UNIVERSITY OF SOUTHAMPTON

Faculty of Environmental and Life Sciences

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Development of a measure and testing of an approach to evaluate paediatric end of life care in Jordan

by

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Abstract

Introduction

A child's death is a painful experience for family members, regardless of the cause. Previous research has emphasised the need for a standardised measure to assess the quality of paediatric end of life care from carers' perspectives to identify and address services in need of improvement. Paediatric end of life care has received little attention in the Middle East, especially Jordan, where a lack of guidelines hinders healthcare professionals from planning and delivering high quality care.

Aims

To adapt an existing measure of the experiences of bereaved carers of adults - Views Of Informal Carers- Evaluation of Services- Short Form (VOICES-SF) questionnaire -, undertake cross-cultural adaptation and assess the feasibility of conducting a telephone-administered survey in Jordan to evaluate the quality of end of life care provided to dying children from the perspective of bereaved carers.

Methods

This exploratory mixed-methods study entailed three phases. Phase I involved identifying key elements of paediatric end of life care from three sources: literature, bereaved carers and healthcare professionals in the United Kingdom. This led to development of the English VOICES-Children (-C) questionnaire. Phase II involved Arabic translation and cross-cultural adaptation for the Jordanian context. Five experts in Jordan reviewed the Arabic prototype before cognitive testing with bereaved carers in Jordan (N=8). In phase III, the VOICES-C Arabic version was piloted through a telephone administered survey with bereaved carers (N=48) recruited from four hospitals in Jordan. The survey explored feasibility of a protocol for identification, approach and data collection, as well as quality of care.

Results

Phase I involved developing the VOICES-C questionnaire items based on three different sources. Items regarding physical, emotional, and spiritual aspects were retained from the adult version of the questionnaire, items relating to sibling support and circumstances surrounding the death were added, and response options were modified to reflect children's services in the UK. In phase II cultural adaptation involved translation and additional modifications to individual items and response options to align with the Jordanian context and ensure Arabic language equivalence. The phase III pilot study confirmed feasibility of the protocol for identification, approach, recruitment and data collection method in order to collect bereaved carers' experiences about end of life care for children with life-limiting conditions by telephone. Distress associated with participation was minimal and procedures to deal with distress were suitable. Findings relating to quality and experiences of care suggested that currently end of life care for children was largely satisfactory in participating sites in Jordan. Negative reports of quality of care were mainly by carers of neonates in rural hospitals concerning coordinating and continuing care whenever available resources were limited.

Conclusion

This study represents a novel contribution to evaluating the quality of end of life care provided to dying children and their families in various hospitals and for different medical conditions in an Arabic-speaking country, Jordan. It examined and confirmed the feasibility of conducting a telephone survey as the method of administration. If the survey is applied on a regional, national, or organisational level, it has the potential to help shape policy and improve care for dying children. Future studies on the current topic in other Arab-speaking countries are recommended.

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Research Thesis: Declaration of Authorship

Print name:	Rawnaq Mohammad Almahadeen
Title of thesis:	Development of a measure and testing of an approach to evaluate paediatric end of life care in Jordan

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

This work was done wholly or mainly while in candidature for a research degree at this University;

Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;

Where I have consulted the published work of others, this is always clearly attributed;

Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

I have acknowledged all main sources of help;

Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

None of this work has been published before submission

Signature: Date: 29/01/2022

Acknowledgements

Praise be to Allah first and foremost

And my success is not but through Allah. Upon Him I have relied, and to Him I return. (Qur’an 11:8) Above all, I am very grateful to Allah, the Great Almighty without His countless blessings and graces. This achievement would not have been possible without His guidance day after day, despite all of the challenges I encountered.

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Dedication

I dedicate my thesis work to my wonderful husband, Ammar, thank you for being there when I needed you by my side throughout my PhD journey. My lovely daughters, Joud and Sadan, thank you for your love, kindness, and delightfulness and for providing meaning to my life during challenging times. Thank you for always providing me with words of encouragement to continue on my journey.

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Finally, I dedicate this work to my lovely country, Jordan. This work is a small expression of my love and gratitude for you.

Definitions and Abbreviations

ACT	Association for Children's Palliative Care
CCA	Cross-Cultural Adaptation
HCP	Healthcare Professionals
HRQOL	Health-Related Quality Of Life
ICD10	International Classification of Diseases 10th Edition
JUH	Jordan University Hospital
KAUH	King Abdullah University Hospital
KHCC	King Hussein Cancer Centre
LLCs	Life-limiting conditions
MCH	Maternity and Child Health
MOH	Ministry of Health
NHPCO	National Hospice and Palliative Care Organization Standards
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NICU	Neonatal Intensive Care Unit
ONS	Office of National Statistics
PICU	Paediatric Intensive Care Units
PPI	Patient and Public Involvement
PROM	Patient-Reported Outcome Measure
RCPCH	Royal College of Paediatrics and Child Health
RMS	Royal Medical Services
VOICES-C	Views of Informal Carers- Evaluation of Services -Children
VOICES-SF	Views Of Informal Carers- Evaluation of Services- Short Form
WHO	World Health Organization

Chapter 1. Introduction and rationale

This chapter provides an introduction to the study by outlining the importance of evaluating end of life care provided to children with life-limiting conditions in the context of services improvement. The rationale for conducting the study is also presented, followed by an outline of the structure of the thesis. For clarity, the researcher refers to children and young people throughout this thesis as ‘children’, however, the terms infant and older children will also be used where it is appropriate. The term ‘carers’ refers to informal carers who care for a sick child on an unpaid basis in their capacity as a family member or friend.

1.1 Introduction and rationale

The loss of a child at any age is a profound event in families. It has been frequently described as an unimaginable and ultimate loss for parents (Wilson, 1988), which affects every aspect of a family’s life and disrupts the dynamics and roles of family members. The prevalence of life-limiting conditions amongst children has increased due to advances in medical care and preventative measures (Himelstein et al., 2004). These advances have contributed to a rise in survival rate in children with life-limiting or life-threatening conditions, who would not have survived previously. Therefore, more children and young people needing treatment and monitoring, in hospital and the community and the care of these children has consequently become an emerging priority for children’s health universally (WHO, 2019). Children with life-limiting conditions require comprehensive care, both curative and palliative. Palliative care should be provided whether the child receives curative care or not and aims to alleviate the severity of pain and other symptoms experienced by these patients (WHO, 1998). Evaluating the quality of end of life care delivered for patients and carers has been identified as an indicator of quality of healthcare services and requires thorough understanding of a populations’ views and experiences to identify the factors affecting the quality of care for dying children across different settings (DoH 2008).

There have been several studies investigating the quality of paediatric end of life care from various healthcare services and settings and these have contributed information on the topic (Monterosso and Kristjanson, 2008, Heath et al., 2009, Inglin et al., 2011, Friedel et al., 2018b, Johnston et al., 2020), however, no studies have been conducted in an Arab Middle Eastern context. In addition, a lack of palliative care training, the absence of national health policies concerned with palliative care and little services development have been identified as substantial barriers to palliative care, except in Turkey and Israel (Bingley and Clark, 2009, Silbermann et al., 2012, Silbermann et al., 2015). Therefore, this thesis aimed to address this gap by developing and testing an approach to gathering information about bereaved carers' perspectives regarding the quality of paediatric end of life care provided to children in the last three months of life in Jordan.

An important way of identifying and understanding the impact of experiences of end of life care on bereaved family members is through evaluating the quality of end of life care provided. However, in children, there is a paucity of robust survey measures to use for this purpose hindering evaluation. Authors of previous research have called for an agreed 'gold-standard' measure to evaluate paediatric end of life care (Friedel et al., 2018a). Coombes et al. (2016) investigated the feasibility of Health-Related Quality Of Life (HRQOL) measures that could be used in paediatric palliative care and found that the aspects of generic HRQOL measures are not relevant to children receiving palliative care, and focused on specific diseases or conditions. None of the existing measures were suitable for use in a population-based survey of paediatric palliative care (Coombes et al., 2016). Friedel et al. (2018a) and Coombes et al. (2016) reviews demonstrated the existing gap in the literature concerned with the quality of paediatric palliative services using a universal tool that can be applied to the diverse diagnoses and settings, and that can address the relevant elements or domains of care involving children. Previous studies have highlighted inequalities in care that exist for seriously ill children (Corr and Corr, 1985, Barnes, 2001, Hill and Coyne, 2012, Kelley and Morrison, 2015); so it is essential that any 'gold-standard' measure enables comparisons of the experiences and quality of care across different diagnoses. Johnston et al. (2017) recommended adapting a measure developed for adult populations to meet the different and unique needs of children and their families receiving end of life and palliative care.

Therefore, this research project aimed to adapt a well-established questionnaire developed for the evaluation of care and services for adult populations the Views of Informal Carers- Evaluation of Services- Short form (VOICES-SF) (Hunt et al., 2011) to evaluate quality of paediatric end of life care as reported by bereaved carers in Jordan. My original intention for this thesis had been to adapt the English version of this questionnaire, making it suitable for paediatrics, and work with healthcare professionals in the UK to test it, however as the preliminary work progressed, my motivation shifted to conducting the research in the Jordanian context, my home country, where end of life care and post-bereavement studies have been under-researched areas for both adult and paediatric patients. I discussed and explored the desirability of conducting the work with my supervisory team in order to produce something useful in my home country and the decision made to move the location of the study to Jordan early in the investigation.

As a PhD student, I (Rawnaq Almahadeen - RA) was part of a research group developing the Views of Informal Carers- Evaluation of Services -Children (VOICES-C) (English version). The development started with a scoping review (conducted by RA -Chapter 4), which aimed to identify, from the literature, important aspects of end of life care for children to inform the adaptation of the VOICES-SF survey. This was followed by interviews conducted by Prof Anne-Sophie Darlington (A-SD) that sought an in-depth understanding of the elements of paediatric end of life care from the perspectives of bereaved carers and healthcare professionals in the UK. Analysis of these interviews was conducted by A-SD and Dr Katherine Hunt (KH) and informed which items from the original VOICES-SF questionnaire should be included in the prototype children's version of the questionnaire. This analysis, in combination with the findings from the scoping review, also determined what new aspects of care the children's version would need to cover, and how the corresponding questionnaire items should be worded. The issues that came forward from the analysis of these interviews, and the scoping review, are presented in Appendix A. It should be pointed out that the English VOICES-C prototype is currently in the process of further testing and refinement with healthcare professionals and bereaved carers in the UK.

There is little evidence exploring the quality of paediatric end of life care, and even less with a population-based approach. Much of the evidence is derived from interpretive studies to obtain descriptions of the perceptions of paediatric patients receiving end of life care and their carers. This study adapted the VOICES-SF questionnaire for use in a paediatric population, pre-tested the VOICES-C, adapted the English version into an Arabic version, and lastly piloted the VOICES-C questionnaire in a sample of bereaved parents in Jordan to investigate bereaved parents' experiences regarding the quality of care.

The aims of the study were achieved using a mixed-method exploratory sequential design. The study began with a scoping literature review to identify what is important in paediatric end of life care from bereaved carers' experiences. The elements identified were integrated with findings from qualitative interviews with bereaved parents and relevant experts' opinion about what is important in paediatric end of life care. Following the development phase, qualitative interviews were employed with bereaved carers about previous experiences and healthcare professionals in multiple sites in the UK to collect and analyse their feedback on the VOICES-C (English versions). The VOICES-C (English version) was adapted for the Jordanian context: translated into the Arabic language followed by interviews with experts and bereaved parents from Jordan to review the VOICES-C (Arabic version). Finally, a feasibility study assessed the practicability of completing the VOICES-C (Arabic version) via telephone interviews, rather than postal self-complete questionnaires, in terms of potential barriers to and facilitators of sampling, recruitment and data collection. The prototype questionnaire included questions designed to yield both quantitative and qualitative data, enabling the researcher to gain a deeper and broader understanding of the bereaved carers' experiences (Onwuegbuzie et al., 2010, Tashakkori and Teddlie, 2010, Creswell and Clark, 2017). The open-ended questions at the end of the VOICES-C questionnaire provided qualitative free-text data and enabled the carer to provide further details and the researcher to obtain a deeper understanding of the important issues regarding end of life care in Jordan. This PhD thesis encompassed three phases:

1. Phase one: Developing VOICES-Child (VOICES-C) (English version). This phase aimed to adapt the VOICES-SF questionnaire to create VOICES-C (English version) using data explored the elements and nuances of paediatric end of life care. These elements were identified through a literature review on what is important to children and families receiving palliative and end of life care; analysis of interviews with healthcare professionals who care for children at the end of life; and analysis of interviews with bereaved carers. The data from these three sources was integrated to identify issues of greatest importance to children and their families and used to develop questionnaire items and response options for the VOICES-C English prototype. This prototype was pretested with nine healthcare professionals and three bereaved parents in the UK to conclude with VOICES-C (English V2) that will be modified for the Jordanian context in the second phase.

2. Phase two A Cross-Cultural Adaptation (CCA) process was implemented to create the VOICES-C (Arabic version) for the Jordanian population. This step entailed recruiting a panel of five experts to review the questionnaire; forward and backward translation of the Arabic prototype; and cognitive interviews with a sample of eight parents in Jordan to ensure a culturally specific questionnaire has been generated. This phase aimed to ensure that the final version reflected the salient elements of paediatric end of life care from the previous phase, in a way that was culturally appropriate and reflective of the Jordanian experience. Based on the participants' feedback, modifications for the Arabic prototype were implemented before the feasibility survey was conducted.

3. Phase three: A feasibility survey was carried out in four healthcare sites in Jordan. This phase aimed to explore the quality of paediatric end of life care in the last three months of life for children with life-limiting conditions from the perspectives of the forty-eight bereaved carers from different healthcare sites using the Arabic VOICES-C questionnaire. The facilitators and barriers to conducting a post-bereavement survey were investigated to assess the methodological and feasibility issues, i.e., the recruitment process, response rates and questionnaire completion rates that relate to the development and implementation of a post-bereavement survey using telephone interviews in Jordan.

1.2 Structure of the thesis

Chapters 1 and 2 outline the introduction, rationale and background of the study. This included the definition of paediatric palliative care and background of issues related to the research topic, such as associated terms with paediatric palliative care, the significance of providing quality paediatric palliative care according to the published guidelines and the outcome measures in end of life care. Chapter 3 discusses the methodological perspectives that were adopted to answer the research questions. Chapter 4 describes a scoping review identifying the elements of paediatric end of life care. Chapters 5 and 6 report the process and the results of the first phase to adapt the VOICES-SF questionnaire to the VOICES-C (English version), before cross-cultural adaptation. Chapters 7 and 8 present the methods used in the cross-cultural adaptation and the findings from adapting the English prototype into the Arabic version for the Jordanian population. Chapters 9 and 10 are focused on the methods and findings of the feasibility study that was carried out in Jordan. The discussion chapter (Chapter 11) summarises the outcomes of the three phases, the strengths and limitations of the study, and recommendations for practice and future work to evaluate palliative care in Jordan, and elsewhere.

Chapter 2. Background

This chapter will provide an overview of evidence on paediatric palliative and end of life care, including: the prevalence of children dying from life-limiting conditions; definitions of palliative care; dimensions of quality end of life care; significance of evaluating quality of palliative care according to published guidelines; and existing outcome measures of the quality of end of life care for children. In addition, literature relating to the Views of Informal Carers-Evaluation of Services-Short Form (VOICES-SF) questionnaire will be presented in detail, including justification for its use in this context. The last section provides an overview of healthcare system, palliative care and cultural and religious norms so readers can situate the study in the Jordanian context.

2.1 Prevalence of childhood life-limiting conditions and mortality

The United Nations Inter-Agency Group for Child Mortality Estimation (UN IGME) was established in 2004 and is led by the United Nations Children's Fund (UNICEF), the World Health Organization (WHO), the World Bank Group and the United Nations Population Division. The UNIGME annual report estimated that globally 7.4 million children, adolescents and young people under 25 years died in 2019 (UN IGME, 2020). Seventy per cent of these children died before reaching the age of five, and around half of under-five years deaths occurred in the first month of a child's life (UN IGME, 2020). In addition, the UNIGME announced that infectious diseases and neonatal-related complications were the leading causes of under-five deaths. Whilst older children and young people (5-24) deaths were caused by injury and interpersonal violence.

Amongst of Western countries, UK-based recent research has investigated the trends associated with the increase in prevalence of children with life-limiting conditions, and reported that more children needed treatment and monitoring, although some would die despite the care received. The studies showed that this population represented the largest proportion of hospital admissions in 2009/2010 (Fraser et al., 2014), of bed stays and deaths in Paediatric Intensive Care Units (PICU) in the UK (Fraser and Parslow, 2018), were at higher risk for a prolonged length of stay at hospitals (Edwards et al., 2012), were more likely to die in PICU during stays longer than seven days (Fraser and Parslow, 2018) and were more likely to die in the community after discharge, which is eight times more than children without life-limiting conditions (Fraser and Parslow, 2018). These studies reflected the rise in the prevalence of children with these life-limiting conditions and highlight their frequent access to healthcare services, both of which raise the burden of these conditions and concerns about whether children receive the appropriate care when needed.

On the other hand, in Jordan, the Ministry of Health (MOH) reported that total childhood deaths in 2015 numbered 1970 in children under the age of 15, compared to 4000 in the UK. The main causes of death in this population were conditions originating in the perinatal period, congenital abnormalities, respiratory and nervous system diseases, followed by neoplasms, according to the International Classification of Diseases 10th Edition (ICD10) (MOH, 2015b). In the same year, 245 children under the age of 14 years were diagnosed with cancer; around half of these children (43%) were under the age of 4 years (MOH, 2015a). However, prevalence data concerning children with life-limiting conditions, apart from cancer, is lacking. Figure 2-1 presents the causes of death among children under the age of 15 in Jordan.

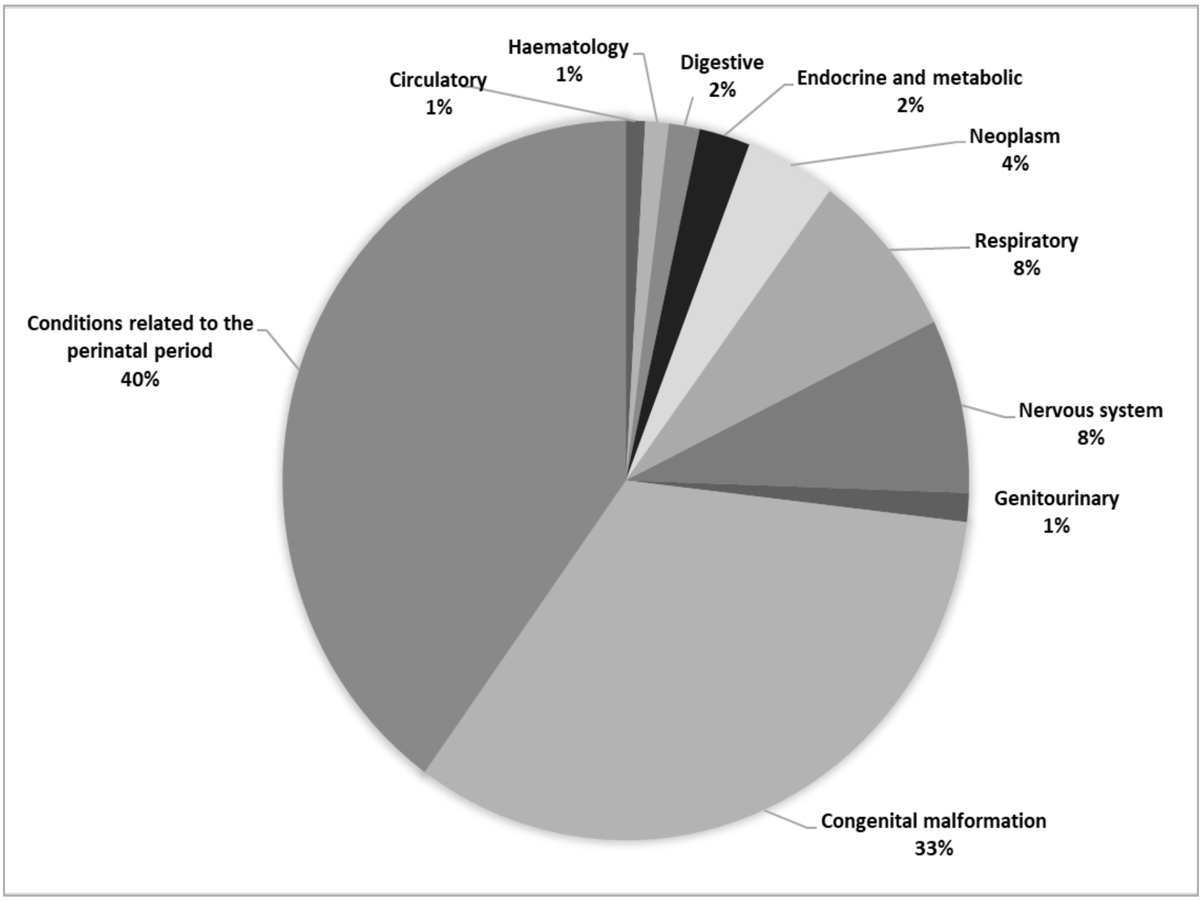


Figure 2-1 Causes of death among children under 15 in Jordan adapted from (MOH, 2015b)

The above-mentioned findings reflect changes in trends over time regarding death rates from communicable diseases to life-limiting conditions and demonstrate the rise in the prevalence of life-limiting conditions among children. Children with life-limiting conditions need extensive care from various services involving hospitals and the community. As demonstrated within the literature, the reported steady increase in prevalence of life-limiting conditions corresponds with an escalating need for specialised paediatric palliative care services (Fraser et al., 2012).

2.2 Definition of palliative care

According to the International Children's Palliative Care Network (ICPCN, 2015), children with life-limiting conditions (LLCs) require palliative care which is defined by the World Health Organisation (WHO), defined as *"an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"* (WHO, 2017).

Palliative care aims to improve the quality of life of patients and families. The ICPCN defined paediatric palliative care as *"an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the whole family and includes the management of distressing symptoms, provision of respite and care from diagnosis through death and bereavement."* (ICPCN, 2015). This care aims to improve the quality of life for children with life-limiting conditions and support their informal carers physically, emotionally and socially (NICE, 2016). Children with life-limiting or life-threatening conditions are a vulnerable population and deserve quality palliative care. This can be achieved by frequent assessment of the quality of care provided to inform the need for modifications in the standards of practice to meet this populations' needs (Aspinal et al., 2003).

Definition of palliative care

Palliative care is an interdisciplinary service; it includes a wide range of services and specialists, for example, hospital doctors and nurses, community nurses, hospice staff, social workers, physiotherapists and chaplains (National Health Service (NHS), 2015, Together for Short Lives, 2018). In addition, it depends on the effective collaboration between different health specialists and social care workers to support people approaching the end of their life to live as well as possible (Kelley and Morrison, 2015, NHS, 2015, NICE, 2016).

Palliative and end of life care are separate but inter-related concepts and models of care. Although there are subtle differences between these terms, the terms end of life care and palliative care are often used interchangeably (NICE, 2016, NHS, 2015). Table 2-1 summarises the differences between palliative care and end of life care. End of life care *is "the provision of supportive and palliative care in response to the assessed needs of patient and family during the last phase of life*."(National Council for Palliative Care (NCPC), 2006, p. 3). National Health Service (NHS) defines end of life care as the care provided for people who *"are likely to die within the next 12 months"(NHS, 2015).* This phase can be identified after a change in the patient's condition that means death is imminent (NICE, 2016), however, it is challenging to predict when an individual might enter this phase.

Table 2-1 The differences between palliative and end of life care

Parameters	Palliative care	End of life care
Time of care	Not only at the time of death, but patients may also receive palliative care while receiving other treatments	Provided for patients who are approaching death
Components of care	Involves physiological, psychological, social and spiritual support	Palliative care Supportive care: providing support for families and friends, planning care, providing what constitutes a *"good death"* bereavement services
Length of care	Begins at the diagnosis, may last longer the end of life care	Begins when the patient is approaching death and lasts for days or months or years.

A broad spectrum of childhood diseases benefits from paediatric palliative care, in this context the eligible groups of children entitled for paediatric palliative care are divided into four groups (Craig et al., 2007, Benini et al., 2008, NHPCO, 2009, Together for Short Lives, 2018);

1. Life-threatening conditions; curative treatment may be feasible but can fail. For example, advanced or progressive cancer or cancer with poor prognosis, complex and severe congenital or acquired heart disease, trauma or sudden severe illness, and extreme prematurity.
2. Life-limiting conditions; premature death is inevitable, long periods of treatment and hospitalisation are needed to prolong life expectancy and facilitate performing life activities. Such as cystic fibrosis, severe immunodeficiency, respiratory failure, renal failure, and neuropathies.
3. Progressive disease without curative treatment; treatment is palliative and may extend over many years. Such as progressive severe metabolic disorders, and certain chromosomal disorders.
4. Irreversible but not progressive conditions with complex health needs leading to complications and premature death. For instance, severe cerebral palsy, multiple disabilities following brain or spinal cord infections or injuries, and prematurity with residual multi-organ dysfunction.

2.3 Dimensions of quality of palliative care

The World Health Organisation (WHO) acknowledged that in order to improve quality of care*,* every child receives care that *"is evidence-based, safe, effective, timely, efficient, equitable and appropriate for their age and stage of development."(WHO, 2018b p.2)*. This definition entails that quality of care not only provides benefits for children, but it also includes minimising preventable injuries and risks. It also should be based on updated knowledge and guidelines using the maximum resources with minimum delay of care. This definition emphasizes the equity in providing care for all service users and considering individual preferences and cultural background.

Dimensions of quality of palliative care

Paediatric palliative care is considered as an approach to provide holistic care for a unique entity - the child and family, which raises the need to establish standards to determine and provide the best practices (Himelstein et al., 2004). Paediatric palliative or end of life disciplines have evolved, and national and international commissioners have formulated guidelines directing the provision and planning of end of life care for young people and their families. In the UK, standards were based on the available evidence to guide paediatric programmes and professionals and take into account the patients' and carers' needs and preferences while providing end of life care (Craig et al., 2007, NICE, 2016).

Other international guidelines include the International Meeting for Palliative Care in Children, Trento (IMPaCCT) standards in Europe (Craig et al., 2007), the National Hospice and Palliative Care Organization Standards in The United States (NHPCO, 2009), the Association for Children's Palliative Care (ACT) guidance (ACT, 2009) and most recently the National Institute for Health and Care Excellence (NICE) guidelines for children and young people with life-limiting conditions in the United Kingdom (NICE, 2016). These guidelines offer core quality principles for planning high-quality care for patients with life-limiting conditions less than 18 years old and their carers, irrespective of the medical condition and the setting, which can include home, hospital or hospice care.

These guidelines share some main principles and recommendations, which include the notion that the child and their family should be at the centre of end of life care, and they should be informed about the condition, available treatment choices and care services, in a sensitive and appropriate manner that considers the child's developmental stage, mental ability, social status, religious beliefs and cultural values. In addition, all children should be provided with continuous care regardless of the place of care, which should be selected based on what the child and the family prefer, and they should be involved in decisions about the care delivery and planning of care. Moreover, it is recommended that a key worker should be assigned to lead and coordinate the provision of care; and healthcare professionals involved in paediatric palliative care should be trained and supported to work in this area.

In a similar vein, the WHO published key standards for improving the quality of care for children and young people (WHO, 2018a). These standards aimed to ensure that children receive the basic elements of care, taking into account that children have unique physical, psychosocial, developmental and cultural needs. The paediatric quality of care framework comprises eight standards covering three main categories: the provision of care, the experience of care and the availability of child and adolescent-friendly resources. The standards are:

1. Evidence-based practices and management of illness; every child receives evidence-based care, for example, all children are thoroughly and promptly assessed according to WHO guidelines, reassessed regularly and protected from harmful practices during their care.
2. Actionable information systems: every child has a complete, accurate record that is accessible to ensure early, appropriate action to improve the care of every child.
3. Functioning referral systems: every child who requires referral receives coordinated care and the decision of referral is made without delay.
4. Effective communication and meaningful participation; all children and their carers are given clear information, enabled to participate effectively, and receive counselling according to their needs and preferences.
5. Respect, protection and fulfilment of children's rights; all children's rights are respected, protected and fulfilled at all times during care, with no discrimination of any kind.
6. Emotional and psychological support; all children and their families are given emotional and psychosocial support that is sensitive to their needs and strengthens their capability.
7. Competent, motivated, empathetic human resources; all children and their families have access to competent, motivated, empathic staff to provide routine care and fulfil the child's needs.
8. Essential child- and adolescent-friendly physical resources. Children are cared for in a safe, well-maintained, child-friendly, age-appropriate environment, and with adequate medical supplies and equipment for routine care and management of common childhood illnesses.

These standards are important and relevant since they can be used to produce a framework for assessing and monitoring the quality of care because they identify what can be tracked to evaluate high-quality routine care.

2.4 The differences in paediatric end of life care compared to adults

Although adult palliative care and paediatric palliative care share core principles, paediatric palliative care is a distinct speciality that considers the unique characteristics of its population (National Hospice and Palliative Care Organization (NHPCO), 2009). Paediatric palliative care has exceptional characteristics from adult palliative care, these are; first, the nature of diseases; the paediatric palliative care involves a wide range of diagnoses from different groups (oncological, neurological, chromosomal, cardiac and respiratory); which makes adult palliative care guidelines inappropriate for children and various specialists are required to meet diverse needs according to each individual case (Hain et al., 2012). Many paediatric diseases are rare conditions, which causes added complexities regarding diagnosis and treatment (Benini et al., 2008, Association for Children's Palliative Care (ACT), 2009, Together for Short Lives, 2018).

Besides the complexity of care due to the involvement of a wide range of professionals from different disciplines and specialities, a child's continuing physical, cognitive and emotional development are additional challenges that will affect the provision of care. Also, how children perceive, communicate and react to care is affected due to their developmental stage, which may produce further complexities relating to how the health care professional may interact with the child (Benini et al., 2008, Association for Children's Palliative Care (ACT), 2009, National Hospice and Palliative Care Organization (NHPCO), 2009).

In addition, in terms of the length of care, paediatric palliative care starts from the diagnosis of a life-limiting condition and extends to include the time of death (Liben et al., 2008) and in comparison to adult palliative care, paediatric palliative care could be longer than expected. Also, paediatric physical resilience is greater in children than adults, which may affect expectations about their condition (National Hospice and Palliative Care Organization (NHPCO), 2009, Fraser et al., 2012). The role of family also differs; children are central members of their families and their illness can affect every member through the trajectory of the illness. Family members include parents, siblings, grandparents or any family member who is responsible for taking care of a child. Family members endure a heavy burden of caring for a dying child (Together for Short Lives, 2018). They are responsible for the child's personal and medical care at home (Benini et al., 2008), communicating with healthcare professionals and making difficult decisions with and mostly on behalf of the child (Price et al., 2005). Lastly, regarding ethical and legal issues; children, unlike adults, do not have their own legal voices when it comes to communicating with healthcare professionals and expressing their choices and wishes (Benini et al., 2008). For these reasons, paediatric palliative care is much more complex than adult palliative care and there is a need for a comprehensive framework that describes and integrates the unique elements of paediatric palliative care in care provision and evaluation.

2.5 Evaluating the quality of end of life care

In 2008, the Department of health in the United Kingdom published the end of life care strategy, which emphasised the importance of providing quality end of life care and considered measuring the end of life care provision as *"a key lever for change"* and essential to monitor progress in care delivery (DoH, 2008). The Department of Health stated that the quality of end of life services is a benchmark for the healthcare services provided for sick and vulnerable individuals (DoH, 2008). Consequently, the quality of end of life care delivered for patients and carers has become a key indicator for the quality of healthcare services. One of the main aims of evaluating healthcare services is to identify the impact of service provision and the processes of providing these services to the individuals' lives, especially, patients with chronic illness or life-threatening conditions that require frequent access to healthcare services (Addington-Hall and McPherson, 2001).

Good quality palliative or end of life care is crucial in alleviating the burden of illness on patients and carers. There are three broad sources of data that can be used to evaluate the quality of provided care; administrative data from national or regional datasets, clinical data from medical records and patient-reported outcomes (Bainbridge and Seow, 2016). The Patient-Reported Outcome Measure (PROM) is *"an assessment of health status and health-related quality of life that comes directly from the patient"* (Medical Research Council, 2009 p.4). Outcomes for children with life-limiting conditions are linked to the effectiveness of healthcare services and any factor affecting the child's and family's life directly, not necessarily the absence of problems (Higginson, 1997) or achieving a goal (Hearn and Higginson, 1997, Downing et al., 2018).

Evaluating the quality of end of life care

The benefits of using outcome measures are that they can evaluate the quality of care from the users' perspectives and indicate the impact of care on individuals (Bainbridge and Seow, 2016, Friedel et al., 2018a), monitor whether care provided meets the current standards, compare the care provided by different services, as well as inform future research and decision-making bodies (Hearn and Higginson, 1997). These measures can identify the gaps in care and support further improvements in care. Data about patient-reported outcomes can be collected from patients themselves or their caregivers (proxies) by self-completion questionnaires or other means such as interviews and focus groups.

Although evaluating palliative or end of life care is usually obtained after the death of the patient, the potential of this data to improve future health care plans, renovate healthcare regulations and enhance quality of life for the patient and family cannot be underestimated (Lynn et al., 1997, Fowler et al., 1999, Seow et al., 2017). Additionally, associated cost savings within the healthcare services will be achieved by prioritising the needs and preferences of patients who are approaching end of life (Petersen, 2014).

Outcome measures proposed for palliative care should address a range of dimensions to provide reliable and sufficient information (Hearn and Higginson, 1997). Higginson (1997) identified the potential aspects of outcome measurements in palliative care as quality of life, quality of dying and bereavement outcomes. Evaluating the quality of palliative care requires a thorough understanding of the populations' views and experiences to identify the factors affecting quality of care of children with life-limiting conditions (Huang et al., 2010, Knapp and Madden, 2010, Friedel et al., 2018a).

In the context of palliative or end of life care, it is morally challenging to collect data from severely ill or dying patients, as many patients, both adult and paediatric, are physically and intellectually impaired at the end of life (Fowler et al., 1999, Tang and McCorkle, 2002, Bainbridge and Seow, 2016, Namisango et al., 2018), or children are too young to understand questions regarding their care (Coombes et al., 2016). Therefore, proxies are often approached to evaluate palliative and end of life care. Proxies include the parents, siblings, grandparents and informal carers. A benefit of collecting evaluation data from proxies is that they are able to provide information on care and experiences around the time of death (which could not be provided by the patient themselves), and it is then possible to evaluate the care offered to carers and relatives, a key aspect of end of life and palliative care (Addington-Hall and Kalra, 2001, Addington-Hall and McPherson, 2001). It is essential to include the services' users in evaluating services to improve the patient experience and ensure that the outcomes of the evaluation reflect the most important needs and aspects of healthcare (Aspinal et al., 2006).

Despite the increasing prevalence of children that require palliative or end of life care (Fraser et al., 2012) and the importance of evaluating end of life care (Fraser et al., 2013), there are no outcome measures to evaluate the quality of care delivered to all children. It was generally agreed that there is a need to develop a universal outcome measure that allows consistent and uniform data to be collected in routine practice across different settings rather than relating to defined conditions (Medical Research Council, 2009, Downing et al., 2018).

2.6 Outcome measures in palliative care

Despite recent progress in the paediatric palliative care discipline, the advances in this field have not been based on robust evidence and the need for further child-based research has been highlighted repeatedly by current studies, particularly to recommend an outcome measure to evaluate the quality of delivered care for children under the age of 18 (Downing et al., 2015, Coombes et al., 2016, Beecham et al., 2016, Downing, 2016, Johnston et al., 2017, Friedel et al., 2018a). Developing a valid tool or outcome measure requires involving patients and carers in designing the measures to ensure that they capture the right outcomes (Medical Research Council, 2009). This gap has been addressed as a research priority in previous studies (Baker et al., 2015, Downing et al., 2015, Ananth et al., 2021).

In examining the paediatric literature, two recent reviews have investigated patient-reported outcome measures used in paediatric palliative care: Coombes et al. (2016) and Friedel et al. (2018a). Coombes et al. (2016) conducted a systematic review, which aimed to investigate the feasibility of Health-Related Quality Of Life (HRQOL) measures that could be used in paediatric palliative care. Forty-one articles were found to meet the eligibility criteria that investigated the psychometric properties of 22 HRQOL measures, although there was a lack of detail within most articles and only one article examined the responsiveness of the measure. Moreover, the results demonstrated that most HRQOL measures for use with children under 18 years were mainly disease-specific, and none of them were identified as useful or feasible for use in children receiving paediatric palliative care. Also, they found that the aspects of generic HRQOL measures were not relevant to children receiving palliative care, but rather is only useful for specific diseases or conditions. Therefore, the authors concluded that none of the existing measures were suitable to be used for a paediatric palliative care population. These findings highlight the pressing need for the development of a universal measure for use in children receiving palliative care.

This was reiterated in the review conducted by Friedel et al. (2018a), which aimed to identify the instruments that have been used in paediatric palliative care that assess the impact paediatric palliative care interventions. This review described the impacts that are assessed by these instruments and their psychometric properties. Unlike the review by Coombes et al. (2016), Friedel et al. (2018a) did not limit the inclusion criteria to a specific dimension of care or the type of care such as supportive, respite and bereavement care. The authors found nineteen eligible studies, fourteen of them used twenty-three predefined instruments, ten of the nineteen were conducted with an oncology population and three studies combined home, community-based and hospital care. Although the studies covered different dimensions of care (physical, psychological, spiritual, satisfaction with communication with healthcare professionals and expressing the child's wishes), none of these studies were found to describe how the dimensions of care were used in the instruments. Predominantly, this review revealed that most of the instruments were lacking adequate psychometric properties, most focused on only one dimension of care and only five of the 23 measures were found to include patient-reported (child) outcome measures.

These reviews demonstrated the existing gap within the literature on outcome measures for children receiving paediatric palliative services; there are no generic paediatric palliative care measures that can be applied to the diverse diagnoses and settings, and that address the relevant dimensions or domains of care involving children (Downing et al., 2018). Researchers and stakeholders have recommended that revising a validated instrument to ensure it is appropriate for use in the entire the paediatric population is the best approach (International Children's Palliative Care Network (ICPCN), Coombes et al., 2016, Johnston et al., 2017). This study addressed this gap and followed the recommendations by research and stakeholders by adapting the VOICES-Short Form questionnaire to ensure it was appropriate for children receiving palliative care for different diseases and conditions and in a variety of settings.

2.6.1 The Views of Informal Carers – Evaluation of Services -Short Form VOICES-SF

In the past decades, the adult end of life care field has undergone substantial growth and change, including expanded research, published guidelines, measuring the quality of care, and increasing public and professional awareness (Kelley and Morrison, 2015). Evaluating the quality of end of life care delivered to patients and carers has become a new indicator of the quality of healthcare services. To monitor the progress of end of life care provision, healthcare professionals need to measure the structure, process and outcomes of care. One way quality of care is evaluated is by gathering patients, bereaved carers or proxies' views and experiences of care through interviews or questionnaires (Addington-Hall and McPherson, 2001, Addington-Hall and O'Callaghan, 2009).

Several studies within the literature have explored quality of care by reporting the views of adult patients and informal carers to identify areas of unmet needs and suggest approaches to satisfy these needs (Lynn et al., 1997, Addington-Hall and McPherson, 2001, Larsson et al., 2004, McPherson and Addington-Hall, 2004, Burt et al., 2010, Lees et al., 2014). Consequently, a number of tools have been designed and verified to measure the quality of care provided for adult patients and families around the time of death (Mayland et al., 2008).

Two systematic reviews reported the diversity of tools used to measure the adult end of life care experience (Lendon et al., 2015) and the quality of death and dying (Hales et al., 2010). Hales et al (2010) identified eighteen tools to measure the quality of death for adult patients, for example, the Quality of Dying and Death questionnaire (QODD), the Good Death Inventory (GDI and the Quality of Dying in Long-term Care (QOD-LTC) surveys. However, the majority of these measures failed to provide a clear definition of *"quality of death"*, nor did they validate the items according to patients' preferences or report the reliability of the measures.

Lendon et al. (2015) identified fifty-one measures to evaluate adult experiences with end of life care including, but not limited to the following: the Family Evaluation of Hospice Care (FEHC), the After-death Bereaved Family Member Interview (ADBFI), the Satisfaction scale for Family members receiving Inpatient Palliative Care (Sat-Fam-IPC), the Family Assessment of Treatment at End of Life (FATE) & FATE-Short Form (FATE-S), the Views of Informal Carers Evaluation of Services (VOICES) survey and the Canadian Health Care Evaluation Project (Lendon et al., 2015). Two of these measures were used at a national level: The After Death Bereaved Family Member Interview in the USA and the Views of Informal Carers—Evaluation of Services (VOICES-SF) survey in the UK.

The Views of Informal Carers – Evaluation of Services-Short Form (VOICES-SF) survey was first developed in the mid-1990s by Professor Julia Addington-Hall and colleagues as a self-completion survey, and it was modified to the latest version (short version) in 2010 (Hunt et al., 2014b, Hunt et al., 2017). The VOICES-SF is a 59-item validated end of life care questionnaire that covers care provided across care settings, as well as patient and family experiences of and preferences for care in the last three months of life. It has been validated and used in various studies across the United Kingdom (Addington-Hall and O'Callaghan, 2009, Hunt et al., 2014a, Hunt et al., 2014b). Furthermore, the VOICES-SF survey has been adapted for use in other countries; for example, in Canada Seow et al. (2016a) modified and validated the VOICES survey and added items about hospice volunteer services, advanced care planning, transition of care and support domains (emotional and spiritual) to the sections of every setting (Seow et al., 2017). In addition, the VOICES-SF survey has been translated and tested in Italy (Costantini et al., 2005) and in Sweden (O'Sullivan et al., 2018) and has been found to be a valid and useful outcome measure.

The VOICES-SF was commissioned by the Department of Health in England 2010/2011 as the first national survey of bereaved carers' views (Department of Health, 2012), which subsequently, has been conducted annually from 2011 to 2015 by the Office for National Statistics (2015) to evaluate the care provided for adult patients in the last months of life. Bereaved carers complete the questionnaire that contains 59 questions regarding different aspects of care. The survey is divided into sections that cover care provided at home, from community nurses, general practitioners, hospitals and hospices. In addition, the questionnaire covers three time periods: the last three months of life, the last two days of life, and surrounding the actual time of death. Each setting has similar subdivisions about communication, being treated with dignity, involvement in decision-making and achieving the preferred place of death, with an aim to enable the comparison of services across settings. The response items use a range of rating scales, multiple-choice and opened-ended items.

Previous studies with VOICES-SF have used the data to, among others, compare the quality of care between hospices and hospitals in terms of; communication, pain management and treatment with dignity (Addington-Hall and O'Callaghan, 2009), or explore factors associated with achieving the deceased's preferences for place of death (Hunt et al., 2014a, Hunt et al., 2014b). The VOICES-SF survey is not restricted for use in particular patient groups or services, and as such can be used to obtain information about the overall care provided in the last three months by all relevant services (ward nurse, community service, care home, hospice and emergency). In addition, the VOICES-SF survey has the key aspects of palliative care; quality of life, quality of dying and bereavement outcomes as proposed by Higginson (1997), meaning that it has the potential to be a useful and valuable outcome measure in evaluating children's palliative care if it is adapted and validated for use in this population. For example, it explores aspects of care such as managing symptoms, emotional and spiritual support, support for carers (including bereavement care), privacy, nutrition/hydration and discussing the patient's wishes and worries.

For the abovementioned reasons, the VOICES-SF questionnaire is a comprehensive outcome measure that has been validated and shown to be useful in a variety of contexts. However, until now, the VOICES-SF has only been validated for use in evaluating adult end of life care and has not been used for the paediatric population. This research aimed to address this gap by adapting VOICES-SF to the paediatric population, and this is outlined in more detail in the following section.

2.7 The Jordanian context

Jordan (officially known as The Hashemite Kingdom of Jordan) is an Arab country located in the Middle East. Its total area is 88,780 Km². It shares its borders with Palestine, Syria, Iraq and Saudi Arabia (Figure 2-2). Jordan has an overall population of 10,3 million and the majority of this population (91.5 %) is urban (Worldometer.info, 2020). The population is predominantly young with a median age of 23.8 and life expectancy of 75.0 years for both sexes. The majority of Jordanians are Muslims (92%) and Christians constitute the largest religious minority (Worldometer.info, 2020). Arabic is the official language in Jordan, but English is widely understood and used in higher education institutions, medical care and large enterprises. Jordan has witnessed changes in the epidemiological trend characterized by a progressive increase in the proportion of non-communicable diseases, especially cardiovascular diseases, cancer and respiratory conditions (Ajlouni, 2011). Cardiovascular diseases are considered the leading cause of death followed by cancer (MOH, 2015b). In Jordan, seventy per cent of cancer patients, both adult and paediatric, are diagnosed with cancer at advanced stages (III and IV) and usually die within one year of their diagnosis. Therefore, the majority of newly diagnosed patients are eligible to receive pain management and palliative care as the most humane and applicable approach to care (Stjernswärd et al., 2007). Abdel-Razeq et al. (2015) acknowledged the need for developing a comprehensive screening programme in Jordan to enable early detection of cancers (particularly breast cancer) in earlier stages where they are treatable and patients have higher survival rates and treatment (Abdel-Razeq et al., 2015).

Figure 2-2 Map of Jordan (Source: World Atlas.com)

2.7.1 Healthcare system in Jordan

Jordan has modern healthcare infrastructures that are distributed among the twelve directorates or governorates, however, the majority of these are highly concentrated in Amman, the capital of Jordan, with the largest portion of the population (Ajlouni, 2011). Medical care services in Jordan are divided into two main sectors: 1) the public sector which includes; the Ministry Of Health (MOH) hospitals, the Royal Medical Services (RMS), and university-affiliated hospitals, and; 2) the private sector (Al-Qadire et al., 2014):

1. Public sector
    - The Ministry Of Health (MOH) is responsible for regulating and delivering the civil health insurance, which includes civil employees, their dependents, low-income individuals, the disabled and all children under the age of 6 years are covered by MOH or civil health insurance (Ajlouni, 2011, Al-Rimawi, 2012). The Jordanian MOH sector is the largest provider of healthcare services comparing to Royal Medical Services and private sectors (Ajlouni, 2011). It provides primary, secondary, and tertiary healthcare services. Primary care is provided solely by the MOH through elementary, comprehensive and Maternity and Child Health (MCH) centres that are spread throughout Jordan in both cities and villages (Al-Qadire et al., 2014). These centres provide curative and preventative medical services such as supplying pharmaceutical prescriptions for chronic patients, first aid, dental, childhood immunisation, obstetric and family planning services, and mainly operated by general practitioners, dentists, midwives, and general nurses (Ajlouni, 2011). MOH operates 31 hospitals in ten governorates. For inpatients services, MOH hospitals are divided into two groups: local hospitals with emergency, paediatric, medical and surgical units and large regional hospitals with more advanced and specialised adult and paediatric services. Figure 2-3 shows the organisational structure of the Jordanian MOH.
    - The Royal Medical Services (RMS) provide secondary and tertiary medical services through 11 hospitals in seven governorates. RMS provides care for military, police, national security individuals, both active and retired, and their dependents, as well as uncovered patients referred from MOH mainly for complicated cases and treatment.
    - University hospitals. There are two university-affiliated hospitals: the Jordan University Hospital (JUH) in Amman and King Abdullah University Hospital (KAUH) in Irbid. These hospitals serve the universities' employees and their dependents, independent private patients and MOH beneficiaries seeking specialised and high-tech diagnostic procedures and complex care (Ajlouni, 2011).
2. Private hospitals cover and provide care for their employees and employees of private firms and individuals who purchase their insurance. This sector attracts foreign patients and promotes the regional role of Jordan in medical tourism (Ajlouni, 2011).

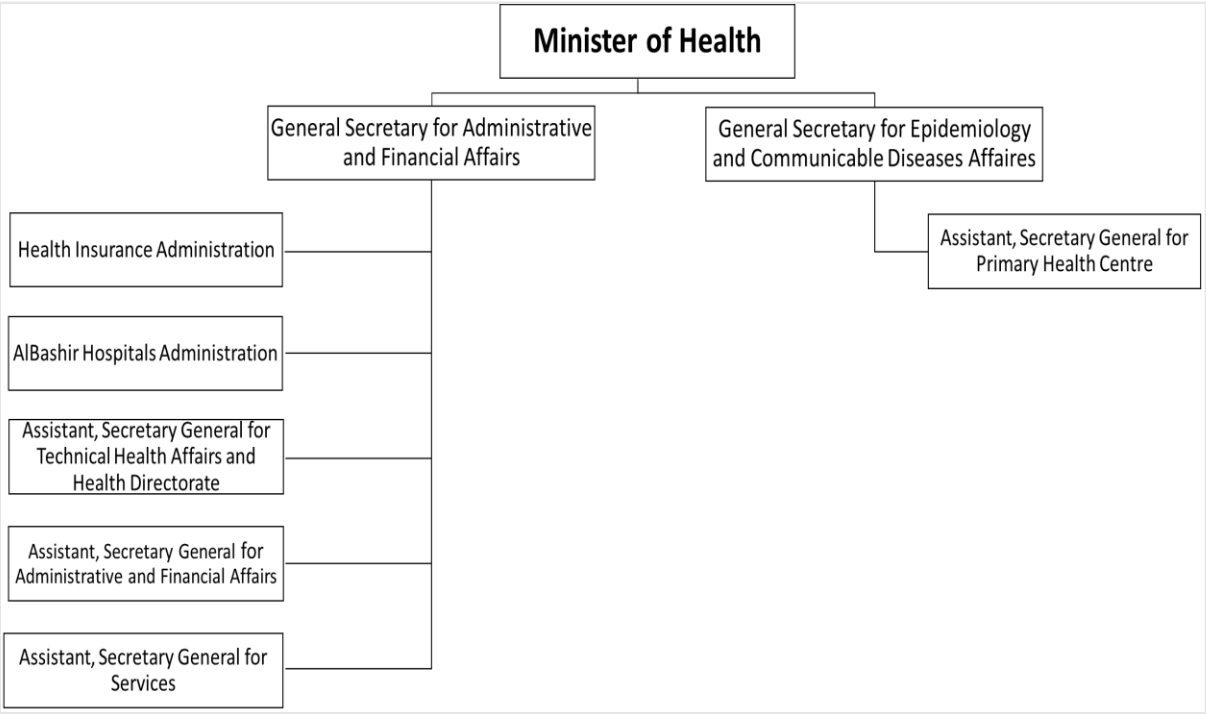


Figure 2-3 The organisational structure of the Jordanian MOH adapted from (Ajlouni, 2011)

The government of Jordan established a national health strategy in order to create comprehensive healthcare services that are available and accessible to all with the collaboration of public and private sectors, as well as, to improve the quality of healthcare services (Ajlouni, 2011). This strategy is set by the High Health Council, comprised of the prime minister as the chairman, the minister of health as vice chairman, director of the RMS, the deans of medical schools and heads of other professional associations and councils. The ministry of health governance is mainly centralised; significant decisions related to management and financing are taken at a senior executive level. Operational decisions are made at the local or state level, such as transferring staff and monitoring activities.

However, the health system in Jordan faces several challenges. For example, demographic changes characterised by an increase in the elderly population and a rise in life expectancy, as well as the shift in epidemiological trends as manifested by the high proportion of non-communicable diseases. Although the majority of healthcare facilities are operated by the government, they are found in major urban areas which result in problems related to accessibility and equity in providing health services for the minorities who live in rural areas (Ajlouni, 2011).

Another issue impacting access to health services is health insurance, which covers about 55 of the overall population and 70% of Jordanians (Nazer and Tuffaha, 2017). A report suggested there is a link between the uninsured population and the presence of a large non-Jordanian population; Palestinians and Syrian refugees (Dana Al Emam, 2016). A fragmented national, paper-based health information system is a further challenge that hinders the dissemination of up-to-date medical information throughout the public health system (Ajlouni, 2011). As a response to this challenge a national e-health initiative (Hakeem) was launched in 2010 and aimed to improve health services by linking up-to-date electronic medical information between primary healthcare centres and hospitals. This information includes diagnostic, laboratory, pharmacological information, physicians' orders, and follow-up clinical documentation (Nassar et al., 2015). Basic health data is collected annually from the MOH and other public and private facilities, and information about the numbers of births and deaths at directorate and national levels are collected, however, there are no standard forms for handling patient personal data and limited epidemiological reports due to ambiguous disease classification (Ajlouni, 2011). There is a need for institutionalised continuous education and training of physicians, nurses, and allied health professionals (Oweis, 2005, Ajlouni, 2011). Reform projects and initiatives were adopted in Jordan with the financial support of international organisations such as the WHO and the United State Agency for International Development (USAID) to address issues regarding establishing training programmes to keep healthcare professionals well trained and experienced, improving quality of care, strengthening health information systems, supporting health communication, and renovation of health centres (Ajlouni, 2011)

2.7.2 Paediatric palliative care in Jordan

Jordan is classified as having generalised palliative care and there is no integration of palliative care into the medical services (Connor, 2014). In the 1990s, palliative care in Jordan was provided exclusively by a MOH hospital in the capital Amman. In 2001, the Jordan Palliative Care Initiative was founded and introduced palliative care to cancer patients, in accordance with the WHO palliative care philosophy. As a result of this initiative, the first palliative care unit was established at King Hussein Cancer Centre (KHCC) becoming the first cancer-specialised centre in Jordan (Omran and Obeidat, 2015). The KHCC is a non-governmental, non-profit institution that provides inpatient, outpatient and home care palliative care services. It is the first centre providing adult and paediatric comprehensive cancer care in the Middle East region. This centre provides tertiary care for more than fifty per cent of cancer patients in

Jordan (Shamieh and Hui, 2015). About seventy-five per cent of its patients are from Jordan and twenty-five per cent from other Middle Eastern countries (Stjernswärd et al., 2007).

In Jordan, paediatric palliative care is provided through paediatric wards in the former health sectors, based on a patient’s healthcare insurance, in addition to the King Hussein Cancer Centre (KHCC). The majority of these services are hospital-based (Bingley and Clark, 2009) except home care provided exclusively by the KHCC home care programme for adults and children based on a comprehensive discharge plan. Unfortunately, only patients within the Amman governorate can benefit from home care, while telephone support is available for all patients and their families throughout the country (Al-Rimawi, 2012).

Jordan has a well-developed healthcare system, in comparison to other Middle Eastern countries, however, the field of palliative care in Jordan is in its early stages (Al-Qadire et al., 2014). The limitations of palliative care in Jordan can be summarised as follows: lack of palliative care education and training in the undergraduate curricula and postgraduate education, palliative care services are mainly focused on cancer patients, there is an uneven distribution of specialised palliative services across governates as advanced palliative services are concentrated in Amman, and there are no hospice and home care services, except those offered by KHCC (Al-Qadire et al., 2014, Omran and Obeidat, 2015, Khader, 2017). In addition, there are no national palliative care guidelines and children are treated according to guidelines adapted from international guidelines, i.e. UK or USA (Al-Rimawi, 2012). As there are no recognised bereavement services or grief support in Jordan after the child’s death, bereaved parents, and mothers, in particular, tend to depend on their religious beliefs and social relationships to provide emotional support (Abdel Razeq and Al-Gamal, 2018).

Although there has been growing interest in investigating paediatric palliative care in Jordan recently, much of the evidence is derived from descriptive studies of the perceptions of paediatric patients receiving end of life care and their parents (Mahadeen et al., 2010, Arabiat et al., 2011, Arabiat and Altamimi, 2013, Abuqamar et al., 2016, Atout et al., 2017, Abdel Razeq and Al-Gamal, 2018, Atout et al., 2019). However, there has been no empirical investigation evaluating the quality of care provided for dying children in Jordan. For example, Mahadeen et al. (2010) explored the mental status of mothers of children with cancer and whether children’s knowledge about their diagnosis impacts mothers’ mental status. The authors found that mothers caring for children with cancer suffer from moderate to severe levels of psychological disturbances using the Depression, Anxiety, Stress Scale (DASS). Although there was not a significant difference in overall distress levels among mothers who informed the children of their diagnosis or did not, the levels of psychological disturbances correlated negatively with the level of the child's knowledge about the diagnosis. The authors attributed poor psychological status that mothers suffered from to maladaptive mechanisms developed while providing care for their children i.e., inability to accept the child's illness and discuss it openly with the ill child. In the same vein, Arabiat et al. (2011) investigated the mothers' perceptions of the amount of information shared with their children about their diagnosis with cancer using open-ended questions focusing on mothers' communication with their children about their illness. Interviewed mothers reported their satisfaction with their approaches, which were categorised into no knowledge, minimal knowledge, and open knowledge of cancer diagnosis and treatment, either directly or by coincidence. The latter group of mothers justified withholding the child's diagnosis to protect the ill child from further distress and losing hope. This view was supported by Atout et al. (2019) who explored experiences of disclosing information among children receiving palliative care, mothers and healthcare professionals at a major public hospital. Data was collected through children's observation during their hospitalisation and semi-structured interviews with mothers, nurses and physicians. The participants adopted *"a protective approach"* when they communicated with each other to avoid the emotional distress they might experience. Mothers and staff avoided informing children about their illness and discussing illness-related topics to avoid upsetting them, while ill children avoided discussing their anxieties to protect their parents.

On the other hand, Arabiat and Altamimi (2013) investigated the perceived needs of parents caring for children with cancer in Jordan and their satisfaction regarding these needs using the Arabic version of the Family Inventory of Needs-Paediatric II questionnaire (FIN-PED II; Monterosso et al., 2006). The majority of parents (78%) reported that their needs were met, however, the most frequent unmet needs were for further information regarding the child's care plan, treatment side effects and prognosis of the illness in a simple language without medical terminology. Two studies explored parents' views regarding certain domains of paediatric palliative care, for example, Abuqamar et al. (2016) utilised the Parent Satisfaction Survey (McPherson et al., 2000) to investigate parents' satisfaction with care provided for children with chronic illness in terms of overall child care, communication of staff, and the environment of paediatric intensive care unit (PICU) at a military hospital. Although the parents expressed their satisfaction with overall care, they were less satisfied with the levels of noise at the unit due to monitors and life-support machines, and the short time that healthcare professionals spend at the child's bedside. In addition, parents reported poor communication from nurses at the PICU and a lack of information regarding medical procedures from physicians. Atout et al. (2017) were more focused on investigating mothers' experiences regarding decision making during the care of children with palliative care needs. The study revealed that the dominant pattern of the level Jordanian mothers' involvement in decision making was such that it gave physicians the major role for deciding the child's treatment options is the predominant pattern. Mothers reported that they adopted this pattern as they considered themselves as *"lay people"* and doubted their ability to decide the most appropriate treatment without the physician's help.

The aforementioned studies have been conducted with children receiving palliative care, mainly cancer, who were recruited through clinics and departments where the child was admitted. Only one study entailed recruiting bereaved parents (Abdel Razeq and Al-Gamal, 2018). The authors undertook a qualitative phenomenological approach to explore bereaved mothers' experiences after losing their neonates in the Neonatal Intensive Care Unit (NICU) within twelve months prior to the interviews. Mothers' reports were categorised into three main themes: longing and grieving, the adaptive work of coping, and moving forward but with a scar. The first theme entailed *"the natural response"* to mothers' loss which was vivid in the first few months and declined over time. The second theme described bereaved mothers' approach to cope with the child's death in order to move on with their lives following the child's loss. Bereaved mothers' acceptance started by searching for a deeper spiritual meaning for their loss such as *"bitter good"* or a *"blessing in disguise"* that helped them to understand and accept the child's death. While others chose to be distracted with their career to escape overthinking of their loss. The bereaved mothers reported the significance of support they received from their social network considering the lack of support from healthcare professionals. The last theme described mothers' willingness to move forward and adjust their environment following their loss without forgetting the deceased child. This was evident by several acts such as planning for having another child with a positive outlook for the next pregnancy, as some of the participants were pregnant at the time of the interviews. The authors justified that, besides social pressure from family members, bereaved mothers sought to relocate their feelings despite their uncertainty and fear about the health of subsequent children.

2.7.3 Cultural background

The extended family is the primary unit in Jordanian society. Although households are comprised of the husband, wife and children, who rarely leave home until the time they marry, the close bonds with extended family members are very strong, as well as bonds on a larger scale such as same surname or tribe name (refers to the origin of different surnames). Jordanians value family unity and commitment to supporting their relatives, which include blood kin, in-laws and individuals from the same tribe. The traditional family structure and organisation have a major implication on daily healthcare practices. For example, emotional and financial support must be provided for close relatives especially during illness and funerals. Individuals who fail to fulfil their responsibilities toward their family will be labelled with shame and disrespect. Therefore, care homes and hospices are not accepted socially among Jordanians because they are perceived as a place for neglected family members.

The concept of patient autonomy is not well established in Eastern communities because the patient is a member of a wide web of individuals who might impose responsibility and obligations toward each other. Close family members are usually involved in providing care for inpatients, medical decisions and receiving news about their diagnosis or prognosis (Silbermann and Hassan, 2011). Due to close ties among family members, they find themselves obligated by their cultural values to support ill individuals.

Islamic faith is the wider affiliation, after tribe and family, in formulating the norms of the Jordanians' lives and practices. Islam, which means *"submission to the will of God"*, is a monotheistic religion that is underpinned by the belief that nothing can happen to people without God's permission, but humans nevertheless have free will (Sarhill et al., 2001). Muslims consider the prophet Muhammad (PBUH; Peace Be Upon Him) as the last in the line of prophets sent to all people around the world. Shari'ah (Islamic law) principles are based on the Quran and the prophet's sayings and practices (Hadith), which is the second fundamental source of Islamic law that explains and supplements what is in Quran scripts. For contemporary controversial issues such as abortion or euthanasia, Muslims seek scholars for Fatwa (jurisprudential decree) which reveals the judgment for an issue under investigation using analogical reasoning to connect it to relevant issue/s, with a valid judgment, in religious scripts from Quran and Hadith. Islam and medical care share the same principles that a human's life and body should be preserved, consequently, it is the responsibility of an individual to comply with the advice of medical professionals. Muslims are obligated to visit the sick and comfort them. Traditionally, extended family members and friends provide spiritual support for people during bad times, such as illness and grieving by praying and reciting the Quran (Sarhill et al., 2001). Illness or grief are perceived as opportunities to reconnect with God and be closer to him by being patient and praying. Moreover, family members and friends consider the taking care of an ill or bereaved person as a spiritual opportunity to gain God's blessings (Silbermann and Hassan, 2011). Therefore, feelings of loneliness and abandonment are rarely experienced by terminally ill or bereaved individuals.

Islamic communities differ from Western communities with regard to how individuals express sadness and coping with their suffering and loss. There is usually little need for professional psychological support for bereaved individuals as the close social network and religious practices provide the support needed (Sarhill et al., 2001, Hedayat, 2006). Muslims' faith influences their psychological status through difficult times because Muslims consider life is a testing ground for people who will be rewarded in the afterlife based on their deeds in life. Illness, pain in particular, is seen as a form of affliction to test believers' faith and removing their sins as long as they are patient, put their trust (Tawakkul) in God, and to not lose hope in God's mercy. In Islam, death is the departure of the soul from the body or the transition from one form of existence to another, therefore brain dead patients are considered dying but not yet dead (Sarhill et al., 2001). Islamic beliefs constantly remind individuals to be prepared for death and accept it as the predestination of any creature that only happens with God's permission, therefore feelings of desperation and thoughts about ending one's life are regarded as denying God's will and authority (Sachedina, 2005). This is not to say that a Muslim is immune to suffering or loss, but rather that the attribution to God is reassuring if embraced with sincerity. The Qur'an recognises human fragility and does not expect humans to deny their suffering, but rather to be dignified in their expression of that suffering (Parkes et al., 2015). Although some Muslims may feel that expressing their sadness and grief may be considered as an objection to God's will, they show the full range of emotional breakdown; from complete silence to loud weeping (Lawrence and Rozmus, 2001). In the same vein, a person's life and body are sacred entities that belong to God only, accordingly decisions regarding ending life i.e. withdrawing treatment and euthanasia are perceived as acts of disobedience to God and deliberate harm to someone's life (Sachedina, 2005). Similarly, post-mortem examinations are not allowed unless there is a legal need.

Decisions regarding life support are usually made by the father or the eldest son/ sibling after consulting a Muslim scholar to provide the religious decree, whenever it is needed. End of life care related issues such as withdrawal of life-supporting equipment and organ donation have been debated among Islamic scholars in the last three decades (Sachedina, 2005). Although organ donation is not explicitly mentioned in the Holy Quran and Hadith. Muslims from the Indian subcontinent do not consent to organ transplantation as the human body only belongs to God, while Muslims from Arab countries consider transplantation permissible to save others' lives (Sarhill et al., 2001). Organ donation is allowed with the donor or legal guardian's consent as a gift, without any profit or harm to the living donor and with minimal disfigurement of the dead donor (Lawrence and Rozmus, 2001).

On the other hand, withdrawing or withholding medical treatment that is seemingly useless were deemed as *"permissible"* by Islamic scholars to comfort terminally ill patients and their families in certain situations; such as withdrawing a brain-dead patient from life support machines to use them for another patient (Aramesh and Shadi, 2007). Yet, debates around what circumstances withdrawing or withholding treatment are deemed permissible are continuing (Ayuba, 2016). To conclude, withdrawing life-saving machines is not accepted by the majority of Muslims because no one knows when a human being will die or has the right to end life as evident in the following Qur'anic verses; *"A person dies when it is written"* (Qur'an 3:185, 29:57, 39:42), *"God gives life, and He makes to die"* (Qur'an 3:156), and *"The enormity of the sin on a person who deliberately terminates a life other than in the course of justice such as murder or spreading mischief in the land, is as if the whole people have been killed by him"* (Qur'an 5:32). In addition, prophet Muhammad (PBUH) prohibited the killing of an innocent soul and considered it as one of the biggest sins (Al kabai'r).

The dead are treated with dignity by removing all clothes, washing the body (Ghusl), wrapping (Shrouding) it in a white sheet, and preparing for burial ceremonies without any delay. Washing and shrouding the deceased are Islamic rites usually done by family members and anyone from the same gender who is familiar with the steps of preparing the body before burial. The Funeral Prayer (Salatul Janaza) is a divine service held over the deceased's body before burial and it is strongly recommended to perform whether you know the deceased or not. This prayer can be inside the mosque or at the cemetery. Early burial is preferable because people from the wide social network come to pay respect to the deceased and family members and usually eat and stay at the deceased's home. Participating in funerals is a meritorious act in Islam for example; expressing condolences, performing prayers, and attending funerals (Silbermann et al., 2012).

Bereavement periods are for three days in which the Quran is recited at the funeral place. Support at this time is provided to grieving family members by concepts that death is the imminent end of everyone and the end of suffering for a terminally ill patient who is in a better place. This attitude impacts how an individual and his family view illness, inevitable death and after death.

In summary, the Jordanian community is homogenous in terms of language, social and cultural norms despite some diverse religious backgrounds and nationalities. These norms impact what individuals and families expect during illness and bereavement and how they deal with them.

2.8 Conclusion

The prevalence of children with life-limiting conditions has been increasing and this raises concerns regarding the quality of care provided for children and their families, especially when the child is approaching death. There have been international advances in the field of paediatric palliative care, however, there is no universal measure to evaluate quality of care. The literature recommends that a measure developed for the adult population be adapted for the paediatric population, taking into consideration the similarities and differences between adult and paediatric palliative care. In addition, paediatric palliative care is an under-researched area in Middle Eastern countries as evidenced by the lack of formal guidelines and protocols for care provision and scarce data about carers' perceptions of paediatric palliative care. Individuals from a certain culture share unique beliefs, practices, roles, and ways of interacting. Cultural and religious values impact the way individuals and families deal with illness and bereavement as well as their expectations of health services. These values also impact medical practices and how people perceive and consequently evaluate quality of care. Therefore, this research aimed to adapt the VOICES-SF questionnaire for the paediatric population, culturally adapt the paediatric version for the Jordanian context, and then conduct a pilot survey to explore feasibility and methods to optimise response and minimise distress.

Chapter 3. Methods

3.1 Introduction

The previous chapters have discussed the importance of providing quality end of life care for children, the need to develop a measure for evaluating this care, and the current gap in literature regarding bereaved parents' views about end of life care from Eastern cultures, specifically Jordan. This chapter describes the philosophical assumptions that inform the research and outline the study approach. This chapter starts with restating the aims and objectives of the study and includes an overview of the research methods, and is followed by an outline of the research methodology adopted to address the research questions. Furthermore, methodological issues concerning the conduct of a survey and cross-cultural adaptation are addressed, as well as the ethical considerations that guided the conduct of this post-bereavement research

3.2 Aims and objectives

3.2.1 Research aims

The key aims of this study were to develop a culturally sensitive measure for evaluating the quality of end of life care for children and their families in a Middle Eastern context; and, using that measure to conduct a survey of bereaved parents to explore quality of end of life care for children in the last three months of their lives in Jordan. In addition, this study aimed to explore feasibility issues that relate to design of a post-bereavement survey and establish optimal methods for survey delivery in Jordan.

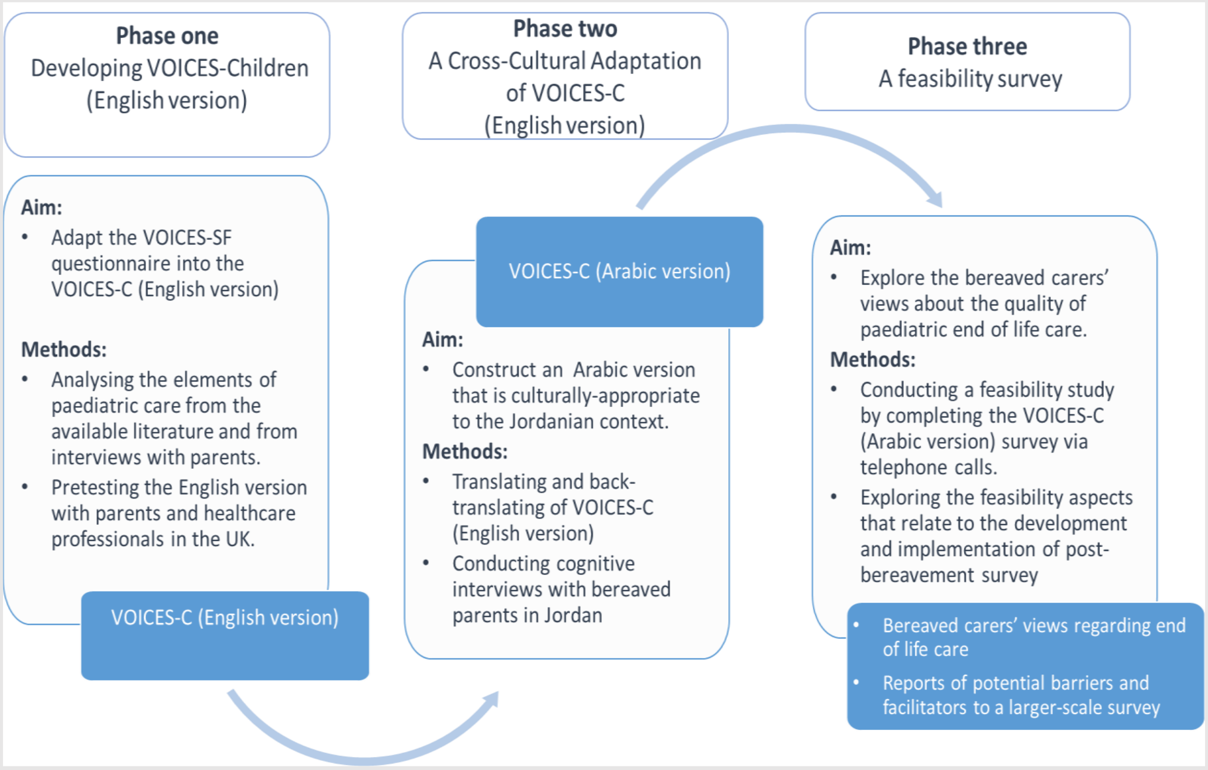
3.2.2 Research questions

1. What are the important elements of quality paediatric end of life care from bereaved parents' perspectives as reported in the literature?
2. What are the important elements of quality end of life care according to interviews with bereaved parents as well as healthcare professionals who work with children at the end of their lives?
3. Which sections/items/response options of the VOICES-SF questionnaire require adaptation in order to reflect the elements of paediatric end of life care?

4. Which items of the VOICES-C (Arabic version) required modification to ensure the questionnaire is culturally suitable, appropriate and acceptable for use in Jordan?
5. What are bereaved carers' views about quality of care provided for their children in the last months of their lives in Jordan?
6. Is it feasible to use a telephone interview approach to collect data from bereaved carers about the quality of end of life care in Jordan?
    a. How long does it take to retrieve and recruit eligible participants?
    b. What is the response rate of a post-bereavement survey in Jordan?
    c. How long do interviews take to conduct when asking participants to complete questionnaires, and how many interviews are needed to complete a questionnaire?
    d. Is there any missing data from completed questionnaires?
    e. Is it socially acceptable to participants to be asked to report any dissatisfaction with care provided?

3.2.3 Structure of the research

The project was divided into three consecutive phases (Figure 3-1).



Phase one
Developing VOICES-Children (English version)

Aim:
- Adapt the VOICES-SF questionnaire into the VOICES-C (English version)

Methods:
- Analysing the elements of paediatric care from the available literature and from interviews with parents.
- Pretesting the English version with parents and healthcare professionals in the UK.

VOICES-C (English version)

Phase two
A Cross-Cultural Adaptation of VOICES-C (English version)

VOICES-C (Arabic version)

Aim:
- Construct an Arabic version that is culturally-appropriate to the Jordanian context.

Methods:
- Translating and back-translating of VOICES-C (English version)
- Conducting cognitive interviews with bereaved parents in Jordan

Phase three
A feasibility survey

Aim:
- Explore the bereaved carers' views about the quality of paediatric end of life care.

Methods:
- Conducting a feasibility study by completing the VOICES-C (Arabic version) survey via telephone calls.
- Exploring the feasibility aspects that relate to the development and implementation of post-bereavement survey

- Bereaved carers' views regarding end of life care
- Reports of potential barriers and facilitators to a larger-scale survey

Figure 3-1 Structure of the research

3.3 Philosophical assumptions

3.3.1 Pragmatism

This research project is based on a pragmatist worldview that is defined as *"a set of ideas that include employing what works using diverse approaches and valuing both subjective and objective knowledge"* (Creswell and Clark, 2017, p. 39). Worldviews are the philosophical ideas that direct the research, both the design of the research and associated procedures of data collection and analysis. There are four worldviews used widely in the literature: post-positivism, constructivism, transformative, and pragmatism (Creswell and Clark, 2017). The postpositivist worldview represents the assumptions that knowledge is out there in the world and needs to be investigated objectively. The constructivist worldview is based on the assumption that knowledge is subjective and needs to be interpreted from the perspective of people. The transformative worldview is based on the need to interlink research inquiry with social justice and human rights and focuses on specific communities or individuals to address issues like marginalization and empowerment. Transformative research aims to make changes by reforming the societies in which individuals live (Tashakkori and Teddlie, 2010).
Lastly, the pragmatism worldview, which is often adopted in mixed methods research, is based on four main principles:

1 Consequences of actions. This approach values actions rather than theorising (Robson, 2011) and offers a justification for the need to mix quantitative and qualitative data to achieve the desired outcomes (Creswell and Clark, 2017).

2 Problem-centred. A pragmatic approach does not dictate which method should be used as long as it is the best method to answer the researcher's question, which requires a sufficient understanding for the qualitative and quantitative methods to choose what is applicable for the study (Feilzer, 2010).

3 Pluralistic. This approach is considered an overarching philosophy because it sits at the middle of the ontological and epistemological stances. It values the existing reality or facts as well as personal values (ontological stance) and affirms that knowledge can be based on the reality and constructed from subjective views (epistemological stance) (Robson, 2011). This approach considers 'the truth' of a phenomenon as a mix of subjective and objective

elements; therefore, it requires the researcher to investigate the phenomenon from different perspectives for enriched understanding (Feilzer, 2010).

4 Real-world practice-oriented. The concept of practical implications, is focused on what works best for the specific research problem and the workability of theories is judged by their applicability and predictability (Robson, 2011).

In this study, the pragmatic approach was employed based on the practicality of answering research questions; each participant had a subjective perspective on what is important to be provided for dying children in the last three months of their lives and should inform any evaluation of the quality of care. Participants' perspectives were investigated in-depth during interviews with healthcare professionals and bereaved carers to adapt the VOICES-SF questionnaire in the UK and adapt the VOICES-C in Jordan. Once the questionnaire was adapted for the paediatric population, it was used to garner the accounts of bereaved parents about the quality of end of life care in Jordan. Therefore, following a pragmatic approach to frame the research enabled the use of the most appropriate methods to answer the research questions about what was important to evaluate the quality of paediatric end of life care, and were therefore incorporated in the modification of the VOICES-SF questionnaire.

3.4 Research methodology

3.4.1 Mixed methods

To address the research aim and associated questions, it was clear that using both qualitative and quantitative methods would be necessary. Mixed methods research is based on selecting and integrating quantitative and qualitative methods to gain deeper and broader understanding of the investigated phenomenon (Johnson et al., 2007, Onwuegbuzie et al., 2010, Tashakkori and Teddlie, 2010). The mixed-methods approach was adopted to gain a more comprehensible understanding of the explored phenomena, as well as to measure the quality of end of life care. Using a mixed-methods approach has been recommended for the development of an instrument and to maximise the appropriateness of this instrument (Onwuegbuzie et al., 2010, Creswell and Clark, 2017) and has, therefore, been selected as an appropriate methodology for this study.

Research methods are often divided into three main categories: qualitative, quantitative, and mixed methods. Creswell and Clark (2017) draw our attention to view these approaches as a continuum rather than distinct categories; this continuum has qualitative and quantitative research at the ends with mixed methods in the middle. Qualitative research is an approach aimed to obtain an understanding of peoples' views and opinions related to a phenomenon or problem. This approach involves collecting data from individuals to be analysed inductively; constructing a general meaning or theory of the problem from multiple individual accounts; however, it can be difficult to examine these views on a large scale. While the quantitative research approach aims to examine an assumption and describe the relationships among variables. This approach collects information deductively, typically using a tool, based on a pre-determined assumption. By testing this assumption, the researcher can obtain a general understanding of these relationships; however, the researcher may fail to attain a deeper explanation of these relationships.

Hence, the mixed methods approach combines elements of both the qualitative and quantitative approaches to examine relationships between variables and gain a greater understanding of a phenomenon. This broader understanding is achieved when the strengths of one approach compensate for the shortcomings of the other. Collins et al. (2006) summarised the purposes for using mixed methods research into four reasons; participant enrichment (e.g. mixing the methods for optimizing the sample), instrument fidelity (e.g. assessing the suitability of an existent tool or developing items for a new tool), treatment integrity (e.g. refine interventions for subsequent stages) and significance enhancement (e.g. clarify the interpretation of qualitative/ quantitative results). Similarly, Johnson et al. (2007) reviewed the definition of mixed methods research in the literature and discussed the elements of these definitions and the purposes for mixing qualitative and quantitative approaches. A mixed methods approach would provide useful research findings with a balance between breadth and depth.

Mixed methods research designs are divided into categories according to the sequence of data collection methods: sequential explanatory; sequential exploratory; convergent parallel; embedded; and multiphase mixed methods (Robson, 2011, Creswell and Clark, 2017). The differences pertaining to the three designs are presented in Table 3-1 below.

Table 3-1 Differences among qualitative, mixed and quantitative methods

Parameters	Quantitative Methods	Mixed Methods	Qualitative Methods
Inquiry	Pre-determined	Both predetermined and emerging methods	Emerging methods
Methods of data collection	Instrument-based questions	Both open- and closed-ended questions	Open-ended questions
The nature of collected data	Performance data, attitude data, observational data, and census data	Multiple forms of data drawing on all possibilities	Interview data, observation data, document data, and audio-visual data
Methods of data analysis	Statistical analysis	Statistical and text analysis	Text and image analysis
The nature of analysis outcome	Statistical interpretation	Across databases interpretation	Themes, patterns interpretation

The mixed methods approach used for this research project followed a sequential exploratory design, which involved conducting two consecutive phases. Firstly, a qualitative analysis was used to ensure the adapted questionnaire captured the relevant elements of quality end of life care from the perspectives of bereaved carers and relevant healthcare professionals. This was used to adapt the questionnaire for the paediatric population (Phase I), and to adapt the paediatric questionnaire for the Jordanian context (phases II). The second phase involved a quantitative analysis of the collected data regarding quality of end of life care using the adapted questionnaire and feasibility issues such as response rate, completion rate and length of interviews (phase III). The sequential exploratory design was chosen because the VOICES-SF survey focuses on bereaved carers' subjective perceptions about the quality of care and this design enabled the researcher to explore the field of paediatric end of life care from bereaved parents' perspectives before investigating their views through survey methods in Jordan.

3.5 Summary of three phases

By adopting a pragmatic approach, the researcher considered an exploratory mixed methods design for this research project. Engaging and working with services users throughout research design and quality improvement was threaded through the first two phases. In phase I, bereaved carers were involved in determining the elements and, consequently, the questionnaire items to evaluate end of life care. Phase I entailed identifying elements of paediatric end of life care from the literature, and collecting and analysing qualitative data to explore bereaved carers' perspectives. The exploratory nature of the first phase enabled the researcher to revise the VOICES-SF questionnaire based on the target population's perspectives. The codes from parents' reports were structured into items or variables in the questionnaire and validated to ensure that the questionnaire was suitable to be used for bereaved carers. The findings from this phase resulted in an English version of the VOICES-C questionnaire. In phase II bereaved carers in Jordan were involved in refining the questionnaire and protocols for conducting the feasibility study. This entailed adapting the VOICES-C English version into an Arabic version according to Jordanian bereaved parents' and healthcare professionals' opinions. Phase III included collecting and analysing data from a sample of bereaved parents in Jordan to determine the quality of end of life care, as well as the feasibility of a telephone-administered survey approach to completing the questionnaire.

3.6 Ethical considerations

Ethical concerns are a crucial aspect that must be considered when conducting research with humans and in particular, in research with bereaved carers these concerns are absolutely paramount (Friedel et al., 2018a). A robust research plan includes identifying the potential risks and burdens imposed by participation in a study in order to develop a mitigation strategy in advance. End of life care or bereavement research is a sensitive and emotive topic, and the patients or proxies are vulnerable to experience stress caused by their participation. The Royal College of Paediatrics and Child Health published guidelines for the ethical conduct of medical research involving children (RCPCH, 2000). Due to their unique needs, it is necessary for medical research involving children to be conducted to promote the child's wellbeing and health. Nevertheless, children are a vulnerable population that require additional attention because they lack the legal voice of adults (NHPCO, 2009). Their vulnerability is further intensified when they are receiving palliative care. Vulnerability means the participants within a study have difficulties in providing informed consent and need additional protection for their interests (Addington-Hall et al., 2007). This vulnerability arises from the physical, psychological and social distress experienced by the patients, and the sensitive nature of that specific time, because in most cases, the patients are dying or had died. Indeed, conducting any research involving human participants has specific standard principles; beneficence, non-maleficence, obtaining informed consent, anonymity, confidentiality, security of data and the right to withdraw at any time. These ethical principles were considered throughout this research project and are discussed in detail in the subsequent.

3.6.1 Beneficence and non-maleficence

This principle entails maximising possible benefits for the participant, protecting participants from potential harm and deciding when the benefits should be foregone because of the harms (Singer and Bossarte, 2006). Certain studies do not have a direct benefit to the participants; however, this is not necessarily unethical. For example, questionnaires and observation studies do not have benefits like treatment or intervention studies (Groves et al., 2009). The researcher should estimate the benefits and risks associated with conducting the research. The potential benefits should be assessed by reviewing those that will benefit from the research and how. The risks are ranged from minimal risks i.e. discomfort resulting from questioning and observing to high risks caused by invasive procedures (RCPCH, 2000).

In this study, it was anticipated that there will be some risk to the participants due to the nature of the questionnaire, which asks participants to recall a sad and distressing period of time. It was hoped, however, that this risk would be slightly minimised due to subsequent time that had passed between their experiences of palliative care and completing the questionnaire survey; hence, carers were not expected or requested to complete the survey immediately following the loss of a child. In addition, during the interviews, the researcher ensured there was someone with participants or who they could call on if they felt distressed by the interview. Also, some participants may have found the process cathartic and helpful, as talking about their experience could help them to express and release their emotions regarding their opinions, views and perceptions of the care that they received (Baddeley and Singer, 2008). It was also hoped that understanding the implications of the wider benefits of potential improvements in palliative and end of life care for other patients in the future would provide encouragement and incentive to take part (Wohleber et al., 2012, Kentish-Barnes et al., 2015). Moreover, if any participants found the process emotionally distressing, they would be offered follow-up support with paediatric hospices and the researcher.

3.6.2 Informed consent

An information sheet and consent form were distributed to the participants to introduce the study and to obtain their agreement to participate. The forms included information about the research, expectations regarding the participants' contributions and explaining the process of assured anonymity and confidentiality (i.e., how participants' identities would be kept private meaning that a participant would never be traceable from the reported and presented data). The participants were informed that they had the right to withdraw from the research at any time and without providing any reasons. Bereaved carers that consent to participate in the study were also be offered follow-up support, especially if they experienced any emotional distress because of the study procedure or if they chose to stop participating in the study for the same reason.

3.6.3 Confidentiality

It is the researcher's responsibility to protect the personal data of subjects participating in the research. Any identifiable information obtained from study participants were treated as highly confidential and protected by deleting any identifiers and assigning an ID number to each participant in the study. This number referred to the study participant and were kept securely on a password encrypted excel spreadsheet stored in the university repository with limited access to the data. In written documents and reports, participants were referred to by their ID number and not using personally identifiable information, according to the University of Southampton Data management policy.

3.6.4 Anonymity

All names were anonymised using numbers or pseudonyms throughout the study and write-up. The researcher produced a document with the personal identifiers, such as child's name and age, and linked ID number. All data were double entered into a password-protected computer database in accordance with the previously assigned participant information number.

Personal identifiable information, which is anticipated to be revealed during the interviews, such as professional roles, names and places, were replaced with fictional substitutes in the transcription and any quotations, in order to decrease the risk of the data being tracked back to a particular participant. All possible considerations were taken to conceal participants' identities so that a reader of the report would be unable to identify the participants in this research project. Participants were ensured of anonymity, unless there is evidence that a parent or staff member is at risk of danger, due to malpractice.

3.6.5 Data storage and management

This section outlines how this research study complied with the University of Southampton data protection policy, including the handling, storing and retention of data. Data was handled in line with the University of Southampton Data Protection Regulation (2018-2019).

A data management plan has been made in accordance with guidelines produced by the University of Southampton. The university recognises the significance of proper management research data; therefore, iSolutions provide services to secure active research data. All digital data were stored securely in a durable appropriate format, stored with adequate metadata and/ or documentation to facilitate identification and support the effective reuse of data, backed up regularly according to the progress of the research project. All digital files were uploaded to a password-protected computer and files deleted following the guidance of the University Of Southampton. Non-digital research data was stored securely in a locked cabinet at the University Of Southampton, labelled and categorised by the researcher to facilitate effective access of research data when needed and destroyed according to the data management policy (The University of Southampton, 2018a, The University of Southampton, 2018b). According to the University of Southampton policies, research data can be retained for longer than ten years.

3.6.6 Conducting research with bereaved parents

Research for children and young people who are receiving palliative or end of life care has become a priority (Baker et al., 2015). However, conducting such research has its difficulties, which have been reported in paediatric participants and attributed to the research's sensitivity, given that the studied population is severely ill or dying children, as well as additional difficulties when the research is conducted after the child's death. Tomlinson et al. (2007) reviewed the literature and addressed the ethical and recruiting challenges to research in palliative or end of life care for children and young people (Tomlinson et al., 2007). The authors concluded the challenges could be divided into two main groups: ethical and practical challenges. The ethical concerns are mainly emphasised prior to conducting the research when applying for ethical approval and permission, in order to protect the participants. These concerns arise from the vulnerability of the population and potential that an undue burden on them would contradict the principles of non-maleficence and beneficence in research. However, disregarding this population from participating in research would hinder a clear understanding of the quality of care directly from the targeted population/stakeholders. In addition, a previous study by Alexander (2010) has shown that bereaved participants reported their participation as being a positive experience since it may enable them to help future patients/ children by determining the best care practices and improve the overall care ultimately. Bereaved parents denied experiencing negative effects due to participating in research but rather appreciated their participation, which allowed them to tell their stories and help inform future care services. Researchers have to consider providing support for all participants to avoid any negative impacts on them. This support should be arranged prior to ethical board’s approval. There is also potential that participants might be invited to be involved in multiple studies because healthcare setting often host several ongoing studies investigating different aspects of end of life care. However, no evidence currently exists on the burden experienced by bereaved parents as a result of participating in multiple studies.

Chapter 4. Phase I Methods and findings: Scoping review

Although commonalities exist between the paediatric and adult end of life care, the unique aspects of paediatric end of life care must be considered and accommodated within the VOICES-C questionnaire. This chapter will report the methods and findings from the scoping review that informed the adaptation of VOICES-SF, which was one of the components undertaken during phase I of the study. This chapter includes the review question, search strategy and the eligibility criteria for studies investigating elements of paediatric end of life care. Summaries of the included studies and thematic analysis are presented in tables. The outcomes of the review form the core concepts used to modify the VOICES-SF questionnaire for the paediatric population.

4.1 Introduction

Paediatric palliative care focuses on improving the lives of children with a life-limiting condition and their family. This complex care impacts the whole family unit and disrupts family dynamics and usual family roles (Kars et al., 2011). In a previous study Mack et al. (2005) aimed to identify and compare how parents and physicians' rate paediatric end of life care. The authors found that although parents and physicians value the same components in care, they have different perspectives on which components associate high-quality end of life care. The parents valued effective communications over managing pain, unlike the physicians who considered pain management as a crucial attribute of high-quality end of life care. Therefore, it is important to consider and include parents' points of view regarding the components of quality end of life care when evaluating the services provided for the children and family.

An initial literature search, prior to the review search, identified three reviews that addressed parents' experiences of paediatric palliative care (Aschenbrenner et al., 2012, Melin-Johansson et al., 2014, Virdun et al., 2015). Although these reviews were conducted at approximately the same time and the aims were broadly similar; which involved exploring the parents' experiences (Aschenbrenner et al., 2012, Melin-Johansson et al., 2014) and the elements of optimal paediatric end of life care (Virdun et al., 2015), the studies included in each review were different. In addition, there were several limitations with each of the three reviews; this can be attributed to discrepancies within the search strategies and inclusion criteria applied by the authors to obtain papers for analysis. In terms of search strategy, Melin-Johansson et al.

(2014) and Virdun et al. (2015) provided sensible search term combinations and clear flow diagrams for the retrieved papers through the sampling process. This contrasted with the Aschenbrenner et al. (2012) review, which lacked a clear description of the retrieved studies and specific inclusion/exclusion criteria for the papers. The authors claimed only that *"the inclusion criteria were expanded to include research studies about parent or family perspectives on end of life care in general"* (Aschenbrenner et al., 2012 p. 516).

Melin-Johansson et al. (2014) reviewed nine papers focusing on the parents' experiences of the child's care. Similarly, Aschenbrenner et al. (2012) focused on investigating the parents' experiences of the child's end of life care, after the expansion of the inclusion criteria due to the limited number of the retrieved papers from the original criteria. Virdun et al. (2015) were interested in the models of paediatric palliative care delivery, and therefore used different criteria to include papers. All things considered, (Aschenbrenner et al., 2012) and Melin-Johansson et al. (2014) shared only three papers between them, while Virdun et al. (2015) included only seven papers, none of which were identified by the other reviews. Regarding assessing the quality of the final papers, the Aschenbrenner et al. (2012) review did not address the quality of the reviewed papers, whereas Virdun et al. (2015) and Melin-Johansson et al. (2014) assessed the quality of included papers using a specific tool or framework.

To conclude, the existing reviews of parental perceptions about what is important in paediatric end of life care are currently lacking and deficient, and were insufficient to inform the adaptation of VOICES-SF. Therefore, a gap existed within the literature and a need for further work to gain more understanding in this area and ensure that no relevant papers examining this topic were missed. Consequently, the subsequent section presents a scoping review of the literature, which was used to provide an insight into the important themes or domains of paediatric palliative care that would be used to inform the adaptation of the VOICES-SF questionnaire.

4.2 Aim and objectives

This review aimed to identify and synthesise the available evidence exploring the meaning of quality of paediatric palliative care. The specific objectives were 1) to identify important components of quality paediatric palliative care from bereaved parents' perspectives and 2) to formulate a draft of the crucial themes of what constitutes quality paediatric palliative care. The review question was 'what is quality paediatric palliative care according to bereaved parents' views?' For the purpose of this review, the term 'child' refers to any person under the age of eighteen receiving care in different facilities, including but not limited to home, hospitals and hospices. Paediatric palliative care or end of life care terms were used interchangeably, subject to differences within the articles from the literature.

4.3 Methods

This review used a systematised approach to searching, selecting and appraising the relevant evidence concerning carers' views of the important elements of paediatric palliative care.

4.3.1 Search strategy

The previous reviews mentioned above helped identify the relevant search terms used to develop the search strategy. These keywords and appropriate databases were discussed with a University of Southampton librarian. The final search strategy and terms were developed by the researcher and discussed with supervisors (Anne-Sophie Darlington and Katherine Hunt). The next step involved using the agreed keywords across different databases that allowed coverage of a broad scope of sources.

From the review question, according to Population, Exposure, Outcome framework (Bettany-Saltikov and McSherry, 2016), the electronic search terms included keywords and phrases to capture the three elements. Each element had a set of related search terms and synonyms applied in the search. The use of the truncation symbol (*) meant that the search included all words with the same root. American spelling 'pediatric' was also considered to avoid missing relevant papers. Table 4-1 presents the keywords used in the search strategy. This literature review was carried out in December 2018 to identify the domains of paediatric end of life care which should be included in the adapted questionnaire. The search criteria were re-run in

August 2021 to identify newly published papers that may provide further information regarding domains of paediatric end of life care. The search did not yield additional relevant papers.

Terms within each element were combined with the Boolean operator ‘Or’. This yielded to the papers that had at least one word from each element. The search results for each element were then combined with the Boolean search ‘And’ to obtain papers that contained terms from all three elements (see Table 4-2). A detailed search term strategy for CINAHL is shown in Appendix B. Five electronic databases; AMED, CINAHL, MEDLINE, PsycINFO and PsychARTICLES, were selected to search for the literature. The retrieved articles from each database were entered into a specific folder representing each database in Endnote X8 software. This software enabled the researcher to remove duplicates from various databases and organise the articles for further screening.

Table 4-1 Keywords used in the search strategy

Population	Exposure	Outcome
Pediatric	Palliative	Perceptions
Paediatric	‘End of life’	Views
Adolescent	Hospice	Experiences
Child*	Terminal	Needs
		Satisfaction
		Quality of care

Table 4-2 Search strategy

Search strategy		
Population	S1	Pediatric
Identify the research focusing on children and young people	S2	Paediatric
	S3	Adolescent
	S4	Child*
	S5	(S1 OR S2 OR S3 OR S4)
Exposure	S6	Palliative
Identify healthcare services related to end of life care	S7	‘End of life’
	S8	Hospice
	S9	Terminal*
	S10	(S6 OR S7 OR S8 OR S9)

Outcome Identify literature exploring the important elements of care	S11	Percep*
	S12	View*
	S13	Experience*
	S14	Need*
	S15	Satisfact*
	S16	quality of care
	S17 (S11 OR S12 OR S13 OR S14 OR S15)	
	S18	**(S5 AND S10 AND S17)**

4.3.2 Study selection

Inclusion criteria included papers and articles that 1) focused on the views of carers regarding their care, 2) aimed to explore the crucial elements of quality palliative care for children and young people, 3) focused on the end of life or palliative care 4) included qualitative, quantitative or mixed methods studies with open-ended questions eliciting the participants' accounts relating to the main topic areas.

Exclusion criteria were, papers that 1) evaluated the carers' views about the quality of care, 2) focused on the healthcare professionals' accounts about the quality of care, 3) did not focus on care provided at the end of life, 4) involved case studies or non-empirical studies, 5) were not fully accessible and where the full text was not available. The rationale for inclusion criteria is presented in Table 4-3.

Table 4-3 Inclusion/ exclusion criteria

Inclusion criteria	Rationale
Full-text English language papers	The researcher speaks English
The patients are under eighteen years old and have life-limiting conditions	The research focuses on the quality of paediatric palliative care provided
Studies must have a descriptive element regarding what is important in paediatric palliative care	The researcher is interested in what is reported as quality paediatric palliative care not measuring the quality
Primary informal carers i.e., parents	The study is focusing on bereaved parents' views, not healthcare professionals.

4.3.3 Data extraction and analysis

Data were extracted from the final papers and tabulated to highlight the relevant information that would answer the review question i.e. author and date, the aim of the study, the methods used to collect data, the characteristics of the participants, and each study's limitations. This template was recommended by Noyes and Lewin (2011) to be applied as a standardised approach for extracting data (Appendix C).

Quality assessment

An essential step in developing a comprehensive review of the literature was appraising the individual papers using a specific framework to assess the quality of the paper. The chosen framework for assessing the quality of the included papers was that proposed by Caldwell et al. (2011). This framework or checklist consists of eighteen items that question the methodological rigour of a paper from the abstract to the conclusion. This framework was chosen because it enabled the researcher to evaluate both qualitative and quantitative studies using the same criteria with segregated sections for qualitative and quantitative studies and maintain uniformity while comparing and reporting the quality of reviewed studies. This framework has been utilised in similar preceding research (Hobbs, 2015, Twycross et al., 2015, Coombs et al., 2017). Figure 4-1 presents Caldwell's framework for critiquing health research. The reviewer assigned a numerical value for the eighteen items in Caldwell's framework (Yes= 2, Not clear= 1, No= 0), with a maximum potential score of thirty-six. Bettany- Saltikov and McSherry (2016, p. 163) suggested the setting of a cut-off point if the researcher intended to include only good quality papers in a review. Although the authors of the framework did not identify specific ranges for high, moderate and poor-quality papers, in this review, the researcher rated very good quality papers as those scored between 27-36, moderate papers those rated 18-26 and poor studies those that scored below 18.

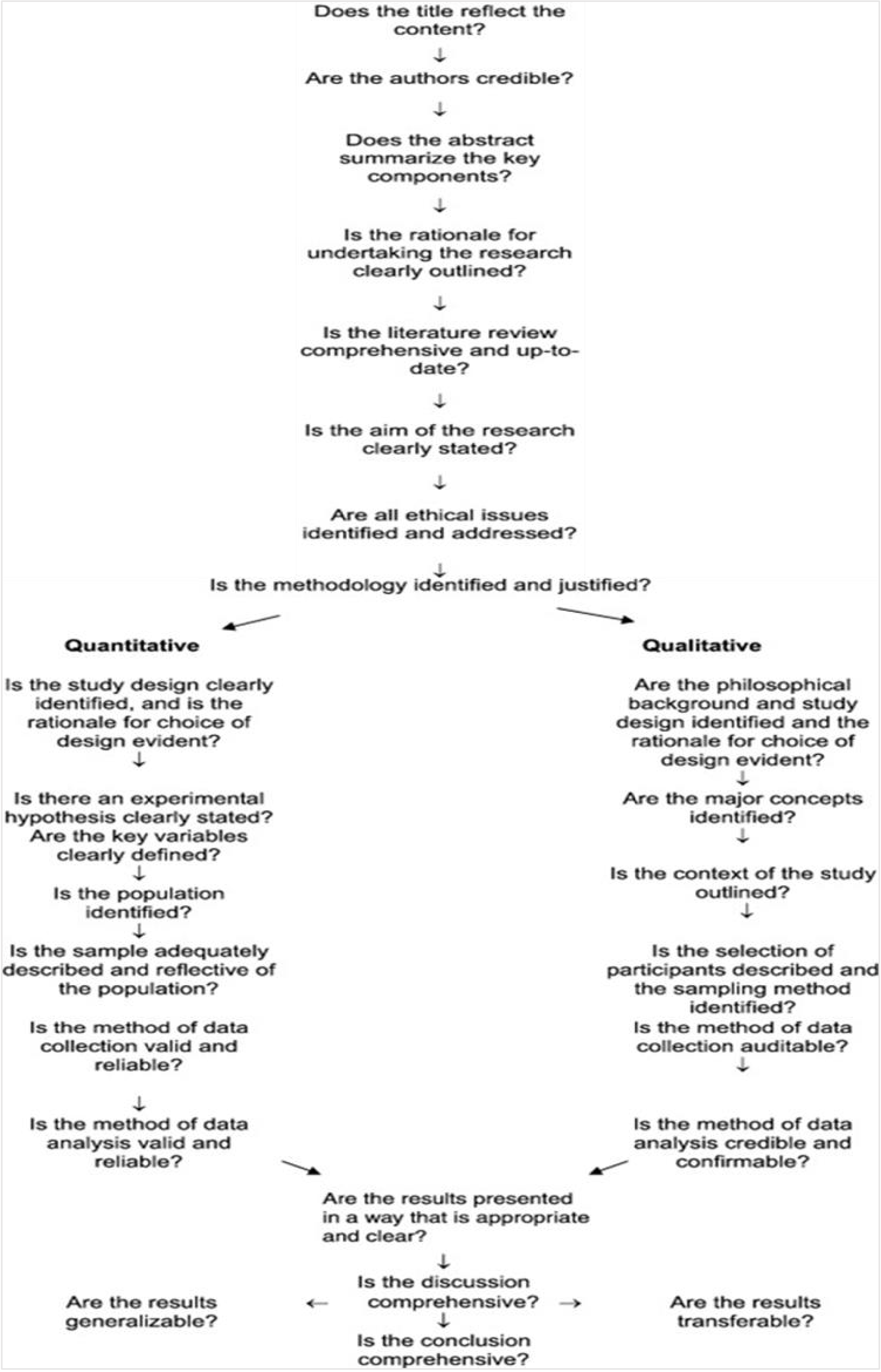


Figure 4-1 Framework for critiquing health research adapted from Caldwell et al. (2011)

4.3.4 Data synthesis

The research papers were then analysed qualitatively for common themes and sub-themes using an inductive thematic analysis approach (Braun and Clarke, 2006). Thematic analysis is a foundational approach for qualitative analysis to identify and report patterns within data. It involves moving back and forward constantly between the entire data and the identified themes to ensure appropriate themes and relevant extracts are strongly linked to data. Included papers were uploaded into NVivo software. This software enabled the researcher to highlight relevant sections from the text and combine them into groups that formed bigger themes or domains. Themes from the findings of each study were combined using an inductive process of reading and re-reading the data and extracted segments.

Firstly, the researcher read the full text of the papers once and wrote down notes for the potential themes expressing the quality of paediatric palliative care. During this step, the researcher identified the possible patterns before starting coding. Secondly, the initial codes were identified by highlighting the segments of text and assigning a meaningful code expressing what is important in paediatric palliative care. Once all papers were coded the next step began. Thirdly, the coded extracts were reviewed to combine similar codes into an overarching theme. At this step, the researcher revised the relationship between codes, themes and levels of themes. Some codes were joined into themes or sub-themes. This step ended with initial themes and subthemes for the next step. Fourthly, the resulted themes and subthemes were revised and refined to ascertain whether the themes matched the data extractions. In addition, some candidate themes became sub-themes of others, for example, in this review, the ‘continuity’ of care theme became a sub-theme under ‘access to care’. The next step involved defining the essence of the themes and determining what aspects of care were captured by each theme. Finally, a map of the recurrent themes of optimal paediatric palliative care was tabulated describing the themes, sub-themes and the studies in which the themes were identified.

4.4 Findings

4.4.1 Search results

The search applied broad keywords with minimal limitations, such as child’s group age or certain illness, to obtain the relevant studies and avoid missing studies that may be useful. In addition, the critical appraisal framework aimed to evaluate the quality of care for different conditions and was not limited to a specific condition. This review complied with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Tricco et al., 2018). The initial results of databases search and numbers of records are presented in Table 4-4.

Table 4-4 The retrieved papers from databases

Database	**Number of retrieved papers after removing duplications / the number of hits for each database**	**Applied limits**
AMED	135/352	Journal articles
CINHAL	747/1657	
PsycARTICLES	41/128	English language papers
PsycINFO	1494/4685	
Medline	2545/5966	No date limits restrictions were applied
Total	4962/ 12788	The search was conducted June 2018

As demonstrated in Figure 4-2, the PRISMA (2009) flow diagram shows the study selection process. The applied limits for the search of databases were peer-reviewed papers in the English language and not restricted to certain publication date range. In total, 12788 records were retrieved using the original inclusion/exclusion criteria (Table 4-4 The retrieved papers from databasesTable 4-4) from searching the databases and were entered into EndNote X8 software to eliminate the duplicate records from different databases, then records were examined to identify those that meet the inclusion criteria in a two-step process to ensure that the literature reviewed was as specific as possible.

Next, the initial records (4962 papers) were screened by reading the titles and the abstracts to review all the possibilities using more stringent inclusion/exclusion criteria, listed in Table 4-3.

During this screening process, it was found necessary to exclude further papers based on additional criteria; for example, some studies were found to have older participants. Also, some studies were excluded because they explored bereaved children or adolescents' views regarding the loss of a parent or if it included only physicians' perspectives. In addition, papers involving pharmacological, non-pharmacological interventions, models of care, evaluating services, treatment and training programmes or exploring parents' experiences about the end of life care for children who died intentionally (adolescent suicide) or accidentally were all excluded. This resulted in a total of 42 potentially eligible papers.

The second step involved examining the full text of the forty-two papers to ensure that the included papers specifically examined what is considered as quality paediatric palliative or end of life care. For this step, only papers that reported what is considered or the elements of optimal paediatric palliative care were included. A total of twenty papers met this inclusion criterion and subsequently, thematic analysis was conducted on these remaining papers.

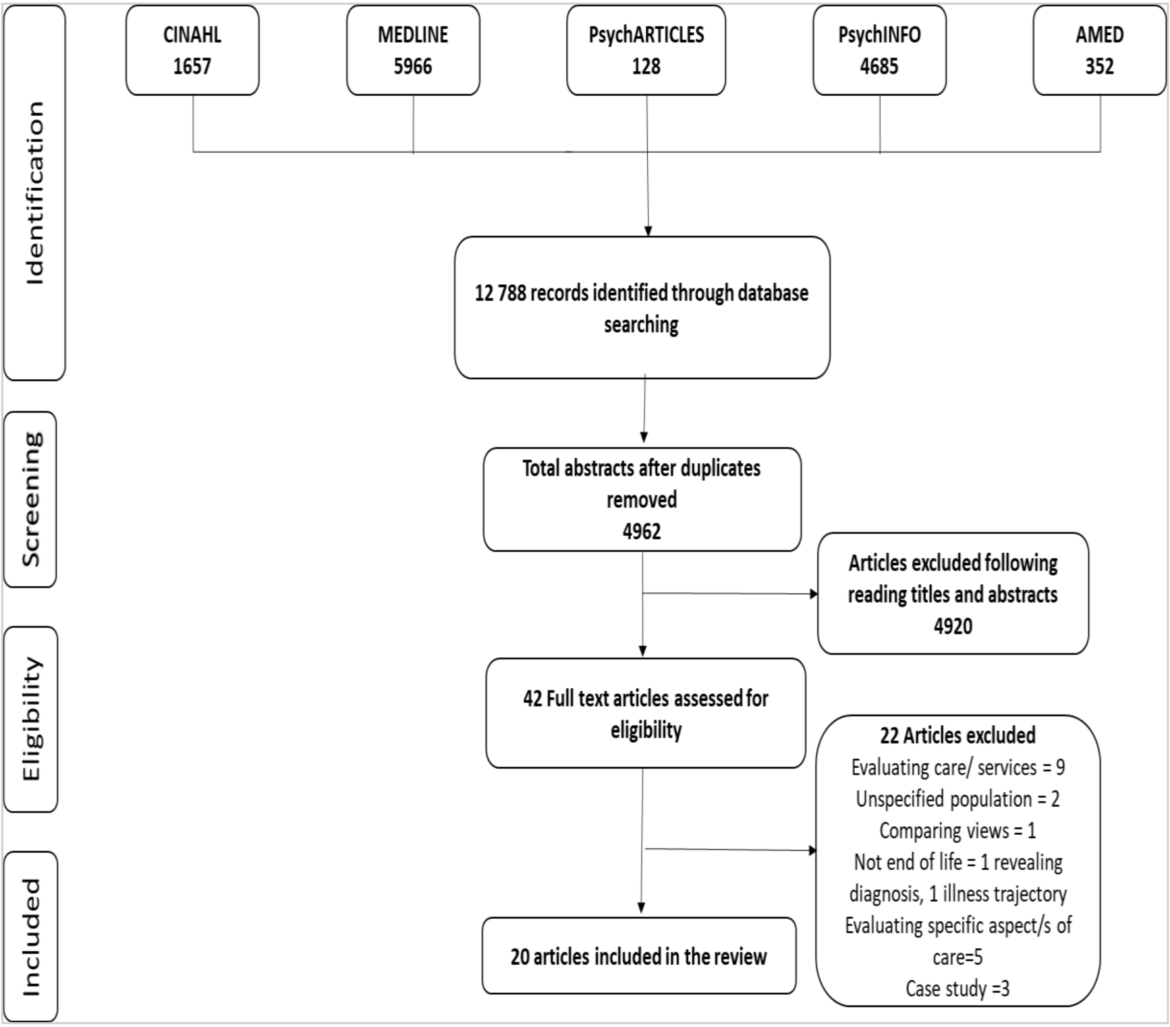


Figure 4-2 PRISMA 2009 flow diagram showing study selection

4.4.2 Summary of included studies

Twenty research papers that explored bereaved parents' experiences of palliative care when their child was dying met the above criteria and were included in this review. The previous reviews (Aschenbrenner et al., 2012, Melin-Johansson et al., 2014, Virdun et al., 2015) included a total of twenty-eight papers, sixteen of which were included in this review. None of the papers reviewed by Virdun et al. (2015) were included in this review because they discussed models of care delivery and this conflicted with the aim of this review.

On the other hand, the following studies that were included in the former reviews (Aschenbrenner et al., 2012, Melin-Johansson et al., 2014) were excluded from this review; Dighe et al. (2008) study was excluded because the authors focused on the parents' concerns and attitudes regarding revealing the child's diagnosis. Additionally, Cherlin et al. (2004) sought to address what family caregivers consider as outstanding practices, however, the population was the carers of terminally ill patients. Three narratives of a single carer's experiences were excluded (Berg, 2006, Dokken, 2006, Macdonald et al., 2008). The last excluded paper was a prospective study conducted by Sharman et al. (2005) to identify the factors affecting parental decision to withdraw life support.

All twenty studies were retrospective studies, of those twenty studies 50% (n=10) were conducted in USA, 20% (n=4) in Australia, 10% (n=2) in Canada, 5% (n=1) in the UK, 5% (n=1) in Switzerland, 5% (n=1) in Brazil and 5% (n=1) in Malaysia. Among all studies, thirteen studies used interviews (James and Johnson, 1997, Contro et al., 2002, Heller and Solomon, 2005, Maynard et al., 2005, Monterosso and Kristjanson, 2008, Widger and Picot, 2008, Meert et al., 2009, Inglin et al., 2011, Weidner et al., 2011, Robert et al., 2012, Brooten et al., 2013, El Halal et al., 2013, Lan and Yun, 2015), four used questionnaires (Davies and Connaughty, 2002, Meyer et al., 2002, Meyer et al., 2006, Monterosso et al., 2009), and three used (Seecharan et al., 2004, Monterosso et al., 2007, Heath et al., 2009). All studies but five (Meyer et al., 2002, Seecharan et al., 2004, Widger and Picot, 2008, Heath et al., 2009, Monterosso et al., 2009) used a qualitative design to investigate carers' experiences while their child was approaching death. The participants were mainly the parents of children who represented different populations; cancer patients, Paediatric Intensive Care Unit (PICU) patients, or recipients of hospice care. The included studies covered the observational period from 1997 to 2015, a time frame of 18 years. Appendix D shows the detailed extracted data for each paper.

Each paper was assessed using the Caldwell et al. (2011) framework and given a score based on the items of the framework. An example of quality assessment for one paper is presented in **Error! Reference source not found.**. Although the majority of reviewed papers were very good quality (17 papers), the results of all papers lacked transferability (qualitative studies) or generalisability (quantitative studies), mainly due to selection bias. For example, the participants were selected from one centre or one hospital, as in Contro et al. (2002), Widger and Picot (2008), Heath et al. (2009), Weidner et al. (2011), Lan and Yun (2015), or staff members were engaged in proposing eligible participants, as in James and Johnson (1997) which acknowledged physicians identified the families that should not be contacted due to their psychological wellbeing or limited diversity. Under-representation of specific groups was a limitation across papers which could result in a source of bias because the majority of the participants represented a particular group of characteristics or particular ethnic background i.e. fathers and non-English speakers (Widger and Picot, 2008, Inglin et al., 2011). Moreover, Meyer et al. (2006) stated that one of their study limitations was that the sample predominantly consisted of white, English-speaking parents (Meyer et al., 2006). Recall bias has been suggested as the main limitation of retrospective studies and this was acknowledged in most of the studies, especially if the elapsed time between the child's death and participation was more than twelve months (James and Johnson, 1997, Contro et al., 2002, Heath et al., 2009, Meert et al., 2009, Weidner et al., 2011, Robert et al., 2012, Lan and Yun, 2015). A map of the resulting themes, associated with the frequencies in good quality papers, was created reflecting the weight of themes within literature and was used later within the survey development process (**Error! Reference source not found.**).

4.4.3 A map of themes to emerge from the literature

A wide range of aspects from the reviewed papers have been reported by carers concerning their child's end of life care and these aspects share many similarities with the main domains of Aschenbrenner et al. (2012) and Melin-Johansson et al. (2014). The essential domains of paediatric palliative care are presented in Figure 4-3, while Appendix G presents the themes and subthemes generated from the reviewed papers.

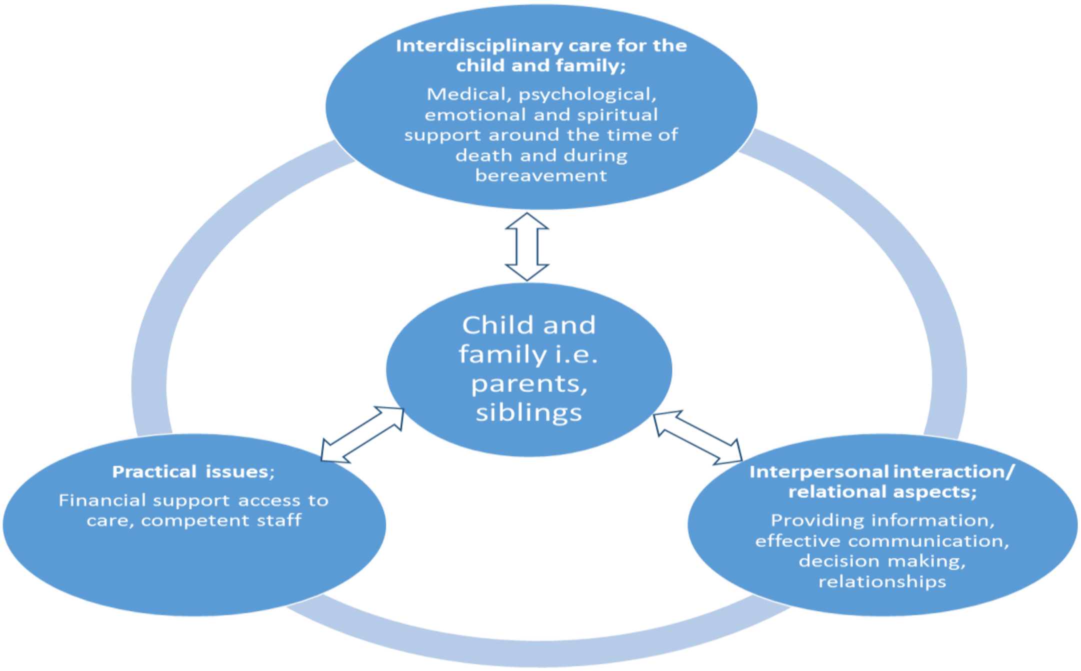


Figure 4-3 The essential themes of paediatric palliative care

From the reviewed papers, the essential domains of care were categorised into three main themes, namely: interpersonal interaction, interdisciplinary care for the child and family members and practical issues. Within the three main themes, a number of sub-themes were identified. The details of each theme and sub-themes are discussed below.

4.4.3.1 Interpersonal Interaction

The first theme of quality paediatric palliative care from the parental perspective is interpersonal interaction. This theme describes the means and characteristics of the interaction among the child, family and healthcare professionals that they felt affected the provision of optimal care. This theme encompasses sub-themes, including information, communication, decision making and relationships.

4.4.3.1.1 Information

The most frequent sub-theme reported in most of the studies relates to **information**. This sub-theme includes providing consistent truthful information about the child's condition or plans for care (Contro et al., 2002, Davies and Connaughty, 2002). For example, the parents from Contro et al. (2002 p.15) valued honesty shown by healthcare professionals regarding the child's condition

> *"And they were honest about not knowing how it was going to go, but they would do everything they could to keep her within the comfort zone. That was so important to me. And the fact that they acknowledged that this is a situation that is not going to have a good outcome."*

A mother in Inglin et al. (2011 p.1034) study expressed her satisfaction with being provided with the information that she felt was important to ask about and she appreciated the opportunity to ask further questions, stating:

> *"My physician didn't embellish anything; he was honest about not being able to make a precise prognosis. I could ask all questions, they were answered by him. I asked how my daughter would die, and he told me that she would become more and more tired and fall 'asleep'".*

Other facets relating to the sub-theme of information were centred around the importance of being informed regarding possible options (Meyer et al., 2002, Heller and Solomon, 2005), being kept up to date about the specialised services (Maynard et al., 2005, Robert et al., 2012) and fundraising events (Maynard et al., 2005), and being told whom was available to talk with carers (Meyer et al., 2002). An example of being aware of the available services was highlighted when *"one mother reported that they had been using in-house care for a year before she realized that they could have supportive care from a family support practitioner."* (Maynard et al., 2005 p.626).

Furthermore, parents from different studies demonstrated an appreciation of some activities to improve information delivery; for example, parents recommended that staff frequently assessed the parents' needs for information and provided information accordingly (Davies and Connaughty, 2002) and kept a hospice diary to record information about the child while the parents were not with him, they appreciated being kept informed about important information, and which was described by one parent as *"A record of the little things you forget."* (Maynard et al., 2005 p.627).

4.4.3.1.2 Communication

The sub-theme of **communication** was reported within the majority of the studies and it entails sensitive interaction especially when delivering bad news (Contro et al., 2002, Meyer et al., 2006, Monterosso and Kristjanson, 2008, Widger and Picot, 2008, Heath et al., 2009, Meert et al., 2009, Inglin et al., 2011, Weidner et al., 2011, El Halal et al., 2013, Lan and Yun, 2015). A few studies highlighted that carers reported conflicts with staff members because healthcare professionals insisted on following standard procedures and imposed care options, instead of discussing the available options and listening to the parents' preferences, as shown in one comment:

> *"He wanted to trach her and I refused to trach her. I told him you prove to me why she needs to be trached and I will [allow you to] trach her, but if you cannot prove to me that she needs to be trached, then she won't be trached."* (Brooten et al., 2013 p.7)

Studies that were conducted in communities with a diverse population with different languages, like the USA, concluded that poor communication was frequently associated with the language barrier (Contro et al., 2002, Weidner et al., 2011), specifically when it came to informing parents that their child is dying (Brooten et al., 2013). Contro et al. (2002) claimed that language barriers compromised the carers' understanding of the child's condition and prognosis yielding to poor parental involvement in the decision-making process. This assumption seems to be applicable since the study was conducted in California, USA and the participants were English and Spanish speaking family members (Contro et al., 2002 p.17). One participant explained,

> *"No one ever told me the baby could die. I never understood what was happening medically. The doctor came out during the operation and asked my wife if they should stop or continue the operation. I didn't understand that the baby would die either way at that point. No interpreter came during this conversation".*

4.4.3.1.4 Decision-making

Another sub-theme that emerged from the studies related to the importance of **decision-making**. The studies concluded that bereaved parents perceive themselves as the child's advocate as a part of the child-parent relationship and they appreciate being actively involved in the decision-making process regarding the child's care (James and Johnson, 1997, Contro et al., 2002, Meyer et al., 2002, Meyer et al., 2006, Heath et al., 2009, Inglin et al., 2011, Brooten et al., 2013). This was explained in a number of parents' comment, *"L. had a preference of who she liked and who she didn't ... when she requested a nurse in the last little while, she got the nurse she wanted all the time."* (James and Johnson, 1997 p.89) and,

> *"We would have a meeting with the doctors, nurses, everybody.—They would tell us exactly how they were gonna do this, why they were gonna do this, [and we were asked] do you approve—do you want to do something different?"* (Brooten et al., 2013 p.7)

In other studies, parents reported their negative experiences about the end of life decisions, with one parent explaining, *"We received the information of what was to be done or what could be done, without deciding"* (El Halal et al., 2013 p.498)

However, it is clear that parents perceive themselves as the voice of their children in this difficult time and wanted to participate to choose what is best for their child. This was highlighted by one parent's statement,

> *"As a mother, I had to fight over and over for my daughter, when nurses took care of her and followed the usual patterns instead of regarding her particular needs. They gave her too much food, and she had a stomachache, but we were told to overlook it for ten days. It is very sad that a mother is not noticed in the hospital, since my daughter cannot express herself."* (Inglin et al., 2011 p.1034)

The bereaved parents established that the most challenging issues concerning decision-making were; redirecting the child to different facilities or services (Weidner et al., 2011), planning the place of death and having an advance care plan for the time of death (Lan and Yun, 2015).

4.4.3.1.5 Relationships

Relationships were highlighted as another important aspect that has been reported frequently in the literature and so formed another sub-theme in this scoping review. Parents frequently expressed the value of trusting bonds with the healthcare professionals (Contro et al., 2002, Robert et al., 2012) who respected the parents' role as providers and knowledgeable experts for their child (Weidner et al., 2011) and being there for the family (Widger and Picot, 2008, Weidner et al., 2011, Heller and Solomon, 2005).

Issues regarding the importance of health care professionals recognising the child as a human being and directly interacting with the child were also raised by parents as significant elements of compassionate care (Weidner et al., 2011, Widger and Picot, 2008, Monterosso and Kristjanson, 2008, Monterosso et al., 2009, James and Johnson, 1997, Heath et al., 2009, Brooten et al., 2013, Meert et al., 2009, Heller and Solomon, 2005). For example, a parent in James and Johnson (1997 p.89) expressed the appreciation of humane interaction; *"The [ill child] really bonded with the nurses a lot and a lot of them were coming over and visiting him…. That was people being people."*

4.4.3.2 Theme 2 - Interdisciplinary care for child and family

The second theme is related to the actual care provided for the child and family members, whether it is physical, psychological, emotional or spiritual. Care at the time of death sometimes referred to the 'quality of death' (Braun et al., 2014), but can also involve other elements. Consequently, a number of sub-themes related to this overarching theme emerged;

4.4.3.2.1 Physical symptoms

Palliative or end of life care is not curative care, but rather it aims to improve the quality of life for the child with a life-limiting condition and their family. This requires managing the **physical symptoms** experienced by the child. These symptoms can include, but are not limited to, pain, fatigue, nausea and vomiting (Kestler and LoBiondo-Wood, 2012, Collins et al., 2000). Pain is the most widely reported physical symptom especially in children with cancer (Kestler and LoBiondo-Wood, 2012) and is frequently associated with poor quality of life (Heath et al., 2009, Wolfe et al., 2000).

Parents often expressed distress at seeing their child in pain (Contro et al., 2002, Meyer et al., 2002, Monterosso and Kristjanson, 2008, Weidner et al., 2011, Widger and Picot, 2008, Seecharan et al., 2004, James and Johnson, 1997). For example, one parent explained:

> *"We told them she didn't do well on morphine. We saw the pain she was in. For 48 hours we kept telling them it wasn't helping. No matter how much morphine they'd give her, she was flopping around on the bed. So we stood there the whole time...she was moaning in pain. [Crying] Those are the images that are the most painful, that she had to suffer. We were helpless. I'm sure they thought what they were doing would work, I'm sure for most kids it works. But for her, it didn't. At that time, we felt we weren't being taken seriously. It's still the image we wake up thinking about."* (Contro et al., 2002 p.17).

Moreover, parents often reported their dissatisfaction regarding pain management during the child's final days (Lan and Yun, 2015, Meyer et al., 2002), for example:

> *"Towards the end, he suffered a lot...It would have been good if during the terminal phase, a team from the hospital could visit us and ease his discomfort and suffering, at least he could have been satisfied during his last moments, seeing he wanted to go to the hospital to have his pain addressed."* (Lan and Yun, 2015 p.297).

4.4.3.2.2 Emotional support

The importance of **emotional support** for the ill child was mentioned conjointly with the physical symptoms' management. It describes the child's and family members' (parents, siblings, grandparents) ability to express and deal with their emotions, particularly, when the child is approaching death, dying and after death (Weidner et al., 2011, Meert et al., 2009, James and Johnson, 1997, Robert et al., 2012, Davies and Connaughty, 2002).

> *"People do sort of disappear when the child's going to die. It's sort of like, they're all gone because they can't cope with it I guess... It's quite devastating and hurtful actually. It's almost like, you almost feel like you've done something wrong or let everybody down...."* (James and Johnson, 1997 p.90).

> *"It's hard for [our daughter] to say goodbye to anybody now... She's better able to talk about him. She used to not be able to."* (Robert et al., 2012 p.28).

Furthermore, parents stressed the importance of providing emotional support for the dying child and enabling them the opportunity to openly talk about death:

> *"Our daughter wanted to talk about [terminal cancer], then didn't.... [Until a doctor asked her], "What are you afraid of?... Dying?... Why?"... That made it easier for her to talk to us, to be in control... She could plan her funeral."* (Robert et al., 2012 p.27).

4.4.3.2.3 Professional psychological support

Despite the fact that parents received emotional support from relatives and friends, the need for **professional psychological support** in times of crisis has been referred to in some studies (Meyer et al., 2002, Inglin et al., 2011, Meert et al., 2009). This support is important to enable the parent/carer to develop and understand the necessary coping mechanisms to deal with different symptoms; such as feeling sad, worried or anxious (Collins et al., 2000, Pritchard et al., 2008). One parent stated:

> *"There was no psychologist contacting me and offering support. That was what I wished to happen—someone from the hospital coming to me and someone available that I could contact later on, who was with us from the beginning."* (Inglin et al., 2011 p.1035).

It is, therefore, necessary to recognise that these feelings are not limited to the child, but rather they are experienced by all family members, so professional psychological support is important for both the child and their family.

4.4.3.2.4 Quality of death

This sub-theme pertains specifically to the parents' reports about the time 'to say goodbye' to the child. Parents reported different elements that contribute to a supportive death, for example, spending more time with the dying child without being rushed (Meyer et al., 2006, Monterosso and Kristjanson, 2008, Davies and Connaughty, 2002, Meert et al., 2009, El Halal et al., 2013). Parents emphasised the importance of providing a private, sacred environment during the last minutes (Meert et al., 2009, Meyer et al., 2006) with one parent saying: *"I asked her* [the nurse], *though she was no longer alive, let me hold her a little bit and stay with her in my lap."* (El Halal et al., 2013 p.499).

> And, *"The nurse who took care of my infant was so kind and compassionate. She stayed in the room with us, but also gave us our space, which was really good. They let us take as much time as we needed to say good-bye."* (Meyer et al., 2006 p.652).

Parents in Widger and Picot (2008) explained the merit of creating monuments (foot or hand-prints) and assist in the bathing or dressing of the child after death as these are the last moments with their child. In another study, logistical issues following a home death were acknowledged by parents (Robert et al., 2012). For example, bereaved father from Lan and Yun (2015) study reported his negative experience following his child's death at home. As home deaths should be reported to the police station, the visiting police officer suspected child abuse because of the purpura on the child's skin and the father had to explain the child's condition.

4.4.3.2.5 Bereavement period

Bereaved parents stressed the importance of continuing care into the **bereavement** period. Parents greatly appreciated receiving follow up calls or letters from the healthcare professionals that cared for the child and knew the family (Contro et al., 2002, Inglin et al., 2011, Weidner et al., 2011, Widger and Picot, 2008, Meert et al., 2009, Davies and Connaughty, 2002, Seecharan et al., 2004, James and Johnson, 1997). Parents also valued healthcare professionals' attendance at the child's funeral, which helped them with their loss (Heller and Solomon, 2005). In a different study, parents expressed their wish to receive anticipatory bereavement support to prepare them to the child's death (Robert et al., 2012).

4.4.3.2.6 Siblings' needs

One of the parental concerns mentioned in the literature was the **siblings' needs.** Although the ill child is the centre of the care, healthcare professionals should respect healthy siblings and anticipate and meet the siblings' needs; for example, allowing healthy siblings access to playrooms during hospital visits (Contro et al., 2002). These needs include the provision of emotional support for the sibling during the ill child's care (Monterosso et al., 2007, Weidner et al., 2011), providing information about the diseases' trajectory and being involved in the ill child's care (Monterosso et al., 2009). One parent stated:

> *"They should be allowed as much time together [with the patient] as possible. Even if they don't show it, it affects them. They should be included in discussions. Staff should pay attention to the siblings, too. Get to know them."* (Contro et al., 2002 p.17).

Another study addressed parents' accounts that supporting siblings should include special consideration with school assignments and absenteeism due to the family's circumstances (James and Johnson, 1997).

4.4.3.2.7 Spiritual support

An issue of concern in the paediatric end of life care is the provision of **spiritual support** for the family. The parents indicated respecting their religious beliefs and traditions as an important element in coping and giving meaning to the situation. The parents highly appreciated counselling from religious personnel during the hospitalizations and after death to perform their rites (Weidner et al., 2011, Meyer et al., 2006, Meyer et al., 2002, Meert et al., 2009). Comments included:
"We have our own coping mechanisms ...I think a person's religion plays a huge role...that is what carried us through, having our faith and our church's support." (Weidner et al., 2011 p.282).

And: *"My faith and trust in God, who was in charge of Jessie. Knowing she would not suffer any more when she went to be home to be with the Lord."* (Meyer et al., 2006 p.652).

4.4.3.3 Theme 3 - Practical Issues

The third theme is the practical concerns of the parents, which may hinder receiving optimal paediatric palliative care. These issues are usually referred to as barriers to the development of paediatric palliative care (Waldman and Wolfe, 2013, Benini et al., 2016, Bradford et al., 2012, Midson and Carter, 2010) and include three sub-themes; access to services, financial issues and competent staff members, which are presented below.

4.4.3.3.1 Access to care service.

Paediatric palliative care is a complex discipline requiring access to different healthcare services. This theme discloses the parental concerns of receiving sustainable care from different disciplines in different settings, in other words, getting the needed care at anytime, anywhere. Parents from several studies reported aspects related to the access to care sub-theme such as inflexibility of the booking system and frequent cancellation of regular hospice stays (Maynard et al., 2005), difficulty of accessing tertiary paediatric centres, especially for patients living in rural areas (Monterosso et al., 2007) or out of hours access to healthcare professionals (Monterosso et al., 2009). These issues were highlighted in the following comments:

"The inflexibility of the booking system was a key area of dissatisfaction. Parents wanted more ability to negotiate when they could access care." (Maynard et al., 2005 p.626).

"Parents in both groups who lived on the outer metropolitan fringes and in rural areas spoke of difficulties accessing the sole tertiary paediatric centre for Western Australia, as well as other specialist services." (Monterosso et al., 2007 p.693).

In addition, coordination of care among interdisciplinary appointments and professionals themselves (Inglin et al., 2011, Monterosso et al., 2007) and having a familiar, consistent caregiver or "key worker" were mentioned as essential components to receive consistent care and was highly valued by parents from different studies (Lan and Yun, 2015, Inglin et al., 2011, Robert et al., 2012, Contro et al., 2002, Heller and Solomon, 2005). For example:

> *"Having one constant person throughout was important. He was honest with us, sometimes he'd say, 'I have no idea,' but then he'd go and talk to someone and get the answer for us. Having one person follow you throughout is probably the biggest sense of relief"* (Contro et al., 2002 p.16).
>
> *"There was the whole care team, physicians, hospitals and home care nurses, psychologist, and a social worker; [...] it was somewhat complicated, because so many people were involved. We coordinated it ourselves. We could reach all these people, because I always asked, "Is there something else that can be done for our daughter?"* (Inglin et al., 2011 p.1034).

The bereaved parents also valued the presence of their child at home at the end of life and this is based on the provision of quality home care services to help parents manage their daily responsibilities (Inglin et al., 2011, Weidner et al., 2011).

> *"There was one number to call when you had problems, and they contacted the person that you needed at that moment...It wasn't like you had 10 numbers...it made it a lot easier for us."* (Weidner et al., 2011 p.282).

4.4.3.3.2 Competent staff

This sub-theme reflects the parents repeated need for paediatric expertise especially in hospices and in-home care services (Brooten et al., 2013, Contro et al., 2002, Robert et al., 2012). This means that healthcare professionals are familiar with the child's condition and needs, confident in providing care and communicating with a dying child.

> *"I couldn't have asked for better.—Those nurses were so good to her.—They took such good care of her. Every time we called, they answered. They didn't get mad that we called so many times.—They understood that we were so far away that we couldn't really get to see her much and they didn't care that we were staying there until like 3 o'clock in the morning.—They didn't let it bother them."* (Brooten et al., 2013 p.6).

> *"I would have liked the same doctor the whole time .... The biggest shock [came when] our doctor said, "I've been here 9 months." That's not what I wanted to hear. I [wanted someone who had] treated thousands."* (Robert et al., 2012 p.324).

4.4.3.3.3 Financial issues

The sub-theme regarding financial issues was raised on some occasions but was found to be the least frequent theme addressed within the reviewed papers. Yet, this theme has been mentioned as a barrier to accessing required services, treatment costs or purchasing devices needed at home because of difficulties in procuring funding and completing forms in order to receive funds (Weidner et al., 2011, Monterosso et al., 2007).

> *"I guess they made you feel that our main concern is our child and being with our child...not coming up with the money for her to be here. The psychologist had contacted*

> *my insurance...she had already filled in my insurance company so I didn't have to reiterate the whole situation and try to figure how things were going to work out.." (Weidner et al., 2011 p.282).*

4.5 Discussion

This review aimed to identify what constitutes the important elements of quality paediatric palliative care as reported by bereaved carers. These elements or themes echoed the core standards of practice (IMPaCCT, 2007, NHPCO, 2009, NICE, 2016, ACT, 2009) and previous studies that measured parents' perspectives regarding the quality of care (Mack et al., 2005, Blazin et al., 2018, Barrera et al., 2013, Wolfe et al., 2000, Xafis et al., 2015, Beccaro et al., 2010, Hechler et al., 2008, Meert et al., 2000). The themes have been divided into three main categories: interpersonal or relational aspects, interdisciplinary care for patients and family and practical aspects.

4.5.1.1 Theme 1 - Interpersonal Interaction

The first theme, and most crucial for parents, is the interpersonal or relational aspects of care. The core of this theme is effective communication which promotes the building of therapeutic relationships between the child, family and healthcare professionals. This finding is in line with the humanistic theory underpinning this research. As highlighted in Franca et al. (2013), communication from nurses can be viewed as a vehicle to establish trust. Recent studies have categorised the primary skills of communication into six categories: Fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions and enabling patient self-management. (Sisk et al., 2018, Blazin et al., 2018, Epstein and Street, 2007). These skills are consistent with the subthemes that emerged during this scoping review of the literature; and involves aspects of care, such as providing information to the patient and family according to their needs, frequent staff assessment in a sensitive manner, evaluating levels of stress for the child and family, showing compassionate communication by involving the child and family in planning the care, and supporting their wishes and decisions. Using medical terminology when communicating with the child and family is another feature of the interactional aspects that may hinder the child's and parents' comprehension and, consequently, restrict their ability to make decisions (Xafis et al., 2015).

Therapeutic communication skills, parents' decision-making and sympathetic relationships have also been found to have a positive impact on the child's and the family's experiences through the end of life care and associated with higher family satisfaction with palliative care (Mack et al., 2005, Ong et al., 2016, Meert et al., 2000, Al-Gharib et al., 2015, Konrad, 2008). On the other hand, the negative impacts of inconsistent information and poor communication have been highlighted in other studies (Homer et al., 1999, Balkin et al., 2015, Kreicbergs et al., 2005). For example, Balkin et al. (2015) argued that poor communication may affect the parents' perception of a child suffering. The authors concluded that parents would report higher levels of child suffering if they were unprepared for their child's death. This can cause the parents to experience long-term distress after the child's death (Kreicbergs et al., 2005, McCarthy et al., 2010) and further emphasises the need for clear, realistic, but also, compassionate communication, which recognises, respects and incorporates the needs of both child and carers. Therefore, the findings of this review clearly demonstrated that communication skills must be applied and evaluated in providing care to achieve high quality end of life care (Blazin et al., 2018, Epstein and Street, 2007).

4.5.1.2 Theme 2 - Interdisciplinary care for child and family

The second theme relates to the actual care provided to the dying child and family. This theme focused on improving the quality of life by providing complex, family-centred care that considers and incorporates the physiological, psychological, emotional and spiritual aspect for the child and family. Commonly reported physical symptoms include pain, shortness of breath, fatigue, nausea and vomiting in both cancer and non-cancer patients (Namisango et al., 2018). Pain is the most reported physical symptom in literature and frequently parents reported 'well managed' pain level for the child (Goldman et al., 2006, Hechler et al., 2008, Von Lutzau et al., 2012, Wolfe et al., 2000).

Psychological symptoms ranged from emotions; sadness, fear and anger, to cognitive and behavioural changes, such as altered consciousness, isolation and disobedience (Namisango et al., 2018); however, it has been argued that psychological symptoms are often neglected and remain untreated (Von Lutzau et al., 2012). The need for anticipatory psychological support for siblings has been frequently emphasised by parents in order to prepare siblings for the child's death and deal with their emotions (Robert et al., 2012). Besides psychological support, spiritual support enables patients and family members to cope with the child’s suffering and imminent loss; however, parents recognised healthcare professionals’ incapability to address and provide the spiritual needs for the patient and family (Feudtner et al., 2003, Liben et al., 2008). This was evident in parents’ preferences to discuss their beliefs with chaplains and spiritual care providers (Arutyunyan et al., 2016). The parental accounts established the need for professional psychological and spiritual support to deal with the child’s and family emotions.

Another sub-theme within this category relates to the sibling needs. In addition to parents’ understandable relative level of inattention of the siblings of a dying child, losing a sibling will inevitably affect the surviving children (Craig, 1997). Although, Eilertsen et al. (2017) concluded that having a dying child can result in positive as well as negative experiences and memories for bereaved siblings. The bereaved siblings’ responses about their experiences were categorised into for different categories; namely, endurance versus vulnerability, growth versus stagnation, family cohesion versus family conflict and professional support versus lack of professional support. These concepts were evident in bereaved siblings and parents’ statements about their lived experiences. For example, parents conveyed two distinct experiences about the relationships with bereaved siblings in a longitudinal study conducted by Barrera et al. (2013) in which it was found that a mother of a surviving 18 years old son stating that following the initial loss, she felt a distance from her surviving child, but indicated that this distance is lessening now that she is focusing more on connecting with the remaining child and building a strong relationship.

However, another mother felt that her relationship with her surviving 8-year-old child was strained and difficult following the loss of her other child, when she described that she loses her patience far more easily and is much less tolerant before she had been before. The mother also explained that this lack of patience and quickness to anger has caused the surviving child to feel she was less important and less loved than the child that had died. These sentiments seemed to cause more resentment and more hurt and add more strain on the relationship of this mother and daughter. Also, in a recent Swedish survey, the surviving siblings expressed a ‘wish for their own support’ as the most important advice to healthcare professionals working with dying children (Lövgren et al., 2016). The siblings explained that they needed attention and support in daily life such as homework or school activities during illness and after the child’s death. In addition, the siblings identified the need to express their feelings and valued small gestures from healthcare professionals like offering them a game to distract younger siblings. The siblings suggested that they should receive information continuously about the child's condition, treatment and prognosis. They even expressed their wish to take part in the ill child's care.

The siblings' advice correspond to parents' perceptions of siblings' needs (Barrera et al., 2013) and responses to the death of a sibling (Crehan, 2004). However, these responses and needs vary according to the developmental stage of the bereaved sibling. Barrera et al. (2013) found that young, bereaved siblings tend to seek more parental attention, while older siblings seek support from peers and social groups. On the other hand, a mother of a 9-year-old surviving child explained that her daughter had joined a support group *(The Bereaved Children's group)*, which enabled her the opportunity to talk to other children that had had the same experience. Therefore, healthcare professionals should assess and meet the siblings' needs frequently in a way that matches to the siblings' developmental stage. Satisfying these needs will impact the psychological well-being of the sibling on the long-term (Lövgren et al., 2018) and should be included and assessed as part of good quality paediatric palliative care.

4.5.1.3 Theme 3 - Practical Issues

The third theme involves the more practical issues and incorporates three elements that can be viewed as the main obstacles to receiving high-quality paediatric palliative care, these elements are secondary to healthcare resources (Kassam et al., 2013). The most important obstacle to equitable care was access to paediatric palliative services or staff members when needed, which was identified as an important issue within this scoping review and is in line with other reports within the literature. For example, Kassam et al. (2013) established that the highly valued elements of access to care include: access to 24/7 telephone advice from a palliative specialist, direct admission policies to hospitals and dedicated palliative inpatient beds. Also, in a study by (Al-Gharib et al., 2015), parents reported poor quality of care because of concerns about securing a bed for the possibility of child's death.

Other elements of accessibility relate to the absence of paediatric palliative care services or practitioners in specific geographical areas (Benini et al., 2016, Liben et al., 2008, Davies et al., 2008, Lindley, 2015, Meyer et al., 2006), or lack of coordination of care between different services, especially when the child is cared for at home. Indeed, the lack of trained staff who have specialised knowledge and skills of paediatric conditions and procedures can be suggested as a key area of concern that needs to be addressed in order to provide good quality paediatric palliative care (Liben et al., 2008, Lindley, 2015, Himelstein et al., 2004, Benini et al., 2016).

Another crucial aspect of the practical issues is the family's financial burden, which can impede them from gaining access to specific services. Literature suggests that parents faced extra costs for treatment and equipment, which involved a large amount of paperwork to cover these costs (Lindley, 2015). Waldman and Wolfe (2013) described financial issues as extremely frustrating for many parents, because although health services may be available, financial support can limit receiving simple medications or services. The financial burden may also cause families to get into debt after the child's death (Corden et al., 2002) with Goldhagen et al. (2016, p. 1) reporting that "*The decrease in hospital utilization and costs and the high HRQoL results indicate that Community-Based Pediatric Palliative Care (CBPPC) has the potential to influence important outcomes for the quality of care available for children with complex medical conditions and their caregivers*."

This review has provided insight into the needs and views of an optimal paediatric end of life care from the perspective of bereaved carers and can be used to inform healthcare professionals. These findings were employed to adapt the VOICES-SF questionnaire for paediatric and young people population.

4.6 Strength and limitations of review

The review had several strengths. First, it used an explicit literature search to inform the initial selection of items for the scoring system. A librarian and other researchers were consulted to refine the search strategy and items that were ultimately selected. Rigorous methods were employed that included a comprehensive electronic search. This was complemented with having a broad focus and using fewer limits in the search, such as the date of studies and group of illness. The aim was to identify as much as possible of available evidence to direct the adaptation process.

The sampling of the studies that focused on exploring the parents' experiences were mostly from one medical setting or geographic area, this may be problematic because it limits the generalisability of the results to the paediatric population with life-limiting conditions. Selection bias is the primary limitation of these sampling strategies leading to over-representation of the population, which was mothers, children with cancer and English language speakers. In addition, only English language studies were included in the review, which may lead to publication bias. Caution is needed when translating findings from this review to a wider population.

4.7 Conclusion

From the literature, it was evident that many different disciplines play significant roles in providing care for children with life-limiting conditions who are approaching death. The most prominent themes were communication and information themes. Communication, verbal or non-verbal, is considered an essential component of care provision because it is based on the quality of interaction among the patients, family and healthcare professionals and it facilitates mutual decision- making among patients, family and healthcare professionals. This leads to providing care that meets the patient's and family's needs and respects their values and wishes within the available resources (Mack et al., 2005, Epstein and Street, 2007, Heath et al., 2009). Physical and psychological support also needs to be provided effectively through a holistic approach, which may impact the quality of life of children negatively if not managed adequately (Abu-Saad Huijer et al., 2013, Heath et al., 2009). In addition, the findings of this review demonstrate that negative parental experiences during paediatric end of life care are frequently associated with poor continuity of care (Seecharan et al., 2004), ineffective communication with professionals (Maynard et al., 2005, Brooten et al., 2013, Homer et al., 1999), poor understanding of the child's condition and care (Brooten et al., 2013) and insensitive interaction with the child (Heath et al., 2009, Brooten et al., 2013).

From the evidence presented in this review the themes identified are not distinct, but rather they overlap with each other. Therefore, the impact of one theme or domain is not limited to itself, but instead it may affect other domains or themes. For example, a parent's notion that having the same team enhanced the continuity of care, information delivery and promoted the quality of care because, *"we didn't have to start from scratch"* (Heller and Solomon, 2005 p.340).

In order to improve the care provided for children at the end of life, there is a critical need to understand the bereaved carers' perspectives regarding quality of care and what they consider important to incorporate and deliver as part of that care. This review has provided important insight into the needs and views of optimal paediatric end of life care from the perspective of bereaved carers to inform healthcare professionals. The domains or themes of care have been to interrelate in that particular unmet need or negative experience could amplify negative impacts on bereaved carers and family members. These findings are relevant and important and were used to inform the adaption process and generate a version specific to children.

Chapter 5. Phase I Methods: Development of VOICES-C prototype

5.1 Introduction

The development of VOICES-C questionnaire was a multi-step process that included integrating findings from the scoping review of child and family priorities of end of life care, qualitative interviews with bereaved carers and healthcare professionals who worked with children at the end of their lives in the UK in order to create a prototype version of VOICES-C. The VOICES-C prototype was then subjected to pretesting with healthcare professionals, and cognitive interviews with bereaved carers. This chapter describes the methods employed with a small sample of health professionals and bereaved carers to establish the initial content validity of the prototype and their opinions regarding the VOICES-C prototype. The reliability of the adapted survey was not tested because the VOICES-SF questionnaire is a multifactor descriptive survey that does not have an aggregated score based on the test items (Streiner and Norman, 2008). The comments from healthcare professionals and carers were summarised and considered carefully in order to make decisions regarding amendments to the questionnaire.

As a part of my work in developing the VOICES-C questionnaire, I conducted a scoping review of the literature to generate the main elements of paediatric end of life care. This was followed by interviews with bereaved carers and healthcare professionals conducted by A-SD. Analysis of the interviews with carers and healthcare professionals (A-SD and KH) in conjunction with literature review findings identified the most important relevant elements that should be used to adapt the VOICES-SF to produce the prototype.

The VOICES-SF survey consists of 59 items (**Error! Reference source not found.**), and adaptation of this questionnaire to develop the prototype children's version sought to maintain consistency in wording and response options as these had undergone testing during the development of VOICES-SF. A key aim for the children's version was to keep it as concise as possible to avoid increasing burden on the respondent; i.e., the degree to which a participant experiences their response to the survey as time-consuming or emotionally stressful (Lavrakas, 2008). The VOICES-C prototype consists of 75 questions (Appendix I) and one open-ended or free text response item. Closed-ended items are presented in categorical and Likert-type response options. The questionnaire included specific sections for end of life care at home, hospice and hospital wards (NICU, PICU and paediatric wards) with the same questions covered in each of these sections. In addition, there are sections about the overall care provided in the last two days of life, hours surrounding the time of death and planning the care. The questionnaire routing directs participants to the following sections they should complete, which are relevant to their experience, based on their answers to the first two introductory questions of the questionnaire. As a result, it is unlikely that any participant would need to complete all sections. The questionnaire ends with demographics questions relating to both the participants' and the deceased child (age, ethnic group and participant's relationship to the child).

Once the prototype had been developed, a testing phase followed. This involved cognitive interviews with bereaved parents (conducted by A-SD) and interviews with healthcare professionals to gather their feedback on the questionnaire (conducted by RA).

5.2 Pre-testing the survey

The UK VOICES-C prototype was examined by relevant healthcare professionals and bereaved carers in the UK to ensure that content validity and sensitivity were achieved in the prototype.

5.2.1 Cognitive interviews

Surveys or patient reported outcome measures are tools that provide information from the patient about a disease and its services or interventions, they also aim to measure concepts from the patients' perspective (Medical Research Council, 2009). Pretesting measures or questionnaires is an indispensable stage in the process of questionnaire design (Presser and Blair, 1994, Willis, 2016). Since the source of data is human beings responding to the questions, cognitive principles regarding how participants understand questions, structure their memories, form and report a response. Researchers have focused on evaluating questionnaires and identifying sources of response errors (Rothgeb et al., 2007). There are different methods for evaluating questionnaires, for example, expert review, cognitive interviewing and respondent debriefing. To evaluate the VOICES-C prototype a combination of two approaches, expert panel and cognitive interviewing, were employed to identify the content validity of the prototype questionnaire produced from the previous phase. This phase entailed collecting detailed information from participants and experts with relevant knowledge in the field of paediatric end of life care to identify potential problems with the questionnaire (Presser et al., 2004).

Drennan (2003) suggested that cognitive interviewing is "*the most valuable"* approach to pre-testing and validating a sensitive questionnaire. Cognitive interviewing is based on the cognitive theory that involves the understanding of information processing, including recalling, understanding words, attention span and reasoning, as well as how knowledge is organised in the memory and how memory is retrieved (Tourangeau and Rasinski, 1988). Cognitive interviews employ two methods of verbal report; think-aloud and verbal probing (Haeger et al., 2012). These methods are used to obtain the respondents' thoughts about the questionnaire while or immediately after answering the questions (Presser et al., 2004). Verbal probing entails asking additional questions to find out more information from the participants. These questions can be predetermined or spontaneous. In designing and pretesting a questionnaire, cognitive interviews enable the examination of the question-answering process to understand what the respondent will experience when completing the questionnaire by providing insight into how the questions are understood and answered from the respondent's perspective (Hales et al., 2012). Basically, the main aim is to detect problems within questionnaire items and identify potential sources of response error, such as the wording of an item, terminology, order of questions, difficult retrieval and suitability of response options (Presser et al., 2004, Jobe, 2003).

In addition, the cognitive interviews were considered as a form of Patient and Public Involvement (PPI) whilst developing the VOICES-C questionnaire. PPI in research refers to carrying out the research with or by members of the public rather than to, for, or about them (Staley, 2009), i.e. the active participation of people with experience of the condition or care pathway in question in prioritising, designing, implementing and disseminating the research, in addition to patient or public participation as research subjects (Staniszewska et al., 2012, Bate et al., 2016). PPI is based on the concept that people who are impacted by research have the right to have their 'voice' incorporated into the research process (Bate et al., 2016). The word public in health research encompasses parents, informal caregivers, and service users.

Patients or service users can be involved in the research process in different forms and different stages. Involvement can range from consulting possible participants to elucidate their opinions to collaborating in the research process. Public involvement can happen in the early stages of research, for example identifying the need for the research to disseminate the findings. Previous research has supported employing PPI to refine and improve questionnaires' content, research relevance and acceptability (Staniszewska et al., 2012). Unlike sampling for data collection, the sample is not necessarily representative because the aim is obtaining the public active collaboration as research members, not subjects. This collaboration was essential for identifying the most valid items, revising the questionnaire, and modifying feasibility survey protocols. It was important to involve carers who had experience in paediatric end of life services because it would offer valuable insight into the relevance of the questionnaire and report their concerns. Feedback from participants aimed to inform changes in VOICES-C by assessing the participants' ability to understand the questions, answer them successfully and, subsequently, yield accurate results (Souza et al., 2017). In addition, carers' involvement aimed to examine the target population's willingness to participate and improve recruitment processes to increase the likelihood of carers' participation.

5.2.2 Aim and objectives

This step aimed to examine the extent to which the VOICES-C prototype asked questions that frequently reflected the available services providing care in the UK to the target population and acceptable to bereaved carers to inform amendments to the VOICES-C prototype. The objectives for this step were to examine whether

- the questionnaire captured the essential elements of services pertinent to provision of end of life care to a paediatric population in the UK,
- questionnaire items were readable and comprehensible,
- terminology used was accurate and thoughtful,
- response options were deemed suitable and inclusive from the perspectives of relevant healthcare professionals and bereaved carers.

5.2.3 Sample and eligibility criteria

The sample for this phase included healthcare professionals in England with related experience of providing care for children with life-limiting conditions and bereaved carers whose child died from a life-limiting condition. It was intended to ensure a wide range of views from different professional groups involved in caring for this population across different settings, therefore healthcare professionals from different professions were contacted from Southampton Children's Hospital, a centre with comprehensive paediatric services, PICU and NICU, and Naomi House and Jacksplace Hospices for children and young adults. The inclusion criteria were any healthcare professional with experience of at least two years working with paediatric patients approaching the end of life. Eligible professions included paediatric nurses, paediatricians, and specialists from the hospital's units and nurses, community workers and family counsellors from the hospice.

For the bereaved carers' sample, recruitment sought to generate a maximum variation sample to reflect a wide range of experiences. A convenience sample of bereaved carers who met the inclusion criteria and agreed to participate was recruited through the participating sites to review the prototype questionnaire (Miller et al., 2014, Willis, 2006). The inclusion criteria were English speaking bereaved carers' that cared for a child with a life-limiting condition who had died due to his/her condition at home, in hospital or in a hospice. No time limits were applied to carers in respect of the time elapsed from the child's death. Exclusion criteria were non-English speaking carers, non-bereaved carers, bereaved carers who lost their child due to suicide or accident, or their deceased child was older than 18 years old.

5.2.4 Recruitment

5.2.4.1 Healthcare professionals

After obtaining ethical approvals from the Faculty of Health Science, University of Southampton and Health Research Authority (HRA) and the Research and Development department (R&D), managers at Southampton Children's Hospital's units and Naomi House and Jacksplace hospices were asked to nominate eligible healthcare professionals. Healthcare professionals were contacted via their professional emails inviting them to participate in the study (see Appendix J.1.1). Documents attached with the emails included a participation information sheet, consent form and a copy of the prototype questionnaire. Subsequent arrangements were made to undertake interviews at a place and time suitable once they had agreed to participate. An email reminder was sent after ten days to participants who did not respond (see Appendix J.1.2)

5.2.4.2 Bereaved carers

Potential participants who met the inclusion criteria were identified and approached initially by a member of the clinical team from the participating sites. The healthcare professional was provided with a participant information sheet, consent form and a copy of the questionnaire which informed the bereaved carers about the study and the researcher's contact details (university email) (see Appendices J.1.3 and J.1.4). Once a bereaved carer had contacted the researcher and provided initial agreement to participate, arrangements were made for the interviews to take place. The interviews with bereaved carers were conducted by A-SD, rather than myself, in consideration of the topic's sensitivity and differences in culture between myself and the interviewees. These cultural differences might have served to create a barrier to effective and considerate communication. The interviews were conducted by phone, at a day and time mutually convenient for the participant and the interviewer. Although written consent was not taken, participants provided verbal recorded consent before starting the interviews, since these were telephone-administered interviews. Participants were encouraged before the interview to ask any questions and were informed of the processes to protect anonymity and confidentiality. In addition, participants were reminded of their right to withdraw from the study at any time without giving any reason.

5.2.5 Data collection

Pretesting questionnaires is an indispensable stage in the process of questionnaire design (Presser and Blair, 1994, Willis, 2016). Researchers have focused on evaluating questionnaires and identifying sources of response errors (Rothgeb et al., 2007). There are different methods for evaluating questionnaires, for example, expert review, cognitive interviewing and respondent debriefing. To evaluate the VOICES-C prototype a combination of two approaches were used, an expert panel for healthcare professionals and cognitive interviewing of bereaved carers.

5.2.5.1 Healthcare professionals

This step focused on an examination of the questionnaire by eliciting the views of healthcare professionals' who took part as members of an expert panel regarding the clarity and breadth of content of questionnaire items (Johnson et al., 2011), and whether they were relevant to available services. Panel members were experts on the topic of interest and familiar with the target population. This approach entailed presenting a questionnaire to experts by email or interview (face-to-face or telephone). The interviewer used predetermined follow-up probing questions to obtain feedback on the questionnaire's content, structure and applicability for evaluating the paediatric end of life care (see Appendix J.1.5). Groves et al. (2009) outlined the types of potential difficulties with each question that may impact the response process. These issues might include complex syntax, requiring working memory overload, use of imprecise or vague nouns or phrases, or unfamiliar terms, multifaceted questions, unclear question purpose and incompatibility of the question with the response options.

A copy of the prototype questionnaire, to provide them with the conceptual basis of the questionnaire i.e., evaluating the quality paediatric end of life care provided by a wide range of healthcare professionals was made available to panel members ahead of the meeting. At the beginning of interviews, the purpose of the study was explained and written informed consent obtained from participants in face to face interviews and verbal recorded consent for telephone interviews. Whilst participants navigated through the questionnaire, they were asked to assess the questionnaire's structure, wording, comprehensiveness and relevance to practice. In addition, the experts were asked to suggest revisions to items or terms they found problematic (Grant and Davis, 1997). For example, all experts were asked (Does the questionnaire capture the essence of the paediatric end of life care?) and (Is there any item or aspect missing that we should include in the questionnaire?) The interviews were audio-recorded, and notes made of comments from participants next to each item on the actual prototype questionnaire during the interview (Johnson et al., 2011).

5.2.5.2 Bereaved carers

During the interviews with bereaved carers, they were asked to read the questionnaire and provide feedback about the questions and response options. Interviews used a pre-determined interview schedule with probes to elicit an in-depth understanding of participants' perceptions of the content and sensitivity of the questionnaire and ensure it was an authentic representation of current practice. This approach is more convenient, comparing to focus groups, in terms of time-saving and ensures that important topics are covered (Drennan, 2003, Turner et al., 2007). All interviews were audio-recorded and transcribed verbatim.

Pre-testing the survey

Participants were asked to read the questionnaire and verbalise their opinions regarding the structure, readability and wordiness of questions, in addition to whether the topics and wording of items applied to carers and service providers in the UK. In addition, participants informed the researcher of the extent to which the terms and questions in the questionnaire were acceptable and commonly used with bereaved carers (Johnson et al., 2011). Furthermore, the participants were asked to suggest any changes regarding the comments they had highlighted, especially regarding the appropriate terms to be used in the questionnaire.

5.2.6 Data analysis

5.2.6.1 Healthcare professionals

A framework analysis approach was employed to analyse data from experts' interviews. This approach is used to analyse qualitative data based on a systematic structure (Hackett and Strickland, 2019). The main feature of framework analysis is the output which is a matrix of rows and columns corresponding to the cases and codes, respectively. An example of framework analysis for the first three questions is shown in Appendix J.2. The case is an individual interviewee or another unit of analysis, whereas the code is a conceptual label assigned to extracts from raw data (Gale et al., 2013). This approach enabled the researcher to compare data across cases, as well as identify codes reported in each case. Each interview was transcribed verbatim and a summary of experts' feedback and notes from the interviews was generated. The researcher reviewed each interview summary to become familiar with the main problems with the questionnaire. Next, open coding was conducted to identify and label the problems in relation to each question. Subsequently, the codes across the interviews were reviewed and compared to group relevant codes together according to the analytical framework (see section 6.2). This analytical framework was applied by indexing the reported problems to the corresponding codes and categories. Finally, a table was generated to chart the questions (cases) and reported problems (codes).

5.2.6.2 Bereaved carers

Cognitive interviews were analysed using the steps outlined by Knafl et al. (2007), which include; transcribing the interviews, summarising the participants' responses to each item and identifying the categories of problems across the entire dataset, analysing each item summary and making decisions about the items.

1. After each interview, the audio recording was transcribed in preparation for the analysis process. The interviews were transcribed into written accounts revealing how participants perceived the questions and response options.
2. The researcher identified each participant's comments on every individual item within the questionnaire and produced a summary of the participant's responses for each item from the transcripts.
3. The summaries from all interviews were compiled into one document outlining all the comments next to the corresponding item (Appendix J.3).
4. Summaries of each question were reviewed and coded into specific categories reflecting the nature of problems and concluding with suggestions for the changes because each category required different actions. (Irwin et al., 2009, Knafl et al., 2007).
5. Finally, the findings from these summaries were synthesised to conclude the overall problems of each question and propose potential amendments to overcome these problems. Carers' contribution at this stage was in decision making about the possible changes in the questions and responses according to how they perceived and interpreted the questionnaire.

5.3 Chapter summary

This chapter has discussed the process of developing and pretesting the VOICES-C prototype with healthcare professionals and bereaved carers in the UK. Pretesting was required to ensure the questionnaire was easy to understand by participants and relevant to available services. The results are reported in the next chapter, including participants' characteristics, analysis of feedback given regarding the prototype structure and items, as well as recommendations for amendments to the VOICES questionnaire.

Chapter 6. Phase I Findings: Development of VOICES-C prototype

The findings from the healthcare professionals and carers' interviews are summarised in this chapter. The characteristics of participants were described i.e., the demographic data of the healthcare professionals and bereaved parents in the UK. Then it moves to the results from analysis based on the framework approach. The chapter concludes with a summary of the suggested amendments to the prototype and the revised VOICES-C questionnaire (English version) that was used in the subsequent cross-cultural adaptation phase.

6.1 Participant characteristics

6.1.1 Healthcare professionals

Of thirteen healthcare professionals approached by email, nine responded and subsequently participated: seven nurses, one family counsellor and one neonatal consultant. Five out of the nine were from the Naomi House and Jacksplace hospice. The interviews were conducted by telephone (n=4) and in person (n=4), and one response was received by email. Participants' clinical experience ranged from 5 to 22 years. Eight healthcare professionals provided their feedback and opinions about the questionnaire through interviews ranging from 25 to 70 minutes. Healthcare professionals' characteristics and demographic data are summarised in Table 6-1.

Table 6-1 Healthcare professionals' characteristics

Participant ID	Profession	Place of work	Work experience (yrs.)	Interview duration (mins.)	Mode of interview
RA01/ HOSPICE	Nurse	Hospice	20	70	Face-to-face
JD01/ HOSPICE	Nurse	Hospice	13	30	Face-to-face
RA02/ HOSPICE	Family counsellor	Hospice	3	25	Telephone
JD02/ PICU	Nurse	Hospital/PICU	8	35	Telephone
RA03/ HOSPICE	Nurse	Hospice	11	30	Telephone
JD03/ PICU	Nurse	Hospital - PICU	15	45	Telephone
JD04/ PICU	Nurse	Hospital - PICU	5	25	Face-to-face
RA04/ NICU	Doctor / consultant	Hospital/NICU	7	50	Face-to-face
ER01/ HOSPICE	Nurse	Hospice	22	NA	Email response

6.1.2 Bereaved carers

It proved very difficult to recruit bereaved carers in the UK. Two phone interviews were conducted with bereaved mothers and one piece of written feedback was received from a carer (the feedback did not indicate the identity of the carer). The deceased children were two male and one female neonates. Bereaved carers were recruited through the NICU from the Southampton University Hospitals NHS Trust, University of Southampton teaching hospital. One carer interview lasted 75 minutes and the other 33 minutes.

6.2 Analytical framework

To maintain consistency among participants' reports and to enable the researcher to synthesise the findings, both expert and bereaved carers' interviews used the same analytical framework to categorise the problematic issues reported by participants. The researcher identified two main categories that reflected the cognitive processes proposed by Tourangeau (1984) i.e. comprehension, and forming a response. A third category was added to ensure that any issue did not fall under the two categories was addressed. Appendix J.4 presents examples of the analytical framework i.e., problematic questions with corresponding categories and proposed changes. These categories are

1. Comprehension
    - Question structure, which includes incorrect tenses, wordiness and poor syntax
    - Question content: this category encompasses the items including unpleasant or offensive or confusing words i.e., has broad concepts or multiple inferences, unclear references (the parent or the whole family), undefined references and limited applicability to the paediatric population or services.
2. Response options: this category focuses on the problematic response options which include more than one option with the same interpretation or meaning, inapplicable options and missing options.
3. Other: this category entails emerging issues that do not fall under the aforementioned categories

6.3 Findings from interviews

6.3.1 Healthcare professionals

General comments

Overall feedback from the healthcare professionals was positive. Although the questionnaire might be considered long (75 questions), healthcare professionals considered it captured the main principles of care provided for the dying children and reflected components of multidisciplinary care; one participant commented "*it is long, but it is worthy*" (Hospice nurse, 20 years' experience).

Another healthcare professional stated that "*the questionnaire has the right length, questions are important*" (PICU nurse, 8 years' experience). When participants were asked whether anything was missing that should have been added, a participant replied, "*No more questions needed to be added because the questionnaire is already comprehensive*" (Hospice family counsellor, 5 years' experience).

Healthcare professionals were keen to protect bereaved carers from additional distress and focused on questions' sensitivity and how bereaved carers might perceive particular questions when remembering their deceased child. This was evident from the suggestion to add an introductory section leading to the questionnaire and preparing the carers emotionally instead of starting directly with the question (How long had she been ill before she died?)

1. Comprehension

o Question structure

During the interviews, healthcare professionals made comments about questions they felt needed further revision in terms of a question's form and wording. Two participants commented on questions 3, 4, and 5 (see Appendix I) because while these asked about the services used, response options are related to the professionals. Participants recommended changing the wording of the questions for more consistency. In addition, another two participants highlighted that questions 8, 11, 33, 41, and 68 were *"confusing"* and needed to be reorganised by moving the phrase "in the last three months" to the beginning of each question for better comprehension. Questions 21, 30, and 38 regarding siblings' support were criticised as unclear as to the identity of the visitor. The participants explained that there is potential for the item's meaning to be *"misunderstood"* to mean the healthcare professionals had visited the child, not the siblings. Furthermore, three healthcare professionals, from different units and backgrounds, brought to our attention that questions 23, 32, and 40 (Did you feel listened to and acknowledged as a parent, as an expert about your child?), had two different concepts i.e., "parent" and "expert" that cannot be combined. The participant might be a parent but not an expert necessarily, which is the case for the parents of neonates who die very early, as stated by a NICU consultant. One typo "I" was recognised by a participant in question 49, item b, which should be deleted because the question statement had "were you".

- **Question content**

This category included participants' comments concerning terms felt to have unclear meaning or that needed more clarification on what was being asked about, or inappropriate terms felt to be potentially distressing for respondents. The main remarks that most of the participants consistently raised were regarding the phrase "looked after in a caring way" in questions 13, 16, 25, 34, 42 and 53. Four experts from hospice and PICU reported that phrase needed more clarification because care may be interpreted differently as it depends on the parents' definition of care and at any point in the child's illness journey. Similarly, the term "trust" in questions 22, 31, and 39 was found as a "*challenging aspect*" (Hospice nurse, 20 years' experience) and "*tricky item*". The participant explained that trust is a broad concept and has many levels and may vary among different care professionals within the same setting. In addition, seven respondents considered that the term "Key" in question 6 (Was there a key health professional responsible for her care?) is difficult to comprehend and "*It might be open for interpretation of the parents*" (NICU doctor, 7 years' experience), in other words, the parents may think this term refers to the consultant or community nurse who cared for the child on a regular basis instead of a named worker to be approached for care coordination (see scoping review above). The healthcare professionals suggested adding a question to understand how the parents identified this key worker. On the other hand, the term "live" in question 15, (Did she live or stay in hospital at any time during her last three months of life?), was perceived as inappropriate because it indicated that the hospital was the child's residence. The healthcare professionals preferred using "stay" or "admit" instead of "live". Finally, the healthcare professionals felt that the questions regarding the siblings' support (21, 30, and 38) required further explanation to define which aspect of support is being asked about, such as comfort or playrooms or food.

Lastly, some items were felt to have limited applicability, including items felt not to apply to a paediatric population and care services. A hospice nurse noted that a general practitioner (GP) in question 8 is unlikely to be involved in the care of children approaching the end of life.

Findings from interviews

2. Response options

The majority of the participants (7 out of 9) viewed the options “Completely”, “Some of the time” and “Partially” as confusing and may have the same meaning, and as a result it would be difficult to choose between them. One participant pointed out that “*Completely, some of the time and partially might be a slight cross-over.”* (PICU nurse, 5 years’ experience), another healthcare professional commented that *“Mostly implies kind of ‘majority of the time’, generally.*” (Hospice nurse, 13 years’ experience). One respondent thought that the response options of Question 1 (How long had she been ill before she died?) were complicated and should be changed, as she stated: “*Timeframe is a little bit confusing: “One or more but less than” ... I needed to read it more than once to understand. Maybe changing into ‘between’ might be easier*.” (PICU nurse, 8 years’ experience).

A participant recommended adding an option to Question 49 concerning whether carers had sufficient time or access to spiritual support at the time surrounding the child’s death. In contrast, the participants recommended deleting options from the Question 3 (When she was at home in the last three months of life, did she get any help at home from any of the services listed below?), as they do not apply for the provided services, such as: “A Marie Curie nurse” and “Occupational therapist (OT)”. In addition, the response “Marie Curie” in Question 3 refers to the used services, this service doesn’t provide children with the end of life care. Furthermore, a participant suggested adding a response when asking “Were you offered a place to sleep to be close to her?” The suggestion is “Yes, it was close to the hospital”.

3. Other

A hospice nurse found response options for question 9 to be very precise, which may cause failure to answer the question, because in retrospect it could be difficult for bereaved carers to remember exactly the number of times out of hours care was called urgently. The participant explained that the options should encompass broader ranges and simpler wording so the bereaved carers would find it easy to respond.

6.3.2 Bereaved carers

General comments

The bereaved carers appreciated the questionnaire being outlined according to the gender of the child which made it more personal and sensitive. In addition, they valued the open-ended question at the end of the questionnaire because it enabled future respondents to make comments and elaborate on their experiences. The participants were asked how they would like to receive the questionnaire. A mother said that she would prefer to receive the letter in person with a letter implying what is in the envelope and to complete the questionnaire whenever she is ready. The same mother suggested receiving the questionnaire, preferably when parents leave the hospital, and ask them to open the envelope whenever they are ready or when they attend their consultation appointment to talk about what happened to the child.

1. Comprehension

Question structure

Carers did not have concerns regarding the structure of certain questions, however, their main comment was regarding the overall structure of questionnaire as it had many sections that may not apply all to participants. One carer recommended that the first question should be worded to direct the participants to relevant sections and save reading through the whole document.

Question content

Unlike the healthcare professionals, carers did not experience problems interpreting the meaning of words or phrases that were reported as vague by healthcare professionals, particularly the words “care” and “trust”. A mother of a neonate girl stated that *“it will be very interesting to see peoples’ response”* to “trust” questions, as this question reflects the relationships between carers and healthcare professionals. The carers did not identify any words as unsuitable or offensive.

2. Response options.

One carer recommended splitting the options of Question 22, concerning the trust in healthcare professionals, into “doctors” and “nurses”, because the parents *“build rapport and relationships”* with nurses who provide the care most of the time, whereas doctors *“come and go”*.

3. Other

All carers highlighted a general concern regarding the beginning of the questionnaire as it started with a “*quite abrupt*” question, as described by two mothers. Therefore, they recommended an introduction outlining the aim of the questionnaire and setting the scene for the respondents. All carers suggested moving the questions regarding the demographic data to the beginning. One carer suggested adding a section about organ donation because their child’s “*last day revolved around this*”.

Given that both participants were the carers of neonates, they highlighted a major problem in terms of limited applicability of several sections to their experience, in addition to unclear signposting within the questionnaire guiding them to relevant sections only to prevent them from losing their way. This problem caused the carers to feel confused and lost while completing the questionnaire, therefore they recommended a separate questionnaire or section for the neonatal population to make it shorter and manageable. A similar suggestion regarding the siblings’ questions was reported by one mother since their deceased child was their first child and did not have sibling/s, which would be the case for many neonates.

6.4 Discussion

The findings to emerge from the experts and bereaved carers identified general difficulties and recommendations for amendment of the VOICES-C prototype in order to produce a final version of the VOICES-C questionnaire (Willis, 2006). Items and response options reported by participants as being clear and comprehensible were retained, whilst other items and response options were modified or deleted. In accordance with Presser and Blair (1994), different pretesting approaches would identify different problems in the questionnaire, although the findings from these approaches may overlap. The overall findings addressed key problems future respondents may encounter related to the questions’ content, the questionnaire’s layout and a few problems related to the relevance of response options. Appendix J.5 details the findings concerning each question and suggested changes to the prototype.

In general, decisions about amending items due to the clarity of certain words or phrases were taken based on the experts’ and carers’ feedback. However, carers’ opinions were prioritised whenever a variation in reports had emerged since the proposed questionnaire aims to obtain the carers’ views regarding the quality of care. For example, a few experts expressed their concerns around whether there is might be confusion as to the meaning of the terms “caring” and “trust”, whereas carers understood these terms and perceived them as appropriate.

Therefore, these terms were retained in the questionnaire. In the same vein, the response options for questions evaluating the trust between the carers and healthcare professionals were amended to enable the carers to evaluate trust among nurses and doctors independently. Although doctors and nurses work collaboratively, they have different scopes of care provision and therefore the assessment of trust should be differentiated. Correspondingly, the questionnaire's structure was amended according to the carers' opinions to ease the opening of the questionnaire and help the respondents find their way through the questionnaire easily.
On the other hand, comments and suggestions from the healthcare professionals were considered regarding other sections because the carers reviewed the questions related to the neonatal unit and they did not review other sections, such as urgent out of hours care, PICU, ward, community services, etc.

According to Miller et al. (2014), participants' characteristics or groups may influence how participants perceive the items and why they would experience particular problems. For this study, these characteristics that shaped how the participants perceived the questionnaire items were the group of participants, i.e. healthcare professionals or carers, healthcare professionals' background and length of experience. The results demonstrated that healthcare professionals and parents interpreted the questionnaire items differently, which is supported by previous research indicating the discrepancies of parents and clinical staff members' views of the quality of care (Contro et al., 2004). Findings from the experts and bereaved carers yielded the following amendments:

1. For question 1 (How long had she been ill before she died?), the response options were reworded to a simpler phrasing for better comprehension, for example, "Between one day and one week", "Between one week and one month", etc.
2. The response options in question 3 (When she was at home in the last three months of life, did she get any help at home from any of the services listed below?) were changed as follows; "A Marie Curie nurse" and "Occupational therapist" options were deleted, the options "consultant" and "palliative care nurse" were added.
3. For the same question, the word "services" in the question statement was changed into "professionals".
4. The following two questions 11 and 12 were re-worded, by replacing "services" with "professionals" to align with question 10.
5. To address the problems in the questionnaire's layout, an introductory section with instructions on how to complete the questionnaire was added.

6. The questionnaire was reorganised by moving the demographic information section to the beginning of the questionnaire, as well as, signposting the following sections to make it a less complex cognitive task and guide the respondents through the questionnaire.
7. Response options of items regarding the trust between parents and healthcare professionals were amended to include two columns one for doctors and another for nurses.
8. The questions regarding the sibling/s were highlighted in orange colour to enable the parents to skip these questions easily.
9. The neonatal section was moved later to skip reading other sections that may not apply (a shorter version to be considered)
10. Adding a section about organ donation (to be considered with the research team).

The main limitations of this phase were the sample size and characteristics of bereaved carers recruited through the NICU with a complete lack of representation of carers of older children who would have reviewed the remaining questions regarding hospice, hospital ward and community services. In addition, expert panel members were exclusively recruited from two institutions in the same city findings may not be representative of the experiences of healthcare professionals working with dying children in other settings and locations.

6.5 Chapter summary

Expert panel and cognitive interviews approaches were executed to evaluate the VOICES-C prototype and identify problematic issues from the relevant professional care providers and bereaved carers. The interviews revealed a range of problems with respect to certain questions. Minor amendments to the prototype had to be made before looking to proceed with a cross-cultural adaptation for the Jordanian population and produce a VOICES-C (Arabic version). Appendix J.6 presents the revised version of the VOICES-C questionnaire that resulted from this phase.

Chapter 7. Phase II Methods: Cross-cultural adaptation

7.1 Introduction

This chapter describes the methods used to produce a questionnaire suitable for feasibility testing in the Jordanian context. The VOICES-SF questionnaire was initially adapted to make it suitable for a paediatric population (i.e., the VOICES-C), and this was then followed by a process of cross-cultural adaptation (CCA) to develop an Arabic version of the VOICES-C questionnaire. Following WHO guidelines for adapting instruments, this phase entailed three steps: reviewing the questionnaire by a panel of experts familiar with paediatric healthcare services in Jordan; translating the English version of the questionnaire; and pretesting the questionnaire with a sample of bereaved carers in Jordan (WHO, 2007). This chapter describes the steps taken to undertake the cross-cultural adaptation, to recruit and interview a panel of experts and a group of bereaved parents whose child had experienced the end of life care.

7.2 Cross-Cultural Adaptation (CAA)

7.2.1 Definition

In order to evaluate the quality of paediatric end of life care in Jordan, there was a need for a reliable, culturally sensitive outcome measure. Developing a new outcome measure is a time and resource-intensive process, therefore adapting a previously established and validated measure is an alternative approach to investigate the same concept/s in another culture and/or languages, or make a comparison across different cultures (Guillemin et al., 1993, Sousa and Rojjanasrirat, 2011, Peters, 2011). The process of cross-cultural adaptation (CCA) involves not only the translation of an outcome measure into a new language but also ensuring equivalence of meaning before presenting a measure to another culture. This ensures uniformity in the meaning and intent of the original measure by including equivalent concepts and valid terms in the target culture and/or language (Beaton et al., 2000, Yu et al., 2004), i.e. cultural equivalence (Jones et al., 2001). Beaton et al. (2000) categorised the aspects of equivalence into four areas:

1. Semantic: the evaluation of the meaning of word and the grammar of items. Boggatz et al. (2009, cited in Khalaila, 2013) introduced four types of semantic problems: offensive items, interchangeable items, irrelevant items and items with different possible interpretations. Moreover, each language has unique grammatical rules which may impact the translation process. For example, word order in the sentence, comma and tense usage in the Arabic language differ from the English language, and this may influence the adaptation of a questionnaire from the English language into Arabic language (Khalaila, 2013).
2. Idiomatic: a term in the source questionnaire may not have an equivalent corresponding in the target version, therefore, there will be a need to develop an equivalent expression in the target questionnaire.
3. Experiential: This aspect of equivalence considers the cultural and regional differences in the CCA process to include applicable terms or concepts. For example, the daily routines and habits which may differ from one culture to another, such as eating with a fork or taking a bath for relaxation that are not common norms in some cultures or countries.
4. Conceptual: although a term may have a corresponding equivalent in the target language, this doesn’t necessarily mean an equivalent concept for the target population has been achieved. In other words, a term indicates different conceptual meanings from one culture to another. For example, the term “family” in Eastern cultures is interpreted by most people to mean the extended family, whereas in Western cultures it more often means the nuclear family. In addition, certain traditional therapies used to improve quality of life mentioned in specific cultures or groups may not be used in the target culture, therefore the researcher has to investigate the salient therapies for the target culture and include them in the adapted measure (Corless et al., 2001).

The CCA process should be conducted according to standardised, rigorous methods to ensure the functionality and value of the outcome measure are consistent across different cultures and/or languages (Machado et al., 2018). The literature on CCA outlined the main issues that should be considered during the translation and adaption process, for example; before conducting CCA, the main issue to explore is assessing whether the existing measure and underlying concepts are valid and applicable in both the source and target culture, though perhaps with some variations (Corless et al., 2001, Gjersing et al., 2010, Epstein et al., 2015).

Translation should be concise and relevant to the most common audience from the target population and consider age and gender differences between the source and target populations to avoid any offensive statements (World Health Organization (WHO), 2007).
Brislin et al. (1973) proposed useful rules for wording items to achieve equivalence in CCA, which are: using short sentences in the active voice; using nouns instead of pronouns; and avoiding suggestive expressions, ambiguous terms, metaphors or general terms that may imply more than one meaning and applying decentring (Brislin et al., 1973).

7.2.2 Guidelines for cross-cultural adaptation

Machado et al. (2018) reviewed methodological models used in the CCA of outcome measures in nursing research. There are three different guidelines that relate to CCA: Brislin (1986), Beaton et al. (2000) and the World Health Organization (WHO) (2007). The authors reported that the first two guidelines are the most frequently used in practice (Machado et al., 2018). The model developed by Beaton et al. (2000) entails six main steps; forward translation, synthesis of translations, back translation, an expert committee, pre-testing and an audit to review the previous steps. Back translation, as the name suggests, means to retranslate the questionnaire from the target language into the original language in order to be compared with the original questionnaire and reveal any inconsistencies. The Brislin (1986) model encompasses forward translation, backward translation, evaluating the semantic equivalence and pilot testing. The World Health Organization (WHO) (2007) recommended a four-step process to achieve conceptually equivalent instruments including; forward translation, expert panel, back translation, pretesting and cognitive interviewing, and the development of a final version. Table 7-1 presents a detailed overview of these three guidelines.

Table 7-1 Guidelines for cross-cultural translation and adaptation

	Brislin (1986)	Beaton (2000)	WHO (2007)
Number of steps	4	6	5
Steps	T*, BT**, semantic equivalent, and pilot study	T, reconciliation, BT, a committee of experts, pre-test, and audit of the adaptation process	T, expert panel, BT, pretesting and cognitive interviews, and the final version
Characteristics of steps	• T: one bilingual translator produces a version • BT: one bilingual translator will retranslate the questionnaire from the target language into the source language • Semantic equivalent: group discussion with all translators to agree on the most accurate and easily understood terms. This version is BT with two more bilingual experts • Pretesting of the new version with monolingual or bilingual participants	• T: two individual translators produce two separate versions • Reconciliation: a third independent translator joins the forward translators to synthesise one version of the questionnaire • BT: two translators blind to the original questionnaire produce two separate versions • Committee of experts: including all translators and methodologists to consolidate all versions. • Pre-test: the new questionnaire will be tested with 30-40 respondents • Audit of the adaptation process: this step involves reviewing the adaptation process by a committee or the developers to ensure that the recommended guidelines were followed.	• T: one healthcare professionals knowledgeable with English, native target language speaker • Expert panel: include the original translator and bilingual experts • BT: an independent translator whose mother tongue is English and has no knowledge of the original questionnaire • Pretesting: min 10 respondents • Final version from the iteration of previous steps
Outcomes of steps	• T: one version of the questionnaire in the target language. • BT: a version of the questionnaire in the source language • Semantic equivalence: an agreed-upon questionnaire in the target version. • Pre-testing: testing functional equivalence preferably with bilingual participants using the two language versions.	• T: two versions with a written report for each version • Reconciliation: written report with the joined version • BT: two versions with a written report for each version • Expert committee: prototype version with a written report • Pretesting: a complete version with a written report • Submission of all reports and versions to be appraised by the committee	• T: one version of the questionnaire • Expert panel: a complete translated version • BT: refinement of versions to achieve a satisfactory version • Pretesting: a written report of the cognitive interviews and the participants' details • Final version
Comments	Pros: This approach focuses on achieving an equivalent version by employing translators and healthcare professionals. Cons: Cannot estimate the number of translators because it is repeated until achieving an equivalent version. It lacks the potential participants' input throughout the translation process, before the pilot study. For better results, pretesting with bilingual participants which may be unfeasible	Pros: It includes experts and participants to verify the questionnaire Cons: Impractical process due to: It needs at least four translators; two forward and two back translators. The need a multidisciplinary team to review the questionnaire, in addition to the translators, healthcare professionals, language professionals and methodologists It requires a larger sample for pre-testing the questionnaire.	Pros: This approach obtains future participants' feedback before the pilot survey. Needs panel of experts at least three and 10 participants for pretesting: a more feasible guideline. Cons: Lack of specific requirements for the translators and experts

Notes: T*: translation BT**: back translation

The three approaches overlap in four main aspects. These areas are discussed below.

1. Translation

According to the steps of CCA as described by Brislin (1986) and the World Health Organisation (WHO, 2007), the instrument must be translated into the target language by a bilingual health professional, whose mother tongue is the target language, with a background in the topic/area to be investigated should conduct the translation of the source measure. On the other hand, Beaton et al. (2000) suggested that at least two bilingual translators should conduct the initial translation who are native speakers of the target language and from different backgrounds; one of them from a medical or clinical background and aware of the concept being investigated. Each translator will conduct the translation independently and produce a report to justify their decisions for the wording, highlight the challenging wording choices and inspect any discrepancies between the two translations to improve any poor wording of the questionnaire instructions, items and response options. This is followed by a synthesis of the two translated versions into one version. This step is conducted in the presence of the researcher and the two translators to achieve a consensus on the questionnaire's content, appended with a report documenting the synthesis process and the resolved issues. The resulting questionnaire is then used in the next step.

2. Back translation

This step encompasses the back translation of the questionnaire from the target language into the source language. The guidelines proposed by Brislin (1986) and WHO (2007) recommend that back-translation should be conducted by a bilingual expert who is not familiar with the original instrument, whilst Beaton et al. (2000) recommended it should be executed by two 'blind' translators, at a minimum. Although the guidelines varied in the number of translators required for this step, there was a consensus among guidelines that back translators must be unaware of the original questionnaire to ensure that the adapted questionnaire is valid and replicates the original version's content as well as to emphasise any imprecise wordings or meaning in the adapted questionnaire.

3. Expert panel

This step outlines the involvement of experts to review the adapted questionnaire and produce a refined version for the back-translation step. For example, the Brislin (1986) guideline aims to achieve semantic equivalence which entails reviewing and comparing the original and back-translated versions by a group discussion, including the translators, to reveal any disparities between the versions. Beaton et al. (2000) committee aims to achieve consensus and consolidate all the versions of the questionnaire into one version to be tested. As detailed by Beaton et al. (2000), the committee should include the previous translators, linguistics, methodologists, and healthcare professionals. Whereas, the WHO guidelines (WHO, 2007) stated that the panel aims to identify any inappropriate and irrelevant terms in the initial version and to make decisions of the appropriate correspondences in the pre-final questionnaire. The panel includes the original translator and other health experts.

4. Pretesting

This step involved pretesting the adapted questionnaires with respondents to examine whether the adapted questionnaire is valid as well as equivalent to the original questionnaire. During this step, a group of subjects from the target population are recruited to ensure that the adapted version retains its equivalence and is applicable in the new context. Beaton et al. (2000) and WHO (2007) guidelines established that the refined instrument should be tested with a representative sample from the target population using a cognitive interview approach. This step entails asking participants to read the adapted instrument and verbalise what they think each item means and rephrasing questions to examine the readability and comprehension of the instrument. In addition, participants are asked to choose a suitable expression from different alternative expressions, if there is more than one that might be applicable. This step should be thoroughly documented to track changes in the initial version. A final version of the adapted instrument is produced after iterative cycles of the previous steps. While Brislin (1986) recommended conducting a pilot study of an adapted questionnaire with respondents to identify upcoming problems when implementing study protocols before conducting a large survey.

To summarise, the main steps of the three aforementioned guidelines are broadly similar; forward translation, synthesis of initial measure, back translation, review of differences between the original and new measure and pretesting the final version to ensure the accuracy and validity of the translated measure. However, there is no consensus concerning the inclusion of a step involving a review committee and piloting the instrument, and a lack of consistency and justification exists regarding the characteristics; language fluency or background, and the number of translators and back translators (Acquadro et al., 2008, Machado et al., 2018). In general, the literature has recommended the benefits of having fluent bilingual forward translators with a familiarity of the questionnaire's content or investigated area (Guillemin et al., 1993, Beaton et al., 2000, WHO, 2007), in order to minimise the chances of creating difficult or irrelevant items. Beaton's model suggested including more than one translator or using a group of translators, in order to gain different perspectives. A review of the methodological approaches of CCA revealed there were no psychometric differences in questionnaires resulting from a dual-panel approach or forward-backwards translation (Epstein et al., 2015).

7.2.3 Challenges

The main challenge in cross-cultural research is *"to adapt it in a culturally relevant and comprehensible form while maintaining the meaning and intent of the original items"*. Failing to achieve a culturally relevant instrument could lead to faulty results and compromise the validity and relativity of the new instrument (Sperber, 2004, p. 124). Challenges may be encountered that relate to:

1. Linguistic issues that arise when there is no equivalent words or colloquial expressions for the items in the second language (Hunt and Bhopal, 2004, Epstein et al., 2015) or there are differences between the source and target language regarding the grammatical and syntactical styles (Yu et al., 2004); or the target language has dialectical variations, which means the target language has differences based on the geographical regions or race (Lenz et al., 2017).
2. Cultural problems because a concept/item in the original instrument has meanings in the source culture but has another or no meaning in the target cultures, i.e. it is irrelevant (Hunt and Bhopal, 2004, Yu et al., 2004, Epstein et al., 2015). In the same vein, Wang et al. (2006) recognised that employing forward and back translators from the same educational or socioeconomic background may be a source of error that produces an

instrument with irrelevant content due to the lack of cultural representation of the target population. Although the translator may encounter items that can be translated easily, such as demographic information items, the translator must evaluate the items carefully and assess which items cannot be translated literally. Sources of error are literal translations which may lead to items with vague and/or poor relevance to the target population/ context (Van Widenfelt et al., 2005).

Wang et al. (2006) suggested strategies to overcome these challenges; selecting the translators carefully, especially the back translator, who should be blinded to the original instrument and the forward translator; and employing a team to review the adapted instrument to minimise the translating pitfalls and piloting the instrument with a representative sample to identify how future participants would perceive and understand the adapted instrument. The aforementioned challenges are general issues mentioned in the literature, however, the researcher may encounter other practical challenges related to the nature of the research area that relates to the original instrument or the targeted population, such as the availability of bilingual experts to review the translated questionnaire or the characteristics of the target population i.e. age and educational level (Cha et al., 2007).

Given that previous literature has not shown evidence in favour of one guideline of cross-cultural adaptation (Peters, 2011), for this study, the WHO guideline was adopted to capture the complex aspects of end of life care and ensure that the adapted VOICES-C was equivalent and valid for the new context. This guideline was chosen because of its practicality in terms of time and resources needed to implement the CCA process. The Brislin (1986) guideline did not specify the number of translators because it is based on a repetitive approach to achieve equivalence and focuses on achieving linguistic equivalence and lacks the input of the target population before conducting the pretesting step. The Beaton et al. (2000) guideline required a multidisciplinary expert panel and a larger sample to pre-test the questionnaire which might have been unattainable. Furthermore, it was essential to adopt a guideline encompassing an expert panel and cognitive interviews, and to involve healthcare professionals and bereaved carers in the adaptation process to ensure the adapted questionnaire retained the essence of the original questionnaire, as well as being appropriate for the Jordanian context, given the significant differences between end of life care services provided in the UK and Jordan.

7.3 Aim and objectives

This phase aimed to adapt the VOICES-C questionnaire to ensure it was culturally congruent for use in a population of bereaved carers in Jordan and relied on the involvement of Jordanian experts to review the English version of the VOICES-C questionnaire and based on this review produce a suitable version for the next step- translation and back-translation. The last step was a series of cognitive interviews with bereaved parents in Jordan to refine the VOICES-C prototype (Arabic version) to ensure the structure and content of the Arabic version were relevant and appropriate to the paediatric end of life services in Jordan, as well as sensitive and acceptable to bereaved parents. In addition, issues regarding preferences on timing and approach to recruitment, and the degree of stress caused by the interview were explored.

7.4 Expert panel

This step aimed to determine the conceptual and content congruence of VOICES-C items as recommended by the WHO (WHO, 2007) in order to identify inappropriate and irrelevant terms and make decisions about necessary modifications before the forward translation process. Gjersing et al. (2010) highlight the need to assess the conceptual relevance of a questionnaire as a whole and, subsequently, individual items, with relevant experts from the target population.

7.4.1 Sample and eligibility criteria

Use of a multidisciplinary panel with relevant expertise in the field of paediatric palliative care was anticipated would result in a better-adapted questionnaire (Guillemin et al., 1993). To be eligible to become a member of the panel included being a bilingual expert (with Arabic as his/her mother tongue but proficient in English), from the Jordanian culture and familiar with palliative care services provided in Jordan.

Instructions, items and response options were evaluated in terms of cultural relevance and content validity. Although the WHO guideline is not clear in terms of a panel's required qualifications, composition of the panel was crucial to achieving an equivalent questionnaire by obtaining relevant and experienced professionals' opinions on the prototype. It was aimed to recruit 5-7 participants from different healthcare backgrounds who had experience of providing paediatric palliative care through medical, surgical, intensive and oncology departments to help ensure optimum adaptation of the questionnaire.

7.4.2 Recruitment

Experts invited to participate in the panel were identified from published papers concerning palliative care in Jordan. One member was suggested by another expert based on his work at the tertiary cancer centre. Potential members were contacted initially through their professional email addresses to invite them to join the panel and outline what would be involved (Appendix K.1).

7.4.3 Data collection

Once an expert responded, a call was arranged at a convenient time to introduce the research study and discuss any concerns and queries. Once participation was agreed upon, an email was sent to the expert with a copy of the VOICES-C (English version) questionnaire and a request to add their comments concerning questionnaire items and response options. In addition, the experts had the choice to send their feedback via email or by personal interview by phone or Microsoft Teams. Panel members provided their feedback independently from one another. Experts were asked to review the questionnaire, comment on the questions, and suggest any relevant amendments such as how to reformat questions or add suitable responses.

7.4.4 Data analysis

Feedback was analysed using a framework analysis approach in order to reach the point where it was possible to identify necessary additions, deletions and modifications to items and response options. This approach comprised five steps; familiarisation, identifying a thematic framework; indexing; charting; and mapping and interpretation.

The initial step involved reading and rereading written feedbacks, interview scripts and comments, then a list of expected categories that could be placed within the framework was developed. These categories labelled the comments and feedback from the experts into meaningful and coherent data extracts. Once the themes had been identified, the data were examined and indexed into the relevant category to form a chart. Following this step, direct quotes and notes were indexed within the relevant category in the chart. Finally, interpretation of problems and suitable amendments were listed (Appendix K.2).

Another table was developed of the key problems emerging from the analysis of panel members' comments and notes regarding content relevance in the Jordanian context. Appendix K.3 presents the categories used during the framework analysis and items related to each category. In addition, suggestions for amendments were added to the table, such as deleting irrelevant items, modifying existing items, and adding any significant items missing to ensure best fit to the context of health services in Jordan. Comments were entered into a table consisting of the four problem categories, representing aspects of equivalence Beaton et al. (2000):

- Semantic problems: which focused on the words' meaning and grammar of items. The items belonging to this group were translated and rephrased into an acceptable format using the most suitable words.
- Idiomatic problems: which included the items that did not have corresponding terms in the Arabic language. For this category, the problematic items were replaced with items relevant to the target population or examples added as required.
- Experiential problems: which captured the cultural differences in daily life activities and experiences for the Jordanian population. The solution to this type of problem was to delete or replace the problematic items with similar items experienced by the target population.
- Conceptual problems: which included items that do not have equivalent concepts in the Jordanian population or culture. The solution to this category was to delete or replace the problematic items.

7.5 Translation and back translation

This step aimed to achieve an Arabic language version of the VOICES-C that is clear and expressed in a common Arabic language. In addition, this step aimed to ensure linguistic equivalence was achieved whilst maintaining the intended meaning and conceptual framework of the VOICES-C questionnaire (English version). According to the WHO guidelines, this should be conducted one translator, preferably a healthcare professional familiar with end of life care terminology and with the questionnaire conceptual framework of the original questionnaire. The translator should be bilingual i.e., native Arabic language speaker with knowledge of the English language. On the other hand, the back-translator should be bilingual and with no knowledge of the original questionnaire. The back-translated prototype was reviewed by one of the supervisors (KH) to validate the accuracy of the translation and ensure nothing was lost or misinterpreted in the translation. The English version of VOICES-C was then translated by the researcher (bilingual in Arabic and English) into the Arabic language. This translation was be back-translated by a bilingual translator and reviewed by a member of the supervisory team to ensure consistency with the English version.

7.6 Cognitive interviews in Jordan (bereaved carers)

The purpose of this step was to identify the need for and nature of amendments to the Arabic prototype and develop the protocol for the feasibility study i.e., what was the most appropriate way to approach bereaved carers, who might make the first contact and determine what length of time should have elapsed since death of a child to minimise the chance of provoking significant distress amongst recruited bereaved carers.

7.6.1 Sample and eligibility criteria

Cognitive interviews were conducted with Jordanian bereaved carers representing the target population for the feasibility survey. The sample was drawn from two governmental (public) hospitals in Amman and Alkarak cities. The rationale for choosing these hospitals was that the former was a major hospital, while the latter was a local hospital which allowed the researcher to approach a diverse sample in terms of diagnoses and services provided because usually children are transferred to major hospitals in Amman for care. Both hospitals have a medical paediatric department, a neonatal intensive care unit (NICU) and a paediatric intensive care unit (PICU). All departments were considered whilst recruiting carers for this step to increase the range of participants potentially approached and variation in their experiences.

Sampling window

Studies involving bereaved parents involve a variety of elapsed time frames since a child's death. Two recent studies explored bereaved parents' opinions about their experience of participating in bereavement research (Butler et al., 2017, Donovan et al., 2019). In the original Butler et al (2017) study, eligible parents were those who lost a child between six months and four years previously. The most preferred timeframe to be contacted for research was 12 -24 months after a child's death. They explained that this timeframe allowed parents to have some time after the child's death to avoid intense grief and minimise the impact of recall bias (Butler et al., 2018). In the only study conducted with bereaved parents in Jordan, Abdel Razeq and Al-Gamal (2018) recruited mothers of neonates who died within 12 months after being admitted to the NICU's for at least 24 hours. In contrast, Donovan et al. (2019) conducted a pilot study that targeted bereaved parents who lost a child from cancer between six months and six years previously. Participating parents reported that the timeframe to be involved in similar research should be no earlier than four to six months post-death and had "no endpoint".

The elapsed time after a child's death in previous post-bereavement studies varies without any evidence supporting their chosen limit for recruiting bereaved parents; hence, any limit would be arbitrary. In addition, the elapsed time after a relative's death in previous VOICES-SF survey studies in adults was from three to twelve months. In keeping with previous VOICES-SF studies, the elapsed time selected for cognitive interviews was three to twelve months with excluding inviting parents around sensitive dates such as a child's birthday and death anniversary.

Inclusion criteria

Recruitment of participants was conducted in agreement with participating hospitals after obtaining approvals from the University of Southampton Ethics Committee and the Jordanian Ministry of Health (MOH). Inclusion and exclusion criteria for the study are outlined in Table 7-2.**Error! Reference source not found.** Since VOICES-C is a generic tool, not for a specific illness, the targeted population was bereaved carers of children who had died with any life-limiting condition, including cancer, cardiac anomalies, muscular, metabolic or neurodegenerative conditions, and brain injury (Hain et al. 2013). The sample included children under 12 years who were admitted to paediatric units taking into account the cultural and religious age of maturity in Arab nations. In the Arab world, cultural and religious beliefs play a vital role in different life aspects, for example, the maturity age is reached at 12 years, and therefore children older than 12 years old are considered young adults and are admitted to adult hospital departments.

Table 7-2 Inclusion and exclusion criteria for cognitive interviews

Inclusion criteria	Exclusion criteria
• A parent or carer of a child who had died between three and twelve months (avoiding the anniversary of the death or deceased child's birthday) prior to recruitment. • The deceased child was between 0-12 years old at the time of death. • The underlying causes of death was a life-limiting condition (LLC), such as cardiovascular disease (CVD), cancer and others according to the international statistical classification of diseases and related health problems – tenth revision (ICD–10). • The bereaved carer can speak and understand the Arabic language.	• Parents of children that died due to traumatic injuries such as an accident, suicide or sudden death, according to ICD-10. • Parents/carers who cannot speak or understand the Arabic language.

7.6.2 Recruitment

Eligible participants were recruited through public hospitals using an opt-in recruitment approach, which means participants were approached by the researcher only if they agreed to participate in the study. This approach was chosen due to the sensitivity of the subject and participants' vulnerability. The identification and recruitment strategies were as follows:

1. A named nurse (coordinator) was asked to act in this capacity and to contact participating sites on behalf of the researcher. The coordinator was informed of the study's overall aim, the objectives of the phone interviews, eligibility criteria and a list of eligible cases.

2. After obtaining approvals from the University of Southampton and the Jordanian MOH, the researcher contacted the manager of participating hospitals to introduce herself and the study. Arrangements were made for the coordinator to travel to the hospital and meet personnel at the medical records to facilitate identification of childhood deaths from the hospital's records.
3. The coordinator worked with a designated member from the hospital to review medical records and match them with the inclusion criteria. Contact numbers of eligible parents were obtained from the records after excluding ineligible cases. By using this approach the confidentiality and privacy of participants were protected since the researcher did not access any identifiable information about the participants (Butler et al., 2017).
4. The coordinator made the first phone call to potential participants, introduced the study and asked about their willingness to participate. The coordinator was provided with the Arabic versions of the questionnaire, Participation Information Sheet (PIS) and consent form, to guide her in explaining to potential participants what they can expect if they agree to take part in the interviews (Appendix K.4).
5. The coordinator provided a verbal description for participants during the initial call (see Appendices K.4.1 and K.4.2). Participants who agreed to participate and had access to the internet were offered to receive the material by sending a WhatsApp message with a link to the Google Docs website, or by email (see Appendices K.4.3 and K.4.4). This approach was used because Jordan does not have a functioning postal service.
6. After initial contact by the coordinator nurse, and with their consent, carers were contacted by the researcher to arrange the interview date and time within 48 hours.
7. The coordinator provided the researcher with the contact details of potential participants in order to approach them.
8. The researcher contacted the parents by phone and asked if they would be willing to complete the survey over the phone. The researcher attempted to contact participants up to three times if there was no response at the first call (Bowling, 2014).
9. Participants who answered the researcher's call and agreed to complete the questionnaire by telephone were given the choice of completing the survey at that time or scheduling a more convenient time.
10. Participants who asked for further time to think were encouraged to ask further questions about the research and given up to 48 hours to consider their participation.

11. Once a parent had agreed to participate and made an appointment for questionnaire completion with the researcher, the researcher proceeded to conduct the interview.

7.6.3 Data collection

Qualitative data were collected through semi-structured telephone interviews using a pre-determined interview schedule with probes (Appendix K.5) to elicit an in-depth understanding of participants' perceptions of the relevance and suitability of the questionnaire and ensure it was an authentic representation of current practice. This approach is more convenient in terms of time-saving and ensures that all-important topics are covered (Drennan, 2003, Turner et al., 2007). Probing questions were used, reflecting the four key stages of the cognitive model introduced by Tourangeau (1984): comprehension, information retrieval, judgment and forming a response (Czaja, 1998, McPherson and Addington-Hall, 2004, Hales et al., 2012, Drennan, 2003, Irwin et al., 2009).

Furthermore, following the process of working through the questionnaire with participants, the researcher asked participants for additional information regarding their thoughts about the appropriate method to recruit participants in a VOICES-C survey, i.e. when the best time after death to approach them might be, who should make the initial contact with them, how many times they should be approached to participate (reminders), and how they would prefer to receive the survey material. Participants had the opportunity to provide their opinions about the methods of recruiting and completing the questionnaire.

Previous research has shown that bereaved family members were willing to participate in end of life or bereavement research (Head and Faul, 2007, Preston et al., 2009). In this study, it was anticipated there would be some risk of emotional distress to participants due to the nature of the questionnaire, which asked participants to recall a sad and distressing time. It was hoped, however, that this risk would be slightly mitigated due to the time that would have passed between their experiences of palliative care and completing the questionnaire; hence, carers were not recruited immediately following the loss of a child. in addition, the PIS form requested that ahead of the interview participants should identify a person who they would feel comfortable talking to after the interview and ask this person if they would be willing to be contacted by the researcher interviewer in the event that the participant became distressed.

Before conducting the interview, the interviewer reaffirmed that a support person was at the household with the participant or had been identified and agreed to be contacted by the interviewer as requested in the PIS form. Whenever the interviewer sensed the participant was experiencing mild distress, she encouraged the participant to talk to the support person, whether s/he was in the same household or lived nearby. Furthermore, the participants were reminded that they could withdraw from the study or stop the interview at any time, and could complete the survey at another time if they wished.

Taking into account that some questions could cause psychological distress as they would remind the participants of unpleasant experiences associated with their deceased child, participants were asked to rate the emotional distress they experienced during their participation on a scale from 0 to 4, where 0 was not at all and 4 was extremely distressing.

7.6.4 Data analysis

The cognitive interviews were analysed using the steps outlined by Knafl et al. (2007) which include; transcribing the interviews, summarising the participants' responses to each item and identifying the categories/types of problems across the entire data, analysing each item summary and making decisions about the items.

After each interview, the participants' comments and supplementary notes were transcribed in the English language in preparation for the analysis process. Parents' accounts were transcribed to reveal how they perceived the questions and response options. Secondly, each participant's comments on every individual item were identified within the questionnaire and produced a summary of each participant's responses for each item from the transcripts and notes. The third step was summarising each participant's responses into a table to produce an inclusive summary of problems corresponding to each question. Fourthly, the summaries from all interviews were compiled into one table outlining all the comments next to the corresponding item. By conducting these steps, the initial map of problem categories informed the analysis framework. Fifthly, summaries of each question were reviewed and coded into specific categories reflecting the nature of problems and concluding with suggestions for the changes because each category required different actions (Irwin et al., 2009, Knafl et al., 2007). Finally, the findings from these summaries were synthesised to conclude the overall problems related to each question/ item and propose potential amendments to overcome these problems.

7.7 Chapter summary

In this chapter the methods employed in the cross-cultural adaptation, including recruiting panel experts to review the English prototype, and interviewing bereaved carers to amend the Arabic prototype, and methods of analysis have been described. The findings from these different exercises, which culminated in generating VOICES-C (Arabic) survey questionnaire for the later pilot survey, and information informing the data collection protocol to be used will be presented in the next chapter.

Chapter 8. Phase II Findings: Cross-cultural adaptation

This chapter presents a summary of the demographic characteristics of experts participating in the cross-cultural adaptation and bereaved carers recruited to the cognitive interviews and the findings from these exercises, along with the resulting amendments to the VOICES-C questionnaire (Arabic version).

8.1 Expert panel

8.1.1 Participants' characteristics

Experts had a background in healthcare, with relevant knowledge and experience in the field of paediatric palliative care and experience of working in palliative care in Jordan. Five healthcare professionals who met the above criteria were contacted, responded and agreed to participate. Among those invited were individuals with a doctoral degree in nursing, with prior experience working and /or researching in the geographical areas to be included in the survey. Four participants were academic lecturers in Jordanian universities and members of national and international associations concerning: neonatal, paediatric, palliative, or oncology care. One was a nurse who worked at the King Hussein Cancer Centre (KHCC). Three of the experts had published papers on paediatric palliative care in Jordan, two members had experience of translating and adapting patient-reported outcome measures to Arabic. One expert had conducted a post-bereavement study with grieving parents in Jordan. The only expert with no previous experience of working with the paediatric population was recruited due to his involvement in, and knowledge of services provided by, the KHCC and member of the Palliative Care Jordanian Society (PCJS).

8.1.2 Data collection

Two pieces of written feedback were received, and three video conference interviews conducted to obtain experts' comments on the questionnaire resulted from Phase I (Appendix J.6). The pieces of feedback were tracked Microsoft Word documents containing the experts' comments. The recorded interviews were between 63 and 90 minutes. Data were collected over one month. The experts reviewed the entire questionnaire; the introduction associated with questions, questions' wording, and response options, identified and described problems and issues with respect to the Jordanian context.

8.1.3 Results

General comments

The experts valued the process of adapting the VOICES-C questionnaire and acknowledged that although certain types of services and professionals were lacking in paediatric palliative care in Jordan, such as psychological support services, hospice care, and community nursing, this questionnaire *"highlights important aspects which should be addressed"* which implied that the majority of children spend their last days at the hospital not at home with their families (expert 4). One expert appraised that the questionnaire considered different healthcare settings and periods of time throughout a child's journey. She acknowledged that parents' needs and therefore satisfaction might vary according to where the child was on the illness/ death trajectory (expert 5).

The main concern highlighted by the majority of experts (4/5) was about *"being translated carefully"* in order to be comprehensible and acceptable to potential participants. For instance, two experts recommended referring to the deceased child as *"your child"* across the questionnaire instead of *"s/he"* (experts 1 and 4). Another expert expressed concern that the questionnaire was long and difficult to go through for bereaved parents therefore it needed more organisation such as numbered sections for easier navigation (expert 3). Two experts recommended considering a participant's nationality and health insurance provider in Jordan which may impact upon accessibility of certain care services (experts 5 and 4, respectively). One expert pointed out the cultural differences in Jordanian hospitals as children older than twelve years old are considered young adults and usually admitted to adult units/ departments.

Semantic problems

Experts made comments regarding questions they anticipated might be offensive or need amendments regarding a question's structure or included words. For example, questions 1 and 2 (What was your relationship to her?) and (What was her age when she died?) were judged to be very direct and sounded like an *"interrogation"* (expert 4). These questions were felt to need careful translation to ensure they were acceptable to participants. Question 3 (What is your age?) could be misunderstood by participants who might assume that it asked about their age when the child died (expert 3). On the other hand, questions 61 and 63 assumed that a child and sibling/s would be informed about a child's death, which is not always the case in Jordanian culture. Therefore, two experts recommended seeking clarification from participants whether such a conversation had taken place before asking these sorts of questions (experts 4 and 5).

Idiomatic problems

This category included the items deemed by the experts as difficult to translate, either because they did not have an Arabic equivalent, or they were too broad and required further specification in order to be translated appropriately (experts 3, 4 and 5). For instance, two experts commented that the terms "support", "trust", and "needs" in questions 26, 28, 50 respectively were very broad and needed clarification in order to be clear in the Arabic version. Whilst another expert highlighted that question 51, option d included two different concepts "spiritual" and "religious", and that should be addressed separately.

Experiential problems

This category comprised items irrelevant to the target population or the healthcare system. The majority of experts' comments fell into this category. For example, four experts commented that the response options for question 1 (What was your relationship to her?) were irrelevant to the Jordanian population i.e., "foster parent" and "legal guardian". Likewise, response options for questions (5 and 6) were *"irrelevant to the Jordanian community"* (expert 1) based on the fact it is not a racially mixed community. Similarly, question (7) was considered irrelevant to the Jordanian population, therefore the researcher retained the responses "Muslim" and "Christian" only. On the other hand, two items were added to the Arabic version "what is your nationality?" and "What is your health insurance?" as these items address the main factors that influence access to healthcare services in Jordan according to Expert 4's recommendations.

The majority of changes to the questionnaire were in regard to care provided by community services and hospice settings and staff. Two sections and several individual items and response options including community and hospice care were deleted reflecting the lack of any hospice and community healthcare services in Jordan. For example, the options hospice and/ or community nurse for questions 9, 17, 65, 67, and 68 were deleted, and the sections regarding community care (questions19-21) and hospice care (questions 41-48) were also deleted. An item was added at the beginning of the home care section in order to establish whether the child had received any form of professional care at home or not since there are no regular home care services integrated into the Jordanian healthcare system.

Similarly, other items were deemed irrelevant due to available healthcare services or staff. For example, the response options for question 10 (When she was at home in the last three months of life, did she get any help at home from any of the services listed below?) were modified to fit the provided services in Jordan. For example, the options "palliative care nurse", "social worker", "GP", and "hospice at home" were replaced with "a nurse" and "private agency". Consequently, questions 11 and 13 (When she was at home in the last three months of life, did all these professionals work well together?) and (Was there a named health professional responsible for her care?) were deleted as different services do not work cooperatively in Jordan to provide end of life care for children.

Response options for question 17 (The last time this [urgent care out of hours] happened, who did you contact?) were modified to relevant options, such as (GP) was replaced with the (treating doctor/ consultant), (999) was replaced with the emergency phone number in Jordan (911) and the responses (NHS 111), (community nurse), and (a hospice) were deleted.
Lastly, question 25 was modified as, unlike the UK, GPs are not involved in the care of paediatric patients in Jordan and *"GP is not involved in the paediatric care"* (expert 3).

Conceptual problems

This group of problems included two items that were incompatible with cultural and religious concepts. Three experts suggested deleting the options f and g (Have access to a cool bed for her) and (Have access to a cool room for her) related to question 56 as they were inapplicable. Similarly, question 66 (Did she ever say where she would like to die?) was deemed irrelevant because *"most often children are excluded from such conversations and not being told their cancer diagnosis in Jordan"* (expert 1). In the same vein, questions 61 (Who talked to her about death?) and 63 (Did a health professional support you in talking to her sibling(s) about death?) were considered inapplicable to the Jordanian society. These items *"assume that such a conversation has taken"* (experts 4 and 5). However, these items were maintained in the Arabic version to explore families' experiences around the time of death and siblings support considering the lack of evidence from Eastern contexts.

This step illustrated the value added by including experts with relevant knowledge and experience in the field of paediatric palliative care. There were notable differences in contexts of healthcare i.e., the UK and Jordan which were valuable to refine the questionnaire before the forward translation. The experts raised issues about the accuracy of translating certain terms such as ‘support’ and ‘trust’ which may need further specification. These terms have Arabic equivalence terms that can be understood by the target population. The Arabic terms were used without further specification to maintain uniformity with the VOICES-C English version and for further investigation with bereaved carers in a similar manner to the development phase. Changes according to experts’ comments were regarding the Jordanian context i.e., the population, healthcare system and available services and facilities.

Summary of amendments recommended by panel experts:

1. Add “now” to the question statement for the participant’s age.
2. Revise the ethnic groups for questions 5 and 6
3. Add an item regarding participants’ nationality.
4. Add a question about the provider of health insurance
5. Change the options of the religion item (question 5); keep Christian and Muslim.
6. Delete the option “No-she was in a hospice” in question 9.
7. Add an item to ask if there was any home care before asking who provided it.
8. Modify the options of Home care services; keep “a nurse” and add “private agency”
9. Delete questions (11-13) since there are no different services.
10. Update the response options for question 17 to conform with the Jordanian context
11. Delete the community nurse section (question 19-21) because it is inapplicable
12. Delete question 25 because there is not a specific GP assigned to each child according to the healthcare system in Jordan.
13. Delete the hospice section (q41-48)
14. Delete options f and g for question 56
15. Delete the “in hospice” option in questions 67 and 68
16. Revise question 69 options according to the former questions, maintain across-item consistency.

8.2 Translation and back translation

Following the experts' recommendations, the VOICES C (English prototype) was amended and forward translated into the Arabic language independently by the researcher; a native Arabic language speaker with an excellent understanding of English, involved in the development of the original VOICES-C version and had interviewed healthcare professionals from the UK and Jordan. The researcher was keen to emphasise conceptual rather than literal meaning throughout the translation. This translation resulted in VOICES C (Arabic prototype), (Appendix K.6) which was back-translated by a translator (AppendixK.7K.7). The back-translator, who was identified from the researcher's social network in the UK, was fluent in both Arabic and English languages and had knowledge of English linguistic nuances.

The back-translated version was reviewed by one of the research team (KH) one of the researchers who developed the original VOICES-SF and VOICES-C questionnaires, to identify any discrepancies between the VOICES-C prototype and back-translated versions and ensure that the Arabic version reflected the intended concepts in the prototype. The reviewer compared the two versions regarding wording, structure and meaning of the instructions, items and response options. At a virtual meeting, the researcher (forward translator) and the reviewer discussed ambiguities and mistranslated items and reached a consensus that the Arabic prototype was ready to be used during the planned cognitive interviews.

There were no significant conceptual differences between the back-translated and original versions. The reviewer commented on using "your child" instead of using "her" or "his" and explained that participants in the original VOICES-SF preferred "he" or "she" to reflect their personal experience. Additionally, the reviewer expressed her concerns regarding a few poorly structured sentences, although they did have the right meaning. For example, the reviewer described the sentence order as *"odd"* in item 12 (During the last three months of life, and while the child was at home, to what extent the pain your child felt was relieved/ managed?). Additionally, question 20 (Were the services provided by the hospital in good working order with specialist/ physician?) as a *"clunky sentence"*. Moreover, statements of item 37 (Please read the following statements and tick the box where you agree as much as possible in regard to the care provided in the last two days of your child's life) were poorly structured because they *"do not look as full statements that can be answered with agree"*. Finally, statements of question 43 (If you wanted to, after the death of your child, were you able to) did not flow with the question's statement. The back-translation revealed that terms identified previously as 'need careful translation' by experts were translated properly and conformed with the English version.

The researcher confirmed that these questions and statements were comprehensible in the Arabic version and in line with Arabic language grammar. The researcher explained the source of this problem was due to the grammatical differences between Arabic and English languages. For example, regarding question 37, the statement (your child's needs were met) is considered as a full sentence in the Arabic language because in Arabic there are two types of sentences; a noun sentence, that starts with a noun and does not require a verb, and a verb sentence, that starts with a verb. In addition, the statement "Taking enough time with your child", following question 43 aligned with Arabic grammatical rules because "to" is a preposition that should be followed by a noun, not a verb.

Based on the reviewer's recommendations, the researcher decided to amend "your child" in the questionnaire to "she" and "he" thus creating two separate versions of the questionnaire for female and male children. The reviewer and the researcher agreed to examine this issue in the cognitive interviews with bereaved parents from the target population. Following discussion, the researcher retained other questions and statements that preserved the intention of the original questionnaire while maintaining linguistic equivalence. The VOICES-C (Arabic version 1) was tested with the target population in the next step (Appendix K.8).

8.3 Cognitive interviews with bereaved carers in Jordan

8.3.1 Participant characteristics

Thirty-four records of children who died between 1st October 2019 and 1st July 2020 were identified from medical records by the coordinator nurse (KS) in less than two hours at each hospital. These deaths were reviewed by the researcher against the eligibility criteria and 26 cases were eligible to participate in the study. The majority of childhood deaths were neonatal (n=18). After obtaining telephone numbers, 26 parents were contacted by the coordinator nurse over three days between 12 midday and 5 pm. One contact number was no longer used, and 11 contact numbers were not answered after three attempts. Fourteen respondents answered, four of them refused and 10 agreed to participate, of whom eight were interviewed, and two respondents didn't answer the second call to schedule the interview. Figure 8-1 presents a flowchart of the recruitment process. The interviewed participants were six mothers and two fathers, their ages ranged between 20-49 years. The children were four neonates and four older children who had been cared for by public, military and university hospitals and the cancer centre. A summary of bereaved carers' characteristics is presented in Table 8-1.

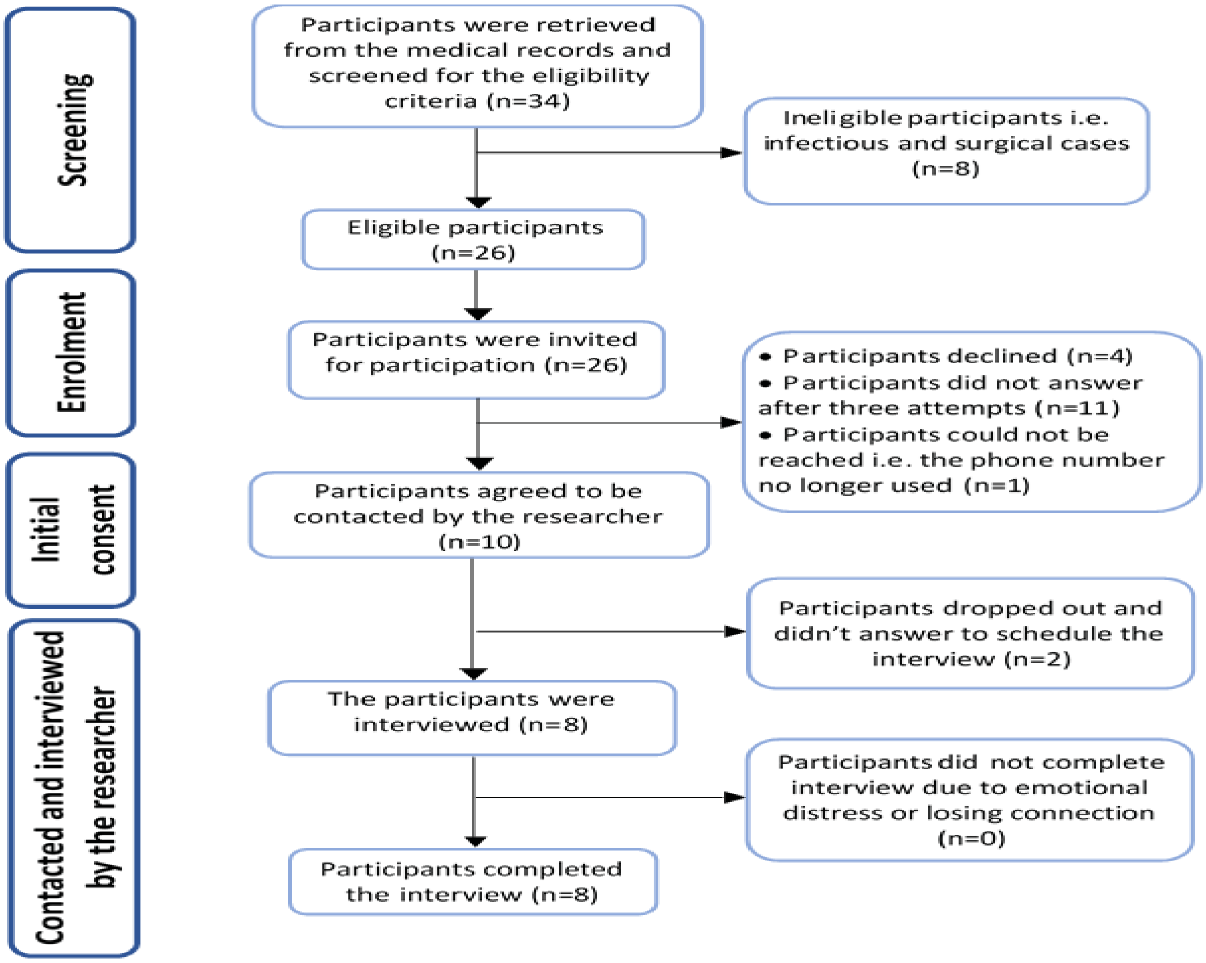


Figure 8-1 A flowchart of the recruitment process for cognitive interviews

Table 8-1 Cognitive interviews' Participants' characteristics

Participant ID/ relationship	Child's age	Elapsed time	Place of death/ ward	Condition	Interview length
CIJO01	7 days	6 months	NICU	Lung collapse	129 mins
CIJO02	15 days	9 months	NICU	Respiratory problems/Prematurity	48 mins
CIJO03	9 years	5 months	ICU ward	Brain tumour	93 mins
CIJO04	12 years	4 months	ICU ward	Congenital disease (Hypercalcaemia)	68 mins
CIJO05	3 days	1 year	NICU	Respiratory problems/Prematurity	46 mins
CIJO06	3 years 10 months	5 months	Home (arrived A&E dead)	Brain atrophy	51 mins
CIJO07	14 days	11 months	NICU	Chronic renal failure	58 mins
CIJO08	11 months	11 months	PICU	Metabolic disorder PKU	59 mins

8.3.2 Data collection

Interviews were conducted over two weeks between the end of October and the beginning of November 2020 at times convenient for the participants. The average length of interviews was 68.6 minutes, and all interviews were completed on one occasion, on a single phone call. All participants had the opportunity to ask questions, confirmed that there was a support person at the household during the interview, and gave their verbal informed consent before completing the questionnaire over the phone. The researcher read the consent form to participants and obtained their verbal consent which was audio recorded. The researcher then started a separate recording for the interview and read the questionnaire while asking participants to complete it and express their interpretations about the items', the associated response options and instructions in order to refine the questionnaire's content. For example, they were asked what they thought about the questionnaire's wording and clarity, what came to their minds when they read words such as "trust" or "support", and how they chose their responses. Structured prompts were used as needed.

Notes and tracked changes were made of participants' comments next to each item on an electronic copy of the questionnaire during the interview (Johnson et al., 2011). During the interviews, participants were encouraged specifically to verbalise their thoughts while answering the prototype regarding the content, language, length, and the probable responses to the questionnaire (Czaja, 1998, Drennan, 2003).

8.3.3 Results

Following the approach of Knafl et al. (2007) to analysing cognitive interviews, four categories of problems in VOICES-C (Arabic) items were identified. Appendix K.9 presents a summary of the problems identified and proposed changes. The categories were:

- Linguistic

This category encompassed the items including inappropriate or confusing words i.e., has broad concepts, multiple inferences or unclear references. For example, question 8 which asked for how long the child was ill, was considered confusing whether it referred to the *"the beginning of the illness"* (mother of a 12-year-old girl) or when the child's condition deteriorated. While a participant (mother of a 9-year-old girl) sought clarification for the term "consultant" in response options for question 15 (The last time this happened, who did you contact?) *"did you mean the consultant at the hospital or who follows the child's condition".*

Turning to the words reported by the panel experts as *"broad"* and needing further specification such as "care" and "trust", these terms were easily understood by the parents. Participants described "care" as *"they were speaking in a kind way and treated her as their child"* (mother of 12 years old girl), *"Being considerate to the child"* (mother of 9 years old girl) and *"compassionate"* (father of 14 days old boy). While a participant said trust is that *"I am confident that the staff will do their best for my child"* (father of 7 days old boy).

- Question structure

This category included items that contained incorrect tenses or grammar and wordiness. There were two incidences where the interviewer had to explain the question to the participants.

For example, the interviewer had to read question 36 (How much of the time was she looked after in a caring way in the last two days of her life?) two times to a participant in order to understand it. The participant (father of 7 days old boy) recommended rephrasing the question for better comprehension.

Another participant (mother of 9 years old girl) asked for clarification of the "support" that might be provided to her in question 39 (I/we had a supportive relationship with the health care professionals). She suggested resolving this issue by adding *"as the child's companion"* to make it clearer for respondents what is meant by support.

- Limited applicability

Questions that fell into this category were those that included words or phrases that did not apply to the available services, religious and cultural beliefs featured in this category. The most frequent comments among participants were related to this category.

For instance, question 38 regarding the level of care in the last two days of life, sub-question e (In the last two days of life, efforts were made to make sure she was in the place we as a family most wanted her to be cared for) was deemed inapplicable to the majority of participants who expressed they didn't have the choice to decide the place of care and they wouldn't have moved the child from the treating unit *"Difficult question, as a parent I want my child with me at home, but I couldn't risk taking him due to his condition"* (father of 7 days old boy).

Similarly, parents verbalised that there wasn't another choice for the place of death in question 55 (Where did you want her to die?) such as *"I didn't have a choice of place of death, because she needed intensive care"* (mother of 3 days old girl). This view was echoed by another informant who stated that *"There are no choices in our culture, the patient will recover or die at the hospital, even if we were offered to take him home, I wouldn't do that because there isn't anything I can do"* (father of 14 days old boy).

As a result, questions 56 (Did the health care staff have a record of this?) and 57 (Do you think you as a family had enough choice about where she died?) were considered irrelevant to the parents' experiences. In their accounts of the issues surrounding telling the child he was going to die, the parents of the oldest two children found that informing them of imminent death is inconsistent with cultural customs among terminally ill children in Jordan (q46). Consequently, questions 53 (Did she ever say where she would like to die?) and 54 (Where did she say that she would like to die?) were inapplicable.

The majority of participants agreed that questions 41 (Were you supported by staff to touch or hold your child at this time?) and 43 (If you wanted to, after her death, were you able to) had items that were irrelevant to current practices in Jordanian society such as spending time with the child's body, dressing it and making memories of the child. Question 44 regarding being contacted by health services or professionals was deemed inapplicable as current health services in Jordan don't provide post-bereavement support and healthcare professionals are not expected to contact the parents. However, two parents (mothers of 9- and 12-years old girls) reported that they had been contacted by professionals who provided care for their child, at a personal level, since their children were admitted recurrently to the ward. Similarly, item d in question 38 regarding religious support in the last two days of life was remarked as uncommon because Muslim priests (Sheikh) rarely have any role in providing religious support to patients and carers and any ceremonies or prayers can be done by family members.

- Response options

The last category reflected the problematic response options which included more than one option with the same interpretation or meaning, and missing options. For instance, participants with children had different answers for questions (23, 32, and 51) regarding siblings' support by the staff when they visited the child at the unit and talked about the child's death. The siblings didn't visit the child at the hospital; therefore, parents' responses were a mix of "No" or "Does not apply" and there was a response missing to differentiate whether siblings were not allowed to visit because of hospital regulations or parents' choice. Similarly, three parents of deceased neonates answered question 30 about being involved in the child's care as "No" or "Does not apply", although they expressed that they didn't ask the staff to do something for the child and the staff didn't encourage them to take part in the care. The response options for question 50 were considered to be missing an option since the siblings were informed of the child’s death and supported by other family members such as aunties. Healthcare professionals didn’t have a well-defined role to speak about death with siblings and support them. Although question 10 asked about the professional care provided when the child was at home in the last three months, parents were unanimous in the view that other family members and relatives had helped in providing care to the child at some point which didn’t have a suitable response in the questionnaire; the available responses were “Yes” and “No”.

- General comments

Bereaved parents valued the initiative of designing a questionnaire to explore their views and evaluate healthcare services. The parents didn’t comment on the questionnaire’s length and overall layout, or the issue of referring to the child as “s/he” or “he” and “she”. All parents expressed that they didn’t hesitate in considering their participation because it was a good deed and participation driven by the desire to help the researcher and parents of terminally ill children.

The next section of the interview was concerned with the additional issues surrounding exploring future recruitment strategies such as the elapsed time since death of the child, the approach to be used to be contacted, and the means of the information sheets and the questionnaire documents. The elapsed time after the child’s death for the interviewed parents ranged from 4 months to 11 months. All parents agreed with approaching future bereaved parents within the first year of the child’s death and avoiding the first two months after and the month of death. Three participants favoured being approached earlier (2-6 months after death) considering the interview as a means of expressing their feelings. The majority of parents expressed that they didn’t mind being contacted either by a nurse or the researcher, only two preferred to be contacted by the researcher as *“an independent third party”*. In the same context, parents recommended sending a message before the initial call to minimise the incidence of dismissed or unanswered calls. All participants preferred receiving the documents by WhatsApp because the majority didn’t have emails and found it convenient to read documents on the phone screen.

When asked about the emotional distress caused by the interviews, four parents (50%) felt that the interview wasn't stressful (score of 0 out of 4), while three felt mild distress (score of 1 out of 4) and one felt moderate distress (score of 2 out of 4) during the interview. However, none of the participants requested to stop the interview at any point and reschedule to complete the interview on another call.

- **Overall parents' experiences about care provided**

In addition to Jordanian parents' feedback about the questionnaire's content and recommendations for future study, interviews provided important insights about end of life care in Jordan. Bereaved parents reported a variety of negative and positive comments about their experiences.

  - **Positive**

In general, half of the bereaved parents reported that the quality of care was "good". Two parents rated the care given as fair, one as outstanding and one as excellent. Parents of older children were more likely to rate the overall quality of care higher than parents of infants. Similarly, the highest rates of communication, relationship and trust with staff members were for parents of older children. Nurses were rated higher than doctors when bereaved parents were asked about trust and treating the child in a caring way.

  - **Negative**

On the other hand, less satisfaction with the overall quality of provided care was reported by parents of younger children i.e., infants. Lower rates of trust, effective communication, being involved in care were reported by these parents. For example, one parent complained of poor coordination in providing care when he needed a second opinion from a private doctor, but he was not supported to seek this opinion. In addition, the same parent stated that staff members' communication was poor especially when breaking the news that the child was going to die.

Summary of amendments according to the bereaved carers:

Based on the bereaved parents' reports and recommendations the following changes were applied:

1. A response option was added to clarify that the child was ill since birth. A free text space was added to allow bereaved parents to elaborate on their responses.
2. Response options for question 10 were retained, but the phrase “not family or friends” was added in the text preceding question 10.
3. Response option for question 15 “the consultant” was updated to “the consultant in charge of/ following her case”. A free text space was added to allow further clarification.
4. Question 20 was rephrased to “Did the hospital services work well together with the consultant in charge of/ following her case?” to maintain conformity across the questionnaire.
5. Response option for question 22 “No” was modified to “No, I would have liked to have been offered somewhere”.
6. Response option “Does not apply” for question 23 was modified to “Does not apply, there were no siblings”, “Does not apply, we did not want her siblings to visit her”, and “Does not apply, the hospital did not allow them to visit her”.
7. Question 29 was rephrased to “Did the hospital services work well together with the consultant in charge of/ following her case?”.
8. Response options for question 30 were added “No, I was not allowed to be involved” and “No, I was not offered to be involved”. A free text space was added to allow further clarification.
9. Response option for question 31 “No” was modified to “No, I would have liked to have been offered somewhere” and “Does not apply, I was already a patient in the hospital”.
10. Response option “Does not apply” for question 32 was modified to “Does not apply, there were no siblings”, “Does not apply, we did not want her siblings to visit her”, and “Does not apply, the hospital did not allow them to visit her”.
11. The phrase “such as the staff spoke to me or invited me to have a cup of coffee” was added to item c in question 37.
12. The phrase “such as reciting religious texts” was added to item d in question 38.
13. Question 38 item e was deleted.
14. Question 39 item d was deleted.

15. Response option for question 41 “No” was modified to “No, I was not allowed to hold or touch the child” and “No, I was not offered to hold or touch the child”. A free text space was added.
16. Question 43 was replaced by “If you wanted to, after her death, were you able to be involved in her wash (perform Ghusl)?”.
17. Question 44 was rephrased to “Since she died, have you talked to any health care providers, about your feelings about her illness and death?”.
18. Response option for question 45 “No” was modified to “No, but I would have liked to” and “No, but I did not want to anyway”. A free text space was added.
19. Response options for question 47 “Does not apply – they did not know she was dying” and “Does not apply – they did not tell me she was dying” were rephrased to “Does not apply – I did not know she was going to die” and “Does not apply – No one told me she was going to die”.
20. Question 47 was changed the order with question 46 “Did she know she was going to die?” for easier navigation.
21. A response option for question 48 was added: “another family member did, such as aunts or grandparents”.
22. A response option for question 48 was added: “another family member did, such as aunts or grandparents”.
23. Questions 53-56 were deleted.
24. Question 57 was rephrased to “Would you have liked as a family to have the choice about where she died?” A free text space was added.
25. Question 58 was deleted.

8.4 Discussion

The findings that emerged from the experts and bereaved carers identified general difficulties and provided recommendations for amendments of the VOICES-C Arabic prototype, and facilitated a culturally appropriate version of the VOICES-C Arabic questionnaire to be employed in the feasibility survey. Items and response options that participants reported being clear and comprehensible were retained, whilst irrelevant items and response options were modified or deleted as well as adding items wherever appropriate.

The expert panel step addressed the four aspects of cultural equivalence, as outlined by Beaton et al. (2000). Generally, the proposed amendments can be divided into two main groups: translation-related and cultural-related amendments. The former group involved amendments to ensure easier understanding by the Jordanian participants, mainly related to the semantic and idiomatic problems. Khalaila (2013) has argued that word order in the sentence, comma and tense usage in the Arabic language differ from the English language, and this may influence the adaption of questionnaires from the English language into the Arabic language.
Amendments mainly related to rewording the questionnaire in an acceptable format, for instance, question 1 (What was your relationship to her?) was reworded to a gentler phrasing when translated. The terms "his/ her" in question 2 (What was her age when she died?) were replaced with "your child" to personalise the question, consequently, this amendment was applied for other questions to maintain consistency across the questionnaire. The word "now" was added to question 3 (What is your age?) in the process of forward translation. On the other hand, questions 61 (Who talked to her about death?) and 63 (Did a health professional support you in talking to her sibling(s) about death?) were retained in the translation since there is a preceding item for question 61 -question 59- asking whether the child knew about his/ her death. In addition, question 63 had a response option implying that no one had talked to the sibling/s. These questions were revised to route participants to other questions if participants select the options "no, not at all", "not sure" or "does not apply".

Beaton et al. (2000) acknowledged that it is difficult to translate colloquialisms and idioms from one language to another, which applies to items in the idiomatic category. Following discussions with supervisors, the terms "support", "trust", and "needs" in questions (26, 38, and 50, correspondingly) were retained in the current version and were further explored with Jordanian bereaved parents through cognitive interviews. This decision was made because the same concerns were highlighted by UK healthcare professionals in the previous phase, however, bereaved parents in the UK did not have problems understanding these terms. Therefore, these terms were explored with questionnaire respondents, i.e., bereaved carers in the following step.

Option d for question 51 (In the last two days of life, the family's spiritual and/or religious needs were considered and supported) retained the word religious and the word spiritual was deleted. This decision was taken on the basis that the Jordanian society is essentially a religious community and spiritual values are primarily linked to religious beliefs.

Most experts' comments revolved around cultural-related amendments which included the problematic items concerning experiential and conceptual categories i.e., relevant terms or activities. First, there were several items concerning medical services provided for children in Jordan. It was anticipated some items or entire sections may be removed, such as sections concerning hospice care and community nursing. Response options "hospice" and community nurse" were deleted from individual items and other existing response options were modified to conform to available services in Jordan such as "999" was replaced with "911". Furthermore, General Practitioners (GP) in Jordan is a title of a practitioner who has, usually, recently graduated and not undertaken any specialised qualification. GPs work at primary health centres and emergency departments and they do not have roles in providing care for paediatric patients, hence wherever appropriate. "GP" was deleted from response options or changed to "the consultant/ treating doctor".

Although most of the medical settings in Jordan offer different diagnostic and clinical services, gaps exist concerning the availability of specialised equipment or staff, except in Amman (Al-Qadire et al., 2014, Omran and Obeidat, 2015). These gaps are commonly filled through staff referring patients to other institutions, however, the access to facilities or institutions are restricted to certain groups of patients based on the healthcare insurance or providers i.e., public, military and private providers. Similarly, patients' nationality would limit receiving advanced care and entail extra expenses. Therefore, two items were added to address these gaps; (what is your nationality?) and (what is your health insurance?). This decision was taken given that these elements may facilitate or limit children's access to certain services and might, consequently, impact the overall experience and quality of care provision.

Although honest communication and providing information are vital elements of palliative care and recommended by clinical guidelines, these elements are influenced by a patient's and family's cultural norms in terms of the amount and type of information given to them (Arabiat et al., 2011). Arabiat et al. (2011) explored the disclosure of cancer diagnosis with mothers of children attending oncology clinics in Jordan. The forms of disclosure as reported by 51 mothers were: (20) open knowledge, (15) minimal knowledge and (16) no knowledge. The majority of mothers who reported that their children knew about their diagnosis and treatment, whether intentionally or accidentally, tended to describe the illness by its location or type to the children and avoided *"the death word or cancer"*. Arabiat et al. (2011) argued that difficulties in revealing diagnosis to the child were based on the Eastern cultural beliefs which do not value revealing cancer diagnosis to children.

These findings are consistent with Rosenberg et al. (2017) who acknowledged the cultural role in disclosing poor prognosis to seriously ill children which is common in cultures that consider families as the central unit of medical decision making, rather than individual patients. This can be driven by carers' concerns of negative impacts of disclosing poor prognosis on quality of life such as losing hope and distressing emotions (Wattanapisit et al., 2020). These conversations can be challenging for healthcare professionals, Rosenberg et al. (2017) recommended phrases that may help professionals to identify grounds of a family's request for nondisclosure and alleviate conflict to serve the good of patients and give them the opportunity to express their hopes and fears. For example, (Can you please tell me about your culture/community/faith?) and (Can you tell me about your experiences in your home community in situations like this?). Reflecting on the culture of the Arab world, the lack of communication between parents and children about revealing the diagnosis and imminent death is evident, however, the items regarding telling the child s/he was going to die, such as question 66, were kept to explore the parents' experiences regarding this issue and their thoughts on the sensitivity of this question through cognitive interviews.

In addition, question 56 (sub-questions f and g) were deleted because keeping a dead body after death contradicts the precepts of Islam. An important Islamic principle is to honour a dead person by early burial ceremonies, usually within 24 hours, and any delay in burial is considered as a desecration of the deceased (Sheikh, 1998).

Regarding the cognitive interview step the overall feedback from bereaved carers was encouraging, considering there is almost no research conducted with bereaved carers in a Middle Eastern context. The findings suggested that the Arabic prototype was well translated and understood by participants since the majority of carers' comments were regarding irrelevant items or concepts. The bereaved carers' feedback was beneficial in clarifying how future participants can perceive the questionnaire and informed further amendments to the questionnaire. The majority of amendments were concerning religious beliefs and cultural values in the Jordanian community. In addition, the findings emphasised salient differences between Eastern and Western contexts since religious beliefs and social habits play an important role in understanding and coping with a child's loss (Abdel Razeq and Al-Gamal, 2018).

Firstly, bereaved carers from Jordan were willing to participate and talk about their experiences in order to help other families who might undergo similar experiences (Hynson et al., 2006). Furthermore, although the questionnaire/ interviews reminded bereaved carers of unpleasant experiences, they reported low levels of psychological distress which could be linked to their religious beliefs. Religious beliefs are the foundation and guiding force for Muslims in good and bad times. For example, one of the six Islamic beliefs is Belief in Qadhaa' & Qadr (Destiny & Divine Decree), the good and evil of destiny are in the power of Allah (Khan, 2015). This belief emphasises God's will who has created everything and has predetermined its course of events. This means whatever happens in one's life is preordained, every human shall die at a particular time and place, and believers should respond to the good or bad that befalls them with thankfulness or patience. Therefore, bereaved carers expressed that they did not consider taking the child home or having a record of the place of death. In addition, Muslims are encouraged to be mindful about death and keep reminding themselves that it is the inevitable destiny of every living creature which allows Muslims to accept their loss and do not consider talking about death as a taboo subject (Kristiansen and Sheikh, 2012). In addition, it was evident in carers' reports concerning receiving psychological support from family members at and after the time of the child's death rather than healthcare professionals. Therefore, items regarding receiving support from healthcare professionals were kept to explore whether carers might have liked to receive any support. The extended family in Eastern culture, especially Arab, is one of the cultural values that play a vital role in providing support at difficult times for the family. For example, extended family members are usually involved in taking care of ill children, helping the bereaved family to collect death certificates and making arrangements for the funeral in order to decrease the family's burden and stress. This is the reason for adopting an approach to assign a support person from the family in the event of psychological distress experienced by participants as a result of cognitive interviews.

Despite the differences in cultural aspects and services provided in the UK and Jordan, the findings of the cognitive interviews highlighted similarities between Western and Eastern contexts. For example, bereaved carers easily understood the inferences of "trust" and "caring way" terms in the questionnaire, unlike healthcare professionals who overthought these terms.

Overall, the protocol implemented during this cognitive interview step identified challenges related to recruiting and collecting data from bereaved carers in Jordan. Following the cognitive interviews, one amendment was introduced to the feasibility protocol considering the approach of future participants. According to bereaved carers' recommendations, to improve the response rate the researcher should avoid calling participants directly because people tend to ignore unknown telephone numbers.

8.5 Chapter summary

This chapter summarised the iterative process of revisions to the Arabic version of the VOICES-C questionnaire as a part of the cross-cultural adaptation process in Jordan. This chapter focused on outlining the demographic characteristics of participants involved in pretesting the VOICES-C questionnaire with five experts and eight bereaved carers in Jordan. The findings from the cross-cultural adaptation process that informed the amendments to the VOICES-C questionnaire summarised.

Chapter 9. Phase III Methods: The feasibility survey

9.1 Introduction

This chapter will present the methods used in the feasibility survey conducted in four hospitals in Jordan. First, the survey's primary aim and objectives will be described. Then approaches employed to identify eligible participants through the approved healthcare sites, recruit participants, collect and analyse data are presented. The survey employed the final Arabic version of the VOICES-C questionnaire developed as a result of phase II (Appendix L.1).

9.2 Survey methodology

One of the goals of measurements in health care is to collect data to evaluate overall health, quality of life or health care services directly from services users. However, the quality of data collected depends on the quality of measures used. Survey methodology is defined as *"the study of sources of error in surveys and how to make the numbers produced by surveys as accurate as possible"* (Groves et al., 2009, p. 3). Survey error refers to the deviation of what is obtained by a survey from the accurate value.

Early development of survey methodology was based on psychological theories (Brenner, 2020) and addressed the ways in which the interviewer, respondents and questions contribute to errors, either accidentally or deliberately, at each level of the cognitive processes of answering questions, i.e. comprehension, recollection, judgment and response. While sociology offered other dimensions to survey methodology by addressing interactional aspects such as understanding interviewer activities during recruitment and interviewing survey respondents (Groves et al., 2009, Brenner, 2020), Groves et al. (2009) differentiated between two types of errors: errors of observation and errors of non-observation. Errors of observation, or measurement errors, refer to deviations of the answers given by respondents to a question from the intended "accurate" answers. These errors are influenced by the interviewer, mode of data collection, questionnaire itself, respondents and post-survey data processing. While non-observation errors refer to the deviation of statistics of respondents from the full population.

Survey methodology

This feasibility study aimed to develop a rigorous and sound methodology for future surveys as well as take into account, and where possible reduce, sources of error and bias. Considering the different categories of errors described above, the main sources of error that were investigated in this study were **the measure itself, identifying and recruiting the sample, the response rate, and mode of data collection**.

1. In designing a survey it is crucial to specify what to measure or "asking the good question" to ensure that the survey collects the intended data (Dillman et al., 2014). This entails decisions regarding the content and format of questions and response options. Therefore, a considerable effort is required to design the survey in order to capture the intended concepts precisely, then the researcher should assess the respondents' ability to understand the questions and answer them successfully (Waltz et al., 2010). Researchers often examine a measure's validity and reliability. Validity can be defined as the extent to which a measure or tool measures what it proposes to measure. While reliability refers to the ability of a measure to produce consistent results when administered at different times or by different observers (Streiner and Norman, 2008). The content and format of the VOICES-C questionnaire were examined to ensure that the questionnaire is relevant to the target population in the first two phases of this project. In this third phase, the process of participants responding to the questions was examined i.e., whether participants could understand and answer the questions easily, as well as whether participants would avoid reporting negative experiences and perceptions of poor quality of care.

2. Identifying the sample is an essential element of survey design that requires financial and physical efforts, not to mention the time spent to obtain and approach the sample. It entails visiting various settings or areas, employing workers to check records within budget and time constraints (Dillman et al., 2014). For this feasibility study, the errors considered were the inclusiveness of medical records in terms of the children's medical conditions that represent the target population, and the extent to which contact telephone numbers used to approach bereaved carers were accurate and in use. Fowler et al. (1999) outlined two methodological challenges for quality of end of life care surveys in terms of selecting participants: 1) identifying the setting from which the sample will be drawn, whether hospitals, care homes or facilities for certain groups of conditions i.e. oncology settings, and; 2) determining at what point of the patients' illness trajectory they are considered eligible, i.e. recently diagnosed with incurable illness, dying patients or deceased patients

for post-bereavement research (Fowler et al., 1999). The authors clarified that the sample can be determined according to the study design, for example, for prospective design studies, the eligible participants could be patients at the last weeks or days of life, whilst retrospective studies would seek carers of patients after their death. Fowler et al. (1999) pointed out an important challenge for prospective studies is identifying the dying patients even though the patient's prognosis can be predicted. While the retrospective design represents a feasible option for collecting data about the quality of care by recruiting a family member after the patient's death instead of the patient himself, there are problems with this approach. Fowler et al. (1999) acknowledged there are two challenges when considering proxies for data collection: identifying proxies who can provide the required information and assessing the reliability of information obtained from those proxies. On the other hand, Addington-Hall et al. (2007) addressed the challenge of accessing only individuals who agree to share their personal information in compliance with data protection and privacy policies in the UK resulting in limitations on achieving a representative sample and, consequently, the generalisability of the findings. Therefore, any reports regarding survey findings should be clear when defining the characteristics of the sample frame to enable the reader to determine whether the sample represented the target population.

3. Part of a survey methodologist's task is to make important decisions regarding **response rate**, the proportion of sampled units/individuals who participate in a study, which is considered a major indicator of survey success (Addington-Hall et al., 2007, Dillman et al., 2014). Given that a high response rate does not necessarily indicate reliable conclusions from the sample, the researcher should examine any differences among respondents and non-respondents characteristics in a matter pertinent to the survey aim and findings (Addington-Hall et al., 2007). For this feasibility study, the researcher sought to improve the response rate and considered a few factors such as clarifying to potential participants that this is university-affiliated research and supported by the Jordanian MOH and recruiting health settings, adopting the most convenient methods to approach bereaved carers and provide them with research material, and to consider designing and sending pre-notifications and reminders to potential participants in a simple and polite Arabic language. In addition to the response rate, differences between the characteristics of respondents and non-respondents, or patterns amongst non-respondents were investigated. Recently,

Brenner (2020) identified potential factors that impact and potentially improve response and rates in surveys, the following were adopted in this study:

a. The organisation that sponsors the survey

This factor entails that potential participants know and trust the survey sponsor which impacts their cooperation i.e., response rate. It was found that governmental-funded surveys have a higher response rate in comparison with other organisations such as private sectors and universities. Brenner (2020) explained that this was due to individuals' belief that the government is legally entitled to collect data about certain topics. Dillman et al. (2014) recommended an initial postal contact clarifying the survey sponsor contact details, providing information for participants about how the findings would make a difference to gain their cooperation.

b. Less burdensome data collection mode

Responding to survey questions is a task associated with additional activities and responsibilities for participants. The mode of data collection may impose additional burdens which may influence their willingness to respond to the survey. Certain data collection modes have factors affecting response such as training of interviewers for interviewer-administered surveys, however, training interviewers will have no impact on self-administered modes (Brenner, 2020). Regarding telephone surveys, people have certain social norms that may influence the response rate, for example, respondents tend to ignore responding to unknown telephone numbers and wait for a voice message from the caller. On the other hand, there are individuals uncomfortable using the internet to respond to a survey and are reluctant to share their details due to fear having their personal data and identity being stolen (Brenner, 2020). The survey length has a negative influence on the response rate for postal and telephone surveys, i.e. the number of pages for postal surveys and the duration of the call for telephone surveys, whilst this effect is less significant for personal interviews (Dillman et al., 2014). Therefore, decisions to make the survey delivery less burdensome in order to increase the response rate should consider the most feasible mode for the target population and length of the questionnaire.

c. Sending appropriate response requests or follow-ups through available channels

It is standard practice to send multiple invitations to a survey, regardless of the survey mode, to improve the response rate. Using pre-notices as well has been shown to encourage potential participants to respond and improve response rates in telephone and mail surveys (Addington-Hall et al., 2007, Wolf et al., 2016). Brenner (2020) pointed out that pre-notifications are needed since social norms have changed; people now receive many marketing calls and posts, therefore they tend to terminate the call and block numbers after multiple call-backs. Regarding reminders, researchers can plan a set of requests or follow-ups at specific times for postal surveys, such as sending a reminder after sending the questionnaire but before regular household garbage collection, to avoid potential participants from discarding the questionnaire before receiving the reminder (Brenner, 2020). Addington-Hall et al. (2007) suggested that at least two reminders are required for postal surveys.

d. Avoid replicating the content and presentation of multiple requests

Research suggests that the content and display of each request should be structured differently to ensure each adds to the previous request and encourages potential participants to respond to the survey (Brenner, 2020). This can be attained by explaining the value of the study, why it is being done, why they are considered eligible and received the request, how their responses will be used, and how their personal data will be protected. In addition, the display of each request could be modified to encourage response, i.e. the envelopes of postal surveys and the introductory screen display of internet surveys (Brenner, 2020). Appropriately phrased, timely planned requests should be formulated to clarify how surveyors ask people to respond to the survey and what to say to them (Wolf et al., 2016, Brenner, 2020).

4. The **mode of data collection** refers to how information is communicated, i.e. presenting the questions and obtaining responses (Wolf et al., 2016). Survey mode is an important decision in survey design and based on several factors such as the nature of study population, the sensitivity of the investigated topic, length of the survey, and the availability of finance and staff (Addington-Hall et al., 2007, Groves et al., 2009). Brenner (2020) stated especially designed survey design according to potential participants' characteristics such as age level of education and economic status, can influence response rates. For example, in a survey targeting senior participants, it is more reasonable to approach participants and deliver the survey materials through post or telephone (Brenner, 2020).

Survey methodology

This survey employed a telephone survey mode to collect data from bereaved carers for several reasons: potential participants were geographically dispersed, therefore, the personal interviews' approach was excluded due to the limited time and lack of available assistance to conduct personal interviews with a large, widely distributed sample (Archibald et al., 2019). In addition, employing a postal survey would be impractical because postal services are not commonly used in Jordan and would make following up participants difficult and might place a burden on the participants to send the complete questionnaire to the researcher. Furthermore, the medical records had telephone numbers often without home address details. According to the Ministry of Information and Communications Technology (MoICT) report concerning the Promotion and Use of Multilingualism and Universal Access to Cyberspace in 2016, 55.6% of household users have an internet connection, 82.8% of Jordanian families own a smartphone, 98.3% of Jordanian families own a mobile phone. Taking into account all of those figures, the ubiquity of mobile or landline telephones in Jordan made telephone-administered survey a more accessible approach (MoICT, 2018).

Another emerging issue, the study coincided with the Coronavirus Disease 2019 (COVID-19) pandemic which meant an approach to data collection should be chosen that maintained social distancing and minimised personal interaction. Using telephone interviews in this study was also considered appropriate because it would minimise exclusion of rural participants, reduce the expenses and time consumed for travelling, maintain the flexibility of the interview arrangement and rescheduling if the participants could not proceed with the interview, and enhance the participants' confidentiality, since limited personal information was known by the researcher beyond the telephone number (Lewis-Beck et al., 2004, Addington-Hall et al., 2007, Upadhyay and Lipkovich, 2020). In addition, telephone interviews enabled participants to be at a convenient, "safe place", such as their own room, during the interview (Butler et al., 2018, Hynson et al., 2006).

Until the end of the Twentieth century, most surveys used one mode of contact and data collection such as face-to-face interviews, postal or telephone surveys, as a result of information technology advancements using multiple survey modes has become more feasible to improve response rates, reduce costs and provide different communication options to participants (Brenner, 2020). Individuals vary in their preferred way of response, for example, some people prefer to respond online whilst others are unable to use this method or do not have internet access. However, this was not possible to follow in this study considering limited information in medical records, time and resources constraints and the COVID pandemic. For example, although **face-to-face interviews** were found to be valuable data collection method for long complex surveys especially with trained interviewers and can increase the quality of collected data as interviewers can clarify any inconsistencies in participants' responses (Addington-Hall et al., 2007), the face-to-face interviews can be costly because of the time required for the interviewer to conduct each interview, and travel to each participant; and interviewer training and experience, especially in sensitive areas which can influence participants' responses. In addition, interviewers should take certain measures to ensure their safety during data collection such as having a companion with them (Addington-Hall et al., 2007). On the other hand, **postal self-administered** surveys are a more affordable method than personal interviews for collecting data from geographically distributed participants since they require less staff and resources (Addington-Hall et al., 2007) and with higher response rates compared with cross-sectional telephone and web surveys (Wolf et al., 2016). It is a more appropriate method to collect sensitive data using simple surveys since the interviewer has more control over who can see the respondent's answers (Addington-Hall et al., 2007). However, this method requires an up-to-date address list (Addington-Hall et al., 2007) and it is subject to mail services' efficiency which requires long periods of time to return completed questionnaires and send reminders to respondents (Groves et al., 2009) which were not available in the Jordanian context.

9.3 Aim and objectives

A pilot survey with a representative sample of Jordanian carers was developed using best practice in survey methods to investigate bereaved carers' views about quality of end of life care for children in Jordan in the last three months of their lives. It aimed to examine the feasibility of undertaking a telephone-administered, post-bereavement survey in Jordan and provide guidance for the planning and execution of future post-bereavement surveys in terms of recruitment, data collection using a telephone interview approach, response rate and survey completion rate.

The specific research questions in this phase were:

1. Is it feasible, acceptable and appropriate to use a telephone interview approach to collect data from bereaved carers about the quality and experiences of paediatric end of life care in Jordan?
    a. How long does it take to identify and recruit eligible participants?
    b. What response rate can be expected for a post-bereavement survey in Jordan?
    c. What length of time would be required for data collection and how many interviews would be needed to enable completion of a questionnaire?
    d. What level of missing data can be expected from this method of data collection?
    e. Do participants appear willing to report dissatisfaction with care provided? i.e., whether participants took the opportunity to report negative experiences.
2. What are bereaved carers' views regarding quality of end of life care provided to children in the last three months of their life?

9.4 Sample and eligibility criteria

Given that this feasibility study aimed to evaluate paediatric services and inform future surveys, five sites representing variation in Jordanian hospitals and service provision were invited to take part in the study in order to include the different types of eligible childhood deaths in the target population. These sites included four hospitals and a cancer centre covering the three areas of Jordan (north, middle, and south). The hospitals were one university-affiliated (King Abdullah University Hospital (KAUH)) and three governmental/ public (one major and two rural) hospitals. All hospitals had a medical paediatric department, neonatal intensive care unit (NICU) and a paediatric intensive care unit (PICU) and all these departments were considered for recruiting participants.

The feasibility study recruited bereaved carers from the Jordanian population using the inclusion and exclusion criteria similar to those used for the cognitive interviews, except the criterion concerning the elapsed time after the child's death (Table 9-1). As a result of knowledge gained through the cognitive interviews the sampling window was extended from 'up to 12 months' to include childhood deaths that occurred 'up to 24' months before the point of sampling. The matter of the appropriate time period for recruiting bereaved carers was investigated during the cognitive interviews and bereaved carers reported it would be appropriate to be contacted at any time after the child's death, after excluding the first three months. Therefore, the elapsed time after the child's death was extended to include any childhood deaths that occurred more than three months before the study and up to two years. A low response rate was antiaipated due to the nature of the study (i.e. losing a child is a profound event) and so the decision to extend the window of deaths was an attempt to increase the size of the target population, and therefore sample. The upper limit on this window of deaths was to minimise the risk of memory bias associated with a long period since the death.

Table 9-1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• A parent or carer of a child who had died between three and 24 months (avoiding the anniversary of the death or deceased child's birthday) prior to recruitment. • The deceased child was between 0-12 years old at the time of death. • The underlying causes of death was a life-limiting condition (LLC), such as cardiovascular disease (CVD), cancer and others according to the international statistical classification of diseases and related health problems – tenth revision (ICD–10). • The bereaved carer can speak and understand the Arabic language.	• Parents of children that died due to traumatic injuries such as an accident, suicide or sudden death, according to ICD-10. • Parents/carers who cannot speak or understand the Arabic language.

9.5 Recruitment

The feasibility survey aimed to recruit up to 25 participants from each site within one month. All eligible records were considered in the recruitment process through medical sites using an opt-in recruitment approach, i.e., participants were approached by the researcher following their acceptance to participate in completing the survey via a phone call from the study coordinator. Participants were contacted initially by a text message sent to the retrieved phone number, as recommended by participants from the cognitive interviews phase, in order to encourage them to answer the call. The recruitment strategy involved the following process:

1. A named nurse (coordinator) was asked to contact participating hospitals and recruit eligible participants on behalf of the researcher. The coordinator, who was a working nurse in the Jordanian MOH, was the same person who recruited bereaved carers for the cognitive interviews.
2. After obtaining approvals from the University of Southampton, the Jordanian MOH, and King Abdullah University Hospital (KAUH) (see Appendix M), the researcher contacted the manager of participating hospitals or the head of paediatric department to introduce herself and the study. Arrangements were made for the coordinator to travel to each of the hospitals and meet personnel at the medical records to facilitate the retrieval of records of childhood deaths.
3. The coordinator worked with a member of the medical records department from each hospital to review the medical records and match them against the inclusion criteria.
4. The researcher was in contact with the coordinator, while she was at the hospitals, and together they reviewed anonymised childhood deaths of potential cases to ensure they represented the target population.
5. The coordinator made the first contact with the bereaved carers via a text message to the contact number registered in the medical records. This text message invited bereaved carers to take part in the research study about quality of paediatric care and informed them they would be called later that day to explain more about the study unless they replied they did not wish to be contacted (Appendix L.2.1).
6. The coordinator made the first phone call to the bereaved carer, introduced the study, and asked about willingness to participate. The coordinator was provided with the Arabic versions of the questionnaire, Participation Information Sheet (PIS) and consent form, to

guide her in explaining to potential participants what they would expect if they agreed to take part in the interviews (Appendices L.2.2 and L.2.3).

7. The coordinator provided a verbal description for participants during the initial call. The carers who agreed to participate received copies of the PIS, consent form and the Arabic version of the questionnaire through WhatsApp messages as recommended by participants from cognitive interviews
8. After the initial call by the coordinator, and with participant consent, the coordinator provided the researcher with the contact details of potential participants in order to approach them.
9. Carers were contacted by the researcher to complete the questionnaire at a mutually agreed time within 48 hours of the initial call.
10. The researcher contacted carers by phone and asked if they were willing to complete the survey over the phone. If there was no answer, the researcher attempted to contact the carers up to three times.
11. Carers, who answered the call and agreed to complete the questionnaire by telephone were given the choice of completing the survey at once or scheduling a more convenient time.
12. Carers, who asked for further time to think, were encouraged to ask further questions about the research and were given up to 48 hours to consider their participation.
13. Once carers agreed to participate and made an appointment for questionnaire completion with the researcher, the researcher proceeded to conduct the interview on the agreed date. Prior to the interviews, all participants had the opportunity to ask questions and were asked for their verbal informed consent, before completing the questionnaire over the phone. Verbal consent was audio-taped with the interview unless participants refused to record their interview.

9.6 Data collection

9.6.1 Feasibility assessment

Following the coordinator's visit to each site, the researcher discussed and recorded data regarding the recruitment process i.e., the time needed to retrieve medical records and corresponding telephone numbers. The researcher kept up to date records of the recruitment process i.e., the name of the child from each site, the status of each carer i.e., no response or refused or agreed, and participants' ID for the carers who agreed to take part in the study.

After each interview the researcher logged data including characteristics of participants (i.e., deceased children and respondents), length of interviews, number of interviews for each participant, number of completed questionnaires, and social acceptability of evaluating end of life care services, as reported by the participants. The researcher kept notes for the quality of data collection mode, i.e., any noises or interruptions during the interviews and the emotional response of bereaved carers during the interviews.

9.6.2 Quality of care

Bereaved carers' reports regarding the care provided to the child were collected from their responses to closed-ended questions which are relevant to their experience and services provided care for the child. In addition, the researcher encouraged carers to express any additional information through the last open-ended question.

9.7 Emotional distress

As participants in the cognitive interviews had reported they were only mildly distressed or not at all distressed, the same approach used in cognitive interviews to mitigate emotional distress was employed in the feasibility study. Before conducting the interview, the interviewer confirmed that a support person had been identified and agreed to be approached by the interviewer as stated in the PIS form. Whenever the researcher identified any emotional distress posed by the study, she would only end the call when the participant felt ready to. If the researcher deemed the conversation had been very stressful and the person was at risk of harm, the researcher would escalate to the next steps:

1. Ask the participant (with their consent) to pass the phone to a family member in the household to discuss her concerns for the participant's welfare and highlight the need for their support before ending the call.
2. In cases where there was no one at home with the participant, the researcher would ask the participant to provide a contact number for a family relative or a close friend to check on and provide the needed support to the participant.
3. The researcher asked the participant if they would agree to a follow-up call on the same day to ensure the safety of the participant.

9.8 Data analysis

9.8.1 Feasibility assessment

The feasibility of the study protocol was assessed by examining the recruitment processes, of screening eligible potential participants, approaching and recruiting individuals and calculating response and retention rates. In addition, characteristics of participants and non-responders were summarised and presented for each hospital. Regarding the quality of data, completion rates to the survey as well as missing item-level data were summarised to identify any redundant items or response options. The number and average length of interviews for each completed survey were also summarised with the percentage of surveys completed. Data collected from participants, such as the date of death, were checked against the hospital records for agreement. Patterns linking the number of approached participants, the completed questionnaire, and positive responses with participant demographics were investigated, such as positive reports of quality of care with child's age or health insurance.

9.8.2 Quantitative data

Each carer's verbal responses to questionnaire items were entered into a separate Microsoft Word document during the interviews labelled with the participant's code. All participants responses were collated in one Microsoft Excel file as soon as it was practicable in preparation for the analysis process. Descriptive analyses were used to describe the sample's characteristics and the site of care provision. Data were summarised from participants' responses into meaningful values and graphs. Descriptive statistics were used to describe participants' demographics, child's clinical attributes and the overall quality of care. Descriptive comparisons were made for carers’ responses based on the child’s age and the hospitals providing care where appropriate. During the interview, carers talked about the child’s condition and further details to clarify the context of their views. Carers’ quotes regarding their view about the provided care were reported under the corresponding question.

9.8.3 Qualitative data

At the end of the questionnaire there was an open-ended or free text item where participants could give their views about anything else important related to the care or death or bereavement period. The free text item provided with richer details regarding provided care by allowing respondents to add new aspects that were not mentioned in the questionnaire and to elaborate on their closed-ended questions’ responses. These data from the open-ended question were transcribed in the English language from the questionnaires and entered into NVivo software for data management. Using this software, relevant sections from the text were highlighted and combined them into categories that form bigger themes or concepts.

Participants’ responses to the open-ended question were identified in the transcripts, categorised and analysed quantitatively for common themes and issues using an inductive content analysis approach (Assarroudi et al., 2018). Content analysis is a systematic approach for identifying key themes and related contexts within qualitative data. It involves moving back and forward between the entire data, categorising the reported issues, counting the frequency of issues taking into account the context of issues (Burnard, 1991).

Using this method, the first step involved translating the exact responses to the potential themes and comments expressing the quality of paediatric palliative care as stated by participants into the English language and entering them with the participants’ ID numbers into a new NVivo project. During this step, possible ways to categorise data were identified. Secondly, transcripts were read and re-read to identify all related issues using an open coding approach. Initial codes, referred to as “nodes”, were identified by highlighting the exact segments of text and assigning a meaningful code as reported by participants. All responses were coded in this way. Thirdly, the coded extracts were reviewed to combine similar codes into an overarching category. At this step, the relationships between codes were reviewed and similar codes were grouped into broader categories or themes. Fourthly, the themes resulted from the third step were revised and refined to confirm that categories matched the extracted data. Finally, the frequencies of themes related to bereaved carers’ experiences during the last three months of a child’s life were calculated (Bowling, 2014). The number of carers who reported themes and subthemes was stated to indicate the frequency of recurring themes and associated terms. Appendix L.3 shows examples of the coding of data for two themes.

Chapter 10. Phase III Findings: The feasibility survey

This chapter presents the findings from the survey regarding feasibility issues, such as identifying and recruiting participants and data collection. A summary of the sample, response rates, demographics of bereaved carers and their deceased children are presented. Data generated by the questionnaire items are presented, thus describing the reported quality of end of life care in Jordan. In addition, variations in the quality of care between the sites and age groups were investigated.

10.1 Sample characteristics

In addition to the approvals from the University of Southampton, ethical approvals were obtained from participating hospitals to allow identification of deaths from medical records. Unfortunately, at this stage, King Hussein Cancer Centre (KHCC) declined to participate in the study. The Ethics Committee of this organisation confirmed that according to the centre's guidelines, post-bereavement interviews should take place on-site at the Cancer Centre to enable the provision of psychological support and manage any associated emotional impact. Although multiple correspondences with the ethics committee reiterated the plan for supporting participants, that the other four hospitals had agreed to participate in this study following a precedent used by other post-bereavement surveys, and the circumstances of the pandemic precluded face-to-face interviews, the centre committee reaffirmed the decision was non-negotiable.

In total, 259 medical records were retrieved for children from all sites who died in the last two years between 1st October 2018 and 1st October 2020. Overall, 142 records were ineligible which included deaths due to infection, sudden and accidental causes, including oesophageal obstruction, airway obstruction, meningitis, encephalitis, chest infection, septic shock, birth asphyxia, pneumonia, intracranial injury due to falls, poisoning and road accident. Eligible records comprised childhood deaths due to non-communicable or sudden causes including oncological, haematological, metabolic, cardiac, respiratory, congenital and perinatal conditions that affect new-borns as complications of pregnancy or delivery. These represent the main causes of death among children as reported by the Ministry Of Health in Jordan

(MOH, 2015b). The records included deaths of children up to twelve years old because that is the age limit for treatment in Jordanian paediatric wards. NICUs treat infants up to 60 days old, when they are transferred to a paediatric ward or PICU, as required.

Of the 117 eligible medical records, 66 records (56%) were for children who had died within the most recent year i.e., October 2019 – September 2020. Corresponding contact numbers for next of kin were retrieved from medical records and they were initially approached by the coordinator. Sixty-one phone numbers (52.1%) were answered by a bereaved family member, while fifty-six initial phone calls (47.9%) were not answered after three attempts or answered by a person who was not related to the deceased child, and consequently had no previous knowledge of the child. Of the sixty-one potential participants where contact was made, forty-eight (78.7%) agreed to complete the survey and thirteen refused to participate. Figure 10-1 presents the breakdown of retrieved telephone numbers from medical records according to their responses.

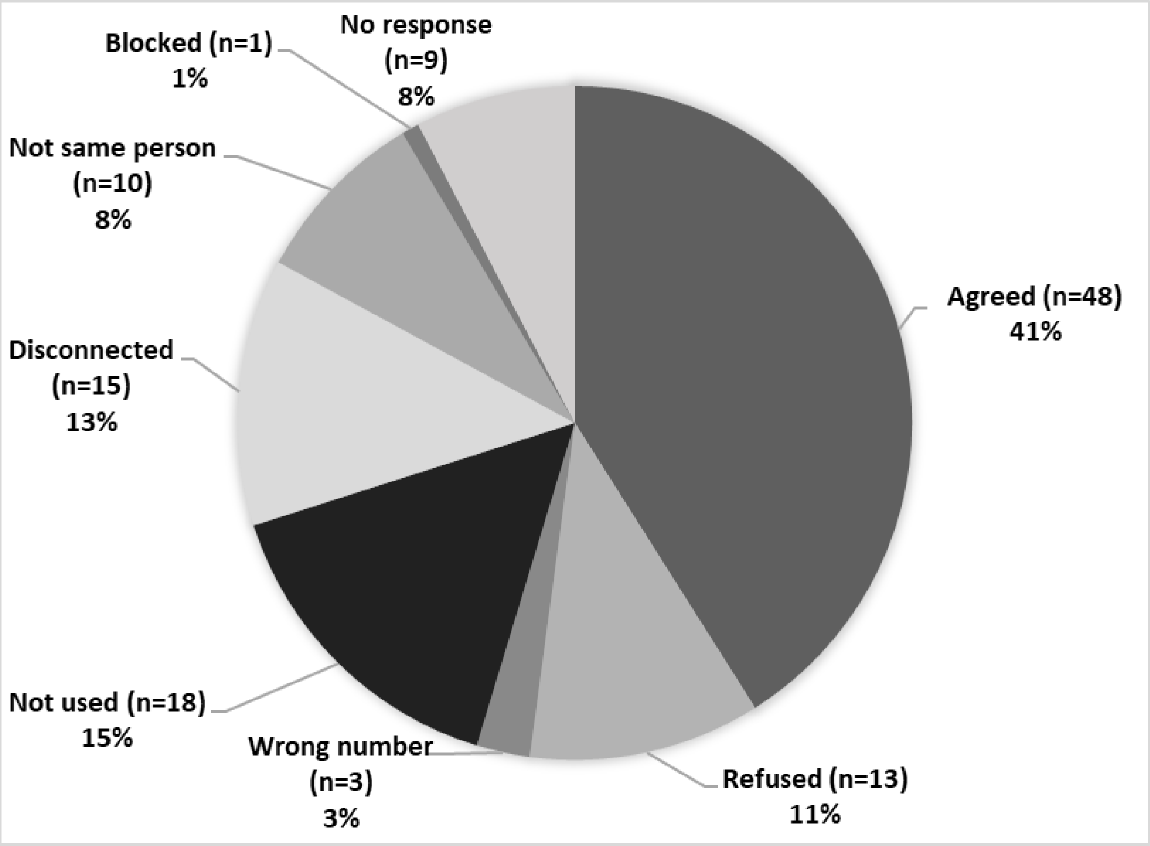


Figure 10-1 Breakdown of responses to telephone calls made to retrieved telephone numbers (n=117)

10.1.1 Respondents vs Non-respondents

Forty-six per cent of non-responses to calls were next of kin of children who had died in the 12 months between October 2018 and September 2019, rather than the subsequent year (October 2019 – September 2020) indicating no pattern between response and time since death. The characteristics of deceased children in the non-respondent group were similar to those in the respondents' group in terms of elapsed time after the child's death, child's age, and underlying causes of death. Table 10-1 presents a comparison between the two groups according to these characteristics. Both groups included children who had died between the ages of a few hours up to 12 years old, and both included a range of causes of death according to the ICD-10 categories (see Figure 10-2). Figure 10-3 compares the proportion of causes of childhood deaths in the respondents' group with the proportion of childhood deaths in Jordan as a whole according to causes of death documented in medical records. These categories include a wide range of conditions such as congenital malformation of the heart or colon, metabolic disorders, heart failure, chronic kidney failure, end-stage renal disease, liver failure, cancer, respiratory distress syndrome, hypotonia, hydrocephalus, cerebral palsy, congenital blood disorders, oesophageal atresia/ fistula, congenital heart disease, systematic lupus, cerebral ischemic attack, cardiac arrest.

Table 10-1 Characteristics of children in respondent and non-respondent groups

	Respondent	**Non-respondent**
Child's age group		
Neonate (less than 2 months)	19	39
Infant (2-12 months)	12	10
Young child (1-5 years)	9	11
Older child (5-12 years)	8	9
ICD-10 category		
Congenital	21	21
Nervous	7	9
Circulatory	5	11
Haematologic	3	0
Perinatal	3	7
Endocrine	2	2
Respiratory	2	4
Neoplasm	2	2
Digestive	2	6
Genitourinary	1	7
Elapsed time		
Oct 2018-Sep 2019	19	32
Oct 2019-Sep 2020	29	37
Total	**48**	**69**

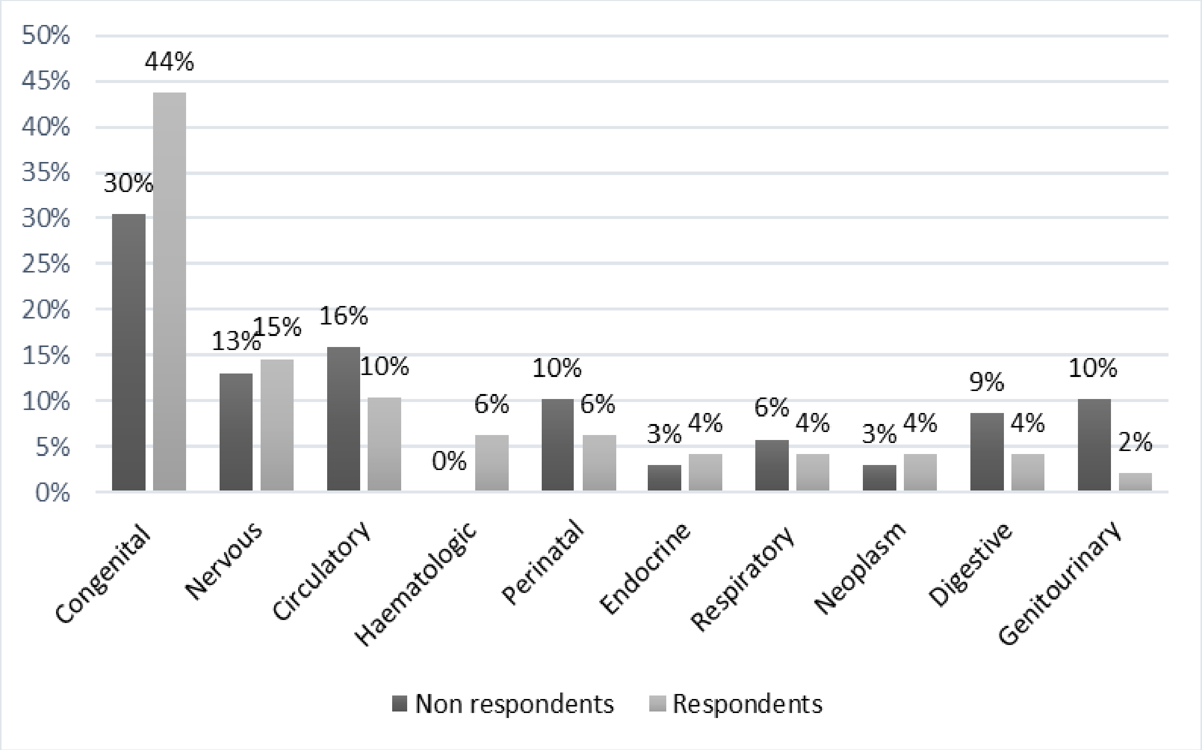


Figure 10-2 Causes of death among children in respondent (n=48) and non-respondent (n=69) groups

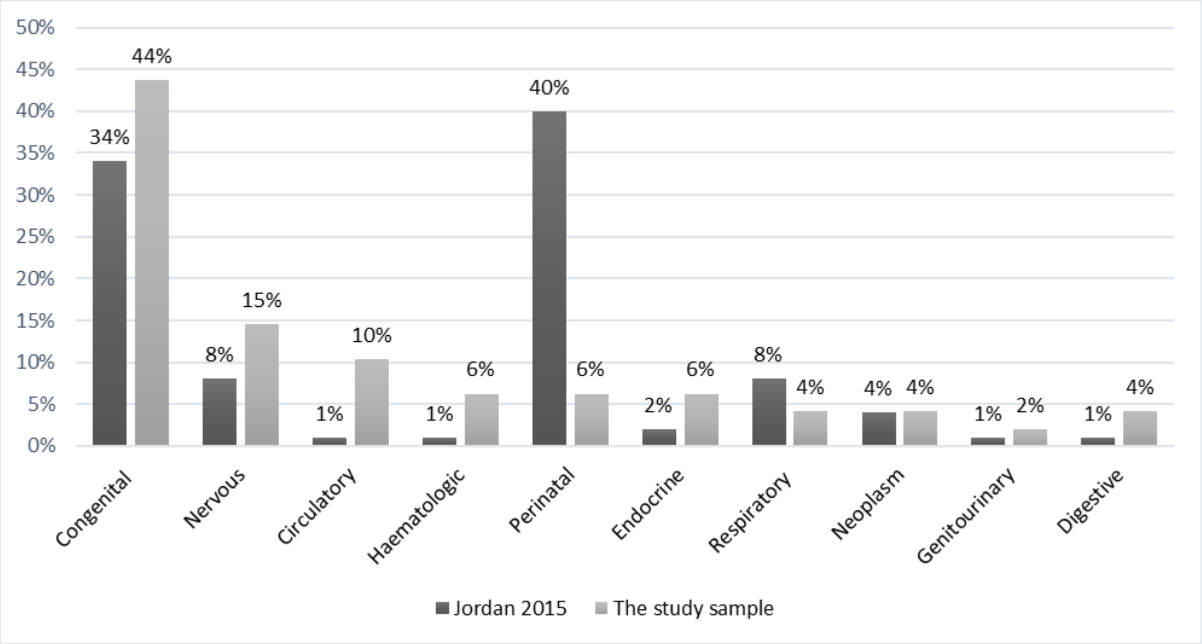


Figure 10-3 Causes of death among children under 15 in Jordan adapted from (MOH, 2015b) and the respondents

10.1.2 Respondents

Forty-eight respondents agreed to participate representing a response rate of 41% for the eligible sample drawn and 78.7% of telephone numbers called and answered, while thirteen respondents (21.3% of respondents, 11.1% of the overall sample) refused to be involved in the study. No demographic details were available concerning carers who refused to participate in the study. Table 10-2 presents the numbers of participants and response rates between sites. The majority of participants were in the 20-29 year and 30-39 year age groups, (37.5% and 35.4% respectively), Jordanian (79.2%) and Muslims (87.5%). The sample comprised a majority of male carers (58.3%), mainly fathers (54.2%). Around two-thirds of deceased children were infants under the age of one year and covered by public health insurance. Table 10-3 presents the demographics of deceased children and their bereaved carers.

In order to characterise recruitment success, Wolf et al. (2005) re-characterised the response rate into contact rate which characterises the success of contacting individuals from the sample, enrolment rate which refers to sample members willing to participate, and the refusal rate. The authors argued that contact rate correlates mainly with the quality of the sampling frame rather than recruitment strategies. For this study, the combined sample size from four sites was 117 potential participants, of these, 61 were contacted, yielding a contact rate = 0.52 because carers' personal numbers changed between the time of the child's death and the time of sampling. The majority of contacted carers were willing to participate with an enrolment rate of = 0.79 and refusal rate = 0.21.

Table 10-2 Number of participants by hospital

Hospital	Total records	Approached carers	Agreed participants	Response rate for each hospital
Alkarak hospital	42	23	11	48%
Prince Hussein hospital	22	10	5	50%
Bashir hospital [*]	87	37	12	32%
King Abdallah hospital (KAUH) [*]	108	47	20	43%
Total	**259**	**117**	**48**	

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[*] Major hospital with advanced services and sub specialities

Table 10-3 Characteristics of participants (n=48)

	Number of participants	Percentage
Relationship to the child		
Father	26	54.2%
Mother	14	29.2%
Grandparent	4	8.3%
Aunt	2	4.2%
Uncle	1	2.1%
Stepmother	1	2.1%
Respondent's age		
20-29	18	37.5%
30-39	17	35.4%
40-49	6	12.5%
50-59	7	14.6%
Respondent's gender		
Male	28	58.3%
Female	20	41.7%
Child's age group		
Neonate (less than 2 months)	19	39.6%
Infant (2-12 months)	12	25.0%
Young child (1-5 years)	9	18.8%
Older child (5-12 years)	8	16.7%
Child's gender		
Male	24	50%
Female	24	50%
Religion		
Muslim	42	87.5%
Christian	6	12.5%
Nationality		
Jordanian	38	79.2%
Syrian	8	16.7%
Palestinian	2	4.2%
Health insurance		
Public	28	58.3%
Military	3	6.3%
Private	2	4.2%
No insurance	15	31.3%

10.2 Methods of identifying and approaching participants

The coordinator obtained digitised records of childhood deaths within the two-year sampling window at each hospital with the assistance of a member of the medical records department. The coordinator then screened records with the researcher against eligibility criteria via the phone. Following that, using the child's national ID number from medical records, the hospital records staff member reviewed the admission's records to obtain a telephone number corresponding to the child's carer. It took the coordinator approximately two hours to obtain death records and associated telephone numbers from each hospital. However, there were inconsistencies among these sites regarding the details included in medical records. For example, one hospital documented a child's name, age, department, date of death and cause of death in the Arabic language. Other hospitals had more advanced records i.e., the birth date, age, unit, mode of admission, length of stay, diagnosis in the English language, in addition to ICD10 codes. Although these sites used forms supplied by the Civil Status and Passport Department to report deaths, the details retrieved from each site were different.

The majority of carers agreed to take part in the study and asked for a copy of the questionnaire on the initial call. Interviews were scheduled within the first 48 hours after carers had been contacted by the coordinator. Some carers did not schedule the interview on the first call due to family issues such as death, illness, or job commitments. These interviews were scheduled later by text messages at the carers' convenience. Thirteen bereaved carers refused to participate stating the reason being the anticipated emotional impact the interview would have on them, which they did not want to experience. The flowchart below (Figure 10-4) presents the recruitment process and the number of eligible carers at each stage.

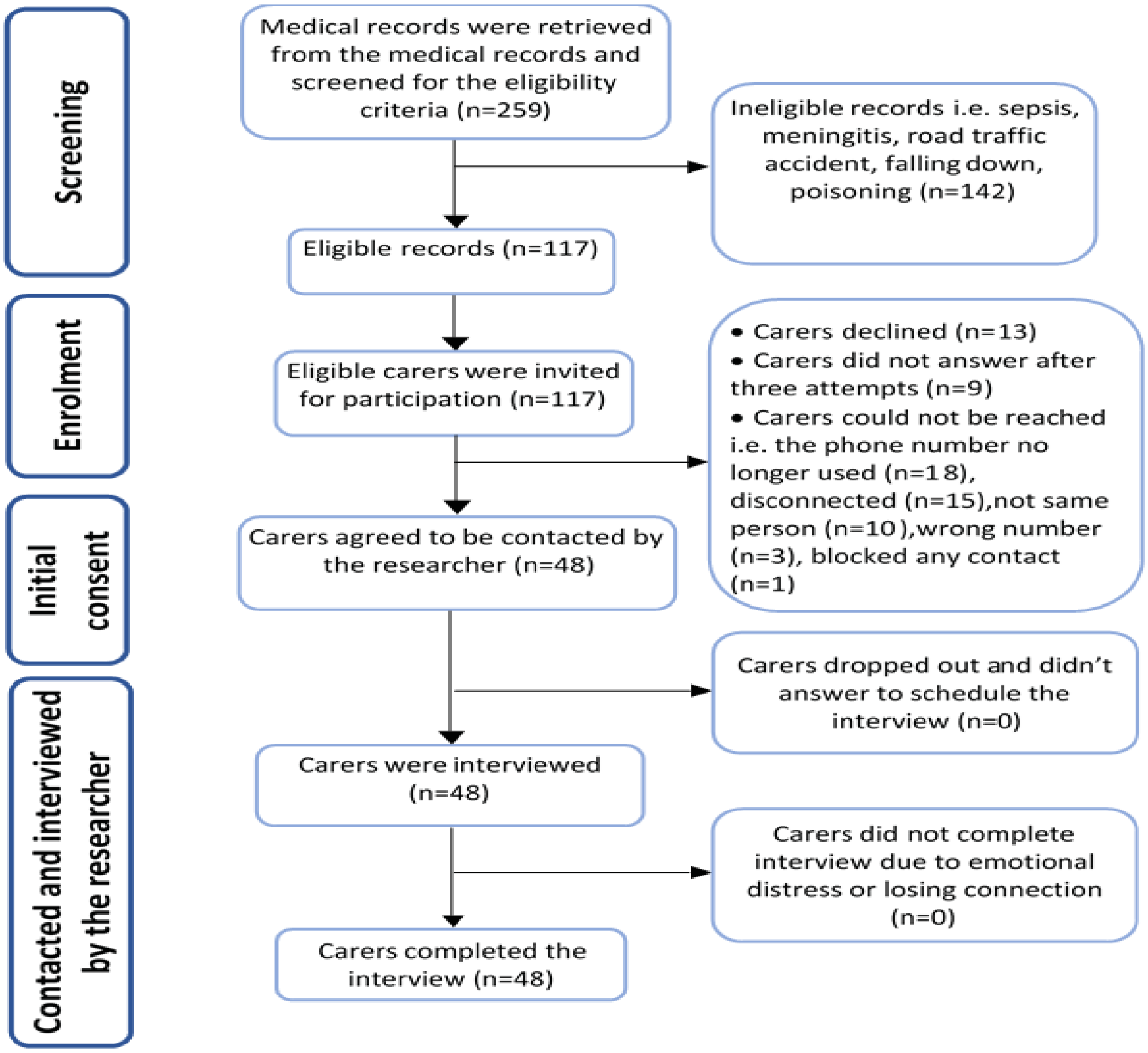

Figure 10-4 A flowchart of the recruitment process

10.3 Mode of data collection

Interviews were conducted over two months. In line with the protocol, at the beginning of the interviews, the researcher confirmed with respondents that they were not alone in the house or that they had someone they could contact in case they needed any support. One carer (a father) was in his car during the interview to avoid any upset to the child's mother. The retention rate was 100%, i.e., all carers who agreed to participate proceeded with the data collection process and completed the questionnaire. All questionnaires were completed during a single phone call with a completion rate of 100% without any missing data. Fourteen carers refused to allow the interviews to be recorded because it made them feel uncomfortable. The remaining carers agreed to the interviews being recorded, which lasted between 10 and 45 minutes. Carers preferred to give details regarding the child's condition to provide the context of their experience throughout the first section (Information about you both). The sound on all telephone interviews was clear, except for three interviews that had some background noise but not enough to affect questionnaire completion. Two recorded interviews were disconnected but the connection was re-established, and questionnaires were completed/ interviews were continued. Although the forms were sent to participants via WhatsApp messages, only one participant had access to a printed out copy of the questionnaire during the interview, which reduced the need for explanations about which question was referred to in the questions and response options. For example, there are two questions regarding satisfaction with their involvement in decision making one for the carers and one for the child which required repetition for other participants. Although it was evident carers did experience emotional distress during the interview, as manifested by the changes in voice tone, nervous laughter and crying, none decided to contact their support person during the interview. Carers appreciated the opportunity to participate in the study in order to help improve medical services for future children and their families. Several carers commented in the following ways:

> *"I asked her mum after you called and she said she hated those days and she didn't want to talk about them. I told her if this study will benefit others why not, that is why I am talking in my car with you"* (father of 11 years old female)

> *"what I care about is to improve medical care more"* (father of 4 years old female)

> *"I don't talk for my sake I am talking for others' interest"* (a father of 7 months old female).

> "*anything I can give to serve other people and children"* (a father of 5 years old female).

Carers did not have any issues with reporting negative experiences, opinions regarding poor quality care and suspicions of possible medical negligence. To the extent that, some of the carers chose to make it clear they did not mind being identified and mention hospital or staff members by names.

10.4 Findings

10.4.1 Quality of care (closed-ended questions)

The subsections below outline detailed data on bereaved carers' responses to questionnaire items. Since children younger than 60 days old were cared for in NICUs whilst other age groups of children received care in PICUs and paediatric units, and the questionnaire has separate sections for NICU/PICU and ward, comparisons according to the unit or the child's age are provided to clarify any patterns between the different units or age groups wherever appropriate.

10.4.1.1 The overall quality of care

This section presents bereaved carers' ratings of overall quality of care. The box below contains the relevant question and response options.

Q.57 Overall, and taking all services into account, how would you rate her care in the last three months of life?

Outstanding Excellent Good Fair Poor Not sure

Three respondents (6.3%) rated the quality of care as "outstanding" (all from a major hospital) whilst four carers, out of five (10.4%) who reported "poor" quality of care were recruited from rural hospitals, and one respondent (2.1%) from a rural hospital responded "not sure" for the question of overall quality of care. On the other hand, the majority rated care as “excellent” (n=23, 47.9%), six of whom were served by rural hospitals. While nine respondents rated the quality of care as “good” (18.8%), only one of these was identified through a rural hospital, and seven respondents reported (14.6%) “fair” care, three of whom were from rural hospitals. Figure 10-5. describes general pattern of reported quality end of life care at the major and rural hospitals. Figure 10-6 shows carers’ rating of care based on the child’s age. Five carers out of twenty-three (21.7%) who rated the care as “excellent” were carers of neonates. Whilst two respondents out of seven who rated the care as “good” were carers of neonate patients. Of the seven respondents who rated the care as “fair” two were neonates’ carers. Overall, responses indicated that positive reports of care were more likely reported by carers of older children at major/urban hospitals, than carers of neonates. Fifteen out of twenty-two carers who reported “excellent” care were served by public hospitals and all five carers who reported “poor” quality of care were funded by public insurance (see Figure 10-7).

Figure 10-6 shows carers’ rating of care based on the child’s age. Five carers out of twenty-three (21.7%) who rated the care as “excellent” were carers of neonates. Whilst two respondents out of seven who rated the care as “good” were carers of neonate patients. Of the seven respondents who rated the care as “fair” two were neonates’ carers. Overall, responses indicated that positive reports of care were more likely reported by carers of older children at major/urban hospitals, than carers of neonates. Fifteen out of twenty-two carers who reported “excellent” care were served by public hospitals and all five carers who reported “poor” quality of care were funded by public insurance (see Figure 10-7).

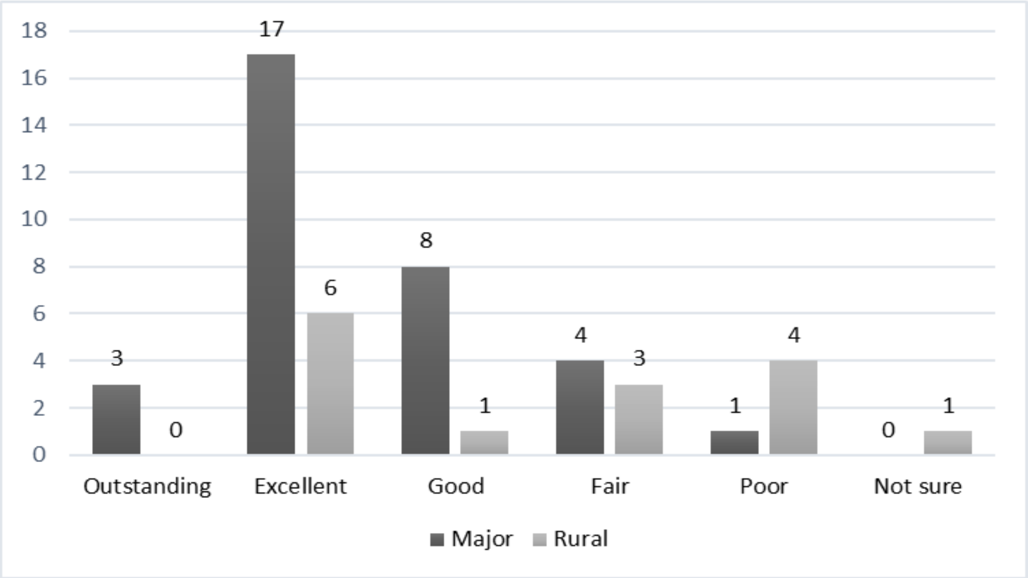

Figure 10-5 Carers' overall quality of care ratings according to treating hospitals

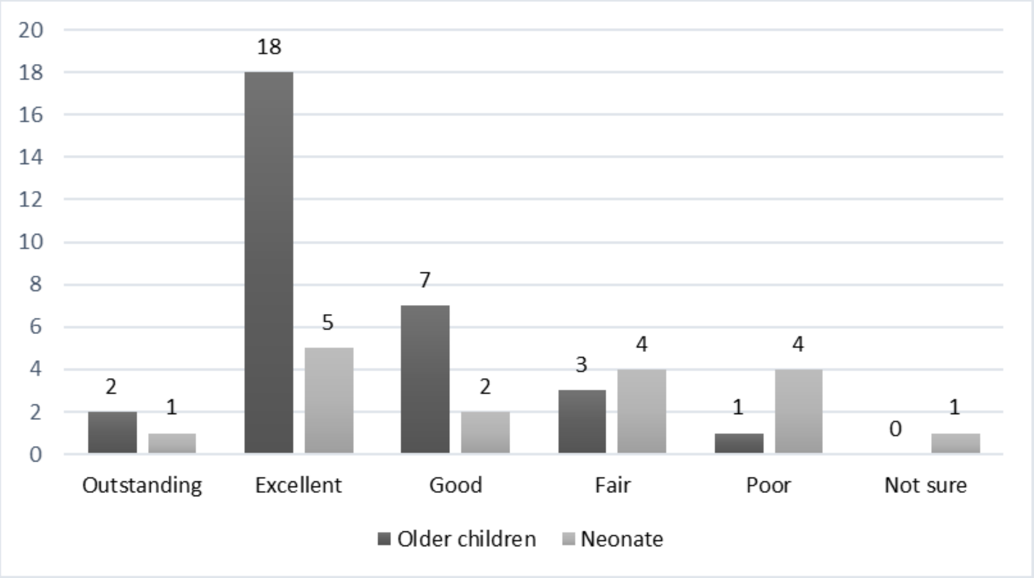

Figure 10-6 Carers' overall quality of care rating response pattern according to child's age

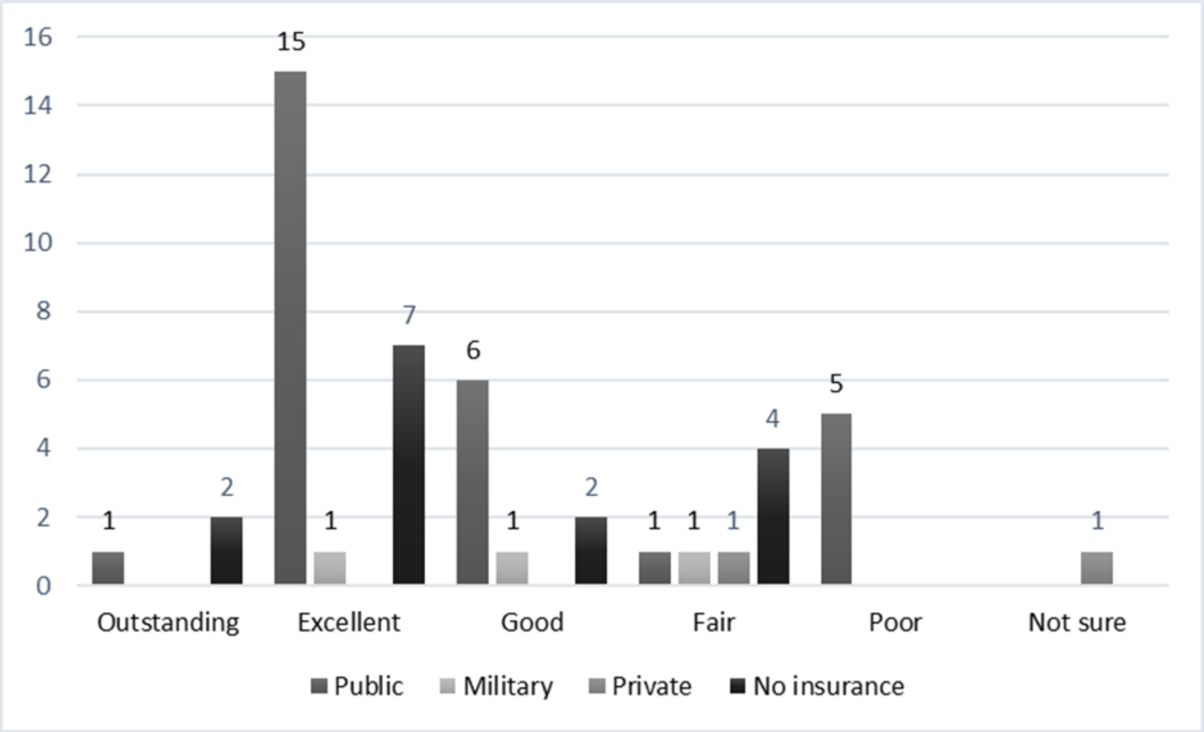

Figure 10-7 Carers' overall quality of care rating response pattern according to health insurance

10.4.1.2 Care at home

When she was at home in the last three months of life, did she get any help at home?

Yes No - she was in the hospital

Who provided this care?

A nurse A private agency Somebody else

Twenty-two participants (41.7%) reported that the deceased child stayed at home in the last three months of life, nineteen of them reported they received help at home. Only one neonate child was at home in the last three months. Thirteen out of nineteen carers (68.4%) who had their child at home in the last three months reported the deceased had received care from family members, primarily parents and grandparents. While three children had received care from a private doctor (15.8%), two were cared for by a nurse (10.5%), and one by a physiotherapist (5.3%) on individual occasions/ on need basis.

Overall, do you feel that the care she got from her consultant in the last three months of life was

Excellent Good Fair Poor Don’t know

Care provided by the consultant was most frequently rated “excellent” (57.9%), followed by “good” (31.6%), and none reported that a consultants’ care was “poor” (Figure 10-8). However, a father of 7 a month old female didn’t answer question 13 (Overall, do you feel that the care she got from her consultant in the last three months of life was) because his child was at home but *“didn’t need professional care”* as he stated.

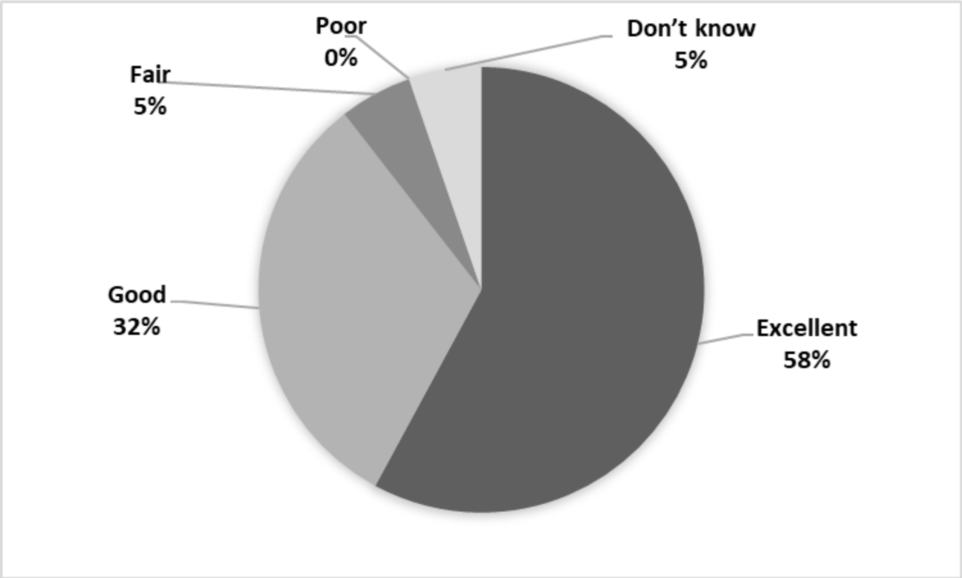

Figure 10-8 Reported quality of care provided by the consultant in last three months of life

During the last three months of her life, while she was at home, how well was her pain relieved?

Does not apply - she did not have any pain	Completely, all of the time	Completely, some of the time	Partially	Not at all	Don't know

According to bereaved carers' reports, seven children, more than a third of the nineteen children, did not experience any pain while four carers said around a fifth of them had their pain relieved partially and five carers (26%) reported that pain was managed completely at home in the last three months (Figure 10-9).

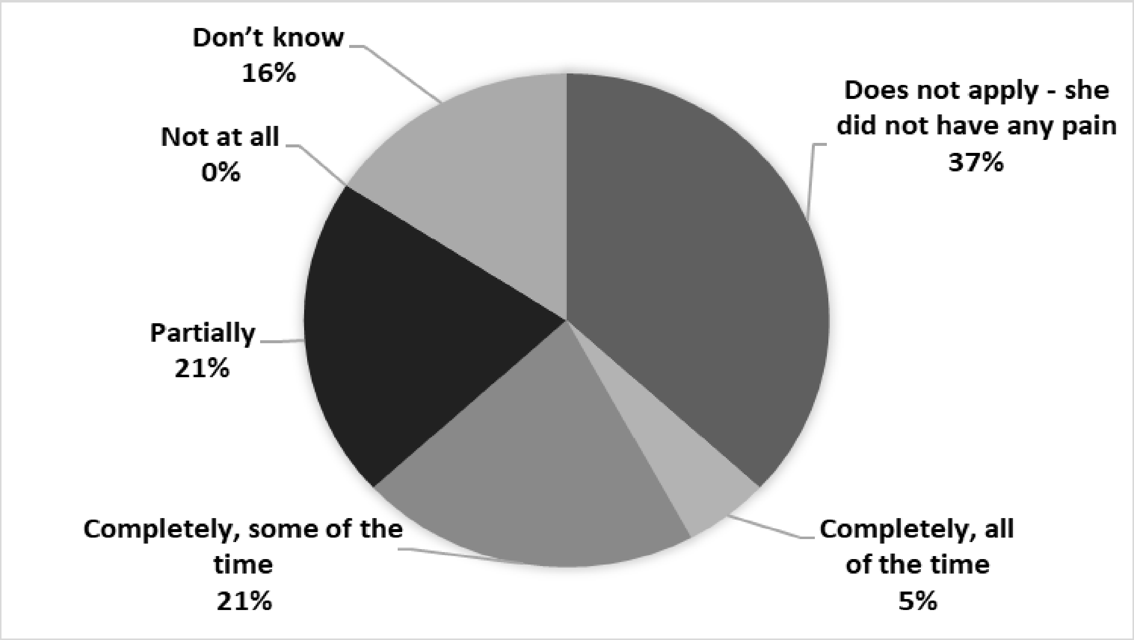

Figure 10-9 Reported pain management at home

In the last three months of life, while she was at home, did you ever need to contact a health professional for something urgent in the evening or at the weekend?

Not at all in the last 3 months
Once or twice
Three or four times
Five times or more
Don't know

The last time this happened, who did you contact?

The consultant in charge of/ following her case
The ward/unit in the hospital
A nurse from the ward
911
Someone else

Q16. Overall, do you feel that the care she got when she needed care urgently in the evenings or weekends in the last three months of life was

Excellent	Good	Fair	Poor	Don’t know

Regarding accessing urgent care out of work hours, six carers (31.6%) who had a child at home in the last three months needed urgent medical care or consultation three or four times, four carers (21.1%) needed care once or twice and three carers (15.3%) needed care five times or more. Four carers reported that they did not need urgent care while the child was at home in the last three months, whilst one carer was not sure (.

Figure 10-10). The majority of carers contacted the ward or the consultant directly, whilst only two carers took the child immediately to the nearest hospital i.e., emergency department, whenever they needed urgent care for the child during weekends and evenings (Figure 10-11). The proportion of carers who had a child at home and rated out of working hours services as “good” was 57.1%, followed by “excellent” (28.6%), and “fair” (14.3%), (Figure 10-12). To sum up, the majority of carers reported that they needed to seek urgent care for their child several times in the last three months and most likely to contact the unit in the hospital for help. However, most but not all carers had adequate pain relief, but overall, most rated care as excellent or good.

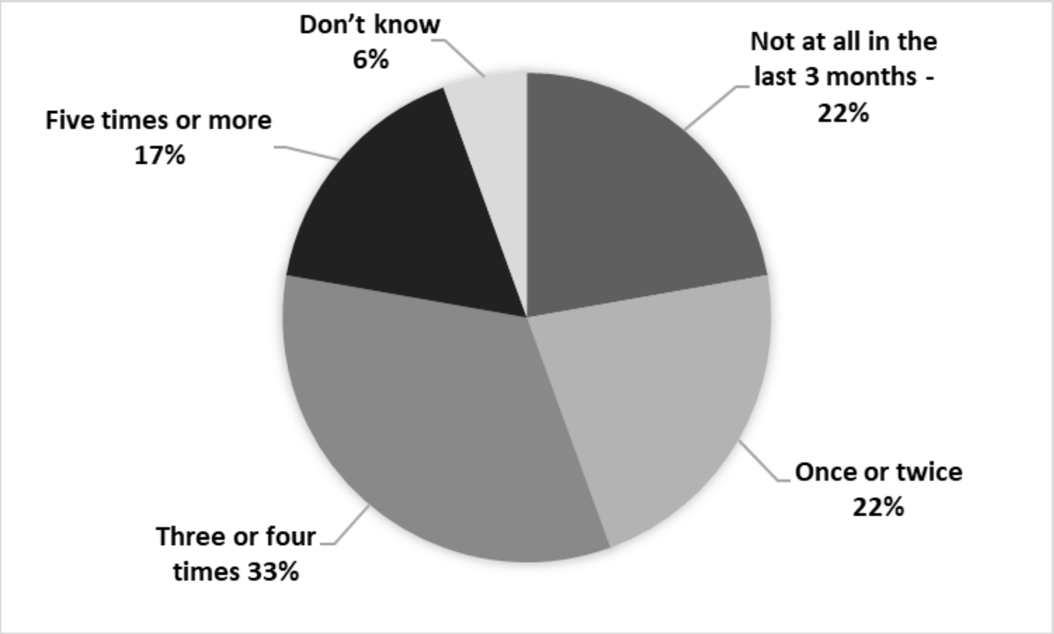

Figure 10-10 How many times did carers need urgent care during the evening or at the weekend

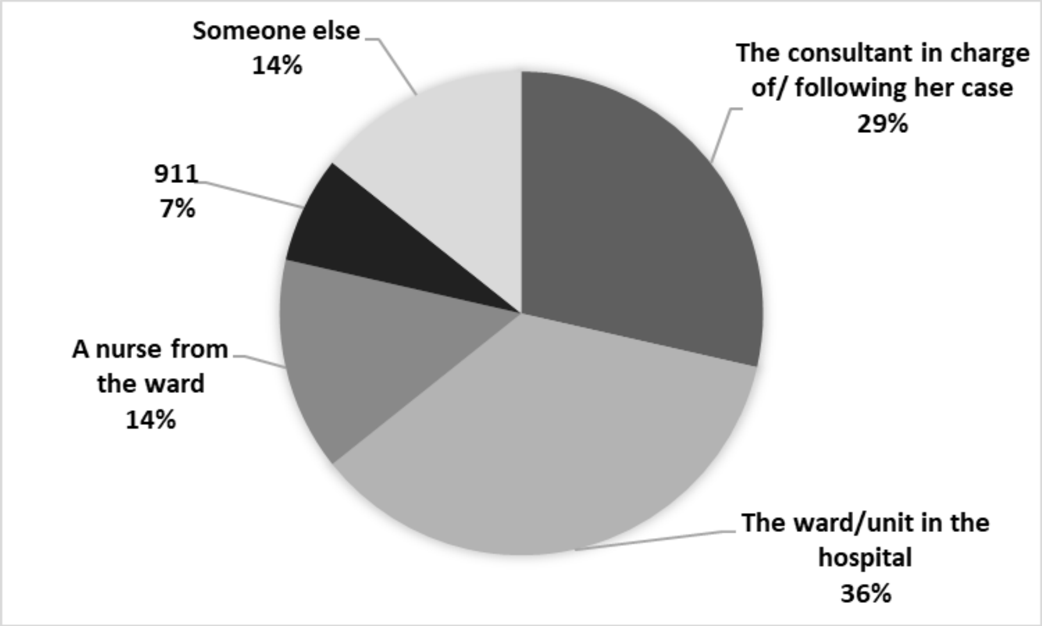

Figure 10-11 Healthcare professionals contacted for urgent care during weekends and evenings

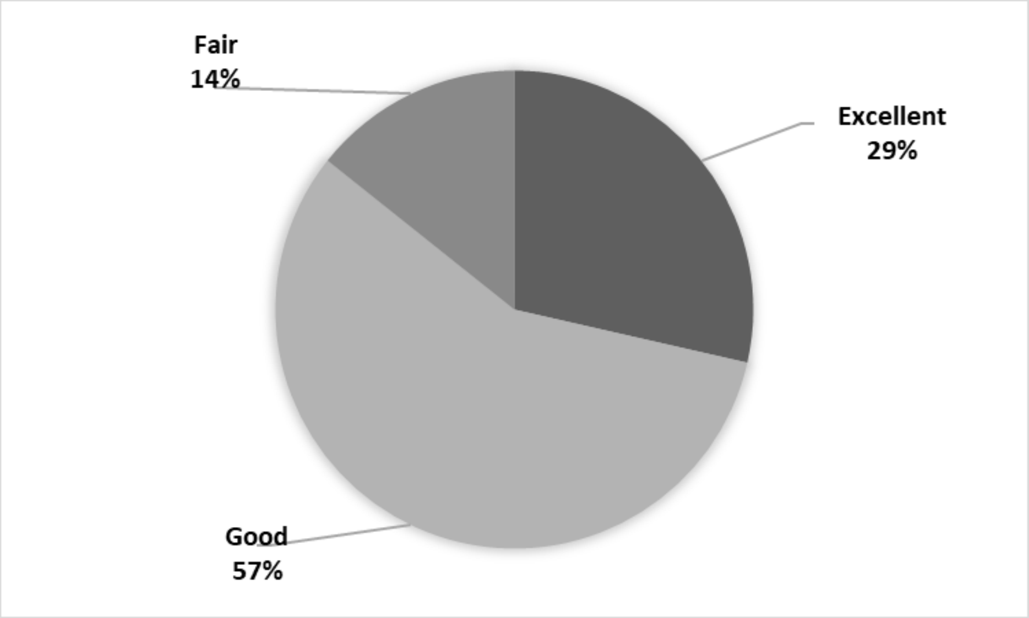

Figure 10-12 Reported quality of urgent care provided in last three months of life when the child needed this during evenings or weekends

10.4.1.3 Child's care at the hospital

In this section, the findings from the questionnaire items regarding care provided for the child in the paediatric ward, NICU and PICU are reported. The number of carers and response frequencies are summarised in supplementary figures. The boxes are the questionnaire items with their precise wording.

10.4.1.3.1 Sympathetic care and trust

Bereaved carers were asked questions regarding whether care was sympathetic and whether they trusted healthcare professionals at the hospital in both paediatric ward and intensive care units (Figure 10-13 and Figure 10-14).

During her last stay on the Paediatric Ward, how much of her time was she looked after in a caring way by the hospital doctors and nurses?

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

In general, thirty-three (69%) carers verbalised positive comments while they were answering questions regarding care provided at hospitals. Thirty-eight (79%) carers responded that the child was always treated in a caring way by nurses and doctors in different units. Carers expressed that the medical team was treating the child *"as if she was their child"* (a father of 4 years old female), another carer said that *"they didn't neglect him [the child] they took good care of him and did everything they could"* (a mother of 6 years old male). A father of 8 months old male stated that *"at [hospital name] I never saw any negligence at all, all nurses were caring and provided excellent care"*.

These positive comments were evident among carers who received care frequently from hospital staff and with more than one child with the same condition, for example, a father of a 4 year old female reported that *"whenever I had to bring her to the hospital when she was very sick, they took very good care of her"* and *"my two daughters [who had the same condition] were being treated special"*. Another father, of a 1 year old male with Down syndrome, expressed that, despite the limited staff numbers, the *"care at [hospital name] considering the staff and overload they did good job"*.

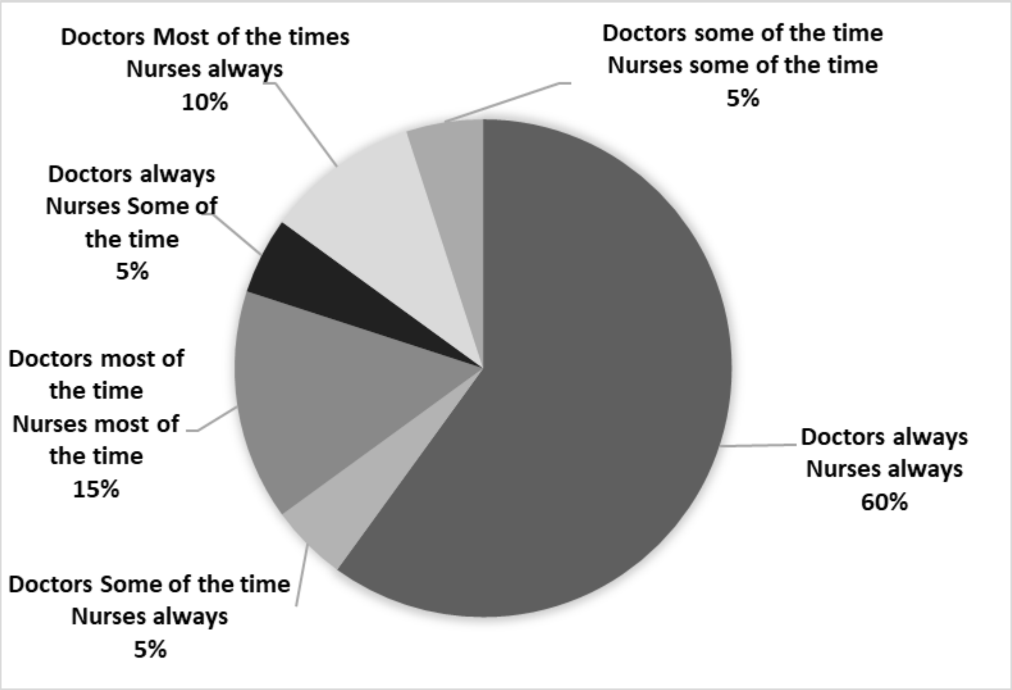

Figure 10-13 Percentage of children looked after in a caring way by the ward doctors and nurses

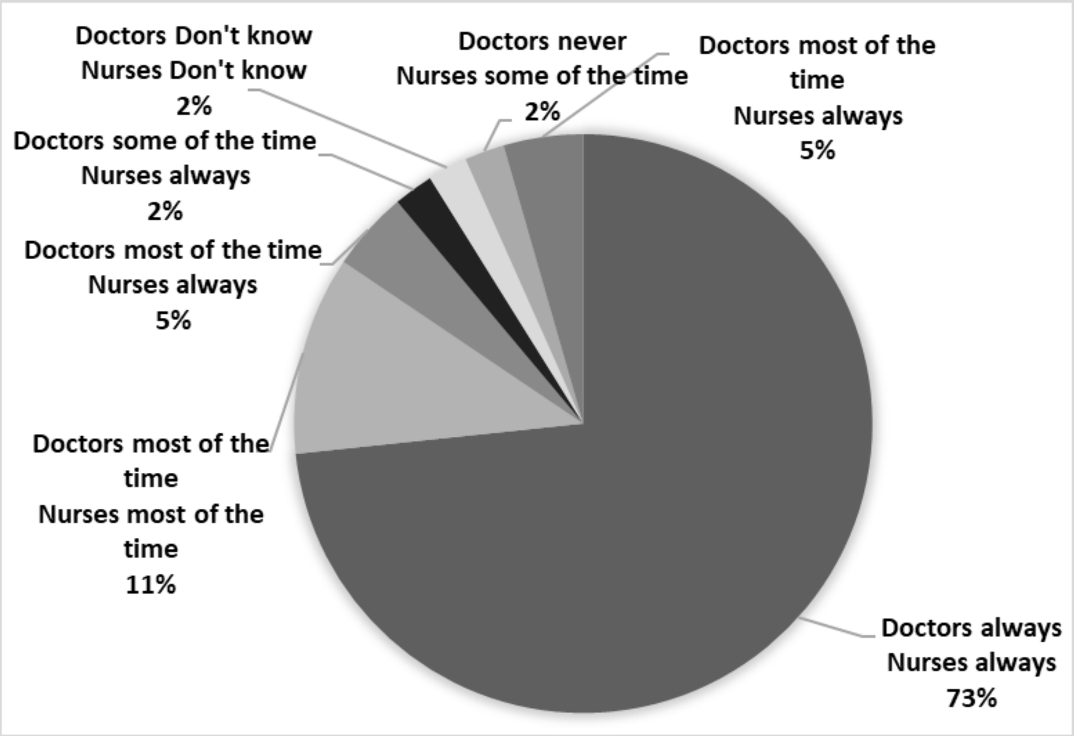

Figure 10-14 Percentage of children looked after in a caring way by the NICU / PICU doctors and nurses

To what extent did you place your trust in the health professionals?
Please answer for both doctors and nurses **Doctors** **Nurses** ☐ ☐ Always ☐ ☐ Most of the time ☐ ☐ Some of the time ☐ ☐ Never ☐ ☐ Don't know

Most bereaved carers gave positive ratings in terms of placing their trust in healthcare professionals, and almost similar ratings were given for doctors and nurses (Figure 10-15 and Figure 10-16). Carers made positive comments regarding putting their trust in the staff as one carer quoted *“after God, we trust the staff”* (a father of 8 months old male). Further comments were made such as *“I trusted them [staff members] 24hrs”* (an uncle of 12 years old male), and *“I trusted them always”* (a father of 5 years old female). However, trust in staff was not universal, and one carer, a mother of a 5 days old neonate, argued that *“if there was good care, he wouldn't have died. I was at the hospital evening and he was good, a few hours later he was dead, how … I can't trust doctors and nurses anymore”*.

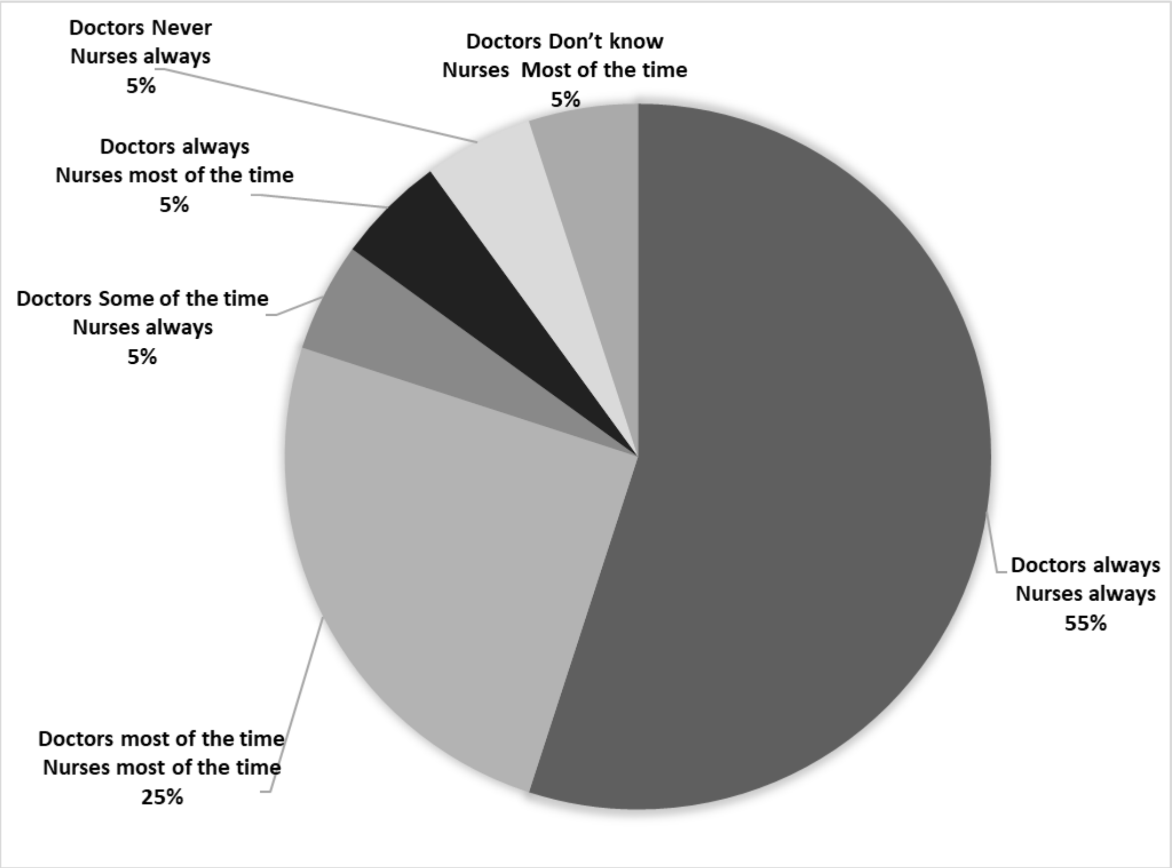

Figure 10-15 Carers’ reports regarding placing their trust in the health professionals (ward)

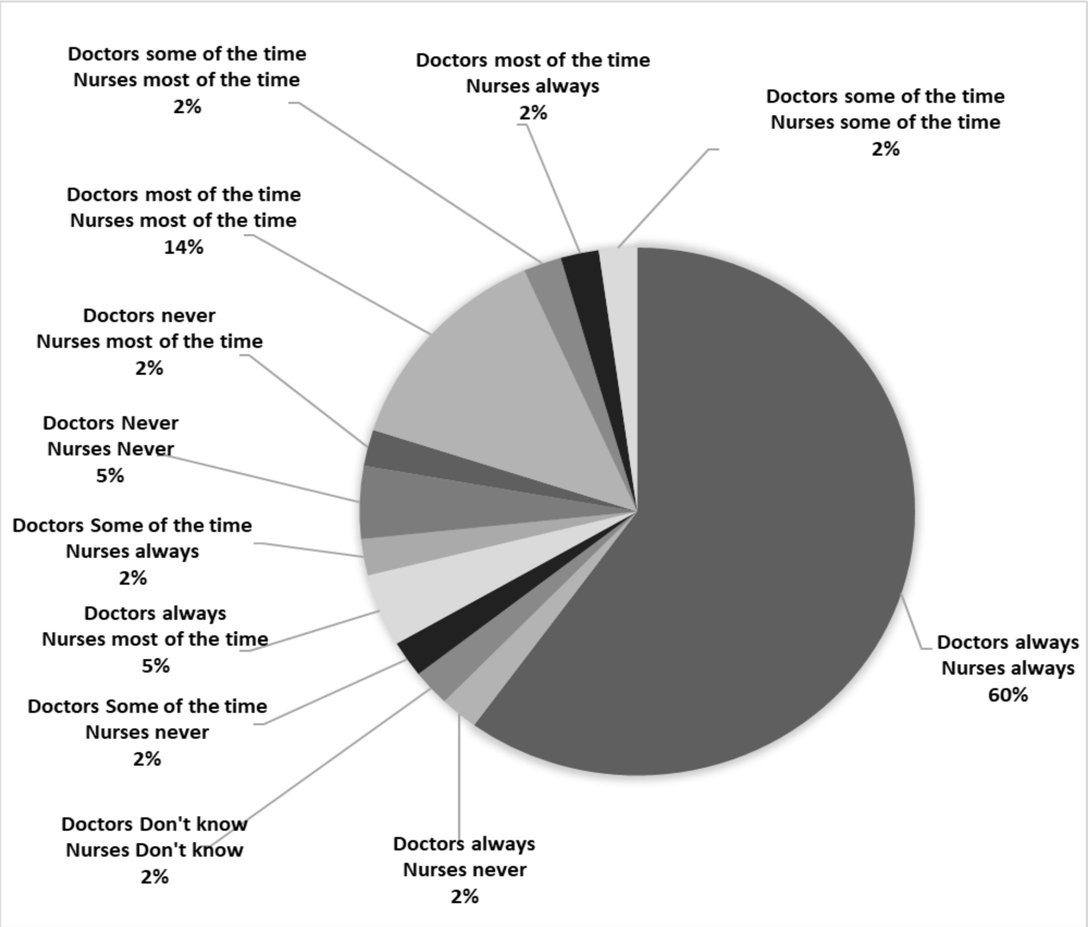

Figure 10-16 Carers' reports regarding placing their trust in the health professionals (NICU and PICU)

10.4.1.3.2 Coordination of care

Sixteen carers (80%) in the paediatric ward and thirty-four carers (75%) in the NICU/ PICU responded that hospital units worked well with the consultant following the child's condition, i.e. "Yes, definitely" and "Yes, to some extent". However, three carers (15%) in the ward and four carers (9%) in intensive units reported that services did not work well with the child's consultant and a carer (5%) and seven carers (16%) answered "Don't know" for the ward and NICU and PICU respectively (Figure 10-17). A greater proportion of carers of children who received care in intensive units were not aware of what was happening because they were not with the child all the time, and therefore, would often answer "Don't know". For instance, a father of a 7 days old male said *"I don't know, I used to go every two days [to check on the child]"*.

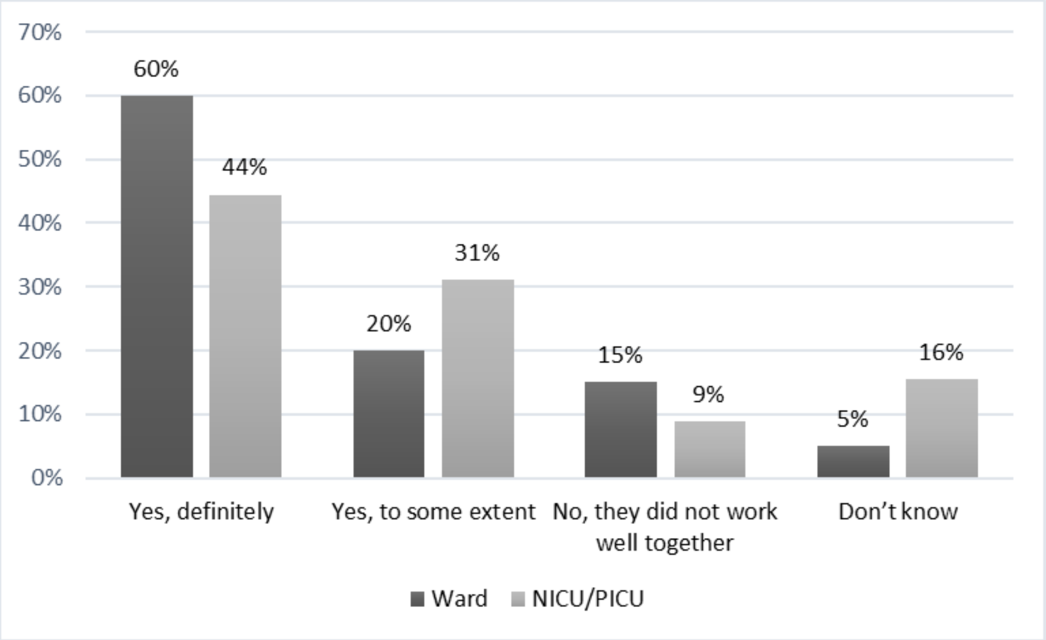

Figure 10-17 Ratings of hospital services working well together with the consultant in charge by different types of hospital units

10.4.1.3.3 Relief of pain in hospital units

During her last stay in the paediatric ward, how well was her pain relieved?					
Does not apply - she did not have any pain	Completely, all of the time	Completely, some of the time	Partially	Not at all	Don't know

Generally, the majority of bereaved carers responded to pain relief questions as "does not apply - she did not have any pain", "completely, all of the time" and "don't know", (Figure 10-18). Bereaved carers elaborated that the children did not suffer from any pain during their hospital stay, or they were not able to tell whether the child was in pain or not since the child was unconscious or sedated. As carers commented: *"they tried to do [relieve the pain] as much as they could ... the mass was affecting his breathing. He had seizures so they gave him sedation"* (a mother of a 1 year old male), and *"the child was unconscious in the last days"* (an uncle of 12 years old male). On the other hand, one carer was not satisfied with pain management for his daughter (7 months old) *"never, we didn't feel that [her pain was relieved], her condition became worse and worse"*.

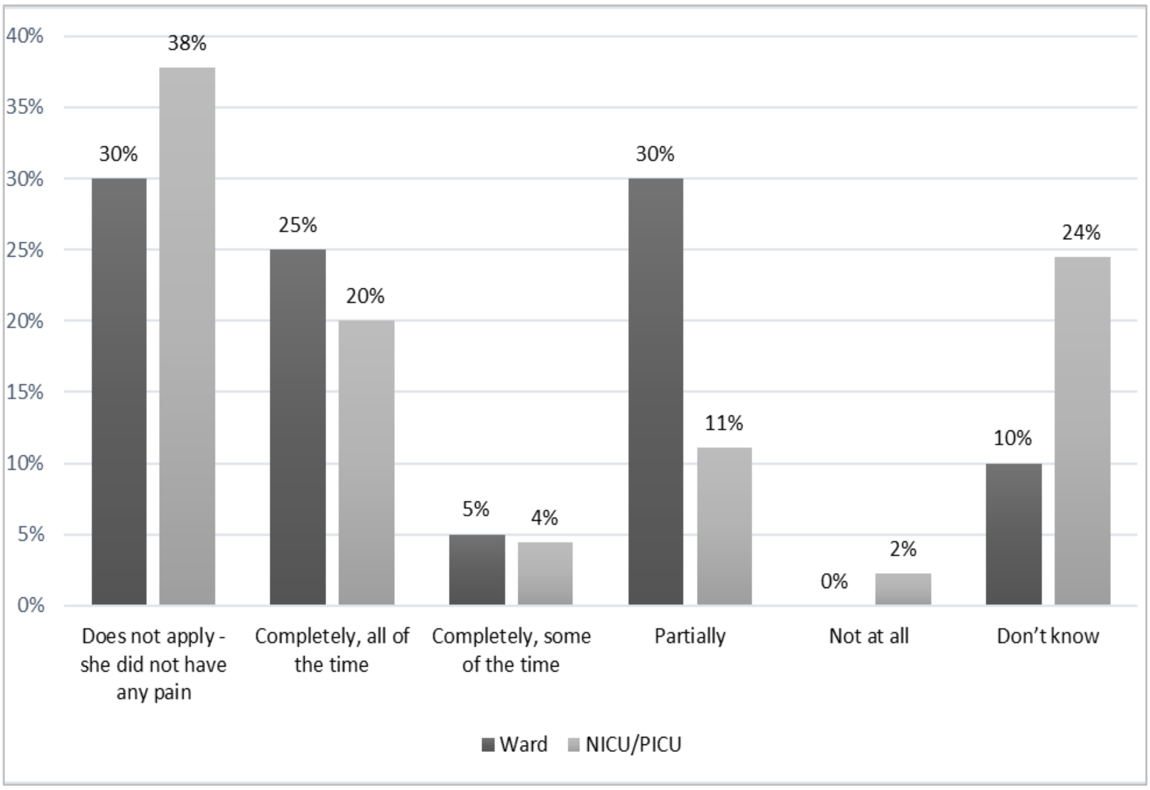

Figure 10-18 Ratings of child's pain management domain in different types of hospital units

10.4.1.3.4 Child’s needs in the last two days

Please look at the following statements and tick the answer box that corresponds most with your opinion about the help provided in the last two days of life

(a) Her needs were met
(b) She had sufficient pain relief
(c) Care and attention were given to problems apart from pain
(d) Her emotional needs were considered and supported
(e) The family’s spiritual and/or religious needs were considered and supported as reciting religious texts

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don’t know

This section entails questionnaire items that address care and support provided to the child in the last two days of life. For the purposes of analysis, response options “strongly agree” and “agree” were collapsed into one category and “disagree” and “strongly disagree” into another category due to the low number of respondents in each sub-category.

Overall, thirty-six carers (75%) reported that the child’s needs were met and only six carers reported that the child’s needs were not met in their last two days. Two carers responded to the child’s needs domain with “Does not apply” and “I don’t know” and one carer neither agreed nor disagreed. Regarding pain management, twenty-one carers (44%) reported that the child did not suffer in the last two days because s/he was on life support. Followed by fifteen carers (31%) who responded: “strongly agree/agree”. Similarly, the majority of carers responded “Doesn’t apply” for managing other problems and emotional support, twenty-nine (60%) and thirty-eight (79%) respectively. Forty-two carers (88%) reported that they were allowed to practice their faith and the healthcare professionals respected their religious needs such as reading Quran or bringing a priest for the child (Figure 10-19).

One negative comment was raised by a father of 7 months old female *“The care at the PICU was very poor, apart from basic care (oxygen and IV fluid): I had to buy a medication that wasn’t available at the hospital, there was overload at the unit, and some staff members were inexperienced”*

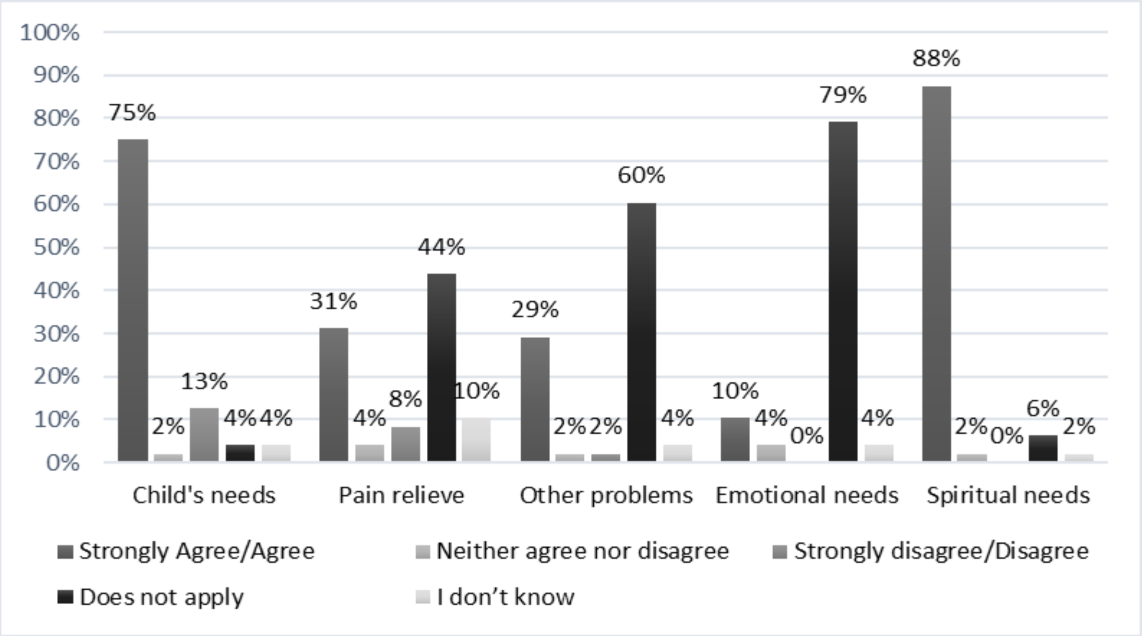

Figure 10-19 Ratings of quality of care given by health professionals to the child in the last two days of life

10.4.1.3.5 Decision making

<table>
<tr><td colspan="5">Looking back over the last three months of her life, was she involved in decisions about her care as much as she would have wanted?</td></tr>
<tr><td>She was involved as much as she wanted to be</td><td>She would have liked to be more involved</td><td>She would have liked to be less involved</td><td>She was not able to be involved</td><td>Not sure</td></tr>
</table>

One item in the questionnaire referred directly to the child’s involvement in the decision-making processes in the last three months. Thirty-seven carers (77%) answered that the child was not able to be involved because s/he was unaware of what was happening i.e., very young, in a coma or on life support, see Figure 10-20. Eight carers responded, “Not sure” and one mother of a 10 years old female reported that the child would have liked to be more involved in her care plan.

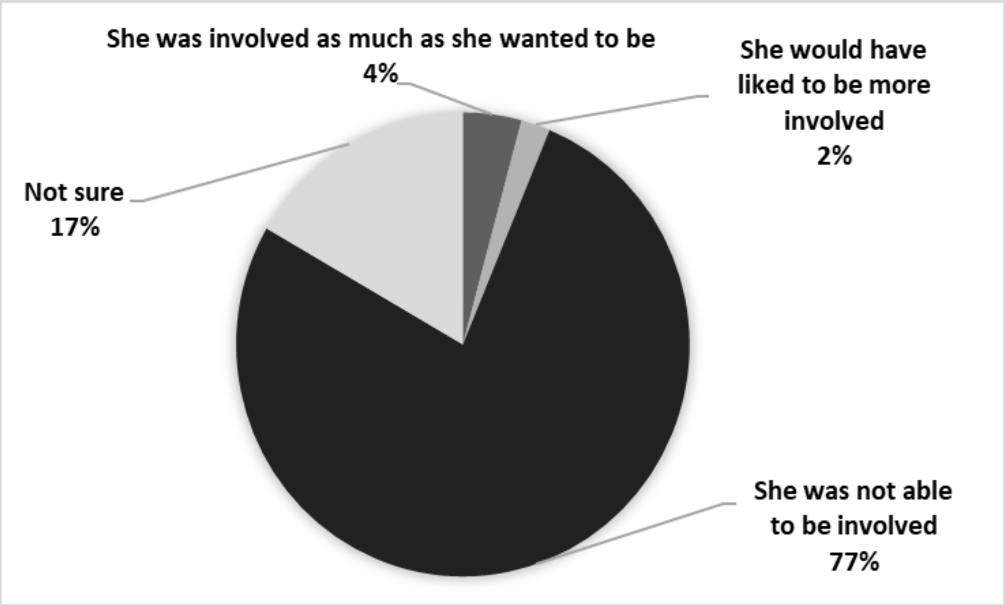

Figure 10-20 Carers’ reports regarding the child being involved in decision making

10.4.1.4 Support for carers

This section covers several questions regarding care and support provided to carers during the child’s hospitalisation in the last three months.

10.4.1.4.1 A place to stay at the hospital

Seventeen out of twenty carers (85%) reported they were allowed to be with the child in the same room in the paediatric ward. In contrast, around half of the bereaved carers of children in NICUs and some PICUs were not allowed to stay at the hospital and expressed their wish to have been offered a place near the child (Figure 10-21). Carers explained they had been informed that it had been the hospital’s policy not to allow relatives to be with severely ill patients, especially during the COVID pandemic. Carers who were allowed to be with their child spent their time on a chair. Although there was not a place to stay overnight with the child, carers reported visiting children daily and calling the unit frequently to check on the child’s condition. A mother of a 6 years old male stated that *“The staff gave me their personal telephone numbers to check on the child”*.

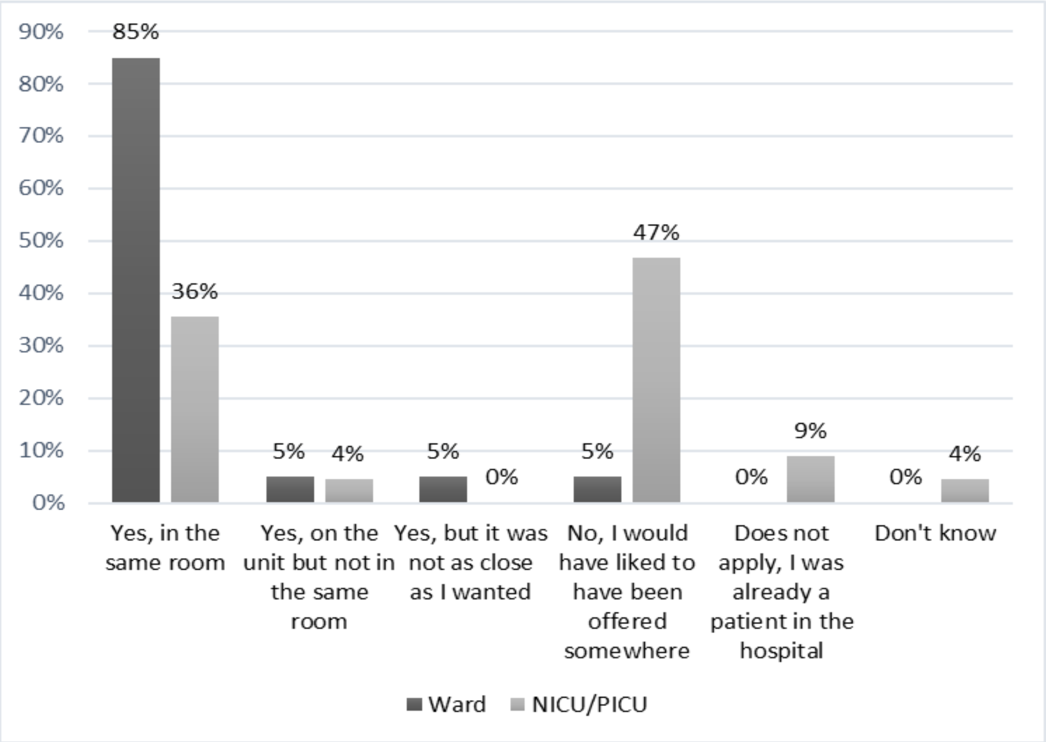

Figure 10-21 Carers' reports about being supported to stay with the child by different types of hospital units

10.4.1.4.2 Involvement in care

Were you supported by staff to be involved in caring for her?				
Yes, definitely	Yes, to some extent	No, I was not allowed to be involved	No, I was not offered to be involved	Don't know

Most carers reported they were supported by healthcare professionals in different units to participate in the child's personal care. Nine carers (20%) were not offered or allowed to provide care for the child, this occurred mainly in intensive care units (Figure 10-22).

Bereaved carers considered providing needed medication and supplies as "being involved" in the child's care. For example, a father of a 5 years old female stated that *"I always asked them if there was medication, they wanted from outside the hospital to bring it".*

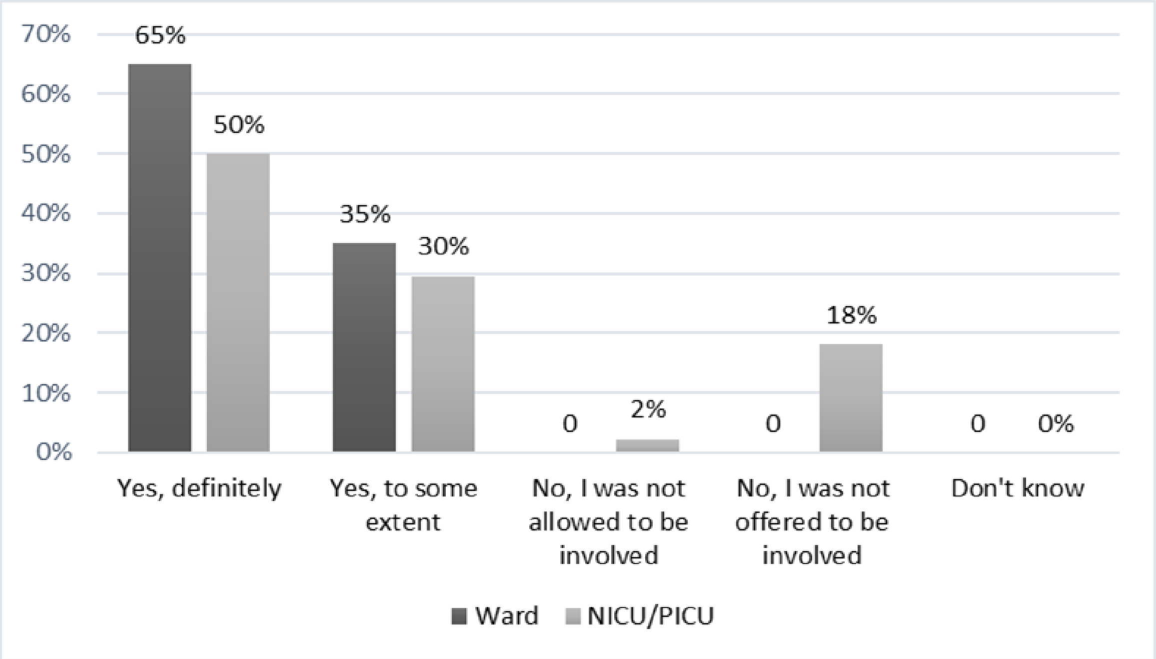

Figure 10-22 Carers' reports about being supported to be involved in caring for the child by different types of hospital units

10.4.1.4.3 Being recognised as an expert

Did you feel listened to and acknowledged as a parent, as an expert about your child?			
Yes, definitely	Yes, to some extent	No	Don't know

All twenty carers of children treated in the ward were listened to by healthcare professionals and acted as the child's advocate by explaining the child's routine and needs to staff. Carers stated: *"they took every detail about her .. generally .. food"* (a father of 5 years old female with a congenital condition), and *"yes, his condition.. how his life at home"* (a father of 1-year-old male with down syndrome child). On the other hand, six carers out of forty-five (13%) who had been in both intensive care units reported that they were not listened to by professionals, see Figure 10-23.

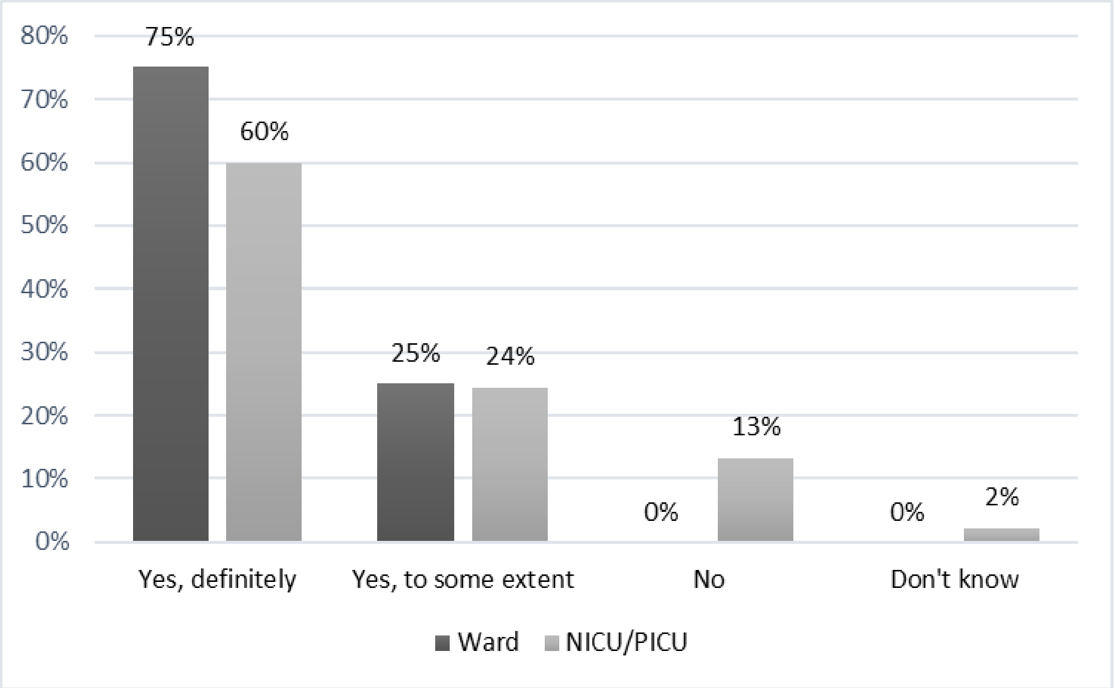

Figure 10-23 Carers' reports about being listened to and acknowledged as a parent, as an expert about the child

10.4.1.4.4 Carers' needs in the last two days

Please look at the following statements and tick the answer box that corresponds most with your opinion about the help provided in the last two days of life

(c) I as a parent was looked after

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don't know

Twenty carers (43%) responded they had been cared for by staff, whilst seventeen carers (36%) reported that their needs were not met in the last two days, the rest answered, "does not apply" and "neither agree nor disagree" (six and four carers respectively) (see Figure 10-24).

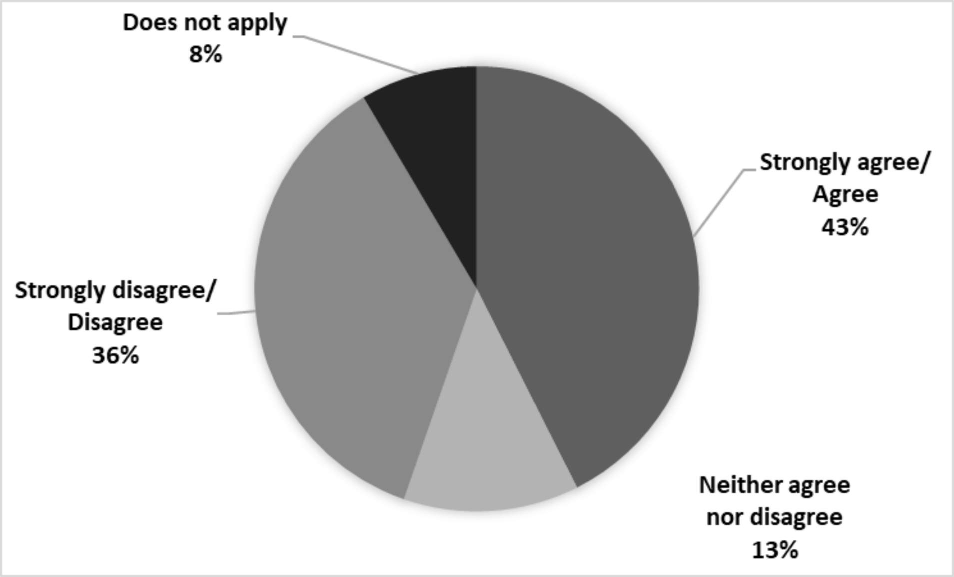

Figure 10-24 Carers' reports about being looked after as a parent

10.4.1.4.5 Being informed

Please look at the following statements and tick the answer box that corresponds most with your opinion about the help provided in the last two days of life

(a) I/we were kept informed on her condition and care

(b) I/we had enough time with staff to ask questions and discuss her condition and care

(c) I/we understood the information provided to us

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don’t know

Thirty-six carers (75%) reported that staff provided information and gave them the time to ask questions about the child’s condition and care plan, while nine carers (19%) reported they were not informed. Ten carers (21%) reported they did not have enough time to ask questions. Only four carers did not understand the information given to them about the child’s condition and plan of care (Figure 10-25). Many carers commented positively on the extent to which they received necessary information concerning the child’s treatment and prognosis: *“whenever there was a problem or he was poorly, I would tell them and they explained to me”* (a mother of 2 years male)

> *“they gave me all the time [to ask] … I used to call the unit every day [to check on the child]”* (an uncle of 12 years old male),
>
> *“at the end, I don’t have medical information, what the doctor says… I will be convinced whether this true or not”* (a father of 35 days old male),
>
> *“when she died a resident doctor called me to his office and explained her condition to me because she had a rare illness”* (a father of 5 years old female),

Other carers reported negative experiences of receiving insufficient information from staff:

> *“whenever I asked him [the doctor] assure me how is the child, he kept saying "Leave to God, Leave it to God” and to come back to here [his office] … he didn’t tell me what was going on or going to happen”* (a father of a 1 day old male)
>
> *“what confused me is that there wasn't a clear diagnosis of his condition, at [hospital name] they did more than 22 tests, but they told me his test results were normal”* (a father of 8 months old male)
>
> *“I didn't have the time [to ask questions] the staff was very busy in PICU with the children”* (father of 4 years old female)

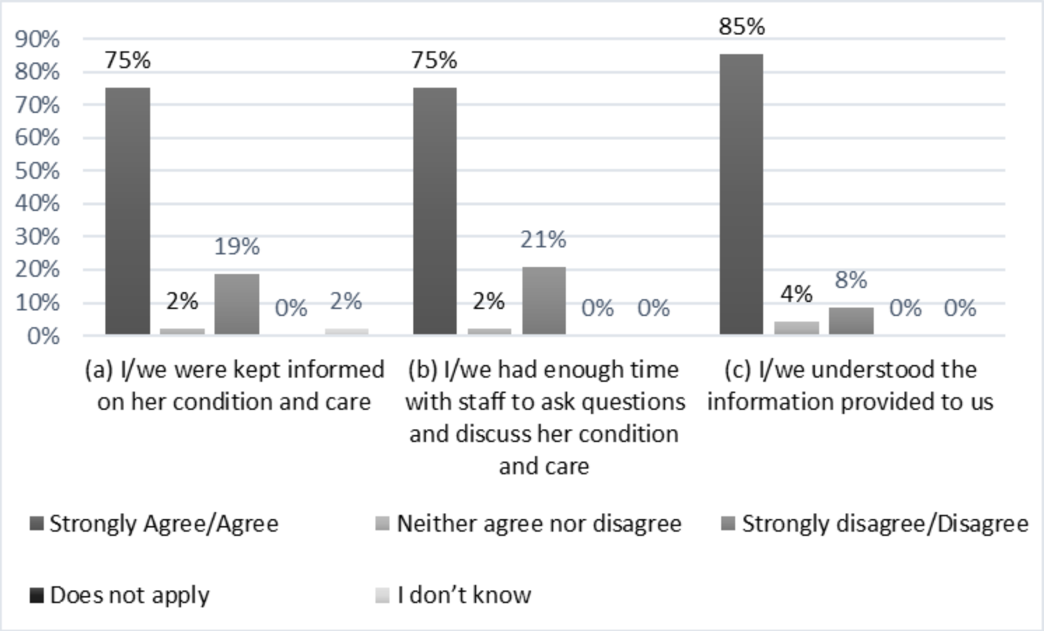

Figure 10-25 Carers’ reports about the help provided in the last two days of life

10.4.1.4.6 Decision making

Looking back over the last three months of her life, were you involved in decisions about her care as much as she would have wanted?			
I was involved as much as she wanted to be	I would have liked to be more involved	I would have liked to be less involved	Not sure

The involvement of carers in decision-making processes was evaluated by two items that asked respondents the extent to which carers were involved in decisions and their satisfaction with their level of involvement. Around half of the carers (46%) expressed they were involved in decisions, however, fourteen carers (29%) stated that they would have liked to be more involved in decisions about the child's care, eight of whom were carers of children less than two months old (Figure 10-26). presents the reported satisfaction of carers about decisions taken in the last three months, with thirty-seven carers (77%) reporting they felt satisfied and that they made the best they could for their children (Figure 10-27). Five out of eight carers who responded "Not sure" regarding decisions made for the child's care were carers of children less than 60 days (Figure 10-28).

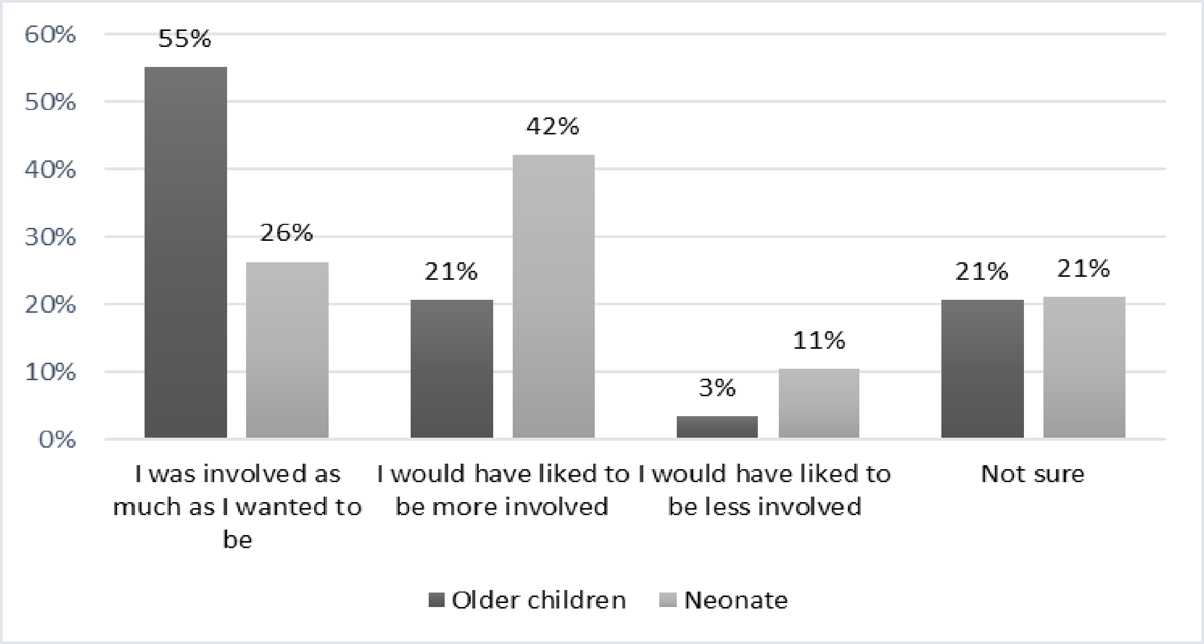

Figure 10-26 Carers' reports regarding being involved in decision making

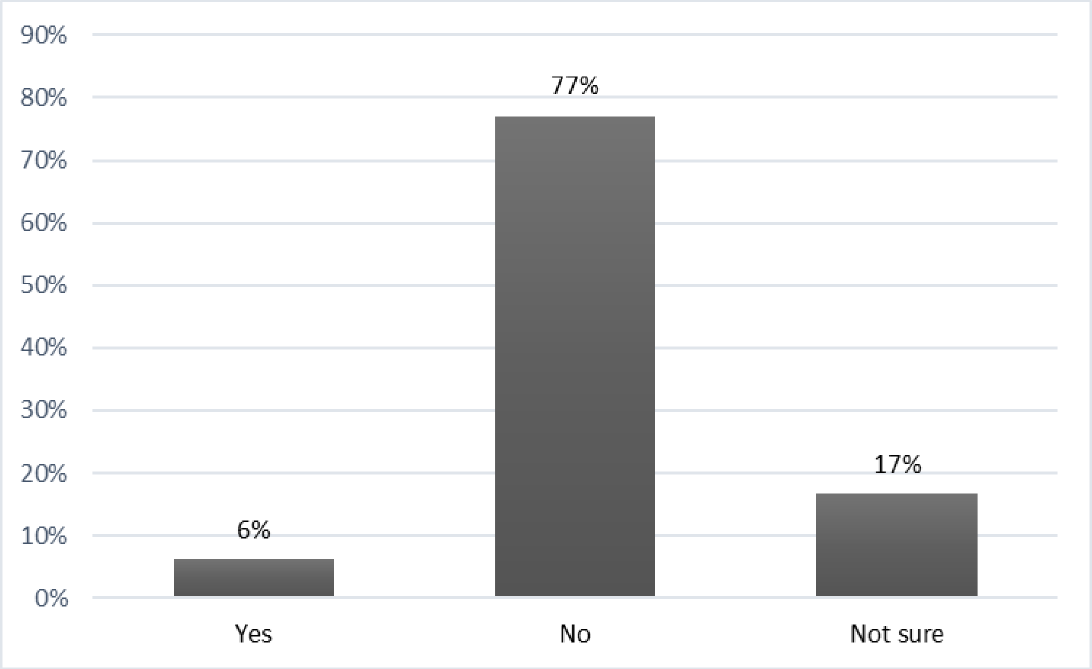

Figure 10-27 Carers' reports regarding satisfaction with the decisions for the child's care

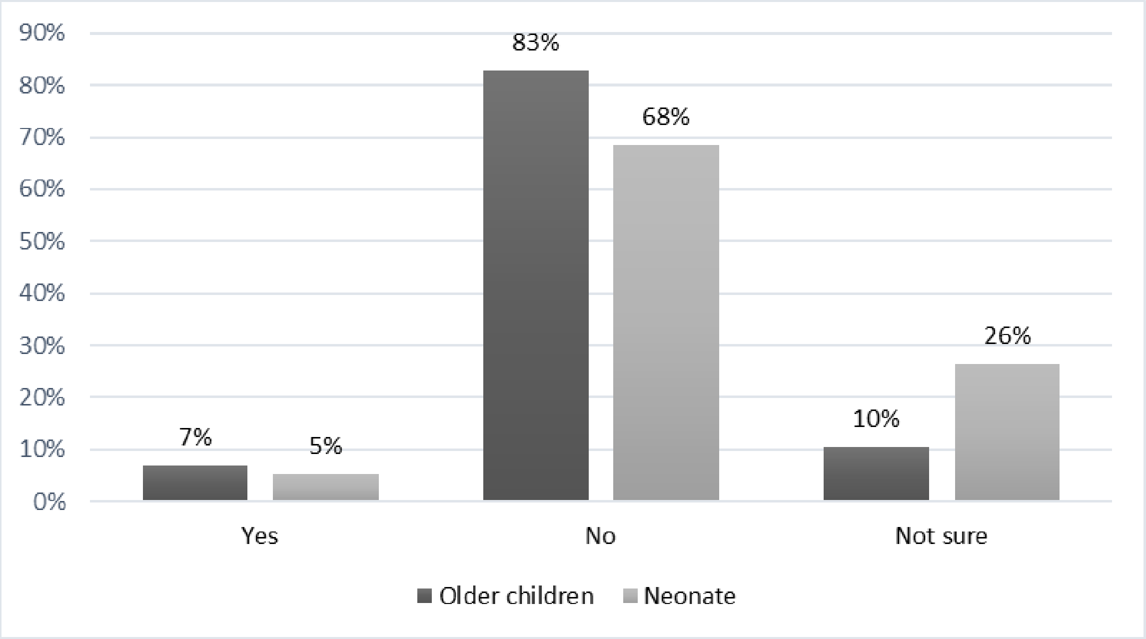

Figure 10-28 Carers' reports regarding satisfaction about decisions regarding child's care according to the child's age

10.4.1.5 Siblings' support

Was / were her sibling(s) supported by health professionals when they visited?						
Yes, definitely	Yes, to some extent	No	Don't know	Does not apply, there were no siblings	Does not apply, we did not want her siblings to visit her	Does not apply, they were not allowed to visit her

In response to questions concerning support for siblings of the deceased child during the last hospitalisation, the vast majority of carers responded with "does not apply" 65% in the ward and 69% in NICU/PICU. Many reasons are given for this, for instance, the deceased may have been the carers' only child at the time of hospitalisation, or the child may have had very young sibling/s, the parents may not have allowed siblings to see the child while poorly, hospital policies may not have allowed visitors in intensive units (Figure 10-29). Four carers in the ward and six carers in intensive units reported that the siblings were supported by healthcare professionals such as to see the child and healthcare professionals had talked to them. A mother of 75 days female elaborated that her *"older daughter visited her once, I wasn't feeling well and she went with her father … Yes she was supported"*.

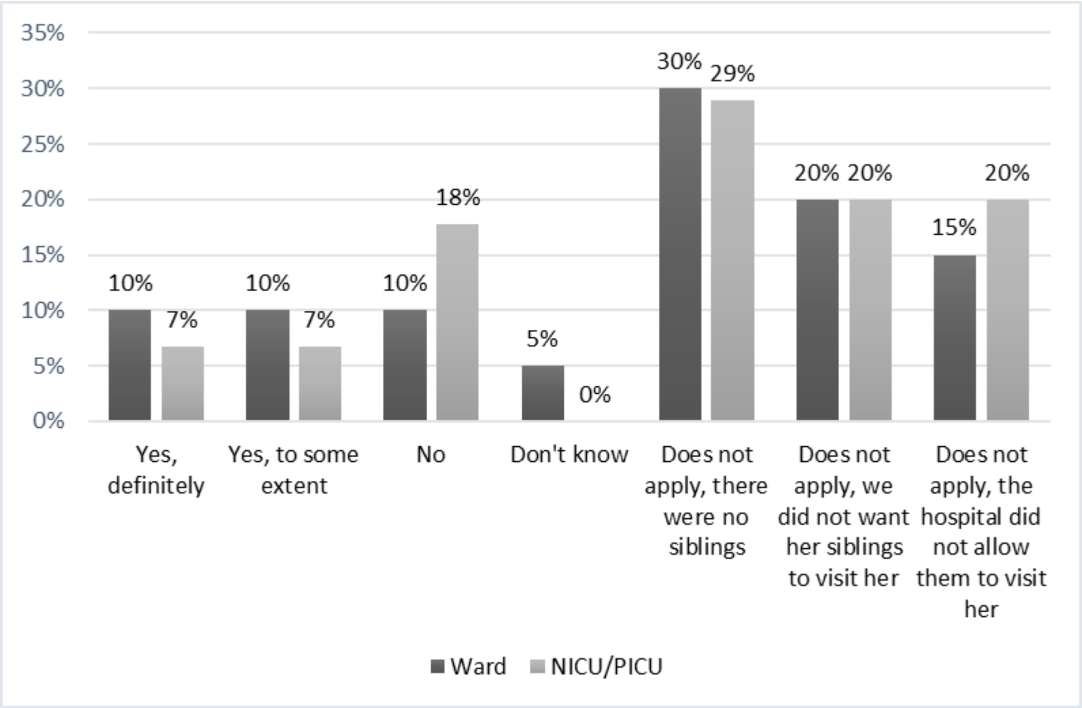

Figure 10-29 Carers' reports regarding siblings' support by health professionals when they visited the child according to the type of hospital unit

<table>
<tr><td colspan="7">Please look at the following statements and tick the answer box that corresponds most with your opinion about the help provided in the last two days of life</td></tr>
<tr><td colspan="7">(b) Her sibling(s) were looked after by staff</td></tr>
<tr><td>Strongly Agree</td><td>Agree</td><td>Neither agree nor disagree</td><td>Disagree</td><td>Strongly disagree</td><td>Does not apply</td><td>I don't know</td></tr>
</table>

When asked whether siblings had received support in the last two days of the child's life, only six carers (12%) agreed that siblings were supported while three carers (6%) disagreed that siblings were looked after by staff members. The rest of those who responded to this item answered "Does not apply" (Figure 10-30).

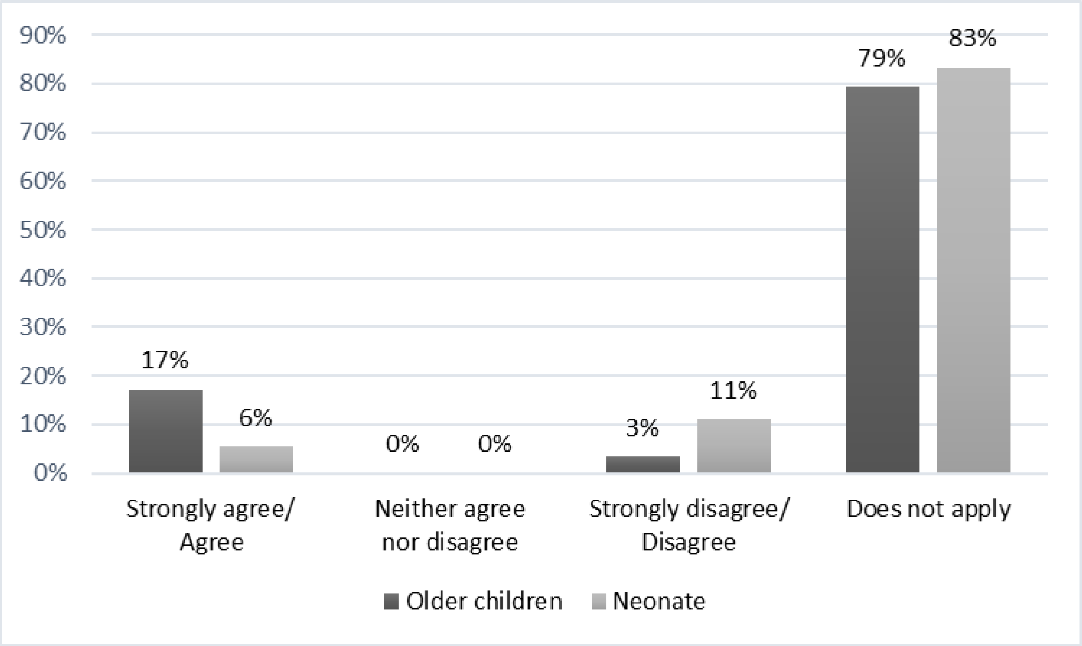

Figure 10-30 Carers' reports regarding siblings' support in the last two days of life according to child's age

10.4.1.6 Around the time of death

Were you or her family given enough help and support by the healthcare team at the actual time of her death?			
Yes, definitely	Yes, to some extent	No, not at all	Not sure

The majority of children (87%) died in intensive care units, whilst two children died in the ward, two in the operation room and two on the way to the hospital. In response to the question (Were you or her family given enough help and support by the healthcare team at the actual time of her death?), most of the interviewed carers (81%) reported they were supported at the time of death, as shown in Figure 10-31. Whilst a few carers indicated they were not supported at the actual time of death who were mainly carers of children less than two months (Figure 10-32).

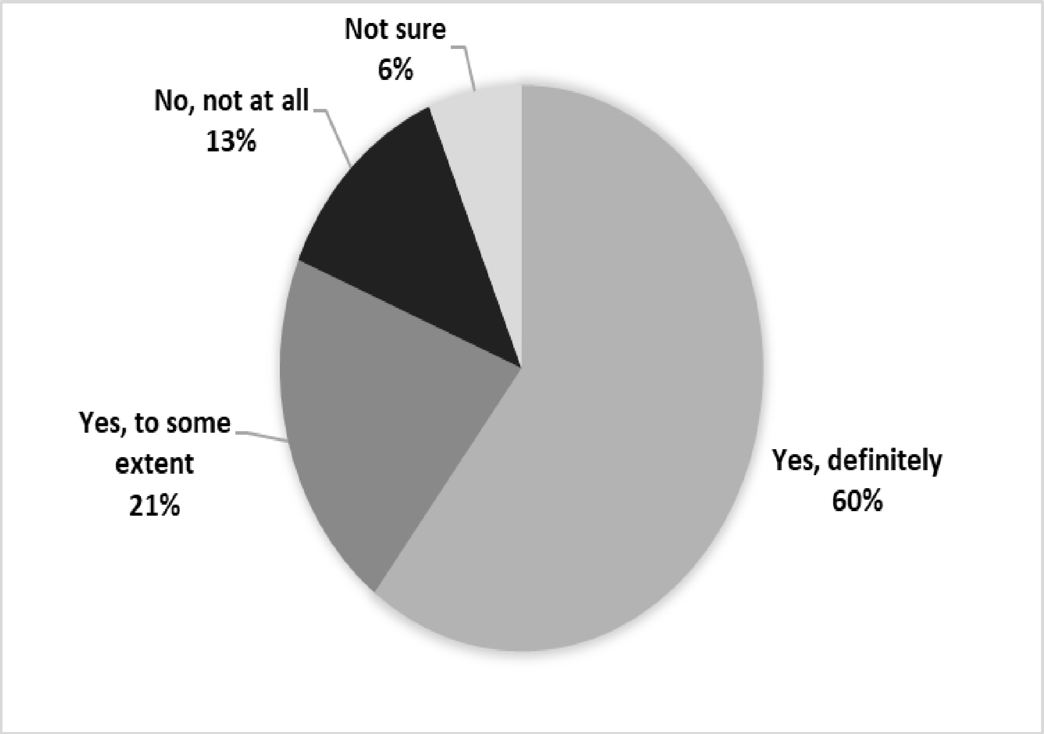

Figure 10-31 Carers' reports regarding support given to the family by healthcare team at the time of death

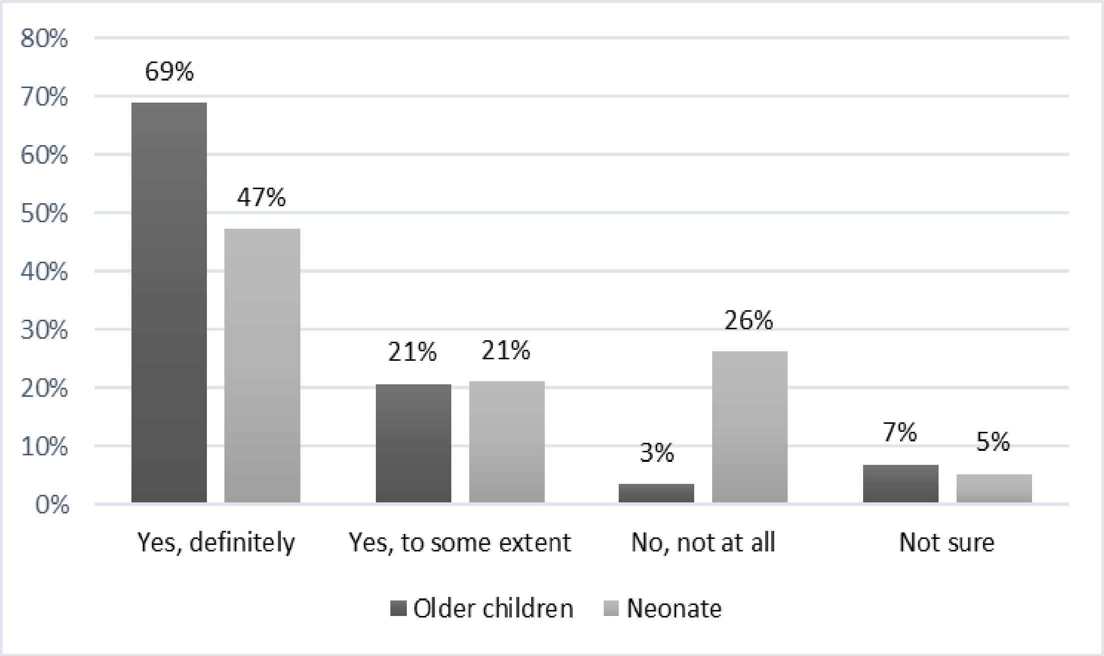

Figure 10-32 Carers' reports regarding support given for the family by healthcare team at time of death according to child's age

Were you supported by staff to touch or hold your child at this time?					
Yes, definitely	Yes, to some extent	No, I was not allowed to hold or touch the child	No, I was not offered to hold or touch the child	Not sure	Not applicable

From the data in Figure 10-33 it is apparent the overall response to the question (Were you supported by staff to touch or hold your child at this time?) was positive. For example, *“medical support they did great job … they left my mum with him after his death” (a father of 5 years old male)* and *“they [the staff members] were very supportive”* (a father of 8 months old male).

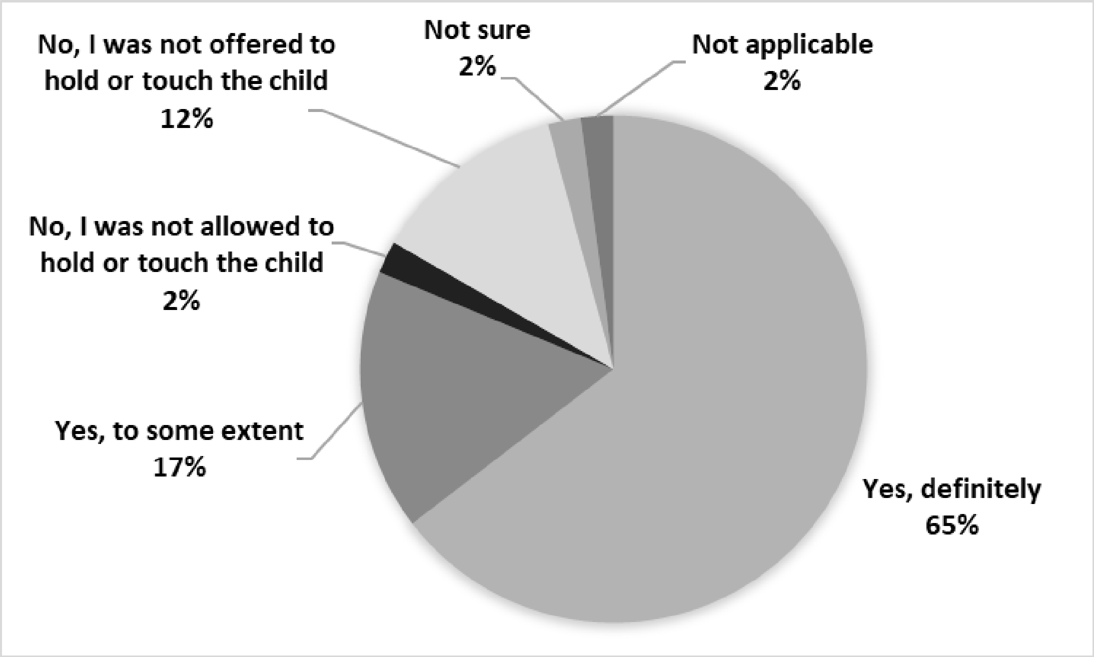

Figure 10-33 Carers’ reports regarding being supported by staff to touch or hold the child at time of death

However, the majority of negative reports were from carers who were not offered the opportunity to hold children less than two months old (Figure 10-34). These reports were a result of the inability to be with the child around the time of death and transferring the child’s body to the morgue quickly, often before carers had arrived at the hospital.

"The child died at the NICU and we were informed by phone. When we arrived, the child was in the morgue" (a father of 22 days female)

"The child died at night; the staff transfer him to the morgue quickly" (a mother of 5 days old male)

"*The child died at PICU, there wasn't anyone with him. we received the news on phone and when we arrived the child was in the morgue*" (a father of 8 months old male)

"The child died at the unit and I was informed by phone. When I arrived at the hospital, the child was in the morgue" (a father of 40 days old female).

"The child was in the morgue when we arrived at the hospital, according to the hospital policy" (a father of 2 days female)

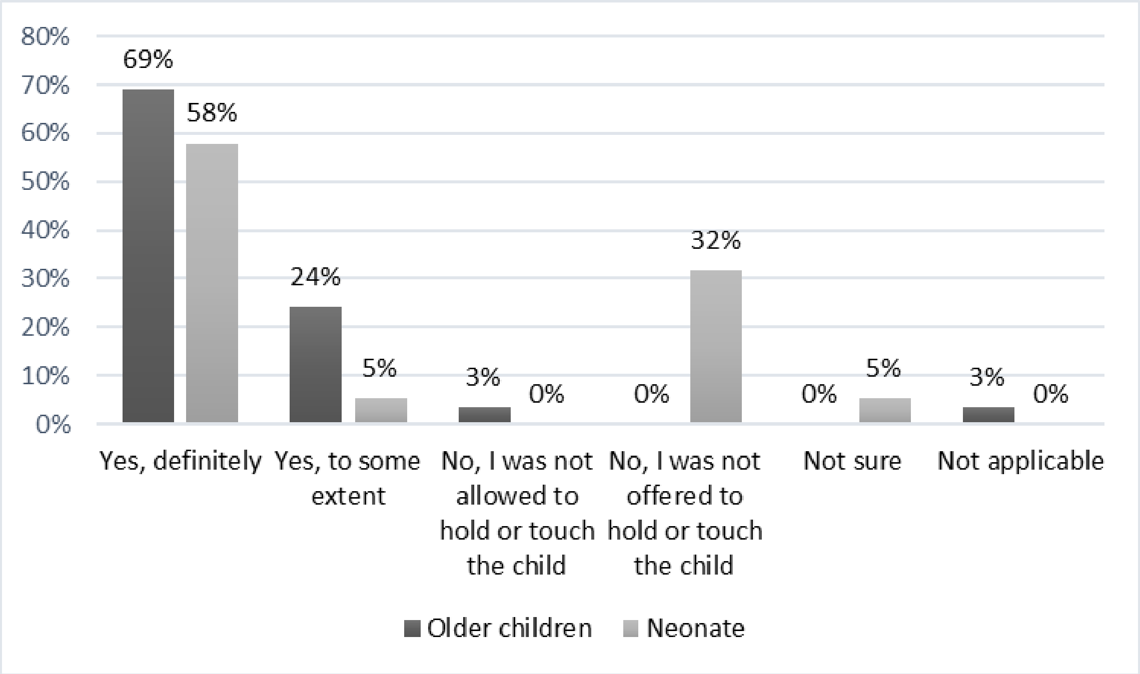

Figure 10-34 Carers' reports regarding being supported by staff to touch or hold the child at the time of death according to child's age

After she died, did staff deal with you or her family in a sensitive manner?			
Yes	No	Not sure	Does not apply – I didn't have contact with staff

Almost two-thirds of those surveyed reported that healthcare professionals were very sensitive towards them after the child's death (Figure 10-35). A minority of participants (15%) indicated that they did not have any interaction with healthcare professionals after the child's death (Figure 10-36). Carers reported their positive experience:

> *"the staff were crying at her death"* (a father of 5 years old female)
>
> *"They hugged me and wiped my tears"* (a mother of 10 years old male)
>
> *"[when the child died] they [staff members] were next to us and said supportive words"* (a mother of 2 months old female)
>
> And a mother of a 1-year-old male commented *"my family and siblings were there; the nurses didn't have the opportunity to support me"*

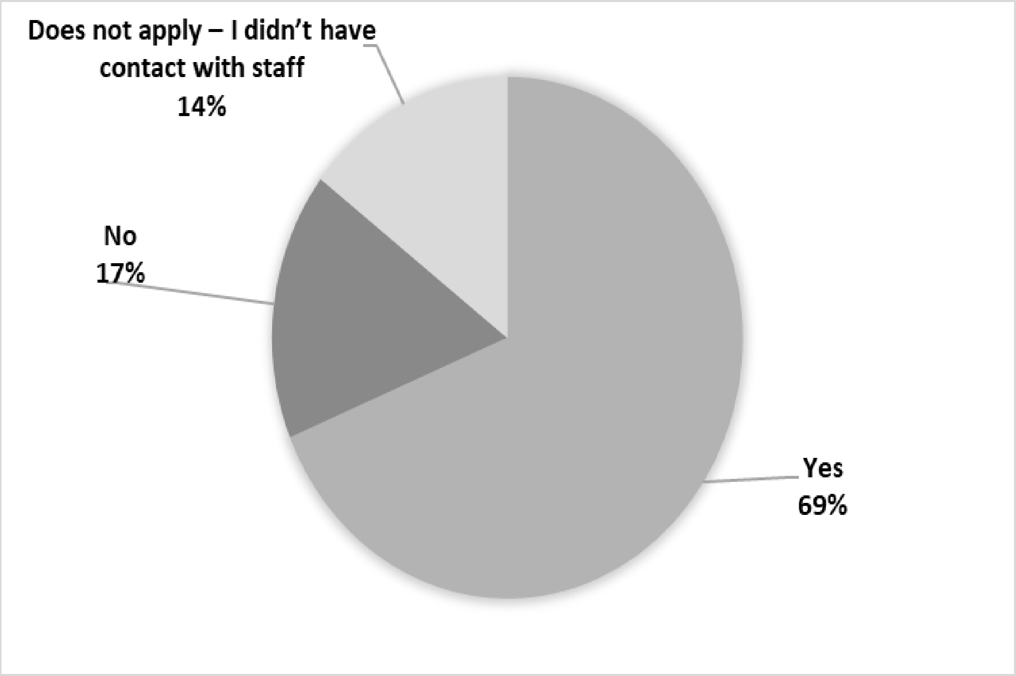

Figure 10-35 Carers' reports regarding staff being sensitive towards them

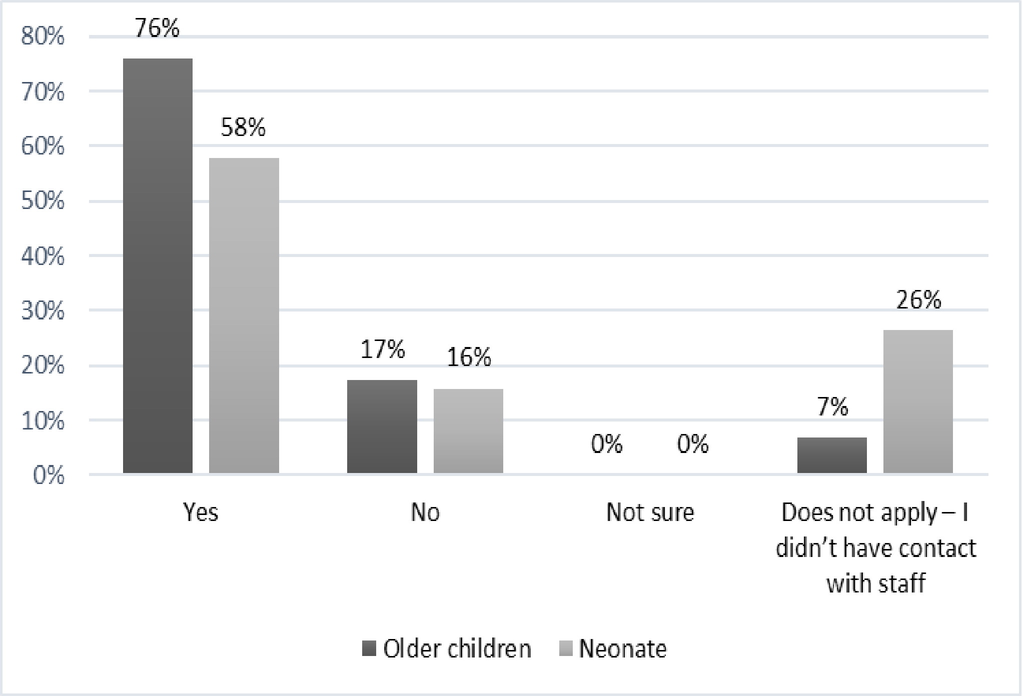

Figure 10-36 Carers' reports regarding staff being sensitive towards them according to child's age

If you wanted to, after her death, were you able to be involved in her wash (perform Ghusl)?				
Yes, definitely	Yes, to some extent	No, not at all	Not sure	Does not apply

Over half of those interviewed reported they were able to bathe the child before burial according to Islamic traditions (called performing Ghusul), and less than half of respondents reported they did not wash the child as they were emotionally incapable of bathing the child after his/her death (Figure 10-37).

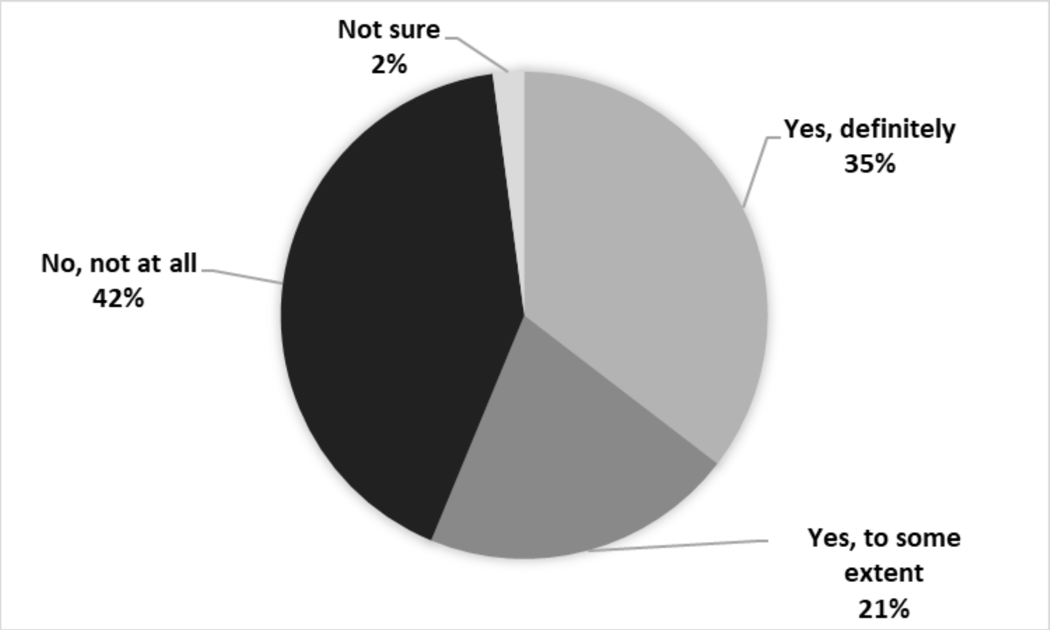

Figure 10-37 Carers' reports regarding being able to wash the child after death

Since she died, have you talked to any health care professionals, about your feelings about her illness and death?			
Yes	No, but I would have liked to	No, but I did not want to anyway	Not sure

Thirty-six respondents indicated that healthcare professionals did not talk to them after the child's death, twenty-one of them stated their wish to have conversation with staff after death and have the chance to understand what had happened to their children (Figure 10-38). As a father of an 11 years old female put it:

> *"I don't know if she [the deceased child] was diagnosed properly or not ... I would have liked to go back [to the hospital] but God gave me serenity.. once I went to the hospital and reached the floor [of the department] then I went back".*
>
> Another carer stated *"I tried to go back to [hospital name] to see the report of death and know the cause of death whether it was because of her death or brain stroke as they said ... I don't know till now"* (father of 4 years old female)

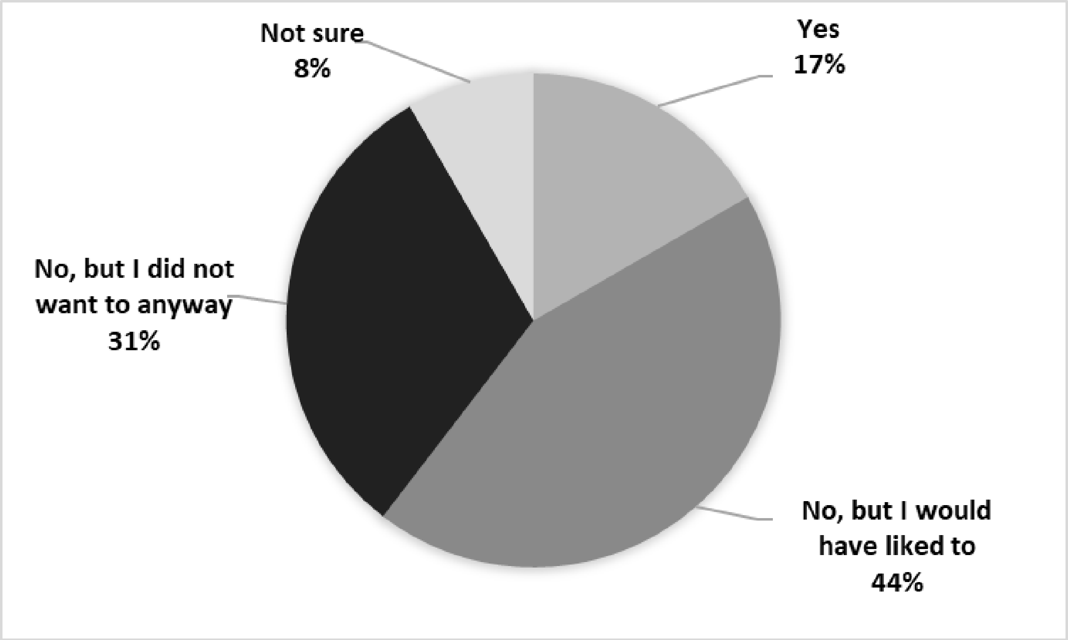

Figure 10-38 Carers' reports regarding being supported since the child's death

Since she died, do you feel that you have received enough support from care professionals?				
Yes, definitely	Yes, to some extent	No, but I would have liked to	No, but I did not want to anyway	Not sure

When carers were asked whether they had felt supported by healthcare professionals since the child had died, the majority commented that they were emotionally supported immediately after the child's death. As shown in Figure 10-39, the majority of carers who disagreed expressed their wish to have the possibility to talk to a healthcare professional about their feelings.

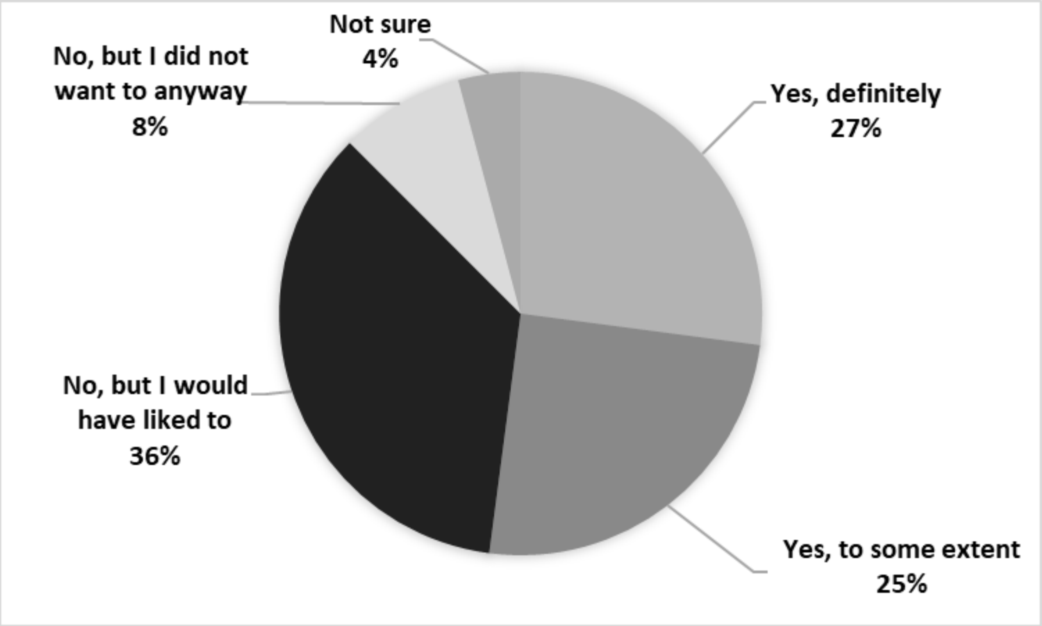

Figure 10-39 Carers' reports regarding receiving enough support from care professionals after death?

In your opinion, did the person who told you she was going to die break the news to you in a sensitive and caring way?					
Yes, definitely	Yes, to some extent	No, not at all	Not sure	Does not apply -I did not know she was going to die	Does not apply -No one told me she was going to die

Did she know she was going to die?					
Yes, certainly	Yes, probably	No, probably not	No, definitely no	Not sure	She was not able to say

According to thirty-four carers, healthcare professionals communicated effectively and sensitively with them when disclosing the child’s death, whereas only two carers disagreed. Ten carers answered “does not apply” as they did not know the child was going to die, or the child died while they were with him/her (Figure 10-40). The majority of carers expressed that the child did not know they were dying. Only three carers stated that the child knew s/he was dying, as shown by Figure 10-41.

> *“I knew that she was going to die because we had a similar case in the family”* (a father of 3 months female)
>
> *“I was standing when the staff was trying to revive her and I saw them when they pulled the sheet on her face, that’s how I knew she was died”* (a father of 4 years old female)
>
> *“he died in my arms, I was praying and saw him staring at me when I hold him I knew he was dying when I called the doctor he came and suctioned him then I told him enough, leave him the child is dead”* (a grandparent of 8 months male)
>
> *“we knew she was going to die but we didn't know when. The doctor told us within this week. On the day she died, she had a fever and her body got very cold quickly. I went to ask the nurses they told me her calcium is down and God is going to take his belonging in the next few hours”* (an auntie of 6 months old female)
>
> *“I saw doctors performing CPR through the glass and I knew she was going to die”* (a grandparent of 6 hours female)

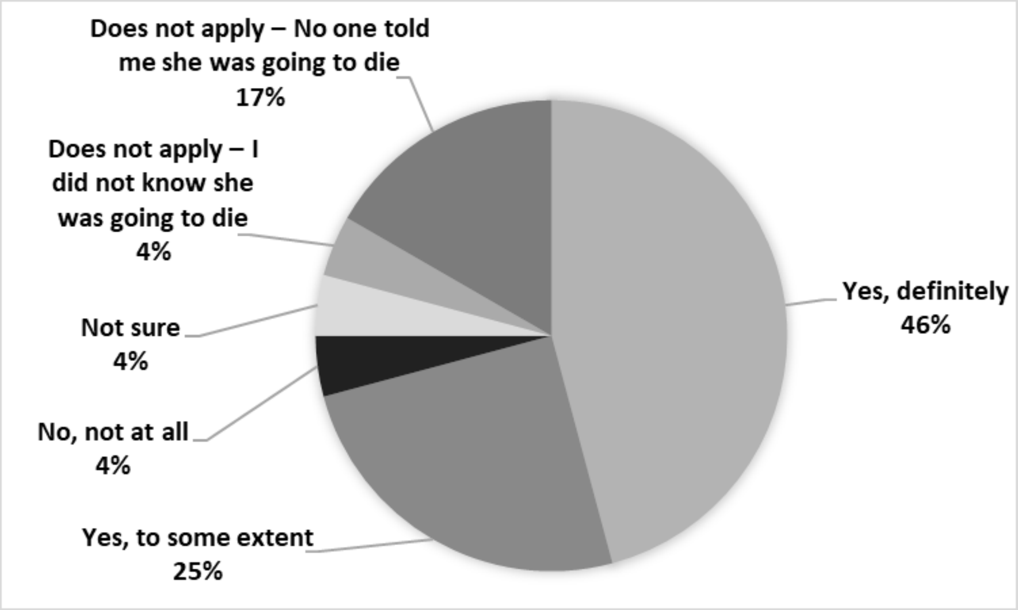

Figure 10-40 Carers' reports regarding if a child was informed in a sensitive and caring way about death

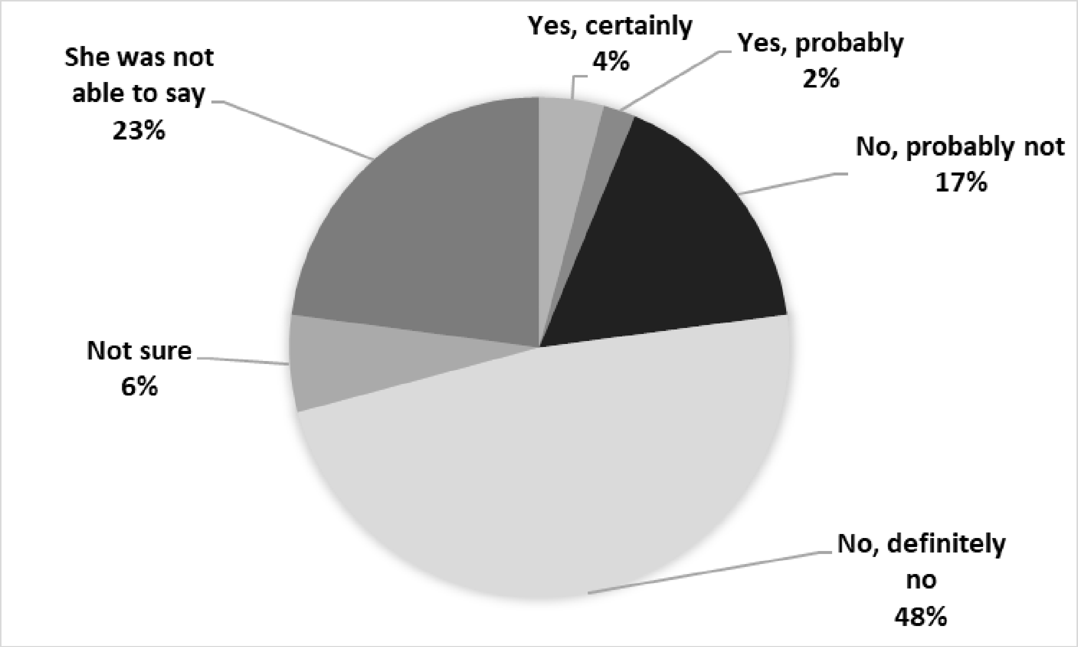

Figure 10-41 Carers' reports on whether the child knew they were going to die

Who talked to her sibling(s) about death?						
I did	My partner did	Another family member did, such as aunts or grandparents	A health professional did	Does not apply	Don’t know	No-one talked to her siblings

Did a health professional support you in talking to her sibling(s) about death?			
Yes	No	Does not apply	Don’t know

Twenty-one carers (43%) did not have other children at the time of death. The majority of bereaved siblings were told about the child’s death by a family member i.e., parent, grandparents, uncles or aunties, and four carers (9%) reported that the siblings heard the phone call when they received the bad news (Figure 10-42). Only five carers (23%) reported having been supported by health professionals in talking with siblings about the child’s death (Figure 10-43).

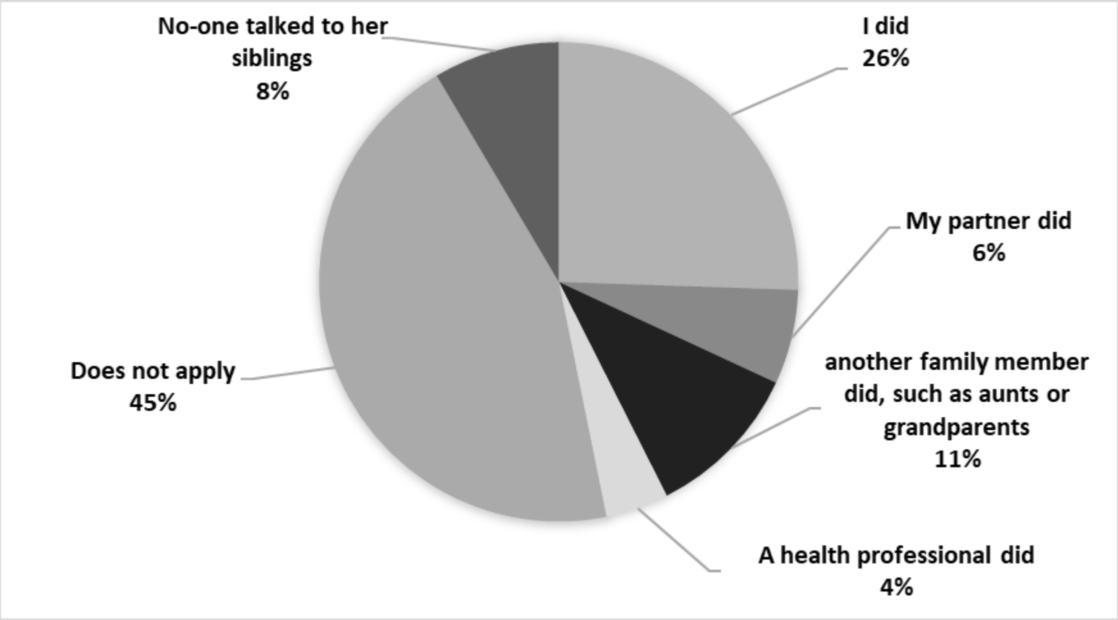

Figure 10-42 Who talked a child's sibling(s) about death?

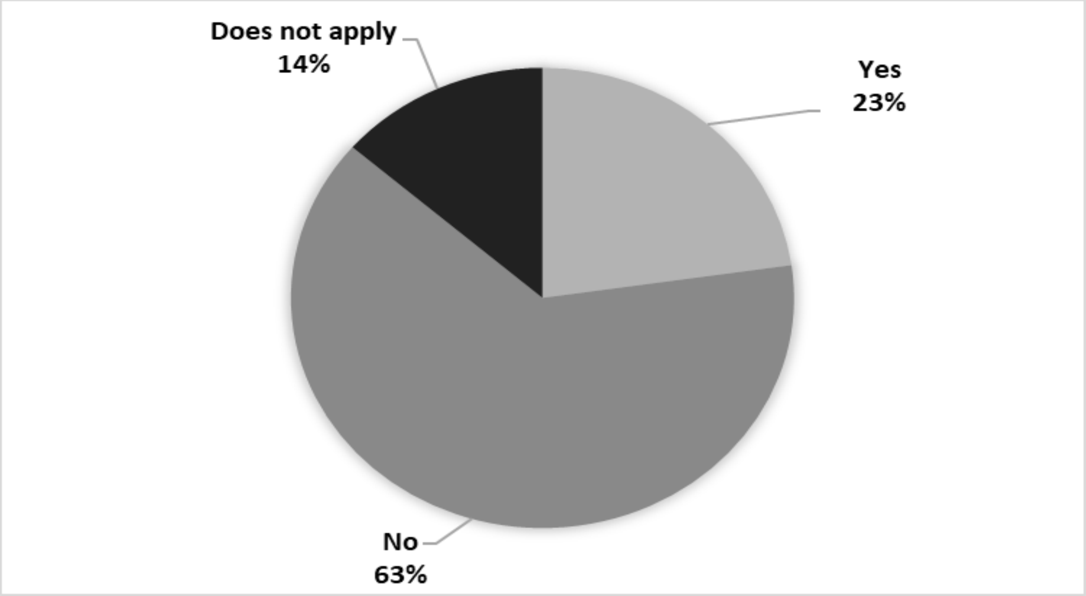

Figure 10-43 Did a health professional support you in talking to a child's sibling(s) about death?

Would you have liked as a family to have choice about where she died?			
Yes	No	Not sure	She died suddenly

Regarding the place of death, carers expressed their faith that no matter what they did or wherever the child was there was nothing to change his/her destiny (see Figure 10-44)

> *"Her time has finished, there was nothing to do"* (a grandparent of 6 hours female)
>
> *"whether he was at the hospital or home he would have died"* (a mother of 2 years old male)
>
> "*God has decreed it and what He willed has happened"* (a mother of 7 days boy)

However, carers raised negative comments regarding their inability to transfer the child to another hospital for more services due to the lack of specialised care i.e. specific medical specialists. A father of a 6 months old female stated:

"*I didn't have any choice about the place of death; I couldn't transfer the child because her condition was very poor",*

while another stated, *"the length of her illness was very short; I didn't have the time to do or decide anything"* (a father of 3 months old female).

Other carers commented: *"I wasn't able to take her to another place because she was on life support and couldn't afford to take her to a private hospital"* (father of 7 months old female),

and *"I wanted to transfer him to another hospital, but it was difficult then because there was a machine... and financial circumstances"* (a father of 35 days old male).

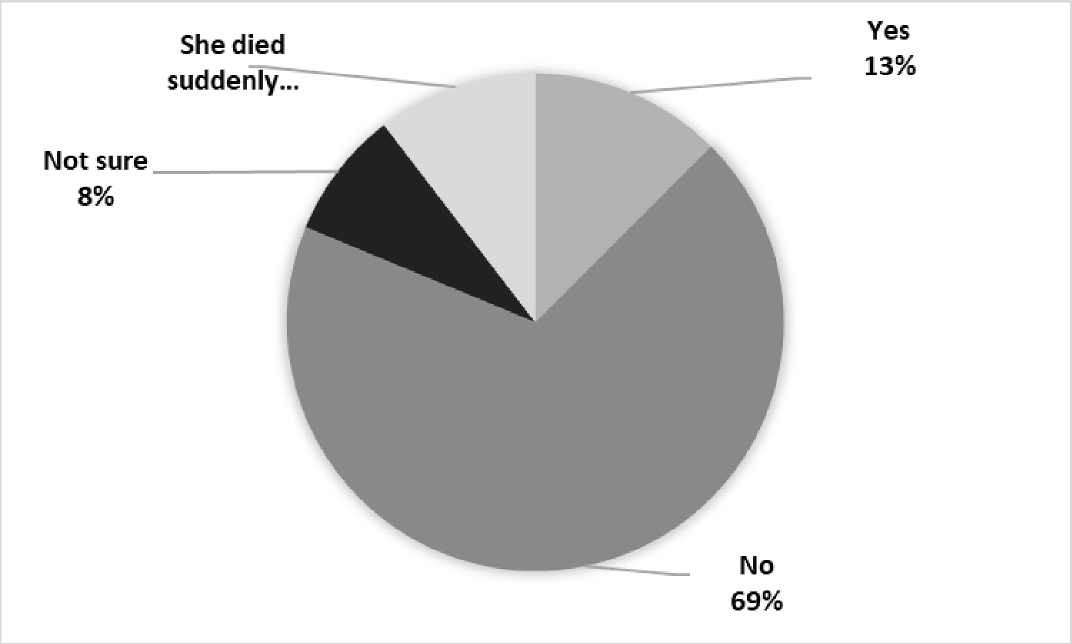

Figure 10-44 Carers' reports regarding family's choice about place of death

10.4.2 Open-ended question

Although there was an open-ended question at the end of the questionnaire to give carers the chance to express their wishes or concerns about end of life care, only eleven carers (23%) responded to this question. Two carers expressed that the questions were *"appropriate"*, and the questionnaire *"covered everything"*. Another carer pointed out that his responses were limited to the unit his child was treated in *"the questionnaire was very comprehensive, but my answers are only related to intensive care unit. Maybe in paediatric ward the care might differ… the nurses are always available and very caring"* (a father of 6 months old female).

Additional attributes of quality paediatric end of life care as reported by carers included access to needed care, communication with healthcare professionals and monitoring healthcare professionals (Figure 10-45).

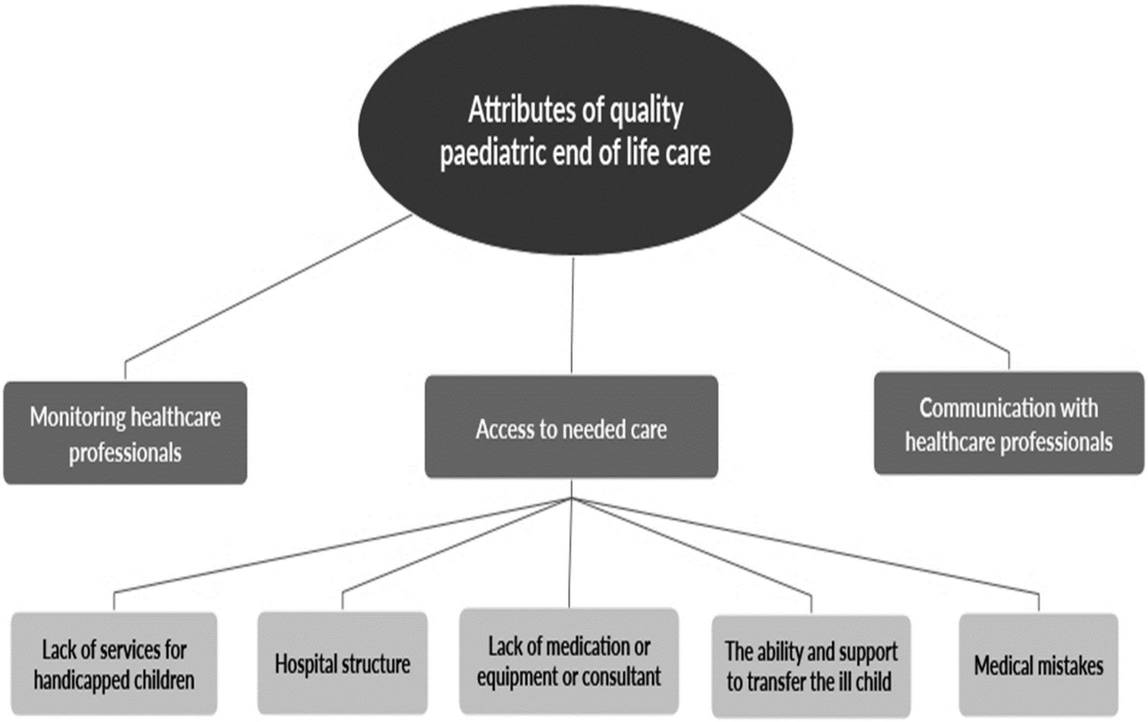

Figure 10-45 Themes that emerged from analysis of responses to open-ended question

10.4.2.1 Access to needed care

Seven carers commented on concerning difficulties in gaining access to medical care i.e. medication, equipment and specialised healthcare professionals especially by carers with public insurance and low-income.

- Lack of care at the treating hospital

Two bereaved carers reported a lack of medication in their treating hospitals in addition to medical experts and supplies, which had to be provided from other hospitals or which they had to buy on their own expenses:

> *"when I asked them for something not available advanced equipment's okay inform me ... I told him [doctor at the hospital] whether to get a [private] doctor he told me no, no need ... I would like to be a question regarding the availability of required specialist"* (a father of 22 days old female),
>
> and *"there should be specialised childcare ... I had to admit him in a hospital far away from our residence. Lack of certain specialities, such as echo technician to perform diagnosis and avoid waiting"* a father of 35 days old male

There were similar reports from bereaved carers throughout the interviews, for example:

> *"what they provided were oxygen and IV fluid that what they offered in PICU, otherwise nothing they asked me for a drug that I had to buy from a pharmacy outside the hospital they told it was not available"* (a father of 7 months old female).
>
> *"for example, when she was on oxygen machine there was a part not available in the hospital, I went to bring it from another hospital or centre"* (a father of 5 years old female)
>
> *"there was a lack of certain specialities"* (a father of 5 years old female)
>
> *"they told me I had to bring a private echo technician on my expenses although I had public insurance, I paid 80 JD for ten minutes"* (a father of 4 days old male)
>
> *"The services are very poor; the child was born with a cardiac condition and there was not a specialist at the hospital. I have been asked to get a private doctor to assess my child. my next child had the same problem at birth, but he survived because he was at a private hospital"* a father of a 1-day old male

- The ability and support to transfer the ill child

This was the second most frequently reported theme and usually associated with the lack of diagnostic equipment or consultant. Two bereaved carers reported they needed and requested to transfer their child to hospitals with more advanced facilities. However, carers stated that they were not fully supported by the treating team to do so, as reported by a father of 5 years old male

> *"I had to discharge my child and took him to a private hospital to know he had a renal syndrome … the first doctor discharged my child due to lack of treatment and a specialised doctor, the doctor refused to transfer the child during the pandemic which I had to get a permission for travelling".*
>
> *"What confused me whenever I asked them what his condition was, they would tell me that they didn't have a clear diagnosis for his condition. He was born healthy and didn't have major problems, admitted mainly for a chest infection then transferred to an advanced hospital but no specific diagnosis was offered"* a father of 8 months old male

Similar comments during the interview were:

> *"I informed them whatever she needs I will do ... if she needs I will transfer her".* (a father of 22 days female)
>
> *"I couldn't transfer the child because her condition was very poor"* (father of 6 months old female)
>
> *"I wasn't able to take her to another place because she was on life support and couldn't afford to take her to a private hospital"* (father of 7 months old female)
>
> *"I wanted to transfer him to another hospital, but it was difficult then because there was a machine ... and financial circumstances"* (a father of 35 days old male).

- Hospital structure

A father of a 4 day old male stated that the hospital was poorly designed because the NICU was far from the delivery room and the doctor had to run with the baby to the NICU:

> *"the conversation was very appropriate I hope this would develop departments concerning child's care; delivery room, NICU and operation room should cooperate to serve the mother and child and should be very close to each other ... all doctors must be available [at caesarean section] in the same room and see what happens to the child ... what I saw this is [operation room] in one side, the NICU on the other side".*

The same carer commented during the interview "*The baby was very distress due to complication during delivery, they had to run with him [the child] to the NICU around 80 meters".*

- Lack of services for disabled children

A father of a boy with down syndrome expressed that his *"son had a very good care at home but there isn't specialised care for children with down syndrome who are totally dependent on parents or another care provider"*

- Medical mistakes

A father of an 11 years old female suggested that he *"would have liked if there is a question about medical mistakes because this what happened to my child".*

10.4.2.2 Communication with healthcare professionals

Two carers reported poor communication and a lack of information from healthcare professionals. Others reported that staff did not communicate in a supportive and appropriate manner, for example:

> *"medical staff paediatric nurses in [hospital name] very bad, I admitted my child first time from 8 am till 11 pm and I did not know what his problem after many investigations and results came up but no one told me what my child was suffering from ... it is not a money thing, individual's personality plays a role because when I returned to the same hospital I was treated better than the private hospital by another doctor according to the individual's personality and manner. The new doctor explained what was going on, what will happen and the medication"* (a father of 5 years old male),
>
> *"they didn't support my psyche, he [the doctor] didn't gave me hope"* (a father of 22 days female)

Additional comment from another carer during interviews was: *"the specialist was very negative he said (God will bring good things), he didn't even try to do anything"* (a father of 7 months old female)

10.4.2.3 Lack of experience and managerial supervision of the staff

Two carers reported the lack of supervision from the hospital of the staff to make sure they were providing the care needed for children at the end of their life which caused their condition to deteriorate further. For example,

> *"I have this question when a mum gives birth, why you [nurse] had this degree ... why don't you take care of newborns ... the mum suffered for months can't you tolerate the baby in the incubator for a month .. more care ... respect mum's who suffered for months ... There should be more supervision all time, every minute every second but there was no care or supervision"* (a mother of 5 days old male)
>
> *"I want to say they have to be strict on nurses because many times they were the reason for his condition to change [get worse] we kept asking them to suction the child but they didn't do and said he didn't need .. although he needed that and his breathing was difficult" "they had the experience but they didn't meet his needs*

whenever he needed something .. they did what suits them" (a grandparent of 8 months old male)

Other carers highlighted the lack of skills and experience of staff in paediatric wards. As carers noted:

"the nursing staff was inexperienced" (a father of 7 months old female),

"nurses didn't have the experience to deal with her, we had to tell them don't do that ... the others before you did that" (a father of 5 years old female)

10.4.3 Summary of main findings from carers' reports

The main findings from bereaved carers' responses to the survey questions are summarised below.

- The majority of bereaved carers were satisfied with the care their child had received and reported "good" to "excellent" quality of care.
- The majority of bereaved carers who reported the quality of care as "fair" or "poor" or "don't know" were carers of young children, mainly less than 60 days old.
- Carers of children who received care at major hospitals were more likely to rate that care as "outstanding" and "excellent" than carers of children who received care at rural hospitals. Whilst no patterns were detected with regard to presence or absence of healthcare insurance and reported quality of care.
- Twenty-five children (52%) were ill since their birth, sixteen of whom were not at home in the last three months of life.
- Carers reported higher satisfaction with pain management, the child's physical needs in the last two days, and spiritual needs which were the focus of staff's attention. On the other hand, there was less satisfaction amongst carers concerning managing other symptoms in the last two days and providing emotional needs for carers, during illness and after death.
- The majority of children were not able to be involved or knew about their death because they were young or unconscious.
- Siblings were not allowed to visit due to hospital policies or parents' choices.

- Bereaved carers were generally satisfied with their choices, and involvement in the child's care.
- The majority of bereaved carers of children who died at intensive care units (where no carers were with the children at the time of death) received the news by phone, saw the child for the last time, and collected the child's body from the morgue
- Twenty-five carers contributed with additional comments during the interview, and eleven responded to the open-ended question at the end of the questionnaire.
- Bereaved carers highlighted the lack of specialist medical professionals and diagnostic equipment in rural hospitals which hindered proper diagnosis of the child's condition and therefore, the quality of care. This was accompanied by a lack of support from healthcare professionals to transfer the child with the assistance of the treating hospital.
- Poor communication and a lack of information about the child's condition was evident among carers' responses, particularly those with young children with newly diagnosed conditions or short-term illnesses (hours and days).
- Bereaved carers highlighted the presence of unsupervised nursing staff mainly in critical care units (NICU and PICU).

10.5 Chapter summary

This chapter has reported the findings of the feasibility survey, including the method of recruitment and administration. Response rates confirmed the feasibility of using the planned research methods to collect routine data from bereaved carers. There was variability across sites regarding overall quality of care, and support provided for the child and family members. The next chapter will present a general discussion of the findings from the three phases of the study.

Chapter 11. Discussion

This chapter will provide a recap of the research aims and summarise the findings of the thesis in light of existing evidence. Issues regarding the feasibility of conducting this type of sensitive survey, such as recruitment methods, administration methods and response rate are also addressed. This is followed by an outline of the strengths and limitations of the research and implications of the results for clinical practice and future research.

11.1 Purpose of the study

Despite advances in paediatric end of life care, the lack of a universal measure to evaluate care has continued to be highlighted (Downing et al., 2015, Beecham et al., 2016, Coombes et al., 2016, Downing, 2016, Johnston et al., 2017, Friedel et al., 2018a). Furthermore, paediatric end of life care has received little attention in Middle-Eastern countries, particularly Jordan, where there is a scarcity of guidelines to help healthcare professionals plan and deliver high quality care to children and their families. (Stjernswärd et al., 2007, Pakseresht et al., 2018). Studies have investigated children's and carers' needs (Higginson, 1997, Feudtner et al., 2003, Klein, 2003, Clarke et al., 2004, Lenton et al., 2004, Nolbris and Hellström, 2005, Sadeghi et al., 2016, Hasanpour et al., 2016), however, the best way(s) to evaluate the care provided across a diverse range of ages and conditions has not yet been established. The purpose of this study was to address this gap by undertaking a cross-cultural adaptation of a pre-validated adult measure of quality and experiences of end of life care-the VOICES-SF (Hunt et al., 2011) - and employ it to investigate quality of end of life care for children as reported by bereaved carers in Jordan, as well as examine the feasibility of a telephone administered survey.

11.2 Key findings

11.2.1 Development phase

While adult and paediatric palliative care share fundamental concepts, paediatric palliative care is a distinct field that considers the unique features of this population. The development phase comprised a scoping literature review (RA), interviews with bereaved parents (A-SD), interviews with health professionals involved in care of children at the end of life (A-SD) and an integrated analysis of these components (A-SD and KH) to determine the essential elements of paediatric end of life care. The outcome of this analysis led to adaptation of the original VOICES-SF questionnaire that involved addition of new items and adaptation of existing items to produce a version suitable prototype for the paediatric context. Key concepts and themes from VOICES-SF were carried over into the paediatric version. These included: overall quality of care at home, hospital, and hospice; access to care; symptom management; dignity and respect; emotional support; bereavement support, and decision-making. However, changes were made to the wording for some of these concepts to reflect the unique needs of the paediatric population and nature of services, whilst maintaining the integrity of the original survey. New concepts were also added, particularly relating to the last days of life and time after the death, to reflect practices unique to care of children such as memory making activities and cool rooms/beds. This prototype was tested in discussions with healthcare professionals (RA) followed by cognitive interviews with bereaved parents (A-SD).

Analysis of data from this testing phase (conducted by RA) enabled the researcher to explore and discuss participants' views on questionnaire items and instructions (Van Widenfelt et al., 2005). Most participants valued the opportunity to discuss and evaluate palliative care services, especially healthcare professionals, who were eager to know bereaved carers' views regarding the quality of services. In general, participants perceived survey items and response options to be acceptable, although parents and healthcare professionals did not always agree on all issues. This lack of consensus was focused on the way parents and healthcare professionals interpreted the terms "trust" and "caring way". Healthcare professionals felt these terms were very broad and required further specification, while parents had no concerns with the terms and felt they appropriately described their experiences. This disparity is not unusual, similar findings were reported in a recent study by Thienprayoon et al. (2020), who emphasised disparities in how parents and care providers define quality home-based hospice and palliative care (HBHPC) in relation to different domains. For example, in terms of the physical aspects of care, Thienprayoon et al. (2020) found that care providers focused on assessing and managing physical symptoms, while parents emphasised those aspects pertaining to promoting a child's comfort and providing adequate assessment and guidance to parents.

Findings from this phase informed further refinement of the prototype and development of the English language version of the VOICES-C questionnaire.

11.2.2 Cross-cultural adaptation phase

WHO guidelines for cultural adaptation were followed to inform the adaptation of the VOICES-C questionnaire for use in Jordan. Contrary to the experience of O'Sullivan et al. (2018), the researcher did not encounter difficulties in translating the VOICES-SF questionnaire into the Arabic language, in terms of achieving linguistic equivalence. The majority of changes required concerned achieving cultural equivalence for the Jordanian population. Findings from the cognitive interviews suggested that the Arabic prototype did not need further revisions in terms of vocabulary or layout. This phase also included stakeholder participation in order to prioritise crucial items based on lived experience and to investigate the feasibility of the survey protocol. This study demonstrated that involving lay and professional stakeholders early in project development was possible and helped to uncover key concerns from the perspectives of service consumers and providers.

Whilst there are a number of cultural and service differences between the UK and Jordan, the interviews with carers and healthcare professionals revealed similarities between the Western and Eastern contexts. As in the UK development phase, as discussed above, bereaved carers easily understood the meanings of the "trust" and "caring way" phrases in the questionnaire, whilst the healthcare professionals reported problems with these terms, seeking clarification and suggesting greater precision in terminology. Abrahamson and Rubin (2012) explored how lay people (consumers) and doctors' (professionals) discourse structures differ in responses to diabetes-related inquiries on a public consumer health information website. The authors found that, in contrast to professional discourse, consumer discourse is more pragmatic and has a greater emphasis on presentational connections, meaning that it is more goal-oriented than professional discourse, as was the case here.

Key findings

Bereaved carers did not hesitate to respond to the invitation to contribute to the cognitive interviews, mainly for altruistic purposes, i.e., to improve paediatric services for the benefit of other children and families in the UK and Jordan. This supports previous research concerning participants in bereavement research who report that their participation had given them the chance to offer an altruistic contribution to help families who will endure the same experience (Hynson et al., 2006, Crowther and Lloyd-Williams, 2012) and hope to improve healthcare service (Dyregrov, 2004, Aroian et al., 2006). Additional motives for Jordanian participants were to express their feelings about their experience since they did not have the chance to talk to healthcare professionals after the child's death, and because of their religious beliefs. This finding is supported by the work of Cook and Bosley (1995) in that religious belief encourages Muslims to help people who need help, and this extends to helping a scholar (the researcher), follow the prophet Mohammad (PBUH):

> *"A Muslim is a brother of another Muslim, so he should not oppress him, nor should he hand him over to an oppressor. Whoever fulfilled the needs of his brother, Allah will fulfil his needs; whoever brought his (Muslim) brother out of a discomfort, Allah will bring him out of the discomforts of the Day of Resurrection, and whoever screened a Muslim, Allah will screen him on the Day of Resurrection."* [1]

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[1] Sahih al-Bukhari 2442: Book 46, Hadith 3

There were some important differences in research contexts between the UK and Jordan that emerged during this phase. First, a clinical gatekeeping effect was less obviously a problem in Jordan, a predominant issue in UK research, especially with palliative populations (Blum et al., 2015). However, there was one hospital setting in Jordan where gatekeeping was evident. The cancer centre in Jordan rejected the ethics application and declined to participate in the study due to concerns raised by the Institutional Review Board (IRB) about participants' emotional reactions to interviews. This could be due to the fact that the cancer centre follows international guidelines and collaborates with the National Cancer Institute of the United States (National Institutes of Health) to establish a comprehensive palliative care programme in Jordan for cancer care, teaching, and research. In addition, the cancer centre's staff use videoconferencing to consult with colleagues at western-based cancer centres in the United States and Canada (Abdel-Razeq et al., 2015) which may lead them to take a more Western approach to research and access to research participants. Wohleber et al. (2012) pointed out that there are different levels of gatekeeping, for example, ethical committees, healthcare professionals, and family members. Gatekeeping can arise from healthcare professionals' concerns about protecting participants from stress imposed by their participation in the research. Therefore, healthcare professionals are usually involved in approaching, as well as identifying, eligible research subjects in end of life care research (Kars et al., 2016). The involvement of healthcare professionals in Jordan facilitated the recruitment of bereaved carers from two sites and the acquisition of a diverse sample of bereaved carers in a relatively short period of time. This can be contrasted with the significant difficulties encountered Darlington and Hunt in recruiting bereaved carers to review the UK version. Therefore, greater efforts are needed to ensure that researchers anticipate and minimise inappropriate gatekeeping while approaching potential participants.

Another difference between cultures was the upper age limit to receive children's services. Within the western context, children's services and research involving children encompass individuals up to 18 years old. However, in Jordan, children under the age of 12 are normally admitted to paediatric facilities in Jordan, whilst young people between the ages of 12 and 18 are usually admitted to adult units. Similar age limitations of up to 14 years apply in the Kingdom of Saudi Arabia (KSA) (King Faisal Specialist Hospital & Research Centre, 2022) and up to 13 years old in the United Arab Emirates (UAE) (Dubai Health Authority, 2022). This stems from the religious belief that an individual is accountable for his deeds and considered as an adult after puberty. The prophet Mohammad (PBUH) said *"The Pen has been* *lifted from three: from the child until he reaches puberty, from the sleeper until he wakes up and from the insane until he regains his sanity"[2],* which means there are three people whose actions are not recorded: the sleeper until he wakes up, the minor until he grows up, and the insane until he comes back to his senses or recovers. This age restriction had no effect on the questionnaire's cross-cultural adaption, but it did limit the age range of the target population to patients under the age of 12 years old. This means there are still many unanswered questions about the transition of children older than 12 years with life-limiting conditions to adult services in Jordan. Further work is required to explore palliative and end of life care experiences in this population, as well as determine whether the adult version of VOICES-SF would be a suitable tool to measure these experiences.

Another cultural difference that was observed was the relationship of the participant to the deceased child. In the UK carers in the development phase were exclusively parents, whilst in Jordan, carers who participated in the feasibility survey included parents, grandparents, aunts, uncles, and a step-mother. This might be explained by the fact that family members play an important role in Eastern cultures during hard times such as illness. They can be involved in providing care or staying with the child at the hospital while the mother is at home with other children or having a short break (Silbermann and Hassan, 2011, Gustafson and Lazenby, 2019). The term "family" is also interpreted differently across cultures. In Western cultures, this refers to the "nuclear family," whereas in Eastern cultures, it refers to the "extended family," which includes grandparents, uncles, and aunties. This extended family may be involved in the child's care in Western societies, but they are less likely to be considered in the decision-making process for the child's care. Almansour et al. (2020) have established that it is cultural norm for extended family members to have a prominent role in end of life decisions, not simply care provision and supervision.

Lastly, approaches to dealing with loss differ across cultures. People who are unfamiliar with the rites and traditions that accompany bereavement may not appreciate the necessary rites or understand why the bereaved expect to undertake certain procedures and duties in order to move on. Death is a sensitive subject in Western society, and opinions differ on the extent to which it has been a taboo (Chapple et al., 2015). In certain cultures, it is acceptable for people to express their feelings or memories about a deceased relative or friend, whereas in other

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[2] Musnad Ahmad 940: Book 5, Hadith 367

cultures, such conversation is frowned upon. As a result, friends and family members might even be reluctant to bring up the subject, making it difficult for those left behind to find someone with whom to share their feelings (Donna Burke, 2016). However, therapists, nurses, pastors, and other professionals encourage the bereaved to express themselves and provide them with opportunities to listen and discuss, and this is considered a common practice in the western world (Parkes et al., 2015). For Eastern cultures, where Islam is the dominant belief, death is viewed as a transfer from this world to the next, where one will be rewarded for their earthly deeds. There is an understanding that death is inevitable and that it is a part of the human experience. There are few taboos around discussing death, and it is not something to be opposed or battled against, but rather something to be accepted as part of the broader divine plan and a topic on which one is urged to reflect constantly (Sheikh, 1998). According to participants, their strong religious views and faith in God had a significant impact on their ability to accept and cope with death. Though it is terrible, death is determined by God at the most appropriate time and must thus be accepted with patience and tolerance. Participants referred to verses from the Holy Quran as they expressed their acceptance of death. In comparison to participants from Western contexts, it can be anticipated that bereaved carers in Eastern situations, such as Jordan, are more tolerant and eager to participate in post-bereavement studies with fewer psychological unfavourable effects. However, this finding does not negate the need for healthcare professionals to examine grieving carers' psychological needs, as bereaved carers in Jordan expressed a desire to speak with a health practitioner who had cared for their child up to the time of their death.

11.2.3 Feasibility of the survey

11.2.3.1 Methods of identifying and approaching participants

The strategies used to identify and recruit bereaved carers in Jordan were acceptable and fruitful. In the feasibility study the approach to carers initially via a text message, as advised by bereaved carers during cognitive interviews was also successful. Respondents, whether related to the deceased child or not, were more likely to answer the subsequent telephone call if a text message had been sent in advance, and a large proportion of those answering calls agreed to complete the questionnaire. Sending a text message in advance stating that participants would be called later in connection with university research appeared to encourage respondents to accept the call and reduced respondents' rejection in accordance with past recommendations (Brenner, 2020, Dillman et al., 2014). Given the vulnerability of the target population and the low response rate of previous VOICES-SF surveys (33 percent) (Hunt et al., 2014a, Hunt et al., 2014b, Seow et al., 2016b) the response rate achieved in the feasibility testing phase (41 percent for the eligible sample drawn and 78.7 percent of answered telephone numbers) was good. The difference between the 41% overall response rate and the rate observed in answered telephone numbers (78.7%) was largely a result of bereaved carers changing their personal numbers in the period between their child's death and the time of sampling, since only nine numbers (7.7%) did not answer the initial call. The proportion who changed their number seemed unrelated to time elapsed since the child's death as there was an even spread of unused/incorrect numbers among parents whose child died across the sampling window (three months and 48 months before sampling). Researchers should keep this in mind when using the telephone to approach eligible participants in the future as a certain proportion of participants will not be reachable as a result of changed telephone numbers. This is likely to have a profound impact on response rate as this study found that once contacted, a high proportion of carers were willing to participate (78.7%).

11.2.3.2 Mode of data collection

Overall, the VOICES-C questionnaire was useful for reporting quality of paediatric end of life care. It was also able to identify important care issues that needed improvement, according to bereaved carers' comments throughout the interview and responses to the open-ended question. The decision to opt for telephone interviews as the mode of administration was made due to considerations of available resources (Boynton, 2004); namely the lack of postal services in Jordan precluded a postal survey, but also because the sample was widely distributed across the country, and the unprecedented circumstances of the COVID pandemic meant that travel to conduct face-to-face interviews was both unfeasible and prohibited.

Considering the limited literature on conducting telephone interviews about sensitive research topics, the findings build on and extend upon previous research by demonstrating the feasibility of telephone interviews in the context of end-of-life research (Hinds et al., 2007). Carers were willing to discuss sensitive topics, like their mental and physical wellbeing, and would tolerate a lengthy interview that had the potential to cause distress (distress during interviews discussed below) using this method (Van Dyke, 2009). The final sample consisted of 48 completed surveys with no missing data, and bereaved carers were able to complete the questionnaire during one phone call (between 10 and 45 minutes), at their convenience, in terms of time and place, without any additional burdens of travel or rescheduling personal commitments.

In the original VOICES development paper, Addington-Hall et al. (1998) reported postal questionnaires were better at enabling respondents to express dissatisfaction than face to face interviews, perhaps because they did not fear speaking out about unsatisfactory practice in front of a researcher. The present findings, on the other hand, are consistent with previous research using telephone interviews that has found that the telephone approach is less likely than face-to-face interviews to result in socially desirable responses due to its minimal interviewer effect and limited participant identifiers available to the interviewer (Lewis-Beck et al., 2004), and is less susceptible to item non-response errors than postal surveys (De Leeuw et al., 2003).

It might thus be concluded that doing telephone-administered interviews for sensitive topics is the mode of choice and is more efficient than face-to-face interviews in environments where postal services are unavailable, especially when conducting a survey for a widely-disperse population. It's important to be aware of the potential influence on response rate as a result of people changing their numbers, which could result in a smaller sample size than expected, even though there are clear benefits to this strategy that outweigh the resource implications. Therefore, it is recommended for future research that bereaved carers should be contacted shortly after the death of a child (see section 11.4.1). This would offer a solution to the lack of post-bereavement services, functional postal services and changing carers' telephone numbers in Jordan.

11.2.3.3 Managing emotional distress

Due to the sensitivity of the topic, it was anticipated participants might experience psychological distress. To compensate for Jordan's lack of professional support services, this study employed a protocol to manage emotional distress that drew on their own social network. Participants were encouraged to access support from the researcher, or their social network, if they needed it either during or following the interviews. Institutionalization of emotional support and dependence on formal psychological support networks are not the preferred options in Arab culture, as people often seek assistance from their family in times of need (Azaiza et al., 2010). Therefore, the researcher questioned participants who were displaying signs of distress whether they would like to halt the interview or notify the support person (identified ahead of the interview as recommended in the PIS). Despite distress being obvious to the researcher on four occasions, which was manifested by changes in voice tone or slight crying and mainly by the questions that asked about the time around death (O'Sullivan et al., 2018), bereaved carers did not request the interview stop, nor did the researcher believe the interaction to be so stressful and the subject in danger of incurring harm that it necessitated escalation to the next step, which included calling the support person. This finding has important implications for investigating bereaved participants' needs for follow-up support in future studies in order to develop services to support bereaved carers.

11.2.4 Quality of care

Paediatric end of life care consists of complex elements at different points in the illness trajectory. To evaluate this care, these elements need to be assessed from service users' perspectives. Carers' expression of satisfaction is considered an outcome measure of the care received in the field of end of life care where recovery or absence of illness cannot be achieved. In recent years, evaluation of the performance of healthcare organisations has shifted from focusing solely on clinical treatment toward evaluating and embracing "patient experience" as an essential measure of quality (Black et al., 2018). The discussion of the research findings in relation to quality of care has been divided into three sub-sections: inequalities in overall quality of care, bereaved carers' positive and negative views on care quality.

11.2.4.1 Inequalities in quality of care:

11.2.4.1.1 Participant characteristics

The sample consisted primarily of young, bereaved carers (under the age of 39), which reflected the demographic characteristics of the Jordanian population as a whole. The sample was largely representative as it included children of various ages and nationalities, as well as children with a variety of diagnoses from different settings across Jordan's three geographical regions. Patterns of greater satisfaction were more evident among caregivers of older children cared for in major hospitals, whereas there appeared to be no pattern in satisfaction according to a child's nationality or health insurance status i.e., presence or absence of health insurance. A previous study in Ghana found no statistically significant difference in perceptions about quality between insured and uninsured patients, even though there was a considerable disparity in financial access to care between insured and uninsured patients, consistent with the current findings (Abuosi et al., 2016). A possible explanation for these findings is that uninsured patients are grateful that at least some care was provided given their uninsured status.

Key findings

The majority of participants were males, mainly fathers, who explained they were more emotionally capable of reporting their experience and were more informed than the mothers of what had happened during hospitalisation, especially for neonates. This finding confirms previous studies in Western contexts that reported that death had a bigger impact on female bereaved carers than on males in Switzerland (Bergstraesser et al., 2015) and that Finnish fathers experience brief and less intense depression than mothers (Aho et al., 2009). Although speaking about the deceased is acceptable in certain cultures, such as Jordan, bereaved people may see such talk as compromising their own health or safety, so they may avoid it completely (Parkes et al., 2015). This was evident in fathers' participation in the Jordanian context in the role of "family gatekeepers" (Aroian et al., 2006), when fathers completed the questionnaire on behalf of mothers in an attempt to protect them from the stress associated with completing it, especially after they had already moved on from the experience. In addition, mothers of neonates who were at home or admitted to a postpartum ward, did not know what the child's condition was, might visit the baby only once a day, and checked on the child by calling the unit. Bereaved mothers perceived these as reasonable justifications for not knowing about the child and, consequently, they were less likely to participate in the study. When they knew or believed that their child was dying, some fathers tried to prevent the mother from seeing the infant in a deteriorated state and, subsequently, in a state of depression. There are still many unanswered questions, such as whether healthcare professionals should encourage neonatal mothers to see their child before death, or whether it is unacceptable because other family members perceive it as exposing mothers to further harm and adding to their grief.

11.2.4.1.2 Setting hospital or unit

One unexpected finding was that low levels of satisfaction with care were more commonly reported by carers of children in intensive care units. This might be due to units' original regulations that tended to limit carers' access to the child during hospitalisation and keep them updated by telephone as to their child's prognosis. Bereaved carers of neonates tended not to be informed of the care plan and the most up-to-date prognosis of the child. This meant that carers had questions and concerns at the time of interviews. These findings confirm the association between negative quality of care reports and carers' involvement and physical proximity to their children. Physical proximity entails being close to the child before and after death in intensive care units, even during resuscitation, and holding the child while the body is still warm (Youngblut and Brooten, 2012). Physical distance was associated with Jordanian bereaved carers' feelings of stress because their children died at units alone, many expressed confusion as the child was doing well before they received the bad news by phone, and there was uncertainty about whether it was the unit's policy to transfer the child to the morgue shortly after receiving the news about the death. Parents mentioned that their baby's body was still warm when they arrived at the hospital morgue and found this a very distressing experience.

Serlachius et al. (2018) identified themes concerning neonatal parents' experiences during admission to and discharge from a NICU in a tertiary hospital. Parents described feelings of disempowerment due to lack of control which was a result of lack of knowledge, feeling redundant and a *"bystander"* in their child's care (Serlachius et al., 2018). Similar findings were reported by Falkenburg et al. (2016) who addressed the importance of physical closeness to the child at all times in PICUs. The authors identified two subthemes concerning physical closeness from bereaved carers' interviews: physical separation and physical intimacy. The authors reported that physical contact with a dying child was *"necessary"* for mothers and fathers, and the PICU environment was perceived to be a barrier to holding the child and providing the physical care parents desired, especially for children admitted to intensive care immediately after birth. Vivid memories of these experiences were sustained five years after the child's death (Falkenburg et al., 2016).

In addition to a distance between carers and their child, carers in my study often poor practice in communicating the death of their child, reporting that the news was delivered. The fact that their child was already in the morgue by the time they arrived in the hospital meant they did not have any privacy nor proper moments with their child to say goodbye. A link between experiences of parental bereavement and the series of events that take place in the final moments of infants life has been reported in the literature (Tan et al., 2012). The authors found that during the difficult time immediately following the death of their child parents treasured their memories of their infant. Parents described parenting behaviours (such as holding and dressing) and expressed gratitude for the opportunity to build these memories with their child. Having the knowledge that they had provided love and comfort to their child became a comforting memory for parents. A study by Marçola et al. (2020) reported similar findings about the manner in which bad news was delivered as in this thesis, including the use of difficult language, insufficient professional posture, a demonstration of haste or nervousness, a lack of empathy and affection in the manner in which the news was delivered, as well as failing to give the family hope. In addition, Jordanian because bereaved carers were not able to be with the child in intensive care units, it meant that they did not know and trust the staff to deal with the child in a caring way. Trust in healthcare professionals is an important component of care quality; a recent study found that insured patients were dissatisfied with their healthcare experiences primarily for reasons such as a lack of trust in their healthcare and insurance providers (Badu et al., 2019). This lack of trust and a good relationship could explain why neonatal carers were more likely to report poor quality of care than carers of older children, and it appears that taking these aspects of care into account for neonatal caregivers has the potential to improve satisfaction in overall care.

11.2.4.2 Positive reports of quality of care

Access to information and communication are considered the most frequently mentioned domains when measuring the quality of care in after death surveys (Melin-Johansson et al., 2014, Lendon et al., 2015). Parents of children with life-limiting conditions frequently describe a lack of information and poor communication during the different stages of the illness (Freeman et al., 2004). Some bereaved carers from a previous study expressed their comfort with an autopsy examination for the deceased child as it could explain why the child had died (Sullivan and Monagle, 2011). In this survey respondents expressed high levels of satisfaction with communication and being kept informed, except for carers of newborns, who complained about a lack of comprehensive, clear information regarding the child's changing status, treatment options, and most recent prognosis as stated earlier as a result of the lack of adequate physical proximity to the child.

The study's findings suggest that caregivers of older children or children with long-term disease experiences, such as cancer, who have recurrent hospital admissions in a dedicated unit seem to have benefited from good quality, compassionate care, where they had trust in the health professionals looking after their child and reported that their child was looked after in a caring way. However, as has been described above, this was not the case for neonates and their families. An important part of this was the lack of special bonds formed between the family and the healthcare professionals. As a result, there were stark differences in carers' satisfaction and reports of compassionate care between the two groups of carers. Compassionate care plays a *"pivotal role"* in therapeutic relationships and impacts patients' perceptions of care quality. Sinclair et al. (2016) reviewed the literature concerning compassionate care which occurs between two individuals, one who suffers and another who wants to relieve it. They found that in clinical communication, compassionate care can be manifested by healthcare professionals' warm demeanour, willingness to engage, and active listening to patients. In addition, the authors asserted that compassion has positive impacts on patients, family members and healthcare professionals (Sinclair et al., 2016). The neonatal units in participating settings in Jordan created barriers to this communication by restricting family access to the babies under their care. However, participant reports suggest that it was not just a lack of access that contributed to poor communication, the way that bad news was delivered and sporadic telephone updates on the child's care and status meant that carers were not communicated with in a compassionate way.

Key findings

The majority of bereaved carers reported the child's needs were met concerning the alleviation of physical suffering, mainly pain management, which is unsurprising given that the relief of physiological problems is considered the priority of end of life care (Boyden et al., 2021). Other physical problems, such as breathing difficulty or nausea, and emotional needs in the last two days were more frequently reported by bereaved carers as not applicable. The majority of children were on life support or too young to express their needs. This reflects the challenges faced by healthcare professionals whilst assessing and managing young children's symptoms in the absence of defined protocols (Cortezzo and Meyer, 2020), which can contribute to quality of care dissatisfaction and ineffective symptom management.

One element of paediatric end of life care most frequently reported with satisfaction by bereaved carers in Jordan was support for religious practices during the care for an ill child. Bereaved carers frequently reported that healthcare professionals respected and supported them to perform their religious practices. These findings are in agreement with those of Al Omari et al. (2017) who reported adolescents in Jordan relied on their religious beliefs to cope with their cancer. These findings may be explained by the fact that religious beliefs and practices in Jordan have a major influence on bereaved parents' psychological status. For example, parents and older children received comfort in praying, reciting or listening to Quran (Lawrence and Rozmus, 2001, Al-Zaru et al., 2013), as well as family members reciting Quran at the bedside (Leong et al., 2016). Muslims perceive illness and death with patience and acceptance. This was evident in bereaved carers reports concerning their acceptance of the child's death as according to the religious concept that when an individual's time of death comes, nothing can change this no matter what you do or where you are (Bushnaq, 2008), as well as, the prophet Mohammad (PBUH) saying,

> *"How wonderful is the case of a believer; there is good for him in everything, and this applies only to a believer. If prosperity attends him, he expresses gratitude to Allah and that is good for him; and if adversity befalls him, he endures it patiently and that is better for him"*[3].

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[3] Riyad as-Salihin, The Book of Miscellany – Book 1, Chapter: Patience and Perseverance, Hadith 27

11.2.4.3 Negative reports of quality of care

Even though Jordan has improved its international palliative care ranking and is well placed when compared to other Middle Eastern countries, such as Iran, Lebanon, and Turkey (Khanali Mojen et al., 2017), findings indicate that a comprehensive family-centred approach to paediatric palliative care could improve the support of parents and siblings of children (Ebadinejad et al., 2020), who are not considered beneficiaries of medical and nursing care by healthcare professionals. Findings indicated bereaved carers often did not receive psychological support around the time of and after the child's death, although some carers reported they were not in need of support from healthcare professionals, probably because bereaved carers were usually surrounded by family members who provide support in Eastern cultures (Abdel Razeq and Al-Gamal, 2018). This is an area with room for improvement across units and sites since a sizeable proportion of bereaved carers (21 out of 48) reported they would have liked to talk to a healthcare professional after the child's death.

This study found that bereaved carers reported not disclosing the diagnosis and prognosis to the child or to its siblings due to the conservative nature of Middle-Eastern communities and considering it *"cruel and inhumane"* (Silbermann and Hassan, 2011). This study showed a lack of emotional support for siblings, which is unsurprising since cultural practices avoid disclosing the imminent death of the child to siblings and involving siblings in caring for dying children in Jordan. These findings are consistent with Wilkins and Woodgate (2005) review to understand the siblings' perceptions of a child's cancer experience. The authors identified four unmet themes as reported in the literature by siblings and noted that siblings' needs were often overlooked and there is a need for sibling support services. Needs of siblings previously identified include sharing appropriate information with them regarding what is going to happen, receiving supportive communication, and being involved in the care of the ill child (Lövgren et al., 2016, Wallin et al., 2016, Freeman et al., 2003, Eileen et al., 2012, Barrera et al., 2013). The unique bond between siblings is a fundamental relationship in the child's life; therefore, the death of a sibling can have a profound impact on the surviving sibling (Eaton Russell et al., 2018). This is an unexplored area in the Middle East that requires additional research to determine the effect of childhood death on surviving siblings in a culture that does not disclose prognosis. Thus, it can be argued that a culturally specific care model based on benchmarks from one culture cannot be applied to another without first considering the possible consequences and comparing those benchmarks to that new culture.

Aside from reports related to neonatal services, bereaved carers' negative experiences were mostly linked to aspects of care coordination and continuity like the provision of specialised care at the same hospital (for example in cases of rural hospitals with limited resources), or the transfer of the child from a small to a major hospital. Children with life-limiting conditions require complex care from different healthcare professionals, which might require seeking services from different health institutions. Therefore, care coordination has been identified as an essential element of end of life care in literature and guidelines (NICE, 2017, WHO, 2018a). However, effective complex care coordination relies on a robust network of relevant healthcare professionals (Coller and Ehlenbach, 2019) and is driven by patient and family needs for services across various settings to achieve ultimately *"better care, better health, and lower cost"* (Turchi and Antonelli, 2014). A separate issue relating to care coordination and the lack of an effective network among different healthcare professionals and services in Jordan was that the concept of a preferred place of death (especially 'home') was not perceived as a choice for bereaved carers, since they reported being unable to transfer their child to another hospital, and discharge to the home setting at the end of life was not an option. This can be explained by the lack of community health services in Jordan, as there is no home or hospice support for dying children. It might be a barrier to the development of hospice institutions and services in Jordan as it is perceived negatively by carers in Jordan as a place for abandoned dying patients (Silbermann et al., 2012). Unless more qualitative research is done to determine what constitutes quality paediatric end-of-life care, it is reasonable to hypothesise that hospice care is not an essential component of quality end of life care in Jordan, contrary to Western contexts and literature. Dying at home has been identified as an indicator of good-quality end of life care (Dussel et al., 2009), since it is associated with several factors, such as physicians clearly communicating treatment options during the end of life period, the availability of healthcare professionals, and local hospices to provide care and support for children at home (Linton and Feudtner, 2008, Dussel et al., 2009). According to these findings, it can be inferred that a culture's model of care cannot be simply duplicated and accepted by other cultures. The most important goal is that services meet people's needs. Further research is required to determine where people in Jordan would choose to receive care if all options were available. In the future, when community services become more established, people may opt to die at home. If people choose to die at home, surrounded by their loved ones and with quality care from qualified specialists, services should seek to fulfil their preferences for care and death.

A shortage of healthcare professionals such as cardiologists and necessary equipment was reported by several carers even though participants still provided positive reports of the quality of paediatric end of life care. These findings were consistent with the Khader et al. (2018) study which assessed health services provided for mothers and newborns in multiple Jordanian hospitals in different sectors. The study focused on assessing health services in various sites according to the availability of essential resources i.e., equipment, supplies, documentation, and competent staff for mothers' and newborns' care, to identify areas of improvement and to reduce maternal and newborn mortality rates. The study concluded that the numbers of obstetricians and paediatricians were inadequate in ten out of thirty-two hospitals assessed. A similar shortage of neonatologists was reported in fourteen hospitals, as well as nurses and midwives. Ten hospitals lacked advanced equipment for advanced resuscitation of babies in operating theatres. In addition, the authors reported a lack of basic and essential equipment in NICUs in some hospitals, such as the number of incubators and resuscitation tables, ventilators, Continuous Positive Airway Pressure (CPAP) machines, and pulse oximeters. According to bereaved caregivers, the quality of end of life care can be considerably improved by supporting transfers between other units or settings where appropriate healthcare experts or services are available. Inadequate resources led to major issues with the quality of care. It's clear from the Khader report and other research that Jordan's end of life care for children is not deficient in quality; rather, the quality of treatment in neonatal facilities has to be improved.

Around one-third of the participants expressed a desire to be more involved in decisions concerning the child's care, particularly in neonatal intensive care units. Additionally, a third of bereaved carers who were asked whether they were discontent with their own decisions about their child's care, predominantly carers of neonates, expressed their uncertainty. This could be attributed to a lack of adequate information about their child's condition and care (Arlettaz et al., 2005) as well as a powerlessness to make decisions about their children's care because they were not actively involved in that care or in decision-making processes (Mendizabal-Espinosa and Price, 2021).

Key findings

Although this study sought to develop a universal measure of end of life care based on benchmarks and elements of quality cited in the literature (as well as parent and health professional accounts), the findings from this thesis raise intriguing questions regarding the extent to which these elements constitute high quality care in Eastern contexts. For example, whilst sibling support, bereavement support, and disclosing the diagnosis are considered essential elements in guidelines for dying children in Western contexts, such as the International Meeting for Palliative Care in Children, Trento (IMPaCCT) standards in Europe (Craig et al., 2007), the National Hospice and Palliative Care Organization Standards in the United States (NHPCO, 2009), and the National Institute for Health and Care Excellence in the UK (NICE, 2017), these elements were not regarded necessary by Jordanian carers. It is for health professionals, researchers, policymakers, and most importantly, the people of Jordan to decide what represents high quality and compassionate palliative and end of life care for children, and their families. Once this has been established, services can set about refining and redesigning their offerings, and evaluating the impact of those changes on patient and carer reports of quality and satisfaction.

11.3 Strengths and limitations

11.3.1 Strengths

This study has generated new knowledge by providing evidence regarding bereaved carers' experiences in Jordan and is the first attempt to understand carers' views regarding end of life care provided using a comprehensive survey. It was evident during the scoping review that there had been some limited work done to explore bereaved carers' views on paediatric end of life care from a Middle Eastern context. In addition, findings from the scoping review provided a strong connection between the elements of care for adult and paediatric populations, which supported the utility of using the VOICES-SF survey as a starting point for the cross-cultural adaptation process. That adaptation was meticulously planned and adhered to strict guidelines for translation.

In this mixed-methods study the contributions of bereaved carers and healthcare professionals from the UK and Jordan contexts were incorporated at different stages to ensure that their views, preferences and experiences informed the design and conduct of the study and its materials. For instance, the development of the paediatric-specific version of the questionnaire used semi-structured interviews to allow participants to express their views regarding essential elements of end of life care. Moreover, interactions with bereaved carers from Jordan during the cross-cultural adaptation phase served as a guide for designing the feasibility protocol in terms of methods and timing of approach and delivery of the questionnaire in the feasibility study. Unlike studies identified by the scoping review, among the strengths of this feasibility study was that it included children who died due to life-limiting conditions covering the full range of ICD-10 categories of causes of childhood deaths across the different regions of Jordan. In addition, the sample was not limited to female carers, it also included male participants, a group underrepresented in previous similar surveys.

11.3.2 Limitations

Although the findings provide preliminary evidence of the quality of paediatric end of life care in Jordan across four hospitals, they do not represent the quality of paediatric end of life care in hospitals comprising the military sector and the national cancer centre, a significant setting where children are cared for as end of life approaches. For example, the national cancer centre - KHCC - is the exclusive provider of home care and post-bereavement follow-up for bereaved carers of children with cancer. Future studies should be conducted in collaboration with the cancer centre to examine community models of care. The cancer centre is the ideal place to begin exploring the issue of preferences of place of care and death, as well as the cultural implications of the implemented model. The sample had some limitations with respect to coverage of children across all medical conditions and age ranges. For example, recruitment was limited to paediatric wards that care for children under the age of 12 years old and the sample was biased toward children under the age of two months, while older children were underrepresented. This underrepresentation could be attributed to the non-participation of the cancer centre, as it is the only institution with comprehensive cancer care in Jordan and it is more likely that children with cancer will receive care exclusively from the centre. In addition, since the cancer centre declined to participate, children with cancer were underrepresented in the feasibility survey. A previous study that recruited carers through a regional cancer centre and a regional children's hospice in the UK reported disparities in parents' experiences about service provision and organisation between children cared for by oncological and non-oncological services (Price et al., 2012), therefore, such issues need to be explored in Jordan in future research and the validity of the questionnaire tested in this organisational context. Another problem that was not sufficiently addressed in this study, given the limited proportion of participants with military and private health insurance, was the extent to which healthcare insurance provider leads to disparities in quality of care.

Notwithstanding the relatively limited sample of bereaved carers recruited during the first two phases (development phase and cross-cultural phase), findings from the cognitive interviews in the UK and Jordan suggest that the VOICES-C items were valid for the investigation of quality end of life care. Although the intention was to include experts from a range of medical backgrounds involved in providing care for children approaching end of life in the UK and Jordan to assess the VOICES-C prototype, the expert panel in Jordan only included members from nursing backgrounds, a limitation of these phases.

11.4 Implications for practice and research

11.4.1 Practice

Evaluating healthcare services according to service users' views can lead to the possibility of making important improvements in care provision. This study adapted and piloted the VOICES-C questionnaire for the Jordanian population. At the national level, a key policy priority should be to develop national guidelines about the essential elements of quality paediatric end of life care derived from qualitative work to determine quality benchmarks of quality end of life care across settings in Eastern contexts. In addition, since the patient's family is not typically regarded as a target of medical or nursing care by healthcare providers, integration of family-centred care concepts that involve the inclusion of the care of the family in national guidelines is required in order to promote quality palliative care. Greater efforts are needed to facilitate a child's transfer to another facility to improve care coordination between different sectors and services; and to create a system to tackle issues related to the lack of specialists and advanced equipment. Despite the importance of post-bereavement support, Jordan lacks formal services, whether medical, social, or religious, to provide professional psychological support for bereaved carers, particularly those caring for children in intensive care units. Whilst this study does not suggest a need to develop bereavement services to be available for all bereaved carers after their child's death, it does suggest a need to give families the opportunity to discuss their child's care and death with a health professional who knew the child. At the hospital level, a reasonable approach to tackling this issue might be to solicit contact with bereaved carers shortly after the child's death by a healthcare professional familiar with the child and family to express condolences, offer emotional support, and allow carers to ask any questions.

Another significant practical implication that needs addressing is the inconsistency of details recorded in medical records and death certificates across different sites, such as who writes death reports and the minimum medical and personal details included in the death certificate. This was recently acknowledged by Khader et al. (2020) in a qualitative study of the inconsistency and inaccuracy of stillbirth and neonatal death registrations, as reported by eighty Jordanian health professionals. To understand carers' collective experiences, regular monitoring of care should be carried out in various settings. Standard, up-to-date documentation with valid personal and medical data is required to monitor childhood deaths in

Jordan, as well as to support efficient identification and recruitment of target populations for future studies. How to complete health records should be taught to healthcare professionals as part of their ongoing education and training.

Regarding the practicalities of conducting a post-bereavement survey, it is recommended that bereaved carers should be contacted after the death. This should be used to offer carers an opportunity to discuss their child's care and death, as discussed above, but also in order to offer the VOICES-C questionnaire. This would offer a solution to the lack of postal services in Jordan, the fact that there is no system of family practitioners, and the finding that individuals tend to change their telephone numbers. For the Jordanian population, religion and culture appeared to be the most powerful elements during the grief process. In Islam, for example, the mourning period is at least three days following the death and lasts for up to a month. Whereas in Western contexts, a period beyond three months after the death is recommended to have elapsed before an approach for research purposes is made (Akard et al., 2014). Therefore, communication around a month after the child's death could be used to introduce the VOICES-C questionnaire in Jordan.

At unit level healthcare professionals should allow carers to see, touch and be involved in a child's care during hospitalisation in intensive care units. And after the child's death, healthcare professionals should be encouraged to keep the deceased's body in the unit to allow bereaved carers to have some time with the child instead of solely collecting "*the body*" from the morgue, in cases where the child died in the unit alone without carers present. Therefore, an additional space i.e., spare bed/ cot might be provided to keep the child in until family members arrive and have time to say a proper goodbye.

11.4.2 Research

Although this study sought to investigate bereaved carers' views regarding quality of end of life care for children suffering from various medical conditions, the feasibility study did not yield generalisable findings and future research should be undertaken with a larger sample including settings not included in this study, namely the military sector and the cancer centre, to more fully understand quality of paediatric end of life care in Jordan. Once validated in these contexts, steps should be taken to design, secure funding for, and administer a survey on a national basis to establish a baseline for care quality in this population in Jordan. The issue of inequities in care provision according to health insurance and nationality is an intriguing one that could be explored in further research. For example, whether significant differences exist in how Jordanian and non-Jordanian carers, or carers of children without health insurance rank quality of care. Including older children (those older than 12 years old) in future research could help researchers identify discrepancies in the quality of end of life care as a result of the transition from paediatric to adult-directed services.

Although respondents were provided with research documents ahead of the interview such as a participation information sheet (PIS) and the VOICES-C questionnaire, the researcher often needed to repeat questions or response options to participants because participants did not have a copy of the questionnaire in front of them at the time of the interview. In general, therefore, it seems that having a copy of the questionnaire to hand during the interview may enhance participants' ability to follow the questions. Since telephone interviews are limited to the auditory mode of communication, adding a visual element, such as a printed copy of the questionnaire, could help ensure participants fully comprehend the questions (de Leeuw et al., 2008) and help them navigate the questionnaire and respond to questions (Dillman et al., 2014).

Finally, there is a definite need for a neonatal version of the questionnaire and further investigation into the neonatal population considering the unique experiences carers reported in terms of the short time of illness, diagnosis unfamiliarity, limited opportunity to be involved in care and tendency for carers not to be given access to the child in the NICU.

11.5 Conclusions

The loss of a child is a traumatic event for family members who are left behind. The quality of care offered to dying children must be monitored on a frequent basis to ensure they are getting the best care possible by reviewing carers’ views. This is the first study to investigate a national sample of bereaved carers in Jordan, exploring their views about paediatric end of life care using a comprehensive questionnaire designed specifically for paediatric patients. The study identified fundamental elements of paediatric end of life care from the perspective of bereaved caregivers with the goal of designing a universal questionnaire (the VOICES-C questionnaire). In addition, the study identified crucial considerations for recruiting bereaved carers, such as the time frame for approaching bereaved carers, the mode of first contact with potential participants, and the mode of questionnaire distribution.

This research study is also noteworthy because it is the first to explore quality paediatric end of life care from stakeholders' and healthcare professionals’ perspectives across Western and Eastern contexts, namely the United Kingdom and Jordan. Furthermore, it sought to determine the feasibility of conducting telephone interviews as the survey method, which was deemed feasible. Its goal was to inform the methods of future surveys in a way that would yield the greatest possible response, while also causing the least amount of distress for participants and allowing for the most efficient use of time.

Existing literature largely addresses the quality of care bereaved carers report in Western cultures and countries. This study is unique as it explored the perspectives of bereaved caregivers of children with life-limiting conditions by rating the quality of paediatric end of life care in Jordan. Findings indicated the majority of carers had positive experiences with their child’s end of life care and they were highly satisfied with the care their child received. The main issue affecting all patients' quality of care was a shortage of resources, particularly doctors, drugs, and other essential supplies and equipment to work with. In the context of this national study that included different inpatient care settings and medical conditions, inequalities in care were minor and require further investigation with a larger sample size to produce more conclusive results.

Based on the findings of this study, it appears that conducting a survey via telephone interviews on a large scale is feasible. This research represents a significant step forward in the evaluation of the quality of end of life care provided to dying children and their families in Arabic-speaking countries. Therefore, it is recommended that future surveys be conducted for comparative purposes in other Arab-speaking countries. It is recommended that the feasibility survey protocol for the identification of bereaved carers and administration of the survey is followed, as it was found to be appropriate and acceptable to participants and yielded a good response rate. This study has the potential to inform policy development and support quality improvement in care provided to dying children and their families if implemented at an organisational, regional, or national level.

References

ABDEL-RAZEQ, H., ATTIGA, F. & MANSOUR, A. 2015. Cancer care in Jordan. *Hematology/Oncology and Stem Cell Therapy,* 8**,** 64-70.

ABDEL RAZEQ, N. & AL-GAMAL, E. 2018. Maternal Bereavement: Mothers' Lived Experience of Losing a Newborn Infant in Jordan. *Journal of Hospice and Palliative Nursing,* 20**,** 137-145.

ABRAHAMSON, J. A. & RUBIN, V. L. 2012. Discourse structure differences in lay and professional health communication. *Journal of Documentation,* 68**,** 826-851.

ABU-SAAD HUIJER, H., SAGHERIAN, K., TAMIM, H., NAIFEH KHOURY, M. & ABBOUD, M. R. 2013. Quality of palliative care in children with cancer in Lebanon. *Journal Medical Libanais,* 61**,** 228-236.

ABUOSI, A. A., DOMFEH, K. A., ABOR, J. Y. & NKETIAH-AMPONSAH, E. 2016. Health insurance and quality of care: Comparing perceptions of quality between insured and uninsured patients in Ghana’s hospitals. *International Journal for Equity in Health,* 15.

ABUQAMAR, M., ARABIAT, D. H. & HOLMES, S. 2016. Parents' Perceived Satisfaction of Care, Communication and Environment of the Pediatric Intensive Care Units at a Tertiary Children's Hospital. *Journal of Pediatric Nursing,* 31**,** e177-e184.

ACQUADRO, C., CONWAY, K., HAREENDRAN, A. & AARONSON, N. 2008. Literature Review of Methods to Translate Health-Related Quality of Life Questionnaires for Use in Multinational Clinical Trials. *Value in Health,* 11**,** 509-521.

ADDINGTON-HALL, J. & KALRA, L. 2001. Measuring quality of life - Who should measure quality of life? *British Medical Journal,* 322**,** 1417-1420.

ADDINGTON-HALL, J. & MCPHERSON, C. 2001. After-Death Interviews with Surrogates/Bereaved Family Members. *Journal of Pain and Symptom Management,* 22**,** 784-790.

ADDINGTON-HALL, J., WALKER, L., JONES, C., KARLSEN, S. & MCCARTHY, M. 1998. A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death. *Journal of Epidemiology and Community Health,* 52**,** 802-807.

ADDINGTON-HALL, J. M., BRUERA, E., HIGGINSON, I. J. & PAYNE, S. 2007. *Research Methods in Palliative Care,* Oxford, UNITED KINGDOM, Oxford University Press USA - OSO.

ADDINGTON-HALL, J. M. & O'CALLAGHAN, A. C. 2009. A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative Medicine,* 23**,** 190-197.

AHO, A. L., TARKKA, M.-T., ÅSTEDT-KURKI, P. & KAUNONEN, M. 2009. Fathers' Experience of Social Support After the Death of a Child. *American Journal of Men's Health,* 3**,** 93-103.

References

AJLOUNI, M. 2011. Jordan Health System Profile 2010. World Health Organization, Eastern Mediterranean Regional Office (EMRO)

AKARD, T. F., GILMER, M. J., MILLER, K., STEELE, A. C., HANCOCK, K., BARRERA, M., COMPAS, B., DAVIES, B., DIETRICH, M. S., FAIRCLOUGH, D. L., HOGAN, N. S., VANNATTA, K. & GERHARDT, C. A. 2014. Factors affecting recruitment and participation of bereaved parents and siblings in grief research. 22**,** 75-79.

AL-GHARIB, R. M., ABU-SAAD HUIJER, H. & DARWISH, H. 2015. Quality of care and relationships as reported by children with cancer and their parents. *Annals Of Palliative Medicine,* 4**,** 22-31.

AL-QADIRE, M., OMRAN, S. & TAYYEM, M. 2014. Palliative care in Jordan: accomplishments and challenges. *Palliative care to the cancer patient.* Nova Science Publishers, New York.

AL-RIMAWI, H. S. 2012. Pediatric oncology situation analysis (Jordan). *Journal Of Pediatric Hematology/Oncology,* 34 S15-S18.

AL-ZARU, I., OWEIS, A. & GHARAIBEH, H. 2013. Cultural definitions of quality of care: Perspectives of Jordanian patients. *Journal of Research in Nursing,* 18**,** 307-317.

AL OMARI, O., WYNADEN, D., AL-OMARI, H. & KHATATBEH, M. 2017. Coping Strategies of Jordanian Adolescents With Cancer. *Journal of Pediatric Oncology Nursing,* 34**,** 35-43.

ALEXANDER, S. J. 2010. 'As long as it helps somebody': why vulnerable people participate in research. *Int J Palliat Nurs,* 16**,** 174-9.

ALMANSOUR, I. M., HASANIEN, A. A. & SALEH, Z. T. 2020. Mortality Rate, Demographics, and Clinical Attributes of Patients Dying in the Intensive Care Unit of a Comprehensive Cancer Center in Jordan: A Descriptive Study. *OMEGA - Journal of Death and Dying***,** 003022282092392.

ANANTH, P., MUN, S., REFFAT, N., LI, R., SEDGHI, T., BILODEAU, M., SNAMAN, J., GROSS, C. P., MA, X. & WOLFE, J. 2021. A Stakeholder-Driven Qualitative Study to Define High Quality End-of-Life Care for Children with Cancer. *Journal of Pain and Symptom Management,* 72.

ARABIAT, D. H., ALQAISSI, N. M. & HAMDAN-MANSOUR, A. M. 2011. Children's knowledge of cancer diagnosis and treatment: Jordanian mothers' perceptions and satisfaction with the process. *International Nursing Review,* 58**,** 443-449.

ARABIAT, D. H. & ALTAMIMI, A. 2013. Unmet care needs of parents of children with cancer in Jordan: implications for bed-side practice. *Journal of Clinical Nursing,* 22**,** 531-539.

ARAMESH, K. & SHADI, H. 2007. Euthanasia: an Islamic ethical perspective. 6.

ARCHIBALD, M. M., AMBAGTSHEER, R. C., CASEY, M. G. & LAWLESS, M. 2019. Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants. *International Journal of Qualitative Methods,* 18**,** 160940691987459.

ARLETTAZ, R., MIETH, D., BUCHER, H.-U., DUC, G. & FAUCHÈRE, J.-C. 2005. End-of-life decisions in delivery room and neonatal intensive care unit. *Acta Paediatrica,* 94**,** 1626-1631.

AROIAN, K. J., KATZ, A. & KULWICKI, A. 2006. Recruiting and Retaining Arab Muslim Mothers and Children for Research. *Journal of Nursing Scholarship,* 38**,** 255-261.

ARUTYUNYAN, T., ODETOLA, F., SWIERINGA, R. & NIEDNER, M. 2016. Religion and Spiritual Care in Pediatric Intensive Care Unit. *The American Journal Of Hospice & Palliative Care,* 35**,** 1049909116682016-1049909116682016.

ASCHENBRENNER, A. P., WINTERS, J. M. & BELKNAP, R. A. 2012. Integrative review: parent perspectives on care of their child at the end of life. *J Pediatr Nurs,* 27**,** 514-22.

ASPINAL, F., ADDINGTON-HALL, J., HUGHES, R. & HIGGINSON, I. J. 2003. Using satisfaction to measure the quality of palliative care: a review of the literature. *J Adv Nurs,* 42**,** 324-39.

ASPINAL, F., HUGHES, R., DUNCKLEY, M. & ADDINGTON-HALL, J. 2006. What is important to measure in the last months and weeks of life?: A modified nominal group study. *International Journal of Nursing Studies,* 43**,** 393-403.

ASSARROUDI, A., HESHMATI NABAVI, F., ARMAT, M. R., EBADI, A. & VAISMORADI, M. 2018. Directed qualitative content analysis: the description and elaboration of its underpinning methods and data analysis process. *Journal of Research in Nursing,* 23**,** 42-55.

ASSOCIATION FOR CHILDREN'S PALLIATIVE CARE (ACT) 2009. A Guide to the Development of Children's Palliative Care Services. Third edition ed.

ATOUT, M., HEMINGWAY, P. & SEYMOUR, J. 2017. The Experience of Decision Making in the Care of Children with Palliative Care Needs: The Experiences of Jordanian Mothers. *Comprehensive Child & Adolescent Nursing,* 40**,** 240-256.

ATOUT, M., HEMINGWAY, P. & SEYMOUR, J. 2019. The Practice of Mutual Protection in the Care of Children with Palliative Care Needs: A Multiple Qualitative Case Study Approach from Jordan. *Journal of Pediatric Nursing,* 45**,** e9-e18.

AYUBA, M. A. 2016. EUTHANASIA: A MUSLIM'S PERSPECTIVE. *Scriptura,* 115.

AZAIZA, F., RON, P., SHOHAM, M. & GIGINI, I. 2010. Death and Dying Anxiety Among Elderly Arab Muslims in Israel. *Death Studies,* 34**,** 351-364.

BADDELEY, J. L. & SINGER, J. A. 2008. Telling losses: Personality correlates and functions of bereavement narratives. *Journal of Research in Personality,* 42**,** 421-438.

BADU, E., AGYEI-BAFFOUR, P., OFORI ACHEAMPONG, I., OPOKU, M. P. & ADDAI-DONKOR, K. 2019. Perceived satisfaction with health services under National Health Insurance Scheme: Clients' perspectives. *The International Journal of Health Planning and Management,* 34.

BAINBRIDGE, D. & SEOW, H. 2016. Measuring the Quality of Palliative Care at End of Life: An Overview of Data Sources. *Healthy Aging & Clinical Care in the Elderly,* 8**,** 9-15.

References

BAKER, J. N., LEVINE, D. R., HINDS, P. S., WEAVER, M. S., CUNNINGHAM, M. J., JOHNSON, L., ANGHELESCU, D., MANDRELL, B., GIBSON, D. V., JONES, B., WOLFE, J., FEUDTNER, C., FRIEBERT, S., CARTER, B. & KANE, J. R. 2015. Research Priorities in Pediatric Palliative Care. *The Journal Of Pediatrics,* 167**,** 467-70.e3.

BALKIN, E. M., WOLFE, J., ZINIEL, S. I., LANG, P., THIAGARAJAN, R., DILLIS, S., FYNN-THOMPSON, F. & BLUME, E. D. 2015. Physician and Parent Perceptions of Prognosis and End-of-Life Experience in Children with Advanced Heart Disease. *Journal of Palliative Medicine,* 18**,** 318-323.

BARNES, K. 2001. Staff stress in the children's hospice: causes, effects and coping strategies. *International Journal of Palliative Nursing,* 7**,** 248-254.

BARRERA, M., ALAM, R., D'AGOSTINO, N. M., NICHOLAS, D. B. & SCHNEIDERMAN, G. 2013. Parental perceptions of siblings' grieving after a childhood cancer death: A longitudinal study. *Death Studies,* 37**,** 25-46.

BATE, J., RANASINGHE, N., LING, R., PRESTON, J., NIGHTINGALE, R. & DENEGRI, S. 2016. Public and patient involvement in paediatric research. *Archives of disease in childhood - Education & practice edition,* 101**,** 158-161.

BEATON, D. E., BOMBARDIER, C., GUILLEMIN, F. & FERRAZ, M. B. 2000. Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures. *Spine,* 25**,** 3186-3191.

BECCARO, M., CARACENI, A. & COSTANTINI, M. 2010. End-of-life care in Italian hospitals: Quality of and satisfaction with care from the caregivers' point of view—Results from the Italian survey of the dying of cancer. *Journal of Pain and Symptom Management,* 39**,** 1003-1015.

BEECHAM, E., HUDSON, B. F., OOSTENDORP, L., CANDY, B., JONES, L., VICKERSTAFF, V., LAKHANPAUL, M., STONE, P., CHAMBERS, L., HALL, D., HALL, K., GANESHAMOORTHY, T., COMAC, M. & BLUEBOND-LANGNER, M. 2016. A call for increased paediatric palliative care research: Identifying barriers. *Palliative Medicine,* 30**,** 979-980.

BENINI, F., ORZALESI, M., DE SANTI, A., CONGEDI, S., LAZZARIN, P., PELLEGATTA, F., DE ZEN, L., SPIZZICHINO, M. & ALLEVA, E. 2016. Barriers to the development of pediatric palliative care in Italy. *Annali Dell'istituto Superiore Di Sanita,* 52**,** 558-564.

BENINI, F., SPIZZICHINO, M., TRAPANOTTO, M. & FERRANTE, A. 2008. Pediatric palliative care. *Italian Journal Of Pediatrics,* 34**,** 4-4.

BERG, S. 2006. In their own voices: families discuss end-of-life decision making--part 2. *Pediatric Nursing,* 32**,** 238.

BERGSTRAESSER, E., INGLIN, S., HORNUNG, R. & LANDOLT, M. A. 2015. Dyadic Coping of Parents After the Death of a Child. *Death Studies,* 39**,** 128-138.

BETTANY- SALTIKOV, J. & MCSHERRY, R. 2016. *How To Do a Systematic Literature Review in Nursing: A Step-By-Step Guide.*

BINGLEY, A. & CLARK, D. 2009. A Comparative Review of Palliative Care Development in Six Countries Represented by the Middle East Cancer Consortium (MECC). *Journal of Pain & Symptom Management,* 37**,** 287-296.

BLACK, A., MCGLINCHEY, T., GAMBLES, M., ELLERSHAW, J. & MAYLAND, C. R. 2018. The 'lived experience' of palliative care patients in one acute hospital setting – a qualitative study. *BMC Palliative Care,* 17.

BLAZIN, L., CECCHINI, C., HABASHY, C., KAYE, E. & BAKER, J. 2018. Communicating Effectively in Pediatric Cancer Care: Translating Evidence into Practice. *Children,* 5**,** 40.

BLUM, D., INAUEN, R., BINSWANGER, J. & STRASSER, F. 2015. Barriers to research in palliative care: A systematic literature review. *Progress in Palliative Care,* 23**,** 75-84.

BOWLING, A. 2014. *Research Methods in Health: Investigating Health and Health Services*, McGraw-Hill Education.

BOYDEN, J. Y., ERSEK, M., DEATRICK, J. A., WIDGER, K., LARAGIONE, G., LORD, B. & FEUDTNER, C. 2021. What Do Parents Value Regarding Pediatric Palliative and Hospice Care in the Home Setting? *Journal of pain and symptom management,* 61**,** 12-23.

BOYNTON, P. M. 2004. Administering, analysing, and reporting your questionnaire. *BMJ,* 328**,** 1372-1375.

BRADFORD, N., IRVING, H., MURRAY, J., PEDERSEN, L.-A., ROYLANCE, J., CROWE, L. & HERBERT, A. 2012. Paediatric palliative care services in Queensland: an exploration of the barriers, gaps and plans for service development. *Neonatal, Paediatric & Child Health Nursing,* 15**,** 2-7.

BRAUN, M., HASSON-OHAYON, I., HALES, S., ZIMMERMANN, C., RYDALL, A., PERETZ, T. & RODIN, G. 2014. Quality of dying and death with cancer in Israel. *Supportive Care in Cancer,* 22**,** 1973-1980.

BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3**,** 77-101.

BRENNER, P. S. 2020. *Understanding Survey Methodology: Sociological Theory and Applications*, Springer International Publishing.

BRISLIN, R. 1986. The wording and translation of research instruments. *In:* LONNER, W. J. & BERRY, J. W. (eds.) *Field methods in cross-cultural research.* Sage Publications, Inc.

BRISLIN, R. W., LONNER, W. J. & THORNDIKE, R. M. 1973. *Cross-cultural research methods,* New York, John Wiley & Sons.

BROOTEN, D., YOUNGBLUT, J. A., SEAGRAVE, L., CAICEDO, C., HAWTHORNE, D., HIDALGO, I. & ROCHE, R. 2013. Parent's perceptions of health care providers actions around child ICU death: What helped, what did not. *AM J HOSP PALLIAT MED,* 30**,** 40.

BURNARD, P. 1991. A method of analysing interview transcripts in qualitative research. *Nurse Educ Today,* 11**,** 461-6.

BURT, J., SHIPMAN, C., RICHARDSON, A., REAM, E. & ADDINGTON-HALL, J. 2010. The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives. *Age Ageing,* 39**,** 86-91.

BUSHNAQ, M. 2008. Palliative Care in Jordan: Culturally Sensitive Practice. *Journal of Palliative Medicine,* 11**,** 1292-1293.

BUTLER, A. E., HALL, H. & COPNELL, B. 2017. Ethical and Practical Realities of Using Letters for Recruitment in Bereavement Research. *Research in Nursing & Health,* 40.

BUTLER, A. E., HALL, H. & COPNELL, B. 2018. Bereaved parents' experiences of research participation. *BMC Palliative Care,* 17**,** 122.

CALDWELL, K., HENSHAW, L. & TAYLOR, G. 2011. Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today,* 31**,** e1-e7.

CHA, E.-S., KIM, K. H. & ERLEN, J. A. 2007. Translation of scales in cross-cultural research: issues and techniques. *Journal of Advanced Nursing,* 58**,** 386-395.

CHAPPLE, A., ZIEBLAND, S. & HAWTON, K. 2015. Taboo and the different death? Perceptions of those bereaved by suicide or other traumatic death. *Sociology of Health & Illness,* 37**,** 610-625.

CHERLIN, E., SCHULMAN-GREEN, D., MCCORKLE, R., JOHNSON-HURZELER, R. & BRADLEY, E. 2004. Family perceptions of clinicians' outstanding practices in end-of-life care. *Journal of palliative care,* 20**,** 113-116.

CLARKE, S., MITCHELL, W. & SLOPER, P. 2004. Care and support needs of children and young people with cancer and leukaemia and their families. *Social Policy Research Unit, University of York.*

COLLER, R. J. & EHLENBACH, M. L. 2019. Making Time to Coordinate Care for Children With Medical Complexity. *Pediatrics,* 143**,** e20182958.

COLLINS, J. J., BYRNES, M. E., DUNKEL, I. J., LAPIN, J., NADEL, T., THALER, H. T., POLYAK, T., RAPKIN, B. & PORTENOY, R. K. 2000. The Measurement of Symptoms in Children with Cancer. *Journal of Pain and Symptom Management,* 19**,** 363-377.

COLLINS, K. M., ONWUEGBUZIE, A. J. & SUTTON, I. L. 2006. A model incorporating the rationale and purpose for conducting mixed methods research in special education and beyond. *Learning disabilities: a contemporary journal,* 4**,** 67-100.

CONNOR, S. 2014. The global atlas of palliative care at the end of life: An advocacy tool. *European Journal of Palliative Care,* 21**,** 180-183.

CONTRO, N., LARSON, J., SCOFIELD, S., SOURKES, B. & COHEN, H. 2002. Family perspectives on the quality of pediatric palliative care. *Archives Of Pediatrics & Adolescent Medicine,* 156**,** 14-19.

CONTRO, N. A., LARSON, J., SCOFIELD, S., SOURKES, B. & COHEN, H. J. 2004. Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics,* 114**,** 1248-1252.

COOK, A. S. & BOSLEY, G. 1995. The Experience of Participating in Bereavement Research: Stressful or Therapeutic? : Death Studies.

COOMBES, L. H., WISEMAN, T., LUCAS, G., SANGHA, A. & MURTAGH, F. E. M. 2016. Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use. *Palliative Medicine,* 30**,** 935-949.

COOMBS, M. A., PARKER, R., RANSE, K., ENDACOTT, R. & BLOOMER, M. J. 2017. An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care. *Journal of Advanced Nursing,* 73**,** 39-55.

CORDEN, A., SLOPER, P. & SAINSBURY, R. 2002. Financial effects for families after the death of a disabled or chronically ill child: a neglected dimension of bereavement. *Child: Care, Health And Development,* 28**,** 199-204.

CORLESS, I. B., NICHOLAS, P. K. & NOKES, K. M. 2001. Issues in Cross-cultural Quality-of-Life Research. *Journal of Nursing Scholarship,* 33**,** 15-20.

CORR, C. A. & CORR, D. M. 1985. Pediatric hospice care. *Pediatrics,* 76**,** 774-780.

CORTEZZO, D. E. & MEYER, M. 2020. Neonatal End-of-Life Symptom Management. *Frontiers in Pediatrics,* 8.

COSTANTINI, M., BECCARO, M. & MERLO, F. 2005. The last three months of life of Italian cancer patients. Methods, sample characteristics and response rate of the Italian Survey of the Dying of Cancer (ISDOC). *PALLIATIVE MEDICINE,* 19**,** 628.

CRAIG, F., ABU-SAAD, H., BENINI, F., KUTTNER, L., WOOD, C., FERARIS, P. C. & ZERNIKOW, B. 2007. IMPaCCT: Standards for paediatric palliative care in Europe. *European Journal of Palliative Care,* 14**,** 2-7.

CRAIG, P. 1997. Ethical and practical considerations in palliative child care and the support needs of parents and siblings. *Child Care in Practice,* 3**,** 64.

CREHAN, G. 2004. The surviving sibling: The effects of sibling death in childhood. *Psychoanalytic Psychotherapy,* 18**,** 202-219.

CRESWELL, J. W. & CLARK, V. L. P. 2017. *Designing and Conducting Mixed Methods Research,* Los Angeles ; London SAGE Publications.

CROWTHER, J. L. & LLOYD-WILLIAMS, M. 2012. Researching sensitive and emotive topics: The participants' voice. *Research Ethics,* 8**,** 200-211.

CZAJA, R. 1998. Questionnaire pretesting comes of age. *Marketing Bulletin-Department of Marketing Massey University,* 9**,** 52-66.

DANA AL EMAM. 2016. '55% of population, 68% of Jordanians covered by health insurance'. *The Jordan Times*.

DAVIES, B. & CONNAUGHTY, S. 2002. Pediatric end-of-life care: lessons learned from parents. *J Nurs Adm,* 32**,** 5-6.

DAVIES, B., SEHRING, S. A., PARTRIDGE, J. C., COOPER, B. A., HUGHES, A., PHILP, J. C., AMIDI-NOURI, A. & KRAMER, R. F. 2008. Barriers to Palliative Care for Children: Perceptions of Pediatric Health Care Providers. *Pediatrics,* 121**,** 282.

DE LEEUW, E. D., HOX, J. & DILLMAN, D. 2008. *International Handbook of Survey Methodology,* Florence, UNITED STATES, Taylor & Francis Group.

DE LEEUW, E. D., HOX, J. J. & HUISMAN, M. 2003. Prevention and treatment of item nonresponse. *Journal of Official Statistics,* 19**,** 153-176.

DEPARTMENT OF HEALTH 2012. First national VOICES survey of bereaved people . Accessed 11 Jul 2017. London: DH.

DEPARTMENT OF HEALTH (DOH). 2008. *End of Life Care Strategy Promoting high quality care for all adults at the end of life* [Online]. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf [Accessed 15 Apr. 2017].

DIGHE, M., JADHAV, S., MUCKADEN, M. A. & SOVANI, A. 2008. Parental concerns in children requiring palliative care. *Indian Journal of Palliative Care,* 14**,** 16-22.

DILLMAN, D. A., SMYTH, J. D. & CHRISTIAN, L. M. 2014. *Internet, Phone, Mail, and Mixed-Mode Surveys : The Tailored Design Method,* New York, UNITED STATES, John Wiley & Sons, Incorporated.

DOKKEN, D. L. 2006. In their own voices: families discuss end-of-life decision making -- part 1. *Pediatric Nursing,* 32**,** 173-175.

DONNA BURKE. 2016. *Saying Goodbye in America: How Western Medicine Shapes the Dying Experience* [Online]. Death with Dignity. Available: https://deathwithdignity.org/news/2016/08/saying-goodbye-america/ [Accessed 1/1/2022].

DONOVAN, L. A., WAKEFIELD, C. E., RUSSELL, V., HETHERINGTON, K. & COHN, R. J. 2019. Brief report: Bereaved parents informing research design: The place of a pilot study. *Death Studies,* 43**,** 62-69.

DOWNING, J. 2016. Editorial for palliative medicine. *Palliative Medicine,* 30**,** 902-903.

DOWNING, J., KNAPP, C., MUCKADEN, M. A., FOWLER-KERRY, S. & MARSTON, J. 2015. Priorities for global research into children's palliative care: results of an International Delphi Study. *BMC Palliative Care,* 14**,** 36-36.

DOWNING, J., NAMISANGO, E. & HARDING, R. 2018. Outcome measurement in paediatric palliative care: lessons from the past and future developments. *Annals of Palliative Medicine,* 7**,** S151-S163.

DRENNAN, J. 2003. Cognitive interviewing: verbal data in the design and pretesting of questionnaires. *J Adv Nurs,* 42**,** 57-63.

DUBAI HEALTH AUTHORITY. 2022. *Pediatric Medical* [Online]. Available: https://www.dha.gov.ae/en/latifahospital/pages/pediatricmedical.aspx [Accessed 1/1/2022].

DUSSEL, V., KREICBERGS, U., HILDEN, J. M., WATTERSON, J., MOORE, C., TURNER, B. G., WEEKS, J. C. & WOLFE, J. 2009. Looking beyond where children die: determinants and effects of planning a child's location of death. *Journal of Pain & Symptom Management,* 37**,** 33-43.

DYREGROV, K. 2004. Bereaved parents' experience of research participation. *Social Science & Medicine,* 58**,** 391-400.

EATON RUSSELL, C., WIDGER, K., BEAUNE, L., NEVILLE, A., CADELL, S., STEELE, R., RAPOPORT, A., RUGG, M. & BARRERA, M. 2018. Siblings' voices: A prospective investigation of experiences with a dying child. *Death Studies,* 42**,** 184-194.

EBADINEJAD, Z., RASSOULI, M. & FAKHR-MOVAHEDI, A. 2020. Compliance of palliative care standards in children with cancer in select Middle Eastern countries: a comparative study. *Int J Palliat Nurs,* 26**,** 354-361.

EDWARDS, J. D., HOUTROW, A. J., VASILEVSKIS, E. E., REHM, R. S., MARKOVITZ, B. P., GRAHAM, R. J. & DUDLEY, R. A. 2012. Chronic conditions among children admitted to U.S. pediatric intensive care units: Their prevalence and impact on risk for mortality and prolonged length of stay*. *Critical Care Medicine,* 40**,** 2196-2203.

EILEEN, R. O. S., JOYCE, S., TRACEY, R. & CATHLEEN, C. 2012. The Needs of Siblings of Children With Cancer: A Nursing Perspective. *Journal of Pediatric Oncology Nursing,* 29**,** 221-231.

EILERTSEN, M. B., LOVGREN, M., WALLIN, A. E. & KREICBERGS, U. 2017. Cancer-bereaved siblings' positive and negative memories and experiences of illness and death: A nationwide follow-up. *Palliat Support Care,* 16**,** 1-8.

EL HALAL, G. M., PIVA, J. P., LAGO, P. M., EL HALAL, M. G., CABRAL, F. C., NILSON, C. & GARCIA, P. C. 2013. Parents' perspectives on the deaths of their children in two Brazilian paediatric intensive care units. *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING,* 19**,** 495-502.

EPSTEIN, J., SANTO, R. M. & GUILLEMIN, F. 2015. A review of guidelines for cross-cultural adaptation of questionnaires could not bring out a consensus. *Journal of Clinical Epidemiology,* 68**,** 435-441.

EPSTEIN, R. & STREET, R. L. 2007. *Patient-centered communication in cancer care: promoting healing and reducing suffering*, National Cancer Institute, US Department of Health and Human Services ….

FALKENBURG, J. L., TIBBOEL, D., GANZEVOORT, R. R., GISCHLER, S., HAGOORT, J. & VAN DIJK, M. 2016. Parental physical proximity in end-of-life care in the PICU. *Pediatric Critical Care Medicine,* 17**,** e212-e217.

FEILZER, M. Y. 2010. Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. *Journal of Mixed Methods Research,* 4**,** 6-16.

FEUDTNER, C., HANEY, J. & DIMMERS, M. A. 2003. Spiritual care needs of hospitalized children and their families: a national survey of pastoral care providers' perceptions. *Pediatrics,* 111**,** e67-e72.

FOWLER, F. J., COPPOLA, K. M. & TENO, J. M. 1999. Methodological challenges for measuring quality of care at the end of life. *J Pain Symptom Manage,* 17.

FRANCA, J. R., DA COSTA, S. F., LOPES, M. E., DA NOBREGA, M. M. & DE FRANCA, I. S. 2013. The importance of communication in pediatric oncology palliative care: focus on Humanistic Nursing Theory. *Rev Lat Am Enfermagem,* 21**,** 780-6.

FRASER, L., MILLER, M., ALDRIDGE, J., MCKINNEY, P. A. & PARSLOW, R. C. 2013. Prevalence of life-limiting and lifethreatening conditions in young adults in England 2000-2010; FINAL REPORT FOR TOGETHER FOR SHORT LIVES. University of York.

FRASER, L. K., LIDSTONE, V., MILLER, M., ALDRIDGE, J., NORMAN, P., MCKINNEY, P. A. & PARSLOW, R. C. 2014. Patterns of diagnoses among children and young adults with life-limiting conditions: A secondary analysis of a national dataset. *Palliative Medicine,* 28**,** 513-520.

FRASER, L. K., MILLER, M., HAIN, R., NORMAN, P., ALDRIDGE, J., MCKINNEY, P. A. & PARSLOW, R. C. 2012. Rising national prevalence of life-limiting conditions in children in England. *Pediatrics,* 129**,** e923-9.

FRASER, L. K. & PARSLOW, R. 2018. Children with life-limiting conditions in paediatric intensive care units: a national cohort, data linkage study. *Archives of Disease in Childhood,* 103**,** 540-547.

FREEMAN, K., O'DELL, C. & MEOLA, C. 2003. Childhood brain tumors: children's and siblings' concerns regarding the diagnosis and phase of illness. *Journal of Pediatric Oncology Nursing,* 20**,** 133-140.

FREEMAN, K., O'DELL, C. & MEOLA, C. 2004. Childhood brain tumors: parental concerns and stressors by phase of illness. *Journal of Pediatric Oncology Nursing,* 21**,** 87-97.

FRIEDEL, M., AUJOULAT, I., DUBOIS, A.-C. & DEGRYSE, J.-M. 2018a. Instruments to Measure Outcomes in Pediatric Palliative Care: A Systematic Review. *Pediatrics,* 143**,** e20182379.

FRIEDEL, M., BRICHARD, B., FONTEYNE, C., RENARD, M., MISSON, J.-P., VANDECRUYS, E., TONON, C., VERFAILLIE, F., HENDRIJCKX, G., ANDERSSON, N., RUYSSEVELDT, I., MOENS, K., DEGRYSE, J.-M. & AUJOULAT, I. 2018b. Building Bridges, Paediatric Palliative Care in Belgium: A secondary data analysis of annual paediatric liaison team reports from 2010 to 2014. *BMC palliative care,* 17**,** 77.

GALE, N. K., HEATH, G., CAMERON, E., RASHID, S. & REDWOOD, S. 2013. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology,* 13**,** 117.

GJERSING, L., CAPLEHORN, J. R. & CLAUSEN, T. 2010. Cross-cultural adaptation of research instruments: language, setting, time and statistical considerations. *BMC Medical Research Methodology,* 10**,** 13.

GOLDHAGEN, J., FAFARD, M., KOMATZ, K., EASON, T. & LIVINGOOD, W. C. 2016. Community-based pediatric palliative care for health related quality of life, hospital utilization and costs lessons learned from a pilot study. *Bmc Palliative Care,* 15.

GOLDMAN, A., HEWITT, M., COLLINS, G. S., CHILDS, M. & HAIN, R. 2006. Symptoms in children/young people with progressive malignant disease: United Kingdom Children's Cancer Study Group/Paediatric Oncology Nurses Forum survey. *PEDIATRICS,* 117**,** e1179.

GRANT, J. S. & DAVIS, L. L. 1997. Selection and use of content experts for instrument development. *Research in Nursing & Health,* 20**,** 269-274.

GROVES, R. M., FOWLER, F. J., COUPER, M. P., LEPKOWSKI, J. M., SINGER, E. & TOURANGEAU, R. 2009. *Survey Methodology,* Hoboken, N.J., Wiley.

GUILLEMIN, F., BOMBARDIER, C. & BEATON, D. 1993. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *Journal of clinical epidemiology,* 46**,** 1417-1432.

GUSTAFSON, C. & LAZENBY, M. 2019. Assessing the Unique Experiences and Needs of Muslim Oncology Patients Receiving Palliative and End-of-Life Care: An Integrative Review. *Journal of Palliative Care,* 34**,** 52-61.

HACKETT, A. & STRICKLAND, K. 2019. Using the framework approach to analyse qualitative data: a worked example. *Nurse Researcher,* 26**,** 8-13.

HAEGER, H., LAMBERT, A. D., KINZIE, J. & GIESER, J. 2012. Using cognitive interviews to improve survey instruments. *Association for Institutional Research, New Orleans*.

HAIN, R., HECKFORD, E. & MCCULLOCH, R. 2012. Paediatric palliative medicine in the UK: past, present, future. *Archives of Disease in Childhood,* 97**,** 381-384.

HALES, S., GAGLIESE, L., NISSIM, R., ZIMMERMANN, C. & RODIN, G. 2012. Understanding Bereaved Caregiver Evaluations of the Quality of Dying and Death: An Application of Cognitive Interviewing Methodology to the Quality of Dying and Death Questionnaire. *Journal of Pain and Symptom Management,* 43**,** 195-204.

HALES, S., ZIMMERMANN, C. & RODIN, G. 2010. The quality of dying and death: a systematic review of measures. *Palliat Med,* 24.

HASANPOUR, M., SADEGHI, N. & HEIDARZADEH, M. 2016. Parental needs in infant's end-of-life and bereavement in NICU: A qualitative study. *Journal Of Education And Health Promotion,* 5**,** 19-19.

HEAD, B. & FAUL, A. 2007. Research Risks and Benefits as Perceived by Persons With a Terminal Prognosis. *Journal of Hospice & Palliative Nursing,* 9**,** 256-263.

HEARN, J. & HIGGINSON, I. J. 1997. Outcome measures in palliative care for advanced cancer patients: a review. *J Public Health Med,* 19**,** 193-9.

HEATH, J., CLARKE, N., MCCARTHY, M., DONATH, S., ANDERSON, V. & WOLFE, J. 2009. Quality of care at the end of life in children with cancer. *J Paediatr Child Health,* 45.

HECHLER, T., BLANKENBURG, M., FRIEDRICHSDORF, S. J., GARSKE, D., HUBNER, B., MENKE, A., WAMSLER, C., WOLFE, J. & ZERNIKOW, B. 2008. Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klinische Padiatrie,* 220**,** 166-174.

HEDAYAT, K. 2006. When the spirit leaves: Childhood death, grieving, and bereavement in Islam. *Journal of Palliative Medicine,* 9**,** 1282-1291.

HELLER, K. S. & SOLOMON, M. Z. 2005. Continuity of care and caring: what matters to parents of children with life-threatening conditions. *Journal Of Pediatric Nursing,* 20**,** 335-346.

HIGGINSON, I. 1997. Health care needs assessment: palliative and terminal care. *In:* STEVENS, A. & RAFTERY , J. (eds.) *Health care needs assessment.* Oxford: Radcliffe Medical.

HILL, K. & COYNE, I. 2012. Palliative care nursing for children in the UK and Ireland. *British Journal of Nursing,* 21**,** 276-281.

HIMELSTEIN, B. P., HILDEN, J. M., BOLDT, A. M. & WEISSMAN, D. 2004. Pediatric palliative care. *N Engl J Med,* 350**,** 1752-62.

HINDS, P., BURGHEN, E. & PRITCHARD, M. 2007. Conducting end-of-life studies in pediatric oncology. *West J Nurs Res,* 29.

HOBBS, K. 2015. Which factors influence the development of post-traumatic stress disorder in patients with burn injuries? A systematic review of the literature. *Burns,* 41**,** 421-430.

HOMER, C. J., MARINO, B., CLEARY, P. D., ALPERT, H. R., SMITH, B., CROWLEY GANSER, C. M., BRUSTOWICZ, R. M. & GOLDMANN, D. A. 1999. Quality of care at a children's hospital: the parent's perspective. *Archives Of Pediatrics & Adolescent Medicine,* 153**,** 1123-1129.

HUANG, I. C., SHENKMAN, E. A., MADDEN, V. L., VADAPARAMPIL, S., QUINN, G. & KNAPP, C. A. 2010. Measuring quality of life in pediatric palliative care: challenges and potential solutions. *Palliative Medicine,* 24**,** 175-182.

HUNT, K. J., RICHARDSON, A., DARLINGTON, A. E. & ADDINGTON-HALL, J. M. 2017. Developing the methods and questionnaire (VOICES-SF) for a national retrospective mortality follow-back survey of palliative and end-of-life care in England. *BMJ Support Palliat Care,* 9:e5.

HUNT, K. J., SHLOMO, N. & ADDINGTON-HALL, J. 2014a. End-of-life care and achieving preferences for place of death in England: results of a population-based survey using the VOICES-SF questionnaire. *Palliat Med,* 28**,** 412-21.

HUNT, K. J., SHLOMO, N. & ADDINGTON-HALL, J. 2014b. End-of-life care and preferences for place of death among the oldest old: results of a population-based survey using VOICES-Short Form. *J Palliat Med,* 17**,** 176-82.

HUNT, K. J., SHLOMO, N., RICHARDSON, A. & ADDINGTON-HALL, J. 2011. VOICES Redesign and Testing to Inform a National End of Life Care Survey. Southampton: University of Southampton.

HUNT, S. M. & BHOPAL, R. 2004. Self report in clinical and epidemiological studies with non-English speakers: the challenge of language and culture. *Journal of Epidemiology & Community Health,* 58**,** 618-622.

HYNSON, J. L., ARONI, R., BAULD, C. & SAWYER, S. M. 2006. Research with bereaved parents: a question of how not why. 20**,** 805-811.

INGLIN, S., HORNUNG, R. & BERGSTRAESSER, E. 2011. Palliative care for children and adolescents in Switzerland: a needs analysis across three diagnostic groups. *European Journal Of Pediatrics,* 170**,** 1031-1038.

INTERNATIONAL CHILDREN’S PALLIATIVE CARE NETWORK (ICPCN). *International Children’s Palliative Care Network: Vision, mission, & aims* [Online]. Available: http://www.icpcn.org/about-icpcn/vision-mission-aims/ [Accessed].

INTERNATIONAL CHILDREN’S PALLIATIVE CARE NETWORK (ICPCN). 2015. *What is Children’s Palliative Care?* [Online]. Available: http://www.icpcn.org/about-icpcn/what-is-childrens-palliative-care/ [Accessed].

IRWIN, D. E., VARNI, J. W., YEATTS, K. & DEWALT, D. A. 2009. Cognitive interviewing methodology in the development of a pediatric item bank: a patient reported outcomes measurement information system (PROMIS) study. *Health and Quality of Life Outcomes,* 7**,** 3.

JAMES, L. & JOHNSON, B. 1997. The needs of parents of pediatric oncology patients during the palliative care phase. *Journal Of Pediatric Oncology Nursing: Official Journal Of The Association Of Pediatric Oncology Nurses,* 14**,** 83-95.

JOBE, J. B. 2003. Cognitive psychology and self-reports: Models and methods. *Quality of Life Research,* 12**,** 219-227.

JOHNSON, C., AARONSON, N., BLAZEBY, J. M., BOTTOMLEY, A., FAYERS, P., KOLLER, M., KULIŚ, D., RAMAGE, J., SPRANGERS, M., VELIKOVA, G. & YOUNG, T. 2011. EORTC QUALITY OF LIFE GROUP. Guidelines for Developing Questionnaire Modules. 4 ed.: European Organisation for Research and Treatment of Cancer.

JOHNSON, R. B., ONWUEGBUZIE, A. J. & TURNER, L. A. 2007. Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research,* 1**,** 112-133.

JOHNSTON, E. E., MOLINA, J., MARTINEZ, I., DIONNE-ODOM, J. N., CURRIE, E. R., CROWL, T., BUTTERWORTH, L., CHAMBERLAIN, L. J., BHATIA, S., ROSENBERG, A. R. & DIONNE-ODOM, J. N. 2020. Bereaved parents' views on end-of-life care for children with cancer: Quality marker implications. *Cancer (0008543X),* 126**,** 3352-3359.

JOHNSTON, E. E., ROSENBERG, A. R. & KAMAL, A. H. 2017. Pediatric-Specific End-of-Life Care Quality Measures: An Unmet Need of a Vulnerable Population. *Journal of Oncology Practice,* 13**,** e874-e880.

JONES, P. S., LEE, J. W., PHILLIPS, L. R., ZHANG, X. E. & JACELDO, K. B. 2001. An Adaptation of Brislin's Translation Model for Cross-cultural Research. *Nursing Research,* 50**,** 300-304.

KARS, M. C., GRYPDONCK, M. H. F. & VAN DELDEN, J. J. M. 2011. Being a Parent of a Child With Cancer Throughout the End-of-Life Course. *Oncology Nursing Forum,* 38**,** E260-71.

KARS, M. C., VAN THIEL, G. J., VAN DER GRAAF, R., MOORS, M., DE GRAEFF, A. & VAN DELDEN, J. J. 2016. A systematic review of reasons for gatekeeping in palliative care research. *Palliative Medicine,* 30**,** 533-548.

KASSAM, A., SKIADARESIS, J., HABIB, S., ALEXANDER, S. & WOLFE, J. 2013. Moving toward quality palliative cancer care: parent and clinician perspectives on gaps between what matters and what is accessible. *Journal of Clinical Oncology,* 31**,** 910-915.

KELLEY, A. S. & MORRISON, R. S. 2015. Palliative Care for the Seriously Ill. *New England Journal of Medicine,* 373**,** 747-755.

KENTISH-BARNES, N., MCADAM, J. L., KOUKI, S., COHEN-SOLAL, Z., CHAIZE, M., GALON, M., SOUPPART, V., PUNTILLO, K. A. & AZOULAY, E. 2015. Research Participation for Bereaved Family Members: Experience and Insights From a Qualitative Study. *Crit Care Med,* 43**,** 1839-45.

KESTLER, S. A. & LOBIONDO-WOOD, G. 2012. Review of symptom experiences in children and adolescents with cancer. *Cancer Nursing,* 35**,** e31-e49.

KHADER, K. 2017. Cultural Challenges in Implementing Palliative Care Services in Jordan. *Palliative Medicine and Hospice Care - Open Journal,* SE**,** S68-S72.

KHADER, Y., AL-SHEYAB, N., ALYAHYA, M. & BATIEHA, A. 2020. Registration, documentation, and auditing of stillbirths and neonatal deaths in Jordan from healthcare professionals' perspectives: reality, challenges and suggestions. *The Journal of Maternal-Fetal & Neonatal Medicine,* 33**,** 3338-3348.

KHADER, Y. S., ALYAHYA, M., AL-SHEYAB, N., SHATTNAWI, K., SAQER, H. R. & BATIEHA, A. 2018. Evaluation of maternal and newborn health services in Jordan. *Journal of Multidisciplinary Healthcare,* 11**,** 439-456.

KHALAILA, R. 2013. Translation of Questionnaires Into Arabic in Cross-Cultural Research. *Journal of Transcultural Nursing,* 24**,** 363-370.

KHAN, A. A. 2015. Qada and Qadr Predestination. *Defence Journal,* 19**,** 35-49.

KHANALI MOJEN, L., RASSOULI, M., ESHGHI, P., SARI, A. A. & KARIMOOI, M. H. 2017. Palliative Care for Children with Cancer in the Middle East: A Comparative Study. *Indian Journal Of Palliative Care,* 23**,** 379-386.

KING FAISAL SPECIALIST HOSPITAL & RESEARCH CENTRE. 2022. *Pediatrics* [Online]. Available: https://www.kfshrc.edu.sa/en/home/hospitals/jeddah/pediatricsj [Accessed 1/1/2022].

KLEIN, J. 2003. Special needs of dying children & their families not being met. *Oncology Times,* 25**,** 13-14.

KNAFL, K., DEATRICK, J., GALLO, A., HOLCOMBE, G., BAKITAS, M. & DIXON, J. 2007. The analysis and interpretation of cognitive interviews for instrument development. *Res Nurs Health,* 30.

KNAPP, C. & MADDEN, V. 2010. Conducting Outcomes Research in Pediatric Palliative Care. *American Journal of Hospice and Palliative Medicine®,* 27**,** 277-281.

KONRAD, S. C. 2008. Mothers' perspectives on qualities of care in their relationships with health care professionals: the influence of relational and communicative competencies. *Journal Of Social Work In End-Of-Life & Palliative Care,* 4**,** 38-56.

KREICBERGS, U., VALDIMARSDÓTTIR, U., ONELÖV, E., BJÖRK, O., STEINECK, G. & HENTER, J. I. 2005. Care-related distress: a nationwide study of parents who lost their child to cancer. *Journal of Clinical Oncology,* 23**,** 9162-9171.

KRISTIANSEN, M. & SHEIKH, A. 2012. Understanding faith considerations when caring for bereaved Muslims. *Journal of the Royal Society of Medicine,* 105**,** 513-517.

LAN, K. G. & YUN, L. W. 2015. Parents' perspectives on the important aspects of care in children dying from life limiting conditions: A qualitative study. *The Medical Journal Of Malaysia,* 70**,** 295-299.

LARSSON, B. W., LARSSON, G. & CARLSON, S. R. 2004. Advanced home care: patients' opinions on quality compared with those of family members. *J Clin Nurs,* 13.

LAVRAKAS, P. J. 2008. *Encyclopedia of Survey Research Methods,* Thousand Oaks, California.

LAWRENCE, P. & ROZMUS, C. 2001. Culturally Sensitive Care of the Muslim Patient. *Journal of Transcultural Nursing,* 12**,** 228-233.

LEES, C., MAYLAND, C., WEST, A. & GERMAINE, A. 2014. Quality of end-of-life care for those who die at home: views and experiences of bereaved relatives and carers. *International Journal of Palliative Nursing,* 20**,** 63-63.

LENDON, J. P., AHLUWALIA, S. C., WALLING, A. M., LORENZ, K. A., OLUWATOLA, O. A., ANHANG PRICE, R., QUIGLEY, D. & TENO, J. M. 2015. Measuring Experience With End-of-Life Care: A Systematic Literature Review. *J Pain Symptom Manage,* 49**,** 904-15 e1-3.

LENTON, S., FRANCK, L. & SALT, A. 2004. Children with complex health care needs: supporting the child and family in the community. *Child: Care, Health & Development,* 30**,** 191-192.

LENZ, A. S., GÓMEZ SOLER, I., DELL'AQUILLA, J. & URIBE, P. M. 2017. Translation and Cross-Cultural Adaptation of Assessments for Use in Counseling Research. *Measurement and Evaluation in Counseling and Development,* 50**,** 224-231.

LEONG, M., OLNICK, S., AKMAL, T., COPENHAVER, A. & RAZZAK, R. 2016. How Islam Influences End-of-Life Care: Education for Palliative Care Clinicians. *Journal of Pain and Symptom Management,* 52**,** 771-774.e3.

LEWIS-BECK, M. S., BRYMAN, A. & LIAO, T. F. 2004. Telephone survey. *The SAGE Encyclopedia of Social Science Research Methods.* Thousand Oaks, California: SAGE Publications, Inc.

LIBEN, S., PAPADATOU, D. & WOLFE, J. 2008. Paediatric palliative care: Challenges and emerging ideas. *The Lancet,* 371**,** 852-864.

LINDLEY, L. C. 2015. Determinants of access to pediatric hospice care: A conceptual model. *Journal Of Hospice And Palliative Nursing: JHPN: The Official Journal Of The Hospice And Palliative Nurses Association,* 17**,** 113-118.

LINTON, J. M. & FEUDTNER, C. 2008. What accounts for differences or disparities in pediatric palliative and end-of-life care? A systematic review focusing on possible multilevel mechanisms. *Pediatrics,* 122**,** 574-582.

LÖVGREN, M., BYLUND-GRENKLO, T., JALMSELL, L., WALLIN, A. E. & KREICBERGS, U. 2016. Bereaved Siblings' Advice to Health Care Professionals Working With Children With Cancer and Their Families. *Journal Of Pediatric Oncology Nursing: Official Journal Of The Association Of Pediatric Oncology Nurses,* 33**,** 297-305.

LÖVGREN, M., SVEEN, J., NYBERG, T., EILEGARD WALLIN, A., PRIGERSON, H. G., STEINECK, G. & KREICBERGS, U. 2018. Care at End of Life Influences Grief: A Nationwide Long-Term Follow-Up among Young Adults Who Lost a Brother or Sister to Childhood Cancer. *J Palliat Med,* 21**,** 156-162.

LYNN, J., TENO, J. M., PHILLIPS, R. S., WU, A. W., DESBIENS, N. & HARROLD, J. 1997. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT investigators. Study to understand prognoses and preferences for outcomes and risks of treatments. *Ann Intern Med,* 2.

MACDONALD, M. E., LIBEN, S., CARNEVALE, F. A. & COHEN, S. R. 2008. Signs of life and signs of death: Brain death and other mixed messages at the end of life. *Journal of Child Health Care,* 12**,** 92-105.

MACHADO, R. D. S., FERNANDES, A. D. D. B. F., OLIVEIRA, A. L. C. B. D., SOARES, L. S., GOUVEIA, M. T. D. O. & SILVA, G. R. F. D. 2018. Métodos de adaptação transcultural de instrumentos na área da enfermagem. *Revista Gaúcha de Enfermagem,* 39.

MACK, J. W., HILDEN, J. M., WATTERSON, J., MOORE, C., TURNER, B., GRIER, H. E., WEEKS, J. C. & WOLFE, J. 2005. Parent and physician perspectives on quality of care at the end of life in children with cancer. *Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology,* 23**,** 9155-9161.

MAHADEEN, A. I., ARABIAT, D. H., ABDELKADER, R. H. & HAMDAN-MANSOUR, A. M. 2010. Maternal distress among Jordanian mothers caring for children with cancer in Jordan. *Jordan Medical Journal,* 44**,** 404-412.

MARÇOLA, L., ZOBOLI, I., POLASTRINI, R. T. V. & BARBOSA, S. M. M. D. 2020. BREAKING BAD NEWS IN A NEONATAL INTENSIVE CARE: THE PARENT'S EVALUATION. *Revista Paulista de Pediatria,* 38.

MAYLAND, C. R., WILLIAMS, E. M. I. & ELLERSHAW, J. E. 2008. How well do current instruments using bereaved relatives' views evaluate care, for dying patients? *Palliative Medicine,* 22**,** 133-144.

MAYNARD, L., RENNIE, T., SHIRTLIFFE, J. & VICKERS, D. 2005. Seeking and using families' views to shape children's hospice services. *International Journal of Palliative Nursing,* 11**,** 624-630.

MCCARTHY, M. C., CLARKE, N. E., TING, C. L., CONROY, R., ANDERSON, V. A. & HEATH, J. A. 2010. Prevalence and Predictors of Parental Grief and Depression after the Death of a Child from Cancer. *Journal of Palliative Medicine,* 13**,** 1321-1326.

MCPHERSON, C. J. & ADDINGTON-HALL, J. M. 2004. Evaluating palliative care: bereaved family members' evaluations of patients' pain, anxiety and depression. *Journal of Pain and Symptom Management,* 28**,** 104-114.

MCPHERSON, M. L., SACHDEVA, R. C. & JEFFERSON, L. S. 2000. Development of a survey to measure parent satisfaction in a pediatric intensive care unit. *Critical Care Medicine,* 28.

MEDICAL RESEARCH COUNCIL 2009. Patient-Reported Outcome Measures (PROMs): Identifying UK Research Priorities London: Royal College of Physicians.

MEERT, K. L., BRILLER, S. H., SCHIM, S. M., THURSTON, C. & KABEL, A. 2009. Examining the needs of bereaved parents in the pediatric intensive care unit: A qualitative study. *Death Studies,* 33**,** 712-740.

MEERT, K. L., THURSTON, C. S. & SARNAIK, A. P. 2000. End-of-life decision-making and satisfaction with care: parental perspectives. *Pediatric Critical Care Medicine: A Journal Of The Society Of Critical Care Medicine And The World Federation Of Pediatric Intensive And Critical Care Societies,* 1**,** 179-185.

MELIN-JOHANSSON, C., AXELSSON, I., JONSSON GRUNDBERG, M. & HALLQVIST, F. 2014. When a child dies: Parents' experiences of palliative care-an integrative literature review. *Journal of Pediatric Nursing,* 29**,** 660-669.

MENDIZABAL-ESPINOSA, R. M. & PRICE, J. E. 2021. Family centred neonatal palliative care in children's hospices: A qualitative study of parents' experiences. *Journal of Neonatal Nursing,* 27**,** 141-146.

MEYER, E., RITHOLZ, M., BURNS, J. & TRUOG, R. 2006. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics,* 117.

MEYER, E. C., BURNS, J. P., GRIFFITH, J. L. & TRUOG, R. D. 2002. Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine,* 30**,** 226-231.

MIDSON, R. & CARTER, B. 2010. Addressing end of life care issues in a tertiary treatment centre: lessons learned from surveying parents' experiences. *Journal Of Child Health*

Care: For Professionals Working With Children In The Hospital And Community, 14**,** 52-66.

MILLER, K., CHEPP, V., PADILLA, J. L., WILLSON, S. & PADILLA, J. L. 2014. *Cognitive Interviewing Methodology : A Sociological Approach for Survey Question Evaluation,* Somerset, UNITED STATES, John Wiley & Sons, Incorporated.

MINISTRY OF INFORMATION AND COMMUNICATIONS TECHNOLOGY (MOICT) 2018. Response Of The Hashemite Kingdom Of Jordan On The Implementation Of The Recommendation Concerning The Promotion And Use Of Multilingualism And Universal Access To Cyberspace.

MONTEROSSO, L. & KRISTJANSON, L. J. 2008. Supportive and palliative care needs of families of children who die from cancer: an Australian study. *Palliative Medicine,* 22**,** 59-69.

MONTEROSSO, L., KRISTJANSON, L. J., AOUN, S. & PHILLIPS, M. B. 2007. Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service. *Palliative Medicine,* 21**,** 689-696.

MONTEROSSO, L., KRISTJANSON, L. J. & DADD, G. 2006. Content validity and reliability testing of the FIN-PED II: A tool to measure care needs of parents of children with cancer. *J Nurs Meas,* 14**,** 31-44.

MONTEROSSO, L., KRISTJANSON, L. J. & PHILLIPS, M. B. 2009. The supportive and palliative care needs of Australian families of children who die from cancer. *Palliative Medicine,* 23**,** 526-536.

NAMISANGO, E., BRISTOWE, K., ALLSOP, M. J., MURTAGH, F. E. M., ABAS, M., HIGGINSON, I. J., DOWNING, J. & HARDING, R. 2018. Symptoms and Concerns Among Children and Young People with Life-Limiting and Life-Threatening Conditions: A Systematic Review Highlighting Meaningful Health Outcomes. *The Patient,* 12.

NASSAR, D. A., OTHMAN, M., HAYAJNEH, J. A. & ALI, N. A. 2015. An Integrated Success Model for an Electronic Health Record: A Case Study of Hakeem Jordan. *Procedia Economics and Finance,* 23**,** 95-103.

NATIONAL COUNCIL FOR PALLIATIVE CARE (NCPC). 2006. *End of Life Care Strategy.* [Online]. London. : The National Council for Palliative Care Submission. Available: www.ncpc.org.uk/sites/default/files/NCPC_EoLC_Submission.pdf [Accessed].

NATIONAL HEALTH SERVICE (NHS). 2015. *End of life care* [Online]. Available: http://www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx [Accessed 17 Apr. 2017].

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION (NHPCO). 2009. *Standards for Pediatric Hospice/Palliative Care* [Online]. Available: https://www.nhpco.org/sites/default/files/public/quality/Ped_Pall_Care%20_Standard.pdf.pdf [Accessed].

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE). 2016. *End of life care for infants, children and young people with life-limiting conditions: planning and management* [Online]. Available: https://www.nice.org.uk/guidance/ng61/chapter/Recommendations#terms-used-in-this-guideline [Accessed 17 April 2017 2017].

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE) 2017. End of life care for infants, children and young people.

NAZER, L. H. & TUFFAHA, H. 2017. Health Care and Pharmacy Practice in Jordan. *The Canadian Journal of Hospital Pharmacy,* 70.

NOLBRIS, M. & HELLSTRÖM, A.-L. 2005. Siblings' Needs and Issues When a Brother or Sister Dies of Cancer. *Journal of Pediatric Oncology Nursing,* 22**,** 227-233.

NOYES, J. & LEWIN, S. 2011. Chapter 5: Extracting qualitative evidence. . *In:* NOYES J, B. A., HANNES K, HARDEN A, HARRIS J, LEWIN S, LOCKWOOD C (ed.) *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions.* . Cochrane Collaboration Qualitative Methods Group.

O'SULLIVAN, A., OHLEN, J., ALVARIZA, A. & HAKANSON, C. 2018. Adaptation and validation of the VOICES (SF) questionnaire - for evaluation of end-of-life care in Sweden. 32**,** 1254-1260.

OFFICE FOR NATIONAL STATISTICS. 2015. *Statistical Bulletin:National Survey of Bereaved People (VOICES): England, 2015* [Online]. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015 [Accessed].

OMRAN, S. & OBEIDAT, R. 2015. Palliative care nursing in Jordan. *J Palliat Care Med* S4-005.

ONG, J., BRENNSTEINER, A., CHOW, E. & HEBERT, R. S. 2016. Correlates of Family Satisfaction with Hospice Care: General Inpatient Hospice Care versus Routine Home Hospice Care. *Journal Of Palliative Medicine,* 19**,** 97-100.

ONWUEGBUZIE, A. J., BUSTAMANTE, R. M. & NELSON, J. A. 2010. Mixed research as a tool for developing quantitative instruments. *Journal of Mixed Methods Research,* 4**,** 56-78.

OWEIS, A. I. 2005. Bringing the professional challenges for nursing in Jordan to light. *International Journal of Nursing Practice,* 11**,** 244-249.

PAKSERESHT, M., BARAZ, S., RASOULI, M., REJE, N. & ROSTAMI, S. 2018. A Comparative Study of the Situation of Bereavement Care for Children with Cancer in Iran with Selected Countries. *International Journal of Pediatrics,* 6**,** 7253-7263.

PARKES, C. M., LAUNGANI, P. & YOUNG, B. 2015. *Death and bereavement across cultures,* London, Routledge.

PETERS, M. 2011. Translating patient-reported outcome measures (PROMs) for cross-cultural studies. *In:* JENKINSON, C., BROMBERG, M. B. & PETERS, M. (eds.) *Quality of Life Measurement in Neurodegenerative and Related Conditions.* Cambridge: Cambridge University Press.

PETERSEN, C. L. 2014. Spiritual care of the child with cancer at the end of life: A concept analysis. *Journal of Advanced Nursing,* 70**,** 1243-1253.

PRESSER, S. & BLAIR, J. 1994. Survey Pretesting: Do Different Methods Produce Different Results? *Sociological Methodology,* 24**,** 73-104.

PRESSER, S., ROTHGEB, J. M., COUPER, M. P., LESSLER, J. T., MARTIN, E., MARTIN, J. & SINGER, E. 2004. *Methods for Testing and Evaluating Survey Questionnaires,* New Jersey, Wiley.

PRESTON, N., PAYNE, S. & TODD, C. 2009. Conducting research in palliative care patients: a burden or an opportunity? *Int J Palliat Nurs,* 15**,** 524-5.

PRICE, J., JORDAN, J., PRIOR, L. & PARKES, J. 2012. Comparing the needs of families of children dying from malignant and non-malignant disease: an in-depth qualitative study. *BMJ Supportive & Palliative Care,* 2**,** 127-132.

PRICE, J., MCNEILLY, P. & MCFARLANE, M. 2005. Paediatric palliative care in the UK: past, present and future. *International Journal of Palliative Nursing,* 11**,** 124-126.

PRITCHARD, M., BURGHEN, E., SRIVASTAVA, D. K., OKUMA, J., ANDERSON, L., POWELL, B., FURMAN, W. L. & HINDS, P. S. 2008. Cancer-Related Symptoms Most Concerning to Parents During the Last Week and Last Day of Their Child's Life. *Pediatrics,* 121**,** e1301-9.

ROBERT, R., ZHUKOVSKY, D. S., MAURICIO, R., GILMORE, K., MORRISON, S. & PALOS, G. R. 2012. Bereaved Parents' Perspectives on Pediatric Palliative Care. *Journal of Social Work in End-of-Life & Palliative Care,* 8**,** 316-338.

ROBSON, C. 2011. *Real World Research*, Wiley.

ROSENBERG, A. R., STARKS, H., UNGURU, Y., FEUDTNER, C. & DIEKEMA, D. 2017. Truth Telling in the Setting of Cultural Differences and Incurable Pediatric Illness. *JAMA Pediatrics,* 171**,** 1113.

ROTHGEB, J., WILLIS, G. & FORSYTH, B. 2007. Questionnaire Pretesting Methods: Do Different Techniques and Different Organizations Produce Similar Results? *Bulletin of Sociological Methodology/Bulletin de Méthodologie Sociologique,* 96**,** 5-31.

ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH: ETHICS ADVISORY COMMITTEE (RCPCH) 2000. Guidelines for the ethical conduct of medical research involving children. *Archives of Disease in Childhood,* 82**,** 177-182.

SACHEDINA, A. 2005. End-of-life: the Islamic view. *The Lancet,* 366**,** 774-779.

SADEGHI, N., HASANPOUR, M., HEIDARZADEH, M., ALAMOLHODA, A. & WALDMAN, E. 2016. Spiritual Needs of Families With Bereavement and Loss of an Infant in the Neonatal Intensive Care Unit: A Qualitative Study. *Journal Of Pain And Symptom Management,* 52**,** 35-42.

SARHILL, N., LEGRAND, S., ISLAMBOULI, R., DAVIS, M. P. & WALSH, D. 2001. The terminally ill Muslim: Death and dying from the Muslim perspective. *American Journal of Hospice and Palliative Medicine®,* 18**,** 251-255.

SEECHARAN, G. A., ANDRESEN, E. M., NORRIS, K. & TOCE, S. S. 2004. Parents' assessment of quality of care and grief following a child's death. *Archives of Pediatrics & Adolescent Medicine,* 158**,** 515-520.

SEOW, H., BAINBRIDGE, D., BROUWERS, M., POND, G. & CAIRNEY, J. 2017. Validation of a modified VOICES survey to measure end-of-life care quality: the CaregiverVoice survey. *BMC Palliative Care,* 16**,** 44.

SEOW, H., BAINBRIDGE, D., BRYANT, D., GUTHRIE, D., UROWITZ, S. & ZWICKER, V. 2016a. The CaregiverVoice survey: A pilot study surveying bereaved caregivers to measure the caregiver and patient experience at end-of-life. *J Pall Med,* 19**,** 712-719.

SEOW, H., BAINBRIDGE, D., BRYANT, D., GUTHRIE, D., UROWITZ, S., ZWICKER, V. & MARSHALL, D. 2016b. The CaregiverVoice Survey: A Pilot Study Surveying Bereaved Caregivers To Measure the Caregiver and Patient Experience at End of Life. *Journal of Palliative Medicine,* 19**,** 712-719.

SERLACHIUS, A., HAMES, J., JUTH, V., GARTON, D., ROWLEY, S. & PETRIE, K. J. 2018. Parental experiences of family-centred care from admission to discharge in the neonatal intensive care unit. *Journal of Paediatrics and Child Health,* 54**,** 1227-1233.

SHAMIEH, O. & HUI, D. 2015. A Comprehensive Palliative Care Program at a Tertiary Cancer Center in Jordan. *American Journal of Hospice and Palliative Medicine®,* 32**,** 238-242.

SHARMAN, M., MEERT, K. L. & SARNAIK, A. P. 2005. What influences parents' decisions to limit or withdraw life support? *Pediatric Critical Care Medicine: A Journal Of The Society Of Critical Care Medicine And The World Federation Of Pediatric Intensive And Critical Care Societies,* 6**,** 513-518.

SHEIKH, A. 1998. Death and Dying—a Muslim Perspective. *Journal of the Royal Society of Medicine,* 91**,** 138-140.

SILBERMANN, M., ARNAOUT, M., DAHER, M., NESTOROS, S., PITSILLIDES, B., CHARALAMBOUS, H., GULTEKIN, M., FAHMI, R., MOSTAFA, K. A. H., KHLEIF, A. D., MANASRAH, N. & OBERMAN, A. 2012. Palliative cancer care in Middle Eastern countries: accomplishments and challenges. *Annals of Oncology,* 23**,** iii15-iii28.

SILBERMANN, M., FINK, R. M., MIN, S.-J., MANCUSO, M. P., BRANT, J., HAJJAR, R., AL-ALFI, N., BAIDER, L., TURKER, I., ELSHAMY, K., GHRAYEB, I., AL-JADIRY, M., KHADER, K., KAV, S., CHARALAMBOUS, H., USLU, R., KEBUDI, R., BARSELA, G., KURUKU, N., MUTAFOGLU, K., OZALP-SENEL, G., OBERMAN, A., KISLEV, L., KHLEIF, M., KEOPPI, N., NESTOROS, S., ABDALLA, R. F., RASSOULI, M., MORAG, A., SABAR, R., NIMRI, O., AL-QADIRE, M., AL-KHALAILEH, M., TAYYEM, M., DOUMIT, M., PUNJWANI, R., RASHEED, O., FALLATAH, F., CAN, G., AHMED, J. & STRODE, D. 2015. Evaluating palliative care needs in Middle Eastern countries. *Journal Of Palliative Medicine,* 18**,** 18-25.

SILBERMANN, M. & HASSAN, E. A. 2011. Cultural Perspectives in Cancer Care: Impact of Islamic Traditions and Practices in Middle Eastern Countries. *Journal of Pediatric Hematology/Oncology,* 33.

SINCLAIR, S., NORRIS, J. M., MCCONNELL, S. J., CHOCHINOV, H. M., HACK, T. F., HAGEN, N. A., MCCLEMENT, S. & BOUCHAL, S. R. 2016. Compassion: a scoping review of the healthcare literature. *BMC Palliative Care,* 15.

SINGER, E. & BOSSARTE, R. M. 2006. Incentives for survey participation when are they "coercive"? *Am J Prev Med,* 31**,** 411-8.

SISK, B. A., MACK, J. W., ASHWORTH, R. & DUBOIS, J. 2018. Communication in pediatric oncology: State of the field and research agenda. *Pediatr Blood Cancer,* 65.

SOUSA, V. D. & ROJJANASRIRAT, W. 2011. Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline. *Journal of Evaluation in Clinical Practice,* 17**,** 268-274.

SOUZA, A. C., ALEXANDRE, N. M. C. & GUIRARDELLO, E. B. 2017. Psychometric properties in instruments evaluation of reliability and validity. *Epidemiol Serv Saude,* 26**,** 649-659.

SPERBER, A. D. 2004. Translation and validation of study instruments for cross-cultural research. *Gastroenterology,* 126**,** S124-S128.

STALEY, K. 2009. Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research. INVOLVE, Eastleigh.

STANISZEWSKA, S., HAYWOOD, K. L., BRETT, J. & TUTTON, L. 2012. Patient and Public Involvement in Patient-Reported Outcome Measures. *The Patient: Patient-Centered Outcomes Research,* 5**,** 79-87.

STJERNSWÄRD, J., FERRIS, F. D., KHLEIF, S. N., JAMOUS, W., TREISH, I. M., MILHEM, M., BUSHNAQ, M., AL KHATEIB, A., AL SHTIAT, M. N., WHEELER, M. S. & ALWAN, A. 2007. Jordan Palliative Care Initiative: A WHO Demonstration Project. *Journal of Pain and Symptom Management,* 33**,** 628-633.

STREINER, D. L. & NORMAN, G. R. 2008. *Health measurement scales: a practical guide to the development and use,* New York, Oxford University Press.

SULLIVAN, J. & MONAGLE, P. 2011. Bereaved Parents' Perceptions of the Autopsy Examination of Their Child. *Pediatrics,* 127**,** e1013-e1020.

TAN, J. S., DOCHERTY, S. L., BARFIELD, R. & BRANDON, D. H. 2012. Addressing parental bereavement support needs at the end of life for infants with complex chronic conditions. *Journal of Palliative Medicine,* 15**,** 579-584.

TANG, S. T. & MCCORKLE, R. 2002. Use of family proxies in quality of life research for cancer patients at the end of life: a literature review. *Cancer Invest,* 20**,** 1086-104.

TASHAKKORI, A. & TEDDLIE, C. 2010. *SAGE Handbook of Mixed Methods in Social & Behavioral Research*, SAGE Publications.

THE MINISTRY OF HEALTH HASHEMITE KINGDOM OF JORDAN (MOH) 2015a. Cancer Incidence in Jordan - 2015.

THE MINISTRY OF HEALTH HASHEMITE KINGDOM OF JORDAN (MOH) 2015b. Mortality Data in Jordan 2015

THE UNIVERSITY OF SOUTHAMPTON. 2018a. *Research Data Management: Destruction* [Online]. Available: http://library.soton.ac.uk/researchdata/destruction [Accessed].

THE UNIVERSITY OF SOUTHAMPTON. 2018b. *Research Data Management: Storing your data* [Online]. Available: http://library.soton.ac.uk/researchdata/home [Accessed].

THIENPRAYOON, R., GROSSOEHME, D., HUMPHREY, L., PESTIAN, T., FRIMPONG-MANSO, M., MALCOLM, H., KITAMURA, E., JENKINS, R. & FRIEBERT, S. 2020. 'There's just no way to help, and they did' Parents name compassionate care as a new domain of quality in pediatric home-based hospice and palliative care. *Journal of Palliative Medicine,* 23**,** 767-776.

TOGETHER FOR SHORT LIVES 2018. A Guide to Children's Palliative Care. 4th ed. Bristol.

TOMLINSON, D., BARTELS, U., HENDERSHOT, E., CONSTATIN, J., WRATHALL, G. & SUNG, L. 2007. Challenges to participation in paediatric palliative care research: a review of the literature. *Palliative Medicine,* 21**,** 435-440.

TOURANGEAU, R. 1984. Cognitive sciences and survey methods. *In:* JABINE, T. B., STRAF, M. L., TANUR, J. M. & TOURANGEAU, R. (eds.) *Cognitive aspects of survey methodology: Building a bridge between disciplines.* Washington: National Academies Press.

TOURANGEAU, R. & RASINSKI, K. A. 1988. Cognitive processes underlying context effects in attitude measurement. *Psychological bulletin,* 103**,** 299.

TRICCO, A. C., LILLIE, E., ZARIN, W., O'BRIEN, K. K., COLQUHOUN, H., LEVAC, D., MOHER, D., PETERS, M. D. J., HORSLEY, T., WEEKS, L., HEMPEL, S., AKL, E. A., CHANG, C., MCGOWAN, J., STEWART, L., HARTLING, L., ALDCROFT, A., WILSON, M. G., GARRITTY, C., LEWIN, S., GODFREY, C. M., MACDONALD, M. T., LANGLOIS, E. V., SOARES-WEISER, K., MORIARTY, J., CLIFFORD, T., TUNCALP, O. & STRAUS, S. E. 2018. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med,* 169**,** 467-473.

TURCHI, R. M. & ANTONELLI, R. C. 2014. Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. *PEDIATRICS,* 133**,** e1451-e1460.

TURNER, R. R., QUITTNER, A. L., PARASURAMAN, B. M., KALLICH, J. D. & CLEELAND, C. S. 2007. Patient-reported outcomes: instrument development and selection issues. *Value Health,* 10 S86-93.

TWYCROSS, A., PARKER, R., WILLIAMS, A. & GIBSON, F. 2015. Cancer-related pain and pain management: sources, prevalence, and the experiences of children and parents. *Journal of Pediatric Oncology Nursing,* 32**,** 369-384.

UNITED NATIONS INTER-AGENCY GROUP FOR CHILD MORTALITY ESTIMATION (UN IGME) 2020. Levels and Trends in Child Mortality: 2020 Report. New York, USA: United Nations Children's Fund (UNICEF).

UPADHYAY, U. D. & LIPKOVICH, H. 2020. Using online technologies to improve diversity and inclusion in cognitive interviews with young people. *BMC Medical Research Methodology,* 20.

VAN DYKE, N. 2009. Methodological issues in the design and conduct of public health computer assisted telephone interview surveys: The case of informal carers in Australia. *Australian Journal of Primary Health,* 15**,** 132-138.

VAN WIDENFELT, B. M., TREFFERS, P. D. A., DE BEURS, E., SIEBELINK, B. M. & KOUDIJS, E. 2005. Translation and Cross-Cultural Adaptation of Assessment Instruments Used in Psychological Research With Children and Families. *Clinical Child and Family Psychology Review,* 8**,** 135-147.

VIRDUN, C., BROWN, N., PHILLIPS, J., LUCKETT, T., AGAR, M., GREEN, A. & DAVIDSON, P. M. 2015. Elements of optimal paediatric palliative care for children and young people: An integrative review using a systematic approach. *Collegian,* 22**,** 421-431.

VON LUTZAU, P., OTTO, M., HECHLER, T., METZING, S., WOLFE, J. & ZERNIKOW, B. 2012. Children Dying from Cancer: Parents' perspectives on symptoms, quality of life, characteristics of death, and end-of-life decisions. *J PALLIAT CARE,* 28**,** 274.

WALDMAN, E. & WOLFE, J. 2013. High symptom burden in children with cancer and high parental satisfaction: why the disconnect? *Annals Of Palliative Medicine,* 2**,** 54-55.

WALLIN, A. E., STEINECK, G., NYBERG, T. & KREICBERGS, U. 2016. Insufficient communication and anxiety in cancer-bereaved siblings: A nationwide long-term follow-up. *Palliative & supportive care,* 14**,** 488-494.

WALTZ, C. F. D. P. R. N. F., STRICKLAND, O. L. D. P. R. N. F. & LENZ, E. R. D. P. R. N. F. 2010. *Measurement in Nursing and Health Research : Fourth Edition,* New York, UNITED STATES, Springer Publishing Company.

WANG, W.-L., LEE, H.-L. & FETZER, S. J. 2006. Challenges and Strategies of Instrument Translation. *Western Journal of Nursing Research,* 28**,** 310-321.

WATTANAPISIT, S., WAGLAND, R. & HUNT, K. 2020. Prognostic disclosure and quality of life in palliative care: a systematic review. *BMJ Supportive &amp; Palliative Care***,** bmjspcare-2020-002460.

WEIDNER, N. J., CAMERON, M., LEE, R. C., MCBRIDE, J., MATHIAS, E. J. & BYCZKOWSKI, T. L. 2011. End-of-life care for the dying child: What matters most to parents. *Journal of Palliative Care,* 27**,** 279-286.

WIDGER, K. & PICOT, C. 2008. Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatric Nursing,* 34**,** 53-58.

WILKINS, K. L. & WOODGATE, R. L. 2005. A review of qualitative research on the childhood cancer experience from the perspective of siblings: a need to give them a voice. *J Pediatr Oncol Nurs,* 22**,** 305-19.

WILLIS, G. 2006. Cognitive interviewing as a tool for improving the informed consent process. *Journal Of Empirical Research On Human Research Ethics: JERHRE,* 1**,** 9-24.

WILLIS, G. 2016. Questionnaire Pretesting. *In:* WOLF, C., JOYE, D., SMITH, T. & FU, Y. (eds.) *The SAGE Handbook of Survey Methodology.* London: SAGE Publications.

WILSON, D. C. 1988. The ultimate loss: The dying child. *Loss, Grief & Care,* 2**,** 125-130.

WOHLEBER, A. M., MCKITRICK, D. S. & DAVIS, S. E. 2012. Designing Research With Hospice and Palliative Care Populations. *American Journal of Hospice & Palliative Medicine,* 29**,** 335-345.

WOLF, C., JOYE, D., SMITH, T. & FU, Y.-C. 2016. *The SAGE Handbook of Survey Methodology,* London, UNITED KINGDOM, SAGE Publications.

WOLF, H. K., KUULASMAA, K., TOLONEN, H., SANS, S., MOLARIUS, A. & EASTWOOD, B. J. 2005. Effect of sampling frames on response rates in the WHO MONICA risk factor surveys. *European Journal of Epidemiology,* 20**,** 293-299.

WOLFE, J., GRIER, H. E., KLAR, N., LEVIN, S. B., ELLENBOGEN, J. M., SALEM-SCHATZ, S., EMANUEL, E. J. & WEEKS, J. C. 2000. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med,* 342**,** 326-33.

WORLD HEALTH ORGANIZATION (WHO). 1998. *Cancer pain relief and palliative care in children* [Online]. Available: http://apps.who.int/iris/bitstream/10665/42001/1/9241545127.pdf [Accessed 10 April 2017].

WORLD HEALTH ORGANIZATION (WHO). 2007. *Process of translation and adaptation of instruments* [Online]. Available: https://www.who.int/substance_abuse/research_tools/translation/en/# [Accessed].

WORLD HEALTH ORGANIZATION (WHO). 2017. *WHO Definition of Palliative Care* [Online]. Available: http://www.who.int/cancer/palliative/definition/en/ [Accessed 15 Apr. 2017].

WORLD HEALTH ORGANIZATION (WHO). 2018a. *Standards for improving the quality of care for children and young adolescents in health facilities* [Online]. Available: http://apps.who.int/iris/bitstream/handle/10665/272346/9789241565554-eng.pdf?ua=1 [Accessed].

WORLD HEALTH ORGANIZATION (WHO). 2018b. *What is the quality of care and why is it important?* [Online]. Available: https://www.who.int/maternal_child_adolescent/topics/quality-of-care/definition/en/ [Accessed].

WORLD HEALTH ORGANIZATION (WHO). 2019. *Children: reducing mortality* [Online]. Available: http://www.who.int/mediacentre/factsheets/fs178/en/ [Accessed November 2019].

WORLDOMETER.INFO. 2020. *Jordan Population* [Online]. Available: https://www.worldometers.info/world-population/jordan-population/ [Accessed 04/03/2020].

XAFIS, V., WILKINSON, D. & SULLIVAN, J. 2015. What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback. *BMC Palliative Care,* 14**,** 19-19.

YOUNGBLUT, J. M. & BROOTEN, D. 2012. Perinatal and pediatric issues in palliative and end-of-life care from the 2011 Summit on the Science of Compassion. *Nursing Outlook,* 60**,** 343-350.

YU, D. S. F., LEE, D. T. F. & WOO, J. 2004. Issues and Challenges of Instrument Translation. *Western Journal of Nursing Research,* 26**,** 307-320.

Appendices

Appendix A The themes brought from different sources

	QUALITATIVE ANALYSIS - PARENTS	**QUALITATIVE ANALYSIS - HCPs**	**INDUCTIVE THEMES FROM BLINDED ANALYSTS**	**LITERATURE THEMES**
SPACE	Place to stay: Room in ward Feeling at home Importance of environment Able to visit outside of visiting hours Place for child to stay, where necessary Place for siblings, suitable visitation etc. Allowed to come and go as they please towards EOL		Time and place to say goodbye Traumatic death – not having time and space to say goodbye Space to retreat to Belonging in the space or place	
	Feeling vulnerable			
INFORMATION	Staying updated Wanting to be aware of all information Getting too much information Up to date information Constant information Timing of palliative care conversation	Knowing what will happen (for instance re symptom control) Consistent, up-to-date information, not given all at once Knowing what services are available and what might happen	Managing information communication Personality type and managing information Organisational communication	Providing consistent, honest information about the child's condition with common language Being informed with the possible options Kept up to date about the specialised services, fundraising events and who to talk to Stay up-to-date with the child's activities and health condition Staff should frequently assess the parents' needs for information and providing information accordingly

The themes brought from different sources

	QUALITATIVE ANALYSIS - PARENTS	**QUALITATIVE ANALYSIS - HCPs**	**INDUCTIVE THEMES FROM BLINDED ANALYSTS**	**LITERATURE THEMES**
	Errors Treatment delays Negligence and failures			
CONTINUITY OF CARE – KEY PERSON CO-ORDINATION OF SERVICES AND ACCESS TO CARE	Continuity of care A person attached to them Trust and bond Relationship Named nurse Discontinuity of care at weekends and bank holidays – OOHs failures Knowing the system to get results Key responsible person = good care, no responsible person = bad care	Having some familiar caring for child Routine and rapport with staff Trust Staff knowing child's needs Good OOHs care, still possible to contact a HCP Coordination of services, so don't have to keep repeating things and minimises impact of HCPs in daily life	Key person	Difficult if regular staff members who know the child and family are unavailable Inflexibility of the booking system and frequent cancellation of regular respite/ hospice stays Difficulty in accessing tertiary paediatric centre (for patients living in rural areas) Out of hours access to health care professionals Coordination of care among interdisciplinary appointments and professionals Lack of a consistent caregiver or key worker especially with home care Sufficient provision of home care services to help parents manage care at home Digital health services to avoid long distance travelling An interesting finding was Continuity of care builds relationships

	QUALITATIVE ANALYSIS - PARENTS	**QUALITATIVE ANALYSIS - HCPs**	**INDUCTIVE THEMES FROM BLINDED ANALYSTS**	**LITERATURE THEMES**
				between parents and staff, enhances information sharing and care quality of care
COMMUNICATION	Opportunity to ask questions Being listened to Honesty with prognosis and bad news Breaking bad news	Listening to parents Listening- not being fobbed off.	Competence of and trust in HCPs Trust in HCP Mistrust in HCP Mistrust in HCP	Honest and sensitive interaction especially when delivering bad news Not impose care options but discuss the available options Poor communication frequently associated with language barrier specifically when informing parents that their child is dying
DECISION-MAKING	Parental choice in decision-making Choice at EOL Being able to trust you own judgement Parental choice Options about where to be at EOL Treatment decisions	Have control over decisions Give parents as much control as possible – medications, when, equipment Being listened to – wishes heard Being involved in decisions about care and no decisions made they didn't want Choice over place of death		Parents as child's advocate and should be being actively involved in decision-making process Challenging issues concerning decision-making: redirecting child to different services, transferring to adult services especially for children with special needs, planning place of death and having an advance care

The themes brought from different sources

	QUALITATIVE ANALYSIS - PARENTS	QUALITATIVE ANALYSIS - HCPs	INDUCTIVE THEMES FROM BLINDED ANALYSTS	LITERATURE THEMES
				plan for the time of death.
	Last hours of life		Symptom management	
	Have questions related to settings: PICU/NICU/Hospice			
PARENTING – PARENTAL ROLE	Being able to parent Parenting Being able to be a parent Importance of role as a mother Maintaining parental role Ensuring QOL- good parenting	Still being able to be the parent when child in hospital, even in high care	Being trusted parenting in public	Respecting the parents' role as providers and knowledge experts for their child
HOURS AROUND DEATH	Care immediately after death : hours surrounding death Space and time after death Choice at EOL Enough time Funeral planning Having cool bed Having cool room How long to keep the child Hours around death Separate room Cool room Cool bed Staff seeing child for who they are, even after death Meeting with clinical team in days after death Actions: Bathing Clothes Memories Doing important things after death	Organ donation can help coping after death		Spending more time with the child without being rushed Enough privacy Sacred environment Assist in bathing or dressing after death Support with logistics following home death
RELATIONSHIPS - CARE	Parents as units of care Listening to parents Parents as experts Community of parents	Really being there for the whole family Support to get through the day (for those "least resilient") Good relationships with HCPs Support for both parents, not just the mother		Trusting bonds with HCPs and being there for the family
AFTERCARE - BEREAVEMENT	Aftercare/bereavement Direct bereavement support Support after bereavement	Being with families after death		Continued bereavement support by staff

	QUALITATIVE ANALYSIS - PARENTS	**QUALITATIVE ANALYSIS - HCPs**	**INDUCTIVE THEMES FROM BLINDED ANALYSTS**	**LITERATURE THEMES**
	Accessible HCP in bereavement Voluntary sector bereavement support Continued support from GP, also for siblings Remembering days Acknowledgement or recognition of grandparent grief and the impact on parents Lack of support from HCPs and other agencies (allowances stopped for disabled child, no support with sorting things out)	Having a hug Remembering families Continuity after death Connecting with other families		who cared for child and knew all family members Anticipatory bereavement support Support from religious leaders
PREPARING ON WHAT IS TO COME (CAN ALSO GO IN INFORMATION SECTION)	Being made aware of what it will be like/ anticipatory Prepping for what it might be like Have information to prepare Knowledge of what to expect			
	Sharing experiences with other parents			
TRUST IN HCPS	Did you trust your HCPS to make the right decisions for you? Lack of confidence in staff		Competence of and trust in HCPs Trust in HCP Mistrust in HCP Mistrust in HCP	Paediatric expertise especially in hospice and home care services Knowledgeable and experienced staff
UNDERSTAFFING - OVERCROWDING	Understaffing/overcrowding Disparity of quality of nurses Understaffing Lack of confidence in staff General paeds wards – poor care Fear of generalist service Lack of training of staff – particularly in special needs	Enough care, no neglect		
PERSONALISED CARE	Connections with child Personalised care Making time for human caring interactions Connecting with child Connecting with parents Acknowledgement of enormity of situation	Feel child is safe in hands of HCPs Seeing the child for who they are, getting to know the child Love and real caring	Legacy Child as a person	Recognising the child as a human being and direct interaction with child is compassionate care

The themes brought from different sources

	QUALITATIVE ANALYSIS - PARENTS	**QUALITATIVE ANALYSIS - HCPs**	**INDUCTIVE THEMES FROM BLINDED ANALYSTS**	**LITERATURE THEMES**
		Child matters, is important "the most special" Attention and time, not being rushed		Engaging with the child during all interactions, even treatment administration
CARE FOR PARENT	Neglected health of mother Care for the parent Did you feel care for as a parent? Did you feel you were able to carry out your role as a parent Support to tell child they are dying Acts of kindness & keeping parents going (e.g. bringing parents cups of tea	Just being there with them while it is happening Reading the room (as parents won't speak up) Routine important Listening- not being fobbed off. Treating family as family		Lack of financial support Professional psychological support Spiritual support and support from religious leaders before and after death
TOUCH	Not being able to touch the child Not being able to touch Seeking permission to hold Holding Staff encouraging parents to get into bed with child in PICU Facilitating cuddles with child for parents		Touch and holding of the body	
MAKING MEMORIES	Making memories (teddy photo) Nurse platted child's hair and cut it off to keep			Creating monuments (foot or hand prints)
INTERACTIONS WITH HCPS	Concerns about being a complainer as a mother Acknowledging presence Part of the care situation Being believed Parental choice Sensitivity and humanity after death Seeking permission to hold Not feeling a bother Respecting / trust as experts about their child Parents as experts	Avoid the feeling of 'being discharged' by providers of active treatment when palliative care team step in		
	GP coming to home – and continued support Being 'discharged' from active care and moved to palliative care means loss of relationships with staff Parental voice and opinion listened to and respected			

	QUALITATIVE ANALYSIS - PARENTS	**QUALITATIVE ANALYSIS - HCPs**	**INDUCTIVE THEMES FROM BLINDED ANALYSTS**	**LITERATURE THEMES**
	Children being special			
SIBLINGS	Impact on siblings Support for siblings (and emotional) How to break bad news to siblings Support for the siblings Support for the child Arrangements for care for sibs	Care for siblings (e.g. organising play scheme) Care for others: Dad, grandparents Recognising and addressing siblings' needs		Support for healthy siblings such as access to playrooms during hospital visits, provision of emotional support, respected by the staff, informed about disease trajectory and involved in the ill child's care Special consideration with school assignments and absenteeism
CHILD WITH COMPLEX NEEDS	Stress of caring for child with complex needs Importance of care for child at home Support from school Grandparents Ensuring QOL- good parenting Time + support to make decisions Grow confidence Learning new skills Sufficient OT/PT support Required equipment provided in timely manner Support for child to stay at home Training and support to care for complex needs Treatment burden on parents, may be in charge of complex care			
LEARNING DIFFICULTIES	Discrimination of those with learning disabilities Child with learning disabilities not rates as highly as other children Judgement about QOL in relation to disabilities			
INSENSITIVE REMARKS	HCPS saying insensitive things.			
SYMPTOM CARE		Good symptom control		Good pain management

The themes brought from different sources

	QUALITATIVE ANALYSIS - PARENTS	QUALITATIVE ANALYSIS - HCPs	INDUCTIVE THEMES FROM BLINDED ANALYSTS	LITERATURE THEMES
		Anticipatory care around symptoms Making sure parents know what to expect		Emotional support for the child, especially during pain

Appendix B**Search strategy for CINAHL**

Population	S1	(MH "Intensive Care Units, Pediatric") OR (MH "Hospitals, Pediatric") OR (MH "Pediatric Units") OR (MH "Childhood Neoplasms") OR (MH "Pediatric Oncology Nursing") OR (MH "Association of Pediatric Oncology Nurses") OR (MH "Pediatric Cardiology") OR (MH "Pediatric Nurse Practitioners") OR (MH "Child, Hospitalized")OR (MH "Adolescent, Hospitalized")
	S2	TI (child* or pedatric* or paediatric* or adolescent*) OR AB (child* or pedatric* or paediatric* or adolescent*)
	S3 (S1 OR S2)	
Exposure	S4	(MH "Palliative Care") OR (MH "Hospice and Palliative Nursing") OR (MH "Cancer Care Facilities") OR (MH "Hospice Patients") OR (MH "Hospice and Palliative Nursing") OR (MH "National Association for Home Care & Hospice") OR (MH "Hospice and Palliative Nurses Association") OR (MH "Hospice Care") OR (MH "Hospices") OR (MH "Terminal Care") OR (MH "Terminally Ill Patients") OR (MH "Cancer Care Facilities")
	S5	TI (end N2 (life)) OR AB (end N2 (life)) OR TI (terminal N1 (car* or illness*)) OR AB (terminal N1 (car* or illness*)) OR TI (palliative N1(car* or service*)) OR AB (palliative N1(car* or service*)) OR TI (Hospice N1 (car* or service*)) OR AB (Hospice N1 (car* or service*))
	S6 (S4 or S5	
Outcome	S7	(MH "Quality of Health Care") OR (MH "Quality of Nursing Care") OR (MH "Quality of Care Research")
	S8	TI (quality N2(car*)) OR AB (quality N2(car*))
	S9 (S7 or S8)	

Appendix C**Data extraction form**

Data extraction field	**Information extracted**
Context and participants	Detailed information is extracted on the study setting, participants, the intervention delivered etc. This may aid later interpretation and synthesis by helping to retain the context in which the data are embedded. For example, it may be important to know whether a particular issue emerged from data collection with nurses or doctors or whether there was variation in views across settings, such as respondents interviewed in care homes and those interviewed at home. If context is lost during the synthesis process, the findings of the primary studies may be misinterpreted. To avoid this, referral back to the original papers may be used alongside extracted data during the analysis process.
Study design and methods used	This includes the methodological approach taken by the study; the specific data collection and analysis methods utilized; and any theoretical models used to interpret or contextualize the findings. The data extraction approach, and therefore the data extraction template, may need to be flexible so as to accommodate data collected within different qualitative methodologies (ethnography, phenomenology etc.) and using different methods (interview, focus groups, observations, document analysis etc.).
Context and participants	Detailed information is extracted on the study setting, participants, the intervention delivered etc. This may aid later interpretation and synthesis by helping to retain the context in which the data are embedded. For example, it may be important to know whether a particular issue emerged from data collection with nurses or doctors or whether there was variation in views across settings, such as respondents interviewed in care homes and those interviewed at home. If context is lost during the synthesis process, the findings of the primary studies may be misinterpreted. To avoid this, referral back to the original papers may be used alongside extracted data during the analysis process.

Appendix D **Papers included in the review**

Paper	Aim	Methods	Sample	Findings
James and Johnson (1997)	Investigate the parents perceptions regarding their needs while their child is dying with cancer because the gap in literature was parental accounts, instead of healthcare professionals, regarding their needs during palliative care phase	Authors used semi-structured interviews with open-ended questions (qualitative study).	The sample included eleven parents of eight children died from cancer 1 to 3 years before the study were invited to the study who speak and understand English, and resided in specific area in Canada. The physicians eliminated 19 families (emotional instability, unable to locate, unknown)	The authors recognised three main themes; first, maintaining normal life for the child while being recognised as special, The second theme was the need to feel cared for and respected, sensitive consistent and empathetic delivery of information. Thirdly, retain parenting responsibility; continuing caregiving to the child with medical advice, being informed to manage the child's condition, continue caring of other children and managing home and career which is manifested by the need for occasional respite care

Papers included in the review

Paper	Aim	Methods	Sample	Findings
Contro et al 2002	To obtain personal accounts of families experiences and suggestion to improve palliative care	Interviews; Yes/ no or Likert scale questions. The parents were allowed to elaborate and bring out new issues.	Sixty-eight parents representing forty-four children who received treatment at children hospital in California 6-30 months period between the death and the interviews.	Parents reported insensitive communication especially when delivering a bad news, feeling patronised, their judgments were disregarded, lack of support for siblings' needs and ineffective pain management especially at home.

Paper	Aim	Methods	Sample	Findings
Davies and Connaughty 2002	Not stated	The parental questionnaire consisted of 21 questions, most requiring both a response to a summated Likert-type scale and a descriptive response enabling parents to document details related to their experience in their own words about the support they received on the day their child died and since the death.	45 parents of children who died during a 2-year period in a regional children's hospital in San Francisco, USA.	Parents perceived that staff lacked compassion and were so focused on cure and treatment that they were unable to interact effectively or support parents whose child was not curable. Parents suggest that staff frequently anticipate parents' needs for information and offer information accordingly.
Meyer et al 2002	The purpose of this study was to examine the perspectives and priorities of parents for improved end-of-life care in the PICU.	Questionnaire; 28 Likert scale and five open ended-questions Quantitative	Fifty-six parents representing 56 out of 96 eligible families from three paediatric hospitals in Boston	The parents reported poor pain management and lack of sense of control (decision-making). Most of the parents were well informed and socially supported by their families and friends. In addition, parents reported the availability of religious support.

Papers included in the review

Paper	Aim	Methods	Sample	Findings
Seecharan et al 2004	To assess parental grief and satisfaction with their child's care and to compare these aspects by parent sex, type of death, and overall experience.	Quantitative study (based on qualitative phase which is not mentioned in this paper) In-depth interviews using two validated questionnaires to assess the quality and satisfaction with paediatric palliative care	79 parents or legal guardians of 59 children who died between January 1998 and December 2000 (sudden or anticipated death) in one hospital. USA	Most parents demonstrated high levels of satisfaction with middle range of grieve. Study showed that mothers have more prolonged grief especially in unexpected deaths Mothers with positive experiences reported higher scores of satisfaction, the most important aspects of care were pain management, communication and bereavement support

Paper	Aim	Methods	Sample	Findings
Heller and Solomon (2005)	Investigate bereaved parents needs and concerns regarding the care of children with life-threatening in particular during the child's last hospitalization and dying process and how would healthcare providers address these needs (focusing on continuity of care)	Semi-structured interviews by phone with open-ended questions 23 items Qualitative	36 parents of children died 3-10 months prior the interviews from 3 hospitals in the USA	Continuity Builds humans Relationships and Promotes Caring (consistent caregiver), parents and child are being recognised as a human being, continuity of care enhance information and expertise sharing, negative experiences usually happened due poor continuity of care (familiar staff were not available), staff are being there through and after child's death
Maynard et al (2005)	To report exploring parents' experiences regarding the services delivered in three hospice sites (quality assurance initiative).	Semi-structured interviews for six focus groups based on previous series of parent groups. Qualitative methods	Twenty-nine parents of children used three hospice care sites in UK (formed 2 Focus group discussions in each hospice centre)	Parents reported dissatisfaction with the communication process and information about the available services The parents expressed their concerns regarding the unmet needs of siblings, transition to adult services and support services for foster carers and adoptive parents

Papers included in the review

Paper	Aim	Methods	Sample	Findings
Meyer et al (2006)	Identify the parents' views of the priorities for end of life care and recommendations for end of life care	Qualitative study reported the parents' responses to open-ended questions (four questions) from a designed questionnaire.	Fifty-six parents representing 56 out of 96 eligible families from three paediatric hospitals in Boston.12-45 months has elapsed after the child's death	The parents identified six priorities; communication and care coordination, access to staff, complete information, emotional expression, maintaining parent-child relationship and faith rituals
Monterosso et al (2007)	Obtain the views of the parents and service providers regarding the palliative care, barriers and facilitating factors associated with this care.	Mixed methods study. The authors utilised six questionnaires through telephone and face-to-face interviews for 129 parents. Then 38 semi-structured interviews were conducted by telephone or face to face.	129 parents participated in the study (out of 257 were contacted). Participants were identified through five centres in Western Australia. The participants were divided into two groups; cancer and non-cancer groups. Death happened 6-36 months prior the study	The emerged themes are: Caring impact on personal relationships among parents themselves and siblings, financial assistance, thorough information regarding the care, the parents' skills as a carer', access to services, and coordination issues The study explored the views of two groups and showed the significant differences in needs between the two groups

Paper	Aim	Methods	Sample	Findings
Monterosso and Kristjanson (2008)	Explore the bereaved parents' experiences during palliative care and their supportive care needs during the child's illness	A qualitative study used face-to-face or telephone semi-structured interviews	24 bereaved parents from five paediatric oncology centres in Western Australia. Death happened 6-36 months prior the study.	The parent's lack of understanding of the concepts of palliative care. The practical priorities in end of life care; dying at home and spending more time with the child, honest relationships with medical professionals (no false hope) The study provided in-depth parents' views regarding the practical issues of end of life care.
Widger K and Picot C (2008)	Describe the quality of end of life care delivered at the time of and afterwards the death.	The authors developed a questionnaire for the study. The questionnaire contained 14 domains and was reviewed by panel of experts. Quantitative	Forty-one parents representing 38 families who received services through Canadian tertiary centre and lost their child 12-24 months before the study	Parents' frequently reported communication and information needs as vital issues that need improvement. In addition, managing pain, sensitive healthcare professionals and after death counselling services. Parents expressed their wish to create memories for their child.

Papers included in the review

Paper	Aim	Methods	Sample	Findings
Heath et al (2009)	Investigate the bereaved parents satisfaction regarding the quality of care provided for their children with cancer	Semi-structured interviews and modified questionnaire to rate parental satisfaction with the care quantitative	96 parents of children died from cancer between 1996 and 2004 in a hospital in Australia.	The majority of parents were satisfied with the care provided by oncologists, nurses and other staff members, these ratings were associated with sensitive communication, clear information, and direct interaction with the child
Meert et al (2009)	Obtain in-depth understanding about the parents needs around paediatric deaths in PICU	: two phases qualitative study; first interviews with parents followed by focus groups – triangulated themes from the two sources were presented in the article	In interviews phase, 33 parents of children died in PICU 18 -36 months prior the study in USA. 13 parent of children died 10 months- 3.5 years prior to study were recruited for focus groups phase	Four categories of themes were identified: Elements of the category; Who I Am, While My Child Was Dying, My Child's Death and My bereavement journey

Paper	Aim	Methods	Sample	Findings
Monterosso et al (2009)	Identify the bereaved parents' of children who died from cancer perceptions regarding the provided care in hospital and community settings	Face-to-face or telephone questionnaires in three tertiary centres in Western Australia. The authors used four questionnaires. Quantitative	69 out of 207 eligible bereaved parents from three oncology centres. Death happened 6-36 months prior the study	The participants' perceived needs, using PCNS questionnaire, are; Carer needs; honest information regarding pain management and maintain the child's lifestyle. Service needs; access to services and available financial assistance Family needs; sincere relationships between family members and healthcare professionals
Inglin et al (2011)	Identifying the needs of families whose child receive palliative care among three diagnostic groups; cancer, neurobiological conditions and other conditions.	The authors used open-ended interviews Qualitative study.	Fifteen parents of children who received treatment in one of four hospitals in Switzerland. The death was within two years before the study	Parents' stressed the importance of honest communication, access to staff, home care services, and bereavement service's needs. The parents preferred home care services to spend more time with other children. The parents highlighted the struggling in coordination of services and appointments and the lack of psychosocial support for parents of children with non-oncological conditions. The study revealed the differences of needs among the three groups.

Papers included in the review

Paper	Aim	Methods	Sample	Findings
Weidner et al (2011)	To determine what are the essential dimensions of end of life care as reported by bereaved parents.	Semi-structured interviews by phone, face-to-face or focus groups (parents' choice). Qualitative	The participants were twenty-nine parents representing 20 families. Parents of children who died less than six months before the study were excluded. Participants from large hospital in Midwestern USA.	The resulted themes: Respecting the family's role in caring the child. Providing comfort. Spiritual care. Access to care and resources. Communication. Support parental decision-making. Humanisation.
Robert et al (2012)	Exploring the needs of the bereaved parents of children who received care at a national cancer centre in USA	A qualitative study, focus group interviews using an interview script containing five domains based on a literature review and consulting panel of experts.	Parents of 79 children who received care form the tertiary centre were eligible for the study. 14 parents from 9 families participated who lost a child one year, minimum, before the study.	According to the authors' interview two of the five themes; communication and emotional care, discussed in the interviews were mentioned more frequently than the other three; decision-making, spiritual care and symptom management. Two themes has emerged standards of care and social support.

Paper	Aim	Methods	Sample	Findings
Brooten et al (2013)	Describe parents perspectives of healthcare providers' actions that helped or did not around a child's death in ICU	Semi-structured interviews using a standardised protocol for this study in two languages, English and Spanish qualitative	63 parents of children died 7 months before the study in NICU (Neonatal Intensive Care Unit) or PICU (Paediatric Intensive Care Unit)from 4 hospitals in the USA	What helped most: compassionate, sensitive staff; understandable explanations of infant's/child's condition; experienced, competent nurses; providers did everything to help infant/ child; and parents' involvement in care decisions. What did not help: insensitive, non-supportive staff; conflict between providers and parents; communication problems around the death; inexperienced nurses and doctors; parents not understanding child's disease, care, complications
Elhalal et al (2013)	To evaluate the end of life care provided for terminally ill children as reported by their parents.	Semi-structured interviews after a meeting with the medical staff. Qualitative	Fifteen parents of nine children who died 6-12 months prior the study in two Brazilian PICUs.	Parents reported problematic communication, especially regarding the used terminology. Parents' participation in decision making was limited based on how well they were informed. Parents reported lack of privacy around the time of death

Papers included in the review

Paper	Aim	Methods	Sample	Findings
Lan and Yun (2015)	Gather parents' experiences and views of their children end of life care.	Focus groups and in-depth interviews. Qualitative	Thirteen parents of eight children participated in this study. The children received care in the Paediatric Department in a Malaysian hospital. Death happened 1-2 years before the interview	The parents' concerns were around Open communications with the patient, if applicable. Poor symptoms management. Choices the place of death. Lack of a key worker. Lack of a terminal plan. Practical issues after home death.

Appendix E **An example of quality assessment**

Very good 🟩 **moderate** 🟧 **poor** 🟥

Paper Elhalal et al (2013)

	Quantitative	**Qualitative**	**Yes** **2**	**Not clear** **1**	**No** **0**
1.	Does the title reflect the content?		X		
2.	Are the authors credible?		X		
3.	Does the abstract summarize the key points?		X		
4.	Is the rationale for undertaking the research clearly outlined?		X		
5.	Is the literature review comprehensive and up to date?		X		
6.	Is the aim of the research clearly stated?		X		
7.	Are the ethical issues identified and addressed?		X		
8.	Is methodology identified and justified			X	
9.	Is the study design clearly identified and is the rationale for choice of design evident?	Are the philosophical background and study design identified and the rationale for choice design evident?		X	
10.	Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	Are the major concepts identified?	X		
11.	Is the population identified	Is the context of the study outlined?	X		
12.	Is the sample adequately described and reflective of the population?	Is the selection of the participants described and the sampling method identified?	X		
13.	Is the method of data collection valid and reliable?	Is the method of data collection auditable?		X	
14.	Is the method of data analysis valid and reliable?	Is the method of data analysis credible and confirmable		X	
15.	Are the results presented in a way that is appropriate and clear		X		
16.	Are the results generalizable	Are the results transferable?		X	
17.	Is the discussion comprehensive		X		
18.	Is the conclusion comprehensive		X		
	Total /36……………………….		31/36		

Appendix F **Map of overall themes and frequencies from papers reviewed**

Paper's quality Very good 🟩 Moderate 🟧 Poor 🟥

Papers	**Interpersonal interaction**				**Interdisciplinary care for the child and family**							**Practical issues**		
	Quality of communication	Information delivery	Decision making	Relationships	Bereavement support	Quality of death	Siblings' needs	Emotional support	Physical symptoms management	Psychological support	Spiritual support	Access to care services	Competent staff	Financial support
🟩 James & Johnson (1997)	X	X	X	X	X		X	X				X		
🟧 Contro et al (2002)	X	X	X	X	X	X	X		X			X	X	
🟥 Davies and Connaughty (2002)	X	X		X	X	X		X				X		
🟩 Meyer et al (2002)		X	X		X				X	X	X			
🟩 Seecharan et al (2004)	X				X				X					
🟩 Heller and Solomon (2005)	X	X	X	X	X			X				X		
🟧 Maynard et al (2005)	X	X					X					X		X
🟩 Meyer et al (2006)	X	X	X			X		X			X	X		

Map of overall themes and frequencies from papers reviewed

Papers	Interpersonal interaction				Interdisciplinary care for the child and family							Practical issues		
	Quality of communication	Information delivery	Decision making	Relationships	Bereavement support	Quality of death	Siblings' needs	Emotional support	Physical symptoms management	Psychological support	Spiritual support	Access to care services	Competent staff	Financial support
Monterosso et al (2007)		X				X	X					X		X
Monterosso and Kristjanson (2008)	X	X		X		X			X					
Widger K and Picot C (2008)	X	X		X	X	X			X			X		
Heath et al (2009)	X	X		X								X		
Meert et al (2009)	X		X	X	X	X		X		X	X			
Monterosso et al (2009)		X		X			X					X		
Inglin et al (2011)	X	X	X		X					X		X		
Weidner et al (2011)	X	X	X	X	X		X	X			X	X		X
Robert et al (2012)	X	X	X	X	X	X	X	X				X	X	
Brooten et al (2013)	X	X	X	X								X	X	

Papers	**Interpersonal interaction**				**Interdisciplinary care for the child and family**							**Practical issues**		
	Quality of communication	Information delivery	Decision making	Relationships	Bereavement support	Quality of death	Siblings’ needs	Emotional support	Physical symptoms management	Psychological support	Spiritual support	Access to care services	Competent staff	Financial support
Elhalal et al (2013)	X	X	X			X								
Lan and Yun (2015)	X		X						X			X	X	
Frequency of themes (in high quality papers)	12	12	9	8	9	7	7	5	5	3	4	11	4	2

Appendix G Themes from the literature review

Themes	Description	Subthemes	Papers
Information	The healthcare professionals anticipate, provide the child and family with the details about the child's condition, prognosis and treatment options.	Providing consistent, honest information about the deterioration of child's health status	(Contro et al., 2002, Meyer et al., 2006, Inglin et al., 2011, Maynard et al., 2005, Meyer et al., 2002, Monterosso and Kristjanson, 2008, Monterosso et al., 2007, Monterosso et al., 2009, Robert et al., 2012, Weidner et al., 2011, Widger and Picot, 2008, Brooten et al., 2013, Davies and Connaughty, 2002, El Halal et al., 2013, Heath et al., 2009, Heller and Solomon, 2005, James and Johnson, 1997)
		Answering further questions	(Inglin et al., 2011, Brooten et al., 2013)
		Being up to date about the specialised services	(Maynard et al., 2005, Robert et al., 2012)
Communication **Communication**	This theme focuses on the way of delivering information and interaction among the child, family, and healthcare professional	Honest and sensitive interactions with carers.	(Contro et al., 2002, Lan and Yun, 2015, Inglin et al., 2011, Meyer et al., 2006, Monterosso and Kristjanson, 2008, Weidner et al., 2011, Widger and Picot, 2008, Brooten et al., 2013, El Halal et al., 2013, Heath et al., 2009, Robert et al., 2012, James and Johnson, 1997).

		Imposing options/ treatment rather than discussing them	(Brooten et al., 2013)
		Communicate with the child directly	(Heath et al., 2009)
		Communication among healthcare professionals	(Heller and Solomon, 2005, Widger and Picot, 2008)
Involvement in decision making	Patient and family participate in planning the place of care/death and having an advance care plan for the time of death based on their preferences	The child's care i.e. treatment and procedures	(Contro et al., 2002, Inglin et al., 2011, Meyer et al., 2002, Meyer et al., 2006, Brooten et al., 2013, El Halal et al., 2013, James and Johnson, 1997, Meert et al., 2009, Weidner et al., 2011).
		Redirecting the child to palliative care or different unit	(Weidner et al., 2011)
		Planning the place of death and having an advance care plan for the time of death	(Lan and Yun, 2015)
Relationships		Trusting bonds with the healthcare professionals	(Contro et al., 2002, Robert et al., 2012)
Relationships		Respecting the parents' role as care providers and knowledge experts for their child	(Weidner et al., 2011)

	Healthcare professionals develop compassionate and respectful bonds with the child and family; respect and support family members' roles and bonds with the child	Support and be there for the family	(Widger and Picot, 2008, Weidner et al., 2011, Davies and Connaughty, 2002).
		Respecting the child and providing humane care	(Weidner et al., 2011, Widger and Picot, 2008, Monterosso and Kristjanson, 2008, Monterosso et al., 2009, Davies and Connaughty, 2002, Heller and Solomon, 2005, Meert et al., 2009)
		Maintain parental role	(Meert et al., 2009, Robert et al., 2012)
Managing physical symptoms	The child experienced the minimum level of physical suffering and the physical symptoms were controlled adequately.	Alleviating physical discomfort	(Contro et al., 2002, Lan and Yun, 2015, Meyer et al., 2002, Monterosso and Kristjanson, 2008, Seecharan et al., 2004, Weidner et al., 2011, Widger and Picot, 2008)
Emotional support	The child, parents and family members have the opportunity to express their emotions.	Acknowledge the emotional needs and provide supportive environment	(Weidner et al., 2011, Davies and Connaughty, 2002, Heller and Solomon, 2005, James and Johnson, 1997, Meert et al., 2009)
Psychological support	Provision of professional psychological services	A psychologist is present to provide advice and support for child and family	(Meyer et al., 2006, Meyer et al., 2002, Inglin et al., 2011, Meert et al., 2009).
Quality of care at the time of death		Creating monuments (foot or handprints)	(Meert et al., 2009, Meyer et al., 2006, Widger and Picot, 2008)
		Assist in bathing or dressing after death	(Weidner et al., 2011)

	Parental accounts that relevant to the time of child's death and after it.	Spending more time with the child	(Meyer et al., 2006, Monterosso and Kristjanson, 2008, Davies and Connaughty, 2002, El Halal et al., 2013, Meert et al., 2009)
Bereavement services	This theme describes parents and family had the proper support after the child's death	Follow up bereavement services by the staff who knew the family for all family members	(Contro et al., 2002, Inglin et al., 2011, Weidner et al., 2011, Widger and Picot, 2008, Davies and Connaughty, 2002, Heller and Solomon, 2005, James and Johnson, 1997, Meert et al., 2009, Meyer et al., 2002, Seecharan et al., 2004).
		Parents expressed their wish to have an anticipatory bereavement support	(Robert et al., 2012).
Siblings' needs	This theme describes addressing and providing services or care for healthy siblings	Improving the services for healthy siblings such as access to playrooms during hospital visits	(Contro et al., 2002)
		Being respected from the staff	(Contro et al., 2002)
		Being informed about the disease trajectory and involved in ill child's care	(Monterosso et al., 2009).
		Providing emotional / bereavement support	(Weidner et al., 2011, Monterosso et al., 2007, Maynard et al., 2005, Robert et al., 2012)

Spiritual support	This theme focuses on parents' recognizing religious beliefs and receiving support from religious personnel	Respecting religious beliefs and customs	(Weidner et al., 2011, Meyer et al., 2006, Meyer et al., 2002, Meert et al., 2009)
Access to care services	The availability and sustainability of care from different healthcare professionals, out of regular hours	Consistent caregiver or keyworker	(Contro et al., 2002, Davies and Connaughty, 2002, Heller and Solomon, 2005, Inglin et al., 2011, Lan and Yun, 2015, Robert et al., 2012)
Access to care services		Difficulty to contact healthcare professional/ setting	(Heath et al., 2009, Monterosso et al., 2007, Monterosso et al., 2009)
		Flexibility of the booking system	(Maynard et al., 2005, Inglin et al., 2011, Monterosso et al., 2007)
		Continuity and coordination of care among interdisciplinary appointments and professionals themselves especially for children being cared at home	(Brooten et al., 2013, Heath et al., 2009, Heller and Solomon, 2005, Meyer et al., 2006, Robert et al., 2012, Widger and Picot, 2008, Inglin et al., 2011, James and Johnson, 1997, Weidner et al., 2011)
		Transferring the child to adult services	(Maynard et al., 2005)
Staff competency	Healthcare professionals are competent and used to work with	Experienced, knowledgeable practitioners	(Brooten et al., 2013, Contro et al., 2002, Lan and Yun, 2015, Robert et al., 2012)

	children at the end of life		
Financial support	This theme focuses on parents being able to fund the child's care.	Available financial resources	(Weidner et al., 2011, Monterosso et al., 2007, Maynard et al., 2005)

Appendix H The VOICE-SF questionnaire-Female version

VOICES

Views Of Informal Carers - Evaluation of Services

This questionnaire is about the care and services received by you and your friend/relative in the lastmonths of her life. The information you give will help us improve care for people who are dying, andfor their family and friends. Your views are, therefore, important to us.

We realise this questionnaire may bring back strong memories. If you feel upset or distressed, you donot have to continue with the questionnaire and can stop at any time.

We are interested in finding out the experiences of all people who have died whether suddenly, after a short illness, or after a long illness. We also think it is important to find out about the care you and the family received at the time of death and in the months since then. Some of the questions may not be relevant to you. Please fill in as much of the questionnaire as you can.

Your answers to these questions will be treated as strictly confidential. No names will be usedin the reports we write.

Instructions

As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box or boxes, like this ☑. If you make a mistake or wish to change youranswer, cross through the answer you do NOT want, like this ☒.

If you would rather not answer one of the questions, please go on to the next one.

We are very interested in what you have to say. Please continue on extra sheets if necessary.

Q1. How long had she been ill before she died?

Tick one only

☐ She was not ill - she died suddenly

☐ Less than 24 hours

☐ One day or more, but less than one week

☐ One week or more, but less than one month

☐ One month or more, but less than six months

☐ Six months or more but less than one year

☐ One year or more

If she died suddenly with no illness or time for care, **please go to Q38**.
Otherwise, please continue with the questions below.

Q2. Did she spend any time at home during the last three months of life?

Tick one only

☐ Yes - **go to Q3**

☐ She was in a care home for the whole 3 months – **go to Q12**

☐ No - **go to Q24**

Care at Home

These questions are about care at home – not in a care home.

Q3. When she was at home in the last three months of life, did she get any help at home from any of the services listed below?

These may be provided by different organisations, such as voluntary organisations, a private agency or social services

Tick all that apply

☐ A district or community nurse (a nurse in uniform who comes to the house)

☐ A Macmillan nurse, hospice home care nurse or specialist (a palliative care nurse who visits or telephones to talk and advise on medications and other aspects of care. They do not wear a uniform)

☐ A Marie Curie nurse (someone who comes to the house for a few hours or overnight to care for the patient).

☐ Any other nurse at home

☐ Home care worker, home care aide or home help

☐ Social worker / support worker

☐ Counsellor

☐ Religious leader

☐ Meals-on-wheels or other home delivered meals

☐ Hospice at home

☐ Occupational therapist (OT)

☐ Rapid response team (a team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)

☐ She did not receive any care

☐ Don’t know

☐ Something else – please write in the space below

____

____

Q4. When she was at home in the last three months of life, did all these services work well together?

Tick all that apply

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ She did not receive any care

☐ Don't know

Please feel free to make comments in the space below

____

____

____

____

Q5. Overall, do you feel that you and your family got as much help and support from these services as you needed when caring for her?

☐ Yes, we got as much support as we wanted

☐ Yes, we got some support but not as much as we wanted

☐ No, although we tried to get more help

☐ No, but we did not ask for more help

☐ We did not need help

Please feel free to make comments in the space below

____

____

____

____

Q6. During the last three months of her life, while she was at home, how well was her pain relieved?

Tick all that apply

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Please feel free to make comments in the space below

____

____

____

____

Urgent Care Provided Out of Hours

Q7. In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent in the evening or at the weekend?

Tick one only

☐ Not at all in the last 3 months -

go to Q12

☐ Once or twice - **go to Q8**

☐ Three or four times -**go to Q8**

☐ Five times or more - **go to Q8**

☐ Don’t know - **go to Q12**

Q8. The last time this happened, who did she contact, or who was contacted on her behalf?

Tick one only

☐ Her GP or the out-of-hours number

☐ NHS Direct

☐ District nurses

☐ Macmillan nurses

☐ She used her ‘lifeline’ pendant

☐ A hospice

☐ 999

☐ Something else- please write in the space below

____

____

____

Q9. What happened as a result? Was she

Tick one only

☐ Visited by her GP at home

☐ Visited by another GP at home

☐ Visited by a nurse at home

☐ Visited by a hospice doctor at home

☐ Given medical advice over the telephone

☐ Given another number to ring to get medical advice

☐ Advised to go to an out-of-hours GP surgery

☐ Advised to go to the GP surgery when it opened

☐ Advised to go to an Accident and Emergency Department at a hospital

☐ Advised to call 999

☐ Something else – please write in the space below:

____

____

Q10. In your opinion, was this the right thing for them to do, or not?

Tick one only

☐ Yes

☐ No

☐ Not sure

Q11. Overall, do you feel that the care she got when she needed care urgently in the evenings or weekends in the last three months of life was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don’t know

District and Community Nurses

If she had care in the last 3 months from community nurses **go to Q12**.

If she did not**; go to Q15**.

Q12. How often did the district or community nurses visit (at the most frequent time)?

Tick one only

☐ More than once a day

☐ Every day

☐ 2-6 times a week

☐ Once a week

☐ 2-3 times a month

☐ Less often

☐ Don't know

Q13. How much of the time was she treated with respect and dignity by the district and community nurses?

Tick one only

☐ Always

☐ Most of the time

☐ Some of the time

☐ Never

☐ Don't know

Q14. Overall, do you feel that the care she got from the district and community nurses in the last three months of life was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

Care from the GP

Q15. In the last 3 months, how often did she see the GP she preferred to see?

Tick one only

☐ Always or almost always

☐ A lot of the time

☐ Some of the time

☐ Never or almost never

☐ She didn't try to see a particular GP

☐ She did not need to see a GP – **go to Q20**

Q16. How much of the time was she treated with respect and dignity by the GPs?

Tick one only

☐ Always

☐ Most of the time

☐ Some of the time

☐ Never

☐ Don't know

Q17. Were you able to discuss any worries and fears you may have had about her condition, treatment or tests with the GPs?

Tick one only

☐ I had no worries or fears to discuss

☐ Yes, I discussed them as much as I wanted

☐ Yes, I discussed them, but not as much as I wanted

☐ No, although I tried to discuss them

☐ No, but I did not try to discuss them

Q18. Overall, if the GP visited her at home in the last three months, how easy or difficult was it to get him/her to visit?

Tick one only

☐ Very easy

☐ Fairly easy

☐ Fairly difficult

☐ Very difficult

☐ She wanted the GPs to visit but they would not visit

☐ Does not apply – the GP did not need to visit

☐ Don't know

Q19. Overall, do you feel that the care she got from the GP in the last three months of life was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

Please feel free to make comments in the space below

____

____

____

Care Homes

Q20. Did she live or stay in a care home at any time during her last three months of life?

☐ Yes, she was in a care home – please write the name of the care home in the space below:

____

☐ No – **go to Q24**

☐ Don't know – **go to Q24**

Q21. How much of the time was she treated with respect and dignity by the staff at the care home?

Tick one only

☐ Always

☐ Most of the time

☐ Some of the time

☐ Never

☐ Don't know

Q22. During the last three months of her life, while she was in the care home, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q23. Overall, do you feel that the care she got from the care home in the last three months of life was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

Last Hospital Admission

Q24. Did she stay in hospital at any time during her last three months of life?

Tick one only

☐ Yes – please write the name of the last hospital she stayed in, in the space below:

____

☐ No – **go to Q29**

☐ Don't know – **go to Q29**

Q25. During her last hospital admission, how much of the time was she treated with respect and dignity by the hospital doctors and nurses?

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q26. During this last hospital admission, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q27. Did the hospital services work well together with her GP and other services outside of the hospital?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ Don't know

Q28. Overall, do you feel that the care she got from the staff in the hospital on that admission was:

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don’t know

Last Hospice Admission

Q29. Did she stay in a hospice at any time during her last three months of life?

Tick one only

☐ Yes – please write the name of the last hospice she stayed in, in the space below:

____

____

☐ No – go to Q33

☐ Don’t know – go to Q33

Q30. How much of the time was she treated with respect and dignity by the hospice doctors and nurses?

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don’t know

Q31. During the last three months of her life, while she was in the hospice, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don’t know

Q32. Overall, do you feel that the care she got from the staff in the hospice was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don’t know

Experiences in Last 2 Days of Life

Q33. During her last two days of life was she:

Tick one only

☐ At home all the time

☐ In a care home all the time

☐ In a hospital all the time

☐ In a hospice all the time

☐ Other – please write in the space below:

____

____

Q34. How much of the time was she treated with respect and dignity in the last two days of life?

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don’t know

Q35. Please look at the following statements and tick the answer box that corresponds most with your opinion about the help she received in the last two days of life

Tick only one box for each question (a – c)

	Strongly Agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**Does not apply**	**Don’t know**
(a) There was enough help available to meet her personal care needs (such as toileting needs)	☐	☐	☐	☐	☐	☐	☐
(b) There was enough help with nursing care, such as giving medicine and helping her find a comfortable position in bed	☐	☐	☐	☐	☐	☐	☐
(c) The bed area and surrounding environment had adequate privacy for her	☐	☐	☐	☐	☐	☐	☐

Q36. During the last two days, how do you assess the overall level of support given in the following areas from those caring for her

Tick only one box for each question (a – e)

	Excellent	Good	Fair	Poor	Does not apply	I don't know
(a) Relief of pain	☐	☐	☐	☐	☐	☐
(b) Relief of symptoms other than pain	☐	☐	☐	☐	☐	☐
(c) Spiritual support	☐	☐	☐	☐	☐	☐
(d) Emotional support	☐	☐	☐	☐	☐	☐
(e) Support to stay where she wanted to be	☐	☐	☐	☐	☐	☐

Circumstances Surrounding Her Death

Q37. Did she know she was likely to die?

Tick one only

☐ Yes, certainly

☐ Yes, probably

☐ No, probably not

☐ No, definitely

☐ Not sure

Q38. In your opinion, did the person who told her she was likely to die break the news to you in a sensitive and caring way?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, not at all

☐ Don't know

☐ Does not apply – they did not know she was dying

☐ Does not apply – they did not tell her she was dying

Q39. Were you contacted soon enough to give you time to be with her before she died?

Tick one only

☐ Yes

☐ No

☐ I was there already

☐ It was not clear that she was going to die soon

☐ I couldn't have got there anyway

Q40. Where did she die?

☐ In her own home

☐ In the home of another family member or friend

☐ In a hospital ward – please write the name of the hospital in the space below:

____

____

☐ In a hospital Accident and Emergency Department – please write the name of the hospital in the space below:

____

____

☐ In a hospital Intensive Care Unit – please write the name of the hospital in the space below:

____

____

☐ In a hospice – please write the name of the hospice in the space below:

____

____

☐ In a care home – please write the name of the care home in the space below:

____

____

☐ In an ambulance on the way to hospital/ hospice

☐ Somewhere else – please write in the space below

____

____

Q41. Did she ever say where she would like to die?

Tick one only

☐ Yes – ***go to Q42***

☐ No – ***go to Q44***

☐ Not sure **– *go to Q44***

Q42. Where did she say that she would like to die?

Tick one only

☐ At home

☐ In a hospice

☐ In a hospital

☐ In a care home

☐ She said she did not mind where she died

☐ She changed her mind about where she wanted to die

☐ Somewhere else – please write in the space below

____

____

Q43. Did the health care staff have a record of this?

Tick one only

☐ Yes

☐ No

☐ Not sure

Q44. Do you think she had enough choice about where she died?

☐ Yes

☐ No

☐ Not sure

☐ She died suddenly

Q45. On balance, do you think that she died in the right place?

☐ Yes

☐ No

☐ Not sure

Q46. Were you or her family given enough help and support by the healthcare team at the actual time of her death?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, not at all

☐ Don’t know

Q47. After she died, did staff deal with you or her family in a sensitive manner?

Tick one only

☐ Yes

☐ No

☐ Don’t know

☐ Does not apply, I didn’t have contact with staff

Please feel free to make comments in the space below:

____

____

Q48. Looking back over the last three months of her life, was she involved in decisions about her care as much as she would have wanted?

☐ She was involved as much as she wanted to be

☐ She would have liked to be more involved

☐ She would have liked to be less involved

☐ Don’t know

Q49. Looking back over the last three months of her life, were you involved in decisions about her care as much as you would have wanted?

☐ I was involved as much as I wanted to be

☐ I would have liked to be more involved

☐ I would have liked to be less involved

☐ Don’t know

Q50. Were any decisions made about her care that she would not have wanted?

☐ Yes

☐ No

☐ Don’t know

Please feel free to make comments in the space below:

____

____

Q51. Overall, and taking all services into account, how would you rate her care in the last three months of life?

Tick one only

☐ Outstanding

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don’t know

Q52. Since she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about her illness and death?

Tick one only

☐ Yes

☐ No, but I would have liked to

☐ No, but I did not want to anyway

☐ Not sure

Information About You Both

Q53. What was your relationship to her?

Were you her:

☐ Husband/Partner

☐ Son/Daughter

☐ Brother/Sister

☐ Son-in- law/Daughter-in-law

☐ Parent

☐ Other relative

☐ Friend

☐ Neighbour

☐ Staff in care home

☐ Warden (sheltered accommodation)

☐ Other official

☐ Someone else

Q54. What is your age?

☐ 18 – 19

☐ 20 – 29

☐ 30 – 39

☐ 40 – 49

☐ 50 – 51

☐ 60 – 69

☐ 70 – 79

☐ 80 – 89

☐ 90+

Q55. Are you:

☐ Male

☐ Female

Q56. Please could you indicate to which ethnic group you belong to:

White

☐ English /Welsh /Scottish /Northern Irish /British

☐ Irish

☐ Gypsy or Irish traveller

☐ Any other white background

Mixed / Multiple ethnic group

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background

Asian / Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

Black African / Caribbean / Black British

☐ African

☐ Caribbean

☐ Any other Black African / Caribbean background

Other ethnic group

☐ Arab

☐ Any other ethnic group

Q57. Please could you indicate to which ethnic group she belonged to:

White

☐ English /Welsh /Scottish /Northern Irish /British

☐ Irish

☐ Gypsy or Irish traveller

☐ Any other white background

Mixed / Multiple ethnic group

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background

Asian / Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

Black African / Caribbean / Black British

☐ African

☐ Caribbean

☐ Any other Black African / Caribbean background

Other ethnic group

☐ Arab

☐ Any other ethnic group

Q58. What is her age when she died?

☐ 18 – 19

☐ 20 – 29

☐ 30 – 39

☐ 40 – 49

☐ 50 – 51

☐ 60 – 69

☐ 70 – 79

☐ 80 – 89

☐ 90+

Q59. What was her religion?

☐ No religion

☐ Christian (all denominations)

☐ Buddhist

☐ Hindu

☐ Jewish

☐ Muslim

☐ Sikh

☐ Any other religion - please write in the space below

____

What, if anything, was good about the care?

What, if anything, was bad about the care?

Please use the space below if there is anything you would like to say about the care provided.

Thank you for taking the time to completethis questionnaire.

We would be very grateful if you couldreturn it to us in the Freepost envelopeprovided.

Appendix I The VOICES-C prototype

Q1. How long had she been ill before she died?

Tick one only

☐ She was not ill - she died suddenly – ***Go to Q42***

☐ Less than 24 hours

☐ One day or more, but less than one week

☐ One week or more, but less than one month

☐ One month or more, but less than six months

☐ Six months or more but less than one year

☐ One year or more

Q2. Did she spend any time at home during the last three months of life?

☐ Yes - ***Go to Q3***

☐ No - she was in hospital – ***Go to Q15***

☐ No - she was in a hospice – ***Go to Q34***

CARE AT HOME

These questions are about care at home

Q3. When she was at home in the last three months of life, did she get any help at home from any of the services listed below?

These may be provided by different organisations, such as voluntary organisations, a private agency or social services

Tick all that apply

☐ A nurse (a nurse in uniform who comes to the house)

☐ A children's community nurse (a nurse who visits or telephones to talk and advise on medications and other aspects of care. They do not wear a uniform)

☐ A Marie Curie nurse (someone who comes to the house for a few hours or overnight to care for your child).

☐ Any other nurse at home

☐ Home care worker, home care aide or home help

☐ Social worker / family support worker

☐ Play therapist

☐ Religious leader

☐ Hospice at home

☐ Occupational therapist (OT)

☐ Physiotherapist

☐ She did not receive any care

☐ Don't know

☐ Something else ***– please write in the space below***

____

____

Q4. When she was at home in the last three months of life, did all these services work well together?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ She did not receive any care

☐ Don't know

Q5. Overall, in the last three months of her life, do you feel that you and your family got as much help and support from these services as you needed when caring for her?

Tick one only

☐ Yes, we got as much support as we needed

☐ Yes, we got some support but not as much as we needed

☐ No, although we tried to get more help

☐ No, but we did not ask for more help

☐ We did not need help

Q6. Was there a key health professional responsible for her care?

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q7. During the last three months of her life, while she was at home, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q8. Overall, do you feel that the care she got from her GP in the last three months of life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

URGENT CARE PROVIDED OUT OF HOURS

Q9. In the last three months of life, while she was at home, did you ever need to contact a health professional for something urgent in the evening or at the weekend?

☐ Not at all in the last 3 months - *Go to Q12*

☐ Once or twice - ***Go to Q10***

☐ Three or four times - ***Go to Q10***

☐ Five times or more - ***Go to Q10***

☐ Don't know - ***Go to Q12***

Q10. The last time this happened, who did you contact?

☐ Her GP or the out-of-hours number

☐ Someone from the paediatric team

☐ The ward / unit in the hospital

☐ NHS 111 (formerly NHS Direct)

☐ Community nurse

☐ A hospice

☐ 999

☐ Someone else

Q11. Overall, do you feel that the care she got when she needed care urgently in the evenings or weekends in the last three months of life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

COMMUNITY NURSES

If she had care in the last 3 months from community nurses go to Q12. If she did not; go to Q15.

Q12. How often, in the last three months of her life, did a community nurse visit (at the most frequent time)?

Tick one only

☐ More than once a day

☐ Every day

☐ 2-6 times a week

☐ Once a week

☐ 2-3 times a month

☐ Don't know

Q13. How much of the time was she looked after in a caring way by community nurses in the last three months of her life?

Tick one only

☐ Always

☐ Most of the time

☐ Some of the time

☐ Never

☐ Don't know

Q14. Overall, do you feel that the care she got from the community nurses in the last three months of life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

LAST HOSPITAL STAY

Q15. Did she live or stay in hospital at any time during her last three months of life?

☐ Yes – she was in the Neonatal Intensive Care Unit (NICU) – ***Go to Q16***

☐ Yes – she was in the Paediatric Intensive Care Unit (PICU) – ***Go to Q16***

☐ Yes – she was on the Paediatric Ward – ***Go to Q25***

☐ Yes – she was in the Neonatal / Paediatric Intensive Care Unit (NICU / PICU) and on the Paediatric Ward – ***Go to Q16***

☐ No – ***Go to Q34***

☐ Don't know – ***Go to Q34***

CARE IN NICU OR PICU

Q16. During her last hospital admission in the Neonatal / Paediatric Intensive Care Unit (NICU / PICU), how much of her time was she looked after in a caring way by the hospital doctors and nurses?

Tick one only

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time

☐ ☐ Some of the time
☐ ☐ Never
☐ ☐ Don't know

Q17. During her time in NICU / PICU, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain
☐ Completely, all of the time
☐ Completely, some of the time
☐ Partially
☐ Not at all
☐ Don't know

Q18. Did the hospital services work well together with her GP and other services outside of the hospital?

Tick one only

☐ Yes, definitely
☐ Yes, to some extent
☐ No, they did not work well together
☐ Don't know

Q19. Were you supported by staff to be involved in caring for her?

Tick one only

☐ Yes, definitely
☐ Yes, to some extent
☐ No
☐ Don't know

Q20. Were you offered a place to sleep to be close to her?

Tick one only

☐ Yes, in the same room
☐ Yes, on the unit but not in the same room
☐ Yes, but it was not as close as I wanted
☐ No
☐ Don't know

Q21. Was / were her sibling(s) supported by health professionals when they visited?

Tick one only

☐ Yes, definitely
☐ Yes, to some extent
☐ No
☐ Don't know
☐ Does not apply

Q22. To what extent did you place your trust in the health professionals

Tick one only

☐ Completely all over the time
☐ Completely some of the time
☐ Partially
☐ Not at all
☐ Don't know

Q23. Did you feel listened to and acknowledged as a parent, as an expert about your child?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q24. Overall, do you feel that the care she got from the staff on the unit in the last three months of her life was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

CARE IN PAEDIATRIC WARD

Q25. During her last stay on the Paediatric Ward, how much of her time was she looked after in a caring way by the hospital doctors and nurses?

Tick one only

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q26. During her last stay in paediatric ward, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q27. Did the hospital services work well together with her GP and other services outside of the hospital?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ Don't know

Q28. Were you supported by staff to be involved in caring for her?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q29. Were you offered a place to sleep to be close to her?

Tick one only

☐ Yes, in the same room

☐ Yes, on the unit but not in the same room

☐ Yes, but it was not as close as I wanted

☐ No

☐ Don't know

Q30. Was / were her sibling(s) supported by health professionals when they visited?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

☐ Does not apply

Q31. To what extent did you place your trust in the health professionals

Tick one only

☐ Completely all over the time

☐ Completely some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q32. Did you feel listened to and acknowledged as a parent, as an expert about your child?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q33. Overall, do you feel that the care she got from the staff on the ward in the last three months of her life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

LAST HOSPICE STAY

If she had care in the last 3 months from a hospice go to Q34. If she did not; go to Q42

Q34. How much of the time was she looked after in a caring way by the hospice doctors and nurses?

Tick one only

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q35. During the last three months of her life, while she was in the hospice, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q36. Were you supported by staff to be involved in caring for her?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q37. Were you offered a place to sleep to be close to her?

Tick one only

☐ Yes, in the same room

☐ Yes, on the unit but not in the same room

☐ Yes, but it was not as close as I wanted

☐ No

☐ Don't know

Q38. Was / were her sibling(s) supported by health professionals when they visited?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

☐ Does not apply

Q39. To what extent did you place your trust in the health professionals?

Tick one only

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q40. Did you feel listened to and acknowledged as a parent, as an expert about your child?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q41. Overall, do you feel that the care she got from the staff in the hospice in the last three months of her life was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

EXPERIENCES IN LAST 2 DAYS OF LIFE

Q42. How much of the time was she looked after in a caring way in the last two days of her life?

Tick one only

Please answer for both doctors and nurses

Doctors Nurses

☐ ☐ Always

☐ ☐ Most of the time

☐ ☐ Some of the time

☐ ☐ Never

☐ ☐ Don’t know

Q43. **Please look at the following statements and tick the answer box that corresponds most with your opinion about the help provided in the last two days of life**

Tick only one response per statement (a – c)

	Strongly Agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**Does not apply**	**I don’t know**
(a) Her needs were met	☐	☐	☐	☐	☐	☐	☐
(b) Her sibling(s) were looked after by staff	☐	☐	☐	☐	☐	☐	☐
(c) I as a parent was looked after	☐	☐	☐	☐	☐	☐	☐

Q44. **As far as you are able to say, how much do you agree with the following statements about the overall level of care given by health professionals to her in the last two days of life?**

Tick only one response per statement (a – e)

	Strongly Agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**Does not apply**	**I don’t know**
(a) In the last two days of life she had sufficient pain relief	☐	☐	☐	☐	☐	☐	☐
(b) In the last two days of life care and attention were given to problems apart from pain	☐	☐	☐	☐	☐	☐	☐
(c) In the last two days of life her emotional needs were considered and supported	☒	☐	☐	☐	☐	☐	☐
d) In the last two days of life the family’s spiritual and/or religious needs were considered and supported	☐	☐	☐	☐	☐	☐	☐

e) In the last two days of life efforts were made to make sure she was in the place we as a family most wanted her to be cared for	☐	☐	☐	☐	☐	☐	☐

Q45. **Overall, how much do you agree with the following statements about communication between you and health care professionals in the last two days of her life?**

Tick only one response per statement (a – d)

	Strongly Agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**Does not apply**	**I don't know**
(a) I/we were kept informed on her condition and care	☐	☐	☐	☐	☐	☐	☐
(b) I/we had enough time with staff to ask questions and discuss her condition and care	☐	☐	☐	☐	☐	☐	☐
(c) I/we understood information provided to us	☐	☐	☐	☐	☐	☐	☐
d) I/we had a supportive relationship with the health care professionals	☐	☐	☐	☐	☐	☐	☐

HOURS SURROUNDING HER DEATH

Q46. **Were you or her family given enough help and support by the healthcare team at the actual time of her death?**

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Not sure

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

____

____

____

____

Q47. Were you supported by staff to touch or hold your child at this time?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Not sure

☐ Not applicable

Q48. After she died, did staff deal with you or her family in a sensitive manner?

Tick one only

☐ Yes

☐ No

☐ Not sure

☐ Does not apply – I didn't have contact with staff

Q49. If you wanted to, after her death, were you able to:

Tick only one response per statement (a – g)

	Yes, definitely	**Yes, to some extent**	**No, not at all**	**Not sure**	**Not applicable**
(a) Have enough time with her	☐	☐	☐	☐	☐
(b) I Have enough privacy with her	☐	☐	☐	☐	☐
(c) Bathe her	☐	☐	☐	☐	☐
(d) Dress her	☐	☐	☐	☐	☐
(e) Do memory-making activities (for example foot and hand prints)	☐	☐	☐	☐	☐
(f) Have access to a cool bed for her	☐	☐	☐	☐	☐
(g) Have access to a cool room for her	☐	☐	☐	☐	☐

Q50. Since she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about her illness and death

Tick one only

☐ Yes
☐ No, but I would have liked to
☐ No, but I did not want to anyway
☐ Not sure

Q51. Since she died, do you feel that you have received enough support from health and social services, or from a bereavement service?

Tick one only

☐ Yes, definitely
☐ Yes, to some extent
☐ No
☐ Not sure

PLANNING HER CARE

Q52. Did she know she was going to die?

Tick one only

☐ Yes, certainly
☐ Yes, probably
☐ No, probably not
☐ No, definitely no
☐ Not sure
☐ She was not able to say

Q53. In your opinion, did the person who told you she was going to die break the news to you in a sensitive and caring way?

Tick one only

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all
☐ Not sure
☐ Does not apply – they did not know she was dying
☐ Does not apply – they did not tell me she was dying

Q54. Who talked to her about death?

☐ I did
☐ My partner did
☐ A health professional did
☐ Does not apply
☐ Don’t know

Q55. Did a health professional support you in talking to your child about death?

☐ Yes
☐ No
☐ Does not apply
☐ Don’t know

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

____

____

____

____

Q56. Who talked to her sibling(s) about death?

☐ I did
☐ My partner did
☐ A health professional did
☐ Does not apply

☐ Don't know

☐ No-one talked to her siblings

Q57. Did a health professional support you in talking to her sibling(s) about death?

☐ Yes

☐ No

☐ Does not apply

☐ Don't know

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

____

____

____

____

Q58. Where did she die?

☐ At home

☐ In PICU

☐ In NICU

☐ On the paediatric ward

☐ In a hospice

☐ In a hospital Accident and Emergency Department

☐ In an ambulance on the way to hospital or hospice

☐ Somewhere else

Q59. Did she ever say where she would like to die?

Tick one only

☐ Yes – ***Go to Q60***

☐ No – ***Go to Q61***

☐ Not sure – ***Go to Q61***

☐ Does not apply - ***Go to Q61***

Q60. Where did she say that she would like to die?

Tick one only

☐ At home

☐ In a hospice

☐ In a hospital

☐ She changed her mind about where she wanted to die

☐ She was not able to say

☐ Somewhere else

☐ Not applicable

Q61. Where did you want her to die?

Tick one only

☐ At home

☐ In a hospice

☐ In a hospital

☐ I changed my mind about where I wanted her to die

☐ Somewhere else

☐ Not applicable

Q62. Did the health care staff have a record of this?

☐ Yes

☐ No

☐ Not sure

Q63. Do you think you as a family had enough choice about where she died?

☐ Yes

☐ No

☐ Not sure

☐ She died suddenly

Q64. On balance, do you think that she died in the right place?

☐ Yes

☐ No

☐ Not sure

Q65. Looking back over the last three months of her life, was she involved in decisions about her care as much as she would have wanted?

☐ She was involved as much as she wanted to be

☐ She would have liked to be more involved

☐ She would have liked to be less involved

☐ She was not able to be involved

☐ Not sure

Q66. Looking back over the last three months of her life, were you involved in decisions about her care as much as you would have wanted?

☐ I was involved as much as I wanted to be

☐ I would have liked to be more involved

☐ I would have liked to be less involved

☐ Not sure

Q67. Looking back over the last three months of her life, were any decisions made about her care that you were not happy with?

☐ Yes

☐ No

☐ Not sure

Q68. Overall, and taking all services into account, how would you rate her care in the last three months of life?

Tick one only

☐ Outstanding

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Not sure

INFORMATION ABOUT YOU BOTH

Q69. What was your relationship to her?

Were you her:

☐ Mother

☐ Father

☐ Step-mother

☐ Step-father

☐ Grandparent

☐ Sibling

☐ Legal guardian

☐ Other – please write in the space below:

____

____

____

____

Q70. What was her age when she died?

PLEASE GIVE DAYS, WEEKS, MONTHS OR YEARS

Q71. What is your age?

☐ 18 – 19

☐ 20 – 29

☐ 30 – 39

☐ 40 – 49

☐ 50 – 51

☐ 60 – 69

☐ 70 – 79

☐ 80 – 89

☐ 90+

Q72. Are you:

☐ Male

☐ Female

Q73. Please could you indicate to which ethnic group <u>you</u> belong to:

White

☐ English /Welsh /Scottish /Northern Irish /British

☐ Irish

☐ Gypsy or Irish traveller

☐ Any other white background

Mixed / Multiple ethnic group

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background

Asian / Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

Black African / Caribbean / Black British

☐ African

☐ Caribbean

☐ Any other Black African / Caribbean background

Other ethnic group

☐ Arab

☐ Any other ethnic group

Q74. Please could you indicate to which ethnic group <u>she</u> belonged to:

White

☐ English /Welsh /Scottish /Northern Irish /British

☐ Irish

☐ Gypsy or Irish traveller

☐ Any other white background

Mixed / Multiple ethnic group

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background

Asian / Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

Black African / Caribbean / Black British

☐ African

☐ Caribbean

☐ Any other Black African / Caribbean background

Other ethnic group

☐ Arab

☐ Any other ethnic group

Q75. What was her religion?

☐ No religion

☐ Christian (all denominations)

☐ Buddhist

☐ Hindu

☐ Jewish

☐ Muslim

☐ Sikh

☐ Any other religion

PLEASE USE THE SPACE BELOW IF THERE IS ANYTHING YOU WOULD LIKE TO SAY ABOUT THE CARE PROVIDED.

Information written here may be combined with information on other people's experiences, and provided to NHS and University approved researchers, to inform studies on improving end of life care. All information provided to researchers will be anonymised. To help us ensure confidentiality please do not give names of people or places.

Thank you for taking the time to complete this questionnaire. We would be very grateful if you could return it to us in the Freepost envelope provided, or post to:

School of Health Sciences
FREEPOST xxxxxxx
Southampton
SO17 1BJ

Appendix J Phase I documents

J.1 Healthcare professionals recruitment materials

J.1.1 Invitation email

STUDY TITLE:
VOICES-C: Understanding the views of bereaved parents and health professionals about a questionnaire to evaluate services for children

Dear healthcare professionals,

My name is Rawnaq, I am writing to you on behalf of myself and my research team Prof. Anne-Sophie Darlington, Dr Kathrine Hunt, Dr Richard Wagland and Jitske Dijkstra at The University Of Southampton.

Thank you for accepting to take part in our research and provide us with your opinions regarding the Paediatric version (VOICES-C) of the Views of Informal Carers Evaluation Survey-Short Form (VOICES-SF) questionnaire. We want to benefit from your professional experience since you are involved in providing care for children and young people approaching death. Your opinions will help us to improve the questionnaire's suitability and sensitivity to be used for bereaved carers.

Please do not hesitate to contact us for further information or if you have any questions through my contact details directly or the contact details shown in the Participation Information Sheet (PIS).

Could please email me a convenient time and place for you to conduct the interviews after you have the time to review the questionnaire.

Thank you very much in advance for your cooperation.

Rawnaq Almahadeen

J.1.2 Reminder email

Dear Healthcare professionals,

Last week, we have sent you an email about participating in our research about the VOICES-C questionnaire.

I understand you might be too busy to prepare the questionnaire in advance. To take account with your busy schedules, I would like to suggest that we, Rawnaq and I, will be available at the hospital in the next following days on any preferred time or moment which is available for you. This could be during your lunchbreak or before your shift starts or after your shift is over, we are available on any time. The most important thing for us to know is the general impression of the healthcare professionals about the VOICES-C questionnaire, you do not have to assess the questionnaire in detail.

As a gesture of appreciation for your cooperation, we will bring tea, cake and biscuits.

Please let me know on which day you will be at the hospital, and we make sure that you will not have too much inconvenience due to our presence.

Kind regards,

Rawnaq Almahadeen

J.1.3 Consent form

STUDY TITLE:
VOICES-C: Understanding the views of bereaved parents and health professionals about a questionnaire to evaluate services for children

Participant Study Number ☐

CONSENT FORM FOR PARTICIPANTS

You need to agree to all the points if you want to take part in this study. Please put your initials in each box if you agree.

- I confirm that I have read and understood the information sheet version 3 dated 09.05.2019 for this study and have had the opportunity to consider the information and ask questions, and that I am happy with the answers. ☐
- I confirm that my involvement in this study is voluntary and that I am free to leave the study at any time, without giving any reason and without my treatment, care or legal rights being affected. I understand that should I withdraw from the study then the information collected about me up to this point may still be used for the purposes of achieving the objectives of the study unless I request that it is not used. ☐
- I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used). ☐
- I give permission for the information about me which has been generated from this study to be held in a computer (in a coded anonymised way). ☐
- I give permission for our discussion to be audio-recorded. ☐
- I agree to take part in this research project and agree for my data to be used for the purposes of this study. ☐
- I would like to receive a summary of the findings when they are available. ☐

Print name ………………………………… Sign ………………………………… Date ………………………

Researcher name ………………………………… Sign ………………………………… Date ………………………

J.1.4 Participation Information Sheet (PIS)

STUDY TITLE:
VOICES-C: Understanding the views of bereaved parents and health professionals about a questionnaire to evaluate services for children

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a research study to get your views on a questionnaire about the care provided to children in the last months of life. We would like your help to understand whether this questionnaire is acceptable from the perspective of bereaved parents. Before you decide, we would like you to understand why the study is being done and what it will involve. Take time to make the decision. If you wish, the researcher can contact you by telephone or email in 1 or 2 days.

What will happen if I take part?

Taking part involves talking to a researcher, either face-to-face at your place of work, individually or in a focus group, or on the telephone. If enough healthcare professionals from your place or work would like to also be interviewed, there will be an option to have a group interview (i.e. focus group). During the interview/focus group, the researcher will ask you to look at the paediatric version of the Views of Informal Carers-Evaluation of Services (VOICES). We have adapted this questionnaire to be able to assess the quality of end of life care for children. The questionnaire is about health care provided to people in the last months of life. We would like to ask your opinion on the appropriateness of the questionnaire. For example, you may feel that some questions are not relevant or not appropriate, perhaps you may feel there are some questions missing from the questionnaire.

Why do we want to know what your opinion of the questionnaire?

We are developing VOICES-C as a measure to assess quality of care at the end of life for children, which currently does not exist. We would like to make sure we are asking the right questions in the right way.

Who can take part?

We are asking healthcare professionals working with children around palliative care, who can understand, speak and read English.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

How to contact us

If you have any questions, please contact

Anne-Sophie Darlington, the researcher

Who is organising the study.

☎ +44 (0)23 8059 7888

a.darlington@soton.ac.uk

If you are interested in taking part please return the Reply Slip, or email or telephone the researcher. Contact details are available in the box on the previous page, or on the Invitation Letter.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. You can withdraw by contacting the research team using the contact details on the previous page and any research data collected from you will be destroyed. However, if you take part in a focus group, we will be unable to destroy the audio recording or data collected.

What happens next?

If you do not wish to take part, you do not need to do anything.

If you do decide to take part, you will be asked to sign a consent form at the time of the interview/focus group. We will arrange a time for the interview with the researcher that is most suitable for you. This can either be at your place of work, or on the telephone, whichever is most convenient for you. If you decide to have the interview on the telephone we will ask you to sign the consent form you received with this information sheet and then send it to the researcher ahead of the interview.

- First, the researcher will ask you a few questions about you and your role in caring for children.
- You will be given the questionnaire to read through
- The researcher will ask you your thoughts and opinions on the questionnaires.
- This is a one-off discussion with the researcher. For one-to-one interviews it will take around 30-45 minutes, while the focus group will take around 60 minutes

With your permission, the discussion will be audio-recorded. The recorder can be stopped at any time. The discussions will be transcribed and once members of the research team have listened to and transcribed the recordings they will be deleted.

We hope that you will find taking part in the research interesting.

Will my involvement in this study be kept confidential?

Yes, all information collected about you during the course of the study will be kept strictly confidential. For the purposes of this study, you will be given a unique numbered code. Some of what you say during the interview may be taken as direct quotes and included in scientific research reports or publications, and presented at scientific conferences. Your quote may also shared with parents and organisations who advocate for excellence in care for children. Your name will not be used in any of these, instead we will use pseudonyms for quotes in publications and reports, so that words will not be attributable to you. If you take part in a focus group, your confidentiality cannot be guaranteed as you will take part with other participants. However, all participants will be asked to respect each other's privacy and not repeat discussions outside the room.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential. If you, after having given consent for the study, lose capacity to consent during the study, you will be withdrawn from the study. Identifiable data already collected with consent will be retained and used in the study. No further data will be collected.

All electronic data will be stored on a secure, password-protected University of Southampton database server, accessible only to the research team.

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 15 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

What are the possible risks of taking part?

There are no known risks to participating in this study.

What are the benefits of taking part?

This study will not help you personally. It is hoped that the information will help us to improve the questionnaire.

What will happen to the results of the study?

The study results are likely to be published in scientific journals and report, and also presented at scientific conferences. It may also be shared with parents and organisations who advocate for excellence in care for children.

If you would like to receive a summary of the results in the post once the study is completed we will be happy to send one to you. There is an option to request this on the consent form.

Who is organising this study?

The Chief Investigator for this study is Dr Anne-Sophie Darlington. The study is sponsored by the University of Southampton.

Who has checked this study?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee.

What if there is a problem?

If you are unhappy with anything about this study, please let us know. If you have any concerns you may also contact:

Research Governance Office

University of Southampton

Building 37, Room 4079

University Road

Highfield

Southampton, S017 1BJ

☎ **023 8059 5058**

✉ **Rgoinfo@soton.ac.uk**

J.1.5 Interview protocol

Participants' Demographic information (HCP)

Participant's ID #: |___|___|___|___|___| (Interviewer's initials / 3-digit sequential #)

Date: / / 2019 (DD / MM /YYYY)

Interviewer: ☐ RA ☐ JD

Mode of interview (Check One): ☐ In person ☐ By telephone

Participant's gender ☐ Female ☐ Male

Unit of recruiting (Check One):

☐ PICU ☐ Hospice ☐ Paediatric ward ☐ NICU ☐____________

Profession ______________________________

Length of work experience

☐ Less than 5 year
☐ 5 - 10 years
☐ 10 - 15 years
☐ 15 - 20 years
☐ More than 20 years

Introduction

- Hello! Thank you for taking the time to talk with me today.
- My name is Rawnaq, I came from Jordan and I have a paediatric nursing experience. I'm a PhD student from working with Dr Anne-Sophie Darlington, Dr Kathrine Hunt and Dr Richard Wagland at the University Of Southampton.
- We have been working adapting VOICES questionnaire, which stands for the Views of Informal Carers- Evaluation of Services- Short form. This is a national survey to evaluate the bereaved carers' views about the quality of care during the last three months of life. This survey has been used National services for several years for adult population. Katherine Hunt has been involved in evaluating the end of life care and one of the members of developing the original VOICES questionnaire.
- So far, we developed the items of the questionnaire based on the literature and interviews with bereaved parents. We are looking to explore your opinions about the adapted questionnaire.
- We understand that you are involved in providing care for children and young people approaching death and want to benefit from your experience.
- We are asking for your opinions regarding the appropriateness of questionnaire's content to be used for bereaved carers,
    - Is the questionnaire's wording appropriate and not upsetting?
    - Is there something missing and we need to add any questions?
    - Do the questions reflect the provided services appropriately?

Before we start, I'd like to give you a brief information about the survey we are testing. This survey aims to evaluate the quality of paediatric end of life care in the last three months of the child's life. This questionnaire is adapted from an adult questionnaire for the same purpose. The purpose of this interview is to test paediatric VOICES questionnaire and to see how well the questions in the questionnaire are working. I would like to try out the questions with you and then I would like to ask you follow-up questions about how you chose your answer, your thoughts on what they mean to you, whether they make sense, etc. There are no right or wrong answers, or desirable or undesirable answers.

These questions will help us to learn where and how we can improve this questionnaire. I would like you to feel comfortable saying what you really think and how you really feel. The interview should take about 90 minutes. If you need to take a break at any time, let me know. We are interviewing people representing different backgrounds/ healthcare settings as possible so that we can find the terms and questions that will work best for everyone. Everything you say will remain confidential, meaning that only my supervisors and I will be aware of your answers, the purpose of that is only so we know whom to contact should we have further follow up questions after this interview. If it's okay with you, I will be tape recording our conversation since it is hard for me to write down everything while simultaneously carrying an attentive conversation with you. Is that OK with you?

- YES → (SKIP TO SECTION I)
- NO → (END INTERVIEW)

Section I. Informed consent

🗎 **Place the consent form in front of participant**

1. DID PARTICIPANT HAVE ANY QUESTIONS OR CONCERNS?

- Yes → PLEASE SPECIFY BELOW:
- No → (continue)

2. DID PARTICIPANT READ AND SIGN CONSENT FORM?

- Yes → (GIVE A COPY TO PARTICIPANT, KEEP SIGNED FORM)
- No → (END INTERVIEW)

3. DID PARTICIPANT AGREE TO AUDIO-TAPE?

- Yes
- No

4. TURN ON THE TAPE RECORDER, THEN SAY: Now I would like to confirm on tape that it is fine with you to record the interview.

(SKIP TO SECTION II)

J.2 Summary of data from healthcare professionals

Question	HCPs comments	Summary of the main problems	Suggested changes
Q1			
RA01/ HOSPICE	No comments	The time frame in the response options is confusing “One day or more, but less than one week”	The response options must be changed into a less complicated format “Between one day and one week” “Between one week and one month”
JD01/ HOSPICE	No comments		
RA02/ HOSPICE	No comments		
JD02/ PICU	The time frame is a little bit confusing: “One or more but less than” … I needed to read it more than once to understand. Maybe changing into ‘between’ might be easier.		
RA03/ HOSPICE	The first question is quite direct, this need to be more gently.	Blunt question	Adding a phrase to ease the upcoming question
JD03/ PICU	No comments		
JD04/ PICU	No comments		
ER01/ HOSPICE	This is a very direct and stark question as an opening question. Could this be softened or not be the first question		

Question	HCPs comments	Summary of the main problems	Suggested changes
RA04/ NICU	No comments		
Q2		Hospice stays is shorter than three months (days)	The responses can remain the same because if the child spent some time at hospice it means that s/he spent time at home
RA01/ HOSPICE	No comments		
JD01/ HOSPICE	No comments		
RA02/ HOSPICE	No comments		
JD02/ PICU	No comments		
RA03/ HOSPICE	It is unlikely that a child spends the whole three months in a hospice.		
JD03/ PICU	No comments		
JD04/ PICU	No comments		
ER01/ HOSPICE	No comments		
RA04/ NICU	No comments		
Q3		The participants were not sure about the involvement of certain healthcare professionals: occupational therapists/physiotherapists.	We should reconsider the options “occupational therapist” and “physiotherapist”.
RA01/ HOSPICE	I don’t know if is usual to have an occupational therapist at home, the same applies to a physiotherapist. I am in doubt if Marie Curie nurse is unlikely for paediatrics, I am not sure about that. Home		

Question	HCPs comments	Summary of the main problems	Suggested changes
	care workers might get an in-home care package. (If children have a long history of disorders, they might have a home care package that covers the home care work). It looks the same as a key worker. To be not confused for parents: use home care worker. Maybe you can add (paediatric palliative care) consultant in your options, they do many house visits or 'any sort of medical' (Than, GP or any other consultants will be covered in as well).	Marie Curie doesn't provide services for children. Add missing healthcare professionals; paediatric consultants or any doctor or medical consultant.	The option (A Marie Curie nurse) should be deleted from the responses We have to consider adding an option regarding "doctors/ consultants"
JD01/ HOSPICE	You have mentioned all the professionals. Are these responses applicable to health services? I think so, I was in doubt about the physio and occupational therapist, I was thinking about it and they may need it. It might just get a bet sorted, that will change if someone is in hospital	Confusing; "The question asks about services while the options list healthcare professionals."	We should change "services" into "professionals" or personnel
RA02/ HOSPICE	No comments		
JD02/ PICU	Children community nurse (they do not wear a uniform). I think they do. (I do not know nationally).		
RA03/ HOSPICE	You talk about services, but in the responses, you mixed it with different professionals. You have an option: hospice at home, but this could be also (any) nurse. Are professionals where you are talking about or	Asking about other charities who provide care instead of Marie Curie	No need, to add an option and make it more complicated.

Question	HCPs comments	Summary of the main problems	Suggested changes
	is it the different services (NHS, charity, voluntary services)? I.e. You named Marie Curie (charity), why them and not others? Maybe add an option to ask the parents which services (NHS, Charity etc.) and ask them about the specific healthcare professionals from these services. A nurse (in uniform who comes to the house), children community nurse & Marie Curie nurse; in paediatric is unlikely to have those professions. A nurse from the hospice.		There is a blank space so the participants can write the names of charities
JD03/ PICU	I have worked in [hospice name] as well and there we had health care assistants, music therapists. They might be doctors involved when children are at home? Probably an extra box with nurses/doctors (HCP) related to hospice. (Just not the specific nurse). Maybe if you group the question together (next to each other), it may look be easier.		
JD04/ PICU	No comments		
ER01/ HOSPICE	No comments		
RA04/ NICU	Neonatal home nurses (team from the hospital); do wear uniforms and doing home visits. Doing follow up for children up to six months. When the child has multiple problems or something, the child will be		

Question	HCPs comments	Summary of the main problems	Suggested changes
	referred to paediatric ‘general’ Separately from children community nurses.		

J.3 Summary of data from bereaved carers

Question	Parents comments	Summary of the main problems	Suggested changes
Q1			
P01NICU P02NICU	the first question is quite abrupt at the beginning	Blunt question	Revise the question to be more thoughtful
Q34			No action required
P01NICU	"Caring way" the child will always be cared of; yeah, I think it work is okay	No problem, the phrase "caring way" is well understood by carers as the default way of care	
P02NICU	I like how did you split the doctors and nurses because they are very different. It such a difficult one, it can't be .. wrongly, it is like "oh!!" if she wasn't looked after in a caring way, what other possible way could she looked after?		
Q44			
P01NICU	This question does not apply for little babies	The items do not apply to young children i.e. neonates	Separate section or questionnaire for young children
P02NICU	again question e doesn't apply to me, my situation		

Question	Parents comments	Summary of the main problems	Suggested changes
Q54		The items do not apply to young children i.e. neonates	Separate section or questionnaire for young children
P01NICU	the child is not old enough		
P02NICU	question 54 and 55 they just make me awkward; I just don’t want to read it and I would throw it away.		

J.4 The framework analysis from participants in the UK

Question	Summary of the main problems	Problem's category	Suggested changes
Q1	Time frame in the response options is confusing "One day or more, but less than one week" and "One week or more, but less than one month"	Response options	Less ambiguous phrasing, for example, "Between one day and one week" and "Between one week and one month"
Q2	Hospice stays are usually for a few days and it is unlikely for the child to stay at the hospice for three months	Response options	The responses can remain the same because if the child spent some time at hospice it means that s/he spent time at home
Q3	The participants were not sure about the involvement of certain healthcare professionals: occupational therapist/ physiotherapist. Marie Curie doesn't provide services for children. Add missing healthcare professionals; paediatric consultant or any doctor or medical consultant.	Response options	Reconsider deleting the response options "occupational therapist" and "A Marie Curie nurse" Consider adding an option regarding "doctors/ consultants" Consider adding "palliative care nurses"

Question	Summary of the main problems	Problem's category	Suggested changes
	Confusing; "The question asks about services while the options list healthcare professionals."	Question structure	Consider changing "services" into "professionals"
	Asking about other charities who provide care instead of Marie Curie	Response options	No need, to add an option and make it more complicated.
Q4	This question depends on the term used in the previous question "services"	Question structure	Reconsider "services" according to question 3
	How to measure or define "work well together?"	Unsuitable words/phrases (vague)	No need for clarifying "work well" because it is from the respondent's viewpoint
	The option "she didn't receive any care" is broad and can be understood as there wasn't any care	Unsuitable words/phrases (vague)	Consider adding "she did not receive care from more than one of the mentioned above" or remove any
Q5	This question depends on the term used in the previous question "services"	Question structure	Reconsider "services" according to the question 3&4
	"Caring for" Vague word	Unsuitable words/phrases	Consider "compassionate way"

Q6	The term “key health professional” can be interpreted differently by the parents; doctor or nurse, considering that the child received care from multiple professionals and services	Unsuitable words/phrases (Vague)	Consider replacing “key” with “named”
Q7	The main issue was the two response options are confusing and difficult to choose between them “Completely, some of the time” and “Partially”	Response options	These options are derived from validated VOICES questionnaire. ‘completely some of the time’ means pain relief completely effective at points but some breakthrough pain. ‘partially’ implies that it was never completely gone. Due to is an important distinction, these options remain the same
Q8	The GP is unlikely to provide care for children with approaching the end of life, usually the consultant who is involved in the care	Limited applicability	Consider adding “consultant or paediatrician”
	The readability of the question is poor, and the	Structure of the question	Move “in the last three months” into the beginning of the phrase

	question needs minor changes		
Q9	The response options are too specific and might require a wider range	Recall problems	Consider rewording the options “not at all” once or twice More than twice Five times or more
Q11	The readability of the question is poor, and the question needs minor changes	Structure of the question	Move “in the last three months” into the beginning of the phrase
Q13	The term “caring way” is a broad term with many inferences	Unsuitable words/phrases (Vague)	The inference is okay and there is no need for changes
Q15	The word “live” gives a meaning that the hospital is like home, not in a good way	Unsuitable words/phrases	Consider changing “live” into “stay or spend or admit”
Q16	The term “caring way” is a broad term with many inferences	Unsuitable words/phrases (Vague)	The inference is okay and there is no need for changes
Q17	The main issue was the two response options are confusing and difficult to choose between them “Completely, some of the time” and “Partially”	Response options	These options are derived from validated VOICES questionnaire. ‘completely some of the time’ means pain relief completely effective at points but some breakthrough pain. ‘partially’ implies that it was never completely

	It is difficult to assess the level of pain if the child is sedated		gone. Due to is an important distinction, these options remain the same
			No need for changes there is an option "don't know"
Q20	There is a facility near the hospital close as the parents wanted, but not inside the unit/ward	Response options	The option "Yes, but it was not as close as I wanted" can cover this
Q21	The question might be misunderstood; clarify who did the visits?	Question structure	Consider rearranging the question "Did the health professionals offer emotional support to sibling(s) whilst visiting?"
	The term "support" is broad and needs to be clarified	Unsuitable words/phrases	
Q22	The concept of trust is very broad and massive	Unsuitable words/phrases (Unclear)	Consider clarifying "trust"
	The care is provided from many people at difficult stages, it needs to be more specific	Unsuitable words/phrases (Unclear)	Consider adding, "in general" or "most of the time"
Q23	The question has two aspects "parent" and "expert". For neonates, the parents aren't experts yet	Question structure	Consider deleting "expert"
Q24	The readability of this question is poor and re-define the target service/ setting	Question structure	Consider adding NICU/PICU

Q25	The term “caring way” is a broad term with many inferences	Unsuitable words/phrases (Vague)	Consider another term or rewrite the question “Were you happy with the care provided” Remove this first part of the sentence (how much of the time)
Q26	The main issue was the two response options are confusing and difficult to choose between them “Completely, some of the time” and “Partially”	Response options	These options are derived from validated VOICES questionnaire. ‘completely some of the time’ means pain relief completely effective at points but some breakthrough pain. ‘partially’ implies that it was never completely gone. Due to is an important distinction, these options remain the same
	It is difficult to assess the level of pain if the child is sedated	Response options	No need for changes there is an option “don’t know”
Q30	The question might be misunderstood; clarify who did the visits?	Question structure	Consider rearranging the question “Did the health professionals offer emotional support to sibling(s) whilst visiting?”
Q32	The question has two aspects “parent” and “expert”.	Question structure	Consider deleting “expert”
Q33	The readability of the question is poor and the	Structure of the question	Move “in the last three months” into the beginning of the phrase

	question needs minor changes		Remove this first part of the sentence (how much of the time)
Q34	The term “caring way” is a broad term with many inferences	Unsuitable words/phrases (Vague)	The inference is okay and there is no need for changes
Q35	The main issue was the two response options are confusing and difficult to choose between them “Completely, some of the time” and “Partially” It is difficult to assess the level of pain if the child is sedated	Response options	These options are derived from validated VOICES questionnaire. ‘completely some of the time’ means pain relief completely effective at points but some breakthrough pain. ‘partially’ implies that it was never completely gone. Due to is an important distinction, these options remain the same
		Response options	No need for changes there is an option “don’t know”
Q36	The term “caring way” is a broad term with many inferences	Unsuitable words/phrases (Vague)	The inference is okay and there is no need for changes
Q38	The question might be misunderstood; clarify who did the visits?	Question structure Unsuitable words/phrases	Consider rearranging the question “Did the health professionals offer emotional support to sibling(s) whilst visiting?”

	The term "support" is broad and needs to be clarified		
Q40	The question has two aspects "parent" and "expert". For neonates, the parents aren't experts yet	Structure of the question	Consider deleting "expert"
Q41	The readability of the question is poor and the question needs minor changes	Structure of the question	Move "in the last three months" into the beginning of the phrase
Q42	The term "caring way" is a broad term with many inferences	Unsuitable words/phrases (Vague)	Consider another term or rewrite the question "Were you happy with the care provided" Remove this first part of the sentence (how much of the time)
Q43	The phrase "were the sibling(s) looked after by the staff" can be misunderstood i.e. sitting. Refer to the wellbeing to be more precise for items b and c	Unsuitable words/phrases (broad concept)	Consider rewording the questions into "the staff looked after the wellbeing of her sibling(s)" and "the staff looked after my wellbeing"
Q44	In item b, the phrase "problems apart from pain" is too broad and needs more explanation	Unsuitable words/phrases (Unclear reference)	Consider changing it to "symptoms were managed, apart from pain"

Q46	The question has two aspects the respondent and "family"	Unsuitable words/phrases (Unclear reference)	Consider deleting one of them
Q49	The religious aspect is very important around the time of death, which should be assessed in this section.	Response options (missing)	Consider adding "have access to religious support"
	The word enough is not appropriate for the situation	Unsuitable words/phrases	Consider changing "enough" into "have as much time as I needed/ wanted"
	Two options can be joined to form one option referring to all cooling methods	Response options (join two responses)	These two options can be replaced by one "have access to a cool facility (cot, mat, or room)"
	"I" in item b should is a typo	Question structure	Consider deleting "I"
		Response options (missing)	Consider adding to option b "photographs"
Q52	The option "not sure" is a bit confusing, could imply that the child knew but didn't speak or couldn't speak	Response options	No need for changes, "there is an option was not able to say"
Q53	The options are direct and important. But the last option is unlikely to happen	Response options	No need to delete the last option, the respondent will not tick it

Q54	The word “partner” is broad and refers to different individuals	Unsuitable words/phrases	Add “others” option
Q56	The word “partner” is broad and refers to different individuals.	Unsuitable words/phrases	Consider giving examples or define “partner”
	Other care providers who are not health care professionals should be considered such as counsellors or play therapists	Response options	Consider adding a blank space “other, please specify”
Q59	The phrase “she would like to die” is inappropriate and should be changed into a more sensitive phrase	Unsuitable words/phrases	Consider changing “where did she say she would like to die” into “where she wish/ would prefer to die” or did she ever say/ decide her plans/ wishes for the place of death”
Q60	The phrase “she would like to die” is inappropriate and should be changed into a more sensitive phrase	Unsuitable words/phrases	Consider changing “where did she would like to die” into “where did she wish/ would prefer her to die”
Q61	The phrase “you would like her to die” is inappropriate and should be changed into a more sensitive phrase	Unsuitable words/phrases	Consider changing “where did you want her to die” into “where did you wish/ would prefer her to die”

Q68	The readability of the question is poor, and the question needs minor changes	Structure of the question	Move "in the last three months" into the beginning of the phrase
Q69	A participant highlighted the need to include "foster parent"	Response options	Consider adding "foster parent"/ there is a blank space can cover this option
Q70	It was remarked that the neonates who die within hours do not fall under the mentioned options	Response options	Consider adding the word "hours"
Q71	The participants highlighted the need to revise the age groups of the respondents to include teenage mothers	Response options	Consider adding an option "<18 yrs."

J.5 The changes to the VOICES-Child prototype

Question	Summary of the main problems	Problem's category	Suggested changes
Q1	Time frame in the response options is confusing "One day or more, but less than one week" and "One week or more, but less than one month"	Response options	Rephrasing the response options, for example, "Between one day and one week" and "Between one week and one month"
Q3	The participants were not sure about the involvement of certain healthcare professionals: occupational therapist/ physiotherapist. Marie Curie doesn't provide services for children. Add missing healthcare professionals; paediatric consultant or any doctor or medical consultant.	Response options	Deleting the response options "occupational therapist" and "A Marie Curie nurse" Adding the options "doctors/ consultants" and "palliative care nurses"

Question	Summary of the main problems	Problem's category	Suggested changes
	Confusing; "The question asks about services while the options list healthcare professionals."	Comprehension/ question structure	Changing "services" into "professionals"
Q4	This question depends on the term used in the previous question "services"	Comprehension/ question structure	Changing "services" according to question 3
Q5	This question depends on the term used in the previous question "services"	Comprehension/ question structure	Replacing "services" according to the question 3&4
Q6	The term "key health professional" can be interpreted differently by the parents; doctor or nurse, considering that the child received care from multiple professionals and services	Comprehension/ question content	Replacing "key" with "named"
Q7	The main issue was the two response options are confusing and difficult to choose between them "Completely, some of the time" and "Partially"	Response options	These options are derived from validated VOICES questionnaire. 'completely some of the time' means pain relief completely effective at points but some breakthrough pain. 'partially' implies that it was never completely gone. Due to is an important distinction, these options remain the same

Question	Summary of the main problems	Problem's category	Suggested changes
Q8	The GP is unlikely to provide care for children with approaching the end of life, usually the consultant who is involved in the care	Comprehension/ question content	Replacing GP with "consultant or paediatrician"
Q9	The response options are too specific and might require a wider range	Others	Less than 3 times 3-5 times More than 5 times
Q15	The word "live" gives a meaning that the hospital is like home, not in a good way	Comprehension/ question content	Changing "live" into "stay or spend or admit"
Q21	The question might be misunderstood; clarify who did the visits?	Comprehension/ question structure	Re-wording the question "Did the health professionals offer emotional support to sibling(s) whilst visiting?"
	The term "support" is broad, and we need to clarify the meaning	Comprehension/ question content	
Q23	The question has two aspects "parent" and "expert". For neonates, the parents aren't experts yet	Comprehension/ question structure	Deleting "expert"

Question	Summary of the main problems	Problem's category	Suggested changes
Q24	The readability of this question is poor and re-define the target service/ setting	Comprehension/ question structure	Adding NICU/PICU
Q30	The question might be misunderstood; clarify who did the visits?	Comprehension/ question structure	Re-wording the question "Did the health professionals offer emotional support to sibling(s) whilst visiting?"
	The term "support" is broad, and we need to clarify the meaning	Comprehension/ question content	
Q32	The question has two aspects "parent" and "expert".	Comprehension/ question structure	Deleting "expert"
Q38	The question might be misunderstood; clarify who did the visits?	Comprehension/ question structure	Re-wording the question "Did the health professionals offer emotional support to sibling(s) whilst visiting?"
	The term "support" is broad, and we need to clarify the meaning	Comprehension/ question content	
Q40	The question has two aspects "parent" and "expert". For neonates, the parents aren't experts yet	Comprehension/ question structure	Deleting "expert"

Question	Summary of the main problems	Problem's category	Suggested changes
Q43	The phrase "were the sibling(s) looked after by the staff" can be misunderstood i.e. sitting. Refer to the wellbeing to be more precise for items b and c	Comprehension/ question content	Rewording the question items into b. "into "the staff looked after the wellbeing of her sibling(s)" and c. "the staff looked after my wellbeing"
Q44	In item b, the phrase "problems apart from pain" is too broad and needs more explanation	Comprehension/ question content	Consider changing it to "symptoms were managed, apart from pain"
Q46	The question has two aspects the respondent and "family"	Comprehension/ question content	Deleting "expert"
Q49	The religious aspect is very important around the time of death, which should be assessed in this section.	Response options (missing)	Adding "have access to spiritual support/ perform religious ceremony around/ after the time of death
	The word enough is not appropriate for the situation	Comprehension/ question content	Changing "enough" into "have as much time as I needed/ wanted"
		Response options (join two responses)	These two options can be replaced by one "have access to a cool facility (cot, mat, or room)"

Question	Summary of the main problems	Problem's category	Suggested changes
	Two options can be joined to form one option referring to all cooling methods	Comprehension/ question structure	Deleting "I"
	"I" in item b should is a typo	Response options (missing)	Adding "to" option b "photographs"
Q54	The word "partner" is broad and refers to different individuals	Comprehension/ question content	Adding an option "others, please specify" with a blank space
Q56	The word "partner" is broad and refers to different individuals.	Comprehension/ question content	Adding an option "others, please specify" with a blank space
	Other care providers who are not health care professionals should be considered such as counsellors or play therapists	Response options	
Q59	The phrase "she would like to die" is inappropriate and should be changed into a more sensitive phrase	Comprehension/ question content	Changing "where did she say she would like to die" into "where she wish/ would prefer to die" or did she ever say/ decide her plans/ wishes for the place of death"

Question	Summary of the main problems	Problem's category	Suggested changes
Q60	The phrase "she would like to die" is inappropriate and should be changed into a more sensitive phrase	Comprehension/ question content	Changing "where did she would like to die" into "where did she wish/ would prefer her to die"
Q61	The phrase "you would like her to die" is inappropriate and should be changed into a more sensitive phrase	Comprehension/ question content	Changing "where did you want her to die" into "where did you wish/ would prefer her to die"
Q70	It was remarked that the neonates who die within hours do not fall under the mentioned options	Response options	Consider adding the word "hours"
Q71	The participants highlighted the need to revise the age groups of the respondents to include teenage mothers	Response options	Consider adding an option "<18 yrs."

J.6 The revised VOICES-Child questionnaire

This questionnaire is about the experiences of children who have died after life-limiting condition and their families. The information you give will help us improve care for children who are dying, and for their family and friends. Your views are, therefore, important to us. We realise this questionnaire may bring back strong memories. If you feel upset, you don't have to continue with the questionnaire and can stop at any time. We are interested in finding out about the care provided to you and your child in the last three months of her life. You might find some of the questions or sections are not relevant to you. Please fill in as much of the questionnaire as you can.

Instructions

- As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box or boxes.
- If you make a mistake or wish to change your answer, cross through the answer you do **NOT** want.
- We are also interested in the siblings; if you didn't have other children at that time that you would like to report about, please skip questions highlighted in orange.
- We are very interested in what you have to say. Please continue on extra sheets if necessary.

INFORMATION ABOUT YOU BOTH

Q1. What was your relationship to her? Were you her:

☐ Mother

☐ Father

☐ Step-mother

☐ Step-father

☐ Grandparent

☐ Sibling

☐ Legal guardian

☐ Other – please write in the space below:

____

____

____

Q2. What was her age when she died?

PLEASE GIVE DAYS, WEEKS, MONTHS OR YEARS

____

Q3. What is your age?

☐ < 18

☐ 18 – 19

☐ 20 – 29

☐ 30 – 39

☐ 40 – 49

☐ 50 – 51

☐ 60 – 69

☐ 70 – 79

☐ 80 – 89

☐ 90+

Q4. Are you:

☐ Male

☐ Female

Q5. Please could you indicate to which ethnic group you belong to:

White

☐ English /Welsh /Scottish /Northern Irish /British

☐ Irish

☐ Gypsy or Irish traveller

☒ Any other white background

Mixed / Multiple ethnic group

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background

Asian / Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

Black African / Caribbean / Black British

☐ African

☐ Caribbean

☐ Any other Black African / Caribbean background

Other ethnic group

☐ Arab

☐ Any other ethnic group

Q6. Please could you indicate to which ethnic group she belonged to:

White

☐ English /Welsh /Scottish /Northern Irish /British

☐ Irish

☐ Gypsy or Irish traveller

☐ Any other white background

Mixed / Multiple ethnic group

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background

Asian / Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

Black African / Caribbean / Black British

☐ African

☐ Caribbean

☐ Any other Black African / Caribbean background

Other ethnic group

☐ Arab

☐ Any other ethnic group

Q7. What was her religion?

☐ No religion

☐ Christian (all denominations)

☐ Buddhist

☐ Hindu

☐ Jewish

☐ Muslim

☐ Sikh

☐ Any other religion

Q8. How long had she been ill before she died?

Tick one only

☐ She was not ill - she died suddenly – ***Go to Q49***

☐ Less than 24 hours

☐ Between one day and one week

☐ Between one week and one month

☐ Between one month and six months

☐ Between six months and one year

☐ More than one year

Q9. Did she spend any time at home during the last three months of life?

☐ Yes - ***Go to Q10***

☐ No - she was in hospital – ***Go to Q22***

☐ No - she was in a hospice – ***Go to Q41***

CARE AT HOME

These questions are about care at home

Q10. When she was at home in the last three months of life, did she get any help at home from any of the services listed below?

These may be provided by different organisations, such as voluntary organisations, a private agency or social services

Tick all that apply

☐ A nurse (a nurse in uniform who comes to the house)

☐ Any other nurse at home

☐ GP

☐ Paediatric consultant

☐ Palliative care nurse

☐ Home care worker, home care aide or home help

☐ Social worker / family support worker

☐ Play therapist

☐ Religious leader

☐ Hospice at home

☐ Occupational therapist (OT)

☐ Physiotherapist

☐ She did not receive any care

☐ Don't know

☐ Something else ***– please write in the space below***

____

____

Q11. When she was at home in the last three months of life, did all these services work well together?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ She did not receive any care

☐ Don't know

Q12. Overall, in the last three months of her life, do you feel that you and your family got as much help and support from these services as you needed when caring for her?

Tick one only

☐ Yes, we got as much support as we needed

☐ Yes, we got some support but not as much as we needed

☐ No, although we tried to get more help

☐ No, but we did not ask for more help

☐ We did not need help

Q13. Was there a key health professional responsible for her care?

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q14. During the last three months of her life, while she was at home, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q15. Overall, do you feel that the care she got from her GP in the last three months of life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

URGENT CARE PROVIDED OUT OF HOURS

Q16. In the last three months of life, while she was at home, did you ever need to contact a health professional for something urgent in the evening or at the weekend?

☐ Not at all in the last 3 months - ***Go to Q19***

☐ Once or twice - ***Go to Q17***

☐ Three or four times - ***Go to Q17***

☐ Five times or more - ***Go to Q17***

☐ Don't know - ***Go to Q19***

Q17. The last time this happened, who did you contact?

☐ Her GP or the out-of-hours number

☐ Someone from the paediatric team

☐ The ward / unit in the hospital

☐ NHS 111 (formerly NHS Direct)

☐ Community nurse

☐ A hospice

☐ 999

☐ Someone else

Q18. Overall, do you feel that the care she got when she needed care urgently in the evenings or weekends in the last three months of life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

COMMUNITY NURSES

If she had care in the last 3 months from community nurses go to Q19. If she did not; go to Q22.

Q19. How often, in the last three months of her life, did a community nurse visit (at the most frequent time)?

Tick one only

☐ More than once a day

☐ Every day

☐ 2-6 times a week

☐ Once a week

☐ 2-3 times a month

☐ Don't know

Q20. How much of the time was she looked after in a caring way by community nurses in the last three months of her life?

Tick one only

☐ Always

☐ Most of the time

☐ Some of the time

☐ Never

☐ Don't know

Q21. Overall, do you feel that the care she got from the community nurses in the last three months of life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

LAST HOSPITAL STAY

Q22. Did she or stay in hospital at any time during her last three months of life?

☐ Yes – she was in the Neonatal Intensive Care Unit (NICU) – ***Go to Q32***

☐ Yes – she was in the Paediatric Intensive Care Unit (PICU) – ***Go to Q32***

☐ Yes – she was on the Paediatric Ward – ***Go to Q23***

☐ Yes – she was in the Neonatal / Paediatric Intensive Care Unit (NICU / PICU) and on the Paediatric Ward – ***Go to Q23***

☐ No – ***Go to 41***

☐ Don't know – ***Go to Q41***

CARE IN PAEDIATRIC WARD

Q23. During her <u>last</u> stay on the Paediatric Ward, how much of her time was she looked after in a caring way by the hospital doctors and nurses?

Tick one only

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q24. During her <u>last</u> stay in paediatric ward, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q25. Did the hospital services work well together with her GP and other services outside of the hospital?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ Don't know

Q26. Were you supported by staff to be involved in caring for her?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q27. Were you offered a place to sleep to be close to her?

Tick one only

☐ Yes, in the same room

☐ Yes, on the unit but not in the same room

☐ Yes, but it was not as close as I wanted

☐ No

☐ Don't know

Q28. Was / were her sibling(s) supported by health professionals when they visited?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

☐ Does not apply

Q29. To what extent did you place your trust in the health professionals

Tick one only

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q30. Did you feel listened to and acknowledged as a parent, as an expert about your child?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q31. Overall, do you feel that the care she got from the staff on the ward in the last three months of her life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

CARE IN NICU OR PICU

Q32. During her last hospital admission in the Neonatal / Paediatric Intensive Care Unit (NICU / PICU), how much of her time was she looked after in a caring way by the hospital doctors and nurses?

Tick one only

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q33. During her time in NICU / PICU, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q34. Did the hospital services work well together with her GP and other services outside of the hospital?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ Don't know

Q35. Were you supported by staff to be involved in caring for her?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q36. Were you offered a place to sleep to be close to her?

Tick one only

☐ Yes, in the same room

☐ Yes, on the unit but not in the same room

☐ Yes, but it was not as close as I wanted

☐ No

☐ Don't know

Q37. Was / were her sibling(s) supported by health professionals when they visited?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

☐ Does not apply

Q38. To what extent did you place your trust in the health professionals

Tick one only

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q39. Did you feel listened to and acknowledged as a parent, as an expert about your child?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q40. Overall, do you feel that the care she got from the staff on the unit in the last three months of her life was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

LAST HOSPICE STAY

If she had care in the last 3 months from a hospice go to Q41. If she did not; go to Q49

Q41. How much of the time was she looked after in a caring way by the hospice doctors and nurses?

Tick one only

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q42. During the last three months of her life, while she was in the hospice, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q43. Were you supported by staff to be involved in caring for her?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q44. Were you offered a place to sleep to be close to her?

Tick one only

☐ Yes, in the same room

☐ Yes, on the unit but not in the same room

☐ Yes, but it was not as close as I wanted

☐ No

☐ Don't know

Q45. Was / were her sibling(s) supported by health professionals when they visited?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

☐ Does not apply

Q46. To what extent did you place your trust in the health professionals?

Tick one only

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q47. Did you feel listened to and acknowledged as a parent, as an expert about your child?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q48. **Overall, do you feel that the care she got from the staff in the hospice in the last three months of her life was:**

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

EXPERIENCES IN LAST 2 DAYS OF LIFE

Q49. **How much of the time was she looked after in a caring way in the last two days of her life?**

Tick one only

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q50. **Please look at the following statements and tick the answer box that corresponds most with your opinion about the help provided in the last two days of life**

Tick only one response per statement (a – c)

	Strongly Agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**Does not apply**	**I don't know**
(a) Her needs were met	☐	☐	☐	☐	☐	☐	☐
(b) Her sibling(s) were looked after by staff	☐	☐	☐	☐	☐	☐	☐
(c) I as a parent was looked after	☐	☐	☐	☐	☐	☐	☐

Q51. **As far as you are able to say, how much do you agree with the following statements about the overall level of care given by health professionals to her in the last two days of life?**

Tick only one response per statement (a – e)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don't know
(a) In the last two days of life she had sufficient pain relief	☐	☐	☐	☐	☐	☐	☐
(b) In the last two days of life care and attention were given to problems apart from pain	☐	☐	☐	☐	☐	☐	☐
(c) In the last two days of life her emotional needs were considered and supported	☒	☐	☐	☐	☐	☐	☐
d) In the last two days of life the family's spiritual and/or religious needs were considered and supported	☐	☐	☐	☐	☐	☐	☐
e) In the last two days of life efforts were made to make sure she was in the place we as a family most wanted her to be cared for	☐	☐	☐	☐	☐	☐	☐

Q52. **Overall, how much do you agree with the following statements about communication between you and health care professionals in the last two days of her life?**

Tick only one response per statement (a – d)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don't know
(a) I/we were kept informed on her condition and care	☐	☐	☐	☐	☐	☐	☐
(b) I/we had enough time with staff to ask questions and discuss her condition and care	☐	☐	☐	☐	☐	☐	☐

(c) I/we understood information provided to us	☐	☐	☐	☐	☐	☐	☐
d) I/we had a supportive relationship with the health care professionals	☐	☐	☐	☐	☐	☐	☐

HOURS SURROUNDING HER DEATH

Q53. Were you or her family given enough help and support by the healthcare team at the actual time of her death?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Not sure

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

____

____

____

____

____

Q54. Were you supported by staff to touch or hold your child at this time?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Not sure

☐ Not applicable

Q55. After she died, did staff deal with you or her family in a sensitive manner?

Tick one only

☐ Yes

☐ No

☐ Not sure

☐ Does not apply – I didn't have contact with staff

Q56. If you wanted to, after her death, were you able to:

Tick only one response per statement (a – g)

	Yes, definitely	Yes, to some extent	No, not at all	Not sure	Not applicable
(a) Have enough time with her	☐	☐	☐	☐	☐

(b) Have enough privacy with her	☐	☐	☐	☐	☐
(c) Bathe her	☐	☐	☐	☐	☐
(d) Dress her	☐	☐	☐	☐	☐
(e) Do memory-making activities (for example foot and hand prints)	☐	☐	☐	☐	☐
(f) Have access to a cool bed for her	☐	☐	☐	☐	☐
(g) Have access to a cool room for her	☐	☐	☐	☐	☐

Q57. Since she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about her illness and death

Tick one only

☐ Yes

☐ No, but I would have liked to

☐ No, but I did not want to anyway

☐ Not sure

Q58. Since she died, do you feel that you have received enough support from health and social services, or from a bereavement service?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Not sure

PLANNING HER CARE

Q59. Did she know she was going to die?

Tick one only

☐ Yes, certainly

☐ Yes, probably

☐ No, probably not

☐ No, definitely no

☐ Not sure

☐ She was not able to say

Q60. In your opinion, did the person who told you she was going to die break the news to you in a sensitive and caring way?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, not at all

☐ Not sure

☐ Does not apply – they did not know she was dying

☐ Does not apply – they did not tell me she was dying

Q61. Who talked to her about death?

☐ I did

☐ My partner did

☐ A health professional did

☐ Does not apply

☐ Don't know

Q62. Did a health professional support you in talking to your child about death?

☐ Yes

☐ No

☐ Does not apply

☐ Don't know

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

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____

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____

Q63. Who talked to her sibling(s) about death?

☐ I did

☐ My partner did

☐ A health professional did

☐ Does not apply

☐ Don't know

☐ No-one talked to her siblings

Q64. Did a health professional support you in talking to her sibling(s) about death?

☐ Yes

☐ No

☐ Does not apply

☐ Don't know

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

____

____

____

____

Q65. Where did she die?

☐ At home

☐ In PICU

☐ In NICU

☐ On the paediatric ward

☐ In a hospice

☐ In a hospital Accident and Emergency Department

☐ In an ambulance on the way to hospital or hospice

☐ Somewhere else

Q66. Did she ever say where she would like to die?

Tick one only

☐ Yes – ***Go to Q67***

☐ No – ***Go to Q68***

☐ Not sure ***– Go to Q68***

☐ Does not apply - ***Go to Q68***

Q67. Where did she say that she would like to die?

Tick one only

☐ At home

☐ In a hospice

☐ In a hospital

☐ She changed her mind about where she wanted to die

☐ She was not able to say

☐ Somewhere else

☐ Not applicable

Q68. Where did you want her to die?

Tick one only

☐ At home

☐ In a hospice

☐ In a hospital

☐ I changed my mind about where I wanted her to die

☐ Somewhere else

☐ Not applicable

Q69. Did the health care staff have a record of this?

☐ Yes

☐ No

☐ Not sure

Q70. Do you think you as a family had enough choice about where she died?

☐ Yes

☐ No

☐ Not sure

☐ She died suddenly

Q71. On balance, do you think that she died in the right place?

☐ Yes

☐ No

☐ Not sure

Q72. Looking back over the last three months of her life, was she involved in decisions about her care as much as she would have wanted?

☐ She was involved as much as she wanted to be

☐ She would have liked to be more involved

☐ She would have liked to be less involved

☐ She was not able to be involved

☐ Not sure

Q73. Looking back over the last three months of her life, were you involved in decisions about her care as much as you would have wanted?

☐ I was involved as much as I wanted to be

☐ I would have liked to be more involved

☐ I would have liked to be less involved

☐ Not sure

Q74. Looking back over the last three months of her life, were any decisions made about her care that you were not happy with?

☐ Yes

☐ No

☐ Not sure

Q75. Overall, and taking all services into account, how would you rate her care in the last three months of life?

Tick one only

☐ Outstanding

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Not sure

PLEASE USE THE SPACE BELOW IF THERE IS ANYTHING YOU WOULD LIKE TO SAY ABOUT THE CARE PROVIDED.

Information written here may be combined with information on other people's experiences, and provided to NHS and University approved researchers, to inform studies on improving end of life care. All information provided to researchers will be anonymised. To help us ensure confidentiality please do not give names of people or places.

Thank you for taking the time to complete this questionnaire. We would be very grateful if you could return it to us in the Freepost envelope provided, or post to:

School of Health Sciences
FREEPOST xxxxxxx
Southampton
SO17 1BJ

Appendix K Phase II documents

K.1 Expert panel recruitment email

Dear colleagues,

I hope this email finds you well.
I am writing to you on behalf of myself and my academic supervisor Prof. Alison Richardson at the University Of Southampton to invite you to take part in a research study regarding the quality of paediatric end of life care for children and young people.

We have been working on adapting the VOICES-SF questionnaire, which stands for the Views of Informal Carers- Evaluation of Services- Short form. This is a national survey to evaluate the bereaved carers' views about the quality of care during the last three months of life. This survey has been used to evaluate National services for several years for the adult population. So far, we have developed the items of the questionnaire based on the literature and interviews with bereaved parents.

We understand that you are involved in palliative and end of life care field and we want to benefit from your experience. Your feedback will help us to learn where and how we can improve this questionnaire.
We are asking for your feedback regarding the appropriateness of the questionnaire's content to be used for bereaved carers in Jordan,

- Do the questions reflect the provided services in Jordan appropriately?
- Is there something inapplicable and should be deleted?
- Is there something missing and we need to add?

Kindly find the attached copy of the Views Of Informal Carers Evaluation of Services- Child (VOICES-C) questionnaire and review the items and structure of the questionnaire as agreed in our previous communication. This prototype was developed and pretested with UK healthcare professionals and parents and refined according to their comments. The prototype is in the English language at the moment. Following your feedback, the questionnaire will be refined and translated in preparation for testing with bereaved parents in Jordan.

If you have any questions please do not hesitate to contact me.
Kind regards,
Rawnaq Almahadeen

K.2 Summary of data from the expert panel

Question	***Expert 1***	***Expert 2***	***Expert 3***	***Expert 4***	***Expert 5***	***Category***
Q 1 and 2 ***Relationship to the child and child's age***	Be careful with translation; use you and your child when referring to the child and the parent		Delete stepfather, stepmother, foster parent, and legal guardian options	Use you and the deceased child	Keep stepfather and stepmother	Semantic
Q 3 ***Proxy/ participant age***			Add now to the question statement			Semantic
Q 5 and 6 *(Ethnicity)*	These items are irrelevant for Jordanian context and need to be deleted		These are minorities, in case I come across any non-Arab participants	Delete this item and consider adding socioeconomic status, number of siblings, the deceased child's rank among other children if it applicable, and intellectual status i.e. special needs	Delete and consider adding nationality	Experiential
Q 7 *Religion*	Options are irrelevant for Jordan			Open-ended question "what is your religion?"		Experiential

Question	***Expert 1***	***Expert 2***	***Expert 3***	***Expert 4***	***Expert 5***	***Category***
Q 9 *Did she spend any time at home during the last three months of life?*					Delete hospice from the options	Experiential
Q 10 *When she was at home in the last three months of life, did she get any help at home from any of the services listed below?*	Most of the services/ specialists do not exist in Jordan's hospitals unless the child was admitted to King Hussein Cancer Centre (KHCC)		The care is mainly provided by a palliative care nurse from KHCC.	There is a private/ hiring service to provide daily care, but not comprehensive. which should be considered in the questionnaire	Keep for now till the field test proves there are no other services	Experiential
Q 11 *When she was at home in the last three months of life, did all these professionals work well together*			Delete because there are not many professionals involved in-home care			Experiential
Q 13 *Was there a named health professional responsible for her care?*			Delete			Experiential

Question	***Expert 1***	***Expert 2***	***Expert 3***	***Expert 4***	***Expert 5***	***Category***
Q 17 *The last time this [urgent care out of hours] happened, who did you contact??*	The options are not applicable and need to be adapted		Parents may have the consultant number or the department to call in an emergency (options)	Parents may call a relative nurse or a nurse from the treating team	Relevant options: Went to the clinic then admitted ER Direct contact with the consultant/ resident 911	Experiential
Q 19-21	Community nursing has no effective role in Jordan, therefore, this section needs to be deleted		Delete this section	Delete this section	Delete because it is not applicable in Jordan	Experiential
Q 25 *Did the hospital services work well together with her GP and other services outside of the hospital?*	Not relevant in Jordan, but worth asking for		The GP is not involved in the care; delete this item		Change GP into a consultant	Experiential
Q 26 *Were you supported by staff to be involved in caring for her?*			Support is a vague concept; needs clarification to think of an Arabic equivalence		Clarify what do you mean of “support” and “staff”?	Idiomatic

Question	***Expert 1***	***Expert 2***	***Expert 3***	***Expert 4***	***Expert 5***	***Category***
Q 28 *Was/were her sibling(s) supported by health professionals when they visited?*				There is a lack of family-centred care.		Idiomatic
Q 38. *To what extent did you place your trust in the health professionals?*			Specify, trust difficult to have an equivalence			Idiomatic
Q 41-48	Hospice is not relevant for Jordan context		Delete this section	Not applicable	Delete this section	Experiential
Q 50 option a Her needs were met					Specify which need	Idiomatic
Q 51 option d *In the last two days of life, the family's spiritual and/or religious needs were considered and supported*			Spiritual and religious are different concepts			Idiomatic

Question	***Expert 1***	***Expert 2***	***Expert 3***	***Expert 4***	***Expert 5***	***Category***
Q 56 ***Options f and g*** *Cool bed and cool room*		Not applicable		Not applicable	Delete these options	Conceptual
Q 61 *Who talked to her about death?*				Ask "Did someone talk to the child about death, if yes"	Consider adding "If she knew about her dying,"	Semantic/ Conceptual
Q 63 *Who talked to her sibling(s) about death?*					Consider adding "If the siblings knew about her dying,"	Semantic
Q 65 *Where did she die?*					Delete "In hospice" option	Experiential
Q 66 *Did she ever say where she would like to die?*	Death is a very sensitive issue and most often children are excluded from such conversations and not being told their cancer diagnosis in Jordan.				Consider adding "If she knew she was going to die,"	Conceptual
Q 67 *Where did she say that she would like to die?*					Delete "In hospice" option	Experiential

Question	***Expert 1***	***Expert 2***	***Expert 3***	***Expert 4***	***Expert 5***	***Category***
Q68. *Where did you want her to die?*					Delete “In hospice” option	Experiential

K.3 Summary of problems as reported by the expert panel

Problems category	Question	Suggested changes	Solutions
Semantic problems Inappropriate items, grammar, and syntax issues	Q 1 What was your relationship to her? Were you her	It is a direct short question, may look insensitive. The question needs careful translation	The question will be reworded "what is your relationship to the dead child?"
	Q 2 What was her age when she died?	It is a direct short question, may look insensitive. The question needs careful translation	The word "her/his" will be replaced into "your child"
	Q 3 What is your age?	The question is confusing because the respondent may think the age	Add "now" to the question statement
	Q 61 Who talked to her about death?	An expert expressed that before asking this question it should be established that there was a discussion about the death with the child	The researcher kept the question for the translation, because question (59) asks whether the child knew s/he was going to die.
	Q 63 Who talked to her sibling(s) about death?	An expert expressed that before asking this question it should be established that there was a discussion about the death with the child's sibling/s	The researcher kept the question for the translation. because question (62) asks who talked to the sibling/s about the death and the response options include (no one talked to her siblings).
Idiomatic problems The availability of equivalent word or phrase	Q 26 Were you supported by staff to be involved in caring for her?	The term "support" is very broad and need more specification to be clear for the participants	The researcher kept the question for the translation. During the cognitive interviews will provide clarification.

Problems category	Question	Suggested changes	Solutions
	Q 38 To what extent did you place your trust in the health professionals?	The term "trust" is very broad and need more specification to be clear for the participants	The researcher kept the question for the translation. During the cognitive interviews will provide examples.
	Q 50 option a Her needs were met	The term "needs" is very broad and need more specification to be clear for the participants	This term was kept for the translation. During cognitive interviews, the researcher will enquire about this term.
	Q 51 option d In the last two days of life, the family's spiritual and/or religious needs were considered and supported	The terms "spiritual" and "religious" have different inferences which may be confusing	The researcher deleted the term "spiritual" and kept the term "religious"
Experiential problems Not applied to the target population, the available services, the operated healthcare system or regulations	Q 1 What was your relationship to her? Response options "stepmother", "stepfather", "foster parent" and "legal guardian"	The options are irrelevant to the Jordanian community	The researcher kept the options "stepmother" and "stepfather". The researcher deleted the options "foster parent" and "legal guardian"
	Q 5 Please could you indicate to which ethnic group you belong to:	The question is irrelevant to the Jordanian population	The researcher deleted this question and replaced it with "what is your nationality?"
	Q 6 Please could you indicate to which ethnic group she belonged to:	The response options are irrelevant to the Jordanian population	The researcher deleted this question
	Q 7 What was her religion?	The response options are irrelevant to the Jordanian population	The researcher kept the options "Muslim" and "Christian"
	Q 9 Did she spend any time at home during the last three months of life?	The option "hospice" is inapplicable because there are not any hospice settings	The researcher deleted the option "hospice"

Problems category	Question	Suggested changes	Solutions
	Q 10 When she was at home in the last three months of life, did she get any help at home from any of the services listed below?	Different options are in applicable in Jordan for example; “GP”, “palliative care nurse”, “social worker”, and “hospice at home”	The researcher replaced these options with “a nurse” and “private agency”
	Q 11 When she was at home in the last three months of life, did all these professionals work well together?	There are not different services providing palliative care in Jordan, therefore the cooperation between different care providers is not needed	The researcher deleted this item
	Q 13 Was there a named health professional responsible for her care?	This item is irrelevant to the care team in Jordan and it might be confusing for the participants	The researcher deleted this item
	Q 17 The last time this [urgent care out of hours] happened, who did you contact?	The response options are irrelevant to the available services in Jordan	Response options were replaced with options relevant to the Jordanian context.
	Q 19-21 Community nurses	This section is irrelevant to the available setting providing paediatric palliative care	The researcher deleted this section
	Q 25 Did the hospital services work well together with her GP and other services outside of the hospital?	The term “GP” is irrelevant because GP does not play any role in providing paediatric palliative care	The researcher revised this item by replacing the (GP) with (the treating doctor/ consultant)
	Q 41-48 Last hospice stay	This section is irrelevant to the available setting providing paediatric palliative care	The researcher deleted this section
	Q 65 Where did she die?	The option “hospice” is inapplicable	The researcher deleted this option
	Q 67 Where did she say that she would like to die?	The option “hospice” is inapplicable	The researcher deleted this option

Problems category	Question	Suggested changes	Solutions
	Q 68 Where did you want her to die?	The option “hospice” is inapplicable	The researcher deleted this option
Conceptual problems Irrelevant concepts to the target population	Q 56 Options f and g Cool bed and cool room	These options are irrelevant to the target population due to the contradiction to Islamic laws	The researcher deleted these items
	Q 66 Did she ever say where she would like to die?	Talking about death is very sensitive and usually the children are excluded from such conversations	This item was kept in the Arabic version to explore the parents’ experiences regarding this issue

K.4 Cognitive interviews recruitment materials

K.4.1 Introductory call

Hello is this [PARENT NAME]?

My name is Rawnaq Almahadeen, I'm a PhD student. You have received a call from [coordinator's name], who forwarded your contact number to me and invited you to take part in a research study regarding the quality of paediatric end of life care for children and young people in Jordan.

On behalf of myself and my academic supervisors at the University Of Southampton, I would like to thank you for taking the time to talk with me today and we sincerely hope that you'll feel able to participate in this study. We are very sorry to talk about your child's death and appreciate how difficult it may be to remember this sad time, but by sharing your experience/opinion you may help to improve the quality of care given to other children and young people towards the end of their lives as well as their families.

The study involves reviewing a questionnaire about the quality of care provided to children and young people who are approaching their end of life (VOICES-C questionnaire) and providing your opinions regarding the content, in terms of suitable wording and meaning. This will help us in revising the survey which will be used in future study for evaluating paediatric end of life care in Jordan. Your participation in this study is voluntary and all of your responses are completely anonymous.

Are you okay to proceed with the interview now or schedule for another time?

- PROCEED → Please take your time to understand the summary that I will read to you shortly about the study. Also, please do not hesitate to ask me for further information or if you have any questions.
- SCHEDULE → Have you read the survey material? When would you like to call you again?

K.4.2 Invitation script

P = **Potential Participant; I = Interviewer**

I - May I please speak to [name of potential participant]?

P - Hello, [name of potential participant] speaking. How may I help you?

I - My name is [coordinator's name]. We are conducting interviews as part of a research study to increase our understanding of the quality of paediatric end of life care for children and young people in Jordan. As a bereaved carer who had a child received end of life care in Jordan, I would like to speak with you about the quality of care from your own perspective. There is no compensation for participating in this study however, your participation will be a valuable contribution to our research by revising the survey which will be used in a future study for evaluating paediatric end of life care in Jordan.

Is this a convenient time to give you further information about the interviews?

P - No, could you call back later (agree on a more convenient time to call the person back).
OR
P - Yes, could you provide me with some more information regarding the interviews you will be conducting?

I - Participation in this research includes reviewing a questionnaire about the quality of care provided to children and young people who are approaching their end of life and providing your opinions regarding the content, in terms of suitable wording and meaning. The interview takes around 60 minutes. Your responses to the questions will be kept confidential. Each interview will be assigned a number code to help ensure that personal identifiers are not revealed during the analysis and write up of findings.
With your permission, I would like to send you the study materials which have all of these details along with contact names and numbers to help assist you in deciding on your participation in this study.

P - No thank you.

OR

P - Sure (get contact information from potential participant i.e., email address).

I - Thank you very much for your time. May I call you in 2 or 3 days to see if you are interested in being interviewed, and arrange a day and time that suits you? Once again, if you have any questions or concerns please do not hesitate to contact me using contact details in the Participation Information Sheet (PIS).

P - Good-bye.

I - Good-bye.

K.4.3 Consent form

Participant Identification Number:

STUDY TITLE: Experiences of End of Life care for children with life-limiting conditions reported by bereaved parents' in Jordan.

I will read a list of statements. You need to agree to all the points if you want to take part in this study. I will write your initials in each box if you agree.

1. I confirm that I have understood the information sheet dated 21 September 2020 (Version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I agree to take part in this research project and agree for my data to be used for the purpose of this study. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview without giving a reason, and without my medical care or legal rights being affected. I also understand that I can withdraw my data from use in this study up to 2 weeks following the interview. ☐
4. I understand that the information collected about me will be used in future ethically approved research studies and may be shared anonymously with other researchers. ☐
5. I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. my name will not be used). ☐
6. I understand that data collected during the study may be looked at by individuals from the University of Southampton or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
7. I understand that information collected about me during my participation in this study will be stored on a password-protected computer and that this information will only be used for the purpose of ethically approved research studies. ☐
8. I give permission for our discussion to be audio-recorded. ☐

Name of Participant	Date	Signature
Name of of Person taking consent	Date	

K.4.4 Participant Information Sheet (PIS)

STUDY TITLE:

Experiences of End of Life care for children with life-limiting conditions reported by bereaved parents' in Jordan.

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Take time to make the decision. If anything is not clear or you would like more information before you decide to take part in this research, you can contact the researcher by telephone or email and ask your questions.

What is the research about?

The overall aim of this study is to understand the views of bereaved parents about the end of life services for children and young people. Unfortunately, little is known about the quality of care provided for children and young people at the end of their lives. Therefore, we would like to find out parents' opinions about the quality of care provided for children in the last three months of their life using the attached questionnaire. We are keen to know about the experiences and views through this sensitive time as this will help us to understand how the paediatric end of life care services may be improved in the future.

Why have I been asked to participate?

We are asking bereaved parents and carers who have lost a child (with a life-limiting condition) that has passed away more than three months ago and up to one year.

What will happen to me if I take part?

If you agree to take part in the study, you will be invited to review the questionnaire on the phone. The researcher will read the VOICES-C questionnaire and ask about your views concerning the included questions, response options and wording. This will help us in revising the survey which will be used in future study for evaluating paediatric end of life care in Jordan. The interview will be recorded and may take up to 60 minutes. For example, you may feel that some questions are not relevant or not appropriate; perhaps you may feel some questions are missing from the questionnaire.

Are there any benefits in my taking part?

There are unlikely to be direct benefits to you if you agreed to participate, but it is hoped that the information you provide will help us revise and improve the questionnaire for future use.

Are there any risks involved?

We do not anticipate any harm to you by taking part in this study. Although the interview is not intended to be upsetting, we understand that some questions could distress you, since they will remind you of your child. We would ask that ahead of the interview you identify a person who you would feel comfortable talking to after the interview. Please ask this person if they are okay with being contacted by the researcher, before we meet for the interview. The support person will only be contacted by the interviewer in the event it is deemed essential for them to be contacted.

What data will be collected?

The researcher will collect demographic data about you and your child and information regarding your opinions of the questionnaire.

Will my participation be confidential?

Yes.

The interview is completely confidential but not anonymous. The identity of the participants who take part in the study will remain confidential and you will not be identified in any report or publication. For the purposes of this study, you will be given a unique numbered code. Some of what you say during the interview may be taken as direct quotes and included in scientific research reports. Your name will not be used in any of these quotes so the words will not be attributable to you.

The members of the research team and responsible members of the University of Southampton will access to anonymised data that you provide, and no identifiable information about you will be revealed.

Do I have to take part?

No, it is entirely up to you to decide whether to take part or not. Your participation in this research project is entirely voluntary. Please note that verbal consent will be audio-recorded before conducting the interview.

What happens if I change my mind?

It is important to discuss any concerns you may have with the researcher before you agree to participate. However, if you do not want to continue, you can change your mind at any time throughout the interview. You can withdraw and you do not have to give any reason for this. You can withdraw your data up to 2 weeks after the interview, however, after that time it will be no longer possible to withdraw your data as the researcher will start the data analysis.

What will happen to the results of the research?

The results of the research will be published in scientific journals or publications and presented at scientific conferences. It may also be shared with organisations who advocate for excellence in care for children. It is not planned to feedback any results from the research. However, you can contact the researcher if you would like to receive a summary of the research findings.

Where can I get more information?

If you have any questions, I will be happy to answer any questions you might have.
Please contact Rawnaq Almahadeen, the researcher who is organising the study.
Tel: [PHONE NO]
Email: rma1y14@soton.ac.uk.

What happens if something goes wrong?

If you have a concern or complaint about this study, please contact the researcher who will do her best to address them.
Tel: [PHONE NO]
Email: rma1y14@soton.ac.uk.
If you would like to make a complaint about this study or talk to someone outside of the research team you should contact the University Research Integrity and Governance Team (Address: University of Southampton, Building 28, Highfield, Southampton SO17 1BJ
Tel: +44(0)2380595058
Email: rgoinfo@soton.ac.uk

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).
Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf).

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

Each participant will be assigned a unique study code. Personal information and contact details relating to each of these study identifiers will be stored in a separate locked cabinet to that containing completed questionnaires. Data in electronic format will be password protected and be stored according to University of Southampton regulations. Participants will not be identifiable in any written report/ paper associated with the research. Audio-recordings will be downloaded on to a password protected laptop prior to transcription. Transcriptions will then be anonymised, removing all information that might identify participants. Data will be accessible only by the research team members. All data will be anonymised using unique identifiers, and the personal details that are linked to these identifiers will be kept in a separate locked cabinet or digital file. Anonymised transcripts and audio recordings will be kept, according to University of Southampton regulations, for a period of 10 years. The data collected from this study can be used in future studies in paediatric end of life and palliative care and service evaluation.

Thank you.

For further information, please feel free to contact

Researcher:

Rawnaq Almahadeen

PhD student, Faculty of Environmental and Life Sciences, University of Southampton, Southampton SO17 1BJ Room: 67/1013

Email rma1y14@soton.a.uk

Tel +44(0)7745861282

Researcher's supervisors:

- Prof Alison Richardson

Professor of Cancer Nursing & End of Life Care | Director: Southampton Academy of Research | Director: NIHR ARC Wessex | NIHR Senior Investigator University of Southampton & University Hospital Southampton NHS Foundation Trust Postal address: Southampton General Hospital| Mailpoint 11 | Clinical Academic Facility (Room AA102)| South Academic Block |Tremona Road | Southampton | SO16 6YD.

Tel: +44 (0)2381208494 (Hospital)| +44(0)2380597926(University)

alison.richardson@soton.ac.uk

- Dr Katherine Hunt PhD MSc BN (Hons) RN

Senior Research Fellow Health Sciences Faculty of Environmental and Life Sciences, University of Southampton SO17 1BJ Room: 67/4005

k.j.hunt@soton.ac.uk

- Dr Richard Wagland PhD, MA, BSc, RN

Senior Research Fellow Health Sciences Faculty of Environmental and Life Sciences, University of Southampton SO17 1BJ Room: 67/4005

r.wagland@soton.ac.uk

K.5 Interview schedule

Introduction

- Hello! Thank you for taking the time to talk with me today.
- My name is Rawnaq Almahadeen. I'm a PhD student from working with Dr Alison Richardson, Dr Kathrine Hunt and Dr Richard Wagland at the University of Southampton.
- We have been working to adapt the VOICES-C questionnaire, which stands for the Views of Informal Carers- Evaluation of Services-Children. This questionnaire aims to evaluate the bereaved carers' views about the quality of care during the last three months of life.
- The paediatric version of the questionnaire was adapted in the UK. The items were developed based on the literature and interviews with bereaved parents. We are looking to explore your opinions about the Arabic version and whether it is congruent with the available services and cultural context in Jordan, based on your experience.
- We are asking for your opinions regarding the appropriateness of the questionnaire's content to be used for bereaved carers,
  - Is the questionnaire's wording appropriate and not upsetting?
  - Is there something missing and we need to add any questions?
  - Do the questions reflect the provided services appropriately?
  - Are the provided options suitable for the corresponding questions?

Before we start, I'd like to give you brief information about the interview. The purpose of this interview is to test the VOICES-C (Arabic version) and to see how well the questions in the questionnaire are working. I would like to try out the questions with you and then I would like to ask you follow-up questions about how you chose your answer, your thoughts on what they mean to you, whether they make sense, etc. There are no right or wrong answers, or desirable or undesirable answers. These questions will help us to learn where and how we can improve this questionnaire. I would like you to feel comfortable saying what you really think and how you really feel. The interview should take about 60 minutes. If you need to take a break at any time, let me know. Could you identify who would you contact if you feel bad after the interview? Would you allow me to contact his/her details after the interview in order to check on you?

Everything you say will remain confidential, meaning that only my supervisors and I will be aware of your answers. If it's okay with you, I will be tape-recording our conversation since it is hard for me to write down everything while simultaneously carrying an attentive conversation with you. Is that OK with you?

- YES → (SKIP TO SECTION I)
- NO → (END INTERVIEW)

Phase II documents

Section I. Informed consent

🗎 READ THE CONSENT FORM TO THE PARTICIPANT

1. Did the participant understand and provide verbal consent?

- Yes → (tape-record the verbal consent)
- No → (end interview)

2. Did the participant have any questions or concerns?

- Yes → please specify below:
- No → (continue)

3. Did the participant agree to audiotape the interview?

- Yes
- No

4. TURN ON THE TAPE RECORDER, THEN SAY: Now I would like to audio record that you are willing for this interview to be recorded.

(SKIP TO SECTION II)

Section II Cognitive interviews

Now, if you are ready, I'd like to get started by reading the questionnaire and allow you to answer the questions. This is a self-completing questionnaire, please imagine as if you are answering the questions by your own. While you answer the questions, I will ask you some additional questions about your opinion on certain words and questions.

READ THE VOICES QUESTIONS AND RESPONSE OPTIONS ALOUD

1. Ask scripted probes
2. Add spontaneous, follow-up probes as needed for clarification.

Probes

What did you think of when you chose your answer? ______________________________

Please repeat the question in your own words: ___________________________________

Was it difficult to answer at all? ____

What does *"trust"* mean to you?

____

What do you think they mean by *"caring way"*? Is there some other way to say that? ____

____

Section III. Additional questions

- **Impact of taking part in the study**
  - How do you feel after the interview?
  - If you are going to rate the stress you feel due to the interview, on a scale from 0 to 4, where 0 is not at all and 4 is extremely stressful, how would you rate the interview?
- **Recruitment**
  - How long did it take you to decide to participate in the study?
  - By thinking of the time you were approached after your child's death, do you think it was suitable timing?
  - If we are recruiting participants to complete the questionnaire, in your opinion, when is best to approach bereaved participants?
  - Who would you prefer to make the first contact, a nurse or the researcher?
  - If you do not respond immediately, how many times a participant should be approached?
  - How would you prefer to receive the study material, by email or link to a website?

Section IV. Conclusion

These are all my questions. Thank you very much for your opinions.

- Do you have any overall opinions about the questions?

____

____

____

____

- Do you have any other comments or concerns?

- After hearing all of my questions, do you have any questions for me?

I want to thank you very much for your participation.

The interviewer turns off the tape recorder.

K.6 The VOICES-C Arabic prototype

هذا الاستبيان يهدف إلى تقييم الرعاية المقدمة للأطفال الذين توفوا في الأشهر الثلاثة الأخيرة من حياتهم بسبب حالات مرضية مزمنة. رأيك مهم بالنسبة لنا فالمعلومات ستساعدنا على تحسين الرعاية المقدمة للأطفال وأسرهم. ندرك أن هذا الاستبيان قد يتسبب بشعور كبير بالاستياء، لذلك أنت غير مضطر إلى متابعة الاستبيان ويمكنك التوقف في أي وقت.
يرجى ملء أكبر قدر ممكن من الاستبيان فقد تجد أن بعض الأسئلة أو الأقسام غير ذات صلة بتجربتك.

الإرشادات

- أثناء مراجعة الاستبيان، يُرجى اتباع الإرشادات والإجابة عن الأسئلة بوضع علامة x في المربع أو المربعات المناسب/ة.
- إذا أخطأت بالإجابة أو كنت ترغب بتغيير إجابتك، يرجى شطب الإجابة التي لا تريدها.
- نحن مهتمون أيضاً بالأخوة؛ إذا لم يكن لديك أطفال آخرين في ذلك الوقت، فيرجى تخطي الأسئلة المظللة باللون البرتقالي
- نحن مهتمون بكل ما تقوله لذلك يرجى الكتابة على الورقة الإضافية إذا لزم الأمر.
- لا توجد إجابات صحيحة أو خاطئة فالإجابات الصحيحة هي التي تعبر عن رأيك بصدق. لذلك يرجى الإجابة عن أسئلة هذه الاستبيان بجدية ودقة، مؤكدين لك بأن المعلومات ستعامل بسرية تامة ولن تستخدم إلا لأغراض البحث العلمي فقط.

معلومات عنك وعن طفلك

Q1. ما صلة قرابتك بالطفل المتوفى؟

☐ أم
☐ أب
☐ زوجة الأب
☐ زوج الأم
☐ جد/ة
☐ أخ/ت
☐ غير ذلك، أذكر

Q2. كم كان عمر الطفل عند الوفاة؟

يرجى إعطاء العمر بالأيام / الأسابيع / الأشهر / السنوات

Q3. كم عمرك الآن؟

☐ >18
☐ 18 – 19
☐ 20 – 29
☐ 30 – 39
☐ 40 – 49
☐ 50 – 51
☐ 60 – 69
☐ 70 – 79
☐ 80 – 89
☐ 90+

Q4. الجنس:

☐ ذكر
☐ أنثى

Q5. الديانة؟

☐ مسيحي
☐ مسلم

Q6. ما هي جنسيتك؟

☐ أردني
☐ غير أردني، أذكر

Q7. ما هو تأمينك؟

☐ حكومي
☐ عسكري
☐ خاص
☐ لا يوجد تأمين

Q8. كم من الوقت كان طفلك مريضاً قبل الوفاة؟

اختر إجابة واحدة فقط

☐ لم يكن مريضاً بل توفي فجأة (انتقل إلى قسم 0)
☐ أقل من 24 ساعة
☐ من يوم إلى أسبوع
☐ من أسبوع إلى شهر
☐ من شهر إلى ستة شهور
☐ من ستة شهور إلى سنة
☐ أكثر من سنة

Q9. هل بقي/ أمضى طفلك وقته بالمنزل خلال الأشهر الثلاثة الأخيرة من الحياة؟

☐ نعم
☐ لا، كان في المستشفى (انتقل إلى قسم 0)

الرعاية في المنزل

Q10. عندما كان طفلك في المنزل في الأشهر الثلاثة الأخيرة من الحياة، هل تلقى أي رعاية منزلية؟
هذه الرعاية يمكن أن تقدمها قطاعات مختلفة، حكومية أو خاصة.

☐ نعم

☐ لا (انتقل إلى قسم 0)

Q11. من قدم هذه الرعاية؟

☐ ممرض /ة

☐ وكالة خاصة

Q12. خلال الأشهر الثلاثة الأخيرة من الحياة، عندما كان الطفل/ة في المنزل، إلى أي مدى تم تخفيف الألم الذي شعر به طفلك؟

اختر إجابة واحدة فقط

☐ لا ينطبق لم يكن لديه/ أي ألم

☐ تماماً، كل الوقت

☐ تماماً بعض من الوقت

☐ جزئيّاً

☐ مطلقاً

☐ لا أعلم/ غير متأكد

Q13. بشكل عام، هل تشعر أن الرعاية المقدمة لطفلك من الأخصائيين في الأشهر الثلاثة الأخيرة من الحياة كانت:

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

الرعاية خارج أوقات العمل الرسمي

Q14. عندما كان طفلك في المنزل في الأشهر الثلاثة الأخيرة من الحياة، هل كنت في حاجة إلى الاتصال بأحد من الكادر الصحي لحالة طارئة في المساء أو في عطلة نهاية الأسبوع؟

☐ مطلقاً (انتقل إلى قسم 0)

☐ مرة واحدة أو مرتين

☐ ثلاث أو أربع مرّات

☐ أكثر من خمس مرّات

☐ لا أعلم

Q15. آخر مرة كنت فيه قمت بالاتصال بأحد من الكادر الصحي لحالة طارئة ، من الذي اتصلت به؟

☐ الطبيب الأخصائي/ المعالج

☐ القسم في المستشفى

☐ ممرض من القسم

☐ 911

☐ غير ذلك، أذكر

Q16. بشكل عام، هل تشعر أن الرعاية المقدمة لطفلك في الأشهر الثلاثة الأخيرة من الحياة عندما كان/ت في حاجة ماسة إلى الرعاية في المساء أو في عطلة نهاية الأسبوع كانت:

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

الرعاية في المستشفى

Q17. **هل بقي طفلك في المستشفى في أي وقت خلال الأشهر الثلاثة الأخيرة من الحياة؟**

☐ نعم، قسم الأطفال (انتقل إلى قسم 0)

☐ نعم، قسم الخداج (انتقل إلى قسم 0)

☐ نعم، قسم الرعاية الحثيثة (انتقل إلى قسم 0)

☐ نعم، قسم الأطفال و الخداج/الرعاية الحثيثة (انتقل إلى قسم 0)

☐ لا (انتقل إلى قسم 0)

☐ لا أعلم/ غير متأكد (انتقل إلى قسم 0)

الرعاية في قسم الأطفال

Q18. **خلال الفترة قام طفلك الأخير في قسم الأطفال، كان يتلقى الرعاية برفق واهتمام من قبل الأطباء والتمريض؟**

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q19. **خلال الفترة قام طفلك الأخير في قسم الأطفال، إلى أي مدى تم تخفيف الألم الذي شعر به طفلك؟**

اختر إجابة واحدة فقط

☐ لا ينطبق، لم يكن لديه/ا أي ألم

☐ تماماً، كل الوقت

☐ تماماً بعض الوقت

☐ جزئيّاً

☐ مطلقاً

☐ لا أعلم/ غير متأكد

Q20. **هل كانت الخدمات المقدمة من المستشفى تتعامل بشكل جيد مع الطبيب العائلي/ المعالج ؟**

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا، لم يعملوا معاً بشكل جيد

☐ لا أعلم/ غير متأكد

Q21. **هل تلقيت الدعم من كادر قسم الأطفال للمشاركة في رعاية طفلك؟**

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

Q22. **هل عُرض عليك مكان للنوم بالقرب من طفلك؟**

☐ نعم في نفس الغرفة

☐ نعم بالقرب ولكن في غرفة أخرى

☐ نعم، لكن ليس قريب بطفلي

☐ لا

☐ لا أعلم/ غير متأكد

Q23. **هل تلقيتم الدعم المعنوي للأخوة من قبل كادر قسم الأطفال أثناء زيارتهم للطفل؟**

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق، لم يكن لديه/ا أي أخوة

Q24. إلى أي مدى وضعت ثقتك بكادر قسم الأطفال ؟

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q25. هل شعرت بأنه تم الاستماع لك، كخبير بشؤون طفلك؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

Q26. بشكل عام، هل تشعر أن الرعاية المقدمة لطفلك في الأشهر الثلاثة الأخيرة من الحياة عندما كان/ت في قسم الأطفال كانت:

اختر إجابة واحدة فقط

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

الرعاية في قسم الخداج/العناية الخاصة

Q27. خلال الفترة التي أقام طفلك الأخير في قسم الخداج/ العناية الخاصة، كان يتلقى الرعاية برأفة واهتمام من قبل الأطباء والتمريض؟

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q28. خلال الفترة التي أقام طفلك الأخير في قسم الخداج/ العناية الخاصة, إلى أي مدى تم تخفيف الألم الذي شعر به طفلك؟

اختر إجابة واحدة فقط

☐ لا ينطبق لم يكن لديه/ أي ألم

☐ تماماً، كل الوقت

☐ تماماً بعض من الوقت

☐ جزئياً

☐ مطلقاً

☐ لا أعلم/ غير متأكد

Q29. هل كانت الخدمات المقدمة من المستشفى تتعامل بشكل جيد مع الطبيب الاختصاصي/ المعالج؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا، لم يعملوا معاً بشكل جيد

☐ لا أعلم/ غير متأكد

Q30. **هل تلقيت الدعم من كادر الخداج/ العناية الحثيثة للمشاركة في رعاية طفلك؟**

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

Q31. **هل عُرض عليك مكان للنوم بالقرب من طفلك؟**

☐ نعم في نفس الغرفة

☐ نعم بالقسم ولكن بغرفة أخرى

☐ نعم، لكن ليس قريبا بالقدر الكافي

☐ لا

☐ لا أعلم/ غير متأكد

Q32. **هل تم تقديم الدعم المعنوي للأخوة من قبل كادر الخداج/ العناية الحثيثة أثناء زيارتهم للطفل؟**

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق، لم يكن له/ا أي أخوة

Q33. **إلى أي مدى وضع ثقته بك كادر قسم الخداج/ العناية الحثيثة ؟**

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q34. **هل شعرت بأن تم الاستماع لك، كخبير بشؤون طفلك؟**

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

Q35. **بشكل عام، هل تشعر أن الرعاية المقدمة لطفلك في الأشهر الثلاثة الأخيرة من الحياة عندما كان/ت في قسم الخداج/ العناية الحثيثة كانت:**

اختر إجابة واحدة فقط

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

الرعاية في اليومين الأخيرين من حياة طفلك

Q36. **في اليومين الأخيرين من حياة طفلك، كان يتلقى الرعاية برفق واهتمام من قبل أطباء المستشفى والتمريض؟**

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q37. **يُرجى الاطلاع على العبارات التالية ووضع علامة في مربع الإجابة الذي يتوافق بشكل أكبر مع رأيك بخصوص الرعاية المقدمة في أخر يومين من حياة طفلك:**

اختر إجابة واحدة فقط لكل عبارة

	أوافق بشدة	أوافق	لا أوافق ولا أعارض	أعارض	أعارض بشدة	لا ينطبق	لا أعلم/ غير متأكد
أ) تمت تلبية احتياجاته/ا	☐	☐	☐	☐	☐	☐	☐
ب) تم الاهتمام بأخوته/ا	☐	☐	☐	☐	☐	☐	☐
ج) تم الاهتمام بي كوالد/ة	☐	☐	☐	☐	☐	☐	☐

Q38. **ما مدى موافقتك على العبارات التالية فيما يخص الرعاية المقدمة لطفلك في أخر يومين من الحياة؟**

اختر إجابة واحدة فقط لكل عبارة

	أوافق بشدة	أوافق	لا أوافق ولا أعارض	أعارض	أعارض بشدة	لا ينطبق	لا أعلم/ غير متأكد
أ) تم التخفيف من آلامه/ا	☐	☐	☐	☐	☐	☐	☐
ب) فيما عدا الألم تم الاهتمام بالمشاكل الأخرى مثل الغثيان وضيق التنفس	☐	☐	☐	☐	☐	☐	☐
ج) تم الأخذ في الاعتبار حالته/ا النفسية / مشاعره/ا	☐	☐	☐	☐	☐	☐	☐
د) تم الأخذ في الاعتبار احترام متطلبات الأسرة الدينية	☐	☐	☐	☐	☐	☐	☐
ه) تم بذل مجهود ليتوفى/ه في مكان الرعاية الذي نريد أن نكون فيه كأسرة	☐	☐	☐	☐	☐	☐	☐

Q39. **ما مدى موافقتك على العبارات التالية فيما يخص التواصل بينك وبين مقدمي الرعاية لطفلك في أخر يومين من الحياة؟**

اختر إجابة واحدة فقط لكل عبارة

	أوافق بشدة	أوافق	لا أوافق ولا أعارض	أعارض	أعارض بشدة	لا ينطبق	لا أعلم/ غير متأكد
أ) بقينا على علم بحالة الطفل وخطة الرعاية	☐	☐	☐	☐	☐	☐	☐
ب) كان لدينا الوقت الكافي لطرح الأسئلة ومناقشة حالة الطفل وخطة الرعاية	☐	☐	☐	☐	☐	☐	☐
ج) فهمنا المعلومات التي تم توفيرها لنا	☐	☐	☐	☐	☐	☐	☐
د) كانت لدينا علاقة داعمة مع مقدمي الرعاية الصحية	☐	☐	☐	☐	☐	☐	☐

الساعات المحيطة بوفاة الطفل

Q40. تقييم المساعدة والدعم الفعليين والتي من قبل مقدمي الرعاية في وقت الوفاة؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

يُرجى التعليق في المساحة أدناه

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____

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Q41. هل تم دعمك من قبل مقدمي الرعاية للمس طفلك أو حمله في وقت الوفاة؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق

Q42. بعد وفاته/ا، هل تعامل مقدمو الرعاية معك أو مع عائلته بطريقة حساسة؟

اختر إجابة واحدة فقط

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق، لم نتعامل مع أي فرد من مقدمي الرعاية

Q43. هل إذا أردت بعد وفاة طفلك، هل كنت قادراً على:

اختر إجابة واحدة فقط لكل عبارة

	نعم بالتأكيد	نعم، إلى حد ما	لا، على الإطلاق	لا أعلم/ غير متأكد	لا ينطبق
أ) أخذ الوقت الكافي معه/ا	☐	☐	☐	☐	☐
ب) أخذ الخصوصية الكافية معه/ا	☐	☐	☐	☐	☐
ج) غُسل طفلك	☐	☐	☐	☐	☐
د) تغيير ملابس طفلك	☐	☐	☐	☐	☐
ه) الاحتفاظ بتذكار لطفلك (خصلة من شعره/ا)	☐	☐	☐	☐	☐

Q44. منذ وفاته/ا، هل تحدثت إلى أي شخص من مقدمي الرعاية عن مشاعرك بشأن مرض طفلك ووفاته/ا؟

اختر إجابة واحدة فقط

☐ نعم

☐ لا، ولكنني كنت أود ذلك

☐ لا، لكنني لم أكن أريد على أية حال

☐ لا أعلم/ غير متأكد

Q45. منذ وفاته/ا، هل تشعر بأنك تلقيت دعماً كافياً من مقدمي الرعاية؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

التخطيط للرعاية

Q46. برأيك، هل قام الشخص الذي أخبرك بأنه/ا ستموت، بذلك بطريقة حساسة ؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد
☐ نعم، إلى حد ما
☐ لا، على الإطلاق
☐ لا أعلم/ غير متأكد
☐ لا ينطبق - فهم يعرفوا أن طفلي سيموت
☐ لا ينطبق - لم يخبروني أن طفلي سيموت

Q47. هل كان طفلك يعلم أنه سيموت؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد
☐ نعم، من المحتمل
☐ لا، على الأغلب لا (انتقل إلى السؤال 50)
☐ لا بالتأكيد لا (انتقل إلى السؤال 50)
☐ لا أعلم/ غير متأكد (انتقل إلى السؤال 50)
☐ لم يكن قادر/ة على الكلام (انتقل إلى السؤال 50)

Q48. من تحدث معه/ا عن الوفاة؟

☐ أنا
☐ زوجي/زوجتي
☐ من الكادر الصحي
☐ لا ينطبق
☐ لا أعلم/ غير متأكد

Q49. هل دعمك أحد من الكادر الصحي في التحدث إلى طفلك عن الوفاة؟

☐ نعم
☐ لا
☐ لا أعلم/ غير متأكد
☐ لا ينطبق

يرجى التعليق في المساحة أدناه

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Q50. من تحدث مع الإخوة عن الوفاة؟

☐ أنا
☐ زوجي/زوجتي
☐ من الكادر الصحي
☐ لا ينطبق (انتقل إلى السؤال 52)
☐ لا أعلم/ غير متأكد (انتقل إلى السؤال 52)
☐ لا أحد (انتقل إلى السؤال 52)

Q51. هل دعمك أحد من الكادر الصحي في التحدث إلى الإخوة عن الوفاة؟

☐ نعم
☐ لا
☐ لا أعلم/ غير متأكد
☐ لا ينطبق

يرجى التعليق في المساحة أدناه

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Q52. أين توفي الطفل؟

☐ في البيت
☐ في قسم الأطفال
☐ في قسم الخداج
☐ في قسم العناية الحثيثة
☐ في قسم الطوارئ
☐ في سيارة الإسعاف في الطريق إلى المستشفى
☐ غير ذلك

Q53. هل سبق لطفلك أن قال/ت أين تريد الوفاة؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق

Q54. أين اراد طفلك أن يكون وقت الوفاة؟

☐ في البيت

☐ في المستشفى

☐ غير/ت رأيه/ا بخصوص مكان الوفاة

☐ لم يكن قادر/ة على الكلام

☐ غير ذلك

☐ لا ينطبق

Q55. أين أردت أن يكون طفلك وقت الوفاة؟

☐ في البيت

☐ في المستشفى

☐ غيرت رأيي بخصوص مكان الوفاة

☐ غير ذلك

☐ لا ينطبق

Q56. هل قام أحد من الكادر الطبي بتدوين ذلك؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

Q57. هل تعتقد بأنك كنت تملك الخيار الكافي بخصوص مكان الوفاة؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

☐ توفي الطفل فجأة

Q58. هل تعتقد أن طفلك توفي في المكان الصحيح؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

Q59. بالنظر إلى الأشهر الثلاثة الأخيرة من حياة طفلك، فهل شارك/ت في اتخاذ قرارات بشأن الرعاية المقدمة؟

☐ كان/ت مشترك/ة باتخاذ القرارات كما أراد/ت

☐ كان/ت يفضل/تفضل أن تكون أكثر مشاركة

☐ كان/ت يفضل/تفضل أن تكون أقل مشاركة

☐ لم يكن قادرة على المشاركة

☐ لا أعلم/ غير متأكد

Q60. بالنظر إلى الأشهر الثلاثة الأخيرة من حياة طفلك، فهل شارك/ت في اتخاذ قرارات بشأن الرعاية المقدمة؟

☐ كنت أشارك باتخاذ القرارات كما أردت

☐ كنت أفضّل أن أكون أكثر مشاركة

☐ كنت أفضّل أن أكون أقل مشاركة

☐ لا أعلم/ غير متأكد

Q61. بالنظر إلى الأشهر الثلاثة الأخيرة من حياة طفلك، هل كانت أي قرارات اتخذت بشأن رعايته لم تكن مرضياً عنها؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

Q62. بشكل عام، ومع أخذ كل الخدمات بعين الاعتبار، كيف يمكنك تقييم مستوى الرعاية التي قدمت لطفلك في الأشهر الثلاثة الأخيرة؟

اختر إجابة واحدة فقط

☐ متفوقة/ متقدمة

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

يرجى استخدام المساحة أدناه إذا كان هناك أي شيء تود قوله عن الرعاية المقدمة.

قد يتم جمع المعلومات التي تتعلق بتجربتك وتوفيرها للباحثين المعنيين من قبل الجامعة بهدف تقييم معلومات عن تجربة الرعاية الصحية عند نهاية الحياة. سوف يتم حذف كل المعلومات الشخصية عن المشاركين بالبحث لغايات ضمان السرية. يُرجى عدم إعطاء أسماء الأشخاص أو الأماكن.

K.7 The VOICES-C Back translated version

This questionnaire aims at evaluating the care given to children who passed away in the last three months of their lives due to chronic diseases.
Your opinions are important to us as the information will help us to improve the care provided to the children and their families. We understand that this questionnaire might hurt you. Therefore, you are not obliged to continue with this questionnaire, and you can stop at any time.
Please fill as much as possible of the questionnaire. You might find that some of the questions or sections are not applicable to you.

Instructions

- As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box or boxes.
- If you make a mistake or wish to change your answer, cross through the answer you do **NOT** want.
- We are also interested in the siblings; if you didn’t have other children at that time that you would like to report about, please skip questions highlighted in orange.
- We are very interested in what you have to say. Please continue on extra sheets if necessary.

1 INFORMATION ABOUT YOU BOTH

Q1. What's your relationship to her?

Were you her:

☐ Mother
☐ Father
☐ Step-mother
☐ Step-father
☐ Granddad/ grand mum
☐ Brother/ sister
☐ Legal guardian
☐ Other – specify:

____

____

____

Q2. What was her age when she died?

PLEASE GIVE DAYS, WEEKS, MONTHS OR YEARS

____

Q3. What is your age?

☐ < 18
☐ 18 – 19
☐ 20 – 29
☐ 30 – 39
☐ 40 – 49
☐ 50 – 51
☐ 60 – 69
☐ 70 – 79
☐ 80 – 89
☐ 90+

Q4. Are you:

☐ Male
☐ Female

Q5. What was her religion?

☐ Christian (all denominations)
☐ Muslim

Q6. Please could you indicate to which ethnic group you belong to:

☐ Jordanian
☐ Not Jordanian specify:

____

Q7. What was your insurance?

☐ State/ government
☐ Military
☐ Private
☐ None

Q8. How long had she been ill before she died?

Choose only one answer

☐ She was not ill - she died suddenly – ***Skip to section 5***
☐ Less than 24 hours
☐ 1-7 days
☐ A week - a month
☐ One month - six months
☐ Six months - one year
☐ More than a year

Q9. Did she spend any time at home during the last three months of life?

☐ Yes

☐ No - she was in hospital – ***Skip to section 4***

2 CARE AT HOME

These questions are about care at home. This care can be provided by different sectors public or private

Q10. During the last three months of her/his life, did she receive any care at home?

☐ Yes

☐ No - he was in hospital – ***skip to section*** *Error! Reference source not found.*

Q11. Who provided this care?

Choose all that apply

☒ A nurse

☐ A private agency

☐ Other ***– specify***

____

____

Q12. During the last three months of life, and while the child was at home, to what extent the pain your child felt was relieved/ managed?

Choose only one answer

☐ NA/ did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ I don't know/ I am not sure

Q13. Generally, do you feel the care provided to your child during the last three months of life was

Choose only one answer

☐ Excellent

☐ Good

☐ Acceptable

☐ Bad

☐ I don't know/ I am not sure

3 Care outside working hours

Q14. When your child was at home during the last three months of life, did you need to call any medical professional for an emergency in the evening or the weekend?

☐ Never ***– skip to section*** *Error! Reference source not found.*

☐ Once or twice

☐ 3-4 times

☐ More than 5 times

☐ I don't know

Q15. The last time this happened, who did you contact?

☐ The specialist/ the physician

☐ The hospital department

☐ A nurse from the department

☐ 911

☐ Other ***– specify***

____

____

Q16. In general, do you feel that the care provided for your child during the last three months of life when s/he was in desperate need in the evening or the weekend was

Choose only one answer

☐ Excellent

☐ Good

☐ Acceptable

☐ Bad

☐ I don't know/ I am not sure

4 Care in the hospital

Q17. Did she stay in hospital at any time during her last three months of life?

☐ Yes, on the paediatric ward- **Skip to section** Error! Reference source not found.

☐ Yes, in the neonatal unit - **Skip to section** Error! Reference source not found.

☐ Yes – intensive care unit - **Skip to section 4.2**

☐ Yes –the paediatric/ neonatal/ intensive care – **Skip to section** Error! Reference source not found.

☐ No –**Skip to section 5**

☐ I don't know/ I am not sure **skip to section** Error! Reference source not found.

4.1 CARE IN PAEDIATRIC WARD

Q18. During the last period of your child's stay on the paediatric ward, was the care provided by the doctors and nurses sympathetic and caring?

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Sometimes
☐	☐	I don't know/ I am not sure

Q19. During the last period of your child's stay on the ward, to what extent was your child's pain relieved/ managed?

Choose only one answer

☐ NA/ did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ I don't know/ I am not sure

Q20. Were the services provided by the hospital in good working order with specialist/ physician?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they were not working well

☐ I don't know/ I am not sure

Q21. Did you receive support from the medical staff on the ward to take part in your child's care?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ I don't know/ I am not sure

Q22. Were you offered a place to sleep near your baby?

Choose only one answer

☐ Yes, in the same room
☐ Yes, on the ward but in a different room
☐ Yes, but not near my child
☐ No
☐ I don't know/ I am not sure

Q23. Did the siblings receive emotional support from the paediatric staff during their visit to the child?

Choose only one answer

☐ Yes, definitely
☐ Yes, to some extent
☐ No
☐ I don't know/ I am not sure
☐ NA/ child had no siblings

Q24. To what extent did you have confidence in the paediatric staff

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Sometimes
☐	☐	I don't know/ I am not sure

Q25. Did you feel that you were listened to as someone who knew best about your child?

Choose only one answer

☐ Yes, definitely
☐ Yes, to some extent
☐ No
☐ I don't know/ I am not sure

Q26. Generally, do you feel the care provided to your child in the last three months of life while s/he was on the paediatric ward was

Choose only one answer

☐ Excellent
☐ Good
☐ Acceptable
☐ Bad
☐ I don't know/ I am not sure

4.2 CARE IN NEONATAL/ INTENSIVE UNIT

Q27. During the last period of your child's stay in the Neonatal/ intensive unit, was the care provided by the doctors and nurses sympathetic and caring?

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Sometimes
☐	☐	I don't know/ I am not sure

Q28. During the last period of the child’s stay in NICU / intensive unit, to what extent was your child’s pain relieved/ managed?

Choose only one answer

☐ NA/ did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ I don’t know/ I am not sure

Q29. Were the services provided by the hospital in good working order with specialist/ physician?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they were not working well

☐ I don’t know/ I am not sure

Q30. Did you receive support from the medical staff in NICU / intensive unit to take part in your child’s care?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ I don’t know/ I am not sure

Q31. Were you offered a place to sleep near your baby?

Choose only one answer

☐ Yes, in the same room

☐ Yes, on the ward but in a different room

☐ Yes, but not near my child

☐ No

☐ I don’t know/ I am not sure

☐ Don't know

Q32. Did the siblings receive emotional support from the Neonatal/ intensive unit staff during their visit to the child?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ I don’t know/ I am not sure

☐ NA/ child had no siblings

Q33. To what extent did you have confidence in the staff in the Neonatal/ intensive unit

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Sometimes
☐	☐	I don’t know/ I am not Sure

Q34. Did you feel that you were listened to as someone who knew best about your child?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ I don't know/ I am not sure

Q35. **Generally, do you feel the care provided to your child in the last three months of life while s/he was in the Neonatal/ intensive unit was:**

Choose only one answer

☐ Excellent

☐ Good

☐ Acceptable

☐ Bad

☐ I don't know/ I am not sure

5 Care for your child during the last two days before death

Q36. **During the last two days of your child's life, was the care provided by the doctors and nurses sympathetic and caring?**

Choose only one answer
Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Sometimes
☐	☐	I don't know/ I am not sure

Q37. **Please read the following statements and tick the box where you agree as much as possible in regards of the care provided in the last two days of your child's life**

Choose only one answer for each statement (a – c)

	Strongly Agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**NA**	**I don't know/ I am not sure**
(a) your child's needs were met	☐	☐	☐	☐	☐	☐	☐
(b)care for the child's siblings	☐	☐	☐	☐	☐	☐	☐
(c) care for me as a parent	☐	☐	☐	☐	☐	☐	☐

Q38. **Please read the following statements and tick the box where you agree as much as possible in regards of the overall care provided by medical staff in the last two days of your child's life**

Choose only one answer for each statement (a – e))

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don't know/ I am not sure
(a) S/he had enough pain relief	☐	☐	☐	☐	☐	☐	☐
(b) Care and consideration were provided for other problems apart from pain	☐	☐	☐	☐	☐	☐	☐
(c) Her/ his psychological/ emotional needs were considered	☒	☐	☐	☐	☐	☐	☐
d) The family's religious needs were respected	☐	☐	☐	☐	☐	☐	☐
e) Efforts were made to keep her/ him in a place we as a family wanted her/ him to be	☐	☐	☐	☐	☐	☐	☐

Q39. **To what extent do you agree with following statements in regard to the communication between you and care provider during the last two days of your child's life.**

Choose only one answer for each statement (a – d)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don't know/ I am not sure
(a) I / we were kept informed of the child's case and treatment plan							
(b) I/ we had enough time to ask questions and to discuss the	☐	☐	☐	☐	☐	☐	☐

child’s case and treatment plan							
(c) I/ we understood the information provided to us							
(d) I/ we had supportive relationship with the health care providers	☐	☐	☐	☐	☐	☐	☐

6 The last hours of your child’s life before death

Q40. Enough Help and support were given to me and my family by the care providers at time of death?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ I don’t know/ I am not sure

PLEASE COMMENT IN THE SPACE BELOW

____

____

____

____

____

Q41. Did you receive support from care providers to touch or carry your child at the time of death?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ I don’t know/ I am not sure

☐ NA

Q42. After death, did the care providers treat you or her/ his family sensitively?

Choose only one answer

☐ Yes, definitely

☐ No

☐ I don’t know/ I am not sure

☐ Does not apply – I didn’t deal with anyone from the care providers

Q43. **If you wanted to, after the death of your child, were you able to:**

Choose only one answer for every statement (a – g)

	Yes, definitely	Yes, to some extent	Never	I don't know/ I am not sure	NA
(a) Taking enough time with your child	☐	☐	☐	☐	☐
(b) Having enough privacy with your child	☐	☐	☐	☐	☐
(c) washing your child	☐	☐	☐	☐	☐
(d) changing your child's clothing	☐	☐	☐	☐	☐
(e) Taking a souvenir of your child, e.g. a stamp of his/ her hand or foot					

Q44. Since his/her death, have you spoken to anyone from the care providers about your feelings in regards of your child's illness and her/ his death?

Choose only one answer

☐ Yes

☐ No, but I would like to

☐ No, but I did not want to anyway

☐ I don't know/ I am not sure

Q45. Since her/ his death, do you feel that you have received enough support from the care providers?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ I don't know/ I am not sure

7 PLANNING THE CARE

Q46. Did your child know s/he was going to die?

Choose only one answer

☐ Yes, certainly

☐ Yes, possibly

☐ No, most probably **not*- skip to Q50***

☐ No, definitely not ***skip to Q50***

☐ I don't know/ I am not sure ***skip to Q50***

☐ She was not able to say ***skip to Q50***

Q47. In your view, did the person who informed you that s/he will die, did that sensitively?

Choose only one answer

☐ Yes, definitely

☐ Yes, to some extent

☐ Not at all

☐ I don't know/ I am not sure

☐ NA – they did not know my child was going to die

☐ NA – they didn't inform me that my child would die

Q48. Who talked to her/ him about the death?

☐ I did

☐ My husband/ wife

☐ Medical staff

☐ NA

☐ I don't know/ I am not sure

Q49. Did a health professional support you in talking to your child about death?

☐ Yes

☐ No

☐ NA

☐ I don't know/ I am not sure

PLEASE COMMENT IN THE SPACE BELOW

____

____

____

____

Q50. Who talked to her sibling(s) about death?

☐ Myself

☐ My husband/ wife

☐ Medical staff

☐ NA ***- skip to Q52***

☐ I don't know/ I am not sure ***- skip to Q52***

☐ No-one talked to her siblings ***- skip to Q52***

Q51. Did any medical staff support you to talk to the siblings about the death?

☐ Yes

☐ No

☐ NA

☐ I don't know/ I am not sure

PLEASE COMMENT IN THE SPACE BELOW

____

____

____

____

Q52. Where did the child die?

☐ At home

☐ In intensive care unit

☐ In NICU

☐ On the paediatric ward

☐ In the Emergency Department

☐ In an ambulance on the way to hospital

☐ Other

Q53. Had you child ever said where s/he would wanted to die?

Choose only one answer

☐ Yes – ***Go to Q54***

☐ No – ***Go to Q55***

☐ I don't know/ I am not sure ***– Go to Q55***

☐ NA - ***Go to Q55***

Q54. Where did she say that she would like to die?

Choose only one answer

☐ At home

☐ In a hospital

☐ She changed her mind in regard to where to die

☐ She was unable to say

☐ Other

☐ NA

Q55. Where did you want your child to die?

Choose only one answer

☐ At home

☐ In a hospital

☐ I changed her mind in regard to where to die

☐ Other

☐ NA

Q56. Had anyone from the medical staff record this?

☐ Yes

☐ No

☐ I don't know/ I am not sure

Q57. Do you think you, as a family, had enough choices in regards of place of death?

☐ Yes

☐ No

☐ I don't know/ I am not sure

☐ The child died suddenly

Q58. Do you think your child died in the right place?

☐ Yes

☐ No

☐ I don't know/ I am not sure

Q59. Looking back at the last three months of your child's life, did s/he get involved in taking decisions to do with the provided care?

☐ She was involved in taking the decisions as she wanted

☐ She would rather have more involvement

☐ She would rather have less involvement

☐ She was unable to get involved She would have liked to be more involved

☐ I don't know/ I am not sure

Q60. Looking back at the last three months of your child's life, did you get involved in taking decisions to do with the provided care?

☐ Did get involved as I would

☐ I would have preferred more involvement

☐ I would have preferred less involvement

☐ I don't know/ I am not sure

Q61. Looking back at the last three months of your child's life, was there any decision taken in regard to her care which you were not happy about?

☐ Yes

☐ No

☐ NA

Q62. Generally, taking all services into consideration, how would you evaluate the level of care provided to your child during the last three months?

Choose only one answer

☐ Superb

☐ Excellent

☐ Good

☐ Acceptable

☐ Bad

☐ I don't know/ I am not sure

Please use the space below if there is anything you would like to say about the care provided.

Information of your experience might be collected and made available to certified university researchers in order to provide information about improving health care at end of life. All personal information of the participants will be deleted to insure confidentiality. Please do not give names of people or places.

K.8 The VOICES-C (Arabic version 1)

هذا الاستبيان يهدف إلى تقييم الرعاية المقدمة للأطفال الذين توفوا في الأشهر الثلاثة الأخيرة من حياتهم بسبب حالات مرضية مزمنة. رأيك مهم بالنسبة لنا فهو سيساعدنا على تحسين الرعاية المقدمة للأطفال وأسرهم. ندرك أن هذا الاستبيان قد يتسبب بشعور كبير بالأسى، لذلك أنت غير مضطر إلى متابعة الاستبيان ويمكنك التوقف في أي وقت.

يرجى ملء أكبر قدر ممكن من الاستبيان، قد تجد أن بعض الأسئلة أو الأقسام غير ذات صلة بتجربتك.

الإرشادات

- أثناء مراجعة الاستبيان، يُرجى اتباع الإرشادات والإجابة عن الأسئلة بوضع علامة X في المربع أو المربعات المناسب/ة.
- إذا أخطأت بالإجابة أو كنت ترغب بتغيير إجابتك، يرجى شطب الإجابة التي لا تريدها.
- نحن مهتمون أيضاً بتجربة الأخوة؛ إذا لم يكن لديك أطفال آخرين في ذلك الوقت، فيرجى تخطي الأسئلة المظللة باللون البرتقالي.
- نحن مهتمون بتعليقاتك، لذلك يرجى المتابعة على الورقة الإضافية إذا لزم الأمر.
- لا توجد إجابات صحيحة أو خاطئة، فالإجابات الصحيحة هي التي تعبر عن رأيك بصدق. لذلك يرجى الإجابة عن أسئلة هذه الاستبيان بجدية ودقة، مؤكدين لك بأن المعلومات ستعامل بسرية تامة ولن تستخدم إلا للأغراض البحث العلمي فقط.

1 معلومات عنك وعن طفلك

Q1. ما صلة قرابتك بالطفل المتوفى؟

☐ أم

☐ أب

☐ زوجة الأب

☐ زوج الأم

☐ جد/ة

☐ أخ/ت

☐ غير ذلك، أذكر

Q2. كم كان عمر الطفل عند الوفاة؟

يرجى إعطاء العمر بالأيام / الأسابيع / الأشهر / السنوات

Q3. كم عمرك الآن؟

☐ >18

☐ 18 – 19

☐ 20 – 29

☐ 30 – 39

☐ 40 – 49

☐ 50 – 51

☐ 60 – 69

☐ 70 – 79

☐ 80 – 89

☐ 90+

Q4. الجنس:

☐ ذكر

☐ أنثى

Q5. الديانة؟

☐ مسلم

☐ مسيحي

Q6. ما هي جنسيتك؟

☐ أردني

☐ غير أردني، أذكر

Q7. ما هو تأمينك؟

☐ حكومي

☐ عسكري

☐ خاص

☐ لا يوجد تأمين

Q8. كم من الوقت كان طفلك مريضاً قبل الوفاة؟

اختر إجابة واحدة فقط

☐ لم يكن مريضاً بل توفي فجأة
انتقل إلى قسم 0

☐ أقل من 24 ساعة

☐ من يوم إلى أسبوع

☐ من أسبوع إلى شهر

☐ من شهر إلى ستة أشهر

☐ من ستة أشهر إلى سنة

☐ أكثر من سنة

Q9. هل بقي / أمضى طفلك وقتاً بالمنزل خلال الأشهر الثلاثة الأخيرة من الحياة؟

☐ نعم

☐ لا، كان في المستشفى انتقل إلى قسم 0

2 الرعاية في المنزل

هذه الأسئلة حول الرعاية في المنزل. هذه الرعاية يمكن أن تقدمها قطاعات مختلفة، حكومية أو خاصة.

Q10. عندما كان طفلك في المنزل في الأشهر الثلاثة الأخيرة من الحياة، هل تلقى أي رعاية منزلية؟

اختر كل ما ينطبق

☐ ممرض /ة

☐ وكالة خاصة

☐ غير ذلك، أذكر

Q11. خلال الأشهر الثلاثة الأخيرة من الحياة، عندما كان الطفل/ في المنزل، إلى أي مدى تم تخفيف الألم الذي يشعر به طفلك؟

اختر إجابة واحدة فقط

☐ لا ينطبق لم يكن لديه/ أي ألم

☐ تماماً، كل الوقت

☐ تماماً بعض من الوقت

☐ جزئيًا

☐ مطلقاً

☐ لا أعلم/ غير متأكد

Q12. بشكل عام، هل تشعر أن الرعاية المقدمة لطفلك من الأخصائيين في الأشهر الثلاثة الأخيرة من الحياة كانت:

اختر إجابة واحدة فقط

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

3 الرعاية خارج أوقات العمل الرسمي

Q13. عندما كان طفلك في المنزل في الأشهر الثلاثة الأخيرة من الحياة، هل كنت في حاجة إلى الاتصال بأحد من الكادر الصحي لحالة طارئة في المساء أو في عطلة نهاية الأسبوع؟

☐ مطلقاً – انتقل إلى قسم 0

☐ مرة واحدة أو مرتين

☐ ثلاث أو أربع مرّات

☐ أكثر من خمس مرّات

☐ لا أعلم

Q14. آخر مرة كنت في حاجة للاتصال بأحد من الكادر الصحي لحالة طارئة ، من الذي اتصلت به؟

☐ الطبيب الأخصائي/ المعالج

☐ القسم في المستشفى

☐ ممرض من القسم

☐ 911

☐ غير ذلك، أذكر

Q15. بشكل عام، هل تشعر أن الرعاية المقدمة لطفلك في الأشهر الثلاثة الأخيرة من الحياة عندما كان/ت في حاجة ماسة إلى الرعاية في المساء أو في عطلة نهاية الأسبوع كانت:

اختر إجابة واحدة فقط

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

4 الرعاية في المستشفى

Q16. بقي طفلك في المستشفى في أي وقت خلال الأشهر الثلاثة الأخيرة من الحياة؟

☐ نعم، قسم الأطفال -انتقل إلى قسم 0

☐ نعم، قسم الخداج -انتقل إلى قسم 0

☐ نعم، قسم الرعاية الحثيثة -انتقل إلى قسم 0

☐ نعم، قسم الأطفال و الخداج/الرعاية الحثيثة -انتقل إلى قسم 0

☐ لا -انتقل إلى قسم 0

☐ لا أعلم/ غير متأكد -انتقل إلى قسم 0

4.1 الرعاية في قسم الأطفال

Q17. خلال الفترة قام طفلك الأخير في قسم الأطفال، كان يتلقى الرعاية برأفة و اهتمام من قبل الأطباء والتمريض؟

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q18. خلال الفترة قام طفلك الأخيرة في قسم الأطفال، إلى أي مدى تم تخفيف الألم الذي شعر به طفلك؟

اختر إجابة واحدة فقط

☐ لا ينطبق، لم يكن لديه/ا أي ألم

☐ تماماً، كل الوقت

☐ تماماً بعض الوقت

☐ جزئياً

☐ مطلقاً

☐ لا أعلم/ غير متأكد

Q19. هل كانت الخدمات المقدمة من المستشفى تعمل بشكل جيد مع الطبيب الأخصائي/ المعالج ؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا، لم يعملوا معاً بشكل جيد

☐ لا أعلم/ غير متأكد

Q20. هل تلقيت الدعم من كادر قسم الأطفال للمشاركة في رعاية طفلك؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

Q21. هل عُرض عليك مكان للنوم بالقرب من طفلك؟

☐ نعم، في نفس الغرفة

☐ نعم، بالقسم ولكن في غرفة أخرى

☐ نعم، لكن ليس قريب لطفلي

☐ لا

☐ لا أعلم/ غير متأكد

Q22. هل تلقيتم الدعم المعنوي للأخوة من قبل كادر قسم الأطفال أثناء زيارتهم للطفل؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق، لم يكن لديه/ا أي أخوة

Q23. إلى أي مدى وضعت ثقتك بكادر قسم الأطفال ؟

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q24. هل شعرت بأنه تم الاستماع لك، كشريك بشؤون طفلك؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

Q25. بشكل عام، هل تشعر أن الرعاية المقدمة لطفلك في الأشهر الثلاثة الأخيرة من الحياة عندما كان/ت في قسم الأطفال كانت:

اختر إجابة واحدة فقط

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

4.2 الرعاية في قسم الخداج/ العناية الحثيثة

Q26. خلال الفترة التي أقام طفلك الأخير في قسم الخداج/ العناية الحثيثة، كان يتلقى الرعاية برأفة واهتمام من قبل الأطباء والتمريض؟

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q27. خلال الفترة التي أقام طفلك الأخير في قسم الخداج/ العناية الحثيثة, إلى أي مدى تم تخفيف الألم الذي شعر به طفلك؟

اختر إجابة واحدة فقط

☐ لا ينطبق لم يكن لديه/ أي ألم

☐ تماماً، كل الوقت

☐ تماماً بعض من الوقت

☐ جزئيّاً

☐ مطلقاً

☐ لا أعلم/ غير متأكد

Q28. هل كانت الخدمات المقدمة من المستشفى تعمل بشكل جيد مع الطبيب الأخصائي/ المعالج؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا، لم يعملوا معاً بشكل جيد

☐ لا أعلم/ غير متأكد

Q29. هل تلقيت الدعم من كادر الخداج/ العناية الحثيثة للمشاركة في رعاية طفلك؟

اختر إجابة واحدة فقط

☐ نعم، بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

Q30. هل عُرض عليك مكان للنوم بالقرب من طفلك؟

☐ نعم، في نفس الغرفة

☐ نعم، بالقرب لكن في غرفة أخرى

☐ نعم، لكن ليس قريب بالفعل

☐ لا

☐ لا أعلم/ غير متأكد

Q31. هل تلقيتم الدعم للأخوة من قبل كادر الخداج/ العناية الحثيثة أثناء زيارتهم للطفل؟

اختر إجابة واحدة فقط

☐ نعم، بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق، ليس لديه/ا أي أخوة

Q32. إلى أي مدى وضعت ثقتك بكادر قسم الخداج/ العناية الحثيثة ؟

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q33. هل شعرت بأنه تم احترامك، كشريك ومسؤول عن طفلك؟

اختر إجابة واحدة فقط

☐ نعم، بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

Q34. بشكل عام، هل تشعر أن الرعاية المقدمة لطفلك في الأشهر الثلاثة الأخيرة من الحياة في مكان/ مستشفى قسم الخداج/ العناية الحثيثة كانت:

اختر إجابة واحدة فقط

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

5 الرعاية في آخر يومين من حياة طفلك

Q35. في آخر يومين من حياة طفلك، كان يتلقى الرعاية برأفة واهتمام من قبل أطباء المستشفى والتمريض؟

يرجى الإجابة لكل من الأطباء والتمريض

الأطباء	التمريض	
☐	☐	دائماً
☐	☐	معظم الوقت
☐	☐	أحياناً
☐	☐	مطلقاً
☐	☐	لا أعلم/ غير متأكد

Q36. يُرجى الاطلاع على العبارات التالية ووضع علامة في مربع الإجابة الذي يتوافق بشكل أكبر مع رأيك بخصوص الرعاية المقدمة في آخر يومين من حياة طفلك:

اختر إجابة واحدة فقط لكل عبارة (أ_ج)

	أوافق بشدة	أوافق	لا أوافق ولا أعارض	أعارض	أعارض بشدة	لا ينطبق	لا أعلم/ غير متأكد
د) تمت تلبية احتياجاته/ا	☐	☐	☐	☐	☐	☐	☐
ه) تم الاهتمام بأخوته/ا	☐	☐	☐	☐	☐	☐	☐
و) تم الاهتمام بي كوالد/ة	☐	☐	☐	☐	☐	☐	☐

Q37. ما مدى موافقتك على العبارات التالية بخصوص الرعاية المقدمة لطفلك في آخر يومين من الحياة؟

اختر إجابة واحدة فقط لكل عبارة (أ_ه)

	أوافق بشدة	أوافق	لا أوافق ولا أعارض	أعارض	أعارض بشدة	لا ينطبق	لا أعلم/ غير متأكد
و) تم التخفيف من ألمه/ا	☐	☐	☐	☐	☐	☐	☐
ز) فيما عدا الألم تم الاهتمام بالمشاكل الأخرى مثل الغثيان وضيق التنفس	☐	☐	☐	☐	☐	☐	☐
ح) تم الأخذ في الاعتبار حالته/ا النفسية / مشاعره/ا	☐	☐	☐	☐	☐	☐	☐
ط) تم الأخذ في الاعتبار احترام متطلبات الأسرة الدينية	☐	☐	☐	☐	☐	☐	☐
ي) تم بذل مجهود لتحقيق رغبته/ا في مكان الرعاية الذي نريد أن نكون فيه كأسرة	☐	☐	☐	☐	☐	☐	☐

Q38. ما مدى موافقتك على العبارات التالية بخصوص التواصل بينك وبين مقدمي الرعاية لطفلك في آخر يومين من الحياة؟

اختر إجابة واحدة فقط لكل عبارة (أ_د)

	أوافق بشدة	أوافق	لا أوافق ولا أعارض	أعارض	أعارض بشدة	لا ينطبق	لا أعلم/ غير متأكد
ه) أبقونا على علم بحالة الطفل وخطة الرعاية	☐	☐	☐	☐	☐	☐	☐
و) كان لدينا الوقت الكافي لطرح الأسئلة ومناقشة حالة الطفل وخطة الرعاية	☐	☐	☐	☐	☐	☐	☐
ز) فهمنا المعلومات التي تم توفيرها لنا	☐	☐	☐	☐	☐	☐	☐
ح) كانت لدينا علاقة داعمة مع مقدمي الرعاية الصحية	☐	☐	☐	☐	☐	☐	☐

6 الساعات المحيطة بوفاة الطفل

Q39. تقييم المساعدة والدعم الفعليين والنفسيين من قبل مقدمي الرعاية في وقت الوفاة؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

يُرجى التعليق في المساحة أدناه

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Q40. هل تم دعمك من قبل مقدمي الرعاية للمس طفلك أو حمله في وقت الوفاة؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق

Q41. بعد وفاته/ا، هل تعامل مقدمو الرعاية معك أو مع جثته بطريقة حساسة؟

اختر إجابة واحدة فقط

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق، لم نتعامل مع أي فرد من مقدمي الرعاية

Q42. هل إذا أردت بعد وفاة طفلك، هل كنت قادراً على:

اختر إجابة واحدة فقط لكل عبارة (أ_ه)

	نعم بالتأكيد	نعم، إلى حد ما	لا، على الإطلاق	لا أعلم/ غير متأكد	لا ينطبق
و) أخذ الوقت الكافي مع طفلك	☐	☐	☐	☐	☐
ز) أخذ الخصوصية الكافية مع طفلك	☐	☐	☐	☐	☐
ح) غسل طفلك	☐	☐	☐	☐	☐
ط) تغيير ملابس طفلك	☐	☐	☐	☐	☐
ي) الاحتفاظ بتذكار لطفلك (خصلة من شعره/ا)	☐	☐	☐	☐	☐

Q43. منذ وفاته/ا، هل تحدثت إلى أي شخص من مقدمي الرعاية عن مشاعرك بشأن مرض طفلك ووفاته/ا؟

اختر إجابة واحدة فقط

☐ نعم

☐ لا، ولكنني كنت أود ذلك

☐ لا، لكنني لم أكن أريد على أية حال

☐ لا أعلم/ غير متأكد

Q44. منذ وفاته/ا، هل تشعر بأنك تلقيت دعماً كافياً من مقدمي الرعاية؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا

☐ لا أعلم/ غير متأكد

7 التخطيط للرعاية

Q45. هل كان طفلك يعلم أنه سيموت؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، من المحتمل

☐ لا، على الأغلب لا – انتقل إلى السؤال 49

☐ لا بالتأكيد – انتقل إلى السؤال 49

☐ لا أعلم/ غير متأكد – انتقل إلى السؤال 49

☐ لم يكن قادر/ة على الكلام – انتقل إلى السؤال 49

Q46. برأيك، هل قام الشخص الذي أخبرك بأنه/ا سيموت، بذلك بطريقة حساسة ؟

اختر إجابة واحدة فقط

☐ نعم بالتأكيد

☐ نعم، إلى حد ما

☐ لا، على الإطلاق

☐ لا أعلم/ غير متأكد

☐ لا ينطبق – فهم يعرفوا أن طفلي سيموت

☐ لا ينطبق – لم يخبروني أن طفلي سيموت

Q47. من تحدث معه/ا عن الوفاة؟

☐ أنا

☐ زوجي/زوجتي

☐ من الكادر الصحي

☐ لا ينطبق

☐ لا أعلم/ غير متأكد

Q48. هل دعمك أحد من الكادر الصحي في التحدث إلى طفلك عن الوفاة؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق

يُرجى التعليق في المساحة أدناه

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____

____

Q49. من تحدث مع الإخوة عن الوفاة؟

☐ أنا

☐ زوجي/زوجتي

☐ من الكادر الصحي

☐ لا ينطبق – انتقل إلى السؤال 51

☐ لا أعلم/ غير متأكد انتقل إلى السؤال 51

☐ لا أحد انتقل إلى السؤال 51

Q50. هل دعمك أحد من الكادر الصحي في التحدث إلى الإخوة عن الوفاة؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

☐ لا ينطبق

يُرجى التعليق في المساحة أدناه

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Q51. أين توفي الطفل؟

☐ في البيت

☐ في قسم الأطفال

☐ في قسم الخداج

☐ في قسم العناية الحثيثة

☐ في قسم الطوارئ

☐ في سيارة الإسعاف بالطريق إلى المستشفى

☐ غير ذلك

Q52. هل سبق لطفلك أن قال/ت أين تريد الوفاة؟

☐ نعم - انتقل إلى السؤال 53

☐ لا - انتقل إلى السؤال 54

☐ لا أعلم/ غير متأكد - انتقل إلى السؤال 54

☐ لا ينطبق - انتقل إلى السؤال 54

Q53. أين اراد طفلك أن يكون وقت الوفاة؟

☐ في البيت

☐ في المستشفى

☐ غير/ت رأيه/ا بخصوص مكان الوفاة

☐ لم يكن/تكن قادر/ة على الكلام

☐ غير ذلك

☐ لا ينطبق

Q54. أين أردت أن يكون طفلك وقت الوفاة؟

☐ في البيت

☐ في المستشفى

☐ غيرت رأيي بخصوص مكان الوفاة

☐ غير ذلك

☐ لا ينطبق

Q55. هل قام أحد من الكادر الطبي بتدوين ذلك؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

Q56. هل تعتقد بأنك تمكنت من الخيار المفضل بخصوص مكان الوفاة؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

☐ توفي الطفل فجأة

Q57. هل تعتقد أن طفلك توفي في المكان الصحيح؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

Q58. بالنظر إلى الأشهر الثلاثة الأخيرة من حياة طفلك، هل شارك/ت في اتخاذ القرارات بشأن الرعاية المقدمة؟

☐ كان/ت مشترك/ة باتخاذ القرارات كما أراد/ت

☐ كان/ت يفضل/تفضل أن تكون أكثر مشاركة

☐ كان/ت يفضل/تفضل أن تكون أقل مشاركة

☐ لم يكن/تكن قادرة على المشاركة

☐ لا أعلم/ غير متأكد

Q59. بالنظر إلى الأشهر الثلاثة الأخيرة من حياة طفلك، هل شارك/ت في اتخاذ القرارات بشأن الرعاية المقدمة؟

☐ كنت أشارك باتخاذ القرارات كما أردت

☐ كنت أفضّل أن أكون أكثر مشاركة

☐ كنت أفضّل أن أكون أقل مشاركة

☐ لا أعلم/ غير متأكد

Q60. بالنظر إلى الأشهر الثلاثة الأخيرة من حياة طفلك، هل كانت أي قرارات اتخذت بشأن رعايته لم تكن راضياً عنها؟

☐ نعم

☐ لا

☐ لا أعلم/ غير متأكد

Q61. بشكل عام، ومع أخذ كل الخدمات بعين الاعتبار، كيف يمكنك تقييم مستوى الرعاية التي قُدمت لطفلك في الأشهر الثلاثة الأخيرة؟

اختر إجابة واحدة فقط

☐ متفوقة/ متقدمة

☐ ممتازة

☐ جيدة

☐ مقبولة

☐ سيئة

☐ لا أعلم/ غير متأكد

يرجى استخدام المساحة أدناه إذا كان هناك أي شيء تود قوله عن الرعاية المقدمة.

قد يتم جمع المعلومات المتعلقة بتجربتك وتفسيرها الباحثين المعنيين من قبل الجامعة بهدف تقييم معلومات عن تجربتين الرعاية الصحية عند نهاية الحياة. سوف يتم حذف كل المعلومات الشخصية عن المشاركين بالبحث لغايات ضمان السرية. يُرجى عدم إعطاء أسماء الأشخاص أو الأماكن.

K.9 Summary of problems and potential amendments based on cognitive interviews with bereaved parents in Jordan

Question	Summary of the main problems	Problem's category	Suggested changes
Q8. How long had she been ill before she died?	This question was confusing whether it is referring to the length of illness since diagnosis or since the child's condition worsen	Linguistic problem; confusing wording/ not clear	Retained item, consider adding a resposen option and free text space for further details
Q10. When she was at home in the last three months of life, did she get any help at home?	The child could get help from relatives/ might changing option (no, only care provided by family members)	Response options	Consider modifying "No - she was at the hospital" into "Yes, she was cared by family members"
Q15. The last time this happened, who did you contact?	The participants needed clarification of the term "consultant" i.e. the doctor who followed the child's condition not the consultant at the hospital	Linguistic problem; confusing wording/ not clear	Maybe consider "the doctor following her case"
Q30. Were you supported by staff to be involved in caring for her?	After C/S the mother cannot be with the child at NICU and the child is dependent on medical devices. Therefore, the parents didn't ask, and no one offered them to take a part in the care.	Response options (missing)	Consider adding; "I didn't ask, and no one offered that"

Question	Summary of the main problems	Problem's category	Suggested changes
Q31. Were you offered a place to sleep to be close to her?	The mother was admitted to another department	Response options (missing)	Consider adding "I was admitted to the maternity ward"
Q32. Was / were her sibling(s) supported by health professionals when they visited?	Siblings didn't visit for several reasons mainly the parents' wish;	Response options (missing)	Consider adding "doesn't apply, they didn't visit" "doesn't apply, she didn't have siblings"
Q36. How much of the time was she looked after in a caring way in the last two days of her life?	One participant had a problem understanding the question	Question structure	Consider rephrasing the question "Did you feel that the medical staff was providing care for the child in a caring way"
Q37. Please look at the following statements and tick the answer box that corresponds most with your opinion about the help provided in the last two days of life	There were siblings but they didn't visit	Response options	Options can't be changed
Q38. As far as you are able to say, how much do you agree with the following statements about the overall level of	(d) there isn't any role for religious personnel (Sheikh) or religious ceremonies to be performed around the time of death	Limited applicability; religious or cultural	(d) consider adding (such as, listening or reciting Quran) (e) deleted

Question	Summary of the main problems	Problem's category	Suggested changes
care given by health professionals to her in the last two days of life?	(e) Place of care; there was no choice to consider moving/ discharging the child		
Q39. Overall, how much do you agree with the following statements about communication between you and health care professionals in the last two days of her life?	A participant needed clarification regarding how to be supported by staff	Question structure	d) can be rephrased as "I was supported as the child's companion"
Q41. Were you supported by staff to touch or hold your child at this time?	I didn't ask because I was going to finish the paperwork, no one offered, or the people with me didn't allow me to see the child	Limited applicability;	Keep to be explores in the feasibility study
Q43. If you wanted to, after her death, were you able to:	Burial ceremonies arranged should be arranged quickly, parents didn't ask and were not offered, unless they were waiting for their mean of transport Muslims aren't dressed for burial Washing; we have to wash the dead body before being wrapped and buried	Limited applicability; religious or cultural	Delete the sub items and replaced with one item regarding washing the child

Question	Summary of the main problems	Problem's category	Suggested changes
	Memorials; only keeping clothes or photos		
Q44. Since she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about her illness and death	There isn't any role for hospitals or caregivers to contact bereaved parents after the child's death, however, long-term cases and cancer patients usually have a connection with frequently treated staff i.e. the consultant and nurses from the unit where the child was admitted to	Limited applicability; available services	No need to be changed
Q46. Did she know she was going to die?	Even if the child is aware and can understand, they will not be told of her diagnosis	Limited applicability; religious or cultural	No need to change the options but change the order of questions (46 and 47)
Q47. In your opinion, did the person who told you she was going to die break the news to you in a sensitive and caring way?	Parents were given a general notion that the child was dying if healthcare professionals knew the child was dying	Limited applicability; religious or cultural	No need to change the options but change the order of questions (46 and 47)
Q50. Who talked to her sibling(s) about death?	Sometimes other family members may inform the siblings with the child's death	Response options (missing)	Consider adding; "Another family member" or "Someone else, specify"

Question	Summary of the main problems	Problem's category	Suggested changes
Q53. Did she ever say where she would like to die?	It is uncommon to discuss death and place of death with the child	Limited applicability; religious or cultural	Keep to be explores in the feasibility study
Q54. Where did she say that she would like to die?	It is uncommon to discuss death and place of death with the child	Limited applicability; religious or cultural	Keep to be explores in the feasibility study
Q55. Where did you want her to die?	There was no choice to take the child home	Limited applicability; religious or cultural	Keep to be explores in the feasibility study
Q56. Did the health care staff have a record of this?	There weren't any discussions about the place of death	Limited applicability	Change according to question 55
Q57. Do you think you as a family had enough choice about where she died?	There was no choice to take the child home	Limited applicability; religious or cultural	Keep to be explores in the feasibility study

Appendix L Phase III documents

L.1 VOICES-Child questionnaire (female version 2)

This questionnaire is about the experiences of children who have died after a life-limiting condition and their families. The information you give will help us improve care for children who are dying, and for their family and friends. Your views are, therefore, important to us. We realise this questionnaire may bring back strong memories. If you feel upset, you don't have to continue with the questionnaire and can stop at any time. We are interested in finding out about the care provided to you and your child in the last three months of her life. You might find some of the questions or sections are not relevant to you. Please fill in as much of the questionnaire as you can.

Instructions

- As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box or boxes.
- If you make a mistake or wish to change your answer, cross through the answer you do **NOT** want.
- We are also interested in experiences of siblings; if you didn't have other children at the time of your child's death, please skip the questions highlighted in orange.
- We are very interested in what you have to say. Please continue on extra sheets if necessary.

1 INFORMATION ABOUT YOU BOTH

Q1. What was your relationship to her?

Were you her:

☐ Mother

☐ Father

☐ Stepmother

☐ Stepfather

☐ Grandparent

☐ Sibling

☐ Other – please write in the space below:

____

____

____

Q2. What was her age when she died?

PLEASE GIVE DAYS, WEEKS, MONTHS OR YEARS

____

Q3. What is your age now?

☐ < 18

☐ 18 – 19

☐ 20 – 29

☐ 30 – 39

☐ 40 – 49

☐ 50 – 59

☐ 60 – 69

☐ 70 – 79

☐ 80 – 89

☐ 90+

Q4. Are you:

☐ Male

☐ Female

Q5. What is her religion?

☐ Muslim

☐ Christian (all denominations)

Q6. What is your nationality?

☐ Jordanian

☐ Non-Jordanian – please write in the space below:

____

Q7. What is your health insurance?

☐ Public

☐ Military

☐ Private

☐ No insurance

Q8. How long had she been ill before she died?

Tick one only

☐ She was not ill – she died suddenly – ***Go Section 5***

☐ Less than 24 hours

☐ Between one day and one week

☐ Between one week and one month

☐ Between one month and six months

☐ Between six months and one year

☐ More than one year

☐ She was ill from the moment she was born

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

____

____

____

Q9. Did she spend any time at home during the last three months of life?

☐ Yes

☐ No - she was in the hospital – ***Go to section 4***

2 CARE AT HOME

These questions are about care at home. These may be provided by different organisations, such as a private agency or public services (not family or friends)

Q10. When she was at home in the last three months of life, did she get any help at home?

☐ Yes

☐ No - she was in the hospital – ***Go to section 4***

Q11. Who provided this care?

Tick all that apply

☐ A nurse

☐ A private agency

☐ Somebody else – please write in the space below

____

____

Q12. During the last three months of her life, while she was at home, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don't know

Q13. Overall, do you feel that the care she got from her consultant in the last three months of life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

3 URGENT CARE PROVIDED OUT OF HOURS

Q14. In the last three months of life, while she was at home, did you ever need to contact a health professional for something urgent in the evening or at the weekend?

☐ Not at all in the last 3 months - ***Go to section 4***

☐ Once or twice

☐ Three or four times

☐ Five times or more

☐ Don't know

Q15. The last time this happened, who did you contact?

☐ the consultant in charge of/ following her case

☐ The ward/unit in the hospital

☐ A nurse from the ward

☐ 911

☐ Someone else – please write in the space below

____

Q16. Overall, do you feel that the care she got when she needed care urgently in the evenings or weekends in the last three months of life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don’t know

4 LAST HOSPITAL STAY

Q17. Did she stay in hospital at any time during her last three months of life?

☐ Yes – she was in the Paediatric Ward– **Go to section 4.1**

☐ Yes –she was in the Neonatal Intensive Care Unit (NICU) – **Go to section 4.2**

☐ Yes – she was in the Paediatric Intensive Care Unit (PICU) – **Go to section 4.2**

☐ Yes – she was in the Neonatal / Paediatric Intensive Care Unit (NICU / PICU) and in the Paediatric Ward – **Go to section 4.1**

☐ No – **Go to section 5**

☐ Don’t know – **Go to section 5**

4.1 CARE IN PAEDIATRIC WARD

Q18. During her last stay on the Paediatric Ward, how much of her time was she looked after in a caring way by the hospital doctors and nurses?

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don’t know

Q19. During her last stay in the paediatric ward, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don’t know

Q20. Did the hospital services work well together with the consultant in charge of/ following her case?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ Don’t know

Q21. Were you supported by staff to be involved in caring for her?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q22. Were you offered a place to sleep to be close to her?

☐ Yes, in the same room

☐ Yes, on the unit but not in the same room

☐ Yes, but it was not as close as I wanted

☐ No, I would have liked to have been offered somewhere

☐ Don't know

Q23. Was / were her sibling(s) supported by health professionals when they visited?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

☐ Does not apply, there were no siblings

☐ Does not apply, we did not want her siblings to visit her

☐ Does not apply, the hospital did not allow them to visit her

Q24. To what extent did you place your trust in the health professionals

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don’t know

Q25. Did you feel listened to and acknowledged as a parent, as an expert about your child?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q26. Overall, do you feel that the care she got from the staff on the ward in the last three months of her life was

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don’t know

4.2 CARE IN NICU OR PICU

Q27. During her last hospital admission in the Neonatal / Paediatric Intensive Care Unit (NICU / PICU), how much of her time was she looked after in a caring way by the hospital doctors and nurses?

Please answer for both doctors and nurses

Doctors	**Nurses**	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don’t know

Q28. During her time in NICU / PICU, how well was her pain relieved?

Tick one only

☐ Does not apply - she did not have any pain

☐ Completely, all of the time

☐ Completely, some of the time

☐ Partially

☐ Not at all

☐ Don’t know

Q29. Did the hospital services work well together with the consultant in charge of/ following her case?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, they did not work well together

☐ Don't know

Q30. Were you supported by staff to be involved in caring for her?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, I was not allowed to be involved

☐ No, I was not offered to be involved

☐ Don't know

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

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Q31. Were you offered a place to sleep to be close to her?

Tick one only

☐ Yes, in the same room

☐ Yes, on the unit but not in the same room

☐ Yes, but it was not as close as I wanted

☐ No, I would have liked to have been offered somewhere

☐ Does not apply, I was already a patient in the hospital

☐ Don't know

Q32. Was / were her sibling(s) supported by health professionals when they visited?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

☐ Does not apply, there were no siblings

☐ Does not apply, we did not want her siblings to visit her

☐ Does not apply, they were not allowed to visit her

Q33. To what extent did you place your trust in the health professionals

Tick one only

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q34. Did you feel listened to and acknowledged as a parent about your child?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Don't know

Q35. Overall, do you feel that the care she got from the staff on the unit in the last three months of her life was:

Tick one only

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Don't know

5 EXPERIENCES IN LAST 2 DAYS OF LIFE

Q36. How much of the time was she looked after in a caring way in the last two days of her life?

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

Q37. **Please look at the following statements and tick the answer box that corresponds most with your opinion about the help provided in the last two days of life**

Tick only one response per statement (a-c)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don't know
(a) Her needs were met	☐	☐	☐	☐	☐	☐	☐
(b) Her sibling(s) were looked after by staff	☐	☐	☐	☐	☐	☐	☐
(c) As a parent was looked after, such as the staff spoke to me or invited me to have a cup of coffee	☐	☐	☐	☐	☐	☐	☐

Q38. **As far as you are able to say, how much do you agree with the following statements about the overall level of care given by health professionals to her in the last two days of life?**

Tick only one response per statement (a – d)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don't know
(a) In the last two days of life, she had sufficient pain relief	☐	☐	☐	☐	☐	☐	☐
(b) In the last two days of life, care and attention were given to problems apart from pain	☐	☐	☐	☐	☐	☐	☐
(c) In the last two days of life, her emotional needs were considered and supported	☐	☐	☐	☐	☐	☐	☐
d) In the last two days of life, the family's spiritual and/or religious needs were considered and supported such as reciting religious texts	☐	☐	☐	☐	☐	☐	☐

Q39. Overall, how much do you agree with the following statements about communication between you and health care professionals in the last two days of her life?

Tick only one response per statement (a-c)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	I don't know
(a) I/we were kept informed on her condition and care	☐	☐	☐	☐	☐	☐	☐
(b) I/we had enough time with staff to ask questions and discuss her condition and care	☐	☐	☐	☐	☐	☐	☐
(c) I/we understood the information provided to us	☐	☐	☐	☐	☐	☐	☐

6 HOURS SURROUNDING HER DEATH

Q40. Were you or her family given enough help and support by the healthcare team at the actual time of her death?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, not at all

☐ Not sure

Q41. Were you supported by staff to touch or hold your child at this time?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, I was not allowed to hold or touch the child

☐ No, I was not offered to hold or touch the child

☐ Not sure

☐ Not applicable

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

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Q42. After she died, did staff deal with you or her family in a sensitive manner?

Tick one only

☐ Yes

☐ No

☐ Not sure

☐ Does not apply – I didn't have contact with staff

Q43. If you wanted to, after her death, were you able to be involved in her wash (perform Ghusl)?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, not at all

☐ Not sure

☐ Does not apply

Q44. Since she died, have you talked to any health care professionals, about your feelings about her illness and death

Tick one only

☐ Yes

☐ No, but I would have liked to

☐ No, but I did not want to anyway

☐ Not sure

Q45. Since she died, do you feel that you have received enough support from care professionals?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, but I would have liked to

☐ No, but I did not want to anyway

☐ Not sure

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

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7 PLANNING HER CARE

Q46. In your opinion, did the person who told you she was going to die break the news to you in a sensitive and caring way?

Tick one only

☐ Yes, definitely

☐ Yes, to some extent

☐ No, not at all

☐ Not sure

☐ Does not apply – I did not know she was going to die

☐ Does not apply – No one told me she was going to die

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

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Q47. Did she know she was going to die?

Tick one only

☐ Yes, certainly

☐ Yes, probably

☐ No, probably not – ***Go to question 50***

☐ No, definitely no – ***Go to question 50***

☐ Not sure – ***Go to question 50***

☐ She was not able to say – ***Go to question 50***

Q48. Who talked to her about death?

☐ I did

☐ My partner did

☐ another family member did, such as aunts or grandparents

☐ A health professional did

☐ Does not apply

☐ Don't know

Q49. Did a health professional support you in talking to your child about death?

☐ Yes

☐ No

☐ Does not apply

☐ Don't know

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

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____

____

Q50. Who talked to her sibling(s) about death?

☐ I did

☐ My partner did

☐ another family member did, such as aunts or grandparents

☐ A health professional did

☐ Does not apply – ***Go to question 52***

☐ Don't know – ***Go to question 52***

☐ No-one talked to her siblings – ***Go to question 52***

Q51. Did a health professional support you in talking to her sibling(s) about death?

☐ Yes

☐ No

☐ Does not apply

☐ Don't know

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

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____

Q52. Where did she die?

☐ At home

☐ On the paediatric ward

☐ In NICU

☐ In PICU

☐ In a hospital Emergency Department

☐ In an ambulance on the way to hospital

☐ Somewhere else

Q53. Would you have liked as a family to have choice about where she died?

☐ Yes

☐ No

☐ Not sure

☐ She died suddenly

PLEASE FEEL FREE TO MAKE COMMENTS IN THE SPACE BELOW

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Q54. Looking back over the last three months of her life, was <u>she</u> involved in decisions about her care as much as she would have wanted?

☐ She was involved as much as she wanted to be

☐ She would have liked to be more involved

☐ She would have liked to be less involved

☐ She was not able to be involved

☐ Not sure

Q55. Looking back over the last three months of her life, <u>were you</u> involved in decisions about her care as much as you would have wanted?

☐ I was involved as much as I wanted to be

☐ I would have liked to be more involved

☐ I would have liked to be less involved

☐ Not sure

Q56. Looking back over the last three months of her life, were any decisions made about her care that you were not happy with?

☐ Yes

☐ No

☐ Not sure

Q57. Overall, and taking all services into account, how would you rate her care in the last three months of life?

Tick one only

☐ Outstanding

☐ Excellent

☐ Good

☐ Fair

☐ Poor

☐ Not sure

PLEASE USE THE SPACE BELOW IF THERE IS ANYTHING YOU WOULD LIKE TO SAY ABOUT THE CARE PROVIDED. For example, what was good or bad about the care or if there are particular experiences that you would like to share with us.

All personal information will be deleted by the researcher to ensure confidentiality. To help us to do this, please do not give the names of people or places.

L.2 Feasibility study recruitement materials

L.2.1 First contact text message

Assalam Alaykum

I am the [coordinator name], I am a nurse helping in a research study about the quality of paediatric end of life care. As a bereaved carer who had a child who received end of life care in Jordan, we had your contact number from [site name]. The study involves completing a questionnaire about the quality of care provided to children and young people who are approaching their end of life. Your participation in this study is voluntary and all of your responses are completely anonymous. I will call you later today to explain more about the study. If you do not wish for the researcher to call you, please text back to let us know and we will not bother you.

L.2.2 Consent form

Participant Identification Number:

STUDY TITLE: Experiences of End of Life care for children with life-limiting conditions reported by bereaved parents' in Jordan.

I will read a list of statements. You need to agree to all the points if you want to take part in this study. I will write your initials in each box if you agree.

1. I confirm that I have understood the information sheet dated 21 September 2020 (Version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I agree to take part in this research project and agree for my data to be used for the purpose of this study. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview without giving a reason, and without my medical care or legal rights being affected. I also understand that I can withdraw my data from use in this study up to 2 weeks following the interview. ☐
4. I understand that the information collected about me will be used in future ethically approved research studies and may be shared anonymously with other researchers. ☐
5. I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. my name will not be used). ☐
6. I understand that data collected during the study may be looked at by individuals from the University of Southampton or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
7. I understand that information collected about me during my participation in this study will be stored on a password-protected computer and that this information will only be used for the purpose of ethically approved research studies. ☐
8. I give permission for our discussion to be audio-recorded. ☐

Name of Participant	Date	Signature
Name of of Person taking consent	Date	

L.2.3 Participant Information Sheet (PIS)

STUDY TITLE:

Experiences of End of Life care for children with life-limiting conditions reported by bereaved parents in Jordan.

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Take time to make the decision. If anything is not clear or you would like more information before you decide to take part in this research, you can contact the researcher by telephone or email and ask your questions.

What is the research about?

The overall aim of this study is to understand the views of bereaved parents about the end of life services for children and young people. Unfortunately, little is known about the quality of care provided for children and young people at the end of their lives. Therefore, we would like to find out your opinions about the quality of care provided for your child in the last three months of their life using the attached questionnaire. We are keen to know about your experiences and views through this sensitive time as this will help us to understand how the paediatric end of life care services may be improved in the future.

Why have I been asked to participate?

We are asking bereaved parents and carers who have lost a child (with a life-limiting condition) that has passed away more than three months ago and up to two years.

What will happen to me if I take part?

If you agree to take part in the study, you will be invited to complete the questionnaire on the phone. The researcher will read the VOICES-C questionnaire which asks about your views concerning the end of life care services. The interview will be recorded and may take up to 40 minutes to complete.

Are there any benefits in my taking part?

There are unlikely to be direct benefits to you if you agreed to participate, but it is hoped that the information you provide will help us evaluate and improve the healthcare services provided for children approaching death, and their families.

Are there any risks involved?

We do not anticipate any harm to you by taking part in this study. Although the interview is not intended to be upsetting, we understand that some questions could distress you, since they will remind you of your child. We would ask that ahead of the interview you identify a person who you would feel comfortable talking to after the interview. Please ask this person if they are okay with being contacted by the researcher, before we meet for the interview. The support person will only be contacted by the interviewer in the event it is deemed essential for them to be contacted.

What data will be collected?

The researcher will collect demographic data about you and your child such as age, ethnicity and religion. In addition, information regarding your opinion of the provided care in the last three months of your child's life will be collected.

Will my participation be confidential?

Yes.

The interview is completely confidential but not anonymous. The identity of the participants who take part in the study will remain confidential and you will not be identified in any report or publication. For the purposes of this study, you will be given a unique numbered code. Some of what you say during the interview may be taken as direct quotes and included in scientific research reports. Your name will not be used in any of these quotes so the words will not be attributable to you.

The members of the research team and responsible members of the University of Southampton will access to anonymised data that you provide, but no identifiable information about you will be revealed.

Do I have to take part?

No, it is entirely up to you to decide whether to take part or not. Your participation in this research project is entirely voluntary. Please note that verbal consent will be audio-recorded before completing the questionnaire.

What happens if I change my mind?

It is important to discuss any concerns you may have with the researcher before you agree to participate. However, if you do not want to continue, you can change your mind at any time throughout the completion. You can withdraw and you do not have to give any reason for this. You can withdraw your data up to 2 weeks after the interview, however, after that time it will be no longer possible to withdraw your data as the researcher will start the data analysis.

What will happen to the results of the research?

The results of the research will be published in scientific journals or publications and presented at scientific conferences. It may also be shared with organisations who advocate for excellence in care for children. It is not planned to feedback any results from the research. However, you can contact the researcher if you would like to receive a summary of the research findings.

Where can I get more information?

If you have any questions, I will be happy to answer any questions you might have.
Please contact Rawnaq Almahadeen, the researcher who is organising the study.
Tel: [PHONE NO]
Email: rma1y14@soton.ac.uk.

What happens if something goes wrong?

If you have a concern or complaint about this study, please contact the researcher who will do her best to address them.
Tel: +44 (0)7745861282
Email: rma1y14@soton.ac.uk.
If you would like to make a complaint about this study or talk to someone outside of the research team you should contact the University Research Integrity and Governance Team (Address: University of Southampton, Building 28, Highfield, Southampton SO17 1BJ
Tel: +44(0)2380595058
Email: rgoinfo@soton.ac.uk

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, ‘Personal data’ means any information that relates to and is capable of identifying a living individual. The University’s data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).
This Participant Information Sheet tells you what data is collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf).

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

Each participant will be assigned a unique study code. Personal information and contact details relating to each of these study identifiers will be stored in a separate locked cabinet to that containing completed questionnaires. Data in electronic format will be password protected and be stored according to University of Southampton regulations. Participants will not be identifiable in any written report/ paper associated with the research. Audio-recordings will be downloaded on to a password protected laptop prior to transcription. Transcriptions will then be anonymised, removing all information that might identify participants. Data will be accessible only by the research team members. All data will be anonymised using unique identifiers, and the personal details that are linked to these identifiers will be kept in a separate locked cabinet or digital file. Anonymised transcripts and audio recordings will be kept, according to University of Southampton regulations, for a period of 10 years. The data collected from this study can be used in future studies in paediatric end of life and palliative care and service evaluation.

Thank you.

For further information, please feel free to contact

Researcher:

Rawnaq Almahadeen

PhD student, Faculty of Environmental and Life Sciences, University of Southampton, Southampton SO17 1BJ Room: 67/1013

Email rma1y14@soton.a.uk

Tel +44 (0)7745861282

Researcher's supervisors:

- Alison Richardson

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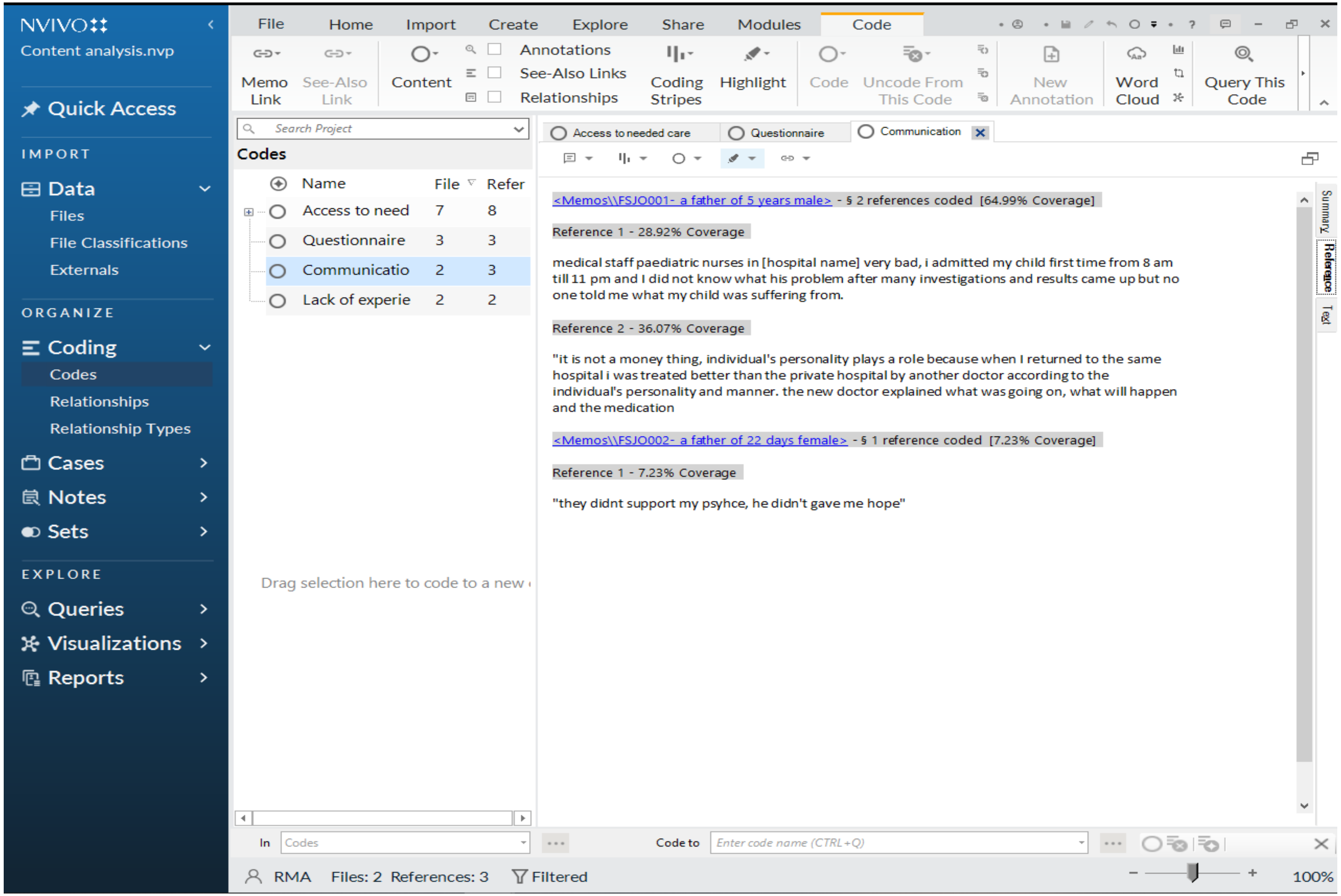
- Dr Richard Wagland PhD, MA, BSc, RN

Senior Research Fellow Health Sciences Faculty of Environmental and Life Sciences, University of Southampton SO17 1BJ Room: 67/4005

r.wagland@soton.ac.uk

L.3 Examples of coding adopted for open-ended question using NVivo



Codes

Name	File	Refer
Access to need	7	8
Questionnaire	3	3
Communicatio	2	3
Lack of experie	2	2

<Memos\\FSJO001- a father of 5 years male> - § 2 references coded [64.99% Coverage]

Reference 1 - 28.92% Coverage

medical staff paediatric nurses in [hospital name] very bad, i admitted my child first time from 8 am till 11 pm and I did not know what his problem after many investigations and results came up but no one told me what my child was suffering from.

Reference 2 - 36.07% Coverage

"it is not a money thing, individual's personality plays a role because when I returned to the same hospital i was treated better than the private hospital by another doctor according to the individual's personality and manner. the new doctor explained what was going on, what will happen and the medication

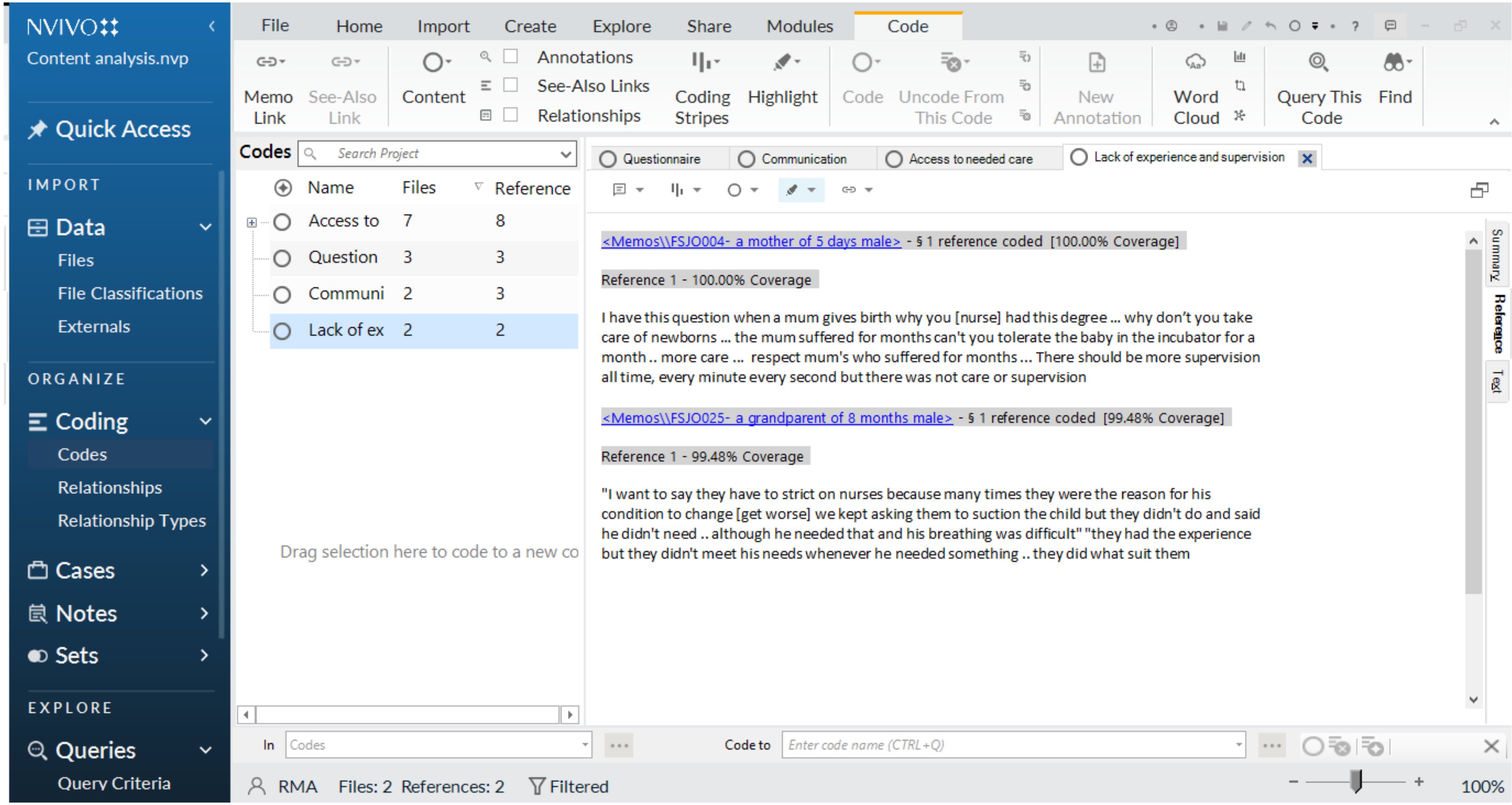
<Memos\\FSJO002- a father of 22 days female> - § 1 reference coded [7.23% Coverage]

Reference 1 - 7.23% Coverage

"they didnt support my psyhce, he didn't gave me hope"

RMA Files: 2 References: 3 Filtered

Phase III documents



Name	Files	Reference
Access to	7	8
Question	3	3
Communi	2	3
Lack of ex	2	2

<Memos\\FSJO004- a mother of 5 days male> - § 1 reference coded [100.00% Coverage]

Reference 1 - 100.00% Coverage

I have this question when a mum gives birth why you [nurse] had this degree ... why don’t you take care of newborns ... the mum suffered for months can't you tolerate the baby in the incubator for a month .. more care ... respect mum's who suffered for months ... There should be more supervision all time, every minute every second but there was not care or supervision

<Memos\\FSJO025- a grandparent of 8 months male> - § 1 reference coded [99.48% Coverage]

Reference 1 - 99.48% Coverage

"I want to say they have to strict on nurses because many times they were the reason for his condition to change [get worse] we kept asking them to suction the child but they didn't do and said he didn't need .. although he needed that and his breathing was difficult" "they had the experience but they didn't meet his needs whenever he needed something .. they did what suit them

Appendix M Jordan approvals

M.1 Ministry of health approval

المملكة الأردنية الهاشمية

وزارة الصحة

الرقم
التاريخ ١٦/٩/ ٢٠٢٠م
الموافق م ب ا/ لجنة أخلاقيات / ١١٤٦٦٦

مدير مديرية التعليم وتطوير الموارد البشرية

تحية طيبة وبعد،

اشارة لكتابكم رقم تطوير/معلومات/٧٦٣٤ تاريخ ٢٠٢٠/٩/٢ بخصوص البحث العلمي المقدم من قبل طالبة الدكتوراه / رونق محمد عبدالله المحادين.

أرفق بطيه قرار لجنة اخلاقيات البحث العلمي والمتضمن الموافقة على اجراء البحث العائد للمذكوره أعلاه.

للاطلاع واجراءاتكم لطفا.

واقبلو فائق الاحترام .....

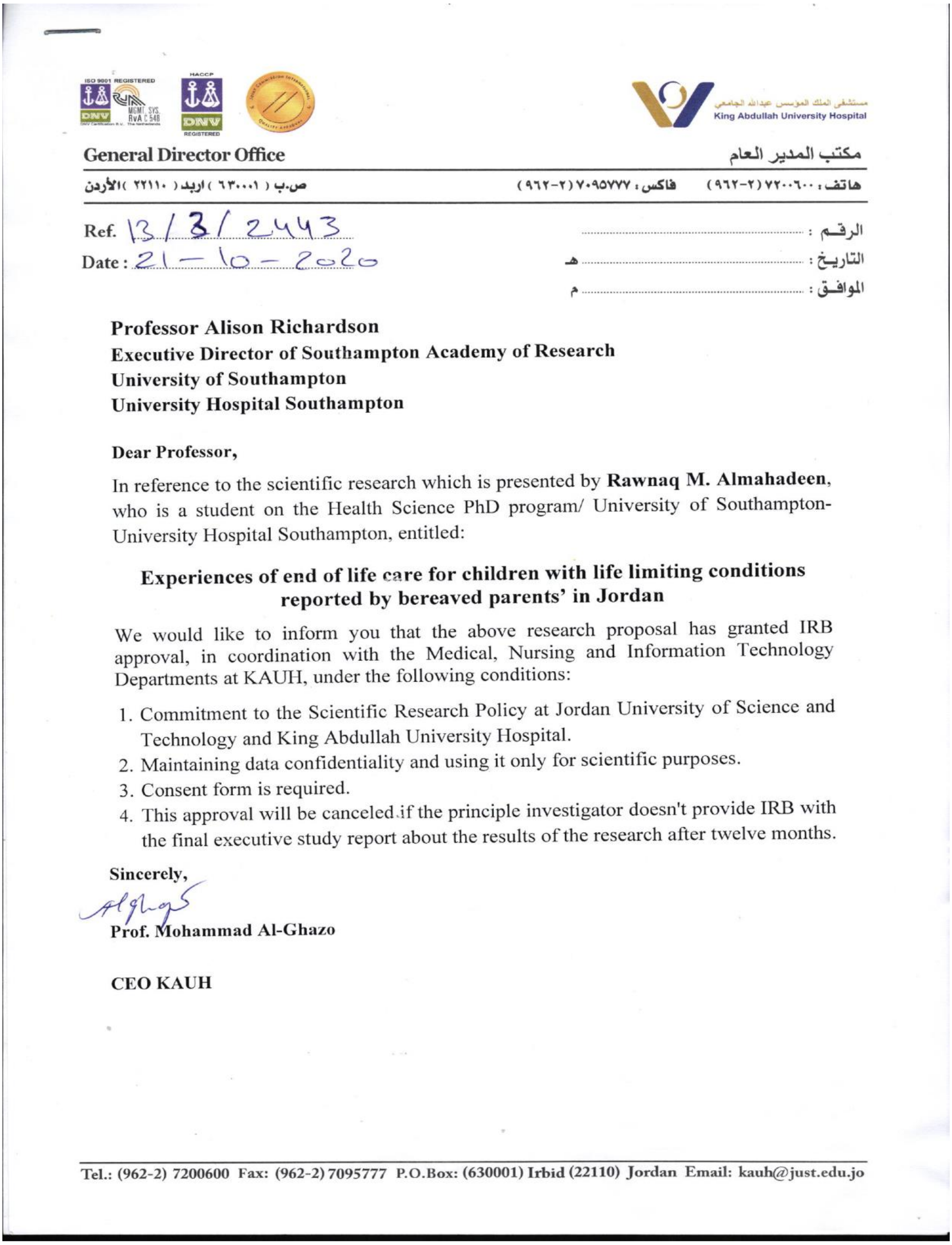
مدير ادارة مستشفيات البشير

الدكتور محمود سليمان زريقات

خ ع

المملكة الأردنية الهاشمية
هاتف: ٠٠٩٦٢٦٥٢٠٠٢٣٠ فاكس: ٠٠٩٦٢٦٥٦٨٨٢٧٣٠ ص.ب ٨٦ عمان ١١١١٨ الأردن. الموقع الإلكتروني: www.moh.gov.jo

M.2 King Adullah University Hospital approval



مستشفى الملك المؤسس عبدالله الجامعي
King Abdullah University Hospital

General Director Office
مكتب المدير العام

هاتف : ٧٢٠٠٦٠٠ (٢-٩٦٢) فاكس : ٧٠٩٥٧٧٧ (٢-٩٦٢) ص.ب (٦٣٠٠٠١) اربد (٢٢١١٠)الأردن

Ref. 13/3/2443
Date : 21-10-2020

الرقم :
التاريخ : هـ
الموافق : م

Professor Alison Richardson
Executive Director of Southampton Academy of Research
University of Southampton
University Hospital Southampton

Dear Professor,

In reference to the scientific research which is presented by **Rawnaq M. Almahadeen**, who is a student on the Health Science PhD program/ University of Southampton- University Hospital Southampton, entitled:

Experiences of end of life care for children with life limiting conditions reported by bereaved parents' in Jordan

We would like to inform you that the above research proposal has granted IRB approval, in coordination with the Medical, Nursing and Information Technology Departments at KAUH, under the following conditions:

1. Commitment to the Scientific Research Policy at Jordan University of Science and Technology and King Abdullah University Hospital.
2. Maintaining data confidentiality and using it only for scientific purposes.
3. Consent form is required.
4. This approval will be canceled if the principle investigator doesn't provide IRB with the final executive study report about the results of the research after twelve months.

Sincerely,

Prof. Mohammad Al-Ghazo

CEO KAUH