseudomonas. Now I'm just not allowed to be in a bay with any other people." (Lara, 12 years)

"They said err it might be TB. So you might, you might. I don't know they said its bone TB but they thought that I might have TB in the lungs, so they put me into isolation." (Simon, 16 years)

Most parents alluded to their reason for isolation and those who knew that they would be admitted they discussed preparing for their time in isolation in their narrative. Imogen's, James' and John's mums were all aware of the reason for isolation, as isolation had been part of their long term condition. Therefore, preparation for their time in hospital had become routine. Imogen was in isolation during a number of admissions, and although her mum had a good understanding of why, she found there was confusion about it between the staff and herself.

"They did give us explanations about ummm..... about infections and, you know the importance of Imogen not being in contact with other children. Sometimes it wasn't explained very well, like I carried on using the ward kitchen because I didn't know and one of the other parents actually said to me, you know, you shouldn't really be using the ward kitchen. Ummm... I was a bit kind of...., I felt a bit silly, you know. A lot of the time, the staff would be like "I don't know why we are doing this" but I can understand if a child has got vomiting and diarrhoea, oh my god of course then isolate." (Imogen's mum)

Similarly, John's and James' mums described the fear of contagion from other children and the need to protect their child from any risk, which may have influenced their narrative tone.

"When we go to clinic he sees everyone in their own room and he doesn't go into the waiting rooms so he's known all the time that he's not supposed to mix with other children. He knows that he has to be careful not to pick up coughs and colds, so he's quite good. He has just been drip fed and at school he knows that there is another child with CF and he knows that they are not supposed to be too near each other." (John's mum)

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“Isolation - I wouldn't have it any other way! I'm really, it's really important, mainly the privacy and I don't want him to get anything else. We are already in there because he is poorly and I don't want anything to compromise him getting better” (James' mum)

By contrast Jessica's mum who had never been in hospital with her daughter before found the level of explanation considerably different.

“I don't actually ever remember it being referred to as isolation, which is probably a good thing because I think that the word isolation does actually sound quite scary..... yes it just feels a bit scary. And I don't think, I don't remember anyone ever using that word. I mean I might have forgotten but I don't remember them mentioning that she was infectious or that they were worried about her infecting others, it was more about the fact getting her closer, somewhere off the ward and somewhere a bit more relaxing. But maybe I heard that wrong.” (Jessica's mum)

Interestingly, Jessica's mum here analysed the word isolation, saying that is a scary word. Furthermore, she commented on her lack of understanding of isolation and this may be due to the acute nature of her admission or her stress, alternatively it may have not been explained to her.

Figure 5.6 Excerpt from Reflective Diary

“Isolation the word – Jessica's mum really homed in on this word. I had never thought about this word before. It is a clinical word and to me it doesn't have any connotations beyond the fact that it means single room isolation. This demonstrated how with fresh eyes a word can be interpreted so differently. Jessica's mum found it a negative word, which she struggled to move beyond. If she had heard this word when she was in hospital, would it have affected her experience. Why did she not hear the word isolation? Was it not used in her presence or did she just not hear it? Interesting use of linguistics and need exploration with other parents particularly those with no experience of hospital.”

The word isolation was further explored by Rachel's mum, in her role as a doctor she does not understand the specifics of being in isolation and feels that there is a role for greater explanation. Rachel's mum not only rationalised the need for explanation, but she also explained that this impacted upon parents and thereby the child. Imogen's and Nicholas' mums described the need for greater information in terms of rationale for isolation. Similarly, Sophie's mum described a similar situation, for her as she was a nurse and a parent in this situation.

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“Well like she said I think that she knew that she was a risk to others, she was contagious. But it was never really explored with her. I guess that was what I had said to her that made her realise that she couldn’t leave the cubicle. But it was never explained to us the rules for the isolation room, which I found hard as I was going on what I do in my work and that apparently wasn’t entirely the system there.” (Sophie’s mum)

This highlighted that with ambiguity in the “isolation rules”, parents were unsure of what they and their child and themselves were allowed to do in terms of precautions and leaving the room. This demonstrates a significant lack of understanding of the reasons for isolation and therefore an inability for parents and children to prepare for the experience. This ambiguity and confusion caused stress to some of these participants and staff members which in turn affected their ability to cope with isolation.

5.6.2 Parental Presence

The parental presence was noted in five child narratives. This subtheme links with Section 5.4.4, Merging of Nurse/Parental Role and Section 5.5.3 Social Contact. The parental presence can help the child cope with the experience. Additionally, for the parents in this study, it was easier to cope if they were resident with their child throughout the experience.

When asked what he remembers about his time in isolation, James replied simply:

“I remember mummy being there!” (James, 7 years)

This was of sufficient significance that James needed to mention it at the beginning of the interview. Similarly, Imogen and Harriet also described repeatedly the presence of their parents whilst in hospital as a source of social contact and support. This was also true of Simon in the beginning of his admission, but with time, he became more familiar with the environment and he felt that he could cope alone.

“At first, when I was in the hospital mum was there for moral support, then she left and there was a thing where you can call the nurse when you need them. And I said to my mother can I do that and she said don’t do it ‘cause ummm they are busy and you are not the only patient here so I didn’t. They were nice when they came. I mean if they were not busy they came, but if they were busy or someone else needed them you had to be understanding of that. By the end, I was..... I really liked staying alone. But when I was sick I was searching for another.” (Simon, 16 years)

Eloise also commented that she valued her own space in isolation. The need for parental presence was impacted by the age of the child as described by John’s mum:

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“He is old enough now to let me leave the room whereas when he was younger I couldn’t even leave the room to have a break. Yeah that was hard. When he was in and he was three, there was a big difference from him being three and being six like he is now, because he can stay in the room on his own. Three was hard because you can’t leave a toddler.” (John’s mum)

Similarly, Eloise’s mum was active in assisting in her care; describing a partnership in care, however she did not feel that she could not leave.

“I must admit whenever I go into hospital I am happy to help out with anything, the bedmaking, fetching and carrying stuff. I wouldn’t expect the staff to do everything, I think..... based on previous visits, it was nursing on demand, and her care was excellent, yeah, I can’t fault it at all. The staff were always there when you wanted, always checking in on you, which helped me and I didn’t have any concerns about leaving her this time.” (Eloise’s mum)

However, Nicholas’ mum did not want to leave him irrespective of his age, because she needed to be aware of his illness trajectory and witness improvement. Erica’s mum also found that her presence was important to her recovery in terms of learning her medical needs for when she was to be discharged, therefore she felt that she had to be with Erica all the time. Sophie’s mum also felt that she needed to stay however, she felt guilt that she was not at home and described *“splitting herself”* to be in both places to avoid the guilt of leaving her children at home, or Sophie in hospital.

Coping with the time in isolation for all groups is affected by the presence of the parents. This subtheme was heavily linked to the subthemes on merging parental/nurse role and time out. Many of the narratives cross references at this point across the themes, demonstrating that control, coping and community are all interlinked and impacted by the parental presence.

5.6.3 Space

The physical space and environment were described in a number of narratives, in both positive and negative contexts. Simon and Sophie described the isolation room in a positive manner; with the view of the helicopter being a highlight of their experience:

Chapter 5 Findings from Children and Parents

"It was a nice experience. I got to see a helicopter land in close distance and...The room was fine. In hospital if the room is like the child's personal room then it would be too much.. The children are in hospital, so I think the room's appearance was fine." (Simon, 16 years)

"I would say that its small, but there was a window to see a little bit of sky and occasionally the helicopter flew by and landed, which was quite cool." (Sophie, 14 years)

James also described *"HIS room"* in a positive manner, saying that he took lots of things in with him and made it his bedroom for the week. By contrast, Nicholas described the isolation room as *"noisy with people outside"* and Lara felt that the space wasn't that stimulating:

"That's the TV, the best bit of my room. Not much else to do, other than watch tv (camera pans back to mum) and sit around all day." (Lara, 12 years)

The parental narratives varied from negative feelings about the space, to feelings that it was sufficient for its purpose. Eloise's and Erica's mums described not worrying about the environment or facilities as long as their daughters were safe and cared for. Jessica's mum had a similar pragmatic approach:

"The room was absolutely fine, quite spacious, ummm it had a sink and I was able to give her milk and wash things up. It was practical for what you needed it to be definitely. But overall I would say it was a more relaxing environment. More to the point it facilitated rest better." (Jessica's mum)

The rest of the parental narratives described the impact of the negative aspects of the space on their ability to cope with their child being in isolation.

"It felt quite claustrophobic as it was quite small. The advantage is that you've got a bit of privacy, but still the noise because they're only sort of partition walls. It's quite noisy, if it's not your child screaming because they're having blood tests, it's the child next door.....And there is no view is there, you're just looking out on more glass windows. Quite depressing in that respect....The day revolved around your bed, so you eat in your bed, sleep in your bed, draw in your bed, so if you're in a room for a large period of time it's quite nice to be able to get out of your bed and maybe move to a table and sit at a table and draw, or sit at a table and watch something or play something. So, you have to do everything on the bed, and you get sick of being on that bed." (Harriet's mum)

Chapter 5 Findings from Children and Parents

“I think that for us the room was quite normal, for what we expected. Obviously space it really goes back to play, I mean we spend a lot of time on the rugs at home, do you know what I mean I know, I’m just thinking somewhere that you can actually play on the floor.” (Freddie’s dad)

“We were confined to his bed and a chair. I mean to be isolated as a child sucks, I mean you can’t go out of the room so to maybe have a bit to play. When we came out he could hardly walk because he had been laid up for so long he was all wobbly in his legs and it took a good couple of weeks for him to get that back.” (Freddie’s mum)

There was an acceptance that the room was an isolation room and not a bedroom, however there was also a desire amongst the parental narratives to make it as homely as possible.

John’s mum stated that *“it’s not like a bedroom, is it?”* Imogen and Nicholas’ mums were concerned with the décor of the isolation room and the impact that this had on their children as indicated in the following excerpts.

“I don’t know, all the fixtures and fittings are all quite old and sort of dark and we went to BMT hospital and we thought this is quite posh. It’s just bright. The bone marrow unit is all bright blue, umm and then every floor is a different colour…….When we went up to BMT hospital, that was brand, brand new and it was all white with colourful flowers on the wall and I mean, wow! And the difference in our mood, I mean we actually remarked on it. We were coming up here for a bone marrow transplant, this is all a bit serious and we got there and were like, this is lovely! And we were all really chirpy, I do think it makes an absolute difference what it looks like.” (Imogen’s mum)

“The single room itself, well it was good for the privacy, but it was very white and very clinical, nothing really in there apart from the beds and the window and the blinds so it could be made more welcoming in terms of décor……I think that stepping into that space is very clinical. I know that it is a clinical space but I think that it could be made much more homely. When we first stepped into the single room he thought it was good because it was single and he liked it. But then because it didn’t come with all the bits like the other rooms (main ward). I think that maybe younger children like other things going on around them and they like to see other people and the noise and the distractions. Whereas older children prefer the privacy and the solitude. Yeah and he is used to a room on his own at home and he is used to that space.” (Nicholas’ mum)

Interestingly, Rachel’s mum, who is a doctor, made note in her narrative about how this situation has influenced her practice for the future. When children are isolated, normally all their care is conducted in that isolation room, however Rachel’s nurse had removed Rachel from the room for her blood tests to a treatment room so that she did not associate the memories of the blood tests with the isolation room.

Chapter 5 Findings from Children and Parents

“The cannulation nightmare happened, the day before we went home and it took over an hour. But they did take us out of the room, well they asked, whether we wanted to go or stay in the room and I am so glad that I did because something that we think about with children we do their bloods or their cannulas in the room or whether you take them somewhere else and I guess for children in isolation for really specific reasons you would have to do it in the room and I think that it was such a horrible experience that that might have been quite hard afterwards, just being in the same room. It’s definitely something that is talked about, I mean I have definitely talked about it with nurses, oh are we going to do the bloods in their room or are we going to take them somewhere else? Or things? But I have kind of been more lead by what the parents feel or what the nurses feel or whatever errrm, whereas I think now I would probably be more keen to remove them from that environment, because that is where they have got to sleep and you know. I think going through an experience like that in the same place is not much fun.” (Rachel’s mum)

The environment and space of isolation room had an impact on the experience of isolation for some children and parents in this study. The description of being physically isolated within a small room and conducting all your daily activities in the same room as comparative with the literature of prison and seclusion used in mental health facilities (Cochran et al, 2018; Shalev, 2017), which may be reason for the negative connotations associated with the environment. Even the word isolation was highlighted by Jessica’s mum as a negative word. The environment was described as a factor which affects the families’ ability to cope with isolation. However, for others the space was accepted, and they coped regardless of the environment.

5.6.4 Need for “Time Out”

The need for time out of isolation was mentioned in three of the child narratives. For children in isolation, there is not often opportunity to leave the isolation room, due to the infection prevention precautions. However, the desire to leave the isolation room was prevalent in these narratives. Lara was desperate to go to the gym in her video diary; she had been promised that she could go to the gym as part of her physiotherapy, which meant that she could leave her isolation room. However, this did not happen on the day that it was promised, and therefore Lara was miserable in her video diary and her tone of voice was down. The following day, her video diary was positive and upbeat:

“Today I’ve been to the gym. I went on the trainer. I think I did quite well. More than I usually do. My aunty is coming round later. Hopefully that should be fun!” (Lara, 12 years)

Chapter 5 Findings from Children and Parents

Eloise described going to the canteen off the ward as a positive experience, simply because she had left the four walls of her isolation room. For James, when asked what he remembered about isolation he recalled a time when he was isolated but was allowed off the ward, outside as it had been snowing:

“I remember that, when mummy chucked a snowball at me and it landed in my mouth and it turned to water” (James, 7 years)

“And we had no gloves did we? Because we didn’t know it was going to snow. You had your socks on your hands!” (James’ mum)

In his brief narrative, James’ first memory shared was the experience of having time out of isolation. This demonstrated the importance of this memory for him, particularly that this wasn’t in his most recent experience of isolation, but the year before.

Of the parents’ narratives only three mentioned the need for time out. This may be because many of the parents were not restricted to staying in the isolation room all the time, the restrictions only applied in some narratives to the children. Rachel’s mum described this desire to get out, but it was a need when her child was irritable and challenging in her behaviour due to her encephalitis. John’s mum simply stated that by getting out of isolation in the day between IV medications, it made the experience of isolation bearable for John, and thereby better for herself. Freddie’s parents described the desire to get out of the isolation room conflicting with the need to be with their child:

“You pop off the ward you are anxious to get back because you are aware that no one is looking after your son and you are like come on come on, come on, open the door for me and you are like hello it is Freddie’s mum again, can you let me in.” (Freddie’s mum)

This desire to get back onto the ward highlighted the guilt on leaving their child, however the need to have some space for a short while. The need for time out is clearly highlighted through all data sources in this section, it also described some of the challenges of allowing time away from the ward. The need for time out for both the child and the parent will affect the child’s experience of isolation, and as this subtheme demonstrates the control of this is often removed from the family when in isolation, which will ultimately affect the child’s experience of isolation.

Chapter 5 Findings from Children and Parents

Coping transcend the subthemes of understanding of isolation, parental presence and space. The theme of coping presents findings which are suggestive of the literature associated with family centred care. For the parents, their experience of isolation may be mirrored onto the child, which illustrates the need for providing care that involves children and their parents within their social construct. The experience of the child is influenced by their age, development and the experience of the parent. Thus staff may need to consider the experience of the family as a unit whilst in isolation in particular, as there are limited sources of other social contact.

5.7 Summary of the Child and Parent Findings

The findings demonstrated that there are a number of overlaps between the perceptions of the experience for the children and parents. However, there are other examples presented in this chapter which demonstrate conflicting findings between the child participants, which may be due to their reasons for isolation, acute or chronic illness and experience of hospitalisation. There are also divergent findings within the child and parent dyads. These findings will be discussed within the context of the staff findings in Section 6.7 and form the basis of the discussion presented in Chapter Seven.

Within the theme of control, the majority of child responses that were represented were in the “need for time out”, whereas the “merging of nursing and parental role” was mentioned the most within the adult responses within this theme. The findings suggested that their experience of isolation was influenced by the control of the environment and whether the family had any previous experience of hospital and more specifically isolation. Another factor was whether their admission to isolation was part of an ongoing health need or an acute admission, as this made a difference to the need for control for the parents and their familiarity to the ward, the staff and the informal rules of the ward environment. The findings in this chapter are suggestive that children and parents who were familiar with the hospital construct as part of their long term condition appeared to have a greater need to control the environment and the situation of isolation, specifically when there was a change from their “norm” i.e. they were moved wards and had to become familiar with another set of people and routine.

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Merging of parental and nursing role was not mentioned by any child in this study and this may have been because children need and expect their parent to be with them in hospital, which is reflective of the contemporary paediatric healthcare within UK. The level of expectation of the parent whilst in hospital was an issue that parents raised. The level of involvement of parents in the child's care was possibly linked to the child's developmental age and their expectation of family centred care.

Community was a theme that was represented within the children's findings specifically with regards to missing out and social isolation. The younger children felt that they were missing out on activities within the hospital ward. Yet the older children were more distressed with missing social activities at home and with their wider social construct, which again links to their developmental level. The parents did not describe missing out or social isolation. Although the parents were in isolation too, they were not always subjected to the same isolation precautions and therefore did not live the same experience of isolation as the child in terms of social isolation and sensory deprivation, and therefore described different perceptions of the experience of isolation. This highlights one of the limitations of using a proxy perspective, as they will not have entirely the same experience as the child, or perceive it in the same way. It also reinforces my initial thoughts presented in Chapter 1; the importance of including the child's voice in research is essential that care is based on their needs.

The impact of separation from their community or social context may have been dependent upon the participants' age, development and on whom they were reliant on support. For example, the findings suggest that the older children missed the social interaction with their peers and did not need the support from their parents as much. This was divergent to the younger children who were more reliant on their parents for their care needs and socialisation. This reflects their developmental level and that different people are on a continuum of the need for time alone and time with others during their illness trajectory, which was reflected in both the child and parent data within this study. The findings are divergent in terms of the need for community between the parents of children with acute vs chronic health care needs. The community that the child and the parent make, whether that be the community outside of the hospital, often for the more acute patients, or the community within the hospital (which may include staff) for the patients that are more

Chapter 5 Findings from Children and Parents

familiar with the hospital, it has an impact upon their isolation experience if they are separated from this community.

Coping was the final theme within the child and parent findings. Understanding of isolation aided the ability to cope with being in isolation, as described predominantly by the parents in this study. The older children and the children with repeated isolation experiences as a consequence of a chronic health need all understood the reason for isolation, therefore they could either prepare for isolation with sources of distraction, or had learned to accept that they would spend their hospitalisation period in isolation. For the parents of the acute admissions there was limited mention of the understanding of isolation and when questioned about it, Jessica's mum drew particular attention to the word isolation – describing it as having negative connotations. By contrast none of the other parents mentioned the word isolation as a negative word, but maybe this may have been as a consequence of their exposure to hospitals as two of the acute patient's parents were healthcare professionals. Parental presence was mentioned in all but one of the children's interviews as a means of comfort and helping to cope with the experience, in accordance with their developmental needs, need for social support and social contact external to the hospital through their phones and the internet. The physical space of the isolation room was described by the children in a positive manner, but predominantly a negative manner by the parents, varying from sufficient for their needs to impacting upon their negativity, despite desiring the single room for privacy.

5.8 Chapter Summary

Chapter Five has presented three key themes associated with the child's experience of single room isolation: control, community and coping. The child's voice has remained central throughout these findings, and the parental sources have been used to supplement the findings and provide dependability through triangulation in the overall narrative of the child's experience of single room isolation. There are divergent findings throughout the themes according to developmental age, reason for isolation and sources of social support from parents or wider sources such as friends at school. These findings will be reviewed within the context of the staff literature in Section 6.7 in Chapter Six and discussed in Chapter Seven within the context of the wider literature and theory.

Chapter 6 Findings from the Staff

6.1 Introduction

This chapter serves to present the findings from the staff. Within the staff there is a wealth of experience, in addition to some fresh eyes to the experience of isolation, this means that more than ever the narratives had to be considered within the context of the individual's social construct. The first part of this chapter is dedicated to introducing the staff that participated in this study. The overall themes are discussed in the same order as the previous chapter to be able to facilitate some comparison. The first theme that will be discussed is control, more specifically for the staff, how they managed parents who wanted to exert their control and the impact for the child in isolation in these circumstances. The second theme presented is the concept of community, in which the staff had emotional responses such as guilt in not being able to spend the same level of time with children in isolation due to the physical restrictions of the isolation room. The final theme that is discussed in this chapter is coping and how the staff describe the coping mechanisms for different families, including preparation for isolation and needing time out. The chapter will culminate with a summary of the findings and a presentation of the metanarrative for this study.

Within this chapter, the abbreviations as presented in Table 6.1, will be used to denote the job role; Nurse (N), healthcare support worker (HCSW), play specialist (PS), Doctor (D) and physiotherapist (PT).

6.2 The Participants – Staff

The staff presented another level of data to the findings, looking at the child's experience from an alternative perspective. Their narrative was often presented as multiple stories, within a narrative that were underpinned by their understanding and experience of caring for children in isolation. In order to understand their findings in context Table 6.1 below presents some key personal data about the healthcare professionals.

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Table 6.1 The Staff

Profession and Number	Professional Experience	Previous Personal Hospital Experience in Isolation
Nurse 1 (N1)	Newly qualified within past 2 months, therefore focusing mainly on experience as a student. Student placements throughout the paediatric wards, not in other hospitals. Current speciality surgical ward.	None
Nurse 2 (N2)	Newly qualified within past 2 months, therefore focusing mainly on experience as a student. Student placements in two other hospitals and on the wards in this hospital. Current speciality Paediatric Intensive Care (PICU).	None
Nurse 3 (N3)	Newly qualified within past 2 months, therefore focusing mainly on experience as a student. Student placements in one other hospital and on multiple wards in this hospital. Current speciality PICU.	Son isolated in source isolation after acquiring respiratory syncytial virus post operatively following cardiac surgery
Nurse 4 (N4)	Band 6 nurse. Qualified 1990. Previous experience working in a hospice and a general paediatrics in another hospital. Current speciality renal ward.	None
Nurse 5 (N5)	Band 7 nurse. Qualified 1982. Previous experience working in general paediatrics and oncology. Current speciality oncology.	Previous experience of hospitalisation in a side room, but not subject to isolation precautions
Nurse 6 (N6)	Nurse specialist. Qualified 1988. Previous experience in one other hospital. Worked in this hospital for a number of years in different roles. Current speciality: Respiratory.	None
Nurse 7 (N7)	Band 5 nurse. Qualified in 2009, and has worked in neonatal unit, emergency department and general medical ward, between two hospitals. Current speciality medical ward.	None

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Nurse 8 (N8)	Band 5 nurse. Qualified in 2007, and worked on a general paediatric ward in a district general hospital, prior to moving to this hospital. Current speciality medical ward.	Isolated as a child aged 13 years for 2 days.
Nurse 9 (N9)	Band 5 Nurse. Qualified 2011 and has worked on a general medical ward, an orthopaedic ward and a PICU in three different hospitals. Current speciality: oncology.	N9's Mum was in protective isolation for short periods during treatment for non-Hodgkin's lymphoma
Nurse 10 (N10)	Band 7 Nurse. Qualified in 1992 and has worked in general medical and renal wards in the UK and Australia. Current speciality renal ward.	None
Nurse 11 (N11)	Band 5 nurse. Qualified in 2008 and has worked in PICU and renal ward. Current speciality: renal ward.	None
Nurse 12 (N12)	Band 5 nurse. Qualified in 2004 and has always worked on the cardiac ward.	None
Healthcare support worker 1 (HCSW1)	Worked as a healthcare support worker for past 4 years. Experience of one other hospital as part of her nursing training. Current speciality medical ward.	None
Play specialist 1 (PS1)	Play specialist. Qualified in 2004 and has worked in nuclear medicine. Current speciality medical ward.	None
Play specialist 2 (PS2)	Play specialist. Qualified in 2008 and has always worked on surgical ward. Prior to becoming a play specialist she was a healthcare support worker on the surgical ward.	None
Play specialist 3 (PS3)	Play specialist. Qualified in 2006 and worked in a district general hospital for 7 years. Current speciality covers orthopaedics and the rest of the children's unit when needed.	None
Physiotherapist 1 (PT1)	Band 6 physiotherapist. Qualified in 2006 and has worked in paediatrics for 5 years, initially in another hospital.	Grandmother was in isolation for a short period
Doctor 1 (D1)	Registrar, qualified for 7 years. Previous experience in three other hospitals and multiple wards in this hospital.	None
Doctor 2 (D2)	Consultant. Qualified in 1999 and has worked throughout paediatrics. Current speciality paediatric infectious diseases and immunology.	None

Chapter 6 Findings from the Staff

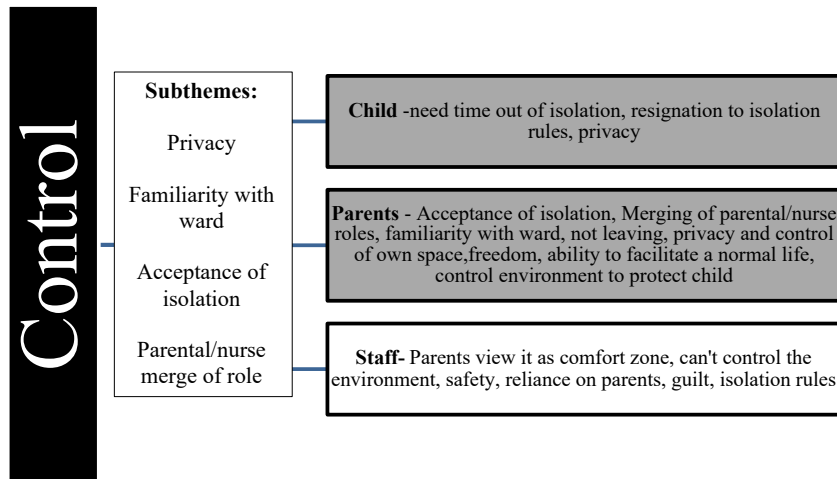
Doctor 3 (D3)	SHO. Qualified in 2010 and has worked in PICU and children's surgical and nephrology wards. Current speciality general paediatrics.	None
Doctor 4 (D4)	Registrar. Qualified in 2003 and has worked throughout the region on paediatric wards. Current speciality emergency paediatrics.	None

As with the parental narratives, some of the participants within the staff had personal experience of isolation as highlighted in Table 6.1, through family or themselves which had to be considered in the analysis. These experiences will have influenced how they understood the experience of isolation and how they presented that narrative to me as the researcher. Although they may have not been in isolation themselves, they had all worked with a number of families who had experienced isolation and were able to share this broader perspective of families' experiences in isolation. Furthermore, there were a number of issues highlighted among the narratives from interactions with families that have thereby implicated upon the healthcare professionals' own clinical practice. The participants were recruited for their professional experience and subsequently, it was found out that some had personal experience of isolation. This is considered a strength of the study as it highlighted the benefits of narrative research as the professionals' back story and experience of personal isolation impacted upon the care that they provided, and the subsequent experience for the patient.

6.3 Control

Control was described throughout most of the staff narratives in different manners; for some they focused on their inability to provide control over the isolation environment and the guilt that this left them with, for others it focused on the challenges pertaining to nursing someone in isolation and not understanding the infection prevention rules, leaving them feeling out of control. These themes will be discussed in the following order: privacy, familiarity with the ward, resignation to isolation, need for time out, merging parental and nurse roles. The theme and sub themes are presented in Figure 6.1 below.

Figure 6.1 Control



6.3.1 Privacy

The majority of the staff mentioned the word privacy in their narratives; some in a positive manner “*their bit of the ward*” (N1) and others in a negative manner suggesting that although the children had privacy they were “*shut away*” (PS3). Additionally, N4, said that the privacy of isolation meant that the children “*were stuck with one parent in a tiny room*”. However, for eleven staff participants, isolation was described as a place where the family maintained their own routine and control of their space, in congruence with the parental descriptions in this section. N5 described a varying need for privacy at different times in children’s illness trajectory, from cancer diagnosis to later treatment.

“In the beginning, when they are first diagnosed I try to give them their own room. It is such a rubbish time I think that they need some time out as a family, not to be with others. I try to let them have this room as long as they need it.” (N5)

“It (isolation) is just the privacy during a very intense time in their lives, if they want to sit there and cry their eyes out they can... a curtain around the bed doesn’t hide anything does it?” (N9)

Both of these quotes described the use of an isolation room, not for infection prevention but to facilitate the privacy that a family required at a challenging time. Similarly, PS3 described the beginning of an illness journey when you are feeling most unwell, as the time when isolation was most tolerated as the patients just wanted to be on their own.

Chapter 6 Findings from the Staff

“As children get better and they are aware of what they are missing on the ward, they no longer want that privacy.” (PS3)

Interestingly, D2 stated that although isolation afforded a little bit more privacy, it did not allow a lot of privacy. Similarly, N6 stated that *“isolation rooms can be like goldfish bowls rather than a private space as patients and staff walk down the corridor peering in to see what is going on.”* This highlighted that although there was a private space for the child, there was not always privacy afforded to that space. By contrast, PS2 recalled a patient who had been placed in isolation and became very introverted during this time. He was a sociable person on the main ward, but in isolation he became very down and insular. PS2 described him *“shutting the world out”* and *“constantly having the curtains closed”*. This demonstrates the manner in which the child and family took the control of their privacy upon themselves. However, within the hospital environment, the nurses need to monitor that child and therefore having all the curtain shut is not always possible, causing the debate on who has control over that environment and subsequent privacy within that environment. This questions whether practitioners are demonstrating a paternalistic attitude or conscious of safety. If the curtains are closed there may be a greater reliance upon the parents to provide care as the nurse will not be visually aware of when the child needs assistance as they would be on a main ward. This concept was echoed in Imogen’s mum’s narrative, where she would accept the privacy but felt that she took on more of the caring role as a compromise. This need for privacy therefore links with the merging of the parental/nursing role in Section 5.4.4.

The concept of privacy is explored by N7, who introduced the concept of isolation challenging staff as Eloise’s mum described:

“It’s a constant balancing act.... Allowing them privacy but needing to observe them, what happens if something happens and you can’t see them? But I understand why they want the curtains shut... it’s a tricky one.” (N7)

Throughout the child, parental and staff data the theme of privacy was described by the participants, often in the context of controlling the environment. Privacy links to the theme of control of isolation, as there was a difference in perception for some participants over

Chapter 6 Findings from the Staff

who controlled the privacy of the room based on the needs of the family from the staff, and the need of the staff to review the patients (Bricher, 1999). This also links to the relationship between the staff, patients and their families and the need for negotiation of care roles, which would remove the challenge of who controlled the privacy of that environment.

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6.3.2 Familiarity with the Ward

In the staff data, familiarity with the ward was mentioned in five narratives. In an excerpt from N4 below, she described that there are a number of long term children who were familiar with the ward and then when put into isolation, even on the same ward, they disliked it.

"Some of the kids really dislike it because they.... Especially our chronic kids what are so used to having, you know, the reign of the whole ward, being able to walk around and say "Hi" to everybody, being sociable, you know, popping off and into the staff room. They are used to being sociable and come and go as they please to the play room so yeah, it's kind of That's really hard on them when they're in isolation." (N4)

This excerpt described the restriction enforced upon children in isolation, where the child has no control on that situation of their environment, compared with the freedom that they have when simply hospitalised. This excerpt also referred to the fact that although the children are familiar with the ward environment, the experience of isolation on that same ward completely alters the child's experience of being in hospital.

N7, N9 and N11 referred to the concept of familiarity with one ward and the fact that families often reported a negative experience of isolation away from their main ward.

"They hate being moved away from our ward.... We have had three children in the past year that have got MMF [Mycophenolate mofetil] colitis, who have got D&V so we have got to isolate them. And then they may be nursed on a different ward, and if there are no cubicles on our ward they have to go elsewhere around the wards which obviously heightens the mood, and there are bad vibes about the other wards." (N11)

This excerpt from N11's narrative aligns with Imogen's mum which described the perceived suboptimal care on a ward with which they were not familiar. This subtheme

Chapter 6 Findings from the Staff

highlighted how staff were aware of the parental perspective that was presented in Section 5.4.2. This is subtheme with which resonated with me and I was able to empathise that formed a part of my reflective diary, as described in Figure 6.2.

Figure 6.2 Excerpt from Reflective Diary

Following an interview with N11:

“The notion that children and families like to stay on one ward was presented in this interview. This is something that I have witnessed in clinical practice -the challenge in particular for parents to transfer to a new ward and learning to trust a whole new set of people. I can think of many children who were keen to move forward to a ward as there were different facilities, yet the parents have always got reservations as they develop trust in one team and then they are resistant to wanting to move to another ward and develop these relationships again. Familiarity breeds confidence in the capabilities of the ward.... I understand how these staff members feel.”

This subtheme described the need for control of the environment and often that control is not possible when the family are not familiar with the ward or hospital, thus the staff are required to dictate or lead care, which is further discussed in Chapter Seven within the theories of control.

6.3.3 Acceptance of Isolation

D2, D4 and PT1 all stated in their interviews that acceptance of isolation only occurred when there is sufficient understanding from the family for the reason for isolation.

“I think that they are quite used to having quite isolated lives, they don't want unprotected people milling about, so they don't get a lot of social exposure and often their child is so sick that they have got other things to worry about, rather than worrying about them being antisocial or being... and they don't feel as though they are being labelled as their child having an infection because often their child doesn't have an infection because they are in protective isolation.”(D2)

D2 described the difference between source and protective isolation, within the paediatric wards in this study, but also through his wider knowledge of working in other hospitals during his training.

“The group that are more complicated are the ones who have, who are in source isolation and they are a far more difficult group because these are children who are put in a cubicle because we are worried that their infection may spread to other people. And how we approach those families is really important because not only do we want the child to be in a cubicle but often we don't want the parent to be milling about here, there and everywhere, we want them to be cleaning their hands before they come out of the cubicle, for fear of infection spreading. I think that those are the parents who sometimes resent

Chapter 6 Findings from the Staff

being in a cubicle, because they are being ostracised, treated like lepers, they are being treated differently. Luckily, they are often, sometimes they are in isolation for relatively short periods, so that kind of resentment about being in a cubicle is relatively short lived.” (D2)

These excerpts not only demonstrated that informing the family helped them adhere to isolation precautions, but also suggested that protective isolation and source isolation received a different response. This was evident in Imogen’s mum’s interview, where she referred to protective isolation (post BMT) in a positive manner, but referred to the cubicle when in source isolation as *“the air of the diseased”* (Section 5.5.2).

“I’m, I think that it varies from child to child. Obviously, children are going to be different. Some are quite introverted so actually they quite like the quiet and they like the fact that they are not being bothered as much, they like the fact that they are left to it. Some are obviously quite extroverted and trying to keep them in their cubicle is like (sighs) ... a massive challenge.” (N4)

N4 and N9 alluded to the fact that personality was not the only cause of how children perceived isolation, it was also related to how well they felt at that time. For example as Simon described, when he was admitted and feeling at his most unwell, isolation was ideal as he could shut himself away. Despite this, N5 described families who wanted their own space, argued with staff to go into isolation, but wanted staff to pop in more frequently to see them. N5 described that the negative reactions came when you moved patients from isolation to the main ward, because they no longer needed the isolation, or on risk assessment there were other patients with a greater need for the single room. D4 extended the debate, saying that although children were prepared for isolation, they could still challenge the decision of entering isolation, particularly if they were bored or missing social interaction.

“For example I worked on a general medical ward here and there were often the CF children that came in and out a few times a year. They are the tricky ones, because they know what to expect, so for some the parents are super organised and bring in everything for them and make it a positive experience and the parent who stays with them distracts them and continues their home routine, but ummm... for others, for example a boy that was on the ward became a nuisance to the nurses because he would often come out of his room and try to sit at the nurses desk, go in the play room, go anywhere really where the other children were. He became quite naughty with it, so the nursing staff asked us to reinforce what they were saying by trying to get him to stay in his room. But he wouldn’t... I think that he just got bored and wanted company, ummm.... I think because he came from a big family and so was used to being around lots of people he found the single room a challenge.” (N4)

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This excerpt from N4 demonstrated that not only personality but also parental presence and distraction played a part in the ability to resign to isolation. Preparation, in addition to information giving improved compliance with isolation. Furthermore, as highlighted in this section, isolation is suited to certain personalities.

Four of the participants knew that they would need isolation on admission to hospital which meant that their reaction in their stories about going into isolation was tempered with expectation from previous episodes, or knowledge of isolation. Interestingly, the other children made no comment on the feelings associated with going into isolation, and only two parents (Nicholas' mum and Erica's mum) described the process of going into isolation.

N6, N11 and PT1 felt that long term patients were “*resigned to their fate of isolation*” which aligned with the narrative of James' and John's mums. Two of the staff (N6 and PS1) alluded to the notion of mirroring behaviour, where if the parent responds to isolation in a positive or negative manner, then the child mirrors that behaviour. This fed into the work of family centred care and involving the parents in the explanations and decisions surrounding care as this impacted upon the child's experience significantly.

“The kids are aware of why they need isolation and why it is happening but I think it is one of those things when you are a kid, somebody tells you but it doesn't mean that much. It does depends on how paranoid the parents are too, because some parents are very, very paranoid about their kids meeting other CF children and mixing whereas other parents are a little bit more relaxed about the whole thing, which shows in the kids.” (N6)

Similar to the experience of children with CF, N10 suggested that explanation creates acceptance amongst children and parents as to why they were in isolation, as Simon described. N10 worked on a renal ward where there were a number of children that had long term conditions and had a good understanding of their condition irrespective of age. N10 described that regular explanation and answering of questions to both parents and the child allowed the patient to adapt to their environment and the rules to which they were subjected as a result of isolation. PS1, N9 and N12 parallel this by stating that children had a positive reaction to isolation when compared with the main ward. However it was noted by these same participants that children did not like the rules that they were subjected to in isolation and until they were fully explained, they did not adapt well to them.

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“I would say that the children and older ones like to be away from the screaming little ones, and they like the fact that they can have their own schedule, but I think that they dislike not being able to go to the kitchen or teenage room when they want to. Yeah I guess they dislike the removal of the independence that they would ordinarily have when they are on the ward.”. (N10)

N12, and PS1 suggested that being in isolation, and knowing that it was only a temporary position improved adaptability to isolation. N8 stated that information giving and promoting the parents’ choice can aid their resignation to isolation.

This highlighted the points made above, that initially isolation was very appealing to many children and parents, because they had their own space, but as they understood the implications of being in isolation and the restrictions that it involved, the patients moved to resent isolation through boredom as described in the theme. N12, and PS1 suggested that being in isolation, and knowing that it was only a temporary position improved adaptability to isolation.

Acceptance of isolation seemed to depend on where the family started the journey of isolation, whether they were freshly admitted to hospital or whether they had been in isolation before and therefore they had preconceptions from the ward that they were familiar with and this affected their response to isolation. The mirroring behaviour between parents and children started on admission to isolation therefore, it was important to establish a positive mirror model for the children to mimic. Acceptance of isolation is affected entirely by the families’ ability to relinquish control or desire to regain control of the situation as described in this subtheme.

6.3.4 Merging of Parental/Nurse Role

Staff display varying perspectives in their narratives; some suggested that the parents should be leading on care and that empowering them was necessary, others feeling guilty that they could not assist the families more due to the pressures of the ward. None of the staff narratives described the parents as “leaving their child” or that the parents should be resident more often, which was presented in the parental data, where they felt guilty for leaving their child. N5, N10, N11 and D2 all described the need to empower parents so that they can advocate for their child; shifting the nursing/parental boundary but empowering parents in the process.

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“The parent is the ultimate advocate for their child, and we as staff need to not be arrogant and we need to listen to parents..... We want more parents to be empowered..... I think that parents find it difficult constantly justifying to staff why they have to be obsessive with their child and I think that it does impact upon their relationship with one another, with staff members.” (D2)

This statement not only identified the challenge for staff, that parents are challenging their practice, through their own empowerment, but highlighted the difficulties that this can cause in the relationship between staff and families, potentially based on a lack of knowledge of the correct isolation precautions, and the parental need to control the situation. It is the family’s strength to challenge practice, that made staff feel more vulnerable, particularly junior staff.

By contrast, N2 described relying on parents to observe their child when they were in an isolation room from a safety point of view.

“It impossible to observe them all the time when you may be in another cubicle, so you’re reliant on your colleagues and when you are doing something with one patient, you have no idea where your colleagues are. That’s when the parents are essential and we HAVE to rely on them to tell us if there are concerns.” (N2)

Similarly, N3 who had also been in isolation with her son reflected upon this, considering both the staff and parental perspective.

“It would be quite nice, if you had more staff or a better patient ratio, to take time to spend with patients and their families. I mean I’ve been in a cubicle myself, with my own child and nobody spoke to me most of the day and you just think it is so tediously boring you just want someone to come and, obviously you want a grown-up conversation. I think that because nurses generally tend to go in and go out and especially if they have got a sicker patient they’re rushed to their like “argghhh”, go in do my obs and get out.” (N3)

The reliance on colleagues and level of pressure to observe all children is described in the narratives of N9 and HCSW1. Similarly, N8 described the shame of not being able to spend time with families in isolation and the safety of this:

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“I think sometimes, like some children have felt, some parents have certainly felt very almost, its more unsafe in isolation, because they feel like the door has to be shut for infection reasons and then we are not hearing the monitors and we are not caring for, because we have to glove and gown to go in and out, sometimes if you are just doing something quick we will pass it in the door or if they want something rather than go in and they feel like they are not having as much contact because you are not actually going in there as often as you probably can, or as often as they would probably like you to. So you can get a reaction and sometimes the children feel that if the parents can't stay with them and they are young themselves, they feel a bit bored and a bit isolated and the nurses don't have the time to sit in with them” (N8)

D4 described the parental role as:

“I think that parents are key on any children's ward and as their doctors we rely upon them to report to us, they are our eyes and ears and they can amuse the children when there are not staff to do that. So, their role is vital to us providing care. I have looked after some children whose parents have not been resident for various reasons and their compliance to treatment has sometimes been hindered by not having a parent there.” (D4)

The reliance on parents to aid in providing care is also [explored by](#) N4, N10, D1 and PT1 | and the need to offer them a break from the intensity of isolation is described in the narratives of HCSW1, PS1, PS3.

This subtheme described some of the challenges for the staff, but also how the physical barrier of isolation impeded the relationship between the healthcare professionals and the family. This may account for the discrepancies in the narratives over who was in control of the situation when a child was in isolation, which impacted upon the role of the nurse and parent; which in turn impacted upon the child's experience.

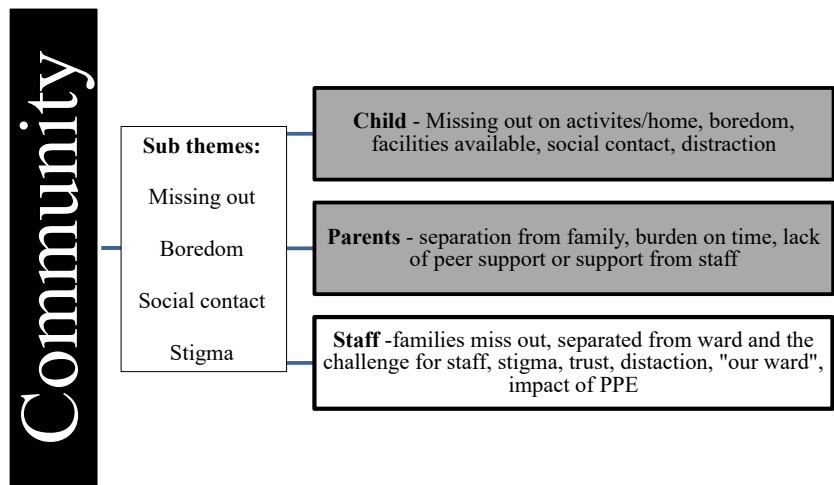
Control transcends the subthemes of privacy, familiarity with the ward, acceptance of isolation and merging of parental/nurse role, and demonstrates some alignment to the parental and children's data presented in Chapter Five. These findings describe the negotiation of care and control of the time in isolation, in alignment with family centred care, which will be discussed in Chapter Seven.

6.4 Community

Community was a key theme that was demonstrated throughout the staff literature.

Community is subdivided into the following subthemes as demonstrated in Figure 6.3.

Figure 6.3 Community



6.4.1 Missing out

The staff narratives mentioned episodes of missing out on activity on the ward. There was a tone of the families missing out on life at home, but also specifically on activities on the ward throughout a number of the staff narratives.

“They don’t like it when they first go into isolation because they know that the play room is there, they know that the facilities are available to them, but some of them they can’t access them. I have to say the parents like being in isolation because they have their own bed and their own space and they don’t have to share the facilities with the other parents as they do in the bay.” (N5)

“When children are isolated in their rooms, on the ward there is now a giant play mat, there is toys galore, there is often magicians out there, it looks amazingly fun and you are stuck in the room. You know as a five year old it like, it must be like torture to them.” (PT1)

The experience of isolation did not simply exclude the children from activities and the toys, but also interaction with other people as described in the following excerpts.

“I think that the children just find it strange because they are confined to a bed, confined to a room. But they don’t need that whole play therapy side of things because there is no

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need for the older children, they do get quite low and quite depressed and they know what's outside and so they know what they are missing out on. We take round a lot of, we take round visitors obviously to different wards and to different environments quite frequently, and I know that a lot of the isolated patients, especially if they are long term are sad about those visitors; they can only wave from the window but they can't actually go in, like the PAT dog or the clown doctors or you know at Easter, when we have visitors, you know they always get a present if they are giving presents around but they don't physically get that contact. I know that can get quite wearing." (PS1)

"I think probably actually the clowns that come round and the people like the entertainers and the hospital dogs and I don't think they go in if you are in isolation either. And therefore that's another thing that you miss out on, but you can probably see. It's the worst thing for the kids" (D3)

Missing out, as described by the children, parents and staff demonstrated the separation from the community of the ward and the implications that this had for the children. There was a notion, certainly from the parents and staff that if the children were unaware of what was available on the ward, it may have been easier to manage the child's feelings. However when they were able to see the activities happening from their isolation room, it was challenging for the child and parent to understand why they couldn't participate and for the staff to explain this to the family. Linguistically, there are some powerful words utilised in this section: "torture", "worst thing" and "it's hell for the family". This demonstrated the emotion behind these narratives and how significant these episodes were in their hospital journey. Missing out on the ward community resulted in the participants feeling separated.

6.4.2 Boredom

Boredom, although more heavily featured in the parent and child data, than the staff, it was a key feature in terms of the need for distraction. N11 described a story of a parent who used to watch the car park for something to do.

"I had one parent admit that her entertainment was watching the staff (laughs) or the carpark, she was like... you wouldn't believe it, this car just tried to ram this one, this car tried to ram that one. And she used to spend her day commenting on the staff car park. She was like I can't go out, I can't do this, I can't do that. I got an update every single time I went in, it was quite comical, but that was what she did to keep herself entertained because all they had got in there is DVDs and a TV." (N11)

The majority of the staff commented on children's boredom and the need for distraction whilst they were separated from the ward by isolation; some offering narratives about

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patients, and some offering ways in which they manage the boredom for the patients and their families.

“It is the children that are just like bored. Umm can’t be entertained or won’t be entertained and it’s usually our job, it’s not as if you can take them out or stuff or you can’t take them to the play room and socialise them with other children ummm... so they will get a lot more frustrated in isolation. And there is kind of a limit, we will take art and crafts stuff in, the play therapist will go in, she is amazing with them, absolutely amazing, but then again that will entertain them for that period but then she does half 7 till 3, 5 days. But again, you know we won’t necessarily have enough time to go in and sit there and do stuff with them, which is a shame. But you know you have got other patients or you simply can’t do that and it’s ok if you have got a student on because you can be like “do you want to go in and entertain them for like an hour or so?” and they will love it. Or an HCA if you have got that, but then again our HCAs are often needed to take patients or do the dinners or make sure that we are ok or do the obs or stuff like that so, so it’s not even as though they are free half of the time to sit and entertain.” (N4)

Similarly N1, N2, N3, N5, N7, N12, PT1, PS3, D1 and HCSW1 described the need to keep the children entertained in isolation to avoid boredom and the burden that this applied to families to provide entertainment in isolation. HCSW1 described the need to maintain a normal routine to avoid boredom for patients in isolation:

“It is one of the biggest things to recovery is keeping in contact with, people and normalising yourself- doing normal activities that you would do, not in hospital. Yeah and being in touch with your friends and family, and doing normal things to keep you going and thinking that you are not in hospital, let alone in isolation” (HCSW1)

N7 provided a narrative of a particular experience [describing](#) one child who was very bored and became emotionally down in isolation, and by moving from isolation when it was possible, his experience of hospital altered significantly. This demonstrated the impact that isolation from a wider community has, in terms of interaction and the need to compare this environment to their home social context.

“A while ago we had a 16 year old Crohns boy, long term, not eating, food-phobia with diarrhoea and he was in a cubicle for an infectious but because being 16, actually he just got thoroughly bored and actually there is only so much that you can do, there is only so many DVDs that you can watch and the best thing with him, the thing that actually made him start recovering, is when we had to move him out because he was no longer infectious, into the bay and he was there helping to look after all the babies. He actually enjoyed himself. So although he was 16 he was actually, he had a lot of siblings at home so he was actually quite used to that sort of thing and he actually kind of bonded with some of the long term children that we had in the bay.....Almost in the bay you can get a sort of like community feel, I would say, where if one child is crying, someone will try and help.

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Obviously they know and they don't go round trying to pick up each other's children and stuff like that. But they will go and try and talk and you know and give them a bit of kind of, you know, comfort". (N7)

In this excerpt above the nurse compares the experience of being in the main bay and nearer to the child's home environment where he was surrounded by his siblings. This is suggestive of needing familiarity and the desire to feel occupied to alleviate the boredom of being alone.

N12 described a cardiac patient who experienced this also:

"It must have been incredibly lonely for him (in isolation) and we saw him just get more and more introverted and I don't know whether that was isolation, his knowledge of his illness and the MRSA bacteraemia or because of the continual animosity with his parents... it's impossible to say but I do think that if he were in a bay it would have been a distraction for him and there would have been other people to talk to. I mean I can think of a lot of parents who have become like that in isolation; upset and stressed and then get more and more quiet and withdrawn but he was the first kid I have seen like that... he was really mature for his age, so I'm not sure all teenagers would be like that... but it was hard to watch, you really couldn't lift him easily." (N12)

The play specialists included in this study, HCSW1, N1, N4, N5 and N12 referred to manners in which they tried to alleviate boredom with distraction. The play specialists and N4 mentioned the use of play boxes as N1 explained:

"We have got isolation boxes with different groups of toys, to keep them amused. So obviously anything that goes in has to be wipeable or has to be throw-away able or take-home able, whichever way it is. Depending on the length of stay of the child, if it is a child that has just come in, we may not be aware of what the bug is, umm, I don't necessarily do a play plan, but if they are going to be in long term then I would set up a play programme. Something as simple as... so that they have someone different going in, they have school depending, if they are isolated the school will go in and do sessions with them" (N1)

As a nurse I could completely empathise with this role and remembered a time when I cared for a child in isolation as a consequence of a long admission with pseudomonas and CF, described in Figure 6.4.

Figure 6.4 Excerpt from Reflective Diary

“When I worked in a local district general hospital I cared for an 11 year old child with cystic fibrosis. He was the eldest of 4 children and consequently his mum was not present on the ward often. His mum was a single mum and he had no contact with his dad. During my 18 months working there he was admitted 3 times, so he was familiar with the ward and the staff. He really struggled with isolation, literally hanging onto his door and waiting for people to pass to talk to him. He didn't have a phone with him or a computer so he was reliant on the TV or the staff for entertainment. He was hard work, we didn't have time to spend with him. He would come out to the desk and sit there, even though he knew he had to be in his room. He was just bored there was nothing for him to do and no one to chat to. He got very disruptive to other patients and it took up our time a lot. But all I could think was what a miserable experience to be alone, and restricted to a single room.”

This section demonstrated the affect that the play therapists can have in terms of distraction, in addition to the other [health care](#) professionals, when time allowed for pastoral care. It also links to the role of the parents in providing some community when they are separated from the ward community. The next section highlights the impact of social media in improving social contact when the physical presence of people is not possible, which is another medium in relieving boredom and providing community to those in isolation.

6.4.3 Social Contact

The staff described both the families' need to isolate themselves and their need for social contact in their narratives, and this was often dependent upon where they were in their illness trajectory and to what degree they were familiar with the ward or hospital. N1 explained that the isolation room was “*their own bubble*” and N5 said that dependent upon the family, a lot of them wanted time alone as a family. N5 expanded this specifically to the oncology ward.

“On diagnosis and in the beginning, I think that the teenagers, they do make friends with other people with cancer and they do realise that it is quite sad because some die. But they are not aware of that when they first get here. When they first get here all they want is someone, someone else who is going through the same thing as them. By the end a lot of the older ones, just want to keep themselves to themselves.... probably for their own emotional protection” (N5)

Contrastingly, N4, N6, N7, N8, N9, N10, N11, N12, HCSW1 and D1 described the socially isolating nature of single room isolation for the child and the parents, and the

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separation from the wider ward community. PS3 suggested that isolation can challenge family relationships as it was abnormal to spend that much time with one family member. Some of the staff explored in their narrative, the use of social media instead of physical presence of a person as a substitute, which improved the experience of isolation.

“Everyone is so much on the internet these days and like it is bad enough being taken out of school for two weeks and being put into an isolation room to have your IV antibiotics but then to have no contact with your friends. It is not text and phones these days it’s all Facebook and WhatsApp and Instagram and then they have no way of communicating with them at all, if they had internet, it would be a saving grace. Without it...you know, that must make the isolation feel a lot worse.” (PT1)

PS1 also describes the benefit of Wi-Fi for one family to allow some social contact and maintenance of their normal routine.

“Actually the world in which we live in everyone chats via Facebook, everyone chats via emails. School, you know schooling homework is all done via email. But you know it is hard and I think that is something that can be really hard for them, because you know they need that contact with their friends. Especially we had one girl in, who was here for over a year and actually that was her lifeline and for parents that are in for a long time also, we’ve got a couple that work from home and they have got their own dongles now so that they can continue to do their work so it doesn’t have an impact on their work life, because obviously some employers there is only so much time you can have off of work and when you are in so much, sort of two or three times a week, like our patients are, especially the dialysis patients.” (PS1)

“I think with the wonder of modern technology things are a bit different now, because even if you are physically isolated you are not socially isolated, providing that you have the internet and a mobile.” (D4)

This demonstrated the emphasis on technologies to enable families to maintain a normal life in isolation. During the period of data collection, none of the children were able to access Wi-Fi within the hospital as it was not available. Some children and parents did have devices that had internet access through a dongle or 3G capabilities, which as described by the staff participants may have improved the experience. However, it does bring into question that no matter how social the media is, it may not be a substitution for human contact as they would receive on the main ward or within their own social construct at home. Given the responses from the nursing staff and parents throughout the subtheme, there was a strong evidence base to support the need for face to face interaction for some of these families [which is supported by the literature](#) (Alsop-Shields, 2002; Attree, 2008; Espezel & Canam, 2003; Galbraith, 1995; Shin & White-Traut, 2005). However, for other

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families the use of social media may have provided them some community whilst in isolation so that they did not feel separated from society, even though they were physically separated from the rest of the ward.

6.4.4 Stigma

Staff narratives had two aspects related to stigma; firstly, the impact PPE had on the family and the wider perception from the ward. Secondly the challenges associated to PPE for the staff, which in turn had impact upon the experience of the family and the stigma that they felt.

N4, N6, D2, D3, PS2 and PS3 perceived that the children and parents felt stigmatised due to being in an isolation room with a sign on the door and an allocated toilet, whether that be for protective or source isolation. PS2 stated that she felt people would feel “ostracised from the ward community by having a sign on their door”.

“I discussed with one patient, I discussed with her how she found it (PPE) and she said that she found it quite restrictive and almost quite embarrassing, because you have got some real grubby thing wrong with her, like grubby was the word that she used, saying that because she is grubby people don’t want to go in and see her and ummm... because they are scared of getting something. You’ve got a sign on your door and you’ve got gloves and apron on you when you come in, it makes you feel, almost, I mean like... some might say that it is a dehumanising experience. I mean she didn’t use those words, but that is how she described it.” (N7)

Many of the staff described the challenges associated with PPE in terms of knowledge of what PPE to use, when to use it and the inconsistency between the nurses. Although this was not a direct description of the child’s experience of isolation, I felt that it was useful data as the impact of the inconsistent use of PPE and confusion surrounding it’s use, may have [had an](#) impact on the child’s experience.

“I think the main one is keeping the parents in the room and knowing what to wear, I mean in terms of PPE. We really struggle and there is little guidance from the docs, even the micro team. I think we need better education as I am not sure and then a family will come back to us and say well PICU wore this and did that and the that just confuses us even more. Are they right or are we right? Who knows! I just wish there were clear guidelines that if a patient has this... you wear that! Clear and simple. Because if we don’t get it, then how are we going to be consistent and how are we going to explain it to a family.” (N6)

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A lack of consistent information can be seen in the patient's behaviours as described by N10.

"I think sometimes it is Chinese whispers, you know and that doesn't help. We quite often find where you know somebody will have said something and it's got a bit changed and you go back and say "why is that patient doing that?" and they will say well we told that we could." (N10)

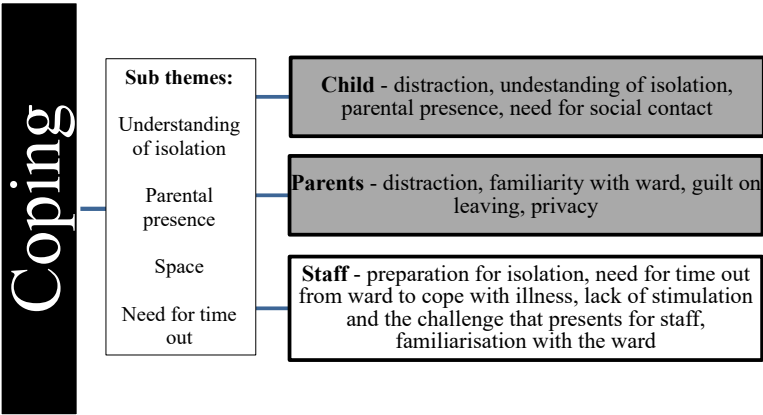
This could have been about the family misinterpreting the information or being defiant of the rules associated with isolation. N4 and N5 described using their common sense in conjunction with the isolation rules to allow the family the best experience, which occasionally meant "breaking the rules". HCSW1 described this inconsistency as frustrating to be able to interpret what as a junior member of the team she was meant to be doing in terms of PPE. Even senior members of the team such as D1 described inconsistencies. This suggests that families may witness these inconsistencies, which may make their experience of feeling ostracised and stigmatised different dependent on the staff caring for them that day. This inconsistency will affect their level of feeling part of the community or separated from it.

Community describes the subthemes of missing out, boredom, social contact and stigma, with recognition of the experience of the child in isolation being different to those on the main ward. The findings within the theme of community are discussed in detail in Section 7.4.2 in the context of the underpinning theoretical perspectives.

6.5 Coping

Coping was a key theme that staff described in how children and their parents experienced isolation. The subthemes are demonstrated in Figure 6.5 below.

Figure 6.5 Coping



6.5.1 Understanding of Isolation

The ambiguity on isolation precautions and explanation of isolation was noted in the narratives of N1, N2, N3, N4, and they referred to feeling inadequate in terms of providing explanations to the family.

“I think that we are very unclear. Yes. And I think that that goes back to the clearness on infection control. Because if you look at it logically, if the child has got EColi or whatever and the parents not, so can they go in there or not? If you know that the parent is definitely ok, then I suppose it is better to be cautious and say “we’ll make you a cup of tea”. We have a lot of very vulnerable patients on the unit, so it is better to be over cautious; I think that’s better than putting the others at risk.” (N4)

N2 alluded to the fact that parents may need continual explanation of their reason for isolation, similar to the patients with chronic conditions to facilitate their understanding of the need for isolation.

“I mean admission to hospital it quite a massive thing. They might not remember the information that we give them and so I think that it is always worth reiterating, every now and then, not every shift maybe but being like “we’ve still grown this bug or something.” So that they can keep understanding that it is to protect other patients and their child as well. But sometimes I just don’t know” (N2)

Contrastingly, D2, PT1, N6 and N10 all described patients, where because of giving them an explanation, there was greater acceptance of the isolation precautions. However, N7 suggested that understanding doesn’t make it any easier to cope with.

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“There is this teenage girl on the unit at the moment who, with all her chronic conditions as well, actually she is very sweet and very lovely, and she understands what is going on and she understands why we are doing it, and you can explain it and she can rationalise it, but it is still doesn’t make it easier for her... she hates it.” (N7)

This overlaps with the subtheme of acceptance of isolation in Section 5.4.3. This excerpt seems to describe a lack of control, despite a good understanding of isolation. This illuminates the relationship between control and coping, and that they are interrelated, dependent on developmental levels and also whether the child is admitted for an acute or chronic condition.

Furthermore, N12 described the fact that knowing it is temporary made the experience easier to cope with.

“Most of our parents are so well informed of their child’s condition they understand what is going on, why we are doing things and that it is not a permanent thing. So... I guess that that makes it easier, knowing it is a temporary thing.” (N12)

The confusion regarding the reason for isolation from the staff may have an effect on how the parents, and ultimately the children experience isolation. This section highlighted that with ambiguity in the “isolation rules”, parents were unsure of what the child and themselves were allowed to do in terms of precautions and leaving the room, as echoed in Section 5.6.1. This describes the tacit knowledge of nurses that develops with experience of exposure to the ward, which is described in the parental findings. The ambiguity and confusion caused stress to some of the children and parents in Chapter Five, and staff members as presented in this section which in turn affected their ability to cope with isolation.

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6.5.2 Parental Presence

For the staff the parental presence made a clear difference to their workload and guilt about not spending extended periods with the children.

“A little girl, the one I was thinking of that hated isolation because it was lonely for her, every time I went in she would be like “can you just play with me” because her mum had gone off or something and you would be like “I can’t” and that is really hard for you because you want to. We do have some play support but it is quite stretched and they want someone to sit and play for ages” (N4)

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Ten staff members described the parents as indispensable in terms of coping with caring for all the needs of the children on their ward at that time, specifically those in isolation. HCSW1 and N1 both used the word “key” with reference to the parents when describing the role of the parents caring for children in isolation. D1 suggested that the presence of the parents “makes or breaks” the experience for the child. This is echoed by N5 who described the experience a young boy that she had cared for recently in isolation.

“Stimulation - they get that from their parents. Or they get nothing. So we had, just had a little boy in isolation for about three weeks and his parents were brilliant, he played games with them, you know if he was at all up for it, they were making games out of things, vomit bowls... whereas some parents want to sit and watch TV all day and that was the big difference for him.....But his parents engaged with him in such a way that most of his day was occupied and I would say he had the best experience of isolation that I have ever seen in twenty odd years.” (N5)

This level of enthusiasm that was demonstrated from the parents made the experience better for the child, the parents and thus made isolation easier to cope with from the point of view of the staff. N6 also discussed the mirroring behaviour between parents and their children in the context of enthusiasm for activity whilst in isolation. However this may have been child-dependent, according to their need for time with parents and time alone, which may be reflective of the child’s developmental level.

6.5.3 Space

Throughout the staff narratives there was acknowledgment that the physical space impacts the child’s experience. N1, N2, N3 and N4 described the isolation room as a large factor on how people cope with their time in isolation as it allows them space to deal with the situation of being in hospital which echoes what Imogen’s mum described in her narrative as presented in Section 5.6.3.

“It would be nice if they could personalise their rooms up a little bit, and just morephysically, a little bit more space, would make a big difference. I mean there isn’t enough space to stretch.” N2

N2 described the physical space and environment of the room that they are in. N6 portrayed how the space of the isolation room is controlled and that the ward may impact upon the person within the isolation room. This is described in the children’s data as presented in Chapter Five, where they describe that the ward intrudes on the experience of

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isolation such as viewing what is available outside of the isolation room, hearing voices outside and the staff entering in when they needed to.

“If they are going to be stuck in a room, they are going to want peace and quiet and they do want to make it their own. And I think that the ward is intruding on you all the time in there, actually the only thing that they are feeling like is actually I am not allowed out but everyone can just pop in here.” N6

Isolation is deemed a private space. N6 felt that the ward environment encroached on this private space; meaning the benefits of isolation and the control of that space are removed from the child. Making the space their own was described by all the play specialists interviewed and three doctors and two nurses. D3 felt that when patients were unwell the space in which they were cared for did not have a bearing on their mood, it was only as they got better, which was also described by Harriet’s mum in Section 5.5.3.

Although it was not the aim of the study to explore the challenges of isolation for the staff, it is an incidental finding within some of the narratives of the staff. The reason for including them within [the analysis and presentation of the findings](#) is that the experience of the isolation room may be influenced by the manner in which the staff portray the experience, as described by Imogen’s mum in Section 5.5.4. In terms of other challenges explored by the staff, HCSW1 suggested that the space can become cramped and difficult to work in. PT1 and N6 suggested that there needed to [have](#) better facilities for the long term well CF patients as the rooms were under stimulating for an extended stay. Their perception of the isolation room and stress from finding the space challenging to work in may be witnessed and interpreted by families in isolation. [This was](#) described by Eloise’s mum, who suggested that staff were overworked, and isolation further compounded their work level. This influenced Eloise’s experience as her mum wanted to provide her care. By contrast Simon was told by his mum not to ring the nurse call button as the nursing staff were busy, which meant that he was reluctant to do so, even when he needed their assistance. This illustrates the interrelated nature of the narratives of the children, parents and staff.

6.5.4 Need for “Time Out”

The need for time out was evident in the staff narratives; they described the need for time out for the parents in the majority, but occasionally for the children. D1 justified the need

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for time out by stating that there is a lot of pressure on parents to entertain a child for the entire time that they are in isolation and sometimes taking them out of isolation for a short period provided relief for both the child and parent. N1, N2, N3, N5, N8, N10 and N12 commented on children needing time out.

N2 accepted the desire for time out of isolation, but described her experience as a student observing nurses ushering families back into isolation.

“I think that they were quite quickly ushered when they came out of their rooms, like when the parents came out of the rooms, you need to try and keep that parent in that room. So, they were quickly ushered back in/ And then also, there is the whole like, when you are on a ward, you know, you have the opportunity to interact with people all the time, whereas they don't have that opportunity because you go in there every four hours at a time. But also the rooms are very bland; there is nothing for the children. I mean the walls aren't even painted, there's no stimulation in there. I can see why they want to get out” (N2)

Similarly N12 described his understanding of how parents experience isolation:

“I think that if you have got a small child in a cubicle and they are ill and stroppy it must be really hard, because you can't get away from it, when at home would you stay in one room with your child all day every day for a week or so? Not often because it would drive you potty so I think it is where we can come in and offer them a break or some time out to allow them space and to give their child space. Because if that child is older then they really don't want to spend every living moment with their parent...Since the parent's accommodation has opened up it has been a bit easier for the longer term parent to have a bit of space as they can leave the child with us and go and get dinner and adult interaction there away from that cubicle.” (N12)

N12 described the parent's accommodation, which is a hotel on the hospital site for parents to stay in whilst their child is in hospital. It has communal facilities where parents can convene and meet other parents. None of the parents of children within this study used the hotel facility as it only opened up in the last six months of data collection, and the parents that were recruited in that period chose not to use that facility. The fact that the three sets of parents recruited in the six months where the hotel was open chose not to use this facility may reflect their reluctance to leave their children as described in Section 5.6.2, particularly when in isolation where there is no one to interact with.

“They (parents) are there twenty-four seven with their child and that's very intense, you know they are not like that at home. They definitely have a bedroom and a living room and a kitchen, so they have space between them some of the time, so I think they, they are very much cooped up and it can get very suffocating.” (PS2)

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These excerpts concurred with the experiences presented by the families, particularly described by Harriet's mum who understood that it was unnatural to be with their child all day, every day in a single room. This was echoed in other parental narratives but not explicitly described.

One interesting narrative was given by N5, who modified her practice based on an experience of allowing a family time out from her oncology ward. She allowed a child time off the ward from protective isolation, based on her parent's request. The child subsequently developed an infection, potentially as a consequence of leaving the isolation room, however that was not proven. This narrative demonstrated the power of an experience affecting future practice for that nurse, which describes tacit knowledge acquisition through experience. Furthermore, it demonstrated the quandary a nurse must experience when making the challenging decision to allow a family some time off the ward when they are under protective isolation measures.

The theme of coping presented the subthemes of understanding of isolation, parental presence, space and need for time out. These findings are suggestive of developmental differences between children pertaining to their ability to cope with isolation. Furthermore, the parental presence and involvement in the child's capacity to cope was highlighted in the staff literature, reinforcing the need for family centred care whilst in isolation, which will be discussed in Chapter Seven.

6.6 Summary of Staff Findings

The staff findings were underpinned with different experiences based on their professional role and their level of experience. Staff presented a different lens on the experience of isolation compared to the parent and the staff, as although they were working with the child's social context, they were not living the experience of the isolation room. Furthermore, the staff are within an environment with which they are familiar to a degree, regardless of their level of experience.

The control of the environment was not explicitly used as a phrase within the staff literature, this is potentially due to the fact they perceive that they are in control as the hospital ward is a familiar social context as their place of work. The staff acknowledged

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that children were “stuck in the room” with one parent which was an alien situation to their home life. This demonstrated the empathy of the staff and the understanding that children in isolation have a different experience of hospitalisation to the children on the main ward. The familiarity with the ward was also mentioned staff as an issue that affected the control of the situation. Staff felt that once they were trusted, parents were willing to leave the ward for short periods, however, the staff that described this were from specialist wards where the children were frequent healthcare users. The time out of isolation demonstrated the developmental processes of staff. Newly qualified staff were focused on the rules, determining what was correct according to policy and putting this in place. N5 with many years of experience demonstrated a different level of practice, which had been affected by years of development within her area of speciality, adapting the “rules” to the children’s needs. Whilst this is not specific to isolation it will determine the experience of isolation according to who is looking after the patient, demonstrating the influence of staff on the experience. The staff participants described issues within partnership of care, related to control and not knowing how to gauge this with families which brings into question the theory of family centred care.

The theme of community is less discussed within the staff data than the child or parental data. This may be because this is solely about the experience of being in isolation and for the staff who are outside of that experience, they were less able to interpret what the children and their families perceived from this. However, staff did acknowledge that children miss out on activities and this voice was particularly present in the play specialists’ data. This was not unexpected as play specialists have a clear role to spend time with children in the hospital and provide therapy through play. Therefore, they would be more likely to interpret the experience from spending time with the children and their families, than clinical staff who had a number of other roles. All staff acknowledged that it was an abnormal situation to be confined and socially isolated from others and the staff described that knowing that the play room was there made it harder. D2 explained that parents had a key role in preventing boredom and allowing children to identify what they were missing. This [acknowledged](#) the pressure that is placed upon parents to be resident and provide distraction, particularly in isolation. Although stigma was not mentioned in the paediatric data and received limited mention in the parental data, the staff perceived that children and parents felt stigmatised by being in isolation and subjected to PPE. This

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highlights the importance of triangulating this data and hearing the child's voice within this subject to provide a complete picture of the experience (Clandinin & Connelly, 2000).

Within the theme of coping, most of the staff focused on the families' ability to cope rather than the staff's ability to cope. One area that was pertinent in terms of the staff's perception of a family's ability to cope, was the ambiguity of isolation precautions and feeling unable to fully explain the reasons for isolation and subsequently what PPE would be used. This lack of knowledge or feeling inadequately prepared to share this knowledge with the children and their parents was aligned to the level of experience that the staff had. Staff acknowledged that parents were indispensable in providing the children's care within isolation as they were unable to meet all the children's needs. Many of the staff commented on different mechanisms that parents had employed to provide distraction to the child, and described the positive effects that this had on the child. This links into the emotional contagion theory whereby the positive attitude and provision of distraction provided a positive experience for the children (Doherty, 1997), and the staff were able to interpret this by spending time with the children and their families in isolation. This also demonstrates the importance of parental presence and the need for negotiation of care roles whilst in hospital within the realms of family centred care and this will be explored in Chapter Seven.

6.7 The Metanarrative of Child, Parent and Staff Findings

Section 6.7 seeks to synthesise the findings presented in Chapter Five and Six in the form of a metanarrative using the themes as the structure. The findings when triangulated demonstrate some confirmatory findings and some conflicting between the child, parental and staff narratives. Overall, the staff findings link into the child and parental narratives to provide a broader and deeper understanding of the experience of isolation, through building a wider picture with their narratives. The differences in the raw data may be as a consequence of the fact that the parent and child are dyad data from the same experience, and the staff data is an overview of their understanding of children's experiences of isolation not specific to one ward, child or experience.

Control is a theme that generated conflict between the staff and parental perspectives in that parents wanted to seek control and staff wanted to maintain control, and this was

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increased in isolation compared with the main ward, as the space of the room is not needed to be shared with other families and therefore the families felt like they could manage that space. Staff were empathetic in their interviews with this, wanting families to maintain their own routines and accepting that at different periods during a chronic or acute illness admission they would have different responses to the parents taking control of the situation. The parents wanted a single room, potentially to allow them the control of the situation. However, the parents wanted the freedom to have social contact of the wider ward for support, sensory stimulation and to alleviate the social isolation of being with one person throughout the period of their child's admission. The child's perspective within the control of the isolation room was potentially influenced by their parents, through emotional contagion. The negotiation for control was between the parents and the staff, rather than the child, which is reflected in the literature pertaining to family centred care and will be explored in Chapter Seven.

The community of the ward, for the staff and the parents was pertinent in their experience. Staff enjoyed caring for those children and families with whom they had developed a professional relationship, and parents felt more comfortable and able to leave their child in isolation when this was the case. This speaks of the trust that is developed with regular interaction, for the children, parents and staff, and this will be discussed in Chapter Seven. The metanarrative described that the longer families had been in hospital the more the family pushed for flexibility in the rules, and the longer staff had been qualified the more they were likely to adapt the isolation rules to allow a family time off the ward, which describes the adaptation of individualised care in accordance with increased familiarity with the social context.

The final theme was coping and it provided some conflicting findings between the child and parent dyad compared with the staff perspectives. Most children and families provided an understanding of the reasons for isolation, but staff described a lack of understanding of who needed isolation and when they were isolated what PPE they should employ. This led to inconsistencies in practice that were presented within this study in the staff and parental narratives. The parental presence was demonstrated in this study to be a source of social contact and support through the children's narratives. Despite the different understanding of the parental presence between the children and parents' narratives, the staff described

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the parental presence as indispensable and [that parents were](#) relied upon for care provision which links with the need for family centred care within isolation.

6.8 Conclusions

A key factor that has been illuminated through Chapter Five and Six is that children and their families perceive the experience of isolation slightly differently to staff. This may be because the staff work within the hospital. Although some staff participants had personal links with being in isolation with family members, or N8 who was isolated for a brief period as a child, they have not lived the experience of being in isolation during this period of time. A child's development is context and time-specific, and their social construct is influenced by all of these factors which will [influence](#) the way they perceive the experience of isolation. This illuminates that staff, regardless of personal experience or understanding as a staff member, cannot provide a narrative of the child's experience. However, through working with children daily within isolation, the staff have provided a number of confirmatory findings to the way in which children presented their story of isolation, and even more which are congruent with the way the parents perceive the experience.

This chapter has presented the findings from the staff data from retrospective interviews. The staff presented their understanding of the child's experience of isolation from their entire career trajectory, not simply one isolation experience, which was key to interpreting these findings. The findings have been presented within the themes of control, community and coping. The staff narratives have been considered within the context of the child and parental data, to illuminate conflicting and confirmatory findings within the metanarrative of the child's experience of isolation which will be discussed in Chapter Seven.

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7.1 Introduction

The previous two chapters have presented excerpts of raw data from the children, parents and staff within the themes of control, community and coping. This thesis has been prefaced with the theoretical perspective that children are social beings who are competent to make decisions and share their experiences of their lives (Alderson & Morrow, 2004). However as presented in Chapter One, the child's perspective on that experience has been rarely sought and predominantly given by a proxy perspective. The aim of giving the child the central voice within this thesis was to gain a better understanding of the child's experience of single room isolation. This thesis demonstrates that it was possible, albeit challenging to allow the child to share their experiences which were valuable, providing insight which contributed to a better understanding of the experience of isolation and implications for clinical practice.

In this chapter, the aims of the study are briefly reviewed to present the extent to which the initial purpose of the research was achieved. The theoretical concepts that underpin the findings from this study are presented within this chapter within the context of the themes. It is acknowledged that the methodological learning as a consequence of using video diary, requires further discussion and was a significant part of the new knowledge generated from this study, in terms of conducting research with children. These methodological findings will be discussed in Chapter Eight within the context of reflections on this study.

7.2 Returning to the Aim of the Study

The aims of this research were to explore the question:

What are the children and young people's experiences of source and protective isolation while in hospital?

The further objectives of this study were:

- To identify how children and young people feel about being in isolation
- To identify the parental perspective of their child being in hospital
- To understand the healthcare provider perspective on how children experience isolation

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The themes that were derived from the data within this study were control, community and coping, which set the overarching metanarrative of this study as presented in Chapter Five and Six. These themes transcend all participant groups to varying degrees, and with divergent findings, as presented in Section 6.7, and will form the structure of the discussion within this chapter. The metanarrative of the experience of isolation, which includes perspectives from the child, parent and staff met the aims of this study.

7.3 Central Issues Arising from the Study Findings

The breadth and depth of the findings were enlightening. In my search to create a synthesis of the findings, I realised that I needed to reflect upon the social construct of the children in the study once again. This enabled me to identify factors, situations, people or influences that appeared to be more powerful for some children and not for others. These differences allowed me to identify theoretical perspectives that cross cut across the three themes. The following theoretical concepts are pertinent issues that warranted further exploration within the themes of this study:

- Developmental theories
- Family centred care
- Social isolation
- Theories of control
- Tacit knowledge

Each of these concepts will be discussed within the context of the themes. In order to provide the context behind these issues a brief overview of these theories is provided in the following parts of this section, prior to entering the discussion of these within the context of each theme.

7.3.1 Developmental Theories

Developmental theories seek to understand the change in children that happens over time; the changes that follow a pattern and move towards greater complexity enhancing their ability to become independent and enhance survival (Daiute, 2008). Within Chapters One and Two there are links with developmental theories, specifically related to Section 1.5 'Children in Hospital' and Section 2.4.1 'Development', which described the paediatric experience of isolation within the theme of development. Within the 20th Century, many

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researchers sought to identify developmental theories within the physical, cognitive and social/emotional domain. The key theories that intertwine with the themes of this study are Bowlby's Theory of Attachment (1969) and Vygotsky's Theory of Social Development (1978).

Bowlby (1969) described attachment theory, between an infant and their caregiver which ensures the infant's survival which links to the developmental literature of infants in long term isolation that was presented in Section 2.4.1. Vygotsky (1978) described his developmental theory based on the concept that children's knowledge is social constructed, and that cultural values and customs dictate what they learn which correlates with Brofenbrenner & Morris (1998) in that symbolic interaction in cultural systems shape the mind. Following the understanding that every function in the child's cultural development appears twice: first on a social level between people, and later on the individual level, inside the child (Vygotsky, 1978); the social construct within which the children interact from birth not only affects them but defines them.

7.3.2 Family Centred Care

Family centred care is a term that is widely used within paediatric health care. As described in Section 1.4, family centred care means that children admitted to hospital can never be treated as single entities, but as part of a unit of care that is the family, thus the parents and siblings are central to the child's wellbeing particularly when removed from their usual social context (Shields, 2015). Despite the term *family centred care* being widely used, it has different meanings and manifestations in clinical care, and research studies have failed to show that nurses actually do practice family centred care (Franck & Callery, 2004; Coyne, 2013). The key differences in the literature between parental presence and participation in care, and within that care; the care by parents, compared with the care for parents are contentious (Callery & Smith, 1991; Casey, 1988; Coyne & Cowley, 2007). Seminal work by Callery & Smith (1991) focused on role negotiation and Casey (1995) focused on partnership nursing care in an attempt to describe the practical implications of providing care to children and their families in hospital. Pragmatic Theory of Children's Nursing as mentioned in Chapter One was proposed by Randall (2016) to bring the focus back to the child, and to draw on those around the child within their usual

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social context, to facilitate children who have illnesses to live a childhood as [similar](#) as possible to that of their peers.

Within family centred care, there is the understanding that people within a child's social context can influence the child's social construct, which can impact the child's experience. The theory of emotional contagion purports that there can be stress contagion between parents and infants. It has long been noted that emotions appear contagious (Darwin, 1872; Reik, 1948), and that individuals infer their emotional state from the emotional expressions and behaviours of another (Bem, 1972; Laird, 1974). Hatfield et al (1994) argued that as people attend or interact with one another they nonconsciously mimic the other's emotional expressions and synchronise their facial, postural and instrumental expressions with those whom they are interacting with. The feedback generated by this mimicry produces congruent emotional experiences.

7.3.3 Social Isolation

Social isolation within the context of this study is defined as low frequencies of peer interaction (Gottman, 1977; Hol et al, 1999; Silva-Gomez et al, 2003). Human beings are social species, and rely on interaction with others for psychosocial support, development and communication (Bailey & Moore, 2018; Cacioppo & Hawkey, 2010).

Bowlby (1960, 1969) and Robertson (1968) described the harmful effects of social isolation on developing children. Studies with hospitalised children and those in foster care were their subjects for providing the context for addressing the effects of isolation (Bowlby, 1960; Robertson, 1968). Some of their studies lacked rigour and control groups, however much of what is known about the effects of separation on children is attributed to these two authors.

7.3.4 Theories of Control

Control is described as bringing the environment into line with one's wishes and bringing oneself in line with the environment (Rothbaum et al, 1982). Control theory stresses how weak bonds between the individuals, their families and society free people to deviate or go against the social norms, or the people who have weak ties would engage in crimes so they could benefit, or gain something that is to their own interest (Hirschi, 1969). Although this

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may appear irrelevant within this research, as deviant behaviours are not crimes, parents of children in isolation were breaking informal rules, in addition to staff adapting policy to facilitate what they perceived as best, holistic care for the families. Thus the parents and staff in this study were demonstrating attempts to ascertain control of a situation and alter the situation to suit their own interests. This denotes that individuals are able to shape their environment to fit their particular needs and developmental potential (Heckhausen & Schulz, 1995).

The second issue within control, is how through the developmental stages of a child's life there is a struggle to acquire control, from the people within power around them. This is described within Erikson's eight Stages of Psychosocial Development (1963), without the use of the word control, he denotes the different stages in life from development of trust vs mistrust at birth, to identity vs role confusion by adolescence. It is through this process that the child's peer group gain greater significance or control within the child's social construct. Intimacy vs isolation is the stage after 18 years, with two further stages considered for later in life. The parents in this study all fell into the intimacy vs isolation age bracket and this will be considered within their findings. Erikson's Stages of Psychosocial Development (1963) purported that personality develops as a result of a psychosocial crisis which could have a positive or negative outcome in terms of development and may account for some of the regressive behaviours that are noted in the findings (Heckhausen & Schulz, 1995).

7.3.5 Tacit Knowledge

Tacit knowledge is described as knowledge or intuition that defies recording (Wyatt, 2001; Herbig et al, 2001). Within healthcare tacit knowledge is obtained through immersion within the profession and a specific clinical environment. Tacit knowledge is acquired implicitly in the course of working and is therefore not easily explained or shared (Herbig et al, 2001). Tacit knowledge may be acquired by parents and children who are frequently in hospital, through exposure.

7.3.6 Summary

These central issues will now be considered within the context of the metanarrative as presented in Section 6.7. The metanarrative will be presented as the themes control,

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community and coping in Section 7.4, 7.5 and 7.6, using the underpinning theories presented in Section 7.3 and relevant literature.

7.4 Discussion of the Metanarrative

The overarching narrative within the findings was that the children begin their journey in isolation struggling for control of the situation and environment, then they develop a desire for community or seek to exclude themselves from community, and finally they ascertain their own coping mechanisms. Although this order of themes formed the metanarrative, depending on life experiences, development and their social construct, for some children this happened concurrently rather than sequentially.

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7.4.1 Control

The metanarrative begins with the struggle for control of the environment of isolation. At home, depending on the child's developmental level, the child and parent will assume positions of control within the child's life or social context. However in hospital there is an added dimension, specifically in isolation, that other forces control of the situation, these forces may be the institutional rules, the illness or the healthcare professionals as the social context shifts. The level of control links to theories of control and family centred care.

7.4.1.1 Theories of Control

The experience of isolation for both the children and the parents caused a loss in autonomy. This loss of autonomy was described more by the older children than younger children, which may have been attributable to the fact the younger children are normally more dependent on others within their daily life. Larson & Richards (1994) credited the feeling of loss of control as a consequence of being placed in an environment in which they are unfamiliar. Control as described in Section 7.4.1 is key to how any experience is perceived, but particularly when the decision to be in a single room without face to face contact with society or their own community is made by someone else. One of the pertinent findings within this study was the conflict of control between the parents and staff over the environment of the isolation room, and specifically the lack of control that a child had in isolation.

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Isolation, as an infection prevention measure is instigated by the healthcare team based on clinical findings or results from investigations. Therefore, the control is immediately removed from the family on admission, or presentation of symptoms which indicate a need for isolation. For some participants, their familiarity with the ward, team and healthcare environment made the acceptance of isolation and control of their environment easier as they knew the routine and what to expect on the ward in general. By contrast to this, as described by Nicholas' mum (in Section 5.4.4) who was new to the healthcare environment, she did not feel able to speak up and advocate for what she thought was the right decision for her son, and for the protection of other patients in terms of infection prevention, as she did not understand the isolation rules. The response to the decision to isolate was described by parents in two different manners; one response was pleasure in the privacy of the single room and the alternative response was the loneliness and need to get out of isolation. The responses to entering into isolation from the children were varied also. The parents that described the isolation experience positively were mainly parents who were used to being in hospital, and therefore, enjoyed the privacy. An example of this was James' mum who was familiar with the hospital routine and therefore, she felt less socially isolated in a cubicle. By contrast for Jessica's mum, she needed space and hadn't even recognised she was in isolation, possibly because of her emotional response to her child's illness she wanted someone else to take control. This demonstrates the different experiences of going into isolation dependent upon the parent's previous experience, awareness of their child's condition and level of support within their own social context.

An individual's ability to cope with a situation is reliant upon their perceived control, their developmental level and the threat to their identity (Breakwell, 1986, Skinner, 1995). This was identified specifically in the children's narratives within this study. This will be explored through the remainder of this section. Within an NHS hospital, where isolation rooms are sparse, it is impossible to have the luxury of determining when, as a patient, you might like a single room. Therefore, the control of being placed in isolation is automatically shifted towards the staff, and the family rarely are part of the decision to be in a single room, as demonstrated in these findings where no child or parent discussed being part of the decision to be in isolation or not. Hirschi (1969) described human beings as selfish beings, who make decisions based on which choice gives them the greatest benefit and thus the greatest ability to cope with a situation.

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In alignment with Hirschi's theory (1969), the parents of the children in this study who were in source isolation expressed greater frustration with the reason for their isolation and thus, greater need to 'get out' of isolation than the parents of children who were subject to protective isolation. This aligned with literature regarding adult patients in isolation (Barratt et al, 2010; Gammon, 1999, Kohle et al, 1971, Vottero & Rittenmeyer, 2012). The control within source isolation is in the hands of the staff, whereas the control within protective isolation is more in the patients' or in this case the parents' control as they want to protect themselves and their child from potentially contagious [pathogens](#). Therefore, they had a vested interest in being in the single room. The need for perceived control was demonstrated in James and his mother's transcript where they were in source and protective isolation as a consequence of his CF. James and his mother had a clear understanding of the need to protect him from further infection and they made the isolation room their own space. Thus, controlling the space and filling it with activities and things to make their time in the isolation room and hospital more pleasant. The greater familiarity the participants had with the hospital environment, the more perceived control they had of their environment, which was displayed in the way the parents brought in activities for their child and took on increasing amounts of the child's care routine, thereby merging the nursing and parental role. This was described in Figure 5.2 where the control of the isolation room environment shifts from the hospital to the family. This brings into question a source of potential conflict between staff and parents when in isolation, over the control of the situation and [necessitates](#) a carefully negotiated plan of care [that](#) must be developed in line with the needs of the family.

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The children that mentioned enjoying the privacy of the single room in this study were the oldest three participants, which could be reflected in the developmental maturity as described by Erikson (1963). For example, the youngest participant Harriet craved company of others and described at interview about the people who had visited her in isolation, and that she had seen another child with a feeding tube in her nose, which for her normalised the experience of having a feeding tube herself. None of these aspects that Harriet described were about control of the environment, but about the need for social contact within the isolation room. For Harriet and the younger children within the study, there was acceptance that they had to be in the [room](#), and it was not a consideration that they articulated at interview that there was another option. However, [for Harriet](#) she

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described at length the need for company and distraction whilst in isolation. By contrast Simon and Eloise, the oldest participants within the study, valued their own space and did not experience social isolation, but isolation did allow time for schoolwork and reflection. Adolescents are at special risk for perceived social isolation according to Laursen & Hartl (2013), due to developmental changes in autonomy, social circles and individuation from their parents. The response of the adolescents to isolation aligned with the literature from adult patients in isolation (presented in Section 2.2.7) who valued time alone for activities and for privacy at times when illness was physically or emotionally demanding (Campbell, 1999). The adult literature also described that there were other times during their period in isolation when there was a need for social contact as part of normalising for return to their community outside of the hospital (Kennedy & Hamilton, 1997). The parents within this study certainly described this same need for time alone or privacy, but also the desire for social contact when they wanted it. There were differing needs for social contact between the parents being dependent on their social context external to the hospital, and level of support available from other family members or peers on the ward, as demonstrated in Section 5.4.1.

The child's attempt for control in isolation was not seen in this study, which may be reflective of the parents assuming control whilst their child was vulnerable, as represented in the literature on children and parental control (Langford, 1948; Wright & Beaver, 2005). The older children within this study described times when they relinquished control of the situation (both Simon and Lara – to staff, Section 5.4.3). However, no children specifically mentioned their parents or staff controlling the situation. This may have been because their parent continued their usual role whilst in isolation, with the only difference of spending all their time with the child. Skinner (1995) and Lazarus (1975) identified that assuming perceived control and subsequent ability to cope were developmentally linked (for developmental theories see Section 6.3.1), which may attune to the reason for the lack of child data within this concept. The children in this study were removed from their normal social context, however due to their parent's presence, the perceived control shift was not felt for the child. Uprichard (2008) attributed to the fact that the parent is the constant and the child will look to them for security in a change in social context. Some of the parents did comment on the shift of control and the increased responsibility in their role that they felt compared with their normal role at home. Yet for the children, regardless of age the

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perceived control of their parents was an extension of their role at home despite the social context changing to the isolation room.

Familiarity with the environment determined the parent's place within the social hierarchy of the ward, and also their familiarity with the "informal rules" of the ward (Feng & Tsai, 2012). From this study it was shown that the knowledge of informal rules allowed parents access to a higher position within the social hierarchy of the ward, and there was a greater reliance on the parents by the staff through greater merging of the parental and nurse role (see Section 5.4.4). Whilst this aligns with the literature pertaining to children's experiences of hospitalisation with chronic illness compared with acute illness, (Balling & McCubbin, 2001; Boyd & Hunsberger, 1998) not specifically isolation, the need for the child and the parent to understand the 'informal rules' of the ward was heightened as a consequence of being removed from social contact with other families, as described by participants in this study. This is a key learning point from the data regarding information sharing between staff, patients and their families, that due to the physical barrier of the isolation room, the frequency of contact may change with staff as described in Section 5.4.4. Thus, the ability to share informal knowledge of the ward, such as where to get things from is compromised, and parents within this study felt that their power and control within the social context was worsened without this knowledge (see Section 5.4.4).

Carver & Schier (1982) argue that there is a hierarchy within the power of control in different social circumstances regardless of age and who secures this control is based on the social hierarchy. For the parents within this study, they had to mediate the balance within the control of the institution and the healthcare providers who provided their care, thus working in partnership with staff. This required a development of trust between the parents and staff, and as described within this study trust was developed by presence and interaction, which was limited by the physical barrier of the isolation room. An area that was not presented in detail in the parental data from this study was the difference between the father and mother's coping mechanisms when their perceived control of their child's care was challenged by the staff. Freddie's dad alluded to this in his interview describing that fathers have different rights to mothers in terms of accessing the ward, specifically that only one parent could be *resident*, and it was inferred by staff that the mum would normally stay. Furthermore, Freddie's father's protectionist attitude in the situation was

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apparent when talking about both his son and wife, in terms of ensuring they had everything that they needed and were prevented from any harm. This protective nature of the father echoed the work of Arockisamy et al (2008), which described protective attitudes in their study of fathers of babies in neonatal units. The paternal perspective within research, and the limited number of fathers that participated in this study will be explored in Chapter Eight. Overall throughout the data from this study and the underpinning literature, the perceived control of the situation affected the adaptability and functionality of the staff, parents and partially the child.

The challenge for control of the isolation experience between the parents and the staff in this study was determined by familiarity with the hospital environment. This imbalance of power and control was determined by the negotiation and understanding of the informal rules, rituals and tacit knowledge of an environment (Nicolini et al, 2008). Two issues surrounding informal rules were identified within this study; the staff confidence in adapting care to the needs of the patient with greater understanding of the informal rules of the clinical environment, and the parental development of knowledge which lead to an imbalance or different balance of negotiation of care between the parent and the staff. This links with the data pertaining to children with chronic illness and hospitalisation where parents take on nursing roles increasingly (Crisp et al, 1996; Frank et al, 1998; Perrin et al, 1993); thus, taking control of the clinical environment and increasing their participation within care decisions. However, within isolation this challenge for the control of the environment is further compounded due to the absence of the visual presence of the nurse as frequently, which for some in this study was a benefit (in terms of their privacy) and for others [it contributed negatively to the experience](#) in terms of feeling isolated. This demonstrates the need for individualised [care](#), which is centred around the family's needs, particularly when physically isolated from other sources of help, support or disturbance.

Nurses within this study demonstrated differing levels of following and adapting the rules, according to the number of years that they had been qualified and their seniority. The newly qualified nurses and junior Band 5 nurses were [rule-based in their decision making](#) and struggled when the “rules” did not provide complete clarity. Yet, the more experienced nurses described ways in which they adapted isolation, within the clinical guidelines, and varied practice to meet the needs of the children and their families. These findings appear

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to align with the literature pertaining to tacit knowledge (Herbig et al, 2001). Knowledge can broadly be defined as explicit (formal education through documented evidence) or tacit (Wyatt, 2001). Tacit knowledge is described as knowledge that develops over time and that defies recording (Abidi et al, 2005). Increasing confidence with the skill of integrating tacit knowledge of a clinical environment is described as the way to develop clinical expertise, and the way in which decisions are made based on their tacit knowledge, [particularly](#) when there is not a clear evidence-based answer (Lake et al, 2009). Tacit knowledge is demonstrated with regards to isolation care and decision making as described in the literature in Section 2.5.4. The level of indecision was demonstrated in this study in terms of the junior nurses not having the experiential or tacit knowledge to support their decision-making regarding isolation around the clinical guidance ([in Section 6.5.1](#)). Tacit knowledge facilitated some of the one-off, personalised decisions that were presented in the findings from the staff in terms of the care that they provide for families in isolation, which is highlighted in the tacit knowledge [literature](#) (Wyatt, 2001). This level of adaptation of the rules or need for tacit knowledge was not evident in the other professions (aside from nurses) and this may be associated with the level of impact or control that the nursing staff have on the child's experience of isolation, and thus the need for the knowledge. Whilst these findings aligned with the literature pertaining to hospitalisation, the experience of isolation further compounds the inability to access the tacit knowledge for staff.

The acquisition of tacit knowledge can be considered in terms of professional development and Vygotsky's theories of development (1978). Vygotsky refers to 'elementary mental functions' as attention, sensation, perception and memory (1978). Eventually, through interaction within the sociocultural environment, these are developed into more sophisticated and effective mental processes/strategies which he refers to as 'higher mental functions' (Eun, 2008). Similarly, the culture within which the nurses work determines their tacit knowledge development.

The development of tacit knowledge and professional development as described using Vygotsky's theory of development (1978) was also highlighted within the parents' narratives of the experience of isolation in this study. As the parents in this study were exposed to isolation for prolonged periods, their knowledge of the informal rules expanded, and they became the expert parents who could contribute more to the care that

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the child received, and also in providing other parents with the tacit knowledge of the informal rules of the social context of the ward. These findings echo the literature pertaining to “expert parents” (Rennick et al, 2019; Smith et al, 2015). For the purpose of this thesis, I have taken a working definition from McDonald et al (2016) of expert parents as those who are involved in providing clinical care and develop a strong understanding of their child’s health needs. In this study the expert parents were parents of children with chronic health needs who understood their child’s needs and felt more able to advocate for their needs in terms of isolation, but also those who had experienced recurrent admissions, not solely to isolation, but also hospital. However, despite the greater knowledge and thus the label of the expert parent, the control of whether or not their child was in isolation remained with the hospital staff, which lead to conflicting responses from these expert parents. This was displayed in the data by Erica’s mother who wanted the privacy of single room isolation, compared with Imogen’s mother who felt socially isolated from activities on the ward. Thus, suggesting that although these two mothers were **both** expert parents, they had divergent opinions in terms of their desire to be in isolation, which for Erica’s mum was about protecting her daughter and for Imogen’s mum was about Imogen and her mum missing the social contact with peers on the ward. This demonstrates the power of the peers on the ward for some children and their families in terms of support and guidance with informal knowledge of the ward.

Interestingly, in two of the acute admissions in this study, the parents noted that there was a need for the pastoral, informal knowledge of the “rules of isolation”. Peer support from other parents has been shown to improve patient experience due to the sharing of the informal knowledge of the ward on larger bays within wards (Kingsnorth et al, 2011). However, this is limited in isolation due to the reduced interaction with the rest of the ward community. Thus, the families in this study were, to a greater extent than those in a ward bay, under the control of the staff as they had no means of learning this informal knowledge from other parents due to the physical barrier of the isolation room.

Overall, despite the different levels of experience that families had with the hospital social context and their previous experiences of isolation, perceived control of the environment was fundamental to their experience of isolation. The data alongside the theories of control highlighted within this section demonstrated that information sharing and trust

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development, within a social context assist with the sharing of control of an environment. The control will now be considered within the context of family centred care in Section 7.4.1.2.

7.4.1.2 Family Centred Care

This study identified that the level of control that a family need is socially constructed and based on their exposure to isolation. The fact that this experience is socially constructed means that family centred care must be considered within the theme. Family centred care has been viewed as fundamental within paediatric nursing, but in recent years it has received criticism in how it is applied in clinical practice as discussed in Section 1.4.

The data from this study described how the family are influential in how a child experiences isolation, through preparation prior to isolation, and for the time whilst in isolation. The findings from this study highlighted that parental presence whilst the child was in isolation provided the child with continuity and security, outside of their normal social context. This study also suggested the blurring of the role of parent and nurse when parents take on additional roles relating to the care of their child while in single room isolation. However, there did not appear to be explicit negotiation between families and staff about their expectations of care roles on entering isolation or hospital and the development of parents' skills beyond that of their usual role at home. Thus, the nursing and parental roles became blurred without clarity of who was taking on which roles, which caused a number of the issues that were highlighted in the previous section pertaining to control. Within the parents in this study, there were a number who had experienced both single room isolation and hospital stays on the main ward. For these parents, the blurring of roles was more apparent whilst in isolation as there was less contact with staff, due to the physical barrier of isolation. This physical barrier is a key reason why family centred care warrants further debate within this study as it is challenged simply due to the physical environment of the isolation room.

The sociocultural developmental perspective (Vygotsky, 1978) posits that social institutions can shape individuals and that individuals can transform social institutions, which is demonstrated in this study. The children within this study were, dependent on the developmental level, reliant upon their parents to varying degrees, often allowing the

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parents to control their life. Seminal work by Langford (1948) found that children's behaviours and need for parental support were altered in the presence of illness. Consistent with Langford (1948), children in this study were affected by the experience of isolation, often apportioning greater control to their parents, in particular in the older children than would be the norm, such as Simon wanting his mother to stay. This may have been a source of comfort, but through this study it was evident that with parental control of the isolation environment, it was possible for the parents to make the environment as similar to their usual home social context as described by James' mother in Section 5.4.3. This study demonstrated that the child's experience of isolation was influenced by the level of conflict for control of the environment, the control that the parent took over the child's experience, and familiarity that the family had with the environment. In accordance with Vygotsky (1978), as development progresses, children move from relying on others for social development to developing their individual needs. This was demonstrated in the parents' need to control the environment for a number of the younger children in this study (Harriet, Imogen, John, Erica, James, Freddie, Nicholas), and the older children seeking control of the environment, enjoying the time away from others to concentrate on other activities, and the reduced mention of parental presence in their interviews (Lara, Simon and Eloise).

Interestingly in this study, none of the children or parents mentioned the negotiation of control or roles between the healthcare professionals and their parents, which supports the evidence base that family centred care whilst a great ideological construction, is not applied clinically (Coyne, 2013; Coyne et al, 2018; Rankin, 2014; Shields, 2010; Shields, 2015). It has been described extensively in the literature that parents want to be involved in their child's care, but they need some negotiation of this with the healthcare team (Casey, 1995; Lee, 2007; Smith et al, 2015); which is echoed within this study. Furthermore, Ford et al (2018) suggested that there was ineffective communication between healthcare professionals, families and children; parental informational needs were left unmet and that there were differing expectations of the role parents have when their child were admitted to hospital, all of which were discussed within the parental narratives in this study. Five parents mentioned providing care, some viewed this as a continuation of what they would be doing for their child at home, yet by contrast three parents viewed this as an additional burden in addition to coordinating their life between home and the isolation room. Heckhausen & Schulz (1995) describes the merging of the parent and nurse role, through

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the movement of control from one to another after development of trust and skills, which was echoed in the findings in this study.

Family centred care is defined as an approach to the planning, delivery and evaluation of health care that is grounded in the partnership between healthcare providers and patients (Shields et al, 2012). As discussed in Section 1.4, family centred care as a theory forms the basis of all that paediatric nurses do in terms of caring for the child within the family unit, whilst their child is in hospital. However, this study reflects the discussion presented in Section 1.4, in that the translation of family centred care into clinical practice and, in particular in isolation care, is not apparent in terms of negotiation of care needs of the child and their family, and how these can be adapted to the physical barriers within isolation. Furthermore, for the practitioners within this study, there was a clear focus on the child within their day to day care and the parents and family were part of their decisions, but the child was central. Yet, considering family centred care, the literature purports that the partnership is made with the entire family (Kuo et al, 2012), and focus of care is for the whole the family, not the child, which was evident from the healthcare professionals in this study.

In Section 1.4, two more recent approaches to involvement of the family in care of children in hospital were presented. Child centred care was proposed by Shields (2015) as a means that children and their interests are required to be central to their healthcare, ensuring that they are active participants within their care. The children within this study all mentioned their parents' presence whilst they were in hospital, thus implying the importance of them within their social construct. Shields (2015) does not advocate that parents are not the focus, but that the focus is on the child and consideration is made for their needs primarily. This was evident throughout the staff narratives in this study. However, for some of the staff, there was greater focus on certain parents ahead of the child, particularly where there was a poor prognosis, or the child was too young, or unable to communicate in a means that the staff could easily interpret. In these situations, the staff relied on the parents to advocate for their child.

The other alternative approach to care of children in hospital that was suggested in Section 1.4 was the Pragmatic Theory of Children's Nursing (Randall, 2016). This theory argues that children living with illness should be given a childhood which is, as far as possible,

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equal to that of their peers (Randall, 2016). In this study, there were a number of examples where the staff, particularly the play specialists' narratives described the way in which they would try to engage with the children using things that they would be familiar with from their usual social context. A number of the parents in this study also described attempting to continue normality as hospital was going to be part of their life for a period of time or intermittently throughout their life. This theory, however, focuses on the children when they are physically able to continue a life equal to their peers. It does not consider the children that may not be physically able to do this. For example, in this study children like Simon who didn't want to engage when he was feeling at his worst, or for Imogen, who wanted to be shut away at periods during her illness when she felt at her worst.

This study demonstrated the importance of parental presence for children of all ages and levels of development, which is advocated in family centred care. However, there was an overreliance on the parental presence, often for pragmatic reasons as reported by staff and parents in this study. For some parents they enjoyed taking on the additional caring roles and privacy to carry out these roles, but for others these additional roles were a burden and source of stress, which was exacerbated by the physical barrier of the isolation room. This demonstrates the importance of open communication regarding the negotiation of the child's care and how this can be provided between the clinical team and family care, to ensure that the child receives the best possible care without anyone feeling burdened.

Child centred care (Shields, 2015) which focuses on the child being an active participant within their care was disputed in some of the narrative within this study. Within some of the narratives within this study (Harriet and Freddie), where the children were too unwell at times to lead on the decision making, and other children were too young. Considering Randall's Pragmatic Theory of Children's Nursing (2016) in this context, would mean that would be a reliance on the other members within their community, most likely their parents to advocate and facilitate their care based on the child's needs. Child centred care (Shields, 2015) would also advocate that where a child can't express a preference then the parents and staff would work together to make a shared decision in the child's best interest. The challenge with both of these theories is to ensure that the balance of power in the decision making is shared and not shifted as a consequence of any one person's viewpoint. Furthermore, the focus must ultimately be on the child and their rights. This challenge is

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heightened when there is a child in isolation that cannot advocate for themselves or make decision such as Erica. Erica's mother described with strong words about advocating for her daughter and protecting their environment within that cubicle, protecting her from any risk of infection. Furthermore, this can cause a source of contention between the family and staff as Imogen's mother described, where Imogen was required to be source isolated for a fixed period due to being positive to a respiratory virus, but she wanted her daughter to attend the Halloween party. This required the staff to not only consider the rights and needs of the child in isolation (Imogen) but also the wider picture of what is going on throughout the unit and associated risks of the child being taken out of isolation. Therefore, neither child centred care or the Pragmatic Theory of Children's Nursing would be useful in terms of supporting the staff decision as they were required by policy and best practice to keep the child in isolation. This same challenge of providing family centred care in isolation was described by Koller et al (2006b) for children in isolation during a SARS outbreak.

However, using child centred care and the Pragmatic Theory of Children's [Nursing](#), it is possible to say that the child should have the same experience in isolation as they would on the wider ward. Therefore, in this situation, bringing some aspects of the Halloween party to Imogen would have allowed her to participate whilst adhering to the infection prevention policy. This presents the challenges of providing isolation care and care based on the individual child's needs, and the subsequent emotional and moral distress that this caused the child, parents and staff within this study.

Additionally, this study has highlighted the reduced interaction of the care team with the child in isolation compared with the children on the main ward. This was observed within the literature for adults in isolation as described in Section 2.2.6 (Evans et al, 2003; Morgan et al, 2009). For the parent and staff participants within this study, there was a description of greater reliance on the parents to provide care, which may denote that the parent may be in a better position to advocate for their child, than the staff. However, as also described in the narratives from the parents, most parents preferred the single room for privacy. Therefore, the parental decisions regarding care may be biased due to their own preferences for a single room and consideration for their own needs (such as the need for privacy as described in Section 5.4.1). This adds another complexity to providing care to

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children in isolation, ensuring that the child's needs are met, without being influenced by parental preferences.

Randall's Pragmatic Theory of Children's Nursing (2016) appears to be the theory that aligned itself most appropriately with what this study observed in terms of care of children and their families in isolation. The staff based the needs of the child within the needs of their wider social network and their family, often relying on families to provide care, which is what this theory purports. Although this theory is observed within this study, this does not suggest that this is most appropriate for current clinical practice throughout paediatric wards. This may be most appropriate based on these findings for isolation; however, the wider ward may have different experience due to the different social context.

As seen in this study, isolation is a unique experience for a child, one that is different from the wider hospital ward, simply due to the nature of the physical barrier and isolation precautions. Therefore, approaches to providing the care to children in isolation needs careful consideration. In isolation there is a greater risk for children that their care may be based on other people's needs such as the parents and professionals who dominated decisions of the child's care, as it was demonstrated in this study. There has been a movement to renew efforts to promote the principles of protection, promotion and participation of rights for children as presented in Section 1.3, which were advocated through the introduction of child centred care (Shields, 2015) and the Pragmatic Theory of Children's Nursing (Randall, 2016). As demonstrated in this study, there is greater acknowledgment of keeping the child central to our care, but yet there was not explicit mention of these theories from practitioners in this study, or the way in which these theories were implemented by children, parents or staff. Despite this, staff and parents did describe a pragmatic approach to managing their child's care whilst in isolation.

Isolation is as Imogen's mother described it "a necessary evil", but the way in which the care in isolation needs to be negotiated and managed between the staff and parents needs careful consideration. This does not suggest that children should not be subjected to isolation if they require it. However, it does mean that the child in isolation should receive the same level of care that any other child within hospital receives. This includes the

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frequency of visits, which does link back to the need for greater focus on child-centred care (Shields, 2015) within contemporary children's nursing, using a pragmatic approach (Randall, 2016), rather than basing care on the needs of the whole family in family centred care. Families need to be consulted to provide this level of care, if the necessary level of care cannot be provided entirely by the nursing team. However pragmatically there needs to be some consideration for the parents, who as discussed in the findings in Chapter Five, are trying to manage their child in hospital alongside other children within their usual social context.

This research supports the Pragmatic Theory of Children's Nursing (Randall, 2016) as a differentiation of family centred care, and the need for individualised care that is based on the needs of the child and those within their social context, to allow the control to be apportioned appropriately to alleviate anxiety, stress and burden on either the family unit or the healthcare team. However, through exploring the findings of this study within the context of child centred care (Shields, 2015), there is a need to place greater emphasis on children's rights and their needs within care, not simply as part of the family's needs. This is part of the cultural shift within the NHS to incorporate the child's perspective in their care, both in practice but also in research as this study has demonstrated. Regardless of the theoretical underpinning or model of family centre care within paediatric healthcare, this study supports that there needs to be a promotion of parent and healthcare professional collaboration in order that the child's needs and wishes are met whilst in hospital; and more specifically when in isolation, when the child cannot have control due to the physical barriers of the room.

7.4.2 Community

The theme of community produced confirmatory findings within the paediatric literature in terms of missing out on activities within the ward and separation from their social life at home (Broeder, 1985; Koller et al, 2006a; Kutsanellou-Meyer & Christ, 1978; Russo et al, 2006). The parental need for social contact with their friends, family and staff was noted in the literature (McKeever et al, 2002; Wu et al, 2005). In this study, the child narratives described the need for social contact and the importance of their family for this. The degree to which they required this social contact varied according to their age and developmental stage. Additionally, the level of distraction that a family provided for the child in terms of

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visitors and activities was associated with the frequency in which the child described the need for social contact and described their feelings of social isolation.

7.4.2.1 Social Isolation

Social isolation was described by children and their parents in terms of missing out from activities and peers, both within the hospital and those in their home social context. The findings from this study in terms of social isolation for children did not align with the literature on adults in isolation in Section 2.2.5, in that adult participants described feelings of loneliness, seclusion, feeling “worlds apart” and had fractured human connectivity, whereas the children did not describe these emotions. This is simply because of the added presence of a resident parent or additional visiting from wider family compared with restricted visiting and no resident family for adults in isolation. Thus, the overall experience of social isolation is fundamentally different for children compared with adults in isolation, as described in the paediatric literature presented in Section 2.4.5.

This study demonstrated the reliance on family, not just for the practical care but also for the interaction and socialisation, which exemplified the human need for interaction and community as described by Casas (1997). Within this study, the degree to which social isolation was perceived, was developmentally affected within the data from the children. Although this echoes the experience of hospitalisation for children, isolation compounds the hospital experience, as children cannot substitute their peers with other children within the hospital for play, conversation and distraction. The child’s community in isolation becomes limited to the people that visit them and the staff. A number of the narratives from this study mentioned the role of their parents in providing distraction, comfort and interaction, yet very few mentioned the role of the staff in this, which is contrary to the roles of the healthcare team in hospitalisation literature (Cruickshank et al, 2005; MacKean et al, 2005; Shields et al, 2012). The parents identified that their children were missing out and bored, but didn’t identify their own personal boredom. This may be because although the parent was in isolation, they were not subjected to the same isolation precautions and therefore could leave the room. Thus, their perception of social isolation was not as strong for themselves as it was for their children.

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Developmentally children perceived being in a single room differently, not just associated to the level of distraction but also associated with the need to feel part of a community. For Harriet and her mum, knowing people were there was about hearing other patients and their families through the walls, this was a source of comfort for them. However, for Lara and Nicholas, hearing other children through the walls was a source of frustration. This demonstrates not only the generational differences between parents and children, but the perceptions of social contact needed for the different generations. This links to Bowlby (1969) and Roberston's (1958) work that described the need of human contact for development. Furthermore, this links to the work on bonding and development, and early need for reciprocal attachment to ensure an infant's needs are met, but later in childhood, these needs are lessened (Sullivan et al., 2011). Thus, for children, their need for social interaction at various points whilst in isolation is determined by health and their perception of social isolation. Furthermore, this describes individualised patient journeys within hospital and the need to individualise the child's care according to their needs at that time.

The role of parents in isolation demonstrates how family centred care cannot be truly possible, as the nursing staff in particular cannot be as present in isolation rooms as they can on the main ward, thus increasing the reliance on the parents as described in this study. Franck & Callery (2004) purport that the term family can be used broadly to refer to the social environment within which parenting is conducted, and therefore family is a range of social relations, which accounts for different family structures and for the older children that seek their community and support from their peers as described in Section 1.4. This links back to the developmental literature and the level of attachment (Bowlby, 1957; Bowlby, 1960; Bowlby, 1969; Bowlby, 1973) and support that the child needs from their parents at different developmental stages and when they use their wider community (peers) for support, which in isolation is a struggle due to the physical limitations of the room. However, the social construct of children may be influenced more broadly in practice today than it was within the period of this study due to greater use of social media. This must be a consideration for practitioners to ascertain where the children will be gaining the support and socialisation that they need to maintain their usual community or social construct, as much as possible whilst in isolation.

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Social contact is not simply face to face, and therefore in the era of [virtual social interaction](#), children within this study used their mobile phones as a means of maintaining contact with their peers outside of the hospital. However, there was no means of establishing social interaction with other children within hospital, thereby distinguishing this experience from the experience of a child in a main bay in hospital. The use of social interaction via electronic means could also be different today than from 2015 when data collection concluded, due to the technological advances and exponential increase in the use of social media, as a means of reducing true social isolation whilst in single room isolation. Miegel & Olsson (2012) purported that generational experience of the internet has naturalised it as a form of communication in a manner that makes distinctions between online and face to face interaction obsolete. This broadens the concept of community for the children in isolation and a few of the older children made comment to this effect in this study. It is likely that today there would be much greater reliance on electronic communication. However, Tates et al (2017) argues that the use of electronic communication is not a substitute for physical contact and face to face communication. This describes the literature pertaining to sensory deprivation, whereby without the physical presence of others in isolation, a person can be developmentally and cognitively impaired (Bruner, 1959; Davis et al, 1961; Soloman et al, 1957). Whilst the literature pertaining to sensory deprivation and social isolation is conducted predominantly in experimental conditions in true isolation, there are findings that transcend across this study and the paediatric literature pertaining to isolation experience as described in Section 2.4.1.

For the parents in this study, social isolation was an issue, despite the fact that they weren't truly under isolation precautions. This may have been the fact that they were describing the child's experience of social isolation, or that they felt the conflict of the need to be in isolation with their child and the need for social interaction for themselves as described in Section 5.5.3. Alternatively, this perceived social isolation from the parents may speak of the generational differences between children and their parents in terms of the use of technology to communicate with peers and their [usual support network](#).

Staff described feelings of social isolation within their own healthcare community as a consequence of caring for children in isolation. They struggled with not sharing ideas and discussing care [in the same way that they would when caring for children in the main bay](#).

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This is described in the staff literature presented in Section 2.5.1 (Kirkland & Weinstein, 1999; Morgan et al, 2009; Saint et al, 2003). Within the staff literature in Section 2.5.1, it was identified that staff visited the patients less frequently, which was not mentioned within this study. This may be reflective of the greater ratio of staff to patients than adult wards work to, compared with the paediatric wards under study. Alternatively, this could be reflective of the role that parents have in paediatric care, in taking on additional nursing roles within their role as a parent. The lack of comment of their own social isolation from staff could have implicated the degree to which the staff felt challenged to work with patients in isolation and the time restrictions which were reported in the literature, but not present in this study. Alternatively, this may simply be that the staff were true to the request to focus on the child's experience, not their own experience at interview. As discussed in Section 7.4.3.1, the development of staff can be aligned to the developmental theory of Vygotsky (1980), and the need for support from their social context (their colleagues and the ward), diminishes in line with their professional development and increases in line with greater levels of tacit knowledge, which in turn reduces their feelings of social isolation.

Emotional contagion has also been shown to occur at a conscious level through social comparison processes in which people look around and compare their affective moods to those of others in their environment and then respond accordingly (Adelman & Zajonc, 1989; Kulik et al, 1993). This is likely to have been heightened in a physical environment where there is limited interaction with anyone beyond the isolation room. Social isolation therefore, demonstrated emotional contagion between parents and children, but also potentially between staff and families as it is described in the literature emotions being transferred between patients and staff (Omdahi & O'Donnell, 1999). In this study, James and his mother were strong examples of emotional contagion in the positive sense. James' narrative described his experience of isolation as a fun time, where he was on his own and received one to one time with his mum, and James' mother wanted the experience to be positive as she knew it would be life-long as part of his CF management. She had conditioned his interpretation of the experience of isolation through preparing games and activities for his time in isolation. Emotional contagion was evident in the transcript linguistically, through the positive phrases that James and his mother used when describing isolation.

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Similarly, emotional contagion was noted during Imogen, Harriet and Eloise's narratives, through the way in which the parents described the isolation room and then the subsequent way the child described the isolation rooms. However, for these three participants and their parents the descriptions were less positive. This mirroring of descriptors may have been associated with the influence of conducting the interviews simultaneously, with the parents present. Yet some of this mirroring of words and emotions in their narratives were reflective of their mirroring of the interpretation of the experience whilst in isolation and subsequent description of it. Harriet independently recalled the therapy dog walking past her cubicle and meeting children not in isolation on the ward, which she was sad about as she did not get to touch the dog. Her mother also recalled this at interview and described how sad this made Harriet that she could not interact with the dog. Harriet's mum described this at interview before Harriet was invited to join the interview. In her interview, Harriet spoke about this in a sad tone. This could have been because of the fact that at the time, whilst in isolation they were both sad that Harriet could not interact with the dog, or that subsequently they had spoken about it at home. Alternatively, it could have been that Harriet brought it to the interview independently and her mum encouraged her to tell me about this experience, by saying "but that made you sad didn't it?". This demonstrates the intertwined nature of parental and child interviews, and the subsequent challenge of segregating where the child and parent narratives were influenced by one another. By contrast within the video diary of Lara, there was evidently no emotional contagion or mirroring behaviours between her mother and her, as her mother was trying to be particularly upbeat about the isolation experience and this was not portrayed in Lara's responses. Again, this demonstrates the heterogeneity of the participants and the subsequent variations of the findings in this study. Overall there may be a greater risk in isolation of mirroring behaviours due to the close proximity the child and their parents are in when compared with their usual social context.

Similarly, for staff there may be an element of emotional contagion from families and their colleagues which may influence the way in which they can provide care in isolation, although this was not evident in the findings in this study. However, within the staff findings there are a number of emotional responses to families in isolation; descriptors such as "*guilt*" on not being able to entertain the children, describing the isolation room as

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“*torture*” and “*hell for the family*”. The staff did not describe whether these responses were used with families, or provided from families. If they were used with families, it could be perceived by families as the staff demonstrating empathy to the situation of isolation.

Loneliness or perceived social isolation is described as contagious in adults (Cacioppo & Hawkey, 2009), resulting in people who feel socially isolated to become objectively more isolated, when surrounding themselves within a network of others who are isolated. This may be of concern for children who are all isolated in hospital.

The level of familiarity with the hospital community and the social construct of the ward can affect the experience for the child in isolation. For some children for example James and John within this study, their mums described that they were used to being in hospital and knew the staff and so their community within hospital was more familiar than the comparison of children such as Harriet, Sophie and Jessica who were acute admissions. Therefore, based on Vygotsky’s theory of development (1978), children who are familiar with a hospital isolation environment may attain the independent level of cultural development at a more rapid pace than children that are faced with isolation for the first time. However, in contrast to this, the children that are isolated regularly may have a different level of sociocultural development within their home social context as a consequence of being isolated in hospital regularly or for a prolonged period, which may have influenced their social construct of isolation. Examples of this were in Simon’s narrative where he stated by missing out on college and having to drop out as he could not keep up with the work and hadn’t made many friends yet, or Sophie who missed her friends and felt like she was missing out of social events with them. This demonstrates the intertwined nature of development and community for the child’s usual social construct.

7.4.3 Coping

The theme of coping was shown to be influenced by the developmental level of the child and the impact of family centred care with the child in isolation. Isolation and the illness trajectory were intertwined and therefore there were some findings which could have been attributed to the experience of their illness. This study demonstrates that the nature of isolation, further compounds the experience of illness and the degree of wellness impacts on the experience of isolation, thereby exemplifying the symbiotic relationship of the two experiences.

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7.4.3.1 Developmental Theories

In this study it was demonstrated that the child's developmental level can not only impact their ability to cope with isolation, but also it can impact the parental experience and the role of the staff. For the children who had not yet reached independent sources of social interaction, they were reliant upon their parents and staff for interaction and entertainment, which some parents described as a challenge or burden. Considering Bowlby's attachment theory (1969), attachment can be to any caregiver, the person who the child considers most predominant within that role. Bowlby described a continuous relationship between a mother and child as a means to finding happiness and satisfaction for both, which was present within this study. Although this is also echoed in the hospitalisation literature (Clift et al 2007; Coyne, 2006), it is more prevalent within the experience of isolation as children have no other sources of distraction or social interaction to support them in coping with isolation. Whilst attachment was purported to be in the relationship between infant and parent, this could be shifted to any person, and suggests that people show a preference for one primary attachment figure (Keller, 2016). Keller (2016) suggested that such a pancultural concept cannot be applied to all children and that the construct must be considered. Although there are tenets of this study that describe the attachment between the child and parent in the manner Bowlby discussed, the need to assess the social construct and context in the manner which Keller (2016) purported was demonstrated in the findings in this study. In terms of coping, the child's support mechanisms, and [their](#) attachment need to be considered within the social context, but also [they need to be](#) considered developmentally in terms of to whom their attachment may be to.

Based on Vygotsky's developmental theory (1978) the acquisition of knowledge is developed through exposure and interaction with the social construct. Through reading the literature presented in Chapter Two and based on Vygotsky's theory, I thought that there would be a clear differentiation of the experiences of the children with acute and chronic conditions. However, the findings in this study are not suggestive that there is a difference in the experience based on whether the child has had repeated admissions to hospital, or whether this was their first experience. This may be that the sample was limited in size and thus attempting to find patterns in the data is challenging in some respects, or it could be attributed to the social context of isolation. From the findings it is possible to say that

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regardless of a chronic condition, even when moved between wards, the experience of isolation is changed, as the tacit knowledge of the ward that they are familiar with was not always applicable to another ward. The experience of moving wards to an unfamiliar setting is compounded in isolation as the family are removed from sources of tacit knowledge sharing between parents and children from other families on the hospital ward. The differences and lack of patterns in the findings indicates that the experience of isolation must be discussed and explored with families on admission to isolation. This will enable care to be based on the families' needs at that time, as the child and their parents' needs may change according to the illness, age of the child and reason for isolation, all of which will affect the child and parents' ability to cope.

7.4.3.2 Family Centred Care

Coping mechanisms of children within isolation were age dependent and supported by parents, denoting the key role of the parents. Although many of the findings within this section are relevant to hospitalisation, the responses are exacerbated by isolation (as described by the participants who had experienced both isolation and hospitalisation). Furthermore, the fact that the child and parent are alone within the isolation room, and that there are very few other circumstances that would necessitate such intense time together within the physical constraints of one room, the social context of isolation is unique for the parent and child.

Younger children (Harriet, James and Imogen) described the need for parental presence, which may have aided their ability to cope with the experience, whereas the older children sought support from peers and people outside of the social context of isolation primarily ahead of their parents. This suggests that the need for family support in order to cope is not consistent throughout the period of childhood and in fact may differ throughout the illness trajectory as described earlier in this chapter.

The need for negotiation of care between staff and parents were noted in the findings, however no participant described the negotiation of care specifically as it was described by Casey (1988) and as it is considered to be part of family centred care (Ford et al, 2018). This study demonstrated that healthcare professionals are on familiar territory whereas the child and parent may be influenced by the social context which may have changed their

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social constructs, thereby leading to an imbalance in power. Additionally, the parent has the stress of a child who is unwell and the burden of trying to maintain their usual home life, potentially for other children as described in Section 5.6.2. For some parent participants they required support in being able to cope with their time in isolation as the staff were more familiar with the environment. However, by contrast the staff did not always report that they felt in control of the isolation room, often describing that they were unsure of the isolation precautions required as described in Section 6.5.1. Thus, although it may appear to families that the staff that are in a position to control the partnership and negotiate the level of care that the parent wants in the provision of care, the staff member may not feel confident to begin this negotiation or lead their care, specifically in isolation. However, as demonstrated in this study and the wider literature (Callery & Smith, 1991), it is rare that nursing staff formally negotiate the participation of care. In this context, however, it could be that there is an additional barrier to effective negotiation in the lack of staff understanding of isolation procedure.

In an attempt to describe the practical implications of negotiation of care and accommodate for differences within the social constructs and experiences of the families, Casey (1995) proposed a model which suggested the intersection of two axes of communication/noncommunication and nurse-centred/patient centred to have four approaches to informal care for families, which are permission, negotiation, exclusion and assumption. These four positions within the model account for a desire from parents to be involved and the level of which communication is necessary regarding this level of involvement. This model requires negotiation and response to the family's needs which requires communication. However within this study it was evident that this did not occur for the patients in isolation within this study. Negotiation is central to this model of care (Lee, 1999), yet it is not practiced, as demonstrated in the findings from this study. As described by parents and staff in this study, the balance of care is not negotiated, it is navigated daily, dependent on the needs of the child at the time, and the needs of the family secondarily. However as purported throughout the family centred care literature, a fundamental part of nursing children is the care of the family as a unit, and yet the practice as described in this study does not reflect this. The reasons for the lack of consistency between theory and practice in terms of care of families, may be due to the physical barrier of isolation, the number of staff available (Coyne, 1995), mutual lack of understanding of

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the parental and nursing roles (Sousa et al, 2013), or simply the lack of coherent understanding of the application of family centred care into practice (Lee, 1999).

Randall's Pragmatic Theory of Children's Nursing (2016) acknowledges the complexity of the world which is interpreted by humans thus forming their social construct. Although the understanding of pragmatic nursing was not overtly present within the paediatric and parental data in this study, there were staff that alluded to applying this level of adaptation of care to the needs of children and their families. For example, for children that did not have a parent resident, [the play specialists, nursing and medical staff described ways of](#) ensuring that they have greater support in order to cope with the experience, [by](#) finding ways in which to bring their usual social context into their isolation room. The level of flexibility of this model and [the](#) acknowledgement of the wider social context of the child aligns with the needs of the families within this study.

A child coping with their experience of isolation is dependent on their family and their own social construct, sufficient support and clear understanding of the need for isolation, [all of which](#) can be supported with medical and nursing care tailored to the child and their families' needs. Children in hospital are unique and children in isolation whilst in hospital have a unique experience, one that needs to be better understood to enable us to care for the children and families, and ensure that their care meets their needs.

7.5 Conclusions

In terms of the research question, which aimed to explore the child's experience of isolation, the findings of this study seem to build in particular on the work of the research pertaining to the child's experience of isolation reviewed in Chapter Two, within the themes of control, community and coping, and more specifically in listening to the child's voice within the research. This chapter demonstrates a number of the underpinning theoretical perspectives that must be considered within paediatric healthcare and have been considered within the context of this study and the themes. The main methodological contribution of this study is the fact that children have valuable contributions within research, which will be further explored in Chapter Eight. The need for future research and consideration of the limitations of this study will be discussed in Chapter Eight also.

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8.1 Introduction

This thesis began with the goal of exploring the child's experience of single room isolation. Chapter Five and Six presented the findings to this study and Chapter Seven discussed these findings within the context of the wider literature and theoretical perspectives. This chapter will reflect upon the study, review its strengths and weaknesses and present recommendations for future practice, research and policy. Finally, overall conclusions will be presented.

8.2 Contributions to Knowledge

This PhD thesis assimilates knowledge from the disciplines of healthcare and education, and was underpinned by social constructivism, the theoretical position of children as useful, knowledgeable members of society and the use of narrative inquiry and narrative analysis. This approach demonstrated originality in terms of conducting research with children in hospital, specifically isolation, in terms of using video diary data, seeking children's perspectives and intertwining the understanding of social constructivism and narrative inquiry within paediatric, hospital-related research. In so doing, this study supports the literature to suggest that children are capable of producing useful data that can inform care, and provide insight into the experience of isolation through their own voice. The study demonstrated that the experience of isolation is dependent upon the child's social construct and context, which was influenced by the extent to which they experienced social isolation, their developmental level, the involvement of their family within their care and the perceived and desired level of control, as presented in Chapter Seven. It also generated new knowledge in terms of the challenges of using video diary as a method of data collection during this time period (2011-2015), in hospital with children as patients. This study found that using interviews with children of various ages did not obtain lesser quality data than [the](#) use of video diary as a participatory method.

The benefits of the dual role of researcher and practitioner were evident in this study, demonstrated by the inherent knowledge that informed the research being based on the clinical skills and knowledge that I have gained thus far in my career. This type of dual-

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role research work has been executed in adult settings and has also demonstrated similar increased depth and insight through this role (Beale & Wilkes, 2001; Currey et al, 2011). The clinical academic role ensured a research question that was clinically relevant, researched with the participants in mind, and it was easy to disseminate the findings in practice areas where action can be taken rapidly. Thereby targeting care at the service-users for whom it is for, i.e. the child primarily.

8.3 Reflecting on the Research Process

In order to present the implications for research, practice and policy of this study, it is first essential to consider the research process in retrospect, beginning with the research philosophy. The strengths and limitations of this study will be discussed concurrently throughout Section 8.3

8.3.1 Philosophy of Children

A key strength of this study for me, as the researcher was the presence of the child's voice throughout the findings, and the fact that the child formed the foundations on which this study was set. Children are key healthcare users and it is my premise that the care provision should be based on their needs. This study attended to this premise, and sets a precedent that regardless of the challenges involved in recruiting children to research, in particular participatory methods, the perseverance in obtaining their perspectives was without question worth it to 'enter their world' and hear their narrative about their experience of isolation. This study demonstrated that children of as young as six years have the capacity to provide assent, understand the purpose of a study and provide data that were valuable, despite the restrictions put in place by the ethical committee.

8.3.2 Social Constructivism

As mentioned at the beginning of this thesis, the study was not approached with an underpinning philosophy and methodology in mind but a need to answer the question of the child's experience in isolation. Social constructivism was selected as the chosen research philosophy as it allowed for individuals to seek understanding in the world in which they live in order to develop subjective meanings of their experiences (Gergen, 2001). Social constructivism coupled with a viewpoint of children that they are reliable, knowledgeable and active members of the hospital community drove the research

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methodology to seek information directly from children, with supporting data from other people who may have influenced their social construct whilst in isolation. Based on this insight, this demonstrates that this study was strengthened by using these methods and that they were congruent with my understanding of children. This underpinning philosophy was another key strength of the study as it allowed for multiple perspectives from the study, and accepted that there were different realities for all children. This was a useful approach when it came to narrative analysis and allowed for the use of the child's voice to "tell their stories" with direct quotes. The use of the direct quotes throughout Chapter Five and Six demonstrated to the reader the audit trail of my interpretation of findings, thereby increasing dependability of the study (Riessman, 2008). Furthermore, to enhance this dependability, primary data in the form of excerpts from interview and video diary transcripts are presented in Appendix 16 and 17, for readers to judge the conclusions make for themselves.

8.3.3 Narrative Inquiry

Narrative inquiry was selected as a structured approach to direct the data collection and formulate a rigorous data analysis method. Storytelling or narratives are an embedded part of daily life for children (Engel, 1999). For example "tell me about your day" becomes a narrative of the child's experiences of their day and therefore when using it in this study, it was a familiar process for the children participating. Narrative inquiry was selected as stories are a means in which children regularly communicate. It was a familiar concept to tell a story and that was how the interviews began, thus making the experience as familiar to the children as possible. The way in which the children delivered the data through their videos and interviews was often as stories of their experiences, and for the adults in the study, often they told short stories within an overarching narrative journeying their child's time in healthcare in general. Narrative inquiry, therefore, proved a very useful approach to underpin the data collection methods used.

8.3.4 Ethics

As discussed throughout this thesis, the child needed to be central to the study and there needed to be an underpinning philosophy, methodology, data collection methods and analysis process that allowed for this. The restrictions put in place by the ethics committee, which were put in place to protect the children and families, aimed to minimise risk of

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coercion. However, through these restrictions, recruitment proved challenging and thereby diluted the child's voice within this study.

Inclusion of children within research is limited by ethical permission and societal acceptance as described in Section 3.8. Despite this study being passed through a paediatric ethics committee, the risk of protecting children's participation in research was deemed a greater need than their voices being heard. Research is not essential, and therefore, the imposed burden and risk of participation must be balanced with the need to hear the child's voice, their right to participate and share their thoughts, which is highlighted in the UN Convention on the Rights of the Child (Unicef, 1989). As discussed in Section 1.3, recent approaches view children as social agents with rights (Huang et al, 2014; Kryritsi, 2019; Tisdall, 2016), and therefore there is greater inclusion of research for and *with* children, not *on* children. Despite the greater societal acceptance that children should participate in research, many of the participatory methods that have been used to engage with children have received critical discussion and criticism in terms of power imbalances and their rigour. I would argue that this study has demonstrated transparently a rigorous method that has engaged children, albeit not using the primary method selected, which generated no power issues that were articulated to the researcher. With greater inclusion of children's voices within studies, it is hoped that there will be greater societal and ethical acceptance of children participating in research, and it will thus become more of a social norm. Furthermore, through this greater participation from children in research, policy, practice and their care can be better tailored to their needs as specified by themselves, not [through use of](#) a proxy (Nilsson et al, 2013).

Since the completion of data collection for this study, anecdotal experiences of ethics committees have suggested that there has been a desire for greater inclusion of the child's voice in research, which is echoed in the literature (Bourke, 2017; Butler et al, 2019; Kryritsi, 2019). However, there is still not yet a critical mass of published literature including the child's voice in research in hospital settings (Elden, 2013). There are a number of research papers which support greater emphasis on the child's right to include their voice in research, which indicates this cultural shift (Abebe & Bessell, 2014; Elden, 2013; Graham et al, 2014; Hammersley, 2014). Despite this cultural movement, there remains the risk of potential coercion, particularly, with children in hospital when they are

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possibly considered more vulnerable, and as such there needs to remain a respect for the protectionist approach to children (Carter, 2009). Section 8.3.5 will discuss the ethical debate within the specific areas of this study that were potentially affected as a consequence of the ethics approval.

8.3.5 Recruitment

Recruitment may have been restricted by the lack of the face to face contact between [the families and myself](#), as the researcher but also as a clinical practitioner. Newington & Metcalfe (2014) identified four themes to recruitment, infrastructure, nature of the study, recruiter characteristics and participants characteristics. Infrastructure within this study supported recruitment in that all ward managers approached were prepared for their wards to participate in the study. However, the frequency of staff referring potential participants was minimal, [with only three referrals](#) throughout the entire study. Thus, I was reliant on visiting the wards frequently to identify potential participants for recruitment, which was labour intensive and may have led to some potential participants being missed, due to the high patient turnover on many of the wards. Despite visiting most days Monday-Friday and over the weekend if working clinically, this method did not recruit sufficient participants. This demonstrates the importance of strong research-focused infrastructure and engagement from all clinical staff. Within the nursing culture, research is not a priority compared with other tasks that a nurse must undertake for their patients within a given shift (Paget et al, 2014). Therefore, as previously noted, a possibility to overcome this lack of staff referral may have been to present the research to the junior medical team for them to identify potential participants, as the medical team have more interaction with research recruitment in their clinical role (Paget et al, 2014).

The nature of the study was a factor that limited the recruitment of the study as children in hospital are unwell, and therefore more vulnerable than in their usual social context. Consequently, potential participants described their reason for non-participation as not wanting to be on a video due to their appearance or being too shy to participate. Additionally, there were reasons for non-participation associated with the use of video diaries such as not wanting to film their experience, or too embarrassed to use the video camera (see Table 5.3). The other reasons for non-participation were associated with logistics in terms of recruitment such as the ward being closed, or patients being

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discharged prior to recruitment. These were out of the realms of control and could have happened with any prospective form of data [collection, however these considerations](#) may need to be [acknowledged for](#) prospective recruitment in studies in the future. The recruitment issues were improved with the use of retrospective interviews as recruitment occurred when patients were discharged, thus reducing the burden to collect data when unwell and vulnerable.

The final two characteristics described by Newington & Metcalfe (2014) are concerned with the researcher and participant characteristics. The literature attests that face to face recruitment builds up a bond between the researcher and the participants early in the research process and they are more likely to participate as it gives the research a personal approach (Phelan and Kinsella, 2013; Powell & Smith, 2009). The ethics committee requested that I did not approach the participants directly until they expressed an interest in participating, therefore the researcher characteristics which Newington & Metcalfe (2014) described did not influence participation and recruitment positively. The use of gatekeepers was employed at the request of the ethics committee as a means of avoiding any possible coercion. This required a proactive attitude and approach to recruitment. Yet [according to Graham et al \(2014\)](#) this could have been eased, and therefore potentially recruited a larger sample of children with more diversity if there were less ethical restrictions and more freedom for me to directly approach the potential participants and their families. For future studies, it is worth considering the need for a personalised approach to recruitment and if face to face recruitment is not possible then the use of interactive media such as videos, or a webpage [may be a useful alternative as it would](#) allow the participant to “meet” the researcher, which has been shown to improve recruitment (Denhoff et al, 2015; Topolovec-Vranic & Natarajn, 2016; Waheed et al, 2015).

The recruitment of children was initially limited to eight years, which was potentially overly conservative, as I successfully recruited and conducted interviews with two children under the age of 8 years (Harriet and James), once permission for this ethical amendment was granted. This demonstrates that age should not be the only determining factor in recruitment, and that children need to be assessed for competence and understanding of the research. This said, there may have been children younger than six years who could have participated, based on [the](#) developmental theories described in this thesis. Yet age is

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predominantly used within the UK as a defining factor for ethical approval within research, not solely a researcher's judgement of competence. It must therefore be acknowledged that the use of age as an exclusion criteria may deny competent and willing children the opportunity to participate.

The lower age limit not only allowed me to access the voice of younger children and hear their story, but also demonstrate that it is possible to conduct research with younger children and gain valuable, useful data from their participation. It would be useful for ethics committees in the future to consider the judgement of researchers within the assessment of competence of children, regardless of age in terms of their participation. One benefit of the clinical academic role is that as a paediatric nurse I understand what children are capable of when in hospital and feeling unwell. This guided my ability to ascertain whether a child was capable of participating and I feel that it would have been possible for me to do this without coercion in the absence of a strict age limit. However, considering the ethics committees' perspectives, this may result in coercion and exploitation of children who do not have sufficient understanding of what they are agreeing to participate in, making the process unethical (Skelton, 2008). There needs to be a considered approach to [ethical approval for research](#); balancing the protection of the child's rights and their autonomy [with their right to participate](#); which may need [ethical decision-making](#) to move away from age as a defining factor (Morrow & Richards, 1996).

This study was conducted within a large regional specialist hospital, which may have limited the number of general paediatric patients that would have been recruited from the specialist wards within this hospital. Within the sample were a number of conditions that would have much of their care on general paediatric wards within district general wards, or would have received shared care between a specialist centre and a district general paediatric ward. The hospital under study is within one geographical area of UK, where the political and nursing policy, climate and practices may not be representative of the entire UK, which could have limited the transferability of these findings. However, due to the rich description of the children and their clinical setting, it is hoped that readers can use these findings within the context of their own clinical setting. The opportunity to conduct this study across multiple sites may generate very interesting findings, however

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pragmatically and logistically this would have been an unachievable task within the constraints of the time allocated and for me as a solo researcher without a team.

The use of electronic communication for recruitment was not considered for this study as in 2010-2011 when the original ethics submission was made, the use of social media and electronic communication was not as commonplace as it is today. Yet in the evolution of time since the study started, electronic recruitment may have been a more appropriate method to recruit. Akard et al (2015) and Close et al (2013) described increased recruitment using electronic communication as part of recruitment. Additionally, Logsdon et al (2015) demonstrated the benefits of using social media and email recruitment, as they were media that young people were accustomed with, and they could evaluate the context in an open platform prior to making a decision regarding participation.

8.3.6 Sample Size

The main limitation that is regularly described in qualitative literature is the sample size (Streubert & Carpenter 1999, Trotter, 2012). The sample size in this study was adapted through numerous modifications and reframing of the make-up of that sample in accordance with the recruitment challenges. It was discussed at length the number of children required to ensure that their voices were not diluted by proxy perspectives. Although there are fewer than originally desired children within the study, the child's voice led the analysis and theme generation. The original plan for 10-20 children that were hoped to be recruited in the original plan for the study using video diaries was adapted to have more parents and staff participate, which supported the children's narratives. It has to be acknowledged that this study does represent a small number of children that participated, when considered in the context of the number of children admitted to isolation within this hospital, or within isolation within the UK or worldwide. It is however possible that the findings from this study could be transferred to similar situations, with similar participants, due to the heterogeneity of the general paediatric patients within this study, and the context-specific rich description of the study construct (Holloway & Wheeler, 2002).

8.3.7 Data Collection Methods

In order to find an appropriate method to retrieve, useful and extensive data from children, in a manner that was approved by the ethical committee, the data collection methods

Deleted: ¶

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needed exploration and debate. Multiple methods were considered, and the video diary method was the first approach used in this study. Trustworthiness of the study was strengthened by meticulous endeavours to ensure transparency throughout the research process as detailed in Chapter Three.

8.3.7.1 Video Diary and Video Stimulated Recall

Video diary data and video stimulated recall was an effective data collection method in the literature within education settings and in healthcare settings where the child was an outpatient or not the patient (Jones et al, 2015; Lomax & Casey, 1998; Mannay, 2016; Noyes, 2004; Rich et al, 2000). The use of video in healthcare has been limited to filming clinical procedures such as resuscitations for education and reflection purposes (Gelbart et al, 2009, Monger, 2014), and specifically in paediatrics for covert surveillance of suspected child abuse (Bauer et al, 2004). The lack of video-based research within the field of health research could be attributable to the lack of information about the analysis of this data, or due to the potential difficulties in gaining ethical approval for this method as described by Sayre and Halling (2007). Additionally, it is possible that lack of literature pertaining to the use of video diary data in hospital may be due to the fact that other studies have struggled to recruit and therefore not produced a publication to present negative findings in terms of the use of video diary data. Thus, an output from this thesis, will be to share the knowledge of the research methods to illuminate the challenges to other researchers. It would be interesting to ascertain if the results of this study, in terms of challenges of recruitment were the same today, where the use of video cameras are more engrained within society.

Table 5.3 in Chapter Five presented some of the reasons for non-participation to the video diary part of the study. The reasons for non-participation included patient clinical issues, patient preferences and clinical researcher issues. Although the use of video diary is not documented in the literature for inpatients on paediatric wards, the use of video diary has been used in other settings and some of these reasons for non-participation echo the work of Harrison (2002), Noyes (2004) and Lomax and Casey (1998). Buchwald et al (2009) suggested that video diary was familiar and confidence inspiring for children, however this study highlighted the converse as some potential participants did not participate as they did not want to be filmed. From the two participants who took part in the video diary element

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of the study, there were comments made in the video and interview regarding the video diary method. From Lara's video diary:

Mum: "*Lara is a bit nervous about using the video camera*"

From Simon's case study, in the video stimulated recall interview:

Interviewer: *Here we are, this is your first video.*

Simon: (as the video starts) *I feel a bit embarrassed!*

Self-image was expressed as a concern by Simon and Lara when making their video diaries. This issue was not anticipated which may be reflective of the age and maturity differences between the researched and myself. Furthermore, this demonstrates that despite my insider knowledge of the health care the children would experience, I did not understand the experience through the child's eyes, again demonstrating the importance of the child's voice within this study. The participants within the video diary part of the study both mentioning self-image could also have been reflective of wider social influences on their social construct and how the children considered that they were perceived by others. Meadow (1969) described children as being at their most vulnerable when in hospital, which may be why children in other studies in educational settings (Rich & Pataschnick, 2002; Noyes, 2004) were keen to participate in video diary data collection more than in this study. The issue of negative self-image and not wanting to be represented within social media, videos and photos is not solely restricted to hospital (Jones et al, 2015; Strasburger, 2010). Within the literature this is reported as an issue for many older children, however being in hospital and feeling unwell may heighten this negativity (Fan & Eiser, 2009; Rokach & Parvini, 2011; Vilhjalmsson et al, 2011). It was evident from the oncology patients that were approached for recruitment that appearance was an issue that affected their participation, and this aligns with oncology literature (Fan & Eiser, 2009). Yet, self-image may also be relevant to any child who feels unwell in hospital, with older children more vulnerable in this respect; this is an area that may warrant further research. There were children that did not participate who suggested that the video was the reason for non-participation and embarrassment about using it, and not all of these were oncology patients. Furthermore, with the increasing use of social media specifically amongst children, this study identified not only an area of research for the future, but also an area

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which may influence health, specifically psychological well-being of paediatric patients and thus needs to be considered in practice (Boyd, 2015).

Another issue within video diary that emerged within this study as an area which supports the use of video diary was [the](#) power imbalance in traditional research methods. For the purposes of this study, I was not involved with the children until consent process, and then again, I was removed from video data collection after I had given the video camera and instructions or filming to the child. Although I had limited involvement in the construction of the video, it could not be said that I was “absent” within their research as I provided guidance on what to film. However, the use of the video diary meant that the power was shifted further towards the children as they could dictate the content of the video diary.

Below is an excerpt from my reflective diary which documented my interactions with Lara and how I perceived her behaviours.

“I am not sure that this participant will talk to the camera. I visited Lara today and she was very monosyllabic in her responses. This could have just been that she was having a bad day, but I am not sure that she will document a lot on the video if she speaks like that to the camera. I worry that she is no longer keen to participate, so I did ask her if she still wanted to participate in the video diary and without her mum present, she did answer “yes”. Maybe as her mum wasn’t there she felt a power imbalance by me being there... I was conscious of this and so I did not stay for long and just encouraged her with what she had done and thanked her for her contribution. This could be an indication of how the physical presence of a researcher would make a teenager ‘clam up’ if chatting to them with limited rapport though. Maybe the video diary is a great entry into their world without me having to interject.” Researcher, from reflective diary.

This demonstrates how Lara could have not shared her experience in detail if I were to interview her, however in the video diary she was able to share her experience when she was alone and with her mum present. The video diary entries where Lara and her mum were both present contained limited conversation from Lara, similar to her level of interaction with me as documented in the excerpt from the diary above. This exemplifies the difference of the presence of an adult and the shift in power relations and subsequent ability to open up in front of the camera. This concern is echoed in the work of Buckingham (2009) and Piper & Frankham (2007) who identified that the video diary may not solely be the work of the participants but may be socially influenced by other people, or the researcher.

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Many of the other reasons for non-participation to the video diary were related to clinical issues related to the dual role of the nurse-researcher, for example the researcher being screened for MRSA PVL. These issues could not be avoided, and they are potential challenges associated with the dual role of a clinical academic nurse. Unforeseen circumstances such as the ward being closed were infrequent; however [this](#) restricted recruitment to this study. There is no way to overcome these restrictions, [yet](#) this should be considered as a possibility when estimating recruitment periods, particular with clinical academic researchers.

Noyes (2004) and Pink (2001) argued that video diary provided a richer form of data. In this study, the video diary data that was collected was more complex in terms of the detail of non-verbal data collection and observing the space and environment in which they experienced isolation. However, neither video diary was long, or documented on each day of their admission. Furthermore, the quality of the data collected with the video diary was considerably less than the interview as I could prompt the narrative as part of the interview. Whereas in the videos I was an absent researcher and although I gave each participant guidance on filming, they only followed this with reference to what not to capture on the video diary. This is identified in a paper by Jones et al (2015), that despite obtaining different data in the form of a video diary, it may not be that all video diaries will provide greater quality and quantity of data than an interview; this was demonstrated in this study.

Buchwald et al (2009) used video diary and interviews in their study, and received good levels of recruitment, however this included face to face recruitment. In Buchwald et al (2009), the children found it challenging to talk to a camera, however they found it easier to identify the camera with the researcher, who they knew from the first interview (Buchwald et al, 2009). This process of interviewing first, and video diary second may have provided more insight for the child to what they needed to film. However, this was not possible in the context of this study where isolation had a finite period, and it was often short term. Buchwald et al's study (2009), does support the theory of face to face recruitment and introduction of the research to develop rapport and engagement in the study to ensure that the data collected by the children were both relevant and detailed.

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Using video diary data with children, there was a risk that a parent may encourage the child to participate and coerce them to complete the video diary, rather than by the child's will alone (Harris et al, 2014). Often children were encouraged in this study to engage with myself by their parents during the interview and video diaries, which could have been perceived as encouragement. This is why it was essential to establish assent with the children that were not deemed competent to consent to participate. For me as a paediatric nurse and researcher I wanted to ensure that the children were aware of what the study entailed, and what they were required to do. Although coercion is documented as a possibility in paediatric research, within this study the opposite often occurred, whereby in addition to the ethics committee being gatekeepers, the parents were gatekeepers also. It is documented in the literature that parents may feel an obligation to protect their child from harm when they are in a vulnerable position, such as hospitalisation through non-participation in research (Elemraid et al, 2013; Sammons et al, 2007). This level of protectionism has been noted in other research areas in research with children (Danby & Farrell, 2004; Gallagher et al, 2009). This reignites the debate of protectionism or allowing children their right to participate as discussed in Section 1.3. This must be a consideration for all researchers working with children, particularly if the children are not allowed to be approached independently.

Despite the challenges with video diary data collection methods in this study, it is my conclusion from this study that this method holds a place for researching children's experience, yet it is a method that warrants further exploration with children in a healthcare setting. In this study I am not convinced that the use of the video stimulated recall added supplementary detail to the interview. However this may have been because there was only one participant to this part of the study and he was the oldest participant, thus his recall was in alignment with adults, whereby he recalled the experience without the need for the video. If this method were to be trialled with younger children, it may have been more useful. Therefore, the use of video stimulated recall interviews cannot be either recommended or refuted as a consequence of this study. On reflection, I selected this method as I believed in the positive aspects of video diary data and video stimulated recall in a time period when video diary was not the norm for children, particularly when ill. In the modern era of social media and electronic communication, there may be an alternative outcome from recruitment to a video diary study.

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8.3.7.2 Retrospective Interviews

Retrospective interviews are used widely in qualitative data collection and narrative inquiry (Engel, 1999). The alternative approach of retrospective interviews aimed to capture the narrative of the experience of isolation, only retrospectively. There was a high percentage of non-participation for children and parents to the interview part of the study in addition to the video diary. The challenge of recruiting to the retrospective interviews was enhanced due to the nature of recruitment being via post, which Parahoo (2014) suggested had reduced chance of recruitment when compared with face to face recruitment. However, in this study, with retrospective interviews sufficient participants were recruited.

It is documented that there are a number of safeguards that can limit the recruitment to studies (Alderson & Morrow, 2011; Houghton et al, 2010), as was evident in this study. The main limiting factor in this study was the use of gatekeepers (as described in Section 8.3.5), which meant that the parent made the decision regarding the child's participation before the child knew about the study. Yet, this was a specification of the ethics committee and a necessary gatekeeper process.

The recruitment of staff to interviews was more rapid, and the percentage of non-participation was considerably lower than that of parents and their children. This more rapid recruitment of staff may have been a result of my presence on the wards in the clinical academic role as described in the literature as a benefit of the clinical academic role (Ashton, 2014; Richards & Emslie, 2000). The familiar nature of research to professionals and the understanding of its clinical benefit may have increased the likelihood of participation. Additionally, the culture of the children's hospital within which the research took part is a research proactive environment, which may have encouraged participation from staff members within that culture.

Retrospective data collection with children introduces the argument of memory recall and how much detail children can remember from an episode of illness that may have happened a period of time before the interview occurred. Participants were only recruited up to one month after discharge and a little bit of initial discussion about the hospital and the room began each interview to refresh the participants' memories, as described in the

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literature (Badinlou et al, 2018; Howard et al, 2006). Through the use of triangulation of data sources with the parents and the child, there were a number of commonalities shown, where the child could recall the event without the detail and the parent provided the detail to that story. This happened in particular in Harriet, Imogen and James' narratives, where the children were the youngest participants.

Another fundamental issue in the literature concerning interviews with children is the impact of the researcher and the willingness of the child to discuss their feelings with a stranger (Graue & Walsh, 1998; Greig et al, 2007; Patton et al, 2015). The literature attests that children may not share their true thoughts and feelings, but rather what they think the researcher wants to hear (Greig et al, 2007; Westcott & Littleton, 2005). In the interest of familiarising the children to the interview process, many of them watched the parents be interviewed, whilst playing with their toys in a nearby room, so that they could observe that it was nothing of concern. For all the child interviews the parents decided to stay with the child. The parents being present may have impacted the data retrieved also (Greig et al 2007), yet in the child's best interest, this was necessary. The parental presence was also a safeguard for me as the researcher, and their presence was useful to elucidate information in some conversations. With the parental presence, there were some guarded responses from the children, such as Nicholas and Eloise's narrative, which consisted of many single one-line responses. This type of response could have been their personality, nerves about the process or the presence of their parents, or my presence. The parental presence potentially impacting upon the data is this study is congruent with the literature pertaining to dyadic interviews, where often one person selectively holds back information due to another person's presence (Morgan et al, 2013). However, the literature also attests that dyadic interviews can produce broader findings as one person recalls an experience that the other would not have remembered without prompt (Morgan et al, 2013; Sohler, 1995). The data provided in this study was strengthened through this triangulation process.

8.3.8 Triangulation of Data Sources

Sandelowski (1995) described triangulation as a means of different data sources corroborating one another, enhancing validity through convergent and consensual findings. The data were triangulated in the form of different perspectives, which enhanced the dependability of the findings through convergent validation and development of analytic

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density or “richness” of the data, and thereby enhancing validity of the findings (Clark, 2017, Fielding, 2012). At times within the interviews, where the child was not present during the parental interview, children recalled the same moment within their hospital stay as their parent, which showed the benefit of using this approach. For the children who were unable to provide the interpretative level of data, the parents were able to offer insight into their child’s understanding of that experience. The parent and child dyad showed some discrepancies and concordance in their findings which demonstrated the differences in understanding of that experience, according to their individual social construct and life experiences. The incorporation of the staff data provided an alternative lens, which sought to explore the wider perspective of children in isolation. Not only did the staff give insight from just the ward where they worked, or for one child’s experience, but also the experience of many children of all ages throughout their experience of working with children within isolation within the hospital under study, and within their career in other hospitals. It is acknowledged that the proxy perspectives used in this study do provide a lens on the child’s experience, yet they are not the child’s experience verbatim, which is a limitation. The proxy lens presented within this study provided alternative views on an experience, which has enhanced the limited child data, thereby increasing dependability of the findings. Furthermore, demonstrating that using the child’s voice as central, and different perspectives to support these findings can provide a rigorous method to complete a piece of paediatric research.

The child and parent data were a dyad exploring the experience of their time in isolation, yet the staff provided an overview of their experience of isolation throughout their career. This meant that the staff data did not describe the same experience as the dyad. However, without this overview data from the staff, there would have been less contextual data to situate the dyads of data from the children and parents. The process of different data sources to build a picture of the landscape is described as completeness (Caldwell, 2014; Tobin & Begley, 2004). Completeness acknowledges that there are multiple realities, thereby offering a deeper and more comprehensive overview of an experience (Tobin & Begley 2004). Without the parent and staff perspective within this study, the data would have lacked depth and breadth of the overall experience for all within that social context.

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8.3.9 Length of Data Collection

The data collection occurred between February 2011 and January 2015, which was prolonged beyond the initial timeframe planned. Repeated resubmission for ethical approval extended the data collection period which was not anticipated. Due to unfamiliar procedures and unforeseen obstacles, this led to considerable time delays in my research timetable; a difficulty not unique to my research as reported by Stalker et al (2004). Parent participants and staff participants were recruited more rapidly, however for me the essential part within the data was the child's voice. Thus, on balance, it was the better option to prolong the data collection period rather than dilute the child's voice in the data. During the data collection period, the ward management and structure of the wards did not change, thus making all the data comparable.

8.3.10 Respondent Bias

The families that responded for participation were skewed towards children with chronic health needs. Within the literature there is a greater level of altruism amongst children and families who attend hospital regularly as part of a chronic health needs, and this may account for them being well represented within the study (Abebe & Bessell, 2014; Hamann et al, 2007). It may also have been that these children and families were more likely to participate as they could see that this research may have an impact on the health care that they will receive in the future, and thus were more willing to participate. The motivation of children to participate in research is not well represented in the literature, and it warrants further exploration to inform future researchers who want to target this population. Similarly, within the parents that participated, there was a doctor and a nurse which may demonstrate a respondent bias, as healthcare workers understand the impact of clinical research, and therefore they want to share their experiences when receiving healthcare. Although this demonstrates respondent bias, it provided another lens- the healthcare provider as a parent.

The children within this study did not represent the ethnically diverse population of the hospital, with only one participant describing themselves as an ethnicity other than white British. Another area that is not well represented in this study is the social diversity. The children within this study were all children with at least one working parent, and the majority were from two parent families. The challenge to recruit children into this study

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did not allow for enhanced purposive sampling in selecting participants beyond those which met the inclusion criteria. Therefore, it was not possible within the purposive sampling to seek out ethnic and social diversity. It was essential to accept participants that responded to the invitation to participate, and the diversity of the sample was not purposively determined. The limitation in terms of diversity could also have been attributed to the lack of translators available to assist with recruiting families who did not use English as their first language. There is some evidence to suggest that there is a difference in willingness to participate in different social groups (Wendler et al, 2005; Yancey et al, 2006). Furthermore, the manners in which to seek to recruit these populations would have been difficult within this research study where recruiting any children to the study posed challenges.

The short answer responses that were given by some of the children could have been representative of the respondent bias in that child participants who wanted to provide the “right” answer in the eyes of their parents, and myself as a nurse and researcher. It is a possibility that the children answered questions at interview in a manner that was socially acceptable, rather than what was actually true for them. A strategy used to overcome this issue was to specify the need to tell the truth regardless of what it was, and that there were no right answers at the beginning of the interview. Furthermore, it was essential to reassure the child and their parent that there were no negative consequences for them or their future care (if applicable), regardless of what was said at interview.

Another part of respondent bias was the lack of father’s participation within the study. Although the study was open to recruit both mums and dads without discrimination, it was the norm that the mum would stay in hospital and thus participated in the study. One father did participate and shared a different insight into the parental experience. It would have been interesting to explore this experience further with other fathers. The literature suggests that fathers have different perspectives on hospital experiences compared with the mothers due to their role of protector, partner, provider and breadwinner (Arockiasamy et al, 2008; Higham & Davies, 2012). The father’s voice was lacking within this study, which was a limitation to the data. A greater contribution from fathers within the data could have added value in how they perceived the experience, and how this impacted upon the child’s social construct and experience. In other paediatric studies the father’s perception has been illuminating in providing the complete family picture of an experience (Garfield & Isacco,

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2011; Sigurdardottir et al, 2016). However, it is acknowledged within the literature that capturing the paternal perspective on a child's experience can be challenging (Davis et al, 2019). It is with regret that more fathers did not participate in this study. However due to the lack of fathers presence on the wards, and the fact that the interviews were conducted when it was most convenient for the child (i.e. during the day), they were often not available to participate or felt that the mother had a greater contribution to the study. These reasons for non-participation are deduced from the mothers. Therefore, it would require further exploration with fathers to seek the narrative of non-participation and if this was a conscious decision or a situational issue, that could be addressed in future studies. For the purpose of this study it was necessary to have a perspective of the parent to support the data that the child provided, not necessarily the conflicting and confirmatory perspectives of both parents. Due to the lack of comparative studies of maternal and paternal perspectives of children in isolation, this may be an area that warrants further research to tailor care to their needs.

Finally, the lack of inclusion of the siblings' voice is something that throughout this research process has become ever more apparent. Family centred care embraces the notion of including all members of the family, but in reality, this tends to be the parents only, who aid in care provision (Barr & McLeod, 2010; Coyne et al, 2018). From anecdotal experience, siblings in hospital often become the forgotten entity. They are often required to visit their sibling in hospital as their parent(s) are there, however there is limited entertainment for the siblings, as reported in the literature (Akard et al, 2014; Prchal & Landolt, 2012). Yet siblings are not allowed to be resident with their sibling who is hospitalised. Many of the parents within this study described the 'juggling act' of managing home-life and hospital-life; and much of that surrounded the challenge in managing the child in hospital with their siblings, and their requirements to maintain some degree of normality within their home life or their social context. The literature attests that siblings of children in hospital struggle, particularly with their sense of self (Yang et al, 2016). From this study, particularly in the parental and staff responses, it was apparent that there is even less to support the experience of siblings of children in isolation. When the sampling was broadened to include parents and staff, including siblings as well could have been a wise consideration, and it is thus something that would be recommended in future work.

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8.3.11 Rigour

The underpinning measures of rigour used within this study were Lincoln & Guba (1985). They divided rigour as being represented by credibility, transferability, dependability and confirmability.

The credibility of this study is exemplified in the rigorous data collection techniques and the strong need to seek the child's voice as central to the piece of research (Patton, 1999). My credibility as a researcher has been enhanced through conducting this study in a rigorous manner. Additionally, my role as nurse enhanced my credibility with staff and families in terms of collecting data with them. The methods used were focused on hearing the child's voice and again, this enhances the credibility of the findings, irrespective of the fact that different approaches were used to gain the child's insight.

Transferability was demonstrated in this study through the thick description of the hospital setting and the description of the participants that was presented throughout the findings to provide the social context within which the findings were given. The use of raw data to support the themes and subthemes also demonstrates the transferability as described by Connelly & Clandinin (1990). Furthermore, through providing a clear audit trail of the decisions that were made throughout this study, transferability was enhanced (Koch, 2006). The use of the reflexive diary excerpts within this thesis aided transferability and transparency of the data and the decision-making processes. The use of the diary initially was for my personal reflection to observe my development as a researcher. However, it became evident when writing in it, that it could be used as data to inform the explanation of the social constructs of the participants. The diary was an invaluable resource when analysing the transcripts and allowed me to "go back" to the interview and review the transcripts within their context. Jootun et al (2013) explained that the relationship between and influence of the researcher and the participants should be made explicit, which is demonstrated in the reflexive diary excerpts. Clandinin & Connelly (2000) explained that narratives become constructed at many levels; in this study by the participants as a personal narrative, but in the presence of the researcher as a jointly constructed narrative. During analysis the narratives became a metanarrative and there was a risk, without use of the raw data that the individual narratives and my personal narrative would be lost, hence the use of raw data. Collaboration occurs in narrative research from beginning to the end (Connelly & Clandinin, 1990). In this study, the stories were outlined and potentially

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revised in my presence as the memories were recalled. In this study this was not perceived as a risk to rigour, as participants shared their story as they perceived it, in the form that they wanted it. The learning from this mutual researcher-researched relationship has been shared in Section 8.5, and it is viewed as a benefit of the clinical academic role.

The dependability of this study has been demonstrated through the use of a strong theoretical framework which has been considered throughout all decisions that were made within this study (Mays & Pope, 1995). Furthermore, through the triangulation of data sources as described in Section 8.3.8, the dependability of this study was enhanced, in order to provide a broader and deeper picture of the experience of isolation.

Confirmability is described as the process of ensuring that the data represent the phenomenon under study (Thomas & Maglivi, 2011). The findings were analysed by myself and then taken to academic supervision and discussed with other academics within the field, to ensure that the findings were represented within the themes.

Overall the rigour of this study was considered at all stages of decision making, to ensure that not only the maximum sampling and use of participatory methods could be incorporated within this study; but also that there were clearly rigorous findings that could be considered for all practitioners working with children in isolation. Lincoln & Guba (1985) was a useful framework to provide a basis to compare the study against during the process to ensure that it met these criteria.

8.4 Implications of the Research Study

This study was designed to be a resource for all who care for children in isolation. Through considering the findings in the context of their own work environment and within the social construct of every patient and family, this study has implications for delivery of care for children in isolation. It also has implications for future education, research and policy, to inform care of children in isolation, which will be discussed in the following sections of this chapter.

8.4.1 Implications for Practice

This study has provided evidence to show that children in single room isolation required different levels of support and interaction at different stages within their time in isolation, in accordance with the metanarrative of control, community and coping. The level of

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support that children needed during their time in isolation was dependent upon their developmental level, need for control, feelings of social isolation and their understanding of partnership and family centred care as demonstrated in the narratives of the children, families and staff within this study. Children and families want to be cared for in an environment where they can extend their usual social construct and not remove themselves from their norms. This study demonstrated that there was a difference in the knowledge of isolation precautions and the informal rules of the ward between the practitioners and the child and parents in isolation. The sharing of the knowledge of informal rules of ward and what to expect in isolation is paramount to empowerment of the parents, and overall how they experience their time in isolation. This knowledge ensured that families knew what to expect when in isolation and enabled them to be prepared and able adapt to the environment of isolation, as demonstrated by participants within this study that were used to isolation. This demonstrated the importance of providing information to all families that enter isolation facilities. Although there were areas that staff felt unprepared [for](#) in terms of knowledge, they understood the isolation precautions, and therefore they could have prepared the families through sharing of knowledge and negotiation of roles in caring for the child. Through empowering children and parents with knowledge regarding isolation, it is possible for them to work collaboratively with staff to ensure that the child's care is based on the child's needs, within the constraints of the ward and the wider NHS. This study demonstrates the power that parental role has in the care and support for the child, but also the need to empower parents with knowledge to ensure an effective collaboration of roles between staff and parents.

The findings highlight the role in which the staff support the child and their family in isolation. In terms of staff provision, the question needs to be raised at a strategic and management level, and potentially on a national level, regarding staff allocation and ratios for patients nursed in a main bay compared with an isolation room. It can be suggested from this study that isolation does place [an additional](#) burden for staff in terms of infection prevention procedures and the need to provide psychosocial care for a child and their parents that are removed from their normal social context, [due to](#) the physical barrier of [the](#) isolation room. [The](#) provision of staff could be considered in terms of volunteers or non-clinical staff such as school staff or play specialists ensuring that children and families in

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isolation are viewed as a priority in terms of the need for distraction, social interaction, support and information regarding the informal rules of the hospital.

As presented throughout this thesis, family centred care is central to paediatric practice. However, as it is discussed in the literature and the findings from this study, there is incongruence between the theoretical understanding of family centred care and the practical application of family centred care (Coyne, 2015). This thesis contests family centred care and purports that family centred care in isolation does not exist in the theoretical premise that it is presented in the literature (Shields, 2015). Family centred care is a concept that is well taught at undergraduate level within paediatric nursing courses in [the](#) UK, but the practical application on wards, specifically in isolation was less evident within this study, than it is described in the literature on the main wards (Franck & Callery, 2004). Despite this, there is evidence throughout the metanarrative of this study that parents are involved in the child's care whilst in isolation; often relied upon by staff to provide the child's care. There is a necessary balance between the care provision by staff and parents on paediatric wards. Without parents, paediatric wards would struggle to provide the same level of care with current staffing levels. Conversely, parents often want to and are the best people to provide their child's care. Tallon et al (2015) proposed that family centred care needs to be focused on the child's health and developmental needs rather than the needs of the organisation. Although, not explicitly described in this study, the literature suggests that these roles need to be negotiated (Casey, 1988; Corlett & Twycross, 2006) to allow transparent role allocation between staff and parents, so that parents do not feel relied upon, but empowered to do what they can for their child.

Parents of children in isolation in this study were not given all the necessary information to provide the care for their child such as the "ward rules" in terms of isolation practices. Therefore, a key recommendation from this thesis is for educational institutions to revisit their teaching around family centred care and consider the alternative perspectives as discussed [in](#) this thesis of Child Centred Care (Coyne et al, 2016) and Pragmatic Theory of Children's Nursing (Randall, 2016) to allow practitioners to draw on these theoretical perspectives in their care provision. From this thesis and my knowledge of clinical practice of providing care for children in isolation, family centred care is partially happening, but challenging to facilitate in isolation. Child centred care (Shields, 2005) as discussed in

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Section 7.4.1.2, has a place in paediatric nursing in isolation, but challenges practitioners when children are unable to specify their needs and desires. I suggest that the Pragmatic Theory of Children's Nursing (Randall, 2016) aligns itself with current practice as displayed in this study. Through enhanced knowledge of both child centred care (Shields, 2005) and the Pragmatic Theory of Children's Nursing (Randall, 2016) at undergraduate level and throughout paediatric nurses' careers, it could support staff to empower parents with knowledge, and allow them capacity to care for their child as they wish, through discussion and negotiation. This level of education needs to be provided both at an academic level to prepare future generations of paediatric nurses, and at a clinical level to staff providing care for children in isolation to support them in opening conversations with families regarding the level of care that they want to provide, and how the staff can support this whilst their child is in isolation. Furthermore, local isolation policy needs to specify the need for education for practitioners providing the care to children in isolation to receive regular updates in terms of negotiating care whilst in isolation.

The findings in this study and incidental findings through challenges in recruitment, highlighted that as a healthcare team we have a tendency to remain protectionist towards children. Through this protectionist attitude, children's rights may not be considered at the forefront of our care decisions, rather the whole family might be considered with the child being part of that decision. This study has shown that children aged six and above can contribute to research, make independent decisions regarding participation in research, articulate the way that they interpret a situation and share these within a research interview. This demonstrates that many children are able to articulate and may not always need the protectionist approach that we assume in society, but more specifically when the child is ill and in hospital. Children's rights need to be respected in the same manner in which adult's rights are respected as described in UN Convention on the Rights of the Child (Unicef, 1989). However in clinical practice, and in research there is a necessity to safeguard children (both by parents and staff), particularly when they are too young or too ill to articulate their care decisions. Therefore, although care needs to be based on the child's rights and wishes firstly, ahead of their parents, the role of those within the child's social construct and those who are seeking to protect them must be considered until they have capacity to make an autonomous decision. These concepts surrounding children's rights can be considered locally when caring for child in hospital, when planning service

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provision and resources within a hospital, or when considering interaction with children within society.

Through this study there is an enhanced understanding of how staff perceive the experience of isolation; both in terms of the personal challenges in providing this care, but also in how they felt families experienced their time in isolation. Although this study is small scale and single site, many of the findings corroborate with the findings as presented in Chapter Two from the paediatric literature. Therefore, there may be sufficient evidence that national isolation policy within the UK should suggest that there is the incorporation of child centred care (Shields, 2015) and the Pragmatic Theory of Children's Nursing (Randall, 2016) into their policy and teaching, to support staff in providing care to the child and their family.

This study served as an opportunity for the participants to reflect specifically on their understanding of the experience of isolation, which is something that they may not normally do as part of their clinical practice. Additionally, for readers of the research and for anyone who hears this research presented, they will also be given the opportunity to hear the child's voices and understand their experience of isolation. In a resource-limited NHS where staff may not have the time to reflect on patient's experience and how this impacts on their care, studies like this allow practitioners to reflect on their experience and with no greater resources, they can make a difference to the patients in their care, through adapting their approach to meet the child's needs primarily, but also acknowledging that the parents' needs are important within a child's stay in isolation, more so than in hospital. I have observed within my own clinical practice throughout this study, that my practice, understanding and compassion towards those in isolation has changed. This study has opened my eyes to the experience of isolation from the child's perspective, and I now care for such children differently; understanding the challenges that they may anticipate in their time in isolation. My hope is that through sharing these findings within this thesis and dissemination, I will enable others in similar roles to see the experience of isolation through the child's eyes and that this in turn will influence the way in which they care for children and families in isolation in the future.

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In summary, when presenting these findings to clinical colleagues within the hospital under study, they wanted to know the key aspects of care that they could change, which I have presented below. These are simple, clinically relevant suggestions for practice, which have been provided to ward managers and staff, however these could be transferable to other clinical areas if considered in context.

- Negotiate the role of parents and nurses in isolation, to provide for the child's needs and ensure parents feel supported
- Provide individualised, pragmatic, child-focused health care, acknowledging that the parents are an important part of the social context of the child, specifically in isolation
- Provide orientation to the ward, the "informal rules" and the reasons for isolation to the child and parents
- Ensure parental support is provided to allow for time out for the parents and different interaction for the children
- Consider the provision of ward resources to alleviate boredom for the children, prioritising children in isolation as they do not have the distraction of the community of the ward
- Acknowledge developmental differences of children
- Acknowledge the role of the staff in providing high quality, supportive care to families, and therefore consider re-evaluating resource management for patients in isolation
- For management and resource allocation: consider the additional burden for the staff in caring for families in isolation

8.4.2 Implications for Future Education

The main implication for education is to share the experiences of the children in isolation, to ensure that practitioners can see the experience through the child's view and tailor their care accordingly. Through dissemination of the findings already through conference posters and presentations, the knowledge of the experience has been shared in terms of the key findings and implications for clinical practice. It is hoped that through sharing the findings of this study, all members of the multidisciplinary team will be educated in the experiences of the participants within this study and they may consider these when caring for children in isolation in the future.

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The staff data presented in this thesis suggested that practitioners needed more support in understanding the guidelines regarding use of PPE and isolation facilities within infection prevention, to inform their own practice and in order that they understand the rationales for isolation practices so that they can explain them to children and families. Infection prevention and the associated isolation precautions is an area that warrants further education at pre-registration level. [Infection prevention and transmission of infection education](#) is required throughout the career of paediatric nurses, as [both](#) early career nurses [and](#) practitioners with many years of experience [described insufficient knowledge to help them in decision making and explaining rationales for decisions to families](#). Furthermore, this education needs to broaden beyond the nursing profession to all members of the multidisciplinary team, particularly those such as play specialists who may not understand all the microbiological reasons for isolation. There needs to be a transparent way to communicate this information between colleagues and from staff to families, to ensure that the information is consistent and thereby reduce any anxiety from children and families regarding the “isolation rules”. This transparency of knowledge could be undertaken with something such as a leaflet or information sheet on the wall of the cubicle to explain the practice within isolation and the “isolation rules”. This could empower nurses who felt less confident in sharing the rules, but also empower parents when they felt that the rules were not being adhered to. Furthermore, it may be [necessary to include](#) the infection prevention team to assist in providing this education and empower nurses and parents to understand the reasons for isolation and the necessary rules within the isolation room.

This study has also highlighted that nursing staff may require greater support and education regarding recruitment to research studies, particularly if future studies have the requirement that researchers are not allowed to approach participants face to face. Research is considered a fundamental part of medical education and is viewed as a priority within their practice and their professional development, however for nurses the same value is not attributed to research (Thompson et al, 2004). In terms of future education and knowledge of evidence-based practice, greater priority needs to be apportioned to increasing the involvement of nurses from students to ward managers within research. With increased involvement, nurses will see the value of such studies and may therefore prioritise recruitment to studies. Furthermore, with greater ownership through involvement

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in research, there is likely to be greater integration of the findings in practice (Parahoo, 2014).

One key strength of this study is the clinical academic role of the researcher. Clinical academic roles allow for a research question to be driven by contemporary practice and from grassroot upwards. This study demonstrates the inherent knowledge that as the researcher I had throughout the research process, in terms of child development, talking to children, understanding the stresses of families in hospital, and the reasons for [isolation](#). This knowledge facilitated easier discussion at interview and understanding some of the inherent knowledge that children in isolation had through living the experience as a staff member. This meant that much of the immersion within a research setting that [a](#) researcher would have to do without a dual role, was removed. The clinical academic role also developed trust in the participants and may have contributed to improved recruitment, particularly in the staff population, through the desire to help a fellow healthcare professional. Furthermore, many participants, particularly the parents commented on their desire to help others who would be in isolation, thus through my clinical role, they felt that the research may be utilised more easily within clinical practice.

Within this study, the clinical academic role has allowed for greater integration of the research findings into the clinical environment, both through formal presentations, but also through working within the multidisciplinary team daily and sharing the findings, so that they may consider it within the context of the care that they are providing. Through greater integration of clinical academic roles within the multidisciplinary team it will produce more clinically relevant studies. Also, through greater integration of clinical academic roles within the NHS [as a whole](#), there may be greater understanding of the research process from clinicians, and this may facilitate improved recruitment to future studies.

Finally in terms of education, it would be desirable if the regulatory bodies for the professionals within this study not only reiterated the importance of research and questioning practice, but also the specific needs of children in isolation. In terms of [undergraduate healthcare professional](#) education, from this study, [I feel that there is an importance to](#) education about the experience of children in isolation and an associated greater understanding of procedures and rationales for isolation care. Secondly this study

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has revealed to me the need for increased learning about research and evidence-based practice for practitioners. For nursing, the Nursing and Midwifery Council Standards for Education (2019) and Code of Conduct (NMC, 2018) do not address the specificities of paediatric nursing or research, and therefore at pre-registration or post qualifying level, this knowledge is not mandatory. However, for the medical team [there](#) is an annual requirement to have some input/participation in research. Finally, within the UK where paediatric-specific nurse training is provided, the understanding of children's rights and the theories surrounding family centred care are taught throughout [nurse](#) training. However in professions that are not paediatric specific and countries worldwide where there is not paediatric-specific nurse training, it will be necessary at an undergraduate level and post qualifying for all practitioners to have some insight into the differences for children in isolation that this thesis highlights, so that the child and their family's care needs can be met.

8.4.3 Implications for Future Research

This study provides two contributions in knowledge; firstly, the findings relevant to children's experience of isolation and secondly, the methodological contribution in terms of video diary use and research methods with children see Section 8.4.3.1.

This study only considers the social construct of the participants within this study, furthermore it only considers the wards within the one paediatric hospital. Therefore, in order to provide more transferable findings to all paediatric wards it will be necessary to broaden this study across many hospitals. In terms of generating further data to support individualising the care to the children's needs it may be necessary to explore how children perceive the room and how the room impacts upon their mood, to further inform [future](#) estates and building developments.

A key finding within this study was related to the research design and the challenge with recruitment to the video diary part of the study. When I began this study I looked to the literature to ascertain an appropriate research design to engage and encourage participation of children. Although there were a number of papers that presented ways to engage children with research (Christenson & Prout, 2002; Punch, 2002), very few of these were specific to the hospital setting. This resulted in the video diary method being trialled which had been used within education and health-settings where the child was not the patient with

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good success (Rich et al, 2000), however in this study this was not the case. Subsequently, in a recent search on this literature (up to December 2019), there have been no papers in the literature that present the challenges of video diary research with children in healthcare settings, and therefore a key output from this study is to publish these incidental findings. This will enable future researchers considering this as a potential method, by providing them with the necessary information on how to execute this research design in their clinical setting. The challenges associated with recruiting to the video diary part of this study may have simply been context-specific to the fact that the study was conducted between 2011-2015, and if the study were conducted now, recruitment to the video diary portion of the study may be greater. Therefore, as part of my post-doctoral work, I aim to use video within future research, as there were benefits to using it in terms of power balancing between the researcher and the child. Furthermore, it would be useful to ascertain if the findings that video diary data was challenging to recruit to, was time-context specific.

In terms of the use of video diary data, there is a significant increase in the use of mobile phones and social media within modern culture in the UK. Therefore, as mentioned previously the interest in participating in video diary study may be increased now as it is more commonplace within society. Additionally, videos could be used to aid recruitment for those who prefer to watch a participant information leaflet or invitation rather than reading it., or for those who are unable to read written English. Further research into the impact and outcomes from using such media in terms of recruitment would be particularly useful for future research with children.

In view of the challenges with recruitment to the video diary, I read vast amounts of literature pertaining to child-appropriate research design methods (Engel,1999; Hill et al, 2016; Punch, 2002), however within this study I did not consult children on the study design. Since the beginning of this study and now in contemporary research practice, there has been a movement to have greater inclusion of patient and public involvement. The use of patient and public involvement would have been beneficial to gauge whether hospitalised children wanted to participate in a study using video diary prior to submitting to ethics and before beginning recruitment. This would have saved time and could have produced another method that children would have been preferable for them. Therefore, a key learning point from this study is the importance of patient and public involvement

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within the study design. Importantly, for any future work using video, it will be an essential part of the study to gain some insight with the population on the study design, through hospital Trust patient and public involvement user groups.

One limitation of the study was the lack of recruitment of children with additional needs, and those who could not communicate in English. These were two exclusion criteria as there was not funding for an interpreter to allow communication between the participant and myself. It would be useful in future studies to attempt to recruit children with additional needs such as communicating through sign language or Makaton, and those for whom English is not their first language to ensure that the findings are more representative of the entire population. This is of particular importance for this study where data [were collected in a regional specialist centre where many children for whom English is not their first language or verbal communication may not be utilised are represented in the hospital population](#). Funding would need to be considered in future studies to facilitate this.

Another area for future research concerns the focus on the maternal perspective rather than the paternal perspective within the parental findings. Recruitment did not specify or limit to one parent participation, nor was the maternal perspective sought out, this merely happened by chance. The inclusion of one father produced some divergent findings on the experience and shared a different experience within the parental findings, which would warrant further exploration. Therefore, for future research within the field of children in isolation, there is a need to explore the father's experience in greater detail. Additionally, within all paediatric healthcare research, this study suggests the value of seeking out paternal experiences [within](#) parental experiences. In addition to this, as mentioned earlier in Section 8.3.5, there is a need to explore the sibling's perspective within the experience of isolation. The inclusion of fathers and siblings' perspectives within other fields has not only been beneficial in terms of staff being able to understand and better support families, but also to work with them in terms of providing care for the child (Koliouli & Gaudron, 2018; Menzies, 2019). Furthermore, there needs to be greater exploration into the reason that fathers did not participate in this study, as is the case in a number of other research papers (Davison et al, 2017; Nicholas et al, 2020). If the cause for non-participation in research by fathers can be explored, it may support researchers in the future to target

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recruitment to [increase the inclusion of fathers in studies](#), to facilitate care for the entire family whilst a child is in isolation.

The reasons for non-participation as shown in Table 5.3 were useful data to suggest reasons why children didn't participate specifically in the video diary part of the study. Many of these findings were congruent with the literature for reasons for non-participation in paediatric studies in general (Barratt et al, 2012; Dockett et al, 2012). However, there were also reasonable levels of non-participation within the interview part of the study. It would be useful for the future of paediatric research to explore reasons for non-participation further. The gatekeepers put in place in this study were imposed by the ethics committee and whilst they did provide a high level of protection to the children in terms of coercion, it may have prevented some children the opportunity to participate. This may warrant further studies to explore why parents elected for non-participation on behalf of their children in this study and similarly to explore the reason that parents opt for their child to participate in this type of research.

Finally, throughout this thesis, the benefits of the clinical academic role have been highlighted. Through anecdotal experience during this research study and the writing of this thesis, I can support the notion that clinical academic roles provide a more clinically relevant form of research, and that the benefits of the role allow for quicker and greater integration of the [findings](#) within practice at the ground level. Although, this is merely anecdotal experience from this one study, there are papers that identify the benefits of such roles in other clinical contexts (Carrick-Sen et al, 2019; Foster, 2018). It will [be](#) an ongoing process to explore clinical academic roles within other contexts to confirm their continued benefit throughout the NHS. [Furthermore there is a need](#) to develop national and international definitions of [clinical academic roles to provide a critical mass in the workforce and develop practitioners](#) worldwide.

In summary, this study has produced some key findings which have produced new knowledge both in terms of the findings and the incidental [findings pertaining to the research methods](#). However as demonstrated within this section of the chapter, there are a number of areas that warrant further exploration in practice, education, and research.

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8.4.3.1 Future of Children's Research Methods

This study demonstrated that children have valuable contributions to participatory research, interviews and also their care. For practitioners this can be considered within the context of the literature that supports that children should be consulted in all areas of practice (Barker & Weller, 2003; Kim, 2015), but also within research in particular in the process of setting up research data collection methods. Further research is required into participatory methods with children in hospital, to find further engaging methods that can be utilised when children are admitted to hospital. In addition, the use of video diary needs to be further explored in hospital settings when the child is not admitted, to support the literature in terms of its use with children in healthcare, within contemporary practice. Furthermore, it may be useful to explore reasons for participation and non-participation into research when children are patients, to provide some ways of illustrating what the issue is, to allow researchers to provide empathetic ways to collect data within a stressful period for the family. Within the realms of video diary data, it may be useful to explore the use of video in terms of recruitment of participants using a video made by the researcher, or potentially consider using media that is familiar to children to seek their participation.

On a national and international [forum](#), the role of children within research is described to be important, however the lack of paediatric data that use the child's voice does not reflect this perception. Therefore academic, social and political debates need to be had to revisit the ethos of including children within research in a meaningful way. At an institutional level, this needs to be considered with regards to writing paediatric specific policies that consider the wider psychosocial and developmental needs of children within hospital. Furthermore, institutional policies need to reflect the needs of paediatric patients and the role that the parent play within their [child's](#) care to produce a discussion regarding family centre care, or partnership of care between families and the staff for all children at admission, to facilitate cohesive, comprehensive care for all children in hospital.

8.4.4 Dissemination

The methodological findings and findings from the data have been presented at local and national research conferences as shown in Appendices 18-22, to inform all clinical and non-clinical staff within the local Trust, in addition to a wider national and international paediatric audience. To ensure that the children's voices who participated in this study are

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not lost, and heard throughout children's nursing worldwide, it is my intention to disseminate the findings of this study through publications in academic and professional journals, and at conferences. The findings will be disseminated broadly to ensure that they are considered by practitioners working with children in isolation, in a hope that care can be individualised to the child's needs.

8.5 Reflexivity

I began my clinical academic journey of the PhD at the beginning of my nursing career having only been qualified as a children's nurse two years. This meant that this study has evolved alongside the development of both my experiences as a nurse and as a researcher. From a social constructionist approach, my understanding of practice and research has become the product of my negotiated constructions of being on this clinical academic journey. Whilst some may consider beginning research in a clinical setting this early into your career as a limitation, I consider this a key strength of the development of this study. I was able to view a children's ward with "fresh" eyes, uninfluenced by years of experience of working with children and families in health care. This meant that identifying the research question was easy as I could review the research needs within the ward without preconceptions. However, the lack of experience meant that potentially I was less direct with the ethics committee in attempting to secure direct contact with the families and the manner in which the children were recruited to the study. This required lots of learning on the job and adaptations to the challenges presented, which have been described in detail in this thesis. This study has demonstrated to me how a question can be derived from clinical practice, and [how it can produce](#) clinically relevant findings which can be easily transferred into practice, with cohesion from the added benefit of the clinical academic role.

This research would not have been conceptualised without the dual role of clinical academic nurse, as I would not have recognised the clinical research question. Clinical academic careers are designed to facilitate research which answers clinical questions and that purpose was completed through this study (Latter et al, 2009). Through my clinical academic role, I perceived the benefits to be that through explaining my role to parents, there was an inherent trust developed simply because I was a nurse and could discuss the experience as a partial "insider". Furthermore, this supported and facilitated my ability to

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rapidly develop a rapport with children, their families and the staff as I was able to speak the language familiar to them in the ward social construct. This is recognised in the literature (Colbourne & Sque, 2004; Jack, 2008; Latter et al, 2009) as a significant benefit to the clinical academic role in terms of data collection, but also in terms of analysis. Through the understanding of working with children clinically and understanding the role of working with parents within this social construct, I demonstrated the positive manner of the dual role in accessing the participants; developing rapport to allow the children and their parents to open up at interview, and analysing the findings within the context of the social construct of isolation. As a clinical academic I consider that this research will be translated more easily into practice as I can explain the research informally, in addition to presenting it locally, nationally and internationally to a broader audience who can hopefully translate the findings from this study into their own clinical practice.

This study has impacted upon me in the same manner as I have impacted upon the study. The study has influenced my professional practice, and it will undoubtedly inform the ongoing development of my future practice as a paediatric nurse caring for families in isolation. This research has demonstrated the importance of professionals understanding the experience of isolation for children and their families in order to understand how to tailor the care to their needs. This research will continue to impact the care that I provide for children and families intensive care where I currently work, for those within the children's hospital, and the wider team as I continue to advocate for the needs of children and families in isolation. It is the hope that through reading this research, others will be able to reflect upon the care that they provide to children in isolation and adapt their care accordingly.

Personally, this research has impacted upon me, specifically since I have become a parent myself. Through conducting this study, I have had the privilege to hear the stories of the children and their parents and their words, emotions and stories have impacted upon the way in which I care for the children in isolation. Since becoming a parent, and more specifically since being a parent of a child in isolation I have greater empathy for those stories and therefore their words are present with me when providing care for children. I am aware of the dynamic nature of all encounters and the influence that I have on others and they have on me.

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Undertaking this research has been an invaluable learning experience. I have gained some understanding of the nature of qualitative research and of the cyclical, sometimes messy and challenging nature of the research process. I have learnt that regardless of the strengths of a data collection method, there may not be sufficient recruitment using that method. This research study has provided me with some key ideas which have helped me examine my own professional values within research and clinical practice, and supported knowledge acquisition that has identified areas for possible change in my own future practice.

8.6 Concluding Comments

This thesis aimed to explore the child's experience of single room isolation. The child's experience is presented in this study through the narratives of the child, parent and staff. This ensured that the child's voice was central to the study with the use of supporting narratives to triangulate data sources to ensure a rigorous research methodology, and value in the findings. The inclusion of children's voices was not without ethical and data collection method challenges, which has provided some of the new knowledge generated from this study. The findings from the data in this study present useful insight for practitioners and researchers. Firstly, there have been methodological implications for innovative methods of data collection with children. Secondly, the key themes from the study: control, community and coping, which provide confirmatory findings within the paediatric isolation and adult isolation literature and also has generated new knowledge. There were convergent findings which identified the different experiences associated with age, source and protective isolation, and chronic and acute illness.

In terms of personal learning that I will take into practice, I have taken the direct words from this study to inform my personal practice. An example of this was described in the narratives. Through participating in the study and reflecting on her own experience of isolation, Rachel's mum will now change her practice as she described in this excerpt below.

"Sometimes I think that you can think that the door is closed if they want the door closed, you know, so actually whatever is going on in there they don't want us to interfere with it, whereas I very much felt that, I was really struggling in that room but I felt like the door had been closed on me and that they you know, that nobody was coming in and I couldn't go out to ask, I didn't feel that I could go and ask for help. This will definitely change me in practice."

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Through writing this thesis my perspectives on the needs of those in isolation has changed and there is no one model of care which meets everyone's criteria whilst in isolation.

Through reading this thesis and considering the wider findings in the context of their care environment, it is hoped that this study will have direct impact upon the care provided to children. It is necessary to highlight these in this thesis to aid others in considering these implications in practice.

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Appendix 1

Search Examples for Adult Literature Search

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CINAHL Search

Search last executed on 25/09/2019

Search limiters English Language, 1970-2019

Number	Searches	Results	Relevant
1	Isolation	11830	
2	Isolation AND Experience	1445	
3	Source Isolation	55	5
5	Protective Isolation	47	4
6	Reverse Isolation	100	0
7	Patient Isolation	1728	
8	Infection AND Isolation	125	
9	Infection AND Isolation AND Experience	55	23

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Appendix 2

Summary Table of Adult Literature

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Reference	Sample	Study Design	Findings	Limitations
Abad, C., Fearday, A. & Safdar, N. (2010) Adverse Effects of Isolation in Hospitalised Patients: A Systematic Review, <i>Journal of Hospital Infection</i> , 76 (2), pp 97-102.	16 studies	Systematic Review	<ul style="list-style-type: none"> Majority of studies showed negative impact on mental well-being and behaviour Higher depression, anxiety and anger scores Few studies found healthcare workers spent less time with patients in isolation 	
Anderson, H., Lindholm, C & Fossum, B. (2011) MRSA – Global Threat and Personal Disaster: Patients’ Experiences, <i>International Nursing Review</i> , 58 (1), pp 47-53.	15 patients with MRSA	Interviews- transcribed verbatim Content analysis	<ul style="list-style-type: none"> Patients perceived MRSA stigmatising, felt they were a threat to the environment Fears of infecting others Fears of being rejected Treatment by healthcare professionals Gaps in staff and patient knowledge of MRSA and transmission of infection resulted in fear, social isolation and suffering 	
Annibali, O., Pensieri, C., Tomarchio, V., Biagoli, V., Pennacchini, M., Tendas, A., Tambone, V. & Tirindelli, M. C. (2017) Protective Isolation for Patients with Haematological Malignancies: A Pilot Study Investigating Patients’ Distress and Use of Time, <i>International Journal of Hematology, Oncology Stem Cell Research</i> , 11 (4), pp 313-318.	18 participants who were hospitalised on haematologic ward in Italian hospital	Descriptive pilot study Self-report questionnaire	<ul style="list-style-type: none"> Isolated patients require support in recreational activity, allow more contacts, provision of free tv and Wi-Fi Patients need to be physically active Isolation-related distress – need psychological support 	

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Barratt, R., Shaban, R. & Moyle, W. (2010) Behind Barriers: Patients Perceptions of Source Isolation for Methicillin Resistant Staphylococcus Aureus (MRSA)'. <i>Australian Journal of Advanced Nursing</i>, 28 (2), pp 53.	10 adults with MRSA in isolation for >3 days. Various wards in one large hospital in New Zealand	Interpretive phenomenological Analysis Semi structured interviews	<ul style="list-style-type: none"> Majority of patients found some positive aspect of being accommodated in isolation Overall experience viewed negatively Living within 4 walls Isolation imposes barriers to expression of identity, relationships and impacts on quality care 	Small sample One location
Barratt, R., Shaban, R. & Moyle, W. (2011) Patient Experience of Source Isolation: Lessons for Clinical Practice.' <i>Contemporary Nurse</i>, 39 (2) pp 180-193.	Literature review of 21 studies	Literature review	<ul style="list-style-type: none"> Psychological effects Challenges with coping with isolation Social isolation Communication and information provision essential to improving experience Physical environment and quality of care impact on the overall experience 	Not a systematic review
Bennett, S. (1983) Patient Perspective- Psychological Effects of Barrier Nursing Isolation, <i>Australian Nurses Journal</i>, 12 (10), pp 36-37.	Unknown	Quantitative Hospital Stress Rating Scale	<ul style="list-style-type: none"> Necessary to orientate the participants to the environment Need to acknowledge that being in isolation is not the patient's choice Psychological and social impact are enhanced the physical barrier of the room itself 	No description of sample size
Biagoli, V., Piredda, M., Annibali, O., Lacorossi, L., D'Angelo, D., Matarese, M., Alvaro, R. & De Marinis, M. G. (2017) Being in Protective Isolation following Autologous Haematopoietic Stem Cell Transplantation: A Phenomenological Study, <i>Journal of Clinical Nursing</i>, 26 (23-24), pp 4467-4478.	Nine patients with haematological malignancies who had been in protective isolation for autologous haematopoietic stem cell transplantation. In an Italian university hospital	Descriptive phenomenological study – interviewed weekly during ambulatory visits (approximately 100+ days post-transplant)	<ul style="list-style-type: none"> Isolation is a defence – defending loved ones, defence from suffering Relieved of burden of socialising 	

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Biagoli, V., Piredda, M., Alvaro, R. & De Marinis, M. G. (2016) The Experiences of Protective Isolation in Patients Undergoing Bone Marrow or Haematopoietic Stem Cell Transplantation: Systematic Review and Metasynthesis, <i>European Journal of Cancer Care</i> , 26 (5), DOI: 10.1111/ecc.12461.		Systematic review and meta-analysis of 11 articles	<ul style="list-style-type: none"> • Isolation is a source of suffering • Isolation can lead to relating with oneself • The person does not close the door to the outside world • Need for external relationships 	
Biagoli, V., Piredda, M., Mauroni, M. R., Alvaro, R. & De Marinis, M. G. (2016) The Lived Experience of Patients in Protective Isolation during their Hospital Stay for Allogenic Haematopoietic stem cell transplantation, <i>European Journal of Oncology Nursing</i> , 24 (1), pp 79-86.	10 patients (7 female, 3 male) age range 28-66 years, who had undergone allogenic stem cell transplantation for haematological malignancy	Interviewed about their hospital stay in protective isolation	<ul style="list-style-type: none"> • Special place to allow for transformation • Light and shade from inside and outside • Transformation of relationships with loved ones and the environment 	
Campbell, T. (1999) Feelings of Oncology Patients about Being Nursed in Protective Isolation as a Consequence of Cancer Chemotherapy Treatment, <i>Journal of Advanced Nursing</i> , 30 (2), pp439-447.	5 patients who had received high dose chemotherapy, who had been isolated in a protective environment for a minimum of 7 days	Qualitative – semi-structured interviews, using constant comparative analysis	<ul style="list-style-type: none"> • Feelings of: • Being shut in – unnatural view or not having a view • Coping with the experience of cancer • Being alone • Difficulty in maintaining contact with the outside world • Not knowing what to expect • Necessity of developing relationships with healthcare professionals 	Small sample

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Catalano, G., Houston, S., Catalano, M., Butera, A. S., Jennings, S. M., Hakala, S. M., Burrows, S. L., Hickey, M. G., Duss, C. V., Skeleton, D. N. & Laliotis, G. J. (2003) Anxiety and Depression in Hospitalized Patients in Resistant Organism Isolation, <i>Southern Medical Journal</i> , 96 (2), pp 141-145.	27 patients isolated for MRSA/VRE 24 Patients not isolated Isolation and infectious diseases unit, USA	Psychological tests	<ul style="list-style-type: none"> Higher scores of anxiety and depression for isolated patients than non-isolated within 7 days of being placed in isolation 	Small sample for statistical analysis
Cava, M. A., Fay, K. E., Beanlands, H. J., McCay, E. A. & Wignall, R. (2005) Risk Perception and Compliance with Quarantine during the SARS Outbreak, <i>Journal of Nursing Scholarship</i> , 37 (4), pp 343-347.	21 interviews from 170 letters sent out who were quarantined as a result of SARS or suspected SARS	Descriptive qualitative design: Interviews	<ul style="list-style-type: none"> Uncertainty Coping with isolation was a challenge in addition to diagnosis Separation, stigma, and scrutiny 	SARS= very small population to sample from Retrospective
Chittick, P., Koppisetty, S., Lombardo, L., Vadhavana, A., Solanski, A., Cumming, K., Agboto, V., Karl, C. & Band, J. (2016) Accessing Patient and Caregiver Understanding of and Satisfaction with the Use of Contact Isolation, <i>American Journal of Infection Control</i> , 44 (6), pp 657-660.	500 patients in contact isolation at a single institution, during 2014 received survey. Response rate 48.7% and 70 carers responded	Prospective survey	<ul style="list-style-type: none"> Positive overall understanding of contact precautions Majority thought that it was explained well to them and adhered to by staff 	Large study but very specific questions
Collins, C., Upright, C. & Aleksich, J. (1989) Reverse Isolation: What Patients Perceive, <i>Oncology Nursing Forum</i> , 16 (5), pp 675-679.	6 people undergoing BMT	Qualitative Interviews	<ul style="list-style-type: none"> Most people understood rationale for isolation Needed more "extensions to the world" Visits from their supports were important Physical side effects of treatment were worse than isolation itself 	Small sample. Limited explanation of methods used

Appendices

Criddle, P. & Potter, J. (2006) Exploring Patients' Views on Colonisation with Meticillin-Resistant Staphylococcus aureus, <i>Journal of Infection Prevention</i>, 7 (2), pp 24-28.	14 MRSA-colonised patients, post discharge from hospital	Phenomenological qualitative interviews	<ul style="list-style-type: none"> Poor information provision Wide range of patient level of understanding and information needs Negative experience of isolation 	Retrospective data
Davies, H. & Rees, J. (2000) Psychological Effects of Isolation Nursing (1): Mood disturbance, <i>Nursing Standard</i>, 14 (28), pp 35-38.	24 subjects	Small audit-style evaluation	<ul style="list-style-type: none"> Mood disturbance was prevalent in more than half of participants 	Not empirical research
Day, H. R., Perencevich, E. N., Harris, A. D. & Gruber-Baldini, A. L. (2013) Depression, Anxiety, and Moods of Hospitalized Patients under Contact Precautions, <i>Infection Control and Epidemiology</i>, 34 (3), pp 251-258.	296 patients	Hospital Anxiety and Depression Scale on hospital day 3. Visual analogue mood scale diaries	<ul style="list-style-type: none"> In contact precautions the patients had baseline symptoms of depression and anxiety higher than control Patient in contact precautions were no more likely to be angry, worried or confused than control 	Surgical patients only
Denton, P. F. (1986) Psychological and Physiological Effects of Isolation', <i>Nursing</i>, 3 (3), pp 88-91.	1 case	Literature review and case example	<ul style="list-style-type: none"> Senses dulled Onset of psychological symptoms Early contact made symptoms of isolation better Enjoyed 'special' status When element of single room choice was removed, and situation was not controlled by patient, experience was much worse 	Single case
Dunn, E., Arber, A. & Gallagher, A. (2016) The Immediacy of Illness and Existential Crisis: Patients' Lived Experience of Under-going Allogenic Stem Cell Transplantation for Haematological Malignancy. A Phenomenological Study, <i>European Journal of Oncology Nursing</i>, 21 (1), pp 90-96.	Participants aged 22-68 years, purposively recruited.	Interpretive phenomenological methodology using semi-structured interviews	<ul style="list-style-type: none"> Enduring uncertainty Major disruption to their lives physically, psychosocially and emotionally, including facing their own mortality 	

Appendices

Dunleavy, R. (1996) Isolation in BMT: A Protection or a Privation, <i>British Journal of Nursing</i>, 5 (11), pp 663-668.	Wards where patients are in isolation following BMT	Observation of four hospitals over three countries	<ul style="list-style-type: none"> The degree to which isolation is enforced depends on the psychological outcomes of the patients 	Observation method only Condition specific
Evans, H. L., Shaffer, M. M., Hughes, M. G. (2003) Contact Isolation in Surgical Patients: A Barrier to Care, <i>Surgery</i>, 134 (2), pp 180-188.	48 observations of isolated patients and 48 non-isolated patients on the surgical floor. Interviews with 26 (9 of which were isolated) Isolated for a variety of multi drug resistant organisms	Prospective observation of patient contact in adjacent isolated and non-isolated patient rooms on surgical wards. Patient perception questionnaire. Retrospective review of incidence of infection.	<ul style="list-style-type: none"> Half the number of contacts with patients in isolation with all healthcare providers Contact time was lower in isolation 	Small number of participants were interviewed
Florey, L., Flynn, L. & Isles, C. (2009) Patient Preferences for Single Rooms or Shared Accommodation in a District General Hospital, <i>Scottish Medical Journal</i>, 54 (2) pp 5-8.	80 patients – 20 medical single room, 20 surgical single room and 40 shared room	Seven point, validated questionnaire	<ul style="list-style-type: none"> Loneliness in isolation Less noise disturbance in isolation Greater privacy in isolation Easier for visitors to come in isolation 	
Gammon, J. (1998) Analysis of the Stressful Effects of Hospitalisation and Source Isolation on Coping and Psychological Constructs, <i>International Journal of Nursing Practice</i>, 4 (2), pp 84-96.	40 adult participants: 20 source isolated cases and 20 routine admission controls on general inpatient wards. Patients isolated for MRSA or gastroenteritis	Quantitative Quasi-Experimental Two groups; Group 1 isolated, Group 2 hospitalised. Data collected on 7 th day of isolation	<ul style="list-style-type: none"> Isolated subjects scored higher on the anxiety score and mean depression score than patients who were hospitalised Greater detrimental effect on their ability to cope in isolation than in hospitalisation Self-esteem score was low on both control and isolated groups 	Small sample

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Gammon, J. (1999) The Psychological Consequences of Source Isolation: A Review of the Literature, <i>Journal of Clinical Nursing</i>, 8 (1), pp 13-21.	No explanation of the number of papers yielded or the method of literature review	Literature review	<ul style="list-style-type: none"> • Reduced level of social interaction, sensory stimulation • Fear of protective clothing 	No explanation of method of literature review or quality of papers presented
Gammon, J. & Hunt, J. (2018) Source Isolation and Patient Wellbeing in Healthcare Settings, <i>British Journal of Nursing</i>, 27 (2), pp 88-91.	25 original papers met inclusion criteria	Literature Review – scoping article	<ul style="list-style-type: none"> • Creates barriers to physical, social and emotional needs • Studies claimed to have uncovered an association between negative patient experiences and isolation 	Scoping review, not primary research
Gasink, L. B., Singer, K., Fishman, N. O., Holmes, W. C., Weiner, M. G., Biker, W. B. & Lautenbach, E. (2008) Contact Isolation for Infection Control in Hospitalized Patients: Is Patient Satisfaction Affected?, <i>Infection Control Hospital Epidemiology</i>, 29 (3), pp 275-278.	43 isolated and 43 non-isolated patients from general medical and surgical wards in USA	Cross sectional cohort survey. Survey where participants responded – usually, always, sometimes, never. Interviews using the standardised questionnaire.	<ul style="list-style-type: none"> • Isolated patients generally responded less favourably to questions regarding hospital experience • Most participants in isolation felt that they lacked knowledge and education regarding isolation but felt that their care was improved through being in isolation 	Survey tool not validated
Gaskill, D., Henderson, A. & Fraser, M. (1997) Exploring the Everyday World of the Patient in Isolation, <i>Oncology Nursing Forum</i>, 24 (4), pp 695-700.	7 Haematology/BMT recipients 19-70 years Isolation for >2 weeks. Large teaching hospital	Interpretive and hermeneutic phenomenology. Interviews and thematic analysis of data.	<ul style="list-style-type: none"> • Inability to recognise staff due to gown and masks • Heightened sensory perceptions • Time for self-reflection and need for privacy • Previous experiences eased their strong understanding of why they are in isolation • Reliance on friends and family and staff 	

Appendices

Gordon, A. M. (1975) Psychological Aspects of Isolator Therapy in Acute Leukaemia, <i>British Journal of Psychiatry</i>, 127, (1), pp 588-590	10 patients aged 20-58 years	Psychiatric interviews	<ul style="list-style-type: none"> • Anxiety on entry • Feelings of claustrophobia, restricted mobility • No patient described social isolation • Anxiety on discharge • No sustained disturbances in mood • Patients found isolation less daunting than they anticipated 	Wide age range. Limited explanation of methods used
Holland, J., Plumb, M., Yates, J., Harris, S., Tuttolomondo, A., Holmes, J. & Holland, J. F. (1977) Psychological Response of Patient with Acute Leukaemia in Germ-Free Environments, <i>Cancer</i>, 40 (2) pp 871-879.	52 patients undergoing chemotherapy in laminar air flow isolation rooms	Nurses completed a patient behaviour observation rating scale – completed at the end of each 8-hour shift. A Forced Choice Questionnaire was given on the 3 rd and 21 st day. Patients were also asked to keep a diary.	<ul style="list-style-type: none"> • No symptoms of sensory deprivation • Positive attitude about treatment • Anxiety and depression scored did not change • Half thought it was better than expected • Missed being able to touch people – spouses and children, which generated feelings of loneliness • A sense of frustration, coldness and lack of emotional warmth – need for visitors • In general patients were not bored • Personality of the nurses was of greater importance to the patients when in isolation 	Condition specific

Appendices

Ibert, F., Eckstein, M., Gunther, F. & Mutters, N. T. (2017) The Relationship between Subjective Perception and the Psychological Effects of Patients in Spatial Isolation , <i>GMS Hygiene and Infection Control</i> , 12 (10), DOI: 10.3205/dgkh000296.	32 isolated patients within three departments of one German hospital	Correlative cross-sectional study. Interviews using questionnaires and scoring systems: Hospital Anxiety and Depression Scale Positive and Negative Affect Schedule, 10 item Big Five Inventory	<ul style="list-style-type: none"> • Significant positive correlation between isolation period and anxiety • Positive correlation between duration of contact with nursing staff and day dreaming • Watching television as an activity was associated with higher levels of anxiety • Surfing the internet had a positive relationship with thinking about beautiful things 	
Kelly, P. (1999) Isolation and Stigma: The Experience of Patients with Active Tuberculosis , <i>Health and Social Care</i> , 16 (4), pp 233-241.	28 patients with active tuberculosis, recruited in TB clinics	Semi structured interviews guided by questions using Kleinmans (1980) explanatory model	<ul style="list-style-type: none"> • All participants felt that their family and friends avoided them • Participants often isolated themselves and became secretive about their illness 	
Kelly-Rossini, L., Perlman, D. C. & Mason, D. J. (1996) The Experience of Respiratory Isolation for HIV-Infected Persons with Tuberculosis , <i>Journal of the Association of Nurses in AIDS Care</i> , 7 (1), pp 29-36.	18 participants in New York Hospitals	Interviews	<ul style="list-style-type: none"> • Mood disturbance during confinement • Staff can enhance patient quality of life and promote adherence to therapy 	Population very small for transferability Limited explanation of data collection methods

Appendices

Kennedy, P. & Hamilton, L. R. (1997) Psychological Impact of the Management of Meticillin Resistance Staphylococcus Aureus (MRSA) in Patients with Spinal Cord Injury , <i>Spinal Cord</i> , 35 (9), pp 617-619.	16 participants who had spinal cord injury and had been isolated for 2 weeks as a result of MRSA, on a spinal unit	Survey, Functional independence measure, Beck Depression Inventory, State anxiety Inventory, Profile of Mood Scale, interviews	<ul style="list-style-type: none"> Isolation affected rehab adversely for 85% of isolated patients Isolation affected mood of 50% of the group 20% felt that privacy as a result of isolation improved their relationships The view of the outside world was significant Isolated patients only significantly more angry than non-isolated 	Specific to spinal injury where rehabilitation can be dependent upon movement
Knowles, H. E. (1993) The Experience of Infectious Patients in Isolation , <i>Nursing Times</i> , 89 (30), pp 53-56.	Purposive sampling: 8 participants and 8 nurses from 7 wards, aged 21-85, spending between 5-12 weeks in hospital Reasons for isolation not reported	Qualitative in-depth interviews: Tape recorded and transcribed. Field notes also taken	<ul style="list-style-type: none"> Patients described- limited physical space, barriers to making contact with other, contact with other patients was not allowed, difficulty passing time, challenges with communication and achieving control Nurses described difficulties dealing with psychological aspects of care, limitations on time, fear of acquiring the infection, misunderstanding with regard to infection control measures, stigma 	Small sample
Kohle, K., Simons, C., Weidlich, S., Dietrich, M. & Durner, A. (1971) Psychological Aspects in the Treatment of Leukemia Patients in the Isolated- Bed System "Life Island" , <i>Psychotherapy and Psychometrics</i> , 19 (1-2), pp 85-91.	9 patients with acute leukaemia	Observation, Interview with patients and spouse/closest relative, Study of psychodynamics, Questionnaires to study stability, aggression, anxiety, coping, frustration and cognitive functions	<ul style="list-style-type: none"> Complete dependency on nursing staff coupled with loss of autonomy Increased confrontation of death Sensory deprivation Anxiety Tension between the nurses and staff 	Small sample. Condition specific.

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Lewis, A. M., Gammon, J. & Hosein, I. (1999) The Pros and Cons of Isolation and Containment, <i>Journal of Hospital Infection</i> , 43 (1), pp 19-23.	Unknown	Literature review	<ul style="list-style-type: none"> Highlights a lack of understanding of the psychological effects of isolation Feelings of being confined, imprisoned, stigmatised, anger depression, low anxiety and a lack of control were demonstrated through multiple studies 	Limited explanation of the literature review method
Livorsi, D. J., Kundu, M. G., Batteiger, B. & Kressel, A. B. (2015) Effect of Contact Precautions for MRSA on Patient Satisfaction Scores, <i>Journal of Hospital Infection</i> , 90 (3), pp 263-266.	Comparison of patients satisfaction scores between 70 isolated patients and 139 non-isolated patients	Case- control study comparing self-reported satisfaction scores. Adjusted analysis	<ul style="list-style-type: none"> No difference in patient satisfaction between the groups Age and educational status affected patient satisfaction but not related to isolation 	
Lupion-Mendoza, C., Antunez-Dominguez, M. J., Gonzalez- Fernandez, C., Romero-Brioso, C. & Rodriguez-Bano, J. (2015) Effects of Isolation on Patients and Staff, <i>American Journal of Infection Control</i> , 43 (4), pp 397-399.	72 pairs of cases and controls were included	Matched case control study and qualitative investigation to identify adverse events associated with isolation	<ul style="list-style-type: none"> Overall care satisfaction was similar among patient in isolation Staff less responsive Isolation associated with depression but not increased anxiety 	
Mackellaig, J. M. (1987) A Study of the Psychological Effects of Intensive Care with Particular Emphasis on Patients in Isolation, <i>Intensive Care Nursing</i> , 2 (4), pp 176-185.	Unknown	Literature Review	<ul style="list-style-type: none"> Changes in orientation, defects of memory and attention are common in ICU patients especially isolation Adapted well and withstood the stress of isolation No authors have written about patients who have been removed from isolation due to psychological reasons Stigma of isolation 	Literature review with limited description of methods used

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Madeo, M. (2003) The Psychological Impact of Isolation, <i>Nursing Times</i>, 99 (7), pp 54-55.	7 patients in MRSA isolation, from acute care wards in UK.	Phenomenological qualitative interviews using thematic analysis	<ul style="list-style-type: none"> • Stigma – sign attached to the door • Some participants preferred a single room • The environment impacted upon their experience in isolation • Communication challenges of isolation 	Limited description of analysis method. No ethical comments in discussion
Madeo, M. & Owen, E. (2002) Isolation- A Patient Satisfaction and Compliance Survey, <i>Journal of Infection Prevention</i>, 3 (3), pp 18-20.	29 participants	Patient satisfaction and compliance survey	<ul style="list-style-type: none"> • 77% described appropriate levels of understanding and appropriate advice regarding isolation • Need for diversional activities • Stigma • Lack of disturbance from other patients • Loneliness and neglect caused by isolation 	Audit, not empirical research. Limited commentary on survey structure or processes
Mayho P. (1999) Barrier Grief, <i>Nursing Times</i>, 95 (31), pp 24-25.	Author in source isolation for pulmonary tuberculosis	Personal reflection on care received in isolation	<ul style="list-style-type: none"> • Lack of control and consultation in source isolation • Regressive behaviour, anger, boredom, loss of control and independence 	Single person case
Mehrotra, P., Croft, L., Day, H. R., Perencevich, E. N., Pinles, L., Harris, A. D., Weingart, S. N. & Morgan, D. J. (2013) Effects of Contact Precautions on Patient Perception of Care and Satisfaction: A Prospective Cohort Study, <i>Infection Control and Hospital Epidemiology</i>, 34 (10), pp 1087-1093.	Total of 528 patients were included in the study	Prospective cohort study, evaluated at admission, and on hospital days 3,7, 14 until discharged, using a standardised interview and Hospital Consumer Assessment of Healthcare Providers and Systems, administered by telephone	<ul style="list-style-type: none"> • 20% perceived an issue with their care • Contact precautions were independently associated with a greater number of perceived concerns with care, including poor coordination of care and a lack of respect for patients' needs and preferences. 	

Appendices

Morgan, D. J., Diekema, D. J., Sepkowitz, K. & Perencevich, E. N. (2009) Adverse Outcomes Associated with Contact Precautions: A Review of the Literature, <i>American Journal of Infection Control</i>, 3 (2), pp 85-93.	15 studies met inclusion criteria, published between 1989 and 2008	Literature Review	<ul style="list-style-type: none"> • Four main adverse outcomes related to isolation identified • Less patient-health care worker contact • Changes in systems of care that produce delay • Increased symptoms of depression and anxiety • Decreased patient satisfaction with care 	
Newton, J., Constable, D. & Senior, V. (2001) Patients' Perceptions of Methicillin-Resistant Staphylococcus Aureus and Source Isolation: A Qualitative Analysis of Source-Isolated Patients, <i>Journal of Hospital Infection</i>, 48 (4), pp 275-280.	19 patients who were barrier nursed in a side room due to MRSA	Qualitative - Semi structured interviews	<ul style="list-style-type: none"> • Misunderstandings over the causes and consequences of MRSA • Patients had a lack of understanding of source isolation and the term barrier nursing • Patients identified positive and negative aspects to source isolation • Only one patient identified MRSA as hospital acquired. 	Little detail provided on interview structure
Oldman, T. (1999) Isolated cases, <i>Nursing Times</i>, 94 (11), pp 67-70.	5 patients and 5 nurses who were caring for those patients (no mention of sampling technique)	Qualitative-semi-structured interviews Thematic analysis of data	<ul style="list-style-type: none"> • Loneliness and stigma of being in isolation • Monotony and issues of control being in isolation • Time for reflection • Nurses perceptions of their patient's feelings were generally accurate 	Lack of thick description
Oldman- Pritchard, T. (2003) Infection Control. A Nurse's Experience of Isolation, <i>Nursing Times</i>, 99 (7), pp 57.	Author as patient	Reflective account	<ul style="list-style-type: none"> • Lack of communication • Boredom • Lack of privacy (no lock on the door) • Sensory deprivation • Lack of control over life • Need for physical movement and stimulation 	Reflective account, not primary research

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Pacheco, M. & Spyropoulous, V. (2010) The Experience of Source Isolation for Clostridium Difficile in Adult Patients and their Families, <i>Canadian Journal of Infection Control</i> , 25 (3), pp 166-174.	10 participants – 5 patients, 5 family members	Qualitative – semi structured interviews	<ul style="list-style-type: none"> Loneliness due to lack of visitation Uncertainty regarding illness trajectory Inconsistencies in provision of information regarding isolation 	
Rees, J., Davies, H. R., Birchall, C. & Price, J. (2000) Psychological Effects of Source Isolation Nursing (Part 1 & 2), <i>Nursing Standard</i> , 14 (29), pp 32-36.	21 participants from acute, rehab, medical and ear, nose and throat wards	Small audit-style evaluation of aspects of clinical care Hospital Anxiety Depression Score Medical notes for demographic data	<ul style="list-style-type: none"> 57% of the sample suffered mood disturbance as a consequence of isolation. Depression appeared to be underestimated by the staff 	Small sample Selective sampling No control group
Roderick, M., Speroni, K. G., Stafford, A. & Seibert, D. J. (2017) <i>American Journal of Infection Control</i> , 45 (3), pp 324-326.	50 hospital patients in contact isolation	Survey study to assess if patients could identify what ranking the healthcare workers had	<ul style="list-style-type: none"> Patients found little difficulty identifying healthcare workers type with large stickers 	
Sasaki, T., Akaho, R., Sakamaki, H., Akiyama, H., Yoshino, M., Hagiya, K. & Atsumi, M. (2000) Mental Disturbances during Isolation in the Bone Marrow Transplant Patients with Leukaemia, <i>Bone Marrow Transplant</i> , 25 (3), pp 315-318.	39 patients with leukaemia received bone marrow transplant in isolation	Tension anxiety score in Profile of Mood States	<ul style="list-style-type: none"> Mental disorders occurred in 16 patients (41%) during the observation period Usually mental illness presented with adjustment disorders, anxiety and/or depression 	Specific to BMT on a single isolation unit
Siddiqui, Z. K., Conway, S. J., Abusamaan, M., Bertram, A., Berry, S. A., Allen, L., Apfel, A., Farley, H., Zhu, J., Wu, A. W. & Brotman, D. J. (2018) Patient Isolation for Infection Control and Patient Experience, <i>Infection Control and Hospital Epidemiology</i> , 18 (1-6), DOI: https://doi.org/10.1017/ice.2018.324 .	Review of surveys of a tertiary hospital over 5 years	Retrospective analysis of patient satisfaction survey results over 5 years	<ul style="list-style-type: none"> Patients in isolation reported worse experience Less staff responsiveness in isolation Similar experiences in other domains 	

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Skyman, E., Sjoström, H. T. & Hellström, L. (2010) Patients' experiences of being infected with MRSA at a hospital and subsequently source isolated, <i>Scandinavian Journal of Caring Sciences</i> , 24 (1), pp 101-107.	6 patients aged between 35-76 years who contracted MRSA and were subsequently isolated for >1 week	Interviews and inter subjective analysis	<ul style="list-style-type: none"> • Patients felt violated having contracted MRSA • Isolation was described as traumatic, albeit accepted as they did not want to spread MRSA • Patients felt that they did not receive rehab on the same terms as patients without MRSA • Patients felt that they did not have enough information about MRSA • Patients felt vulnerable due to the reactions of the nursing staff, family members and other patients'. 	Small sample Single hospital
Stajduhar, K. L., Neithercure, J., Chu, E., Pham, P., Rohde, J., Sicotte, A & Young, K. (2000) Thyroid Cancer: Patients' Experience of Receiving Iodine-131 therapy, <i>Oncology Nursing Forum</i> , 27 (8), pp 1213-1218.	27 patients who were isolated for therapy on an oncology unit	Qualitative interpretative discussion at a focus group and through telephone interviews	<ul style="list-style-type: none"> • Recognising the totality of the experience occurred quicker in isolation • Being isolated impacted upon their experience of the illness trajectory 	Specialised population
Tarzi, S., Kennedy, P., Store, S. & Evans, M. (2001) Methicillin-Resistant Staphylococcus Aureus Psychological Impact of Hospitalization and Isolation in an Older Adult Population, <i>Journal of Hospital Infection</i> , 49 (4), pp 250-254.	22 MRSA positive in isolation and 20 MRSA negative older adults not isolated (>65 years) recruited from 4 care of the elderly rehabilitation wards	Cross-sectional matched control study Mental Test Score was used to exclude patients with dementia, Barthel Index questionnaire was used to identify patients level of independence, Geriatric depression scale, Profile of mood states	<ul style="list-style-type: none"> • Higher levels of depression and anxiety amongst the isolated group • Both groups had increased levels of anger compared with the average for their age, however no difference between the two groups for this score 	Specific to elderly patients only

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Tecchio, C., Bonetto, C. & Bertani, M. (2013) Predictors of Anxiety and Depression in Hematopoietic Stem Cell Transplant Patients during Protective Isolation, <i>Psycho-Oncology</i> , 22 (8), pp 1790-1797.	Anxiety and depression assessed in 107 participants	State-trait anxiety inventory and self-rating depression scoring were completed at admission and fixed time points throughout isolation	<ul style="list-style-type: none"> One tenth of patients suffered from anxiety and depressive symptoms at admission Percentage of depressed patients increased after two weeks of isolation, anxiety did not change over time 	
Thain, C. & Gibbon, B. (1996) An Exploratory Study of Recipients' Perceptions of Bone Marrow Transplantation, <i>Journal of Advanced Nursing</i> , 23 (3), pp 528-535.	10 informants undergoing BMT	Qualitative interview	<ul style="list-style-type: none"> Mortality and death Prison – being left alone was stressful, Relationships – impact of the staff, family members visiting Physical effects – food, environment 	Specific to BMT
Van De Glind, I., De Roode, S. & Goosensen, A. (2007) Do Patients in Hospitals Benefit from Single Rooms? A Literature Review', <i>Health Policy</i> , 84 (2-3), pp 153-161.	25 studies	Literature review	<ul style="list-style-type: none"> Privacy and dignity Moderate effect on sleep, noise and experience 	
Vinski, J., Bertin, M., Sun, Z., Gordon, S. M., Bokar, D., Merlino, J. & Fraser, T. G. (2012) Impact of Isolation on Hospital Consumer Assessment of Healthcare Providers and System Scores: Is Isolation Isolating?, <i>Infection Control and Hospital Epidemiology</i> , 33 (5), pp 513-516.	Not specified	Hospital Consumer Assessment of Healthcare Providers and Systems survey was used to measure the effect of isolation on patient satisfaction	<ul style="list-style-type: none"> Isolated patients reported lower scores for questions regarding doctors' communication and staff responsiveness 	

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Vottero, B. & Rittenmeyer, L. (2012) The Hospitalised Patients' Experience of Being in Protective/Source Isolation: A Systematic Review of Qualitative Evidence, <i>JBIR Database of Systematic Reviews and Implementation Reports</i> , 10 (16), pp 935-976.	12 studies	Systematic Review	<ul style="list-style-type: none"> • Fractured human connectivity • Different capabilities to adapt to the isolation room • Nurses have a significant contribution to the isolation experience • Loss of autonomy 	
Ward, D. (2000) Infection Control: Reducing the Psychological Effects of Isolation, <i>British Journal of Nursing</i> , 9 (3), pp 162-170.	Convenience sample used to get sample for questionnaire (n=21). Purposive sampling used to get participants for interviews (n=5).	Mixed method- Initial questionnaire used to identify a sample for more in-depth semi structured interviews Questionnaire, followed by in depth interviews – transcribed and reviewed by participants	<ul style="list-style-type: none"> • Isolation requires better communication (verbal and written) • Value of visitors • Value of other patients in relieving boredom and loneliness • Greater attention to listening • The need for activity when in isolation • The need for a view of the outside world would alleviate boredom 	Reasons for isolation not reported
Wassenberg, M. W. M., Severs, D. & Bonten, M. J. M. (2010) Psychological impact of short term-isolation measures in hospitalised patients, <i>Journal of Hospital Infection</i> , 75 (2), pp 124-127.	42 isolated patients, 84 non-isolated patients, >18 years. Isolated for resistant bacteria, infectious diarrhoea and other highly contagious infections 24-48 hours in isolation	Cross-sectional matched cohort study in a university teaching hospital covering 1042 beds Questionnaire- Hospital Anxiety Depression Score, Quality of Life tool	<ul style="list-style-type: none"> • Positive attitude towards infection prevention procedures • Reduced level of contact with nursing and medical staff when in isolation • No effect to patients' level of anxiety or depression when isolated 	

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Wilkins, E. G., Ellis, M. E., Dunbar, E. M. & Gibbs, A. (1988) Does Isolation of Patients with Infections Induce Mental Illness?, <i>Journal of Infection</i> , 17 (1), pp 43-37.	41 patients admitted to an infectious diseases' unit	Observation assessment using scales Crown-Crisp Experimental index to measure mental state – scores anxiety	<ul style="list-style-type: none"> Anxiety and agitation were displayed Higher scores associated with a past history of mental illness Anxiety related more to their illness than isolation 	Specific to isolation unit
Zerbe, M. B., Parkerson, S. G. & Spitzer, T. (1994) Laminar Air Flow Versus Reverse Isolation: Nurses' Assessments of Moods, Behaviours, and Activity Levels in Patients Receiving Bone Marrow Transplants, <i>Oncology Nursing Forum</i> , 21 (3), pp 565-568.	Retrospective descriptive chart review, nursing assessments of patient mood, behaviour and activity level	22 patients in Laminar air flow rooms 10 in reverse isolation	<ul style="list-style-type: none"> Patients in Laminar Airflow Rooms had higher levels of anxiety at admission than those in reverse isolation 	Retrospective

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Appendix 3

Search Examples for Paediatric Literature

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CINAHL Search

Executed on 21/08/2019

Search limiters English Language, 1970-2019

Number	Searches	Results	Relevant
1	Isolation AND Experience	3583	
2	Isolation AND Experience AND Infection	265	
3	Search 3 AND Child	40	5
4	Search 1 AND Infant	138	1
5	Search 1 AND Experience AND Child	723	
6	Search 5 AND Infection	13	1
7	Source Isolation AND Experience	853	
8	Search 7 AND Child	188	
9	Search 7 AND Infant	22	0
10	Search 8 AND Infection	13	1
11	Protective Isolation AND Experience	72	15
12	Search 11 AND Child	13	4
13	Search 11 AND Infants	3	2

Embase Search

Executed on 21/08/2019

Search limiters English Language, 1970-2019

Number	Searches	Results	Relevant
1	"Child*" (map heading)	1192395	
2	Isolation (keyword)	640395	
3	Search 1 AND Search 2	25088	
4	Source Isolation (keyword)	29	0
5	Protective Isolation (keyword)	129	1
6	Reverse Isolation (keyword)	129	8
7	Patient Isolation (keyword)	253	0
8	Search 1 AND Search 7	15	0
9	"Infection Prevention" (map heading)	34154	
10	"Infection Control" (map heading)	4	0
11	Search 1 AND Search 2 AND Search 9	15	0
12	Search 1 AND Search 2 AND Search 10	0	0

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Appendix 4

Summary Table of Paediatric Literature

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Appendices

Reference	Sample	Study Design	Findings	Limitations
BROEDER, J. L. (1985) School-Age Children's Perceptions of Isolation after Hospital Discharge, <i>MCN American Journal of Maternal and Child Nursing</i>, 14 (3), pp 153-174.	Six children aged six-11 years who were hospitalised for a relatively brief, non-complicated illness and in isolation for >24hrs	Qualitative – observations by the researcher, interviews in two parts; participants drew a picture of their memories, secondly they were asked to discuss two illustrations.	<ul style="list-style-type: none"> • Infection, contaminate and germs were words that featured highly in their responses, although frequent misconceptions of the words • Four children fully understood their rationale for being in isolation • Understood PPE but only when doing tasks • Masks muffles voices which one child described as scary, although only 2 children drew PPE • Feelings of deprivation at not being allowed to “play in the play room” • Every child said that the nurses appeared scary • Children required education re: isolation 	
CHAN, S. S. C., LEUNG, D., CHUI, H., TIWARI, A. F. Y., WONG, E. M. Y., WONG, D. C. N., BARNSTEINER, J. H. & LAU, Y. L. (2007) Parental response to child's isolation during the SARS outbreak, <i>Ambulatory Pediatrics</i>, 7 (5), pp 401-404.	Convenience sample –Eight parents of seven children (six mothers and one couple) consented to participate in an interview	Qualitative interviews with parents on day of clinical follow up	<ul style="list-style-type: none"> • Understood need for isolation, but distressed about leaving child • Anxiety caused by simultaneously managing child in hospital and life at home • Disruption in work life • Parents reported not telling other members of family, so that they didn't stress them out 	Specific isolation unit. Parental perspectives, so only limited commentary on the child's perspective
CURTIS, P. & NORTHCOTT, A. (2017) The Impact of Single and Shred Rooms on Family Centred Care in Children's Hospitals, <i>Journal of Clinical Nursing</i>, 26 (11-12), pp 1584-1596.	Observation of four wards. Interviews with 17 children aged five-16 years and 60 parents/carers. 60 Nursing staff took part in interviews/focus groups	Qualitative, ethnographic. Phase 1: Observation Phase 2: Interviews Thematic analysis	<ul style="list-style-type: none"> • Role expectations • Family-nurse interactions – family support needs, monitoring children's well-being and survey-assess-interact within spatial contexts • Single rooms directly impact the provision of family centred care 	Children with parents who were able to stay were over-represented. Minimal ethnic minority representation

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DALTON, R. (1981) The Assessment and Enhancement of Development of a Child Being Raised in Reverse Isolation, <i>Journal of the American Academy of Child Psychiatry</i>, 20 (3), pp 611-622.	One boy with SCID	Case study	<ul style="list-style-type: none"> • Motor, cognitive and speech development may proceed normally • Emotional development was affected • Attachment behaviours were affected 	Single case study
DROTAR, D. D., STERN, R. C. & POLMAR, S. H. (1976) Intellectual and Social Development following Prolonged Isolation, <i>The Journal of Pediatrics</i>, 89 (4), pp 675-678.	One Child with SCID	Case study	<ul style="list-style-type: none"> • Mother-child relationship was impaired • One nurse was allocated per child which allowed for lots of input into social care when parent was absent • Difficulties in adapting to home life after discharge • Improvements in development post-discharge 	Single case study
FREEDMAN, D. A., MONTGOMERY, J. R., WILSON, R., BEALMEAR, P. M. & SOUTH, A. M. (1976) Further Observation on the Effect of Reverse Isolation from Birth on Cognitive and Affective Development, <i>Journal of the American Academy of Child Psychiatry</i>, 15 (4), pp 593-603.	One child with SCID	Case study of one boy for 52 months during episodes of reverse isolation – isolator tent and Laminar Airflow room	<ul style="list-style-type: none"> • Motor skills more advanced than normal • Social and affective – less social interactivity 	Single case study

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KOLLER, D. F., NICHOLAS, D. B., GOLDIE, R. S., GEARING, R. & SELKIRK, E. K. (2006) When Family-Centered Care is Challenged by Infectious Disease: Pediatric Health Care Delivery during the SARS Outbreaks, <i>Qualitative Health Research</i>, 16 (1), pp 47-60.	Purposive sampling 23 participants	Ethnographic approach In depth interviews with children, parents and their healthcare providers hospitalised in 2003. Interviews which comprised of semi-structured questions in person or on phone, taped and transcribed. Data from patient healthcare records	<ul style="list-style-type: none"> • The emotional impact of SARS – emotional distress, degrees of sadness, loneliness, worry and fear described • Communication challenges- highlighted importance of open and accurate communication, information sharing • Role changes- feeling of helplessness from parents from lack of choice in not participating in their child's care 	SARS specific
KRONENBERGER, W., CARTER, B. D., EDWARDS, J., MORROW, C., STUART, J. & SENDER, L. (1998) Psychological Adjustment of Mothers of Children undergoing Bone Marrow Transplantation: The Role of Stress, Coping, and Family Factors, <i>Children's Health Care</i>, 27 (2), pp 77-95.	24 mothers	Quantitative prospective study – Measures of stress; Life Experiences Survey, Measures of Stress, Chronic Illness Parental Stress Questionnaire. Measures of Coping; Family Environment	<ul style="list-style-type: none"> • Maternal stress levels are heightened, this may have been more related to disease than isolation 	Mainly focused on maternal perspective
KUTSANELLOU-MEYER, M. & CHRIST, G. (1978) Factors Affecting Coping of Adolescents and Infants on a Reverse Isolation Unit, <i>Social Work in Health Care</i>, 4 (2), pp 125-137.	11 Patients with aplastic anaemia Parents of seven infants with SCID	Case study observations	<ul style="list-style-type: none"> • Craved physical contact • More distressed by separation than they were by possibility of death • Limitations of the physical environment • Need for “outside” communication • Need for peer support 	Only observation by a social worker

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LAZAR, R. M., TAMAROFF, M., NIR, Y., FREUND, B., O'REILLY, R., KIRKPATRICK, D. & KAPOOR, N. (1983) Language Recovery following Isolation for Severe Combined Immunodeficiency Disease, <i>Nature</i>, 306 (3), pp 54-55.	One boy with SCID (by age four he was discharged having spent three and a half years in isolation)	Case study of an infant for first 52 months of life	<ul style="list-style-type: none"> • At nine and a half months appeared to have normal language development • At 21 months still not speaking • Rarely initiated discourse 	Single case study
McKEEVER, P., O'NEILL, S. & MILLER, K. (2002) Managing Space and Marking Time: Mothering Severely Ill Infants in Hospital Isolation, <i>Qualitative Health Research</i>, 12 (8), pp 1020-1032.	Five mothers of infants with SCID	Qualitative in-depth interviews. Descriptive, retrospective exploratory study	<ul style="list-style-type: none"> • Physical characteristics of the room impact upon the mothers' feelings • Loneliness – no one to talk to • Physical isolation of being stuck in the room • Social isolation from friends and family 	Parental perspective – mothers experience only
MOOLA, F. (2018) The Complexities of Contagion: The Experience of Social Isolation among Children and Youth Living with Cystic Fibrosis in Canada, <i>Journal of Child Health Care</i>, 22 (4), pp 631-645.	Nine children and young people aged 10-24 years	Qualitative semi-structured interviews, audiotaped and transcribed verbatim	<ul style="list-style-type: none"> • “All alone” • Navigating risk – rule followers • Online spaces – connecting across time and space 	Lack of diversity in sample

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POWAZEK, M., GOFF, J. R., SCHYVING, J. & PAULSON, M. A. (1978) Emotional Reactions of Children to Isolation in a Cancer Hospital, <i>Journal of Pediatrics</i> , 92 (5), pp 834-837.	123 children and their mothers were evaluated . Self survey reports and behavioural observations by nurses	Quantitative: State Trait anxiety Inventory, Patient Behaviour Rating Checklist, Maternal Depression Scale	<ul style="list-style-type: none"> Mothers (especially those with pre-school children had high levels of state anxiety Older children (>12) were more anxious than younger children Maternal depression did not vary significantly with patient age or type of isolation Positive parental opinions re: protection from germs and convenience of long visiting hours 	
ROTEGARD, A. K. & SYKEPLEIVITENSKAP, K. (2007) Children in an Isolation Unit – Parents’ Informational Needs, <i>Nordic Journal of Nursing Research & Clinical Studies</i> , 27 (4), pp 32-37.	Questionnaire sent to 51 families, with a response rate of 53%	Self-constructed questionnaire. Mothers and/or fathers of children in isolation due to gastroenteritis or RSV.	<ul style="list-style-type: none"> Parents need more information on nurse expectations of the parents and the idea of partnership Need information on discharge and who to contact even on short admissions Information needs to be tailored to the family 	Low response rate
RUSSO, K., DONNELLY, M. & REID, A. J. M. (2006) Segregation - The Perspectives of Young Patients and their Parents, <i>Journal of Cystic Fibrosis</i> , 5 (2), pp 93-99.	Purposive sampling Parents (n=192) patients over 10 years (n=101) were sent the questionnaire – 43% return rate for parents and 23% for children	Qualitative – open-ended questionnaires	<ul style="list-style-type: none"> Parents and children supported segregation Boredom Social impact Pressure for parents to spend more time at hospital Use technology to improve the experience Parents aware of the positive and negative aspects of segregation viewed it as ‘necessary evil 	Limited to one condition Low respondent rate

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SIMONS, C., KOHLE, K., GENSCHER, U. & DIETRICH, M. (1973) The Impact of Reverse Isolation on Early Childhood Development, <i>Psychotherapy and Psychometrics</i>, 22 (2-6), pp 300-309.	Two non-identical twins who suffer from lymphopenic hypogammaglobulinemia	Buhler Hetzer Development Scale Observation	<ul style="list-style-type: none"> Twins main occupation was watching outside Separation anxiety demonstrated aged two Intellectual capacity below average 1 had poor language development 	Case study Dated
TAMAROFF, M., NIR, Y. & STRAKER, N. (1986) Children Reared in a Reverse Isolation Environment: Effects on Cognitive and Emotional Development, <i>Journal of Autism and Developmental Disorders</i>, 16 (4), pp 415-424.	Four infants with SCID	Case study of four infants – look at neonatal and family history, parental involvement during hospitalisation, observation of feeding, psychological development and development as an outpatient	<ul style="list-style-type: none"> No consistent outcome regarding development Isolation is not the most noxious psychological impact, but the lack of parental involvement 	Case study Small sample Limited transferability Dated
VINES, E. E., FISHER, P., CONNIFF, H. & YOUNG, J. (2018) Adolescents' Experiences of Isolation in Cystic Fibrosis, <i>Clinical Practice Pediatric Psychology</i>, 6 (4), pp 375-385.	Nine adolescents with cystic fibrosis who had experienced isolation	Qualitative, semi-structured interview	<ul style="list-style-type: none"> Participants experienced difficulty adjusting to isolation Isolation highlighted sense of threat from cross contamination Isolation highlighted the differences between patients with CF and others 	Contextual factors were not considered as the study was single site
WU, J., MU, P. F., TSAY, S. L. & CHIOU, T. J. (2005) Parental Experience of Family Stress during Hematopoietic Stem Cell Transplantation of Pediatric Patients in Germ-Free Isolation in Taiwan, <i>Cancer Nursing</i>, 28 (5), pp 363-371.	Convenience sampling of parents of children undergoing haematopoietic stem cell transplantation. 11 parents	Qualitative Inquiry – in depth interviews	<ul style="list-style-type: none"> Parental psychological distress Family lifestyle disturbances Challenges with parents' coping strategies Need for family resources 	Only relevant to patients post BMT

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Appendix 5

Search Examples for Staff Literature

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CINAHL Search

Last executed on 25/10/2019

Search limits English Language, 1999-2019

Number	Searches	Results	Relevant
1	Isolation AND Hospital	701	
2	Search 1 AND Staff	441	
3	Source Isolation AND Hospital AND Staff	79	11
4	Protective Isolation AND Hospital AND Staff	53	15
5	Isolation Precautions AND Staff AND Hospital	52	12
6	Search 1 AND Staff Experience	94	9

MEDLINE Search

Last executed on 25/10/2019

Search limits English Language, 1999-2019

Number	Searches	Results	Relevant
1	Isolation	1103457	
2	Search 1 AND Hospital	124733	
3	Isolation precautions AND Hospital	954	
4	Search 3 AND Staff	164	24
5	Search 3 AND "Staff experiences"	12	11

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Appendix 6

Summary Table of Staff Literature

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Reference	Sample	Study Design	Findings	Limitations
ANDERSON, N., JOHNSON, D. & WENDT, L. (2015) Use of Novel Teaching Method to Increase Knowledge and Adherence to Isolation Procedures, <i>Med Surg Nursing</i> , 24 (3), pp 159-164.	30 registered nurses observed pretest, only 12 completed observation after test Over a three month period conducted on a 36 bed medical oncology unit in a community based hospital in south eastern USA	Pretest-posttest, single group, quasi-experimental design used to evaluate effectiveness of isolation educational program on knowledge of and adherence to isolation policies of nursing staff	<ul style="list-style-type: none"> Isolation knowledge increased significantly after education program 	Only one unit Observation not entirely covert Participants were noted to be evasive when they were aware that they were being observed
ALLEN, S. & CRONIN, S. (2012), <i>Dimensions of Critical Care Nursing</i> , 31 (5), pp 290-294.	Observational on one ward	Observational before and after implementation	<ul style="list-style-type: none"> Improvement in the use of isolation precautions among nursing personnel through implementation of an educational intervention and behavioural contract 	
ASKARIAN, M., MEMISH, Z. A. & KHAN, A. A. (2007) Knowledge, Practice, and Attitude Among Iranian Nurses, Midwives, and Students Regarding Standard Isolation Precautions, <i>Infection Control and Hospital Epidemiology</i> , 28 (2), pp 241-244.	Surveyed instructors in nursing, auxiliary nursing and midwifery, as well as student in all three areas 273 completed questionnaire (84% response rate)	Questionnaire	<ul style="list-style-type: none"> In terms of knowledge and practice, nursing, midwifery instructors and student were equal, but auxiliaries had a lower mean attitude score than other groups 	Iranian study, with Iranian trained nurses
BARLOW, G., SACHDEV, N. & NATHWANI, D. (2002) The Use of Adult Isolation Facilities in a UK Infectious Diseases Unit, <i>The Journal of Hospital Infection</i> , 50 (2), pp 127-132.	One infectious diseases unit	Service review of isolation facilities in isolation unit	<ul style="list-style-type: none"> Findings indicate suboptimal use of hospital isolation facilities Some alert infections were housed in open bay beds and low risk were unnecessarily exposed to isolation in infectious diseases unit 	Service review of adult isolation facility

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BEAM, E., GIBBS, S. G., HEWLETT, A. L., IWEN, P. C., SMITH, P. W. & NUSS, S. L. (2015) Clinical Challenges in Isolation Care, <i>American Journal of Nursing</i> , 115 (4), pp 44-49.	24 nursing participants	Participants were video-recorded as they donned and doffed PPE	<ul style="list-style-type: none"> Variations in PPE use noted Behaviours are a safety concern and potential risk for disease transmission 	One American unit
CASSIDY, I. (2006) Student Nurses' Experiences of Caring for Infectious Patients in Source Isolation. A Hermeneutic Phenomenological Study, <i>Journal of Clinical Nursing</i> , 15 (10), pp 1247-1256.	Eight second year students in undergraduate general nursing degree	Hermeneutic phenomenology – unstructured, open-ended and face to face interviews	<ul style="list-style-type: none"> Caring in context; barriers and breaking barriers Challenges between theory and practice “Only a student” Imposed physical, psychological, social and emotional barriers alter caring experience Perception of supernumerary status influenced students' experiences of caring for these patients 	Singe site study in Ireland
CEPEDA, J. A., WHITEHOUSE, T., COOPER, B., HAILS, J., KWAKU, F., TAYLOR, L., HAYMAN, S. COOKSON, B., SHAW, A., KIBBLER, C., SINGER, M., BELLINGHAM, G. & WILSON, A. P. R. (2005) Isolation of Patients in Single Rooms or Cohorts to Reduce Spread of MRSA in Intensive Care Units: Prospective Two-Centre Study, <i>The Lancet</i> , 365 (9456), pp 295-304	Review of practice over one year	Prospective study in three general medical-surgical ICUs	<ul style="list-style-type: none"> MRSA acquisition rates were similar in period between the period when MRSA colonised patients were moved and not moved 	ICU specific

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CHAN-YEUNG, M. (2004) Severe Acute Respiratory Syndrome (SARS) and Healthcare Workers, <i>International Journal of Occupational & Environmental Health</i> , 10 (4), pp 421-427.	No description of literature review process	Literature Review	<ul style="list-style-type: none"> Healthcare workers felt lonely and isolated from the outside world Fear of infection family 	Limited review SARS specific
CHEN, S-L., CHEN, K-L., LEE, L-H. & YANG, C. I. (2016) Working in a Danger Zone: A Qualitative Study of Taiwanese Nurses' Work Experiences in a Negative Pressure Isolation Ward, <i>American Journal of Infection Control</i> , 44 (7), pp 809-814.	10 nurses were interviewed	In depth interviews	<ul style="list-style-type: none"> Complexity of patient care Dissatisfaction with quantity and quality of protective equipment Shortage of nursing staff Continued worries about being infected Sensitivity to self-protection 	Negative-pressure isolation ward specific
CHEN, R., CHOU, K., HUANG, Y. J., WANG, T., LIU, S. & HO, L. (2006) Effects of a SARS Prevention Programme in Taiwan on Nursing Staff's Anxiety, Depression and Sleep Quality: A Longitudinal Survey, <i>International Journal of Nursing Studies</i> , 43 (2), pp 215-225.	116 subjects recruited from nursing staff in largest SARS treatment hospital in Taiwan	Anxiety and Depression scoring Sleep quality reporting scales	<ul style="list-style-type: none"> Nursing staff anxiety, depression and sleep quality started to improve within two weeks of initiation of SARS prevention controls 	SARS specific
CHITTICK, P., KOPPISETTY, S., LOMBARDO, L., VADHAVANA, A., SOLANKI, A., CUMMING, K., AGBOTO, V., KARL, C. & BAND, J. (2016) Assessing Patient and Caregiver Understanding of and Satisfaction with The Use of Contact Isolation, <i>American Journal of Infection Control</i> , 44 (6) pp 657-660.	70 caregivers responded	Survey of patients and patient caregivers in contact isolation, using 5 point Likert scale	<ul style="list-style-type: none"> Contact isolation was viewed as positive by most patients Challenges for staff- felt unprepared to explain to patients the reason for isolation 	

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CLOCK, S. A., COHEN, B., BEHTA, M., ROSS, B. & LARSON, E. L. (2010) Contact Precautions for Multidrug-Resistant Organisms: Current Recommendations and Actual Practice, <i>American Journal of Infection Control</i>, 38 (2), pp 105-111.	Observations of three New York Hospital sites	Observational study of 3 sites	<ul style="list-style-type: none"> • Contact precautions were instituted in 85% of indicated patients • Isolation most necessary in VRE and MRSA • Varying rates of glove and gown use and hand hygiene • Adherence significantly better in ICU 	Not related to the experience of the staff or patients directly
DE FRANCA, S. R., SANT'ANA, E. A., NUNES MAFRA, A. C. C., PRADO, M., GAGLIARDI, G. M., EDMOND, M. B. & MARRA, A. R. (2018) The Impact of Isolation Precautions on Hand Hygiene Frequency by Healthcare Workers, <i>Infection Control and Hospital Epidemiology</i>, 39 (2), pp 245-247.	755 patients participated – 561 with no isolation precautions and 194 with isolation precautions	Study conducted in a private tertiary care in Brazil. Used a radiofrequency device to assess hand hygiene frequency. Isolated and non-isolated patients were compared	<ul style="list-style-type: none"> • Hand hygiene incidences with alcohol sanitiser per patient day ranged from 0.45 to 177.6, median was 63.7 hand hygiene episodes per patients day 	Not experience related
DHAR, S., MARCHAIM, D., TANSEK, R., CHOPRA, T., YOUSUF, A., BHARGAVA, A., MARTIN, E. T., TALBOT, T. R., JOHNSON, L. E., HINGWE, A., ZUCKERMAN, J. M., BONO, B. R., SHUMAN, E. K., POBLETE, J., TRAN, M., KULHANEK, G., THYAGARAJAN, R., NAGAPPAN, V., HERZKE, C., PERL, T. M. & KAYE, K. S. (2014) Contact Precautions: More is Not Necessarily Better, <i>Infection Control and Hospital Epidemiology</i>, 35 (3), pp 213-221.	11 teaching hospitals across USA	Prospective cohort study in 2009 Observation 1013 episodes of care with healthcare workers, monitoring compliance	<ul style="list-style-type: none"> • Compliance variable • As burden of isolation increased, there was a decrease in compliance with hand hygiene 	

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FARRINGTON, M. TRUNDLE, C., REDPATH, C. & ANDERSON, L. (2000) Effects on Nursing Workload of Different Methicillin-Resistant Staphylococcus Aureus (MRSA) Control Strategies, <i>Journal of Hospital Infection</i>, 46 (2), pp 118-122.	Nursing workload evaluated in two MRSA outbreaks	Standardised analysis of epidemiological data for each ward, before, during and after ward closure	<ul style="list-style-type: none"> Workload pressures rise during outbreaks if wards are not closed quickly ad fully 	These findings need to be compared to outbreak control measures
FARYAD, S., INAVAT, S., AFZAL, M. & HUSSAIN, M. (2018) Knowledge, Attitude and Practice of Standard Isolation Precautions Among Registered Nurses of Allied Hospital Faisalabad, <i>International Journal of Scientific & Engineering Research Volume</i>, 9 (5), pp 461-484.	132 nursing participants from Allied hospital, Faisalabad	Descriptive cross-sectional study Convenience sampling	<ul style="list-style-type: none"> Nurses perceive isolation precautions as very important to prevent infection transmission Nurses have good knowledge about standard isolation precautions Attitude was not satisfactory towards standard isolation precautions 	Only considers qualified nursing staff
GHONIM, E. & BENGHUZZI, H. A. (2014) Implementation of Standardized Color Coded Isolation Signs at a Teaching Hospital and Their Effect on Compliance with Isolation Precautions, <i>Biomedical Sciences Instrumentation</i>, 50 (1), pp 353-360.	Review of practice in a tertiary hospital with 722 beds	Interventional study of changing standardised colour signs to inform isolation precautions	<ul style="list-style-type: none"> Communication and cooperation were essential in problem solving, improving patient safety and improving staff knowledge 	

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GOULD, D. & DREY, N. (2013) Student Nurses' Experiences of Infection Prevention and Control During Clinical Placements, <i>American Journal of Infection Control</i> , 41 (9), pp 760-763.	National sample of student nurses in UK- 488 Student nurses completed the survey	Online survey using a Likert style scale with nineteen items with open questions	<ul style="list-style-type: none"> • All participants reported lack of compliance, most frequently in community settings and older people • Incidents most commonly witnessed were failure to comply with hand hygiene protocols, failure to comply with isolation precautions, not changing PPE between patients • Lack of good nursing role models • Medical staff noted to be the staffing group with the most identified poor compliance 	Only researched student perspective
IM, S-B., BAUMANN, S. L., AHN, M., KIM, H., YOUNG, B-H., PARK, M. & LEE, O-J. (2018) The Experience of Korean Nurses During the Middle East Respiratory Syndrome Outbreak, <i>Nursing Science Quarterly</i> , 31 (1), pp 72-76.	Eight South Korean nurses	Qualitative interviews to explore the experience of nurses during an outbreak of MERS (Middle East Respiratory Syndrome) in Autumn 2015	<ul style="list-style-type: none"> • Nurses experienced feeling hopeless, cut off, feeling shame and overworked, feeling pride in fulfilling duties 	
JOHNSON, S., MCNEAL, M., MERMIS, J., POLINER, D. & BURGER, S. (2018) Chasing Zero: Increasing Infection Control Compliance on an Inpatient Cystic Fibrosis Unit, <i>Journal of Nursing Care Quality</i> , 33 (1), pp 67-71.	One CF unit.	<p>Audits of staff adherence pre and post intervention</p> <p>Implementation of safe zone floor decals, staff contracts and infection control in-service videos</p>	<ul style="list-style-type: none"> • Increased and sustainable improvement among each group 	

Appendices

KAGAN, I., FRIDMAN, S., SHALOM, E. & MELNIKOV, S. (2017) The Effect of Working in an Infection Isolation Room on Hospital Nurses' Job Satisfaction, <i>Journal of Nursing Management</i> , 26 (2), pp 120-126.	87 Registered Nurses	Cross-sectional study Convenience sample of nurses who worked in carbapenemase-producing klebsiella pneumoniae isolation rooms in a tertiary medical centre in Israel	<ul style="list-style-type: none"> Job satisfaction correlated with perceived knowledge of carbapenemase-producing klebsiella pneumoniae, experience of working in an isolation room and perceived level of professional function 	
KHO, A. N., DEXTER, P. R., WARVEL, J. S., BELSITO, A. W. COMMISKEY, M., WILSON, S. J., HUI, S. L. & MCDONALD, C. J. (2008) An Effective Computerized Reminder for Contact Isolation of Patients Colonized or Infected with Resistant Organisms, <i>International Journal of Medical Informatics</i> , 7 (3), pp 194-198.	One ward	Measured rates of appropriate contact isolation. Before and after interventional study implementing computerized reminders for contact isolation.	<ul style="list-style-type: none"> The implementation of computerised reminder increased the rate of patients appropriately isolated from 33% to 89% Decrease in time to writing contact isolation orders 	Study specific to MRSA and VRE
KILPATRICK, C., PRIETO, J. & WIGGLESWORTH, N. (2008) Single Room Isolation to Prevent The Transmission of Infection: Development of a Patient Journey Tool to Support Safe Practice, <i>British Journal of Infection Control</i> , 9 (4), pp 19-25.	Not applicable	Presentation of a tool to facilitate learning and practice in relation to transmission-based precautions, designed for use in single room isolation	<ul style="list-style-type: none"> The tool is acceptable to healthcare workers 	

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KIRKLAND, K. B. & WEINSTEIN, J. M. (1999) Adverse Effects of Contact Isolation, <i>The Lancet</i> , 354 (9185), pp 1177-1178.	One ward observed	Observational study	<ul style="list-style-type: none"> Healthcare workers are half as likely to enter the rooms of patients in contact isolation Healthcare workers are more likely to wash their hands after caring for patients not in isolation 	
LANDERS, T., MCWALTERS, J., BEHTA, M., BUFE, G., ROSS, B., VAWDREY, D. K. & LARSON, E. (2010) Terms Used for Isolation Practices by Nurses at An Academic Medical Center, <i>Journal of Advanced Nursing</i> , 66 (10) pp 2309-2319.	317 nurses gave responses to 2215 clinical scenarios	Nurses from an academic medical center on east coast of USA completed a survey consisting of 10 clinical scenarios which asked about PPE and types of isolation	<ul style="list-style-type: none"> PPE was selected for use when not indicated – including gowns, respirators, masks and sterile gloves Inconsistent terminology used, which may account for variations in practice 	
MABEN, J., GRIFFITHS, P., PENFOLD, C., SIMON, M., PIZZO, E., ANDERSON, J., ROBERT, G., HUGHES, J., MURRELLS, Y., BREARLEY, S. & BARLOW, J. (2015) Evaluating A Major Innovation in Hospital Design: Workforce Implications and Impact on Patient and Staff Experiences of All Single Room Hospital Accommodation, <i>Health Service and Delivery Research</i> , Number 3.3. Available from: https://www.ncbi.nlm.nih.gov/books/NBK274434/ doi: 10.3310/hsdr03030.	21 stakeholder interviews, 250 hours of observation, 2 staff interviews, 32 patient interviews, staff survey and staff pedometer data	Mixed methods study to inform pre/post comparison within a single hospital to explore the impact of the move to a newly build hospital with all single rooms. Quasi experimental study in two control hospitals	<ul style="list-style-type: none"> No significant change in proportion of time spent by nursing staff on different activities Staff perceived improvements in patient comfort and confidentiality Staff perceived issues with visibility, surveillance, teamwork, monitoring, safeguarding and remaining close to patients 2/3 patients expressed a preference for single rooms with benefits of comfort and control outweighing disadvantages Some patients experience care as task-driven and functional, and interaction with other patients was absent – leading to a sense of isolation Staff walking distances increased in new hospital 	

Appendices

<p>MAUNDER, R., HUNTER, J., VINCENT, L., BENNETT, J., PELADEAU, N., LEZCZ, M., SADAVOY, J., VERHAEGHE, L. M., STEINBERG, R. & MAZZULI, T. (2003) The Immediate Psychological and Occupational Impact of the 2003 SARS Outbreak in a Teaching Hospital, <i>Canadian Medical Association Journal</i>, 168 (10), pp 1245-1251.</p>	<p>19 patients with SARS, of staff, managers and mental health professionals</p>	<p>Observations, interviews to compile retrospective descriptions of the experiences of staff and patients based on informal observation</p>	<ul style="list-style-type: none"> • Hospital response to SARS was to implement mental health support interventions for patients and staff • Patients with SARS reported fear, loneliness, boredom and anger • Patients were worried about the effects of quarantine and contagion on family members and friends • Patients experienced insomnia • Staff affected by fear of contagion 	<p>SARS specific</p>
<p>MOHAMMADZADEH, M., BEHNAZ, F. & PARSA, S. (2013) Knowledge, Practice and Attitude Towards Standard Isolation Precautions in Nurses, Auxiliary Nurses and Midwives of Shahid Sadoughi Hospital, Yazd, Iran, <i>International Journal of Infection Control</i>, 9 (1), DOI: 10.3396/ijic.v9i1.005.13.</p>	<p>200 Nurses, auxiliary nurses and midwifery staff</p>	<p>Cross-sectional survey about their knowledge, attitude and practice towards standard isolation precautions in a teaching hospital in Iran</p>	<ul style="list-style-type: none"> • Knowledge and attitudes were moderate • Practice was relatively poor 	<p>The questions within the survey did not assess all the concepts of standard isolation</p> <p>No correlation between knowledge, practice and attitude</p>

Appendices

MOORE, G., ALI, S., FITZGERALD, G., MUZSLAY, M., ATKINSON, S., SMITH, S., CRYER, P., GUSH, C. & The SmartIdeas Research Student Group, Wilson, A. P. R. (2010) Ward Assessment of SmartIdeas Project: Bringing Source Isolation to The Patient, <i>Journal of Hospital Infection</i> , 76 (2), pp 103-107.	53 patients	Concurrent collection of environmental samples and staff hand hygiene audit	<ul style="list-style-type: none"> • Hand hygiene compliance on entry or exit to/from an isolation bed space improved • Toilets were mechanically unreliable • Low levels of microbial contamination within all isolated bed spaces 	
MORGAN, D. J., DIEKEMA, D. J., SEPKOWITZ, K. & PERENCEVICH, E. N. (2009) Adverse Outcomes Associated With Contact Precautions: A Review of The Literature, <i>American Journal of Infection Control</i> , 3 (2), pp 85-93.	15 studies met inclusion criteria, published between 1989 and 2008	Literature Review	<ul style="list-style-type: none"> • Four main adverse outcomes related to isolation identified • Less patient-health care worker contact • Changes in systems of care that produce delay • Increased symptoms of depression and anxiety • Decreased patient satisfaction with care 	
NEO, F., EDWARD, K-L. & MILLS, C. (2012) Current Evidence Regarding Non-Compliance with Personal Protective Equipment- An Integrative Review to Illuminate Implications for Nursing Practice, <i>The Journal of Perioperative Nursing in Australia</i> , 25 (4), pp 22-26.	Literature search strategy not described, thus unknown number of papers included.	Integrative review of literature, regarding use of PPE in OR and qualitative research gaps and considerations from perioperative and acute nurses' perspectives	<ul style="list-style-type: none"> • The impact on nurses' motivations for the use of PPE looks at a number of elements such as opinions of colleagues and patients; intrinsic factors such as perceptions, risk appraisal previous experience and risk-taking profile 	

Appendices

NICKELL, L. A., CRIGHTON, E. J., TRACY, S., AL-ENAZY, H., BOLAJI, Y., HANJRAH, S., HUSSAIN, A., MAKHLOUF, S. & UPSHUR, R. E. G. (2004) Psychological Effects of SARS on Hospital Staff: Survey of a Large Tertiary Care Institution, <i>Canadian Medical Association Journal</i> , 170 (5), pp 793-798.	4283 questionnaires distributed, 47% were returned	Questionnaires distributed in one large teaching hospital in Canada	<ul style="list-style-type: none"> • Masks were reported to be the most bothersome infection control precaution • Staff felt an increase level of concern for personal or family health, perception of greater risk of death from SARS, living with children • Emotional distress associated with being a nurse, part-time employment status, lifestyle affected by SARS outbreak and ability to do one's job affected by precautionary measures 	Study was undertaken during initial part of SARS outbreak, this may not be transferable to all SARS situations
PERES, D., SEVERO, M. & FERREIRA, M. A. (2016) Knowledge, Source of Information, and Perception of Portuguese Medical Students and Junior Doctors of Infection Control Precautions, <i>American Journal of Infection Control</i> , 44 (12), pp 1723-1725.	5 th and 6 th year students and junior doctors from Portugal	Questionnaire	<ul style="list-style-type: none"> • Variety of opinions related to the most important source of information for infection control knowledge – between bedside practice, bedside teaching, curriculum and self-learning 	Population represented did not represent all Portuguese medical students. Knowledge does not necessarily translate into attitude and practice
PRIETO, J. & MACLEOD CLARK, J. (2005) Contact Precautions for Clostridium Difficile and Methicillin-Resistant Staphylococcus Aureus (MRSA), <i>Journal of Research in Nursing</i> , 10 (5), pp 511-526.	One hospital ward N=18	Single case study designed to explore nurses' and healthcare assistants' infection control practice Phase 1 observations of practice Phase 2 Implementation Phase 3 Interviews	<ul style="list-style-type: none"> • Participants experience great difficulty comprehending infection control recommendations • Capacity to understand and implement recommendations was hampered by lack of knowledge and irrational beliefs- in relation to patients and themselves • Lack of ability or willingness to exercise clinical judgement in relation to glove use 	

Appendices

<p>RODERICK, M., SPERONI, K. G., STAFFORD, A. & SEIBERT, D. J. (2017) Pilot Evaluation of Isolation Patients' Perceptions on Ability to Identify Types of Health Care Workers When Wearing Isolation Gowns, <i>American Journal of Infection Control</i>, 45 (3), pp 324-326.</p>	<p>50 hospitalised patients on contact isolation</p>	<p>Evaluation of the patient's ability to identify health care worker in isolation gowns with no badge visible, then with pre-printed stickers</p>	<ul style="list-style-type: none"> • Patients ranked their ability to identify healthcare workers as important • 56% of patients felt that staff should wear badge on outside of isolation gowns • Easier to identify role of professionals with a badge 	<p>Simplistic method</p>
<p>SAINT, S., HIGGINS, L. A., NALLAMOTHU, B. K. & CHENOWETH, C. (2003) Do Physicians Examine Patients in Contact Isolation Less Frequently? A Brief Report, <i>American Journal of Infection Control</i>, 31 (6), pp 354-356.</p>	<p>N=139 patients n=31 in contact precautions</p>	<p>Prospective cohort study on inpatient medical services at two university-affiliated medical centres. Observation of senior medical resident and attending physicians during morning round.</p>	<ul style="list-style-type: none"> • Senior medical residents examined 84% contact isolation versus 87% not in contact isolation • Attending physicians examined 35% in contact isolation versus 73% not in contact isolation 	
<p>SAX, H., PERNEGER, T., HUGONNET, S. & HERRAULT, P. (2005) Knowledge of Standard and Isolation Precautions in a Large Teaching Hospital, <i>Infection Control & Hospital Epidemiology</i>, 26 (3), pp 298-304.</p>	<p>1241 questionnaires returned</p>	<p>Self-administered questionnaire in random sample of 1500 nurses and 500 physicians in large teaching hospital</p>	<ul style="list-style-type: none"> • More than half gave correct answers to 10 or more of the knowledge type questions • Reasons for non-compliance were lack of knowledge, lack of time, forgetfulness and lack of means • Knowledge independently associated with exposure to training sessions and less professional experience 	

Appendices

SELBERT, D. J., GABEL SPERONI, K., KYEUNG, M. O., DEVOE, M. C. & JACOBSEN, K. H. (2014) Preventing Transmission of MRSA: A Qualitative Study of Health Care Workers' Attitudes and Suggestions, <i>American Journal of Infection Control</i> , 42 (4), pp 405-411.	N=276 for questionnaire Purposive sampling - 26 acute care healthcare workers (16 nurses, one physician, six allied health professionals, three support staff)	Questionnaire Semi-structured interviews	<ul style="list-style-type: none"> • Participants reported feeling responsible for preventing transmission • Participants reported challenges to following consistent hand hygiene and contact precautions – barriers included patient care demands, equipment, availability of sinks, time pressures, need for signs indicating which patients require contact precautions 	Focused on transmission of MRSA only
SLOTA, M., GREEN, M., FARLEY, A., JANOSKY, J. & CARCILLO, J. (2001) The Role of Gown and Glove Isolation and Strict Handwashing in The Reduction of Nosocomial Infection in Children with Solid Organ Transplantation, <i>Critical Care Medicine</i> , 29 (2), pp 405-412.	Children in 23 bed PICU with solid organ transplantation	Prospective, randomised design of children in 23 bed PICU with solid organ transplantation enrolled into a gown and glove protective isolation protocol	<ul style="list-style-type: none"> • Infection rate overall did not change significantly • Infection rate in gown and glove group reduced significantly • Strict handwashing significantly reduced infection rate in transplant population • Compliance with gowning, gloving and handwashing was only 76% 	
SULIMAN, M., ALOUSH, S., ALJEZAWI, M. & ALBASHATWY, M. (2018) Knowledge and Practice of Isolation Precautions Among Nurses in Jordan, <i>American Journal of Infection Control</i> , 46 (6), pp 680-684.	247 staff questionnaires returned	Cross-sectional descriptive design over 8 hospitals in Jordan. Self-reported questionnaire and observational checklist based on CDC isolation guidelines	<ul style="list-style-type: none"> • Nurses (90%) have a good knowledge of isolation precautions • 65% nurses reported good compliance with isolation precautions • Checklist data confirmed that there is low compliance with standard isolation precautions • Limited use of isolation signs 	Data self-reported

Appendices

TIEDTKE, J. M., STIEL, S., HECKEL, M., HERBST, F. A., STURM, A., SIEBER, C., OSTGATHE, C. & LANG, F. R. (2018) Staff Members' Ambivalence on Caring for Patients with Multidrug-Resistant Bacteria at Their End of Life: A Qualitative study, <i>Journal of Clinical Nursing</i> , 27 (15-16), pp 3115-3122.	35 staff members from a German palliative care unit and a geriatric unit . 40% nurses, 26% physicians and 34% other professionals	Qualitative interviews about their experiences with multidrug resistant bacteria in end of life care and management of colonised or infected patients, in two German hospitals	<ul style="list-style-type: none"> Staff identified impact of MDRO on their behaviour, feeling and attitudes, and required isolation measures Dilemmas when facing diverse demands 	
VAN DE GLIND, I., DE ROODE, S. & GOOSSENSSEN, A. (2007) Do Patients in Hospitals Benefit from Single Rooms? A Literature Review, <i>Health Policy</i> , 84 (2-3), pp 153-161.	25 studies selected	Literature Review	<ul style="list-style-type: none"> Single rooms have a moderate effect on patient satisfaction with care, noise and quality of sleep, experience of privacy and dignity Some studies showed differences, whilst other concluded that single rooms decreased the risk of hospital infections 	Lack of empirical research found
VAYALUMKAI, J. V., STREITENBERGER, L., WRAY, R., GOLDMAN, C., FREEMAN, R., DREWS, S. & MATLOW, A. (2007) Survey of Isolation Practices at a Tertiary Care Pediatric Hospital, <i>American Journal of Infection Control</i> , 35 (4), pp 207-211.	Observation within a tertiary children's hospital	Prospective Observational study between 2004-2005	<ul style="list-style-type: none"> 17% of patients in the hospital were isolated Droplet isolation was the most common form of isolation 74.6% of patients were appropriately isolated. 	

Appendices

WADHWA, M., KALYAN, P. & SHEKHAR, S. (2016) Knowledge, Attitude and Practice of Universal Precautions among the Hospital Staff at Sterling Hospital Vadodara: A Hospital based Study, <i>International Journal of Nursing Education</i>, 8 (3), pp 24-29.	100 respondents – 49 males and 51 females	Questionnaire survey	<ul style="list-style-type: none"> • 91% gave a correct response regarding the base concept of universal precautions • Knowledge and attitude are negatively correlated 	
WIGGLESWORTH, N. & WILCOX, M. H. (2006) Prospective Evaluation of Hospital Isolation Room Capacity, <i>Journal of Hospital Infection</i>, 63 (2), pp 156-161.	12 month prospective observational study of every infection control request for isolation in a 1100 bed teaching hospital.	Prevalence surveys	<ul style="list-style-type: none"> • 845 requirements for patient isolation of which 185 could not be met • ¾ requirements of isolation were due to MRSA or C Difficile • Marked variation between specialist wards in terms of isolation failures 	
WONG, E. L. Y., WONG, S. Y. S., LEE, N., CHEUNG, A. & GRIFFITHS, S. (2011) Healthcare Workers' Duty Concerns of Working in The Isolation Ward During The Novel H1N1 Pandemic, <i>Journal of Clinical Nursing</i>, 21 (9-10), pp 1466-1475.	10 healthcare workers (Four physicians, three nurses and three healthcare assistants)	Qualitative study conducted in 2009 during pandemic alert of H1N1 flu	<ul style="list-style-type: none"> • Professional senses were strongly related to willingness to work • Concerns included appreciation for employers, efficacy and side effects of vaccination, frequent policy changes, unclear criteria of case management, poor facility layout. 	

Appendices

<p>ZHANG, J., WHILE, A. E. & NORMAN, I. J. (2011) Nurses' Knowledge and Risk Perception towards Seasonal Influenza and Vaccination and Their Vaccination Behaviours: A Cross-Sectional Survey, <i>International Journal of Nursing Studies</i>, 48 (10), pp 1281-1289.</p>	<p>N=522 nurses returned completed questionnaires</p>	<p>Cross-sectional survey. Survey instrument to examine nurses' knowledge about influenza and vaccination, risk perception</p>	<ul style="list-style-type: none"> • Influenza vaccination rate among respondents was 36% • Nurses with a high knowledge were more likely to get vaccinated • Nurses with high knowledge were more likely to get vaccinated than those with a low knowledge level • Vaccination nurses more likely to recommend getting vaccine 	
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Appendices

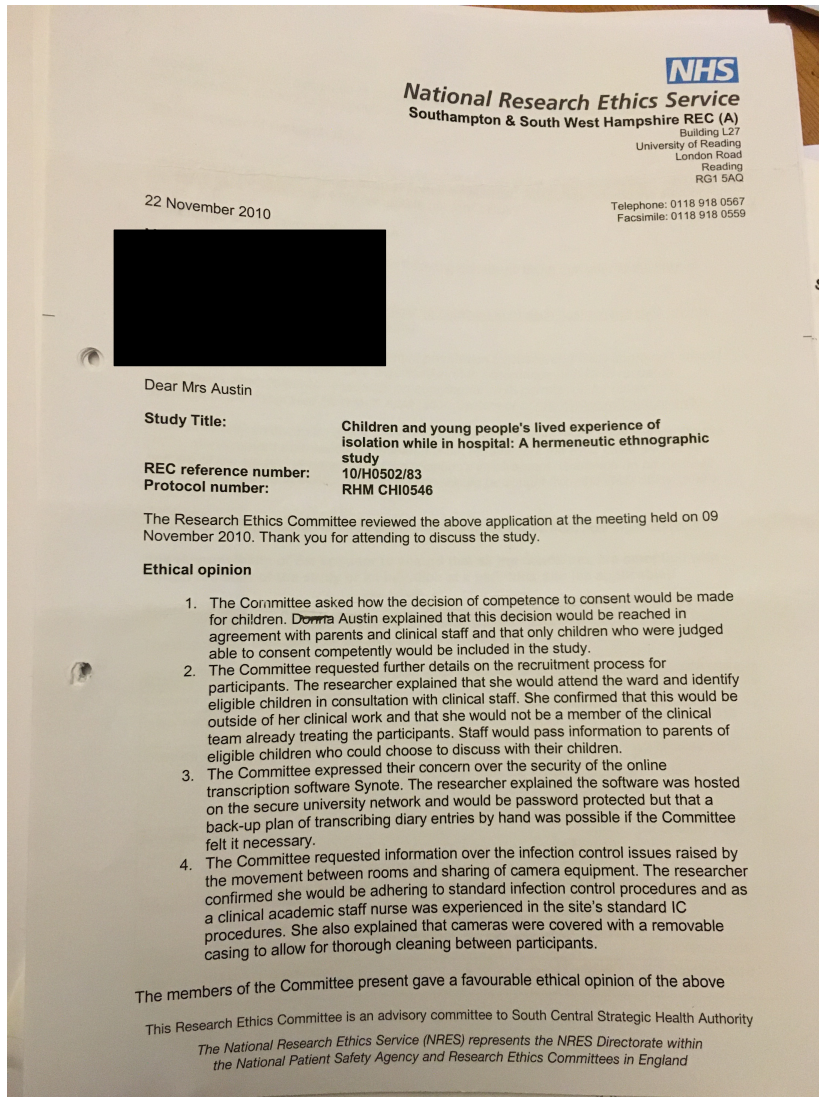
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Appendix 7
Summary of the Development of Methods and
Ethical Amendments

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	Time period	Approach	Number approached/ recruited	Issues
Phase 1	February 2011- October 2011	Approach 1: Children aged 8-17 years to make a video diary whilst in isolation and participate in a video stimulated recall interview after discharge. Parents recruited to participate in a follow up interview. Initially children were recruited from two wards, however after two months with limited recruitment, all the wards on the paediatric unit were included in the study	Number approached: 12 Number participated: 2 children (1 participated in both video diary and follow up interview, 1 participated in only the video diary. Neither parent participated	Key issue requiring amendment: Limited recruitment. 8 years old deemed too conservative, supported by the evidence
	November 2011- April 2012	Approach 2: Method remained the same, but age reduced to include 6 and 7 year old children	Number approached: 19 Number participated: 0	Key issue requiring amendment: limited recruitment to previous methods.
Phase 2	May 2012- October 2012	Approach 3: Children continued to be approached for the video diary. Primacy was given to the video diary method, however if children were not invited to participate in the video diary (e.g. researcher unavailable, child discharged), they were approached for the retrospective interviews. Children who were aged 6-17 years and their parents were asked to participate in a retrospective interview, without the video diary. Also children were asked to identify people who provided their care in isolation and they were approached to participate.	Number approached: 8 children for video diaries 24 children and their parents, 0 staff were approached for interviews Number participated: 1 child and parent in the interviews	Key issue requiring amendment: Limited recruitment and inability to recruit nurses who had specifically cared for the child in the study as the child did not recall the staff who provided their care. Revision made to include any staff providing care to children in isolation in general
	November 2012- March 2013	Approach 4: Children continued to be recruited to the video diary. Alternatively, children aged 6-17 years, parents of the child and parent of children who did not want to participate/too young to participate and any staff who provided care to children in isolation were invited to participate	Number approached: 3 children invited to video diary 11 children, 18 parents, 16 staff invited to retrospective interviews Number participated: 0 video diaries 2 children, 2 parents, 8 staff interviews	Key issue requiring amendment: Limited recruitment to video diary method, more data and better recruitment from retrospective interviews, therefore decision made to stop recruiting to video diaries.
Phase 3	April 2013- January 2015	Approach 5: Removal of the video diary element of the study, and continue with retrospective interviews only	Number approached: 8 children, 17 parents, 20 staff Number recruited: 3 children, 9 parents, 12 staff	

Appendices



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research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	1	22 October 2010
Interview Schedules/Topic Guides	1 - Interview for Parent	22 October 2010
Interview Schedules/Topic Guides	1 - Instruction for use of the Flip video Camera	22 October 2010
Advertisement	1 - Display posters for hospital doors	22 October 2010
Interview Schedules/Topic Guides	1 - Guidelines for filming	22 October 2010
Participant Information Sheet: Child	1	22 October 2010
Letter of invitation to participant	1 - Adult Invitation	22 October 2010

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Appendices

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorates within
the National Patient Safety Agency and Research Ethics Committees in England

Letter of invitation to participant	Letter	22 October 2010
Participant Information Sheet: Adult	1 - Child Invitation Letter	22 October 2010
Participant Consent Form: Data use of Dissemination	1	22 October 2010
Covering Letter	1	22 October 2010
Summary/Synopsis	1	22 October 2010
Letter from Sponsor	1	15 October 2010
Participant Consent Form: Child Assent	1	22 October 2010
Participant Consent Form: Use of Synote	1	22 October 2010
Protocol	1	22 October 2010
Referees or other scientific critique report		17 August 2010
Investigator CV		22 October 2010
Participant Consent Form: Parent	1	22 October 2010
Participant Consent Form: Child Consent	1	22 October 2010
REC application		22 October 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

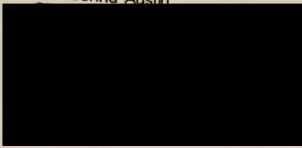
- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

Appendices

NRES Committee South Central - Southampton A
Level 3, Block E
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Tel: 0117 3421381
Fax: 0117 3420446

14 December 2011
Mrs Donna Austin


Dear Mrs Austin

Study title: Children and young people's lived experience of isolation while in hospital: A hermeneutic ethnographic study
Reference: 10/H0502/83
Protocol number: RHM CHI0546
Amendment number: 1
Amendment date: 16 November 2011

The above amendment was reviewed at the meeting of the Sub-Committee held on 13 December 2011.

Ethical opinion
The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents
The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet: Child	2	16 November 2011
Participant Information Sheet: Parent	2	16 November 2011
Protocol	2	16 November 2011
Notice of Substantial Amendment (non-CTIMPs)	1	16 November 2011

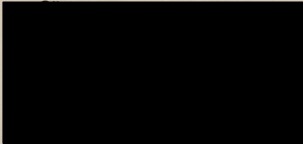
Membership of the Committee
The members of the Committee who took part in the review are listed on the attached sheet.

Appendices

NHS
Health Research Authority
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14 May 2012

Mrs Donna Austin



Dear Mrs Austin

Study title: Children and young people's lived experience of isolation while in hospital: A hermeneutic ethnographic study
REC reference: 10/H0502/83
Amendment number: Substantial Amendment 2 Dated 31.03.12
Amendment date: 23 April 2012

The above amendment was reviewed at the meeting of the Sub-Committee held on 08 May 2012.

Ethical opinion

The members of the Committee taking part in the review decided that they could not give a favourable ethical opinion of the amendment, for the following reasons:

- **There was no sentence about recording interviews in the consent form.**

I regret to inform you that the amendment is therefore not approved. The study should continue in accordance with the documentation previously approved by the Committee.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Mrs Maxine Knight.

Options for further ethical review

- 1. Modifying the amendment**

A Research Ethics Committee established by the Health Research Authority

Appendices

NHS
Health Research Authority
NRES Committee South Central - Southampton A
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22 May 2012

Mrs Donna Austin
[REDACTED]

Dear Mrs Austin

Study title: Children and young people's lived experience of isolation while in hospital: A hermeneutic ethnographic study
REC reference: 10/H0502/83
Protocol number: RHM CHI0546
Amendment number: 2a
Amendment date: 15 May 2012

Thank you for submitting the above amendment, which was received on 17 May 2012. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 14 May 2012 refers).

The modified amendment has been considered on behalf of the Committee by the Vice-Chair.

Ethical opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

Document	Version	Date
Participant Assent Form	2	15 May 2012
Participant Consent Form: Nurses	2	15 May 2012
Participant Consent Form: Child	2	15 May 2012

A Research Ethics Committee established by the Health Research Authority

NHS
Health Research Authority

NRES Committee South Central - Southampton A
Bristol Research Ethics Committee Centre
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15 February 2013

[Redacted]

Dear Mrs Austin

Study title: Children and young people's lived experience of isolation while in hospital: A hermeneutic ethnographic study
REC reference: 10/H0502/83
Protocol number: RHM CHI0546
Amendment number:
Amendment date:
IRAS project ID: 38367

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Parents (without child participant) retrospective invitation	1	21 November 2012
Interview Schedules/Topic Guides	2	21 November 2012
Participant Consent Form: Parents (without child participant)		21 November 2012
Participant Information Sheet: Parents (without child participant) retrospective	1	21 November 2012



Health Research Authority

NRES Committee South Central - Hampshire A

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Tel: 0117 342 1381

19 September 2014

Mrs Donna Austin

Dear Mrs Austin

Study title: Children and young people's lived experience of isolation while in hospital: A hermeneutic ethnographic study
REC reference: 10/H0502/83
Protocol number: RHM CHI0546
Amendment number: 5
Amendment date: 20 August 2014
IRAS project ID: 38367

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

- The Committee requested confirmation from the researchers that the care team have spoken to the participant before the researcher approaches them.
- The researchers confirmed that the care team will have spoken to the participant to ensure that they are in the best possible health and in an appropriate emotional state in order to discuss participation. They will also have given them a small overview of whom I am and the project prior to me meeting them.
- The Committee were happy with this response

Approved documents

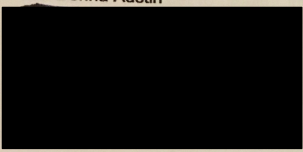
The documents reviewed and approved at the meeting were:

A Research Ethics Committee established by the Health Research Authority

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09 July 2015

Mrs Donna Austin



Dear Mrs Austin


Study title: Children and young people's lived experience of isolation while in hospital: A hermeneutic ethnographic study
REC reference: 10/H0502/83
Protocol number: RHM CHI0546
IRAS project ID: 38367

Thank you for sending the declaration of end of study form, notifying the Research Ethics Committee that the above study concluded on 23 January 2015. I will arrange for the Committee to be notified.

A summary of the final research report should be provided to the Committee within 12 months of the conclusion of the study. This should report on whether the study achieved its objectives, summarise the main findings, and confirm arrangements for publication or dissemination of the research including any feedback to participants.

10/H0502/83:	Please quote this number on all correspondence
---------------------	---

Yours sincerely



Maxine Knight
Rec Manager

Email: nrescommittee.southcentral-hampshirea@nhs.net

Appendices

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Appendix 8

Participant Recruitment Pack for Children to Video Diary Part of
the Study



Invitation: Child

Hello,

My name is Donna. I am a nurse who works here and I am doing a research project with the University of Southampton.

This project is going to explore how children like you feel about being in a room on your own while you are in hospital. To see what it was like you will be asked to make a video diary and have a short chat with me.

I want to invite you to be part of my project because you are in a room on your own in hospital. I would like you to read the leaflet and think about what it says.

Later on, I will come and ask you if you want to join in.

Best Wishes,

Donna Austin

Appendices

<p>What if something bad happens?</p> <p>It is unlikely that something will go wrong. If you are worried about anything to do with this project, talk to your parents who can make a complaint to</p> <p>Who has looked at my project?</p> <p>The project has been checked by experts in research and by people working with children in hospital.</p> <p>What is my name and how can I contact you?</p> <p>My name is: Donna Austin</p> <p>My email address is:</p> <p>My telephone number</p> <p>Thank you</p> 		 <p>Participant Information Sheet for Children and Young People</p> <p>Study Title:</p> <p>The child's experience of single room isolation while in hospital</p> <p>Donna Austin:</p> <p>Reference: 10/H0502/83</p> <p>Version 2: 16/11/2011</p>
<p>Study Title: The child's experience of single room isolation while in</p> <p>Invitation</p> <p>You and your parents are invited to take part in my project to see what you think about being in this room on your own while you are in hospital. You can decide if you want to be part of my project or not. Please read this leaflet and talk to your parents about it. You can also ask me anything about it if you want to.</p> <p>Thank you!</p> <p>Why am I doing this project?</p> <p>When children and young people like you come into hospital they sometimes have to stay in a room on their own. Sometimes they have to stay in this room because they have an infection that other children can catch. Other times it is because they can't go home easily and need to be protected from them.</p> <p>We don't know much about what children and young people think about being in a room by themselves while they are in hospital. I am doing a project and I would like to find out more about it so that we can make things as good as we can for children to be in a room on their own.</p> 	<p>Why have you been chosen?</p> <p>All children and young people like you who are 6-17 years old and are in a room on their own.</p> <p>Do you have to take part in my project?</p> <p>You can decide if you want to take part in my project or not. I will come back later to find out what you have decided. If you don't want to take part, no one will be upset, so don't worry.</p> <p>What happens if you take part in my project?</p> <p>You will be given a video camera to borrow and make a video diary to record what it is like to be in this room. I will tell you how to use the video camera and give you a few rules on what you can film and what you can't film. You will only be allowed to film people who have already said to me that they don't mind being filmed. When you go home I will meet with you and your parents for a chat about what you remember about being in hospital. At this time we will watch bits of your video diary and talk about this. Our chat will be recorded on a tape. I will also look at your medical notes.</p> <p>Is it good for you to take part?</p> <p>Taking part will give you the chance to tell me what it is like to be in this room. It won't make being in hospital any better, but you may help me to make it a better place for other children. As well, it might be a fun thing to do!</p>	<p>Could it be bad for you to take part?</p> <p>No, but if you do get upset about being in the room or taking part in the project then you can talk to your nurse, parents or me. We will be able to find a good way to help you.</p> <p>What will I do with the video and tape?</p> <p>All the information that you give me will be kept safe and will only be seen by me, my mentors and examiners unless you and your parents tell me that I can show other people. It will be put in a locked drawer in my office and on secure computers, so that no one else can get it. If you want to, you can choose a different name to use instead of your real name. I will do presentations to people to tell them what I found out, but your video will not be shown in this unless you and your parents tell me that I can. The presentations could be in UK or abroad.</p> <p>What do you do if you want to stop taking part?</p> <p>You can decide to stop taking part in my project at any time; you just need to tell me. If you do not want me to use any of the video/tape that you made before you finished, I will destroy it, but if you are happy for me to use it, that would be great also!</p> 

Consent Form for Research

(For participants aged 16-17 years who wish to consent independent of their parents)
(For participants who are <16 years and are deemed competent to consent in addition to their parents)

Study Title: The child's experience of single room isolation while in hospital

Researcher: Donna Austin
Participant Identification Number:
Version Number 2: 15/05/2012

Please
initial
box

I confirm that I have read and understood the participant information sheet for the study and that I understand the purpose, particulars of involvement and potential inconveniences of the study ☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

I understand that I will participate in an interview and that it will be recorded on audiotape ☐

I understand that both my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my future healthcare or legal rights being affected ☐

I agree to take part in the above research study ☐

Name of participant Signature Date

Researcher Signature Date

When completed one copy must be given to the participant and one copy must be kept by the researcher.

Researcher Contact Details:

Assent Form for Research

Study Title: The child's experience of single room isolation while in hospital

Researcher: Donna Austin
Participant Identification Number:
Version Number 1: 22/10//10

Please initial box

I have read the information sheet (or it has been read to me)
and I know that I can ask questions if I have any

☐

I agree to make a video diary whilst I am in hospital in this
room. I agree to the video rules and will only film my family
and me

☐

I agree that you can use the video for your study

☐

I agree that I will tell you if I don't want to make the video
anymore

☐

Name of child

Child's Signature

Date

Researcher

Signature

Date

When completed one copy must be put in patient's medical notes, one copy must be given to the participant and one copy must be kept by the researcher.

Researcher Contact Details:

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Appendix 9

Participant Recruitment Pack for Parents to Video Diary Part
of the Study

Invitation: Adult



Dear Parent/Carer,

I am a nurse who is conducting research with the University of Southampton. I am researching what it is like for a child to be in a room on their own while in hospital due to the risk of infection to themselves or others. This is known as being in 'isolation' or 'isolation precautions'

The main purpose of the study is to explore how children and young people feel about being in isolation as a result of having an infection that others could catch, or being at risk of catching an infection from others. The study would involve your child making a video diary and also taking part in an interview. It would also involve you taking part in one short interview about your child's experience of being in isolation.

In order for you to decide whether or not you agree to you and your child taking part, I would be grateful if you could read the enclosed information sheet and consider whether you would be willing to be involved in this study. Once you have read this information and if you are happy to do so, please give the enclosed envelope to your child, which contains a similar information leaflet for them to read.

I will visit you later to discuss any questions that you may have and ask you and your child if you wish to participate.

If you have any further questions about this study, please contact me (Donna Austin) on contact details.

Thank you for your time.

Yours Faithfully,

Donna Austin

Appendices

<p>What will happen to the results that we provide?</p> <p>The results may be reported in health publications, conferences or meetings, but you and your child will not be identified by name or image, unless you give me special consent for this. The researcher will send you a summary of the results.</p> <p>What happens if I change my mind?</p> <p>Participation or not participating in this study will not affect your child's treatment in any way. You and your child can change your mind and stop the study at any point. If you wish to stop, please stop filming and contact me. If you stop the study I will ask you if we can use the data that you have given me already. If you do not wish me to use it, all data that you have given me will be destroyed including the video and audiotape.</p> <p>What happens if there is a problem or I have a complaint?</p> <p>It is unlikely that something will go wrong in the process of making the video diary and the interview. However if you have a concern or a complaint about this study, you should contact</p> <p>Who has reviewed the study?</p> <p>A research ethics committee and hospital trust have given their approval.</p> <p>Thank You</p>	<p>Participant Information Sheet for Parents</p> <p>Study Title:</p> <p>The child's experience of single room isolation while in hospital</p> <p>Denise Austin Reference: 10/H4302/83 Version 2.16/11/2011</p>
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<p>Study Title: The child's experience of single room isolation while in hospital</p> <p>Text Box</p> <p>Invitation to Participate</p> <p>You and your child are invited to take part in a research study which will look at what children and young people think about being in single room isolation whilst in hospital.</p> <p>Before you and your child agree to take part in this study it is important for you to understand why the research is being done and what it will involve. In the envelope enclosed is a child-friendly version of this leaflet, which if you are happy to do so, please give to your child. Please take time to read this information and discuss your decision with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Thank you for your time.</p> <p>What is the purpose of the study?</p> <p>In hospital children are sometimes put in a room on their own because they have an infection that could be passed on to others or because they are at increased risk of catching an infection from others. This is called 'isolation precautions' or 'being in isolation'. Research about adults who are cared for in isolation rooms show that people can experience some advantages and disadvantages. There is very little research that asks what children and their parents think about being in isolation while in hospital. This study aims to find out about children's experiences of being in isolation from their own and their parents' point of view.</p> <p>Why have my child and I been chosen?</p> <p>I am selecting certain children who are in isolation due to the risk of infection while in hospital and are between the ages of 6-17 years to take part, which is why your family has been chosen.</p>	<p>Do I have to take part?</p> <p>No, you can freely decide if you and your child want to participate. More than four hours after you have read this I will visit you. I will make sure that you have had a full time you need to think about this, before you decide. We can discuss any questions that you have and I will ask you if you and your child wish to participate or not. If you decide not to take part you do not have to give a reason, no one will be upset. Whatever you decide, your child will receive the best possible care. If you decide to take part we will ask you to sign a consent form for yourself and your child. We will give you a copy of the consent form. Even if you do decide to take part you can still withdraw at any time.</p> <p>What will happen to my child and I if we decide to take part?</p> <p>All children who are taking part will be loaned a small video camera which they will be asked to use to make a video diary of their time in isolation in hospital. I will show you and your child how to use the camera and give you written instructions. I will explain what and how often to record a diary entry. They will only be allowed to film themselves, you and any member of the family that say that they do not mind being filmed. If you have any other children that may be filmed as part of the video diary, you will have to give consent for them to be filmed also. Your child will make the video diary for the first week of their day or less if they stay for less time in hospital. I will be available for technical support.</p> <p>You will be asked to make notes or use a Dictaphone to make verbal notes of any thoughts that you may have about your child's experience in the room.</p> <p>About two weeks after you've gone home I will meet with you and your child at a place of your choice, for a follow up interview with both of you which will take about 20-30 minutes each. During the interview we will watch bits of the video on a laptop, for your child to comment on. We will also discuss your any notes that you made. The interviews will be recorded on audiotape.</p>	<p>Will this study benefit me and my child?</p> <p>Although there are no benefits to you or your child whilst you are in hospital this time, it is hoped that the results from this study will help us to understand what it is like being in isolation so that we can improve the experience for children in the future.</p> <p>Are there any risks involved?</p> <p>No, there are minimal risks involved with taking part in this study. If you or your child are upset or worried at any point, please tell your nurse or me who will be able to help you in finding some support.</p> <p>Will my child's details be kept confidential?</p> <p>The video diary will be viewed and analysed by the research team and examiners. All data will remain entirely confidential unless prior consent has been given by you and your child, or unless it is requested under a legal court order. The videos will be stored on a password-protected external hard drive and stored securely in a locked office. All other data (audiotapes and field notes) will have names removed from them and will be stored in a locked office. It is University of Southampton policy to store data from research studies for 15 years, in a secure confidential manner. At all times, data with names will be stored separately to data that has names removed.</p> <p>I will look at your child's medical records. However all information that is collected about you and your child during the course of the research including the video and the answers that you give in the interviews will be kept strictly confidential. No names will be identified in any report that is published. The study may be presented in the UK, European Union and outside this.</p> <p>If anything that might threaten the child's safety is seen when watching the video diaries, the researcher has to inform other agencies in accordance with local child protection policies. No video will be released to a third party unless required to do so by law.</p>
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Consent Form for Participation in Research for Parents

Study Title: The child's experience of single room isolation while in hospital

Researcher: Donna Austin

Participant Identification Number:

Version Number 1: 22/10//10

Please initial box

I confirm that I have read and understood the participant information sheet for The study and that I understand the purpose, particulars of involvement and potential inconveniences of the study

☐

I give permission for my child to create a video diary

☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

☐

I give permission for my other children (under the age of 18) to be filmed as part of the video diary.

☐

Their names are:.....

.....

I understand that both my child's and my own participation is voluntary and that I am free to withdraw my child and/or myself at any time, without giving any reason, without my child's healthcare or legal rights being affected

☐

I understand that relevant sections of my child's medical notes and my child's and my own data collected during the study including the video diary, may be looked at by the researcher, supervisors and examiners only

☐

I agree for my child and myself to take part in the above research study

☐

Name of parents

Signature

Date

Researcher

Signature

Date

When completed the original must be put in patient's medical notes, one copy must be given to the participant and one copy must be kept by the researcher.

Researcher Contact Details:

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Appendix 10

Participant Recruitment Pack for Children and their Parent
for the Retrospective Interview



Invitation: Child

Hello,

My name is Donna. I am a nurse who works at XXXXXXXX Hospital and I am doing a research project with the University of Southampton.

This project is going to explore how children like you felt about being in a room on your own while you were in hospital. To see what it was like you will be asked to have a short chat with me.



I want to invite you to be part of my project because you were in a room on your own in hospital. I would like you to read the leaflet and think about what it says.



If you want to help me with my project, ask you parents and they will let me know.

Best Wishes,

Donna Austin

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<p>What if something bad happens?</p> <p>It is unlikely that something will go wrong. If you are worried about anything to do with this project, talk to your parents who can make a complaint to</p>		
<p>Who has looked at my project?</p> <p>The project has been checked by experts in research and by people working with children in hospital.</p>		<p>Participant Information Sheet for Children and Young People</p>
<p>What is my name and how can I contact you?</p> <p>My name is: Donna Austin</p> <p>My email address is:</p> <p>My telephone number</p>		<p>Study Title:</p> <p>The child's experience of single room isolation while in hospital</p>
<p>Thank you</p> 		<p>Donna Austin:</p> <p>Reference: 10/H0502/83 Version: 15/03/2012</p>

<h2>Study Title: The child's experience of single room isolation while in hospital</h2>	<h2>Why have you been chosen?</h2> <p>All children and young people like you who are 6-17 years old and who were in a room on their own when in hospital will be invited to take part in my project.</p>	<h2>Could it be bad for you to take part?</h2> <p>No, but if you do get upset about taking part in the project then you can talk to your nurse, parents or me. We will be able to find a good way to help you.</p>
<h2>Invitation</h2> <p>You and your parents are invited to take part in my project to see what you thought about being in a single room on your own while you were in hospital. You can decide if you want to be part of my project or not. Please read this leaflet and talk to your parents about it. You can also ask me anything about it if you want to.</p> 	<h2>Do you have to take part in my project?</h2> <p>You can decide if you want to take part in my project or not. If you want to participate, you need to let your parents know and they can contact me. If you don't want to take part, no one will be upset, so don't worry.</p>	<h2>What will I do with the interview data?</h2> <p>All the information that you give me will be kept safe and will only be seen by me, my mentors and examiners. It will be put in a locked drawer in my office and on secure computers, so that no one else can get it. If you want to, you can choose a different name to use instead of your real name. I will do presentations to people to tell them what I found out, but your name will never be said. The presentations could be in UK or abroad.</p>
<h2>Thank you!</h2> <h2>Why am I doing this project?</h2> <p>When children and young people like you come into hospital they sometimes have to stay in a room on their own. Sometimes they have to stay in this room because they have an infection that other children can catch. Other times it is because they can catch infections easily and need to be protected from them.</p>	<h2>What happens if you take part in my project?</h2> <p>I will come and visit you and your parents for a chat about what you thought about being in the single room when you were in hospital, notes.</p>	<h2>What do you do if you want to stop taking part?</h2> <p>You can decide to stop taking part in my project at any time; you just need to tell me.</p> 
<p>We don't know much about what children and young people think about being in a room by themselves while they are in hospital. I am doing a project and I would like to find out more about it so that we can make things as good as we can for children to be in a room on their own.</p>	<h2>Is it good for you to take part?</h2> <p>Taking part will give you the chance to tell me what it is like to be in this room. It won't make being in hospital any better, but you may help me to make it a better place for other children. As well, it might be a fun thing to do!</p>	

Consent Form for Research

(For participants aged 16-17 years who wish to consent independent of their parents)
(For participants who are <16 years and are deemed competent to consent in addition to their parents)

Study Title: The child's experience of single room isolation while in hospital

Researcher: Donna Austin
Participant Identification Number:
Version Number 2: 15/05/2012

Please initial box

I confirm that I have read and understood the participant information sheet for the study and that I understand the purpose, particulars of involvement and potential inconveniences of the study

☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

☐

I understand that I will participate in an interview and that it will be recorded on audiotape

☐

I understand that both my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my future healthcare or legal rights being affected

☐

I agree to take part in the above research study

☐

Name of participant

Signature

Date

Researcher

Signature

Date

When completed one copy must be given to the participant and one copy must be kept by the researcher.

Researcher Contact Details:

Assent Form for Research

Study Title: The child's experience of single room isolation while in hospital

Researcher: Donna Austin
Participant Identification Number:
Version Number 2: 15/05/2012

Please
initial
box

I have read the information sheet (or it has been read to me)
and I know that I can ask questions if I have any ☐

I agree to do an interview with you and that it will be recorded
on an audiotape ☐

I agree that you can use the interview for your study ☐

I agree to tell you if I don't want to join in anymore ☐

Name of child

Child's Signature

Date

Researcher

Signature

Date

When completed one copy must be given to the participant and one copy must be kept by the researcher.

Researcher Contact Details:

Invitation: Adult



Dear Parent/Carer,

I am a nurse who is conducting research with the University of Southampton. I am researching what it is like for a child to be in a room on their own while in hospital due to the risk of infection to themselves or others. This is known as being in 'isolation' or 'isolation precautions'

The main purpose of the study is to explore how children and young people feel about being in isolation as a result of having an infection that others could catch, or being at risk of catching an infection from others. The study would involve your child participating in a short interview to find out about their experience in isolation whilst they were in hospital. It would also involve you taking part in one short interview about your child's experience of being in isolation.

In order for you to decide whether or not you agree to you and your child taking part, I would be grateful if you could read the enclosed information sheet and consider whether you would be willing to be involved in this study. Once you have read this information and if you are happy to do so, please give the enclosed envelope to your child, which contains a similar information leaflet for them to read.

Once you have read this information and if you are interested in participating or would like to find out more, please complete the return slip at the bottom of this page including your contact details and I can arrange an interview time with you. We can arrange the interview for a time and place that suits you.

If you have any further questions about this study, please contact me (Donna Austin) on

Thank you for your time.
Yours Faithfully,

Donna Austin



I would like to find out more about the Child's Experience of Isolation Study, by participating in a one off interview with you. I understand that you will contact me to arrange an interview date and time. My contact details are:

Name:

Signature:

Child's Name:


Phone Number:

Mobile Number:

Email:

Please return this in the self addressed envelope provided to

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<p>What will happen to the results that we provide?</p> <p>The results may be reported in health publications, conferences or meetings, but you and your child will not be identified by name. The researcher will send you a summary of the results.</p> <p>What happens if I change my mind?</p> <p>Participation or not participating in this study will not affect your child's treatment in the future in any way. You and your child can change your mind and stop the study at any point. If you wish to stop, please contact me. If you stop the study I will ask you if we can use the data that you have given me already. If you do not wish me to use it, all data that you have given me will be destroyed including the audiotape.</p> <p>What happens if there is a problem or I have a complaint?</p> <p>It is unlikely that something will go wrong in the process of doing the interview. However if you have a concern or a complaint about this study,</p> <p>Who has reviewed the study?</p> <p>A research ethics committee and hospital trust have given it their approval.</p> <p>Thank You!</p>		 <p>Participant Information Sheet for Parents</p> <p>Study Title:</p> <p>The child's experience of single room isolation while in hospital</p> <p>Denise Austin Reference: 10/H0302/83 Version 1.35/03/2012</p>
<p>Study Title: The child's experience of single room isolation while in hospital</p> <p>Invitation to Participate</p> <p>You and your child are invited to take part in a research study which will look at what children and young people think about being in single room isolation whilst in hospital.</p> <p>Before you and your child agree to take part in this study it is important for you to understand why the research is being done and what it will involve. In the envelope enclosed is a child-friendly version of this leaflet, which if you are happy to do so, please give to your child. Please take time to read this information and discuss your decision with others if you wish. Please contact me if there is anything that is not clear or if you would like more information. Thank you for your time.</p> <p>What is the purpose of the study?</p> <p>In hospital children are sometimes put in a room on their own because they have an infection that could be passed on to others or because they are at increased risk of catching an infection from others. This is called 'isolation precautions' or 'being in isolation'. Research about adults who are cared for in isolation rooms show that people can experience some advantages and disadvantages. There is very little research that asks what children and their parents think about being in isolation while in hospital. This study aims to find out about children's experiences of being in isolation from their own and their parents' point of view.</p>	<p>Why have my child and I been chosen?</p> <p>I am selecting certain children who have been in isolation due to the risk of infection while in hospital and are between the ages of 6-17 years to take part, which is why your family has been chosen.</p> <p>Do I have to take part?</p> <p>No, you can freely decide if you and your child want to participate. If you decide that you would like to participate you have to complete and return the return slip at the bottom of the invitation letter to me in the stamped addressed envelope. I will then be in contact to arrange a date and time for the interview. Before the interview we can discuss any questions that you have and we will complete a consent form for your own participation and your child's participation. You will keep a copy of the consent form. You can also stop the interview at any time. If you decide not to take part you do not have to do anything. Whatever you decide, your child will receive the best possible care. We will give you a copy of the consent form.</p> <p>What will happen to my child and I if we decide to take part?</p> <p>I will contact you to arrange a date and time for your interview. It can be any location that is most convenient for you. We will complete a consent form for your participation and your child's participation. Your child will also complete a consent form for their own participation.</p> <p>The interview will be audiotaped and will last between 30-45 minutes.</p>	<p>Will this study benefit me and my child?</p> <p>Although there are no benefits to you or your child whilst at present, it is hoped that the results from this study will help us to understand what it is like being in isolation so that we can improve the experience for children in the future.</p> <p>Are there any risks involved?</p> <p>No, there are minimal risks involved with taking part in this study. If you or your child are upset or worried at any point, please tell me and I will be able to help you in finding some.</p> <p>Will my child's details be kept confidential?</p> <p>All data will remain entirely confidential. All data (audiotapes and transcripts) will have names removed from them and will be stored in a locked office. It is University of Southampton policy to store data from research studies for 15 years, in a secure confidential manner. At all times, data with names will be stored separately to data that has names removed.</p> <p>It is thought that the data may be published in journals and at conferences. No names will be identified in any report that is published. The study may be presented in the UK, European Union and outside this.</p> <p>If anything that might threaten the child's safety is heard when doing the interviews the researcher has to inform other agencies in accordance with local child protection policies.</p>

Consent Form for Participation in Research

Study Title: The child's experience of single room isolation while in hospital

Researcher: Donna Austin
Participant Identification Number:
Version Number 2:15/05/2012

Please initial box

I confirm that I have read and understood the participant information sheet for the study and that I understand the purpose, particulars of involvement and potential inconveniences of the study ☐

I give permission for my child and I to participate in the interview and for the interview to be recorded on audiotape ☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

I understand that both my child's and my own participation is voluntary and that I am free to withdraw my child and/or myself at any time, without giving any reason, without my child's future healthcare or legal rights being affected ☐

I agree for my child and myself to take part in the above research study ☐

Name of parents Signature Date

Researcher Signature Date

When completed one copy must be given to the participant and one copy must be kept by the researcher.

Researcher Contact Details: Donna Austin,

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Appendix 11

Participant Recruitment Pack for Parents Participating
without their Child for the Retrospective Interview

Appendices

Version1:21/11/2012



Invitation: Adult

Dear Parent/Carer,

I am a nurse who is conducting research with the University of Southampton. I am researching what it is like for a child to be in a room on their own while in hospital due to the risk of infection to themselves or others. This is known as being in 'isolation' or 'isolation precautions'

The main purpose of the study is to explore how children and young people feel about being in isolation as a result of having an infection that others could catch, or being at risk of catching an infection from others. The study would involve you participating in a short interview to find out about your child's experience of being in isolation during their recent stay in hospital.

In order for you to decide whether or not to take part, I would be grateful if you could read the enclosed information sheet and consider whether you would be willing to be involved in this study.

Once you have read this information and if you are interested in participating or would like to find out more, please complete the return slip at the bottom of this page including your contact details and I can arrange an interview time with you. We can arrange the interview for a time and place that suits you.

If you have any further questions about this study, please contact me (Donna Austin) on

Thank you for your time.
Yours Faithfully,

Donna Austin



I would like to find out more about the Child's Experience of Isolation Study, by participating in a one off interview with you. I understand that you will contact me to arrange an interview date and time.

My contact details are:

Name:

Child's Name:

Mobile Number:

Please return this in the self addressed envelope provided to

Signature:

Phone Number:

Email:

Consent Form for Participation in Research

Study Title: The child's experience of single room isolation while in hospital

Researcher: Donna Austin
Participant Identification Number:
Version Number 1:21/11/2012

Please initial box

I confirm that I have read and understood the participant information sheet for the study and that I understand the purpose, particulars of involvement and potential inconveniences of the study

☐

I am happy to participate in the interview and for the interview to be recorded on audiotape

☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child's future healthcare or legal rights being affected

☐

I agree to take part in the above research study

☐

Name of parents

Signature

Date

Researcher

Signature

Date

When completed one copy must be given to the participant and one copy must be kept by the researcher.

Researcher Contact Details:

Appendices

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Appendix 12

Participant Recruitment Pack for Staff for the Retrospective
Interview

Appendices

Version 2:01/11/2012



Invitation: Staff

Dear Staff Member,

I am a nurse who is conducting research with the University of Southampton. I am researching what it is like for a child to be in single room isolation while in hospital due to the risk of infection to themselves or others.

The main purpose of the study is to explore how children and young people feel about being in isolation as a result of having an infection that others could catch, or being at risk of catching an infection from others. An important part of this is to find out what you think as staff caring for these children in isolation. This would involve you participating in an interview about your experiences of children being isolated when they are in hospital.

In order for you to decide whether or not you agree to taking part, I would be grateful if you could read the enclosed information sheet and consider whether you would be willing to be involved in this study. Once you have read this information and if you are interested in participating or would like to find out more, please complete the return slip at the bottom of this page including your contact details and I can arrange an interview time with you. We can arrange the interview for a time and place that suits you.

If you have any further questions about this study, please contact me (Donna Austin).
Thank you for your time.

Yours Faithfully,

Donna Austin



I would like to find out more about the Child's Experience of Isolation Study, by participating in a one off interview with you.

I understand that you will contact me to arrange an interview date and time.

My contact details are:

Name:

Job Title:

Mobile Number:

Please return this through internal post to.

Signature:

Phone Number:

Email:

Appendices

<p>What will happen to the results that we provide?</p> <p>The results may be reported in health publications, conferences or meetings, but all data will be anonymised at this point. The researcher will send you a summary of the results.</p> <p>What happens if I change my mind?</p> <p>Participation is entirely voluntary and you can withdraw your consent to participate at any point. If you wish to stop, you simply need to contact me. If you stop the study I will ask you if we can use the data that you have given me already. If you do not wish me to use it, all data that you have given me will be destroyed including the audiotape.</p> <p>What happens if there is a problem or I have a complaint?</p> <p>It is unlikely that something will go wrong in the process of the interview. However if you have a concern or a complaint about this study, you should contact:</p> <p>Who has reviewed the study?</p> <p>A research ethics committee and hospital trust have given it their approval.</p> <p>Thank You!</p>	<p>Participant Information Sheet for Staff</p> <p>Study Title: The child's experience of single room isolation while in hospital</p> <p>Denise Austin Reference: 10/40502/83 Version 135/03/2012</p>
---	--

<p>Study Title: The child's experience of single room isolation while in hospital</p> <p>Invitation to Text Box</p> <p>You are invited to take part in a research study which will look at what children and young people experience when they are in single room isolation whilst in hospital.</p> <p>Before you agree to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read this leaflet and discuss your decisions with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Thank you for your time.</p> <p>What is the purpose of the study?</p> <p>In hospital children are sometimes isolated on their own because they have an infection that could be passed on to others or because they are at increased risk of catching an infection from others. Research about adults who are cared for in isolation rooms show that people can experience some advantages and disadvantages. There is very little research that asks what children think about being in isolation while in hospital. This study aims to find out about children's experiences of being in isolation from the children and those caring for them.</p> <p>Why have I been chosen?</p> <p>I am selecting certain anyone who cares for children who are in isolation due to the risk of infection while in hospital.</p>	<p>Do I have to take part?</p> <p>No, you can freely decide if you want to participate. If you do want to participate, you need to complete the return slip at the bottom of your invitation letter and send it to me via the internal post. I will then contact you to arrange a date and time for interview. We will complete a consent form for participation when we meet. You can keep a copy of this. We can discuss any questions that you have at any point. If you decide not to take part you do not have to take any action.</p> <p>What will happen to me if I decide to take part?</p> <p>I will contact you using the contact details that you provided on the return slip to arrange a time and place to meet. If it is easiest for you we will meet in the hospital but away from the ward where you work to reduce risk of you being disturbed. We will go through interview questions and you can freely describe your experiences of caring for children and young people in isolation. The interview will last between 30 minutes and 1 hour. The interview will be audiotaped so that I can recall all that you have said.</p> <p>Will this study benefit me?</p> <p>Although there are no benefits to you, it is hoped that the results from this study will help us to understand what it is like being in isolation so that we can improve the experience for children in the future. It will give you an opportunity to tell me what the challenges are for you as a nurse on the ward and how this impacts upon the care the children experience.</p>	<p>Are there any risks involved?</p> <p>No, there are minimal risks involved with taking part in this study. If you are upset or worried at any point, please tell me and I will be able to help you in finding some support.</p> <p>Will my details be kept confidential?</p> <p>All data that you provide will be anonymised before anyone else is able to view it. The anonymised data may be viewed by the research team and examiners. Reports and paper may be published and presented in the UK, EU and internationally, however any data used in this will be anonymised also.</p> <p>Any identifiable data will be stored separately to your anonymised data. Electronic data will be stored on an encrypted hard drive and stored in a locked facility and paper copies will have names removed and will be stored in a locked office. It is University of Southampton policy to store data from research studies for 15 years, in a secure confidential manner. At all times, data with names will be stored separately to data that has names removed.</p> <p>If anything that might threaten the children's safety is disclosed in the interviews, the researcher has to inform other agencies in accordance with local child protection policies.</p>
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Consent Form for Staff

Study Title: The child's experience of single room isolation while in hospital

Researcher: Donna Austin

Participant Identification Number:

Version Number 2: 15/05/2012

Please
initial box

I confirm that I have read and understood the participant information sheet for the study and that I understand the purpose, particulars of involvement and potential inconveniences of the study

☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

☐

I understand that I will participate in a one off interview with the researcher which will be recorded on audiotape, and will be used for the study

☐

I understand that both my participation is voluntary and that I am free to withdraw at any time, without giving any reason

☐

I understand that all data that I provide will be anonymised before it is used further for dissemination

☐

I agree to take part in the above research study

☐

Name of participant

Signature

Date

Researcher

Signature

Date

When completed one copy must be given to the participant and one copy must be kept by the researcher.

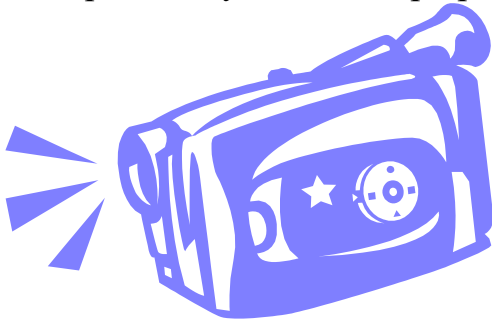
Researcher Contact Details:

Appendices

Appendix 13
Instructions for Filming in Video Diary

Guidelines for Filming

- ☐ Tell the video camera at least once a day how you are feeling and what you have done that day
- ☐ Give me a tour of your room, tell me about what you like and don't like about your room (don't stand up when filming unless your parents or me are there)
- ☐ Only film you, your parents, your brothers and sisters and other family members that have said that you can film them. Don't film your nurses and doctors!
- ☐ Only film when it is light enough that you can see
- ☐ Only film when you are sitting, or when using the wrist strap so that you don't trip up



Instructions for using the Flip

Flip video camera on and off, push the button on the right hand side.



To film, aim the camera and push the red button.

To zoom in whilst you are filming, press the + button. To zoom out push the – button.

To stop filming push the red button again.

To watch the last film back, push the play button.

To watch another video back, push the play button and then select the film that you want by using the arrows. When you have chosen the film that you want, push play.

When watching the film back you can rewind and fast forward using the arrows backwards and forwards.

To delete any film, chose the film you want to delete and then push the rubbish bin.

Highlight delete and then push the red button.

When batteries are flat, contact researcher

To put on the tripod, screw the camera onto the tripod and arrange tripod in desired position

Appendices

Appendices

Appendix 14
Interview Schedule

Appendices

Introduction

Conversation to put the participant at ease and re-establish rapport

Introduction to purpose of interview

Complete consent/assent

Explain use of audiotape recorder

Explain the need for their honesty

Ask for any questions from participant before commencing the interview

Main points

The following domains will be covered during the interview:

- ☐ A typical day in the room
- ☐ The best and worst things about being in the isolation room
- ☐ Aspects of isolation that could be improved
- ☐ The isolation room
- ☐ The feelings associated with being in isolation
- ☐ The level of understanding that a child has of their reason for being in isolation
- ☐ How would the child describe to a friend at school what it was like in isolation

- ☐ Is there anything else that you would like to say about your experience of isolation?

Conclusion

Concluding thoughts

Thank them for their participation.

Version1:31/03/2012

Appendices

Appendix 15
Contact Summary Form
A Completed Example

Appendices

Contact Summary Form

(To be completed after each interview)

Contact type: INTERVIEW
 Participant code: P2001.
 Relationship of persons present to the participant? Mum, sister
 Location: @ home.
 Contact date and time: 13/9/12 1615
 Today's date and time: 13/9/12 1530
 Written by: J. Austin
 Sign: *J. Austin*

1. What were the main issues or themes that struck you in this contact?

*Missing out on activities
 Importance of Mum being there*

2. Key observations

- less depth thought development due to age
- mother very intuitive to how her daughter & other children may feel about isolation. (experienced Mum of 3, but no prior experience of isolation)

3. Summarise the key information that you got (or failed to get) on each of the domains you had for this contact

Domain	Information
Missing out	- missed activities her sisters were involved in at home
Mum/Dad staying	- sleepover perspective - deemed a positive thing
wanting to get out	- the rules meant they were restricted with limited entertainment.

4. Anything else that struck you as interesting, illuminating or important in this contact?

Parallels between comments Mum + Pt. made regarding the dog - independently of one another.

5. Were there any family dynamics that were of interest that became apparent during the interview? E.g. parental presence in CYP interview

*Mother supportive of helping & questioning the child
 other siblings + 1 x friend present.*

6. What modifications or changes might you make for the next interview?

*useful to trial prompts with youngest likely Pt.
 All prompts useful - no changes*

Appendices

Appendix 16
Excerpts from Video Diaries

Appendices

Excerpt from Video Diaries with Simon

Simon Video 003 1 minute 15 seconds 25/11/2011 22.56

(Simon is sitting on his bed. His mother is sitting on the camp bed adjacent to him, eating.)

Simon: (Makes comment to mother in own language. Camera pans from Simon to his Mother who is eating her food on the camp bed.) My mother is now eating some food, it is very tasty. (.) (Camera moves back to Simon, then back to food on mother's lap) Umm the food should be given as per peoples, (Camera move back to Simon) not need, but as per how their diet is. I'm concerned as we Asian people have our kind of food and we get English kind of food, we cant eat it and I'm a little bit sick because we haven't eaten our kind of food for so long that now in the middle of this, (Camera pans back to mother) in the middle of the night, she has woken up to prepare this thing here. (Camera pans back to Simon) So I think food should also be considered. The room is ok, there is nothing wrong with the room, but the TV channels I think, you can give TV channels. (Camera moves to the flat screen TV on the wall).

Excerpt from Video Diaries with Lara

Lara 010 26 seconds 29/03/2011 17.03

(Camera on Mum)

Lara: Say hello

Mum: Hello. I'm Lara's Mum. (Mum smiles)

(Camera pans to Lara's sister – she smiles. Camera pans to TV)

Lara: That's the TV, the best bit of my room. Not much else to do, other than watch tv (camera pans back to mum) and sit around all day (camera pans to ceiling – fairy lights on ceiling).

Lara 014 41 seconds 31/03/2011 13.57

(Camera is on Lara who is sitting on her bed alone in the isolation room)

Lara: Today is Thursday umm (.) 31st March. (Leans head back on pillow). Today I am really bored. Watching TV. (sigh) Today I've been to the gym. I went on the trainer. I think I did quite well. More than I usually do. (.) My aunty is coming round later. Hopefully that should be fun.

Appendices

Appendix 17
Excerpts from Interviews

Excerpt from interview with Freddie's Mum and Dad:

Mum: no, nobody on the ward mentioned it. No, I just picked it up, I picked up. Yes I didn't understand what and where I was allowed to go and where Finley was allowed. And I think I had to find out myself where the parents' rooms was where the showers were umm and if I could leave Finley. Because obviously in intensive care we could go in and out when we wanted to and I felt, because I have got him off to sleep, right I am just going to go off the ward for a minute and he will be fine and I would be like huuuuh. I have got to go out to have a shower or to go downstairs to get some food or something and I felt like they are not looking out, they are not looking after him and he is not even three, what if he gets out and walks, not that he did. But I wouldn't leave him here on his own, I guess maybe I would here, but at someone else's house I wouldn't leave him on his own for any period of time and I felt that obviously they can't have one on one attention, and they were quite happy for me to go, but I would kind of come back and there would be no-one there and I would be like oh god, have you looked out for him? Is he alright? That's, that's the only thing really and being told ok well if you want to leave the room you let us know or you know, information was kind of poor I think, but I think that we expected that because we were told that the care between intensive care and the ward will be different. It was the outreach team who came and told us that.

Excerpt from interview with N4

Nurse 4: I'm thinking, sort of the middle-aged group bracket, I guess. Babies and toddlers can be quite easily amused in cubicles generally. In fact sometimes it's better because they can be contained, (giggles*) toddlers can't they, so they don't wander off. But it's more like for the four to sort of like four to teenager ish age that it can be quite hard. They need a bit more social interaction and stimulation and something to do. Whereas if they are really poorly, poorly then they don't really care. But erm... the teenagers... some of them like it the fact that they, they probably do like the fact that they have got a bit of peace and quiet, the fact that they are not sharing the ward with a load of babies. Again some of them, I know, I'm thinking of specific kids, some of them don't like it because they are sociable, I'm thinking specifically of some of our chronic kids who are so used to coming in and out, in and out, they are used to chatting to people that they know. They probably feel quite sad when they are not allowed to; it's a bit of a dull old day that way.

Appendices

Appendix 18

Poster Presentation at
Faculty of Health Sciences Conference 2011
and
RCN Annual International Research Conference 2011

Poster prize awarded at Faculty of Health Sciences Conference

The Child's Experience of Source and Protective Isolation

Video Diaries and Researching with Children



Dorcas Austin Clinical Academic Staff Nurse, Southampton University Hospitals Trust, Dr Jacqui Prieto and Dr Helen Rushforth Faculty of Health Sciences, University of Southampton. Correspondence to: dms04@oton.ac.uk

Background

Infection prevention is highlighted as a cornerstone of patient safety and is central to healthcare worldwide. It is vital to understand through research the patient's experience of infection prevention procedures in order to provide a robust evidence base that informs quality care. However, there is a paucity of literature related to children's experiences of being in source and protective isolation.

Adult literature suggests that patients in isolation experience loneliness, depression, stigma, a greater need for information, lack of social contact and less contact with health care professionals than the patients on the main open ward (Sammon, 1999). The adult research, however, is not transferable to children due to differing cognitive abilities, social priorities and stages of psychological development.

In the past two decades there has been a move from a paternalistic approach to research with children to one that includes them in the research. However in order to incorporate children as active participants in research, an appropriate method needs to be employed.

Aim

To explore the child's experience of being in source and protective isolation while in hospital.

Study Design

- Qualitative study design using hermeneutic philosophy and ethnographic methods, including video diary, video stimulated recall and interviews
- Purposive sample of 12-18 children aged 8-17
- Setting is a regional hospital on general and oncology paediatric wards
- Data collection commenced in February 2011 and is ongoing
- Analysis is occurring using Spradley's ethnographic analysis structure and NVivo



Video Diary Research

Advantages to video diary data:

- Easy to execute and requires minimum training
- Video data generates more than a 'single instant'
- The participant may disclose more than when in direct contact with the researcher
- Online blogging and reality television means that video diaries are a familiar concept to children
- Participant is in control of the video camera and data
- The participant can film as and when they choose

Challenges of video data:

- Participants may alter their behaviour with the presence of the video camera
- Parental influence over the video diary construction may be an issue
- Participants may identify malpractice or sub-optimal clinical practice, or an issue of child protection
- Challenges in maintaining confidentiality and anonymity
- There is limited guidance how to best analyse video data

(Buckwald et al., 2000; Galloway, 2003; Lurie and Galloway, 2005; Hayes, 2004; Pridmore et al., 2000; Wang and Hsu, 2006)

Results

Preliminary findings suggest:

- Participants are engaged positively with the method
- Loneliness and boredom when family were not present
- The room itself is an uninspiring environment
- Positive elements of isolation have been identified e.g. being away from 'noisy younger children'



Red Video Camera is not subject to data protection legislation and is used in this study

Conclusions

The video diary method of data collection allows the child the control, creativity and flexibility to capture their own perspective.

Initial findings suggest that isolation can be both a positive and distressing experience, and this should be considered when caring for children in isolation.



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Appendices

Appendix 19

Poster Presentation at Postgraduate Showcase, University of
Southampton

Silver Prize awarded

The Child's Experience of Source and Protective Isolation

Video Diaries and Researching with Children



Donna Austin: Clinical Academic Staff Nurse, University Hospitals Southampton Foundation Trust, Dr Jacqui Prieleto and Dr Helen Rushforth: Faculty of Health Sciences, University of Southampton. Correspondence to: dm504@soton.ac.uk

Background

Infection prevention is highlighted as a cornerstone of patient safety and is central to healthcare worldwide. It is vital to understand through research the patient's experience of infection prevention procedures in order to provide a robust evidence base that informs quality care. Isolation care is an important element of infection prevention used to segregate patients who are potentially infectious (source isolation) or immunocompromised (protective isolation), for the protection of patients and others. However, there is a paucity of literature related to children's experiences of being in source and protective isolation.

Adult literature suggests that patients in isolation experience loneliness, depression, stigma, a greater need for information, lack of social contact and less contact with health care professionals than the patients on the main open ward (Gammon, 1999). The adult research, however, is not transferable to children due to differing cognitive abilities, social priorities and stages of psychological development.

In the past two decades there has been a move from a paternalistic approach to research with children to one that includes them in the research. However in order to incorporate children as active participants in research, an appropriate method needs to be employed.

Aim

To explore the child's experience of being in source and protective isolation while in hospital

Study Design

- Qualitative study design using hermeneutic philosophy and ethnographic methods; including video diary, video stimulated recall and interviews
- Purposive sample of children aged 8-17
- Setting is a regional hospital on paediatric wards
- Data collection commenced in February 2011 and is ongoing
- Analysis is occurring using Spradley's ethnographic analysis structure and NVivo



Results

Preliminary findings suggest:

- Participants engage positively with the method
- Loneliness and boredom when family were not present
- The room itself is an uninspiring environment
- Lack of available resources
- Reluctance to push call bell – "the nurses looked busy and I could wait"
- Positive elements of isolation have been identified e.g. being away from "noisy younger children", time spent with parent alone, flexibility in routine, freedom to practice religion

Video Diary Research

Advantages to video diary data:

- Easy to execute and requires minimum training
- Video data generates more than a 'single instant'
- The participant may disclose more than when in direct contact with the researcher
- Online blogging and reality television means that video diaries are a familiar concept to children
- Participant is in control of the video camera and data
- The participant can film as and when they choose

Challenges of video data:

- Participants may alter their behaviour with the presence of the video camera
- Parental influence over the video diary construction may be an issue
- Participants may identify malpractice or sub-optimal clinical practice, or an issue of child protection
- Challenges in maintaining confidentiality and anonymity
- There is limited guidance how to best analyse video data
- Reluctance to engage with this research when feeling unwell

(Duchfield et al, 2000; Gibson, 2000; Lomas and Casey, 1996; Noyes, 2004; Rich et al, 2000; Wang and Prieleto, 2006)



Flip Video Camera is waterproofed for decontamination used in this study

Conclusions

The video diary method of data collection allows the child the control, creativity and flexibility to capture their own perspective.

Initial findings suggest that isolation can be both a positive and distressing experience, and this should be considered when caring for children in isolation.



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Appendices

Appendix 20

Abstract for Oral Presentation at RCN Joint Children and Young
People Conference and Exhibition

RCN Joint Children and Young People Conference and Exhibition Abstract

Title: Children and young people's experiences of source and protective isolation

Aim of the paper: To present a study which explores the experiences of children and young people in isolation in hospital from a hermeneutic ethnographic perspective.

Abstract:

The Department of Health document 'Saving Lives' (2007) identifies the necessity to enhance clinical care for patients cared for in isolation. In hospital children are sometimes nursed in a single room for the purpose of infection prevention. Adult literature suggests patients may experience loneliness, depression, and feelings of stigma when in isolation (Gammon, 1999). It is unknown if this is true for children as there is very limited research related to this topic.

A hermeneutic ethnographic methodology is used to explore children and young people's experiences of isolation. Children and young people aged 6-17 years have been recruited since February 2011. The participants are invited to make a contemporaneous video diary of their time in isolation and participate in a video stimulated recall interview after discharge. Video data provides an insight into the life of the participants without the obtrusive nature of an observer, which gives a richness and complexity to the data (Buchwald et al, 2009). There have been methodological challenges of using video diary data in the study which will be explored in the paper, alongside emergent findings.

Emergent findings suggest positive and negative aspects of the experience of isolation. The preliminary themes from the data will be presented. Understanding children's experiences of isolation will help to inform future services and ultimately aims to reduce the psychosocial impact of isolation.

Learning Outcomes:

1. To understand the experience of isolation from a child or young person's perspective
2. To explore the merits and challenges of video diary data collection method use with children and young people
3. To identify key areas for clinical practice improvement in nursing children and young people in isolation

Professional Biography:

Donna Austin qualified as a children's nurse in 2007 and begun working in paediatric intensive care. In 2008, she obtained funding to conduct research towards her PhD thesis as part of the clinical academic pathway. Her research question has derived from observing clinical practice in different practice settings.

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Appendices

Appendix 21
Abstract for Oral Presentation given at RCN International
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Appendices

Children and young people's experience of source and protective isolation while in hospital

Background

Single room isolation is an essential part of transmission based precautions for the purpose of infection prevention. Literature demonstrates that adults subjected to isolation precautions can experience loneliness, depression, feelings of stigma and confinement (Gammon, 1999; Barratt et al, 2011). There is a dearth of literature that explores the experience of single room isolation for children.

Aims

To explore the child's experience of single room isolation.

Methods

A qualitative study design within the paradigm of social constructivism was conducted using semi structured interviews. An initial plan to collect video diary data had to be modified due to low recruitment. Data collection was conducted between 2011 and 2015. Data was collected over this timeframe to allow for adaptations of data collection methods, to compensate for slow recruitment of children to the study. Participants shared the child's experience viewed through the lens of parents and practitioners as well as the child themselves. Purposive sampling was used; 7 children, 11 parents, 21 staff. Data were transcribed, analysed using narrative analysis (Riessman, 1993), coded and aligned into themes.

Results

The themes that emerged from the data were coping, control and community. Children varied on their responses dependent upon their condition and previous exposure to isolation. Parents described preferring isolation in terms of privacy but felt socially isolated. Staff described the role of parenting and nursing as blurring often in isolation, due to the physical barrier.

Discussion

Although this study cannot give one structured approach to providing care for children in isolation, it encourages practitioners to consider the children in this study within the context of their own care and individualise care according to their needs.

Conclusions

This study generates themes that practitioners can consider in the context of their care setting, however further studies are necessary to explore this experience in other settings.

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Appendix 22

Literature Review published in Nursing Children and Young People

The child's experience of single room isolation: a literature review

Donna Austin and colleagues find that more information is needed on young patients' perspectives of isolation in hospital

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Abstract

Studies have shown that people who require single room isolation while in hospital often feel lonely, sad, worried, bored and in need of information. A literature review identified only 16 papers reporting on the child's experience of isolation. Findings indicate that children feel lonely, are scared of the personal protective equipment and feel bored. Patients' parents feel guilty, worried and under increased pressure to visit their children. It is also suggested that isolation may affect child development.

Keywords

Acute care, child development, child isolation nursing, children's perspective, infection prevention

INFECTION PREVENTION is an issue of patient safety and therefore central to health care worldwide (Department of Health (DH) 2008). Isolation care is an important element of infection prevention used to segregate patients who are potentially infectious or immunocompromised. When isolation is used for the protection of others, the strategy is referred to as source isolation. When isolation is for the protection of the patient, it is known as protective isolation (Weston 2008).

Children and young people may be placed in isolation units, specialist wards and general children's wards, for a variety of reasons, according to local and national guidance on infection (Siegel 2002). Source isolation is used to segregate patients with potentially contagious infections, such as respiratory syncytial virus (RSV), rotavirus and methicillin-resistant *Staphylococcus aureus* (Weston 2008). Protective isolation is used to segregate patients who have immunocompromised conditions and who are vulnerable to acquiring

infections from others, such as patients with human immunodeficiency virus (HIV), those who are undergoing chemotherapy or those who have genetic immunosuppression (Posfay-Barbe *et al* 2008). Children and young people can be in isolation for hours, weeks and, in some cases, months – sometimes alone and in other instances with a parent resident with them in the hospital. Children can also be isolated in their own home, for infectious childhood illnesses or, in some cases, after organ transplantation.

This literature review focuses on children and young people's experiences of isolation in hospital. There has been little study of their experience, which means that current clinical practice can only be based on limited child-specific research, relevant adult literature and conventional wisdom. Research conducted in adults shows that they may suffer psychologically and socially as a result of being in isolation (Knowles 1993, Gammon 1999). Findings from adult studies cannot, however, be transferred to children's settings because of the differing levels of psychological and cognitive development, physiological needs and social priorities of children and young people (Kanner *et al* 2004). This reinforces the importance of child-specific research in this field.

Current practice

Studies have identified a number of infection prevention issues specific to children (Siegel *et al* 2007). In 2004, the DH recommended that 50 per cent of all paediatric hospital bed spaces in new facilities should be in isolation because of the high number of children requiring isolation (compared with adult facilities).

In England, the DH documents (DH 2007, 2008, 2010) tend to focus on healthcare-associated infections (HCIs) and adult guidance, and there is

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limited guidance specific to child health. The most comprehensive, up-to-date clinical guidelines on isolation precautions are from the US Centers for Disease Control and Prevention (Siegel *et al* 2007). The guidance is comprehensive and transferable to the UK, and has evolved to help healthcare workers prioritise those who need isolation. However, the child-specific guidance is not comprehensive. These guidelines, together with local policy, are what informs current practice in the UK, so the experience of children in isolation warrants further research.

Search strategy

Literature for this review was found by a combination of electronic database searches, manual searches and incremental searching. An integrative approach allowed the simultaneous inclusion of quantitative and qualitative studies, to understand the phenomenon in full (Whittemore and Knafl 2005). The search terms used included 'children', 'isolation' and 'experiences'. The terms were refined using synonyms, were truncated and, where appropriate, were used to distil suitable medical subject headings (MeSH). The electronic databases searched were the Cochrane Library, the Allied and Complementary Medicine Database, Applied Social Sciences Index and Abstracts, Cumulative Index to Nursing and Allied Health Literature, Ovid MEDLINE, PsycINFO and Web of Knowledge. For each database, subject headings associated with the search terms were used, to enable accurate retrieval of papers. Searches were also combined using Boolean Logic to capture all relevant papers and included all literature available from the earliest records on electronic databases up to 2011.

In view of the limited number of research papers relating to the child's experience of isolation, older papers and the perspectives of researchers, parents and health professionals were included. In incremental searching, references from one document were followed to find other relevant papers (Crookes and Davies 2004).

Manual searches of Nursing Children and Young People (formerly Paediatric Nursing) and the Journal of Infection Prevention were conducted in issues published between 2009 and 2012, to capture recent publications and to ensure that papers that were overlooked by electronic database searching were included in the review.

What is already known

A review of the literature revealed 16 relevant research papers exploring the experience and the effects of isolation on children's wards between 1970 and 2011. Most of the literature focuses on

Children appeared more concerned with the separation from their family than with the possibility of acquiring an infection

observations of the child's behaviour in isolation and the parents' own perspective, rather than the parents' perception of how their child experiences isolation or the child's view of their own experience. Only three studies directly engage with children; this might be because of the ethical challenges related to researching with children (Kirk 2007). Six studies were excluded, either because they were not primary research or because they focused on the efficacy rather than the experience of isolation.

Previous research

The investigations follow differing methodologies, therefore three critical appraisal tools were required. Those selected were Duffy's quantitative appraisal tool (2005), Atkins and Sampson's critical appraisal tool for case studies (2002) and Greenhalgh's qualitative appraisal tool (1997), because of their applicability to the studies reviewed. Each paper was read numerous times, analysed individually and then analysed in the context of the other studies conducted in that decade.

Many of the studies were conducted in the 1970s (Table 1, page 20) and 1980s (Table 2, page 21) and related specifically to protective isolation for severe combined immunodeficiency (SCID) (Simons *et al* 1973, Drotar *et al* 1976, Freedman *et al* 1976, Dalton 1981, Lazar *et al* 1983, Tamaroff *et al* 1986). The main findings from these papers were that the processes of cognitive, social, psychological and motor development in the child were altered as a result of isolation. It is important to note that, during this era, there was no preceding research so using single-participant cases was acceptable to establish if this area was worthy of further research. Because of the small sample sizes of these studies, limited credence can be attributed to the findings. Furthermore, many of the children in the SCID studies were subject to long-term isolation (duration of three months to five years) which is not representative of the duration of isolation for any child today (Chan and Puck 2005).

Kutsanelou-Meyer and Christ (1978) studied seven parents of children with SCID and 11 children with aplastic anaemia on one protective isolation unit. The findings from this study are potentially more transferable than from a single case. The suggestion was that children appeared more concerned with the separation from their family and

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Table 1 Studies published in the 1970s on isolation of children and young people in hospital

Reference	Sample	Condition	Study design	Findings/perspectives	Limitations
Drotar <i>et al</i> 1976	One boy Duration of isolation: one year, US	Severe combined immunodeficiency (SCID)	Case study of a boy for first 14 months of his life	Observer: bonding between mother and child impaired. Social development of child improved after discharge	Single case Dated study No observational measurement tool used Specific condition
Freedman <i>et al</i> 1976	One boy Duration of isolation: 52 months, US	SCID	Case study of one boy through first 52 months of his life in protective isolation	Observer: his motor skills were more advanced than normal. The boy demonstrated less social interactivity. His language development was delayed	Single case Dated study No observational measurement tool used Specific condition
Kutsanellou- Meyer and Christ 1978	Eleven patients with aplastic anaemia Parents of seven infants with SCID Duration of isolation: 3-20 months, US	SCID Aplastic anaemia	Case study of a unit of adolescents with aplastic anaemia and infants with SCID	Child by proxy of an observer: adolescents appeared to be more distressed by separation from people, activities and objects than the possibility of death. Adolescents attempted to maintain privacy	Dated study Only one setting Single observer
Powazek <i>et al</i> 1978	123 children and their mothers Duration of isolation: not specified, US	Cancer	Quantitative: Trait Anxiety Inventory, Patient Behaviour Rating Checklist and Maternal Depression Scale	Child by proxy of an observer: older children in isolation (> 12 years) were more anxious than younger children. Parents: positive opinions of the infection prevention measures and the convenience of long visiting hours	Dated study No description of sample size calculation No baseline data for behaviour presented Mainly parental data
Simons <i>et al</i> 1973	Non-identical twins with lymphopoenic hypogammaglobulinaemia Duration of isolation: 2.5 years, Germany	SCID	Case study of twins using development scales every three months and observation by the researcher	Observer: separation anxiety, intellectual capacity below average	Only two cases Dated study Very specific condition Type of isolation – no longer common practice

friends than with the possibility of acquiring an infection through being outside their isolation room. Parents and children also felt the need to maintain privacy.

Powazek *et al* (1978) studied the mothers' perspectives and the children's perspectives on protective isolation due to cancer, and concluded through behaviour rating scales that older children scored more highly than younger children in anxiety and depression. The main strength of this study was the large sample size of 123 children, but the scale

did not clarify whether anxiety was due to isolation or other factors.

There was only one study during this period with children as the sole focus, to ascertain their perspectives (Broeder 1985). The author used a draw-and-write technique to enable the children and young people with brief non-complicated illness to draw and discuss their isolation room. This method is age-appropriate and can contribute to memory recall (Christensen and Prout 2002). Although this study suggested that children had an understanding

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Table 2 Studies published in the 1980s on isolation of children and young people in hospital

Reference	Sample	Condition	Study design	Findings/perspectives	Limitations
Broeder 1985	Six children aged six to nine years, isolated for a brief, non-complicated illness Duration of isolation: more than 24 hours, US	Not specified	Qualitative study using observations, interviews and draw-and-write technique	Child: some understanding of the rationale for isolation and personal protective equipment, but found the experience frightening	Limited sample size Retrospective design No description of analysis method
Dalton 1981	One boy Duration of isolation: 13 months, US	Severe combined immunodeficiency (SCID)	Case study of development of the first 28 months of the life of a boy	Observer: motor, cognitive and speech development proceeded normally	Single case Dated study No tools used Specific condition Single observer
Lazar <i>et al</i> 1983	One boy Duration of isolation: three years, nine months, US	SCID	Case study of one boy isolated from age nine months to four years, using scales of infant development	Observer: motor, cognitive and speech development proceeded normally Emotional development and attachment behaviours were affected	Single case Dated study Specific condition No details of interaction or therapy
Tamaroff <i>et al</i> 1986	Four infants Duration of isolation: ten to 52 months, US	Cancer	Case study of four children	Observer: no consistent outcome regarding development Lack of parental involvement and lack of social stimuli in isolation	Small sample size Dated study Specific condition

Table 3 Studies published in the 1990s on isolation of children and young people in hospital

Reference	Sample	Condition	Study design	Findings/perspectives	Limitations
Kronenberg <i>et al</i> 1998	24 mothers of isolated children, US	Bone marrow transplant	Quantitative prospective study, standardised self-report scales	Parents: maternal stress heightened	Difficult to separate impact of isolation from that of illness

of why they were in isolation, it also found that they were scared of the personal protective equipment. However, the small sample of six children and limited description of the methods of analysis require that the findings are viewed judiciously.

The data from the 1970s (Table 2) and 1980s (Table 3) are largely case studies, and for the most part sample only one condition, in particular SCID, which is rare (Chan and Puck 2005). These limitations significantly reduce the transferability of the findings to contemporary children's wards. There is also limited exploration of what the children think about isolation; most of the research is observational or from the perspective of the

parents. However, with the inclusion of Broeder (1985), the research was moving towards the incorporation of children's perspectives and child-appropriate methods. Despite this, during the 1990s this line of research was not continued.

There was a paucity of studies in the 1990s related to isolation, with only one study identified. This explored the experience of 24 mothers caring for a child undergoing bone marrow transplantation in isolation (Kronenberg *et al* 1998). Mothers described isolation as a stressor for themselves, but no comment was made on the child's experience. However, theories of emotional contagion suggest that children may unconsciously mirror parental

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behaviours (Davis and Siegel 2000, Hatfield *et al* 2009). The lack of research in this decade could be because of the ethical obstacles to researching with children (Kirk 2007). Although society had become less paternalistic, and the Children Act of 1989 advocated including children in research, the important ethical considerations of researching with children followed closely (Kirk 2007).

In the 2000s (Table 4) there was an increase in the number of studies in this field and growing interest in children's perspectives, driven by documents such as Every Child Matters (Department for Education and Skills 2003) and the National Service Framework for Children (DH 2004). These suggest that children have valuable perspectives that should be incorporated into practice, but only two (Koller *et al* 2006, Russo *et al* 2006) of six studies produced in the 2000s consider children's experience.

Interest in the impact of source isolation is likely to have been generated from epidemics, such as severe acute respiratory syndrome (SARS) and influenza A H1N1, but the more common indications for source isolation in child health, such as RSV and rotavirus, continued to receive limited research. This is possibly because the impact of shorter isolation may not be thought as severe. However, it is clear from the experiential data from adults in isolation, that there can be psychosocial effects of being in isolation after as little as 24 hours (Knowles 1993).

The research carried out during this era explored parents' own perspectives and recorded their feelings of guilt and fear when leaving their children in isolation (McKeever *et al* 2002, Wu *et al* 2005, Koller *et al* 2006, Chan *et al* 2007). Parents also described the need for information and pressure to spend time at the hospital to relieve their child's boredom and loneliness (Russo *et al* 2006, Rotegard and Sykepleievitenskap 2007).

The two studies that addressed the child's perspective were specific to SARS (Koller *et al* 2006) and cystic fibrosis (Russo *et al* 2006). Koller and colleagues found that children in isolation experienced distress, sadness, loneliness, fear and worry. Only five children were interviewed, but as the total population with SARS is likely to have been small, a sample of five may be representative. Strict isolation policies were implemented and these included parents being separated from their children, which clearly affects transferability of the findings.

Russo and colleagues found that children with cystic fibrosis resented being separated from their peers who also had the condition and were in hospital. They expressed the need for increased use of technology, such as the internet, to communicate

with others to alleviate boredom and social isolation. The study explored children's experiences of isolation using questionnaires (with limited explanation as to format) distributed to 101 children. There was only a 23 per cent response rate and this tended to be from the older children, which significantly affects the validity of the conclusions.

During the 2000s (Table 4), research involved more varied methodology, encompassing parents' and children's perspectives and a wider variety of conditions. However, the use of child-appropriate strategies is scarce, which limits the amount the child may feel able to disclose. Because of the lack of child perspectives, child-friendly methods, larger sample sizes and variety of conditions, no studies can be entirely transferable to contemporary practice.

Adult experiences of isolation

Research among adults in isolation has long had a much stronger evidence base (Knowles 1993, Gammon 1999, Rees *et al* 2000). Findings suggest loneliness, depression, stigma, a greater need for information, lack of social contact, less contact with healthcare professionals than the patients on the main open ward and perceptions that the physical environment was restrictive (Gaskill *et al* 1997, Kennedy and Hamilton 1997, Campbell 1999).

However, some adults did appreciate the privacy (Campbell 1999). Although these findings are not transferable to children and young people, they have suggested additional avenues for enquiry.

Discussion

It is important to recognise that many of the findings are comparable with the wider literature from up to 50 years ago, pertaining to children's experiences of hospital admission in general (Gofman *et al* 1957, Perrin and Gerrity 1981, Forsner *et al* 2009). The additional stressors resulting from isolation include: less space; increased use of personal protective equipment; limited interaction with other children; fewer sources of stimuli – such as access to communal spaces – and the physical and psychological barriers created by isolation.

As indicated by the National Service Framework for Children (DH 2004), children require access to play, education and social facilities, and it is important to find ways of providing these. With the literature published so far, it is impossible to see if these child-specific needs are being met for children isolated in hospital now.

From this literature review it is evident that source and protective isolation affect the child's

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Table 4 Studies published in the 2000s on isolation of children and young people in hospital

Reference	Sample	Condition	Study design	Findings/perspectives	Limitations
Chan <i>et al</i> 2007	Eight parents of seven children Duration of isolation: majority less than eight days, China	Severe acute respiratory syndrome (SARS)	Qualitative study using semi-structured interviews	Parents: anxiety when not allowed to visit children, understood need for isolation, stress when also managing children at home	Limited sample size, retrospective account, potential for researcher bias
Koller <i>et al</i> 2006	Purposive sampling 23 participants: five children, ten parents and eight healthcare providers involved in SARS outbreak in Canada, duration of isolation not specified	SARS	Ethnographic study, interviews with children, parents and health workers	Child: sadness, loneliness, worry and fear Parents: communication challenges, role changes Healthcare workers: communication challenges	Small number of children among the participants, interview not best method with children
McKeever <i>et al</i> 2002	15 mothers of infants who had undergone protective isolation Duration of isolation: average of 10.5 months, Canada	Severe combined immunodeficiency	Descriptive, retrospective exploratory study, in-depth interviews	Parents: mothers experienced loneliness and social and physical isolation	Small sample, not diverse, single setting, specific condition, retrospective account
Rotegard and Sykepleievitenskap 2007	Questionnaire sent to 51 mothers and/or fathers Duration of isolation: Average 3.8 days, Norway	Gastroenteritis or respiratory syncytial virus	Quantitative self-constructed questionnaire	Parents: with family, wanted more information on nurse expectations and partnership	Limited sample, questionnaire unvalidated, unclear analysis, low response
Russo <i>et al</i> 2006	Purposive sampling. 192 parents, 101 patients aged >10 years, in UK Duration of isolation: Average 34 days	Cystic fibrosis	Questionnaires with open and closed questions	Child: disliked being separated from their peers Parents: supported segregation, felt pressure to spend more time at hospital	Low response rate, questionnaires prone to positive response bias
Wu <i>et al</i> 2005	11 parents of children Duration of isolation: ten to 40 days, in Taiwan	Stem cell transplant	Qualitative inquiry, in-depth interviews	Parents: feelings of guilt and pity, poor sleep, eating irregularity, changes in family dynamics, financial burdens	Specific condition, one ward, culturally specific

experience of being in hospital. Most of the studies identified by this review are dated, have small sample sizes, are not representative of the child-health population and use samples specific to one condition. Only four of the investigations found actually asked children what they thought about being in isolation, and only one study was conducted in the UK.

Thus, when reviewing the data on children's experience of isolation as a whole, it becomes clear that there is a considerable need for

further research, with robust clinical studies that specifically explore the child's perspective on being in isolation. Until further research has been conducted, the evidence available thus far can be transferred only very cautiously to practice in other settings, although a few suggestions for practice enhancements can be made.

Conclusion

Isolation has been shown to affect adults on a psychosocial level. There is a paucity of robust

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