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Care practices and incontinence-related stigma for formal carers of people living with a dementia in a care home setting: a qualitative study

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Abstract

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Formal care workers in residential dementia care settings can be considered “dirty” workers, contaminated by the taints and stains of continence care, servility, and perceived moral ambiguity. This can have a significant impact on the maintenance and development of a positive social identity, particularly when this translates into societal devaluation and the “low status” of the care worker role. As social care organisations struggle to maintain and recruit care staff it is increasingly important to understand the lived experiences of care workers.

Using theories of stigma and dirty work, this thesis reports on a qualitative study which investigated how care staff in the UK mitigate or reproduce continence related stigma in care homes, and explores the care practices that aid care staff in this. Semi structured interviews were conducted with care staff to explore their experiences and rationalisation of continence care. Document analysis of guidelines, frameworks and Care Quality Commission (CQC) reports was conducted to establish organisational factors that may influence these experiences.

Three themes arose from the study: (1) Responses to continence and incontinence demonstrated that observations related to continence care were used by external organisations and others as an indicator of care quality, while care workers’ experiences reflected a lack of training and preparation. (2) The need for community evidenced that participants sought to mitigate perceived societal devaluation by forming a community of peers that reinforced shared values and positive social identity. (3) The final theme, group boundaries, established that participants reframed continence care and contact with faeces as a “rite of legitimacy” that demarcated the boundaries of the group and accredited their skillset within the “dirty worker” role. Participants judged others on this accreditation, and actively expelled those who did not successfully pass the rite. Lack of contact with faeces indicated a lack of appreciation, understanding, or consideration of the intricacies of the care worker role. Training and knowledge that come from external organisations or individuals not accredited in this particular way was disregarded or actively ignored.

By understanding the rite of legitimacy, researchers can begin to understand how care workers rationalise their experiences to maintain positive social identities. Additionally, researchers and practitioners can learn to plan more effective interventions to improve dementia care. Interventions such as training programmes require the support and participation of the care workers involved. This may be more easily achieved by someone who has attained accredited status in the care worker community.

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Research Thesis: Declaration of Authorship

Print name:	Leah Lily Fullegar

Title of thesis:	Care practices and incontinence-related stigma for formal carers of people living with a dementia in a care home setting: a qualitative study

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:

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7. None of this work has been published before submission

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Definitions and Abbreviations

CQC: Care Quality Commission

KLOE: Key line of enquiry

NICE: National Institute of Clinical Excellence

DoH: Department of Health

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Chapter 1 Introduction

As a care assistant with over 12 years' experience of care home culture, I have witnessed first-hand the stigma of faecal incontinence. Losing control of one's bowels is socially unacceptable and has the potential to cause distress for individuals experiencing it, in any way. I recall a time when I was 18 years old, assisting an individual living with a dementia to go to the toilet. She did not quite make it in time and defecated in her underwear. She became severely distressed and once we were in the bathroom, she removed her underwear and began waving it around the room. She was apologising profusely, crying, and did not understand how it had happened or what she should do next. She was calling me "mum" and thought she would be in trouble for having an accident. By the time I managed to reassure her, both of us were splattered with faeces. I assisted the individual to wash and shower before using an empty bathroom to wash myself, as there were no staff facilities in the setting. I borrowed clothes from the "lost and found" for the last few hours of the shift.

This experience was not something I could discuss outside of my immediate colleagues. Friends, family members – they did not understand and would react with disgust, distaste or shocked laughter if I tried to share experiences from my day at work. A significant part of my life had to be compartmentalised and hidden from non-care workers.

Care work can be body work, paid labour carried out on the bodies of others in a servile manner (Gimlin, 2007). As a care worker, it was part of my role to assist individuals to wash, dress, mobilise, toilet appropriately, socialise, manage their emotions, maintain relationships with their friends and family. The role can be extremely physically demanding and become embodied in care workers having musculoskeletal symptoms (Backaberg et al., 2015, Hjalmarson and Lundberg, 2015, Rodrigues and Santos, 2016, Gimlin, 2007). I recall numerous times where I was exhausted and in pain from the physical stresses on my body, yet it was not acceptable or possible to rest due to the needs of the people I was supporting.

The physicality of the role contributes to considerable emotional labour. Once I entered the care environment as a worker, there were societal and organisational pressures to focus only on the well-being of the individual being supported, often at the expense of my own well-being. This could not be shown to individuals requiring support, as it is within a care workers duty of care to not impose guilt and blame on the individual. This can result in coping mechanisms requiring intense emotional labour such as face work (Goffman, 2003) and surface acting (Hochschild, 1997). Both mechanisms can result in thoughts, feelings and experiences of the worker being supressed due to the desire to protect those they are supporting. In addition, these internal struggles can become hidden from others outside of the care industry.

This thesis reports on a qualitative study that aims to explore how formal carers of people with a dementia living in residential care home settings mitigate or (re)produce stigma around faecal incontinence and identify the care practices that aid them in this.

The findings from this study show that there was very little significance given to continence care in organisational documents and reports, however care workers in this study felt that they were labelled and judged based on their provision of continence care. To mitigate the social stigma assigned to them due to contact with faeces, care workers reframed organisationally "unimportant" practices such as dementia-specific continence care as a rite of legitimacy that afforded them status and prestige within their occupational group.

1.1 The Adult Care Workforce

The provision of adult social care is a significant concern. The number of unpaid familial carers is reducing due to the need to remain in the workforce, while the prevalence of individuals requiring support and care is increasing due to demographic changes in the population (Meagher, 2006). The increase in demand, along with the economic climate and significant workforce challenges, are having an impact on the well-being of the social care workforce (Care Quality Commission, 2023).

In England, Skills for Care (2021) estimate 1.54 million people were working in the adult care workforce in 2021, an increase of 12 per cent since 2012/13. Out of these 1.54 million people, around 680,000 are estimated to be working in residential adult care settings. This increase in staffing has not kept pace with the growing need for adult social care (Association of Directors of Adult Social Services, 2022). Currently, 54 per cent of care providers state they are struggling to recruit staff, and 31 per cent highlight the difficulty of retaining staff (Care Quality Commission, 2023). Encouraging people to join the social care workforce to meet the demand for care is increasingly important, however the role is often not viewed as desirable.

The majority of individuals working in adult social care in England are female (84 per cent) and hold no relevant qualifications (56 per cent), with only 6 per cent achieving level 4 education or higher (Skills for Care, 2021). Care workers generally have a low level of education, limited career trajectory and low pay (Skills for Care, 2021, Simpson et al., 2016). The predominantly female social care workforce found in England is reflective of that in other countries, such as Spain (Corral, 2016).

The issues facing adult social care in England are not unique. In the U.S.A., Matthews et al. (2018) noted that the demand for residential adult social care has been steadily increasing as the “baby boomer” generation approach retirement age. They describe the North American workforce as having significantly high turnover of staff, resulting in negative impacts on the quality of care being provided. In Australia, Banks (2018) found that poor practices were often caused by a lack of recognition and devaluation. This is frequently demonstrated through the low wages and social status of adult care workers (Banks, 2018, Skills for Care, 2021, Clarke and Ravenswood, 2019).Other researchers in the U.S.A. attribute the high turnover to significant incidences of burnout; the increased likelihood of experiencing violence and verbal abuse from the individuals care workers are supporting; and the socioeconomic status of the workforce increasing their risk of cardiovascular disease (Yeatts et al., 2018, Karlsson et al., 2019, Doran and Resnick, 2017). In Canada, Hilton et al. (2017) found that 24 per cent of nursing staff on an inpatient psychiatric ward scored above the cut off for probable post-traumatic stress disorder (PTSD), ranking the smearing of faeces as one of the worst overall experiences.

In Australia, the adult care workforce is presented as being subject to significant time pressures and demonstrating a poor understanding of key concepts they are supposed to be enacting. Oppert et al. (2018) found that a quarter of the adult care staff in their study had a limited or superficial understanding of person-centred care (PCC). This is reflected by Kalman and Andersson (2014), who concluded that care workers in Sweden had little to no formal training.

The adult social care workforce is therefore highly transient, subject to substantial workplace pressures that they may not be given training for, and exposed to potentially traumatic experiences that may impact their mental health in the long-term. The adult care workforce may be poorly educated, of low socio-economic status and with little opportunity for career progression. Equally, this “low status” workforce is in increasingly high demand. Understanding the individual experiences of care workers may assist in changing perceptions and encouraging growth in the workforce.

1.1.1 Faecal Incontinence and Dementia

Current research suggests that exposure to faeces and incontinence are significant factors in the perceptions of adult social care. While the study described in the previous section by Hilton et al. (2017) took place on a psychiatric ward, Schussler et al. (2016) conducted a study in Germany and found that up to 80 per cent of people with an advanced dementia living in a residential setting experienced either faecal or double incontinence. This estimate is much higher than the 30-40 per cent range in the U.K. (Goodman et al., 2017), or the 52 per cent found by Saga et al. (2013) in Norway.

Furthermore, Ostaszkiewicz et al. (2016d) found that in Australia, care workers directly associated the perceived value of their role with their close contact with faeces, stating “we just do the dirty work”. If exposure to faeces is one of the worst overall experiences (Hilton et al., 2017), and care workers are frequently supporting individuals experiencing incontinence, it is logical to assume that care workers in the U.K. will also develop negative connotations about their role due to their occupational exposures.

This is particularly salient in dementia care. As dementia causes progressive damage to the brain and decline of cognitive function, individuals with a dementia may not recognise when it is socially acceptable to urinate or defecate (Ihnat et al., 2016, Jerez-Roig et al., 2015). They may not recognise the feeling of needing to urinate or defecate or may not recognise the objects which one would normally use, such as a toilet (Kyle, 2009, Kyle, 2012). Individuals with a dementia are therefore more likely to experience urinary or faecal incontinence. Care workers supporting people with a dementia are therefore likely to be exposed to the “dirty” work of continence care.

1.1.2 Dirty Work and Identity

“Dirty work” refers to occupational tasks that impart a taint or contaminate the worker (Ashforth and Kreiner, 1999, Ashforth and Kreiner, 2014).This work is often passively delegated to members of society who are of low socioeconomic status (Ashforth and Mael, 1989). Carrying out dirty work significantly impacts perceptions of self-worth and identity. It has been briefly discussed that adult care is facing a crisis of staff turnover and reduced recruitment. Burnout, social stigma and moral distress are all cited as causing this public health emergency (Ghezeljeh et al., 2022, Briggs, 2022, Palmer et al., 2022). Evidence shows that the social implications of dirty work contribute towards burnout and associated conditions. The personal impact of dirty work on individual identity may therefore be contributing to the social care crisis.

The concept of identity is ever evolving as research progresses. In this thesis, identity refers to the culmination of meanings attached to an individual by themselves and others (Gecas, 1982). This directly intersects with social identity, which theory states derives from membership in various social groups (Abrams, 2001, Tajfel and Turner, 1979). If identity is influenced by the meanings provided by others and social group membership, then the perceptions of wider society regarding an individual’s occupational role are likely to have a significant impact on the individual’s identity. Labels such as “dirty work” that are frequently applied to caring roles, in part due to their contact with faeces, may be associated with negative self-image and identity development.

It is therefore imperative that the emotional and social labour of care workers is understood to improve occupational satisfaction and the quality of care provided in turn. Understanding how care workers rationalise this labour paves the way for further research into interventions and support. Chapter 2 discusses in detail how theories of dirty work and identity may impact the way care workers experience the provision of continence care.

1.2 Body of Knowledge

While there is literature discussing the experience of people with or without a dementia who live with incontinence, there is very little that discusses the experiences of formal care workers. Literature relating to this topic is varied, and mainly focuses on efficacy of interventions to improve outcomes in continence care. Research investigates how to reduce incidents of incontinence and only Ostaszkiewicz et al. (2016d) has reported on the experiences of care workers. Even so, this was not an intended aim of the research, which sought to establish how continence care was determined in residential homes. While the study does advance understandings of how care workers connect continence care to their occupationally low status, the focus on determining continence care means that it does not examine how the participants mitigate the stigma of continence care. There is, therefore, a gap in understanding how care workers rationalise their experiences and how this impacts the social environment of care homes.

1.3 Orientation to the structure of the thesis

This thesis is comprised of ten chapters in total. Chapter 1 introduces the older adult residential care workforce and outlines the research questions. Chapter 2 situates the position of care workers in society and discusses how this may be influenced by continence, incontinence, and faeces. Theory and literature are presented that imply care workers are separated from wider society due to their association with “dirt”. Chapter 3 reports on a literature review examining the current body of knowledge relating to care workers' experiences of continence care. This review of literature highlights gaps in the knowledge, specifically how care workers perceive and rationalise their experiences. Chapter 4 discusses the design of a novel qualitative study. Consideration of the methodological approach is presented with reporting on the methods and approaches to data collection and analyses. Specific consideration is given to the experiences of the researcher, and how these experiences may have influenced or contributed to the data analysis. Chapter 5 gives an overview of the participant demographics and an introduction to the findings chapters.

Chapters 6, 7 and 8 present the key findings from the study reported in this thesis. Chapter 6 presents data from documents and interviews that describe the differences in how organisations and individual care workers consider faeces. Organisationally, little consideration or importance was placed on the provision of continence care. The experiences recounted by participants in this study indicated that they attached considerable meaning to their encounters with faeces, highlighting a discrepancy between the organisational and individual perspectives.

Chapter 7 presents findings relating to the second theme: the participants' perceived need for community. Data in this chapter build on the discrepancy in chapter 6 and show how participants felt their caring natures and identities were ignored by others in society. Participants felt that instead of recognising their decision to be carers as resulting from their identity, people in wider society diminished the choice by associating care work only with faeces. This caused the participants to feel rejected as their identities were not validated, meaning they felt a need to seek and develop a group where their decisions would be accepted and valued.

Chapter 8 presents the final theme resulting from the study data, the formation and protection of group boundaries. Here, the data show that once participants had found a group where their decisions were accepted and valued, the group needed to be clearly defined and protected to mitigate perceived societal rejection. To ensure that the group performed its necessary function, namely validating their social identities and accrediting them with status, the group needed to have definitive boundaries and entry criteria. This chapter demonstrates how the participants reframed contact with faeces, the factor they perceived as being the reason behind their devaluation, as a rite by which group membership was legitimised and accredited.

Chapter 9 offers a discussion of these findings in the context of current theory and literature and presents novel insights into how faeces and group dynamics in residential care are impacted by social identity and status. Finally, chapter 10 draws together the key findings of the work and its contribution to knowledge. The chapter concludes with discussion of implications for practice and research.

1.4 Methodology

The research reported in this thesis sought to answer the question:

How is stigma around faecal incontinence (re)produced or mitigated by care staff in care homes, and what care practices aid care staff in this?

As adult social care in England is currently experiencing a crisis in recruitment and maintenance of staff numbers, it is crucial to understand the perceived experience of being a care worker. As literature suggests “dirty work” and contact with faeces influences the social position of care workers, it is crucial to understand staff experiences of these phenomena. Mitigating societal stigma may help empower the social care workforce.

. There were key research objectives required to answer this research question.

1) To gather care home staff accounts of their interactions with residents living with dementia related to faecal incontinence
2) To develop an understanding of how staff understand their role in relation to continence care and managing associated stigma in these accounts
3) To identify organisational factors that shape practices of staff in these situations

To do achieve these objectives, this thesis reports on qualitative semi-structured interviews and document analysis. Policy and guidance documents were analysed to establish what guidance was given to care workers regarding the provision of continence care. Care home inspection reports were analysed to identify organisational factors that contribute to management of incontinence, and qualitative semi-structured interviews were used to gather lived experience of providing continence care for people with a dementia. The resultant data were analysed using thematic analysis and collated into three main themes.

The epistemological standpoint from which this thesis has developed is interpretivist at its base but influenced by postmodernist and phenomenological beliefs around what knowledge can be produced by the methods involved. The themes and findings resulting from this study reflect a specific collection of experiences and how they are rationalised by the participants in the study. This understanding is then used to interpret social meanings of organisational documents in the context of care workers. The inclusion of phenomenological standpoints increases the importance of reflexivity and acknowledging positionality in this study, consideration of which is given in sections 4.8.

Chapter 2 Care workers, Society and Dirty Work

2.1 Introduction

This chapter outlines the social and theoretical contexts that surround care work and the provision of continence care for individuals with a dementia. Historically, what care work entails has been hidden behind screens due to the inherently private nature of the tasks being performed. Texts are often “coy” and avoid specifically describing the actions undertaken, as the work is considered tacitly obvious and needing no explanation (Lawler, 1991). Furthermore, ongoing desires to professionalise care work lead to dismissive and distant language that leaves individuals unsure or unprepared for what care work entails (Twigg, 2000). Due to this, the role of a care worker is often poorly explained, poorly understood, and only identified by the remarkable experiences that are shared through word of mouth. The lack of discourse around what care work consists of may contribute to the marginalisation of care workers themselves, as the lack of discourse could mean that the application of concepts and theories to practice is potentially absent. This chapter aims to outline care work and situate it within the social and theoretical concept of stigma and dirty work. By positioning care work within these theories, this chapter demonstrates the societal context in which care work is performed. This societal context underpins the behaviours and experiences of formal care workers, providing the foundations on which care workers may build to mitigate or reproduce perceived stigma. By situating formal care work within theories of dirty work and stigma, the knowledge gap surrounding care workers experiences can begin to be explored.

2.1.1 Stigma and Dirty Work

The concepts of stigma and dirty work are intrinsically linked. In his seminal essay, Goffman (1963) developed the theory of stigma as originating from an “attribute that is deeply discrediting” (Goffman, 1963, p. 3). Goffman argued that social life functions due to assigned categories that delineate how individuals behave in social situations. These established rules and expectations allow us to seamlessly interact with others without conscious thought (Goffman, 1963). When the tacit social rules are broken they become the foundation for discrediting attributes underpinning the marks of stigma. To avoid breaking societal rules and being discredited, Goffman posited that individuals will instead attempt to “hide” their discreditable attributes and “pass” as normative when interacting with others.

In Goffman's (1963) work, the examples used to demonstrate discreditable attributes centre around sexuality, physical deformity, or mental health. In the intervening years, considerable discourse has developed around what may constitute a stigmatising attribute. Social norms and values change over time, meaning that the attributes that break social rules evolve. The manifestation of stigma therefore varies due to unique social circumstances; stigma must be considered a fluid concept that adapts and changes with social environments (Link and Phelan, 2001).

Discourse around the concept of "dirt" posits that for agreeable social order to persist, "dirt" must be removed (Ashforth and Kreiner, 2014, Ashforth and Kreiner, 1999, Valtorta et al., 2019). As with the concept of stigma, what constitutes "dirt" is socially constructed (Valtorta et al., 2019a). Having a connection with "dirt" therefore breaks the social rule of cleanliness and sanitation: roles and occupations that are "tainted" by dirt become stigmatised (Valtorta et al., 2019). Goffman's initial theories focused on the individual and personal nature of stigmas, considering how individuals might manage discreditable attributes on a small scale by "passing" as normative in individual interactions. Controlling the flow of social information is therefore one mechanism by which individuals can mitigate stigma in individual interactions, potentially evidenced in care work by a lack of discourse around continence care.

Ensuring continence care takes place behind closed doors means that the discrediting attributes are not immediately visible (Lawler, 1991). However, "passing" as normative is not always possible when the discreditable characteristics are part of your occupation. To this end, Hannam and Bruckert (2012) argued that Goffman's focus on stigma at an individual level ignored the role of society and institutions in regulating discredited individuals.

This section discusses how care work, particularly continence care, can be considered a "dirty" role that provides the foundation for the attribution of stigma. Furthermore, I posit that the role is socially regulated so that the attribution of stigma justifies the delegation of dirty work. It is important to understand who may benefit from this societal system and who may be disadvantaged by it (Proctor and Schiebinger, 2008).

2.2 Agnotology

Using the framework of agnotology outlined by Proctor and Schiebinger (2008), labelling care as dirty work may enable the systematic stigmatisation of care workers. In short, agnotology examines the cultural production of ignorance. The term was coined by historians Proctor and Schiebinger (2008). The use of agnotology in health research is limited, however in other fields the study of ignorance has been utilised to gain a deeper understanding of the topic at hand. An understanding of agnotology enabled Bedford (2010) to analyse how misinformation can be used to further understand societal reactions to climate change. Within this article, Bedford describes how different social strategies combine to create misinformation and disinformation, leading to widespread ignorance about the facts of climate change. Lee (2020) used the theory of agnotology to examine media representations of U.K. leadership during the COVID-19 pandemic. Whilst being a heavily opinionated and political piece, Lee (2020) argues that the U.K. government initially downplayed the severity of the pandemic for their own convoluted financial gain, ignoring scientific evidence and advice. Rose and Bartoli (2020) discuss how advances in technology mean that individuals with little specific knowledge now have platforms to confidently make false and misleading claims, significantly contributing to the production of ignorance.

2.2.1 Types of Ignorance

The making of ignorance is a complex social practice with causes as intricate as those involved in knowledge generation (Tuana, 2008). Proctor and Schiebinger (2008) describe three specific states of ignorance:

- Ignorance as an active construct – “something that is made, maintained and manipulated by means of certain arts or sciences” (Proctor and Schiebinger, 2008, p. 8)
- The lost realm of ignorance – the outcome of selective enquiry and inattention
- Native ignorance – lack of knowledge that is a resource, gaps in research and understanding.

Croissant (2018) furthered the framework of agnotology by describing attributes one can apply to analyses to aid in understanding. Particularly relevant to this discussion are the concepts of *scale* and *intentionality.* Scale refers to “components and systems” (Croissant, 2018, p. 334) that specific knowledge may circulate in. The pyramid shaped power hierarchy that often exists within care settings and the internal cognitive processes of care workers can both be considered “systems” (Jervis, 2001). Cognitive processes such as the Dunning-Kreuger effect (Dunning, 2011), whereby one is ignorant of their own ignorance, contribute to the creation of ignorance within a system. Other potential systems in which knowledge may circulate are illustrated in Figure 1..

Intentionality (Croissant, 2018) refers to the reasons behind the production of ignorance. In Proctor and Schiebinger (2008), Robert Proctor describes how the tobacco industry intentionally withheld crucial information about their products to increase their own profits, deliberately preventing health-critical knowledge from being spread implies a malicious intent. Tuana (2008) analysed the erasure of knowledge about the female orgasm and the structure of the clitoris, the deliberate agnoses and suppression of new knowledge echoing a patriarchal society where women were second rate.

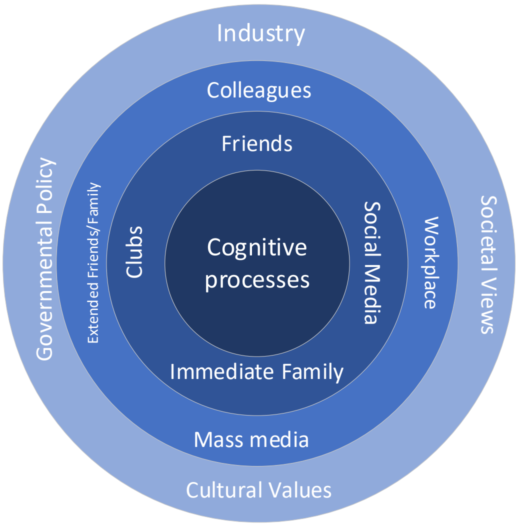

Figure 1 - Systems around Care Workers

Miscommunication, denial, forgetting, selective attention and privacy can all contribute to the construction of ignorance in society; these may be both intentional and unintentional. Ignorance as an "active construct" exists in almost every aspect of modern life. Link and Phelan (2014) discuss this in terms of "stigma power." They argue that stigma acts to achieve the goals and desires of the stigmatisers, due to power imbalances in society. In this study, individuals living with mental illnesses were stigmatised by others in society due to their diagnosis. For the stigmatisers, the aims of these behaviours were to create distance between themselves and those with the discrediting mark. Link and Phelan (2014) found that stigmatised individuals adapted their behaviour to suit the goals of the stigmatisers – they were concerned with staying inside, staying away from others and adopted the position of "downwardly placed." Stigma can therefore be considered one of the systems contributing to the selective attention and privacy ascribed to continence care. Stigmatising individuals who are in "dirty" roles may cause them to withdraw from society, ensuring that wider society is kept "clean". This is particularly relevant if the reasons behind this withdrawal are linked to protecting the privacy of the individuals involved. Protecting privacy becomes a reason to reduce the visibility of certain tasks from society. Once that task is no longer visible, ignorance about the tasks develops.

The concept of "privacy" creating ignorance is particularly salient here. It is due to Lawler's (1991) analysis in "Behind the Screens" it can be appreciated that physically hiding body work behind screens and in private rooms not only protects the privacy of the individual being supported, but obscures the social, moral, and physical taint of the worker.

2.3 Dirty Work, Taints and Stains

The close contact with emotional labour work along with dirty or contaminated objects leads to paid care work being regarded as “dirty” (McMurray and Ward, 2014). Defined as work that is physically, socially or morally tainted (Hughes, 1958), the label “dirty work” reduces the prestige and occupational status of socially valuable workers. Whilst dirty work is necessary for society to function, dirty workers receive no social rewards due to their association with tasks that are “unpleasant, physically disgusting, or associated with things that are symbolically unclean” (Rothman, 1987, p. 228). Ashforth and Kreiner (1999) described the taxonomy of taints.

2.3.1 Moral Taint

Firstly, it is important to understand what is meant by moral taint. Ashforth and Kreiner (1999) define moral taint as resulting from an occupation that is regarded as “sinful” or of dubious virtue (page 415). A facet of dirty work, moral taint implies a moral deficiency in the target individual. By labelling the individual as morally deficient, “valued” members of society can internally justify the subsequent delegation of dirty work and devaluation of such individuals (Hughes, 1962, Ashforth and Humphrey, 1995). Ashforth and Humphrey (1995) argue that attributing dirtiness to others allows oneself to remain “clean” (Douglas, 1966) and therefore ignore the dirty aspects of society. Through an agnotological lens, this is ignorance as an active construct (Proctor and Schiebinger, 2008) (see section 2.2.1). “Valued” or normative members of society actively impose the morally deficient label, allowing them to actively justify delegation of dirty work and actively ignore this tacit societal system. Valtorta et al. (2019a) conducted a study where they investigated associations between dirty work and perceived dehumanising characteristics in individuals with “dirty” roles. They found that those perceived to be morally tainted were also believed to be more animalistic in nature. Participants in this study associated moral taint with reduced human capabilities and development. The attribution “dirt” and moral taint therefore discredited the dirty workers. They were no longer perceived as accredited members of the human race, but deeply discredited animals. The attribution of moral taint is synonymous with the mark of stigma (Goffman, 1963, p.3). Discrediting individuals who are perceived as morally tainted potentially justifies the allocation of dirty work.

It is then important to understand how moral taint and this active systemic ignorance apply in the context of dementia care. The Alzheimer’s Society estimate that 80 per cent of individuals living in care homes have either a dementia or severe memory problems (Prince et al., 2014). With the number of people living with a dementia on the rise, and expected to rise further before 2040, it is likely the percentage of individuals with a dementia living in care homes will also steadily increase (Wittenberg et al., 2019a, Wittenberg et al., 2019b). As such, it is a logical assumption that most residential, adult care workers will provide at least some support for individuals with a dementia throughout their career.

Care workers are frequently presented with difficult situations when supporting individuals with a dementia. An individual may not understand where they are and why; or why their family are not around them. Such instances can easily lead to distress reactions and frustration (Singh et al., 2019, Figueiredo et al., 2013). A recognised response from care workers in such situations is affirming the individual's feelings and diverting or redirecting the individual. This often involves an explicit lie ("your daughter has just popped to the shop") or a tacit affirmation of the individual's false beliefs (Tieu, 2021). There are inherent ethical concerns with this wide-spread practice, with some literature discussing the implications and practical application of therapeutic lying (Meeuwse, 2017, Culley et al., 2013). For care workers, therapeutic lying can be seen as a continuation of person-centred care as outlined by Kitwood (1997) or the VIPS framework created by Brooker (2010). By offering a therapeutic lie, care workers are recognising the individual's personhood and validating their experience in a person-centred way (Tieu, 2021). The lie is offered in the best interests of the individual. However, to those outside of the care industry, lying about important details such as family members may be seen as benefitting the care worker more than the individual. While there is a large gap in the literature regarding approaches to therapeutic lying, there is a recognised power imbalance between care staff and the people they support (Melheim and Hauge, 2010). If individuals being supported are already recognised as being "overpowered" by care workers, therapeutic lying is likely to be seen as taking advantage of the cognitive deficits experienced by people with dementia. Misunderstanding the intention behind therapeutic lying leads to the practice being viewed as intentionally abusive, allowing the label of "morally tainted" to be applied to care workers.

In this example, the interaction between two systems is involved in the scale of this ignorance. One system (the care industry) involves the sharing of knowledge and application of person-centred care, while the other (wider society) has less access to this knowledge and may therefore misinterpret what they are presented with. The discrepancy leads to unintentional judgements being made about care workers; they have broken the agreed societal rules that would enable seamless interaction and have gone against the expected social norm. Moral taint is assigned to them. This "animalises" the individual, discrediting their humanity (Valtorta et al., 2019a). The mark of the stigma therefore justifies the allocation of dirty work to discredited humans (Goffman, 1963, Hughes, 1962).

Further evidence of a moral taint being applied to care workers exists in mass media depictions of care work. Searching for recent news articles online brings up a stark dichotomy in the themes of articles, with some reporting on petting zoo visits and others denouncing individual companies and workers due to avoidable deaths of vulnerable individuals (Vargas, 2022, Conner-Hill, 2022, Dyson, 2022, Oldfield, 2022, Sharpe, 2022, News, 2022). Understandably, there is often named employees at fault when there are failings within a care home. However, these named employees are often portrayed as predatory and animalistic, replicating Valtorta et al. (2019a) and the association between animalism and moral taint. Equally, when positive experiences are reported they often name residents of the mentioned care homes. This creates a sub-conscious association between care staff and *moral deficiency.* It is accepted that media representations directly relate to societal views and attitudes (Whitley and Carmichael, 2022, Starr and Oxlad, 2021). As such, it logically follows that the idea of care staff becomes equivocal with people who are cruel, devious, and intentionally harmful. If wider society accepts this media representation, it becomes easy to view care staff as having a moral taint and therefore acceptable providers of dirty work.

This is not to say that “civilians” in society are content for their relatives to be cared for by those who are “morally deficient”, or even conscious of this label being applied. The process of choosing a long-term care facility is exhausting, complicated and emotionally fraught. Many caregivers experience feelings of guilt and abandonment when deciding to place a loved one in a care home (Teng et al., 2020, Gaudet et al., 2022, Larsen et al., 2020). Couture et al. (2020) completed a systematic review of decision-making processes and found that to combat feelings of guilt, caregivers (“civilians”) put a considerable amount of effort into establishing the quality of care being delivered by their chosen long-term facility. By doing this, they are satisfying themselves that their own relatives are being supported by workers with minimal moral taint. This allows civilians to believe they have found the exception to the rule whilst still labelling other care workers as morally tainted (Hughes, 1962). Despite establishing an acceptable quality of care, many substitute decision makers have difficulty trusting care workers. Rogers et al. (2021) found that less than half of substitute decision makers felt they had complete trust in the care workers supporting their loved one, with significant variation depending on the ethnicities of the stakeholders. While ethnicity is not a focus of this thesis, it is important to acknowledge the impact of intersectionality on the attribution of moral taint. The lack of trust, particularly in the context of vulnerable adults with a cognitive impairment, implies a suspicion that the worker is indeed of dubious virtue. Care workers cannot be fully trusted in a societal system where dirty workers are dehumanised by their moral taint

2.3.2 Social Taint

Social taint is another justification of delegating dirty work. Social taint can be attributed in many ways. This often occurs when an individual has contact with others who are themselves stigmatised, also known as courtesy stigma (Ashforth and Kreiner, 1999). Goffman (1963) introduced this concept and defined it as stigma by association, the idea that society loses respect for a person simply because they associate with an individual who is stigmatised. Research suggests that courtesy stigma exists in care workers due to their association with individuals with a dementia and incontinence (Ostaszkiewicz et al., 2016).

There is a marked distinction between care workers and registered nurses due to the occupational distance between the role and contact with stigmatised people or objects (Jervis, 2001, Clarke and Ravenswood, 2019), with care workers claiming, “we just do the dirty work” (Oppert et al., 2018, Ostaszkiewicz et al., 2016). This is supported by the assertion that the “dirty work” is the only time a nurse can “call rank,” where the low workplace status of care workers is used to ensure they carry out the physically unpleasant tasks (Todd and Woodward, 2018). This is reflected in Valtorta et al. (2019a), who found that participants in their study associated caregivers with physical taint and nurses with social taint. The proximity to dirt is therefore associated more with physical taint (discussed in section 2.3.3) than social taint.

However, the servile nature of care work contributes to the social taint. Bergman and Chalkley (2007) and Ashforth and Kreiner (1999) both attribute social taint as deriving from subservient occupational roles. Although this is typically used to describe people working in hospitality industries, it cannot be denied that care work can be seen as servile and subservient. Unqualified, residential care staff are widely accepted to be marginalised, undervalued, and overburdened (Kadri et al., 2018, Goodman, 2016). Care workers are compelled to carry out servile tasks when those higher on the occupational hierarchy “call rank” (Todd and Woodward, 2018). Care workers are unable to refuse these tasks as this increases the risk of being further labelled of dubious virtue; refusing likely means a vulnerable individual will suffer the consequences. Care workers may experience situations where they do not have autonomy or agency to choose what tasks they complete. Autonomy – or the ability to act volitionally and with choice, is denied to care workers as they do not have the option to refuse. Doing so would result in further moral taint being attributed to them, they would be deemed uncaring and therefore not trustworthy within the care industry.

The lack of autonomy and independence is significantly associated with subordination and social taint (Valtorta et al., 2019a). Carrying out their occupational tasks allows social taint to be attributed due to the perceived servile nature of their role and the socially imposed lack of autonomy over their own actions. The perceived lack of autonomy transforms care workers from unique, valued human beings to a homogenous dirty workforce. Social taint of the unqualified care workers is therefore associated with a lower status within the workplace and wider society, potentially acting as a reason for poor rates of pay as care workers can be seen as “mere instruments for the attainment of their purposes” (Valtorta et al., 2019a, England and Dyck, 2011, Hatton, 2017, Banks, 2018, Hagglund, 2010, Ostaszkiewicz et al., 2016a, Goffman, 1963).

2.3.3 Physical Taint

Finally, physical taint must be understood in the context of care workers. Physical taint derives from contact with dirty or contaminated objects (Ashforth and Kreiner, 1999, Bergman and Chalkley, 2007). Care workers frequently have contact with various “contaminated” bodily fluids. Estimated numbers of individuals in care homes who experience incontinence vary, although around 40 per cent of individuals experience faecal incontinence (Musa et al., 2019, Jerez-Roig et al., 2015). Incontinence is also highly prevalent in individuals with a dementia (Price, 2011, Bardsley, 2013, Goodman et al., 2017).

It is widely accepted that incontinence is a “contaminating” and stigmatised condition (Goodman et al., 2017, Holroyd, 2018, Svedas and Wise, 2012, Hewer-Richards and Goodall, 2020, Chelvanayagam, 2014). This stigma and taboo can be reflected even in care workers, who often place negative meaning to incontinence and attach a physical taint to the individuals they are supporting. These meanings likely stem from an internal aversion, a feeling that arises because of actual or near contact with a “contaminated” item: a leaky body. This causes the individual to carry out an internal risk assessment, “will this make me ill?” If the answer is yes, it is a natural response for humankind to attempt to avoid the contaminant (Rouel et al., 2018). In the case of family or formal carers, this response directly contravenes what they are supposed to do. This incongruency then leads to emotional turmoil in which the individual must rationalise their revulsion response. Presentations of this can be a moral disgust or moral anger, believing “they did that on purpose” takes the blame away from the individual experiencing revulsion and places it squarely on the shoulders of the individual experiencing incontinence (Norton, 2004, Rouel et al., 2018, Butcher, 2020). Therefore, the physical taint associated with incontinence directly impacts the care that is provided and adds to pre-existing emotional labour carried out by the care worker (Ostaszkiewicz, 2017).

However, the central issue contributing to physical taint being attached to care workers is not about what care workers think of the individuals they are supporting, but what wider society perceives as being the contaminant. The stigmatised nature of incontinence causes wider society to focus on that one aspect of care work. Care workers are perceived as “just doing the dirty work” (Ostaszkiewicz et al., 2016d) and then form a dirty connection between society and the hidden, contaminated bodies of people within residential care (Lawler, 1991). Care workers are physically contaminated by their contact with incontinence, and they are then perceived as “spreading” this contamination. This biologisation of care workers as “spreading” and “contaminated” constitutes the *viral dehumanisation* described by Valtorta et al. (2019a), whereby human beings are degraded to having the social function of a virus. The physical contamination therefore becomes a discrediting characteristic and a mark of stigma (Goffman, 1963).

In a separate study, Valtorta et al. (2019b) found that the environment of a dirty worker directly increased feelings of disgust and contributed to the biologisation of workers. In this way, perceptions of residential dementia care environments as being physically contaminated by bodily messes likely result in similar feelings of disgust towards care workers (Martin, 2002, Svedas and Wise, 2012, Bordiak, 2007, Brittain and Shaw, 2007, Rantz et al., 1998). Valtorta et al. (2019b) further posited that this disgust resulting from “dirty” environments is used politically to socially exclude the dirty workers, supporting earlier discussions of the allocation of dirty work contributing to societal systems that benefit specific groups.

The perceived contamination of physical taint constitutes the mark of the stigma (Goffman, 1963). Once considered contaminated and tainted, the care workers societal function is degraded and discredited; their contribution is to “spread” contaminants (Valtorta et al., 2019a). This dehumanisation of social function again serves to justify the allocation of dirty work, enabling the “clean” and “unmarked” members of society to retain their sanitised status (Valtorta et al., 2019b, Hughes, 1962).

2.4 Dirty Work and Identity

Being a “dirty worker” intersects directly with one’s identity and self-esteem. There are many different facets of identity that have been discussed at length in literature. For the purpose of this thesis, identity relates to the formation of self-concept described by Gecas (1982): identity and self-concept are formed by a culmination of meanings attached to an individual by themselves and others. The development of identity is therefore at least partially reliant on social structures and values, such as the attribution and allocation of dirty work.

Social meanings contributing to identity often derive from social roles or their *social identity* (Clarke and Ravenswood, 2019). This is because the labels that are applied to individuals within society have direct impact on how people view themselves. Goffman (1963) argued that these labels underpinning social identity provide the blueprint for social interactions; they define how one is expected to act in any given social situation. Additionally, one’s occupation is a significant source of perceptions of personal identity (Valtorta et al., 2019a, Berkman, 2014, Cheney et al., 2008).

If a care worker is attributed social taint due to their perceived subservience in the workplace, they will be expected to act in a subservient manner as part of their role. If these labels dictate how one behaves during interactions, the individual must embody these labels and incorporate them into their identities and self-concepts. The care worker may find themselves acting subservient to fulfil their role and solidify their social identity. Care workers may therefore begin to see themselves as dirty workers and personify their taints and dirt (Ashforth and Kreiner, 1999, Valtorta et al., 2019a).

Adopting the identity of a “dirty worker” has consequences for the individual’s physical, mental, and social well-being. The reduced prestige and social exclusion associated with dirty work can lead to perceived or legitimate isolation from wider society (Ashforth and Mael, 1989). This isolation, perceived or otherwise, reduces social support networks and increases emotional and physical exhaustion, potentially due to the emotional labour carried out by the individual (Bentein et al., 2017, McMurray and Ward, 2014). Dirty workers struggle to implement effective defence mechanisms to protect themselves from this, so society is left with a workforce that is more prone to burnout and stress related health conditions. Research shows these present frequently in care workers, who have higher incidence of cardio-vascular diseases, depression, anxiety, sleep disorders and musculoskeletal issues (Doran and Resnick, 2017, Hjalmarson and Lundberg, 2015, Slavish et al., 2022, Dhaini et al., 2017, Dietrich et al., 2014, Elwér et al., 2012, Zhao et al., 2022). Furthermore, Dhaini et al. (2017) showed that the poor health outcomes frequently experienced by care workers are associated with a reduced quality of care being provided. It is therefore logical to conclude that the failing bodies of care workers can be held responsible for inefficient and substandard care, cementing the application of a moral taint.

The question remains, however, when is the identity of dirty worker adopted? If dirty work is delegated to individuals in society of lower-socio-economic status, then this likely happens at a very young age. Ashforth and Kreiner (1999) claim that occupational identities are formed as individuals make *conscious* decisions about which work groups or organisations to join, on the basis that membership will enhance their self-concept and self-identity. However, consideration must be given to whether this can really be considered a conscious choice if the individuals involved already belong to a devalued group, such as individuals with a poor education or of “low” socio-economic status (Clarke and Ravenswood, 2019). People in already devalued groups may have reduced access to occupational opportunities, meaning the “choice” about which work group or organisation to join is severely limited. Additionally, individuals in devalued groups may already be subject to marks and stigmas that have caused this devaluation, further dictating how they must act and progress in society (Goffman, 1963).

If the dirty worker identity is adopted from a young age, then this supports the theory that dirty work is delegated to underprivileged individuals based on social status. Strategies individuals employ to mitigate stigma are then not only useful in occupational contexts, but also to provide alternative social cohesion and positive identity.

2.4.1 Socio-economic Status

In western society, direct work on the ageing and leaky body is carried out the least valued, paid and regarded individuals within an organisation (Twigg, 2000). The social status of care workers is widely recognised in academic literature and society (Kadri et al., 2018, Ostaszkiewicz et al., 2016d, Matthews et al., 2018, Yeatts et al., 2018); however, examining this as part of the wider context is often ignored.

The label of dirty work and its impact on socio-economic status is known. When reflecting on his conversations with German citizens in post-Nazi Germany, Hughes (1962) observed that societies delegate “dirty” work to specific groups who then act as agents on society’s behalf. While these observations may be based on extreme circumstances, this concept is reflected in modern day examples of dirty work.

It has already been discussed how caring for individuals who experience incontinence, dementia, and are of advanced age, is “dirty” work. This work is primarily performed by paid care workers, as incontinence, dementia and advanced age are the most common catalysts for admission to a care home (Kyle, 2009, Goodman et al., 2017, Wilson, 2015, Ha and Kim, 2014, Minney and Ranzijn, 2015). It can therefore be accepted that this necessary work is often carried out by a specific and delineated group of people: paid carers. Paid carers act as agents on behalf of wider society to provide support for individuals with dementias, incontinence, and advanced age.

The parallels with Hughes (1962) observations do not end there. He went on to describe how once the agents are identified and performing the “dirty” work, wider society then stigmatises them for it. The agents are disavowed, disowned, and discredited for the work society has mandated they perform. This, again, is reflected in modern day care work. Paid care workers are often viewed as “unmotivated” and blamed for failings in care (Mills and Schejbal, 2007, Drew et al., 2007). There is little to no requirement for education or experience before becoming a paid carer, leading to an image of carers having no valuable skills or knowledge (Ashforth and Kreiner, 1999). Care work is low paid and often characterised by extensive casual or part time roles due to the association with advanced age and occupational pollution (Clarke and Ravenswood, 2019, Kagan and Melendez-Torres, 2015, Ostaszkiewicz et al., 2016d, Twigg, 2000). Failures can then be blamed on the care workers due to their low status and lack of status shield (Kagan and Melendez-Torres, 2015, Hughes, 1962). Simply put, care workers are blamed because they are viewed as inherently blemished, devalued and tainted (Jervis, 2001, Hughes, 1958, McMurray and Ward, 2014). Their *discrediting attributes* contribute to their low status and justify the assignment of further dirty work (Goffman, 1963, Hughes, 1962).

While taints such as these are often considered permanent, an occupational taint is removable when opportunity presents (Bergman and Chalkley, 2007). Opportunities to remove these taints are mostly available through further education and progression in one's career, a route which is less effective for individuals of low socio-economic status (Gulczynska, 2019). If a paid carer does have the opportunity to distance themselves from the polluting aspects of their role, their status begins to rise accordingly (Twigg, 2000, Jervis, 2001, Brittain and Shaw, 2007). They find they can now delegate "dirty" tasks to maintain their distance and status.

Even when care workers are "celebrated", as they were during the COVID-19 pandemic, this is often laudatory and still serves to separate the group from the rest of society. Spellman (2021) examined how COVID-era narratives represented social values and concluded that the weekly "Clap for Carers" initiative, while well intentioned, acted as a substitute for real action against the systemic disadvantage described above. This laudatory socioeconomic othering draws attention away from structural factors maintaining disadvantage (i.e. low pay) and focuses instead on perceived individual characteristics – for example, labelling paid carers as "heroes". These narratives of demarcation provide social distance between the polluted and the "clean" (Douglas, 1966).

I propose that care workers rationalise ignorance in wider society as resulting from a lack of experience, whereas "civilians" are ignorant of their ignorance. It is generally accepted that care workers are often of low socio-economic status and can be viewed as a marginalised, stigmatised and potentially oppressed group (Banks, 2018, Kadri et al., 2018, Ostaszkiewicz et al., 2016d). Using the framework of agnotology, "we do not know, and we do not want to know", or *wilful ignorance*, is a systematic process of self-deception in which one ignores their own position of privilege and their role in the oppression of others (Tuana, 2006, pg. 11, Beddoes, 2019). For "civilians", faecal incontinence stigma leads to reluctance and active avoidance of any contact with faeces (Butcher, 2020, Hewer-Richards and Goodall, 2020, Rouel et al., 2018). By avoiding faeces when societal contact with faeces is potentially necessary in the care of older adults with a dementia, non-carers are cementing their “privileged” role and ignorant of the fact that their own inaction forces people with potentially less socio-economic privilege to have contact with faeces.

2.5 Summary

This chapter demonstrates how care work can be culturally and socially defined as dirty work. Through contact with bodily waste, care workers become physically tainted and “contaminated”. Through subordination and servility to the individuals they support and the hierarchical context in which they work, they can become socially tainted and objectified. Through media representations and contact with vulnerable individuals with reduced or fluctuating capacity, they can become morally tainted. These taints are understood to be discrediting marks that distinguish care workers from accredited members of society, leading to the stigmatisation and marginalisation of the “dirty” care worker occupation. In addition, the label of “dirty work” leads to dehumanisation of care workers, particularly in the context of physically tainted individuals who become biologized and “contaminated”. Using the framework of agnotology, the allocation of dirty work and subsequent dehumanisation, stigmatisation and marginalisation forms a process by which ignorance is created. This ignorance protects the individuals being supported and wider society but begets a process by which the lack of understanding of “what goes on” furthers the dehumanisation and “dirty” labels applied to workers.

Recent research by Valtorta et al. (2019a) into dirty work provides evidence for Ashforth and Kreiner (1999) theoretical taxonomy. This chapter demonstrates that continence care for individuals with a dementia is a socially, morally, and physically tainted activity. The study reported in this thesis builds on this evidence base by identifying how care workers mitigate specific taints and stigmas relating to their role that have previously been hidden behind closed doors and screens (Lawler, 1991).

Chapter 3 Care Staff Attitudes to and Experiences of Incontinence

3.1 Introduction

This section reports on a literature review investigating existing literature on care home staff experiences of providing continence care for people living with a dementia. As discussed in Chapter 2, supporting individuals with a dementia with continence care is an activity that typically takes place behind closed doors and is “hidden.” The social, moral, and physical taint associated with the provision of continence care likely contribute towards stigmas and devaluation experienced by care workers. This chapter will give an overview of the extent to which the existing body of knowledge aids our understanding of this contribution.

Although there is a great deal of research discussing continence care for individuals with a dementia, very few research items take the perspectives of care staff. When their perspectives are considered, it is often in the context of implementing interventions and their personal experiences are used as supporting evidence and not the primary focus of the research. As such, this literature review sought to explore what is already known about experiences of and attitudes towards continence care, along with the context in which it is reported. The CoCoPop tool was used to frame the question: what is known about care staff experiences (Population) of continence and dementia care (Condition) and how is the knowledge presented in research (context) (Mayo et al., 2022).

3.2 Search Strategy

To establish what is already known about staff experiences and attitudes towards providing continence care for people with a dementia, searches of the CINAHL and the PyschInfo databases were conducted. Policy documents and grey literature were not included in this review as the aim was to search for existing academic literature reporting on care workers experiences and attitudes. A scoping review with a systematic approach was used for this literature search, with thematic synthesis used to structure the resulting literature (Grant and Booth, 2009). This approach was chosen as the literature relating to this topic is diverse and fluid with very little explicitly addressing the review question. It was unclear where the boundaries of a systematic review should fall to ensure that all relevant and applicable knowledge was included in the review, therefore an iterative approach was more appropriate. This review maps evidence that encompasses care workers experience of providing continence care. Despite being less methodologically rigorous, the systematic approach involves establishing inclusion and exclusion criteria and reporting on the search strategy in a clear and concise manner.

Iterative searches using the snowball method were carried out to refine the search terms used for the final search (Aveyard, 2014). Four main search areas were identified through previous scoping searches: **dementia, care, staff,** and **continence**. Each of these areas consisted of several major or minor subject titles, a full list of which can be found in Table 1. All refined search terms for each key area were separated by "OR", for example:

Alzheimer's Disease OR dementia OR cognitive impairment

Table 1 - Search criteria

Search number	Key Search Area	Identified search terms (separated by "OR")
1	Dementia	Nursing home patients; dementia; psychological distress; activities of daily living in older age; cognition disorders in old age; dementia patients; Alzheimer's disease; cognitive impairment; dementia nursing; dementia patients in old age
2	Care	Nursing homes; long term care; gerontologic care; residential facilities; health services for the aged; residential care
3	Staff	Caregivers; occupational exposure; caregivers psychosocial factors; practical nurses; nurse attitudes; life experiences; health personnel; nursing home personnel; registered nurses; attitude of health personnel; nursing practice; nursing care; work experiences; nurse patient relations; quality of nursing care; nursing role

4	Continence	Incontinence; incontinence psychosocial factors; incontinence nursing; incontinence psychosocial factors in old age; body fluids; urinary incontinence; faecal incontinence; incontinence complications

The initial search of all terms included in the key search areas was carried out on 11th July 2021 and netted only 4 results. The final searches were conducted on 17th August 2021 and are summarised in Table 2.

Table 2 Searches

Search Number	Included key areas	Results
1	Dementia AND Continence	94
2	Continence AND Care	155

3.2.1 Inclusion and Exclusion Criteria

Only articles that were peer-reviewed, English language, between 1976 – 2021, journal articles with full text available were included in the results. Further inclusion and exclusion criteria for the screening process are shown in Table 3 and Table 4**.**

Table 3 Inclusion Criteria

Studies were included that met the inclusion criteria according to methods, participants, and setting
1. **Studies with care staff, including registered nurses, nursing assistants, personal care assistants, enrolled nurses, practical nurses.**
2. Studies set in care homes, residential homes, nursing homes, aged care facilities, long term care facilities, care centres
3. **Studies that included qualitative or descriptive methods utilised with care staff**

Table 4 Exclusion Criteria

Studies or articles with any of the following elements were excluded from the review
1. **Study type: Publications based on opinions, commentaries, or training-based literature**

2. No mention of including any care staff as participants
3. **Community or non-care-home-based research**
4. **Studies that offer no qualitative or free-entry data**
5. **Studies related to pharmacological interventions**

As a single researcher made the practical decisions regarding which literature to include, the inclusion and exclusion criteria required a large amount of self-governance and were based on the researchers' practical and research experience. In order to gather the experiences of care workers, this researcher decided that qualitative, free-entry data were necessary they provide an insight into the social reality of the participants (Leavy, 2014). In addition, studies that discussed or evaluated pharmacological interventions to manage incontinence were excluded as they are primarily based on the efficacy of the intervention, and not how care staff experienced providing continence care.

The decision was made to include only studies that referred to continence care explicitly, rather than including research around experiences of providing "personal" or "intimate" care. As discussed in Chapter 2, aspects of care work are often ill-defined and discussed due to the private and difficult nature of the activities themselves (Lawler, 1991, van Dongen, 2001). Specifically, the use of "coy" terms that deliberately hide the nature of the activity contribute towards the tacit concealment of labour. While titles such as "personal care" or "intimate care" likely include activities around continence, the lack of specificity creates doubt about relevance for the purposes of this literature review. Link and Phelan (2014) highlighted how hidden, misrecognised processes serve the interests of stigmatisers – separating tainted activities and individuals from society. Therefore, continuing to use phrases that mask the labour being carried out by care workers may contribute to and maintain the societal stigma ascribed to them. After considering the potential implications of broadening the search, it was decided to exclude discussions of personal care.

3.3 Results

3.3.1 PRISMA Diagram of Review Stages

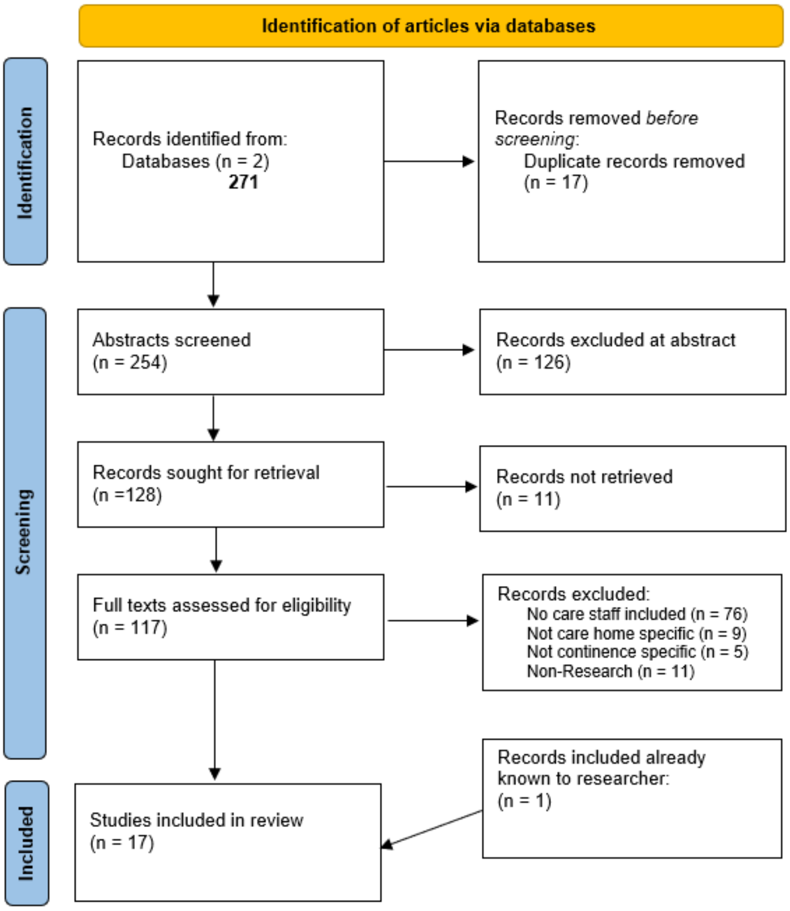

Figure 2 - PRISMA diagram of search steps

In total, 16 studies were reviewed by full text (see data extraction table, page 132). Nationality or origin included: U.S.A. (5), Australia (6), Switzerland (2), Sweden (1), U.K. (1), unspecified (1).

3.4 Review Methods

This review adopted a systematic approach. This involved using early stage elements from systematic review processes such as iterative searches and reporting on the methodology, but for practical reasons does not reach the same standards for comprehensiveness, transparency and rigour (Grant and Booth, 2009). For example, as this literature review was conducted as part of a PhD programme, the literature was not independently screened by a second researcher. While this does have an impact on the credibility of the findings, rigour was maintained through discussion with the authors academic supervisors and reflective practice. The literature for this review was critically evaluated using a CASP checklist (Critical Appraisal Skills Programme, 2018), an overview of which can be found in Appendix C (page 139). The CASP tool is frequently used to assess the rigour of primary qualitative research in literature reviews. The tool encourages the reviewer to consider specific questions designed to highlight methodological strengths or limitations in qualitative research. Despite the tool having previously been shown as less sensitive to methodological issues that other evaluation tools , it is frequently used by novice researchers and endorsed by Cochrane for use in qualitative evidence synthesis (Hannes et al., 2010, Long et al., 2020, Noyes et al., 2018). The 10 questions used in the CASP tool can be found in Figure 3.

1) Was there a clear statement of the aims of the research?
2) Is a qualitative methodology appropriate?
3) Was the research design appropriate to address the aims of the research?
4) Was the recruitment strategy appropriate to the aims of the research?
5) Was the data collected in a way that addressed the research issue?
6) Has the relationship between researcher and participants been adequately considered?
7) Have ethical issues been taken into consideration?
8) Was the data analysis sufficiently rigorous?
9) Is there a clear statement of findings?
10) How valuable is the research?

Figure 3 - The 10 questions of the CASP tool (Critical Appraisal Skills Programme, 2018)

Once the literature included for review had been methodologically evaluated, the studies were analysed using “thematic synthesis” as described by Thomas and Harden (2008) (see Table 5) Initially, data in the form of key concepts were extracted from the literature and compiled in a data extraction table (see Appendix B, page 132). This proved to be quite difficult and reflected the experiences of Sandelowski and Barroso (2002), in that key concepts in research articles can be inconsistently presented and therefore difficult to identify. As such, only reported key concepts and findings were included in the data extraction tables as these were evidently what the original authors deemed important outcomes from their studies. As many of the studies included little to no analysis of qualitative data relevant to this review, these “unreported” findings were included as notes in the data extraction tables. For example, Hägglund and Olai (2017) reported data about care staff experiences of providing continence care, but did not report on analyses of this or using the data to contribute to their research results.

Table 5 - Stages of Thematic Synthesis (Thomas and Harden, 2008)

Stage One: Coding text	**This involved coding excerpts from articles to specific themes or nodes, for example “I also hope the surveyors TRUST us as nurses!” from Dubeau et al. (2007) was coded as “trust”**
Stage Two: Developing themes	This stage involved collating the previous codes into themes, or similar groups. This stage involved reviewing various codes together. The previous quote became situated under the theme “mistrust of skills and knowledge”
Stage Three: Generating analytical themes	The final stage involved reviewing these themes in the context of the theoretical background and developing final theme titles.

As there were very few studies that directly addressed the question in this review, the included studies were read line by line to code apparent concepts and themes. These were then developed into descriptive themes, which became the basis for the final analytical themes discussed in this chapter. These were:

1. Assessing Knowledge and Attitudes
2. Implementation of Interventions
3. Continence Care Management and Decision Making

3.5 Introduction to Care Staff Experiences Literature

The above-described search strategy produced literature discussing staff experiences of providing continence care. All articles included were primary research, however several articles reported on different aspects of the same study. The focal topics of the studies encompassed: assessing knowledge and attitudes of staff (3), implementation of continence care interventions (7), continence care management and decisions (6). All included studies reported on care staff’s opinions, experiences and attitudes relating to their individual study aim.

Whilst reviewing literature for this chapter, it became apparent that the experiences and attitudes of care staff are often not included in resulting data. Many articles discussed in depth the implementation of interventions designed to improve the continence of people with or without dementia living in long term care facilities. These implementations were often met with a mixture of excitement and reluctance from the staff implementing them, however this was generally not explored and only highlighted as an area for further research. Interventions frequently fail to achieve desired outcomes, and this was often reported as resulting from an under- educated and overburdened work force, however only these 16 articles included any analysis or consideration of the practical work care staff are experiencing daily. Therefore, it can be established that understanding *why* interventions to improve continence care succeed or fail in relation to care staff is a severe gap in the existing knowledge base.

3.6 Assessing Knowledge and Attitudes

Of the literature reviewed, three articles assessed the care staff's knowledge of and attitude towards continence care. Of these, two articles originated from Switzerland and one originated from the U.S.A. All three studies utilised questionnaires administered to care home staff consisting of nurses and nursing assistants, an alternative term for the role of a care worker.

When assessing knowledge, all three articles seem to report similar findings. However, attitudes varied greatly depending on the job role of the individual responding. Dubeau et al. (2007) conducted a content analysis of free entry responses to a questionnaire exploring attitudes to incontinence and staff knowledge about updated guidance for continence care. Overall, participants in this study were concerned about proposed changes to continence care. When considering the proposed changes with the concerns raised by participants, Dubeau et al. (2007) concluded that the proposed changes to guidance were unlikely to improve the quality of urinary continence care in nursing homes. They did explore the concerns around the guidance, with one staff nurse stating:

> *"not possible unless you bankrupt our facility by having more help. Seems to me your goal is to close nursing homes"*
> Staff Nurse, Dubeau et al. (2007, p. 476)

The above statement was coded under the theme "expense" with only a passing reference made to the potentially emotional tone contained within the statement. The staff nurse appeared to be concerned about the cost of additional help, but the comment also seemed to imply that the respondent did not trust the intentions of those proposing the changes. In addition, this study highlights, but does not discuss, potential conflict between different staff levels shown with the following statements:

> *"I also hope the surveyors TRUST us as nurses!"*
> Staff Nurse, Dubeau et al. (2007, p. 475)

> *"facilities don't understand the intent and do not have the educated staff to achieve a good outcome"*
> State Surveyor, Dubeau et al. (2007, p. 476)

While the allocated codes of education and expense are appropriate, these statements appear to indicate a lack of trust between two key stakeholders in this nursing home organisation. This line of enquiry was not explored in the original study and possibly represents a lost opportunity to understand the impact of such tensions on the provision of continence care. Considering that the aim of this study was to explore attitudes to incontinence and knowledge about guidance, these lines of enquiry may have been discarded due to not being explicitly related to the study objectives. However, in the context of dirty work, stigma, and associated taints, the interactions and perceptions surrounding a “dirty” task may have important ramifications.

The quantitative data presented showed surveyors were less likely than staff nurses and others to cite practical difficulties with implementation. This may have been due to surveyors being less physically involved in implementation, and therefore being less aware of the practical difficulties involved. If this was the case, hesitancy of staff nurses towards interventions in social care may have arisen from the belief that surveyors did not fully understand their role in relation to continence care.

Despite being evaluated as a high-quality study using the CASP tool (see page 139), this study is difficult to generalise outside of the participant group due to the nature of participant sampling. Dubeau et al. (2007) utilised convenience sampling in this study, meaning that motivation bias likely exists in the participant group and the conclusions drawn should only be applied to that specific context (Stratton, 2021).

The implication that behavioural attitude has an impact on knowledge and practice was reflected in the other two articles included in this theme, Saxer et al. (2009) and Saxer et al. (2008). These articles reported on the same study, which consisted of a cross-sectional questionnaire of 315 nurses and nursing assistants. The study sought to examine the relationship between knowledge, beliefs, attitudes, and continence related practice. Saxer et al. (2009) and Saxer et al. (2008) posited that evaluating knowledge and attitudes of nursing staff has little meaning unless there is a clear relationship between these concepts and quality of practice .The reported study concluded that knowledge and attitude are directly related to practice, but that beliefs about urinary incontinence have no relation to knowledge, attitudes, or practice. Methodological evaluation shows this study produces good quality evidence, however this is mitigated by the lack of reporting of the authors’ own positionality and reflexivity. The authors do not give an account of any steps taken to reduce or acknowledge their own influence when analysing their data, therefore the validity of the qualitative findings cannot be known.

If Saxer et al. (2009)’s finding that nurses attitudes have a corresponding impact on their knowledge and practice is accepted, and it is accepted that the social role of “dirty work” may impact their attitudes, then it may be that the wider societal context of continence care will have an influence the implementation of changes and interventions in continence care. This may explain potential difficulties in professional relationships seen in DuBeau (2005), and may contribute towards poor success rates of interventions in continence care.

If the staff in Dubeau et al. (2007) felt that their knowledge and roles were misunderstood, they may be less likely to act with confidence and autonomy (Banks, 2018, Kadri et al., 2018, Yeatts et al., 2018). A diagram of how this may work is shown in Figure 4. However, it cannot be ignored that some care staff do not have the required knowledge and education about continence care. Nursing assistants had significantly less knowledge about urinary incontinence care when compared to registered nurses, but this was considered satisfactory due to the levels of education required for the differing roles (Saxer et al., 2008). What was not discussed is how this difference in knowledge may impact the autonomy and confidence of the nursing assistants themselves, or whether the difference in knowledge levels impacts the social structure of the care setting. If nurses feel untrusted and undervalued by state surveyors (or those "above" them in the social structure) due a perceived lack of knowledge (Dubeau et al., 2007), it could be assumed that nursing assistants feel similarly towards nurses in these settings. In addition, by not including the voices of "unqualified"[1] care staff the researchers may be tacitly communicating their own lack of appreciation for the lived experiences of those staff. While it is accepted that the nurses included in these studies will have completed higher levels of education than the nursing assistants, this is not discussed or explained as a reason to exclude nursing assistants from the reported studies. The implication is that the experiences and opinions of the nursing assistants are not relevant in the context of residential continence care, whilst the experiences and opinions of qualified nurses are relevant.

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[1] The use of the word "unqualified" is in quotation marks to show that it is a contested term within this thesis.

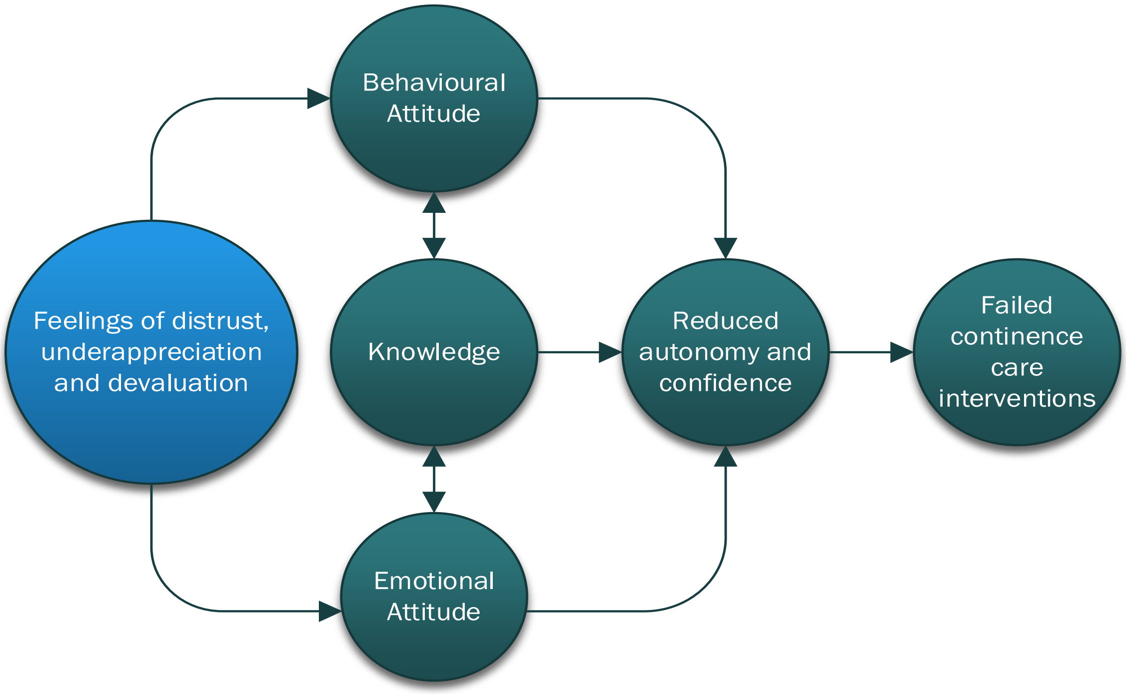

Figure 4 - Devaluation and Work Practice

3.6.1 Summary

The studies reviewed in this section were methodologically evaluated to be of good quality, however there are issues around the transferability of the results and reflexivity of the authors. The studies reviewed for this theme indicate there may be differing levels of knowledge between roles within care staff who participated. This can have a significant relationship to emotional and behavioural attitudes towards not only continence care, but staff relationships and social hierarchies within organisations. This suggests that beliefs and experiences around providing continence care have much deeper meanings that assumed in the reported studies. The lack of attention given to this line of enquiry shows a gap in the knowledge base.

3.7 Implementation of Interventions

The literature for this section consisted of seven articles focusing on implementing interventions and assessing care staff responses to these interventions, although this was often a secondary aim of the studies. In this context, interventions refer to novel organisational or individual management techniques to improve experience of continence care or reduce episodes of incontinence. Articles originated from the U.S.A. (two), the U.K. (one), Sweden (one), Australia (two) and an unspecified location (one). The articles consisted of feasibility studies (three), focus groups (two), intervention and social validation (one), and a workshop-based intervention (one). All studies in this section included care staff in their participant group.

Many of the intervention-based studies cited staffing levels and communication issues as barriers and facilitators to implementing interventions. Lekan-Rutledge et al. (1998) and Mather and Bakas (2002) both investigated common difficulties with implementing interventions. Lekan-Rutledge et al. (1998) evaluated a prompted voiding programme wherein certified nursing assistants (CNAs) from 33 residential facilities took part in three workshops provided by a clinical nurse specialist who was also the lead author on the article. Once the workshops were completed and time was allowed for the prompted voiding to be implemented, CNAs completed questionnaires to evaluate their experience. It is reported in the findings that many of the CNAs highlighted inadequate staffing as a barrier to implementing prompted voiding, this being second only to increased staff communication and support. While consideration is given to the impact of inadequate staffing on quality of care in the discussion portion of this article, the authors provide no recommendations regarding how to combat this. Methodological evaluation of Lekan-Rutledge et al. (1998) using the CASP tool gives the evidence an “adequate” rating, as there is no consideration in the report of potential ethical issues and no clear statement of findings. In addition, there is no discussion of how the workshops were delivered and received. The lack of reflective account or contributions by the lead author, who delivered the workshops to all CNA participants, represents a significant gap in the analysis of how the intervention was delivered. This has potential consequences for the validity of the results, therefore meaning that the findings may not accurately represent the data provided.

Through focus groups with care staff, Mather and Bakas (2002) conducted a study that aimed to establish barriers to the provision of continence care. They identified key themes of excessive workloads, inconsistent cooperation, inconsistent communication and lack of teamwork. The workloads in particular seemed to be a key barrier, as they found that continence care training provided to staff is often unappreciative of the workloads care staff experience. Mather and Bakas (2002) posited that training and education often presented a utopian view of how care homes function daily, leaving staff unequipped to implement their training in the real environment. As the study aimed to identify barriers to provision, key concepts about the meaning and experience of continence care was excluded from the analysis. In the focus groups participants discussed their experiences of providing continence care along with the dynamic management required and the emotional impact.

> *“If you take their hands and sit them on the toilet, the next thing you know, they’re really going. It’s really nice for them because it’s a good feeling to see that they can actually do for themselves,”*

> *"If you toilet them at the right time, then you can keep them dry. It all depends on you."*
> Mather and Bakas (2002, p. 78)

Focus groups are a frequently used method for exploring shared meanings relating to a specific topic, normally of the researcher's choosing (Wagner et al., 2018). By focusing the topics of discussion, groups can create a lost realm of ignorance where lines of enquiry ignore other, potentially useful, phenomena (Proctor and Schiebinger, 2008) (see section 2.2.1). The quotes above, when considered by a researcher with a more exploratory focus, hint towards cognitive processes that may contribute towards how the involved workers approach continence care. "*it's a good feeling"* suggests a level of job satisfaction, while "*it all depends on you"* implies feelings of pressure and burden. Both lines of enquiry are absent from the reported study, which instead focused on training and education as a barrier. Approaching this study with a more exploratory aim may have yielded deeper meanings underpinning why training and education do (or do not) support continence care. The methods and design used to explore the study aim are appropriate, however when methodologically evaluated it became clear that the relationship between researcher and participants was not fully explored. This potentially reduces the validity of the findings.

Another barrier of intervention implementation is the demographics of the care work force. Clarke-O'Neill et al. (2015) conducted a study to investigate the feasibility of using incontinence-associated dermatitis (IAD) tools in routine clinical practice. They did this by taking weekly, high-quality photographs of the skin beneath absorption pads of nursing home residents over the course of eight weeks. Ten representative photos were then chosen and shown to 16 nursing home staff and ten tissue viability nurses (TVN). Participants were then asked to rate the level of IAD using three different tools and a "simple severity scoring system" (SSS) developed specifically for this study. The authors state that they paid particular attention to any practical challenges encountered by staff throughout the study. The study found that there was a significant difference in ability to use various tools between the TVNs and the general nursing home staff. Non-nurses found the IAD tools difficult to use as English was not their first language and were only able to effectively use the SSS tool due to its simplicity and lack of written text. TVNs were able to use all three IAD tools and the SSS effectively but reported that the simplicity of the SSS was preferred as it was less time consuming. Clarke-O'Neill et al. (2015) therefore concluded that any interventions must consider the excessive time pressures and linguistic competence of qualified and “unqualified” nursing staff. This study was methodologically evaluated as being of high quality, with all the requirements for reporting specified in the CASP tool being met.

Consideration must therefore be given not only to the physical practically of education, training, and interventions – but also the format in which it is presented to care staff. By being presented tools in a format that is not easily understandable, care staff are not being given the tools to succeed. To counteract this, Mather and Bakas (2002) suggest that conducting focus groups prior to interventions could help tailor continence programmes to the specific concerns of care workers.

Hägglund and Olai (2017) conducted a follow-up study aiming to describe staff perceptions of enabling and inhibitory factors that influenced implementation of evidence-based practice (EBP). They carried out focus groups which were then analysed using qualitative content analysis. Methodological evaluation shows this is a good quality study, however there is little reported about the relationship between the researchers and the participants. The method of analysis relies on interpretation by the authors, therefore when judging the validity of the findings it would be beneficial for the report to explore their approach to reflexivity.

Hägglund and Olai (2017) identified three themes of both enabling and inhibitory factors: evidence, context, and facilitation. Whether research or clinical evidence was enabling or inhibitory depended on its relevance and the consensus about that evidence. Context depended on the culture and leadership of the service, whilst facilitation depended on the skills and attributes of individuals within the team. As such, Hägglund and Olai (2017) identified many dynamic factors that influence the implementation of interventions.

Ostaszkiewicz et al. (2022b) conducted a feasibility study of a model to guide continence care in residential aged care homes. This was a large study with multiple phases shown in Table 6.

Table 6 - Study stages (Ostaszkiewicz et al., 2022b, pg. 42)

Stage/Objective	Activities
Stage 1: Scoping review	
Identify and summarise evidence about quality continence care for people living in residential aged care homes	- A scoping review of the literature
Identify elements of the Aged Care Quality Standards to inform the design of a best practice model	- A review of databases and websites
Stage 2: Consultation	

Identify residential aged care stakeholders' expectations and understanding of best practice continence care in residential aged care homes	• An online survey of family carers ad residential aged care staff
	• Qualitative interviews with family carers and residential aged care staff
	• Co-design workshops with family carers and residential aged care staff
Stage 3: Co-design of model and knowledge translation resources	
Design a draft model and accompanying knowledge translation resources	• Synthesis of data and initial draft of the model and resources
Stage 4: Pilot trial	
Determine whether the draft model and resources were contextually relevant and fit for purpose in Australian residential aged care homes	• A pilot trial of an education program
	• Qualitative interviews with aged care residents

Methodologically, this is a high-quality study with rigorous methods utilised to achieve the study aims. While the report does not give in depth accounts of the relationship between researcher and participants, steps were taken to validate the study results through qualitative interviews with residents of the study settings. This gave the researchers the opportunity to compare the questionnaire results of the pilot study against the lived experience of the care recipients, using triangulation to corroborate their findings. Overall, the model to guide continence care improved the provision of care for residents and staff alike, however free text entries into the questionnaires established that staff required further support in managing emotions and communication during continence care. This suggests that despite being provided with additional knowledge and training, care staff had difficulty managing the cognitive and emotional processes involved in continence care.

Lancioni et al. (2011) evaluated body-worn alarms for 3 people with Alzheimer’s Disease. The alarms vibrated or made a noise when the individual began urinating, prompting them to take themselves to the toilet and stop urination if able. While there may be socially ethical issues around sounding a physical alarm when an individual is incontinent of urine, the study was generally successful and significantly reduced or completely stopped episodes of urinary incontinence. During the social validation assessment of this intervention, staff seemed to prefer the body worn alarm system over timed toileting, shown through mean ratings on a Likert scale of the two approaches. The reasoning behind this perceived preference is not explored in the study. However, throughout this literature review there have been repeated references to care staff being subjected to excessive workloads. It is therefore feasible that an intervention which encourages self-initiated toileting and removes the need for staff to conduct timed voiding is preferable as it enables staff to refocus their attention on others and reduces their workload.

3.7.1 Summary

Nearly all studies focusing on interventions in relation to continence care found that factors affecting the workforce are the main barrier to implementation. Whilst further training and education were nearly always recommended for care staff, the training and education provided often appeared impractical for the care work environment. In addition, when training and education did provide beneficial outcomes, care staff in these studies reported requiring more assistance with the emotional nature of continence care.

The research investigating continence care frequently utilises intervention-focused designs, where specific and concrete aims are used to investigate an objective reality. Establishing that an intervention has not succeeded due to lack of staff training does not consider the intrinsically diverse way humans experience their roles in society, and the meanings individuals attach to them (Heron, 1996, Neuman, 2014). While many of the studies included employed mixed methods research, this is generally useful for answering specific questions of clinical relevance (Shneerson and Gale, 2015). These studies have, however, highlighted a gap in the knowledge base: how do care workers rationalise their roles, and what meanings do they attach to them? Chapter 2 demonstrates that there are significant social and cognitive processes that are linked to the provision of continence care, research is required to explore whether this exists outside of the theoretical landscape.

3.8 Continence Care Management and Decision Making

Of the literature reviewed, six studies considered barriers and facilitators to how continence care was decided and managed. Of these, four studies originated from Australia and two originated from the U.S.A. Articles in this section utilised surveys (one), interviews (four), non-participant observations (three) and focus groups (one). However, three of the included records reported on different aspects of the same study (Ostaszkiewicz et al., 2016c).

There were significant discrepancies in the preferred outcomes for continence care depending on the stakeholder. In one study conducted by Johnson et al. (2001) care staff reportedly preferred interventions such as prompted voiding to physical continence aids such as pads, whereas family members and individuals living in residential care showed a preference for continence aids. While family members in this study showed a distinct preference for continence aids over prompted voiding, individuals receiving care ranked medications as preferable to either intervention. Nurses and care staff were more likely to prefer invasive interventions such as electrical stimulation over continence aids or medications. Nurses are reported as basing their decisions on a combination of clinical and psychological outcomes, such as reducing the risk of infection and increasing self-esteem. Individuals receiving care prioritised the ease and comfort of interventions along with their ability to reduce dependence and risk of embarrassment. These differences in preferred methods of management may cause conflict between different stakeholder groups, although this is not explored by Johnson et al. (2001). This study therefore highlights preferred management strategies but does not explore in depth how the differing values in decision making may impact the experiences of staff and care recipients. This study was judged as being of low quality due to the lack of discussion around recruitment strategy, data collection, reflexivity and ethical issues.

Ostaszkiewicz et al. (2014) conducted a grounded theory study exploring the ethical issues associated with providing continence care. They found that while care staff in the study were aware that individuals have the right to independence, choice and control, there were multiple factors preventing them from practically implementing these aspects of continence care provision. Due to issues such as workforce constraints, inadequate information and conflicting expectations, care staff were faced with ethically challenging experiences where their ability to enable the individuals they support is challenged by their need to fulfil their obligations. Staff reported having to prioritise the cleanliness and appearance of people they were supporting over other aspects of care to “keep their dignity” (Ostaszkiewicz et al., 2014, p. 181). Therefore, despite care recipient and family member preference for body-worn continence aids, this study suggests that management techniques such as prompted voiding are preferred by staff due to the organisational pressure to present a specific image. Care staff in this study reported feeling pressure to conform to regulations and meet specified outcomes, which inhibited their ability to provide true person-centred care to the individuals they were supporting. This was supported by the discrepancies between preferred management methods (Johnson et al., 2001). The methodological evaluation of Ostaszkiewicz et al. (2014) indicates this is a good quality study, however further exploration of the relationship between researcher and participant would increase the validity of the findings.

The perceived difficulty in enacting care recipient autonomy reported in Ostaszkiewicz et al. (2014) is re-iterated in the alternate analysis of the same data. Ostaszkiewicz et al. (2016c) examined a subset of data relating to night-time continence care collected in the above grounded theory study. In this data set, night-time continence care was found to be ritualistic and based primarily on the belief that all residents within the setting were incontinent most of the time (Ostaszkiewicz et al., 2016c, p. 156). Interview data showed that this belief was often due to individuals being unable to communicate their continence status verbally or behaviourally, leaving the care staff to make decisions on what care should be provided. Due to the pressure to "keep their dignity" (Ostaszkiewicz et al., 2014, p. 181), care staff in this study then made continence care decisions based on organisational regulations rather than preferences of the individual they were supporting.

Through questionnaires distributed to five nursing homes in Australia, Ping et al. (2014) arrived at similar conclusions. Care staff reportedly preferred using prompted or scheduled voiding to manage incontinence, however in this study only 40per cent of care staff reported providing continence assistance according to the specified timings in the individual's care plan. Staff reported that continence assessments and care plans provided them with useful information regarding management of continence care for an individual, however in practice the schedules and care plans were not feasible due to time and organisational pressures.

Ping et al. (2014) explained in their data that identifying the exact time of a voiding event was problematic for care staff. An individual may have a slightly wet continence aid on the initial check, then be saturated moments later. The study authors concluded that additional continence training is required for care staff due to "wastage" of continence aids that are replaced before being saturated (Ping et al., 2014, p. 45). I offer an alternative explanation. Care staff may be prematurely replacing continence aids due to organisational pressure to maintain dignity and a specific organisational image as evidenced by Ostaszkiewicz et al. (2014) and (Ostaszkiewicz et al., 2016c). As care staff can be subject to extreme time pressures, they may decide to replace a slightly wet continence aid knowing that they may not have time to replace it again before the next planned check. This would potentially ensure that incontinence is "contained" as per organisational regulations. Therefore, the organisational and regulatory pressures that some care staff experience could contribute to wastage of resources. Further continence training would not, in this example, tackle the issue causing the wastage. Instead, this would potentially place blame for wastage on care staff. If care workers are blamed for workplace difficulties that are likely out of their control, this may then contribute to those care workers being perceived as having a low occupational status.

Through a further analysis of the data from Ostaszkiewicz et al. (2014), Ostaszkiewicz et al. (2016d) found that care staff in the study already had a negatively impacted self-identity due to the stigmatising nature of their work. In this data set, one member of staff is reported as representing wider societies views about the role as being "just to wipe bums" (Ostaszkiewicz et al., 2016d, p. 2533). The authors concluded that occupational exposure to incontinence contributed to the low occupational status of care work in long-term aged care facilities and acted as a visual marker of social inequalities within these settings. Both Ostaszkiewicz et al. (2016c) and Ostaszkiewicz et al. (2016d) were methodologically evaluated as providing good quality evidence, although lack examination of the relationship between the researcher and the participants.

Resnick et al. (2006) conducted focus groups to explore the beliefs of nursing assistants and directors of nursing about the management of urinary incontinence in nursing homes. Purposive sampling was used to recruit participants to the study, and focus groups were divided into occupational titles. The authors concluded that time pressures significantly impacted how urinary incontinence was managed, however participants recognised that their values and beliefs around team working could mitigate these time pressures. Participants described how utilising a "whole team" approach, where all members of the healthcare team assisted in non-continence-based support, would give nursing assistants more time to effectively manage urinary incontinence. This study was evaluated as providing medium quality evidence. The use of purposive sampling may have biased the participant sample, which is not adequately discussed within the report.

3.8.1 Summary

The studies presented here indicate that care staff preferences for management of continence care is different to that of individuals being supported and family members. This appears to be due to organisational pressures such as staffing levels and large workloads. While the quality of the studies conducted is variable, the studies grouped under this theme generally had more exploratory research designs and were often not aiming to establish or identify issues in relation to specific tasks. There was a notable lack of exploration of the relationships between researcher and participant in all of the reported studies, which presents difficulty in ascertaining the validity of the research findings.

The previous themes in this review have raised questions around the training provided and the meanings that care workers attach to continence care, whereas this theme highlights how social and organisational meanings can change care practices. For example, a focus on "maintaining dignity" leads to wastage of resources (Ostaszkiewicz et al., 2014, Ostaszkiewicz et al., 2016c). If the importance of this was not considered, this wastage was then blamed on a lack of education and further interventions around training were suggested (Ping et al., 2014). This reflects a disconnect between care workers and understandings of their role in relation to continence care, demonstrating another gap in knowledge: how do care workers manage this these conflicting ideas?

3.9 Conclusion

This review of literature aimed to explore what is already known about experiences of and attitudes towards continence care. The included literature shows considerable overlap in different aspects of continence care for care staff. Interventions for continence care are frequently impractical and idealistic. When management techniques are adapted for the busy workplace environment, care staff often remain ill-equipped to implement them due to workloads, time pressures, and societal devaluation. This means that care staff may have to make morally difficult decisions and prioritise individuals in their care that require the most immediate help, potentially leaving others with sub-standard continence care. Care staff may then be blamed for these decisions, furthering their social exclusion and devaluation.

The literature included in this review was of variable quality. Many of the findings and conclusions drawn in the studies lack validity and can only be applied to the settings and participants in which the study was conducted. This indicates that experiences of providing continence care are very context dependent, with surrounding societal and organisational structures impacting the experiences of care workers. Chapter 2 demonstrates how societal beliefs around faeces and continence care impact all individuals within a given society, therefore further research that includes discussion around the reflexivity of the researcher is required.

The literature around assessing knowledge and attitudes showed that the perceived lack of knowledge around continence care on the part of care workers had a much deeper meaning than only impacting how interventions were adopted. It also contributed to an environment where care workers potentially felt distrustful of those in their organisations perceived as being more “knowledgeable”. The reduced knowledge was deemed satisfactory and intellectual development was not needed, as care workers were not perceived as requiring additional knowledge to perform continence care. Despite this, frequent recommendations are made for further training provision to improve continence care. The literature therefore highlights two contrasting beliefs about care workers providing continence care:

1. Continence care does not require significant knowledge.
2. When continence care does not work, it is because care staff do not have enough knowledge.

To be perceived simultaneously as “not requiring knowledge” and “not knowledgeable enough” by individuals who are not care workers potentially causes care workers to feel devalued and unrecognised. It then logically follows that this might contribute to a disconnect between staff members that would, in an ideal world, be working together equally as a team. This demonstrates a way in which continence care contributes towards the separation of “dirty workers” from “clean workers”, discussed in Chapter 2.

This does, however, raise questions regarding care worker experiences of continence care – what knowledge and training is provided? The research methods used do not consider the meanings and experiences of workers in favour of focusing on specific measurable outcomes, meaning that it is difficult to assess the quality or utility of knowledge that is or is not provided. The literature therefore tells us that experiences of continence care have many meanings but does not go on to explore what those meanings might be.

Implementation of interventions highlighted how a lack of reality in training left care workers ill prepared for the environment they were working in. If care workers are not provided with adequate tools and preparation to carry out their role in a manner that is satisfactory; then this may contribute towards their perceived lack of knowledge and therefore their potential distrust of others within their organisations. As discussed in section 2.3 and 2.4, when individuals are not provided with the tools to succeed this can be used as a reason for lack of advancement.

The methods utilised in the reported studies have primarily been focused on answering specific questions, as is the nature of health research that attempts to improve outcomes. However, consideration needs to be given to the benefits of a more exploratory method of enquiry. As the research in this section suggests, the common themes contributing to poor outcomes are lack of training and high workloads. However, when training is implemented this often does not achieve the high-level outcomes expected if this was a sole contributor. As such, going “back to the beginning” to explore the social and cognitive processes that may also explain efficacy and success is a valuable line of enquiry.

Finally, the literature in this review clearly shows that the provision of continence care directly links to a care workers sense of self-identity and value. The self-perception of being someone who *just does the dirty work* (Ostaszkiewicz et al., 2016d) along with dissonant societal perceptions of what is required to carry out said dirty work, lead to considerable emotional labour. When additional layers of complexity are added, for example cognitive impairment and physical needs of individuals being supported, attention must be given to how care workers manage these competing demands.

This literature therefore shows that knowledge around care workers experiences and attitudes towards continence care focuses mainly on organisation and social structures. The literature indicates that care workers in these studies are deemed to be at the bottom of the organisational hierarchy with a low occupational status. In the context of the theory discussed in Chapter 2, it is likely that this is due to the “dirty worker” label associated with continence care. As there is very little direct data about how care workers manage this, this literature review therefore highlights a gap in current knowledge.

3.10 Gaps in Knowledge

The literature described in this section has identified significant gaps in knowledge that when investigated, could help to provide explanations of why interventions in continence care do or do not succeed. The literature highlights how when interventions fail, the blame for this is often placed on the lack of knowledge held by care workers. The literature also highlights, but does not explore, competing concepts that drive care workers, such as maintaining dignity and job satisfaction. The selective lines of enquiry ignore the experiences of care workers, contributing to a lost realm of ignorance and further societal devaluation (Proctor and Schiebinger, 2008). Disregarding the experiences of the individuals who carry out the work means that evidence-based policy or practice recommendations will not reflect the real environment of continence care provision. Suggestions for interventions in continence care may be less likely to succeed if the individual’s developing them do not understand the context in which these interventions are taking place. This could lead to reduced quality of life for the individuals being supported along with the care staff involved.

Additionally, understanding the social and organisational management of complex mechanisms in a particular demographic contributes to current understandings of dirty work and societal structures.

Therefore, the first gap in knowledge is:

What are the experiences of care workers providing continence care?

Research studies reviewed around continence care management and decision making demonstrated that care workers are subjected to significant stigma because of the role as “dirty” continence care workers. As discussed in Chapter 2, these societal labels have a significant impact on how one perceives their identity and value in society, however this is not fully explored in the current research around experiences of incontinence due to selective enquiry. The next knowledge gap is:

How do care staff manage the stigma that is applied to them?

Finally, the literature shows that these experiences and societal phenomena contribute directly to the way in which care workers carry out their roles. This may manifest either in the training provided, or the interventions that succeed or fail. Chapter 2 demonstrated how societal labels such as “dirty” can become embodied in individual actions and social mechanisms. Therefore, another considerable gap in knowledge is:

What care practices are involved in these processes?

These gaps in knowledge were combined to form a singular research question:

How is stigma around faecal incontinence (re)produced or mitigated by care staff in care homes, and what care practices aid care staff in this?

Further discussion of how this question formed the basis for the research in this thesis continues in Chapter 4.

Chapter 4 Methods and Methodology

4.1 Introduction

The research question and objectives for this study are:

How is stigma around faecal incontinence (re)produced or mitigated by care staff in care homes, and what care practices aid care staff in this?

Objectives:

1) To gather care home staff accounts of their interactions with residents living with dementia related to faecal incontinence
2) To develop an understanding of how staff understand their role in relation to continence care and managing associated stigma in these accounts
3) To identify organisational factors that shape practices of staff in these situations

To achieve these a qualitative methodological approach was adopted. Interview based research and document analysis are generally utilised for explorative research aims as they allow freedom in how the objectives are reached (Wagner et al., 2018, Magnusson and Marecek, 2015a). The qualitative interviews were used to meet objectives one and two, whilst the documentary analysis was used to meet objective three.

The aim of this chapter is to describe the methodological design and considerations that took place throughout the development of this study. The chapter begins by giving an overview of the research methods used before explaining the epistemological standpoints considered and other practical issues that arose throughout the research. Particular attention is given to the impact of the COVID-19 pandemic.

4.2 Historical Context of Interview Based Research

Qualitative research is, by nature, an attempt to understand and learn about the meanings attached to lived experiences by the people experiencing them (Magnusson and Marecek, 2015b). By conducting in depth interviews, the researcher is encouraging the participant to reflect on the experiences they are discussing. The participant then selects details of the experience from their minds; this selection and retelling initiates a meaning making process by which understanding can be gained (Seidman, 2006). The inclusion or exclusion of information relating to the experience gives researchers an insight into the individual's understanding of the experience. As one of the primary objectives of this study is to explore how care workers understand and rationalise their role in relation to providing continence care, semi-structured, qualitative interviews were chosen to allow participants to describe and explain their experiences freely, while being guided and satisfying the research interests (Magnusson and Marecek, 2015b, Wagner et al., 2018).

Interviews are, by nature, a social interaction manifesting as a conversation between two people (Briggs, 1986, Neuman, 2014; p350). Defining the interview as an interaction hints to the dyadic and co-operative nature of the interview; data resulting from such conversations is built and created by both the participant and the researcher (Nunkoosing, 2005). However, consideration needs to be given to the power-dynamic that exists between the researcher and participant in any interview. Neuman (2014; p350) reflects my own experience of interviewing when mentioning that participants often have difficulty understanding what is expected of them or what a question means as intended by the researcher. In a research interview, the power often rests with the researcher as they are the person controlling the conversation to some extent, they plan the questions and dictate where the interview goes in order to reach their research objectives (Nunkoosing, 2005). This difficulty understanding their role as a participant in an interview mirrors the passivity and powerlessness that qualitative researchers hope to discourage in participants. Goffman (1981) describes social interactions in interviews as a face-saving performance in which the individual endeavours to present their best self, maintaining their dignity and implying that the power in the interaction lies with the other.

The emotional experiences of both the researcher and the participant help to frame the context of the interview. As stated by Briggs (1986, p. 23): “the interview is thus probably the last place where one should forget that the statements were made in a particular context.” Trier-Bieniek (2012) reported on her study interviewing female fans of a musical artist; a topic resulting from the researcher's own enjoyment and fandom of the artist in question. This researcher found that by sharing her own traumatic experiences that lead to her fandom of this artist, she was able to elicit meaningful narratives from the women she was interviewing. These shared frames of reference that present as shared experiences enable each individual in the interview to negotiate their roles within the context of the unique social interaction they are partaking in. Trier-Bieniek (2012) acknowledges that sharing her own trauma, and allowing research participants to ask questions about that trauma, may have shifted the power imbalance in the interview and enabled the development of a rapport between the participant and the researcher.

However, the concept of “rapport” can be controversial. Whilst it is generally appreciated that the presence of rapport encourages rich data to result from interviews (Cook and Nunkoosing, 2008, Neuman, 2014, p. 446, Nunkoosing, 2005), using the level of rapport to discern the quality of the interview can reduce the validity of the resulting data. It is possible for interviewees to adapt their responses to conform to what they believe the researcher expects from them. An increased rapport does not necessarily equal more “truth” in the data, as rapport-filled interviews can often be saturated with “the flow of legend and cliché” (Riesman and Benny, 1956, p. 10). The important of Riesman’s work cannot be underestimated, even in modern society (Lee, 2008). Thus, the development of rapport can hinder, rather than elicit, the uncovering of knowledge sought by qualitative interviews. Researchers conducting qualitative interviews are therefore required to reflect on their practices and positionality to assess their data.

4.3 Recruitment and Sampling for Qualitative Interviews

The study utilised convenience sampling and snowball sampling. All accessible individuals who met the inclusion and exclusion criteria were invited to participate in the study and were then encouraged to share the study information and contact details amongst their colleagues (Lynn, 2016, Neuman, 2014, Richey and Klein, 2007, Stratton, 2021). Whilst these methods can introduce motivation bias into the study sample and provide a non-representative population for analysis, these methods were chosen due to the unprecedented stresses being placed on care workers due to the COVID-19 pandemic. To improve the dependability of the convenience sampling method, an in-depth description of the recruitment methods has been described below. In addition, the demographics of the recruited participant group have been evaluated against the statistics for the national population of care workers (Chapter 5). Convenience sampling does limit the scope and rigour of this study, however as the study is exploratory the resultant conclusions are intended to be used to develop hypothesis and objectives for further research.

Participants for the study were recruited using informal advertising on social media websites, through industry contacts and through snowballing. Previous literature and reading had warned me of the difficulties of recruiting care assistants to research studies, as such I also endeavoured to utilise the National Institute of Health Research (NIHR) Enabling Research In Care Homes (ENRICH) Research Ready Care Home Network, which comprises of a list of care homes that have self-nominated as willing to participate in research. Unfortunately, the study suffered an early setback in that it was not able to be registered on the ENRICH network due to them prioritising research studies that had been awarded Urgent Public Health Research classification. Gaining this classification would have been a lengthy process and so it was deemed impractical by myself and my academic supervisors. As such, the study relied upon recruitment through social media, industry contacts and snowballing. Participants for the study were offered a £10 shopping voucher as compensation for taking part in the study. A copy of the study flyer used to advertise participation can be found in Appendix E. The participant information sheet and consent form shared with all participants can be found in Appendix F and Appendix G.

Potential participants were encouraged to email or contact me by telephone for more information about the study. For this purpose, I acquired a dedicated mobile phone, separate to my personal device, with a dedicated phone number utilised only for the purposes of the study. This enabled me to not only protect my own private information, but to retain a separation of personal and working life. The use of a separate device meant that I was able to properly follow data protection regulations with little risk of personal information belonging to participants to be accidentally shared or temporarily stored on my personal device.

Initially, the study received very little interest from potential participants. Advertisements were sent to industry contacts, such as care home managers, and dispersed amongst their staff by these contacts. This led to the first three participants taking part between September 2020 and December 2020. In this time, the study information was also posted regularly on Facebook and Twitter and interested parties were encouraged to contact the researcher to obtain more information if they were interested in taking part. Whilst many individuals saw the information on dedicated care assistant groups on Facebook and contacted me for information, none of the individuals accessed through this method decided to take part in the research itself. In early 2021, one of the posts on Twitter gained attention from a senior member of a large care provider. This person not only consented to take part in the study, but shared the advertisement amongst their care staff, leading to a sudden uptake in participation.

4.4 Ethical Considerations

Ethical approval was sought and gained from the University of Southampton Faculty of Environmental and Life Sciences Faculty Ethics Committee. The submitted study protocol can be found in Appendix D.

There were a number of ethical issues to consider in relation to this study. Primarily, recruitment for the study took place during a very difficult time: the global COVID-19 pandemic. During this time, residential care homes were under increased pressure due to fast-spreading and catastrophic infection rates. The population targeted for this study, residential care workers supporting individuals with a dementia, were likely to have increased stress levels and risk of burnout (Röhr et al., 2020, Gordon et al., 2020, Maben and Bridges, 2020, Spilsbury et al., 2020). There was therefore concern about the additional burden requests to take part in a research study might place on individuals. To help mitigate this stress, “passive” recruitment methods were utilised. This means providing information about the study through advertisements which prompt participants to contact the research team independently (Carlson et al., 2014). This gives the potential participants increased power in the researcher-participant relationship and allows them to decide to take part in the study without additional pressure. Once potential participants made contact about the study, additional steps were taken to reduce the potential of burden. Potential participants were sent the study information and care was taken to explain what would be required to take part. Participants were then informed that I would contact them again in 7 days but would not contact them again after that if they did not express interest in taking part. In addition, the participant information sheet given to all potential participants signposted individuals to organisations they could contact if they felt they were struggling with stress, burnout, or any other concerns.

The topics discussed in the interview could potentially cause distress to the participants. Incontinence can be a difficult and embarrassing topic to discuss, and there can be additional stigma for participants when discussing the individuals they are supporting. Each participant was informed at the beginning of the interview that they could stop the process at any time, and regular “check ins” were made throughout interviews to ensure participants felt comfortable.

There were also potential ethical concerns around emotional harm to the researcher. To help mitigate this, the researcher completed a reflective diary after each interview to both record their immediate feelings and considerations of how those feelings may impact the research. Regular supervisory meetings were held to discuss such issues. Further discussion of the reflective diary can be found in section 4.8.2.

Participants in this study were anonymised using a randomly generated pseudonym. The key for this was kept on a password protected document on the University of Southampton’s secure server, which only the researcher could access. Interviews were audio recorded with all names and identifying information being removed in the transcription, including references to colleagues and individuals that participants may have been supporting. Employers and names of settings in which participants were employed were also anonymised, referred to as “Care Provider” and a corresponding number depending on the organisation. Participants were informed of the steps that were taken to ensure their anonymity and confidentiality but were also advised that the researcher would be required to disclose information if there was any indication that an individual was at risk or in danger.

4.5 Claims About Knowledge

The study described in this thesis was conducted with an interpretivist approach towards what knowledge can be gained and how. That is, the author holds the belief that observing social phenomena and interactions leads to the development of theory and concepts, rather than theory leading enquiry (Walliman, 2006). Based on the philosophy of inductivism described by Aristotle, constructivists believe that life experiences lead us to make conclusions that we, as humans, then apply to other areas of our lives. As society has advanced, so have definitions and implications of this epistemological paradigm.

Undertaking qualitative research automatically implies a rejection of positivist leanings as it is an attempt to understand and learn about the meanings attached to lived experiences by the people experiencing them (Magnusson and Marecek, 2015b). As positivism involves the belief that there is a stable social reality that can be empirically analysed, the approach is not appropriate for a study that seeks to explore meanings and perceptions of care workers highly subjective experiences (Walliman, 2006).

If the explanation of qualitative methodology as “co-constructed” as described in section 4.2 is accepted, then the resulting data will be a unique representation of a social episode that needs decoding and deconstructing in context, a postmodernist approach to constructivism (Ryen, 2004). Postmodernist approaches sidestep methodological critiques about the lack of absolute facts by claiming that qualitative enquiry cannot be expected to produce “facts” and “truths” (Kitzinger, 2004). Instead, qualitative enquiry should aim to construct stories and narratives that are situated within their own social context – removing this context removes the social meaning revealed. As such, the social context has a direct bearing on the resultant themes and findings from such research, reflecting a phenomenological standpoint. (Spencer et al., 2020)

To continue accepting the co-construction narrative, then the ramifications of this co-construction must also be considered. Here, it is important to examine the production of ignorance alongside the production of knowledge. If both the researcher and participant work together to construct the resultant narratives, then it stands to reason that they also work together to develop shared agnoses, or areas of ignorance. The production of knowledge equally contributes to the production of ignorance through selective enquiry and inattention (Proctor and Schiebinger, 2008) or through the Dunning-Kruger effect (Dunning, 2011): *“we don’t know what we don’t know”.*

4.5.1 The Production of Ignorance

Agnotology, or the production of ignorance (see section 2.2), is a complex social practice with causes as intricate as those involved in knowledge generation (Tuana, 2008). Proctor and Schiebinger (2008) describe three specific states of ignorance:

- Ignorance as an active construct – “something that is made, maintained and manipulated by means of certain arts or sciences” (Proctor and Schiebinger, 2008, p. 8)
- The lost realm of ignorance – the outcome of selective enquiry and inattention
- Native ignorance – lack of knowledge that is a resource, gaps in research and understanding

Miscommunication, denial, forgetting, selective attention and privacy all contribute to the construction of ignorance in society; these can be both intentional and unintentional. Ignorance as an “active construct”, exists in almost every aspect of modern life. In academia, individuals are encouraged to keep their ideas and research secret to prevent the theft of intellectual property

The use of agnotology in health research is limited, however in other fields the study of ignorance has been utilised to gain a deeper understanding of the topic at hand. Without an understanding of agnotology, societal reluctance to accept climate change and climate science would not be fully understood (Bedford, 2010). The use of agnotology adds understanding to the UK government’s management or mismanagement of the COVID-19 pandemic (Lee, 2020, Rose and Bartoli, 2020) Understanding systemic production of ignorance and how these intersect with systems of oppression can provide methods to rectify ignorance if needed.

However, ignorance is not necessarily the negative phenomenon that society tend to assume. Western societies have a negative bias towards ignorance and generally seek to destroy it by creating knowledge (Smithson, 2008), and there needs to be a distinction between what should and should not be known (Douglas, 1966). Knowledge and information that is not shared and not known must exist to satisfy our own desire for privacy and social etiquette (Warren and Laslett, 1977, Smithson, 2008). There exists an innate human drive to maintain ignorance on the part of others in all affairs.

4.5.2 Research Quality, Validity and Rigour

Discussions around validity are heavily influenced by one’s epistemological position, with positivist views implying that research can only be valid when deriving from large sample sizes and quantitative data (Richards, 2015). Validity, or the extent to which research findings are true to life (Walliman, 2006), therefore depends heavily on the epistemological standpoint used in the research.

The study described in this thesis utilised qualitative interviews and document analysis, both methods which can be described as highly subjective. Section 4.2 established that interviews produce co-constructed narratives that are developed by both the participant and the researcher, and my own experience reflects this knowledge. The co-constructed nature of interview-based research therefore reduces the reliability of the findings. The narratives and themes resulting from this study have been influenced by my own thoughts and experiences, therefore other researchers may have difficulty repeating the study (Rapley, 2004). It is important to consider the impact this has on the validity of the research,

4.5.3 Epistemological Standpoint

To summarise, the epistemological standpoint from which this thesis has developed is interpretivist at its base but influenced by postmodernist and phenomenological beliefs around what knowledge can be produced by the methods involved. The themes and findings resulting from this study reflect a specific collection of experiences and how they are rationalised by the participants in the study. This understanding is then used to interpret social meanings of organisational documents in the context of care workers. The inclusion of phenomenological standpoints increases the importance of reflexivity and acknowledging positionality in this study, consideration of which is given in sections 4.8.

4.6 Data Collection

The methods used to answer the research questions are those commonly included in qualitative research, semi-structured interviews and documentary analysis. The responses gathered through the semi-structured interviews formed the data on which conclusions were drawn through analysis. Interviews were carried out with care home employees across England between September 2020 and May 2021. A reflective diary was kept throughout the duration of the study, from conception to analysis, all data sources were used to answer the research question and meet the research objectives.

4.6.1 Remote, In-Depth Interviews

In-depth interviews were chosen to address the research questions in this study for multiple reasons, the first of which being methodological. The primary research question for this study refers to gaining an understanding of how care staff view their role in relation to continence care, and what meaning they attach to the actions they perform. As such, the methodology of interviews was chosen due to the "interest in understanding the lived experiences of other people and the meaning they make of that experience" (Seidman, 2006).

4.6.1.1 Interview Format

Each of the interviews began with me explaining the study and giving a brief overview of my background working in care and my interest in the topic. I would confirm that the participant is still willing to take part in the interview, and then begin by asking the individual to tell me about their work along with why they chose to "go into care". This initial conversation starter encouraged participants to relax into the interview and often raised points for further discussion as many participants would mention without prompting some of their most memorable continence care experiences.

4.6.1.2 Remote Interviews

Social distancing measures enforced due to the COVID-19 pandemic dictated that in person interviews could not be utilised. Therefore, the experiences and perspectives of care assistants were sought through audio-recorded semi-structured remote interviews which took place on Microsoft Teams or via telephone. Audio was recorded using a separate Dictaphone device placed next to the speakers of either the computer or telephone during the interview. The initial topic guide for the interviews was developed following insights gained from literature and to suit the research question, however the interviews took an iterative form, with the focus of questioning adapting as different themes and insights began to emerge from previous interviews.

The decision to offer a choice of telephone or video interviews was initially a practical one. I was conscious not to exclude potential participants based on their confidence with using, or ability to access, the relevant technology to conduct the interview via video link. This choice of method did however have an unexpected benefit: offering control of the research process to the participant (Hanna, 2012). The use of these remote technologies enabled the participant to effect control over the environment in which the interview took place; they could decide which method they were comfortable with, and who they were comfortable having around them whilst the interview took place (Holt, 2010). This choice in conjunction with the use of a semi-structured interview format served to equalise the levels of control between the researcher and the participant (Farooq, 2015, Trier-Bieniek, 2012, Hanna, 2012). The data resulting from the interviews are therefore more likely to be co-constructed (Nunkoosing, 2005).

The use of telephone or video interviews seemed to intrinsically imply to me that it would be harder to construct rich data with the participants, an initial reluctance which is not uncommon among qualitative researchers (Holt, 2010, Stephens, 2007, Farooq, 2015). Interviews, as defined by Magnusson and Marecek (2015b, p.6), consist of “face to face conversations constructed by the researcher”. The same text goes on to suggest that researchers should “politely decline” requests to carry out telephone interviews as the resulting data would not be comparable to that ensuing from face to face interviews (Magnusson and Marecek, 2015c, pp 42-43). Despite being a relatively recent text, Magnusson and Marecek (2015c) does not appreciate the benefits that conducting telephone interviews can produce. Many researchers have found that offering telephone interviews increased the number of participants willing to take part in their research, as participation did not involve traveling to and from the interview location (Trier-Bieniek, 2012, Hanna, 2012, Holt, 2010, Sturges and Hanrahan, 2004). Moreover, telephone interviews have been found to be particularly effective when discussing potentially personal and difficult topics, potentially due to the lack of intrusion by the researcher into the participant’s personal and private space (Holt, 2010). Telephone interviews open up participation to individuals who may be too busy to take part in traditional face to face interviews (Hanna, 2012). In the context of the COVID-19 pandemic, remote interviews were not simply the only practical way to carry out qualitative interviews, but an unexpected learning experience (Vindrola-Padros et al., 2020).

4.6.2 Documentary Analysis

A documentary analysis phase was undertaken to provide a deeper organisational context for the interview data, and to help meet objective three, identifying organisational factors that shape practices of care staff. Document analysis can be defined as “a systematic procedure for reviewing or evaluating documents” (Bowen, 2009, p. 2). In this study, documents included frameworks and guidelines of continence care for people with a dementia in residential homes. The use of publicly available documents to generate data and insights has the added benefit of being unobtrusive whilst providing potentially rich information (Richards, 2015). In the context of continence care, there is an overwhelming number of documents relating to standards and best practice in care homes – however the quality of this information is largely ignored.

Documentary analysis can be a crucial part of qualitative research. When used in conjunction with qualitative interviews, document analysis can either corroborate or refute the narratives and experiences elicited in participant narratives (Yanow, 2007, p. 411).

4.6.2.1 Identifying documents

Initially, the process began by identifying what documents would be relevant to the research question. As this study aimed to identify care practices related to continence care, I began by doing a preliminary search of national guidelines and frameworks produced by trusted organisations in the UK. In addition, reports from Care Quality Commission (CQC) inspections of care homes were included to identify instances of “good” or “bad” practice. As I was searching for documents based on theoretical relevance, theoretical sampling was used. This is the process of sampling on the basis of concepts that have proven theoretical relevance to the topic of choice (Bowen, 2009). The literature review conducted for this study highlighted specific concepts relevant to continence care: knowledge, interventions, and care management. As such, documents were sought that contained information relating to developing knowledge of continence care (training), performing interventions for continence care (medications) and care management (general guidelines, inspection reports).

An initial search for inspection reports was carried out on the CQC website. In order to obtain a manageable sample of documents, refinement criteria (shown in Figure 6) was added to generate a final sample of 106 inspection reports. This concentrated the sample of inspection reports on one English region. Another search was carried out of guidelines and frameworks of organisations known to the researcher. These organisations are shown in Figure 9 and were chosen based on their contribution to regulation of care homes and relevance to the study location, namely being active in the UK. For example, Dignity in Care and Skills for Care both produce guidance on training care staff and best practice for various care activities. This is also true for the National Institute of Clinical Excellence and the National Health Service. The Department of Health was included as they are responsible for classifying the remit of care homes. Documents relevant to dementia care, continence care and care homes were included (shown in Figure 5). Figure 6 shows the process of refining searches for CQC inspection reports, of which 106 were included in the final sample. In total, 128 documents were included for analysis.

Organisation	Document Type	Refining Criteria	Number of Documents
National Health Service (NHS)	Care Framework	N/A	1
Dignity in Care	National Minimum Standards	N/A	1
National institute for Clinical Excellence (NICE)	Guidelines	Residential Home Nursing Home Older Adults	11
Department of Health (DoH)	Guidelines	Residential or Nursing Home	5

Organisation	Document Type	Refining Criteria	Number of Documents
		Older Adults Dementia	
Skills for Care	Training Guidance	Residential or Nursing Care Dementia Older Adults	4

Figure 5 - Guidance Documents

Search Number	Refining Criteria	Number of documents
1	Inspection Reports	82465
2	Care Home Inspection Reports	23148
3	Care Home Inspection Reports Dementia/Alzheimer's	12258
4	Care Home Inspection Reports Dementia/Alzheimer's Adults over 65 yrs	11897
5	Care Home Inspection Reports (Inspected) Dementia/Alzheimer's Adults over 65 yrs Within 15 miles of Hampshire, UK	106

Figure 6 - CQC Inspection Reports

The 128 documents were uploaded to the NVivo software and organised into groups depending on the type of report and the author. Initially, the 128 documents were read to establish what, if any, mentions were made of continence care. The mentions made varied depending on the type of document being read, as frameworks and guidance provided recommendations whereas inspection reports described failures and successes in practice. As such, it was initially difficult to analyse the different documents as a group. Allocating excerpts from different documents to the same themes (i.e. “Continence Training”) allowed the data set to be viewed and analysed cohesively.

4.7 Method of Analysis

The data for this study were analysed in NVivo using thematic analysis. This method was chosen due to the flexible nature of the process, thematic analysis allows the researcher to use an iterative process that follows the development of concepts and themes in the data set (Braun et al., 2019, Kiger and Varpio, 2020).

The two data sets (interview data and documents) were analysed cohesively within the same NVivo project but organised into groups depending on the type of data. This triangulation can help to give a deeper understanding of the topic being investigated (Morgan, 2022). Synthesising data in this way can be problematic, as the themes resulting from documents are more frequently used to review interview data with additional context (Czypionka et al., 2020, Fylan et al., 2019). In this way, documents can be seen as adding the “thin” description to a “thick” description produced in an interview (Czypionka et al., 2020). However, this adds arbitrary distinctions to what is or is not considered a document. In the study reported in this thesis, the interviews were transcribed before analysis. The process of doing this converts the data into *document* format, meaning that the separation of data type potentially ignores the interplay between the interview and the documents selected (Bowen, 2009, Morgan, 2022). Triangulation means to use both data sets concurrently to increase the credibility of the research. As such, synthesising reports along with interview data allows a thorough description of complex social systems to be produced, as described by Foley and Dowling (2019).

4.7.1 Thematic Analysis

The documents (both interviews and reports) were read in their entirety before any attempt was made to code emergent themes and nodes. This was to become familiar with the data and note down my own initial thoughts and responses (Kiger and Varpio, 2020). I then began generating initial codes that were shared between the different data sets, for example “Continence Training”. Within this code, all mention of training in documents and from interview participants was initially collated for comparison. Once this code was established, the concepts within the code were examined in more detail. This led to differences being highlighted in how training was approached in the documents and perceived by interview participants.

Some codes were specific to the reports and guidelines. For example, where continence care was mentioned as a required training activity it was coded as "Continence Training". Furthermore, the documents were compared against each other and areas in which continence should have been mentioned, as highlighted by other documents, were coded in absentia. The majority of CQC reports included references to malodours associated with continence care. If this was not mentioned, this was highlighted due to the regularity of other documents referring to it.

Table 7 – Worked example of thematic analysis based on Kiger and Varpio (2020)

Stage 1: Familiarising yourself with the data	Reading through data sets and making notes of initial impressions. A phrase that was often repeated in the qualitative interviews stood out: "*a carer would understand*". Each interview participant implied a mutual understanding between care workers.
Stage 2: Generating initial codes	Some examples of initial themes include: ***Hazing****: "I think one of the first things someone said to me was "don't worry, you'll get used to the smell" [laughs] the first thing they said" (qualitative interview)* ***Continence training:*** *"I have never come across any specific training, apart from anecdotal and experiential" (qualitative interview)* *"All relevant staff employed by health or social care providers should undertake training and development relevant to their role on the promotion and management of incontinence in adults, which should include adults with dementia, and also address the functional causes of incontinence." (Document Analysis)*
Stage 3: Searching for themes	This stage involved development of initial codes into themes and concepts. For example, noting my initial impression of mutual understanding along with the original code of "*hazing*" identified a process experienced by care workers. When considered along with "*initial experiences of continence care*" the theme of initiation began to develop.
Stage 4: Reviewing themes	The transcripts and documents were reviewed again to compare codes from elsewhere in the transcripts against developing themes. "**Colleague's incompetence**" (*"I just want to go, "Why are you here? Why don't you just go and work somewhere else?" How about Tesco or Asda or go and do something else. Because that's not the attitude we need")* and "**bonding through incontinence**" were added to the initiation theme as they described the ramifications of the initiation

Stage 5: Defining and naming themes	This was an iterative process by which final themes were defined and solidified. The final definition states: *care workers reframe continence care for people with a dementia as a rite of legitimacy that allows group membership and prestige not allowed by wider society.* This was tested against the following theme definitions identified through the previous steps: 1) Experiential and formal learning undertaken by care workers is not valued by wider society. 2) Care workers associate this devaluation with proximity to faeces, particularly when supporting people with dementia who may defecate in unusual locations or ways 3) Care workers reframe continence care to legitimise group boundaries and assign value within their own organisation and culture
Stage 6: Producing the report	Writing the findings chapters formed the final part of the data analysis. For example, the excerpt previously coded under “colleagues’ incompetence” is now situated under “legitimising the rite” as expelling those who fail the rite creates a definitive group boundary.

4.8 Positionality, Reflexivity, Role Incongruence and Self-reflection

The organisation and completion of remote interviews in this study raised questions regarding my own positionality and context for conducting the interviews. Positionality, described as the viewpoint and position one chooses to adopt in relation to a topic (Manohar et al., 2019), is impacted by the life experiences and attitudes of the individual in question. Acknowledgement of one’s own positionality enables the researcher to effectively identify how their own views and experiences impact the research they are conducting; however, this can only be achieved by reflecting on one’s own assumptions.

This is particularly crucial in the context of health research, as often the researcher has pre-existing experience and a background in the area they are researching (Mendenhall, 2007). A researcher in this situation can either choose to either disregard or critically examine the impact of their prior experience and knowledge. As objectivity cannot be assured in qualitative research, and the researcher is assumed to be subjective, disregarding previous experience decreases the validity of any resulting data and analyses (Dodgson, 2019). One of the potential benefits of this shared experience is the use of familiar language. When communicating with participants in a study in which the researcher has prior experience, the language he or she uses may sub-consciously relate these personal experiences and create an automatic sense of shared pre-understanding and empathetic communication, validating “interpersonal experiential participative knowing” (p206, Heron, 1996).

4.8.1 Me, the Researcher

Personal reflection involves clarifying how my own life experiences may have contributed towards the direction of this research (Olmos-Vega et al., 2022). This section therefore sets out not only my background and training, but also how these have contributed towards values and beliefs I hold and therefore my ontological perspective.

I come from a family where almost every female was or is a form of qualified nurse. My mother was a mental health nurse with a specific interest in dementia, and I encountered people with a dementia from a young age. I set out to complete a degree in mental health nursing when I was 18 but was unable to due to health concerns. Instead I began working in a care home for older adults with or without dementia. I mainly chose to work there because it was within walking distance from my home. While this setting did not provide a high standard of care, my experience there built my confidence and passion for supporting older adults. I realised the importance of the care worker role in advocating for vulnerable people.

I later began working in another care setting that catered specifically for individuals living with a dementia. Through this setting, I was able to attend training and develop my knowledge about dementia. The knowledge gained gave myself and my colleagues confidence to provide appropriate support for the individuals within our care, and I began to see people’s quality of life improving. I decided to complete a foundation degree in Dementia Studies whilst working and then a “top up” course to achieve a bachelor’s degree.

At this time, I was becoming increasingly interested in continence care provision. I was a senior carer who would often be running a team of 8 carers and went on to become a dementia specialist unit manager. I had noticed that if an individual required their bowel movements recording but wore continence aids such as pads, care workers would often record this incorrectly in the documentation. Using the Bristol Stool Chart, care workers would often record an individual as having produced a “5” or “6”, indicating loose stool, when in fact it had been a “3” or “4”. This seemed to be because when an individual defecated in the continence aid, the resulting stool would become malformed and difficult to correctly label. This experience became the basis for my undergraduate dissertation project and eventually lead to my application for this doctoral study, with considerable support from those around me.

4.8.2 Reflective Diary

There are significant parallels between my own experiences and the experiences of participants in this study. Having worked with care workers before becoming a researcher, I was at increased risk of having preconceived notions and assumptions. I began my consideration of how my background might impact the study by keeping a reflective diary (Olmos-Vega et al., 2022).

4.8.2.1 Navigating Competing Identities

Entries in the reflective diary vary considerably throughout the course of interviewing participants, with the majority focusing on my own feelings of inadequacy and, more unexpectedly, my own sense of loss when hearing care assistants talking about their roles and experiences. McIntosh (2023) discussed how the difficulty of transitioning from nurse to researcher can create tensions within the researcher and the project; whilst not a nurse, the transition from carer to researcher was equally difficult.

Entries from the two first interviews in the reflective diary acknowledge feeling that the participants were particularly guarded and slightly unwilling to discuss the sensitive nature of their work I was enquiring about. This lead to a process of interpersonal reflexivity (Olmos-Vega et al., 2022), or consideration of how the relationships surrounding the research influenced my actions. Before beginning the PhD, I was very comfortable in my identity as a care worker. My confidence in this identity began to diminish as I spent less time in a care environment, and I felt myself becoming distant from what had previously been an intrinsic part of me. This showed in my diary entries where I express feeling as though I am grieving a loss when hearing care workers experiences of the people they support.

In other doctoral candidates' recollections of the transition, a recurrent theme is feeling the loss of the previous role and identity (Colbourne and Sque, 2004, McIntosh, 2023, Lotty, 2021). The loss is however closely followed by settling into the "researcher" role. My reflective journal entries show that this was also a difficult transition as I was often referred to as "not a nurse". It seemed unusual for a researcher to come from a non-clinical, non-nursing background – particularly in the field of continence care. I was therefore struggling with the loss of my "carer" identity whilst also feeling that I did not have the credentials to adopt the "researcher" identity.

I was, however, *acting* the researcher. When I initially began interviewing participants, I was very concerned with attempting to remain un-biased and objective, fulfilling only the "researcher" role. I was very aware that despite my prior experience as a care assistant and a potential "insider", I was now a PhD researcher, therefore an "outsider". Maintaining this distance and the lack of acknowledgement of my own experiences resulted in an ineffective interviewing technique, which seemed to produce more guarded responses in the participants I interviewed at that time (Mnyaka and Macleod, 2018). These experiences led to my own difficulty negotiating three concurrent roles within myself: the researcher, the care assistant, and the sub-conscious, but no less important, self-imposed role of being neither. While Lotty (2021) describes their perception of becoming neither one nor the other as being almost liberating, I found the lack of definitive identity troubling and difficult to manage. Supervision became key to identifying these feelings and being assisted to navigate through them. Through the reflective diary and supervision, along with external support and validation of my role, I began to reconstruct a new identity. Being a carer will always be part of my identity, but I would now classify myself as predominantly a researcher (Dikilitaş and Mumford, 2023, Lotty, 2021)

I realised the importance of acknowledging my shared experience with the participants I was interviewing. In the later interviews, participants were much more open about sharing their experiences once we had established familiarity and common ground – our experience of providing care. Positioning myself as both a researcher and a carer impacted my interpretation of my findings and contributed to the synthesis and analysis of the data. As “understanding ourselves is part of the process of understanding others” (Ellis and Berger, 2003, p. 486) it highlighted to me that care workers were reluctant to share these experiences with “outsiders”. By giving my own experiences of providing continence care, I was suddenly trusted with their experiences. As such, my own experience of care and practicing reflexivity about my experiences of conducting the research demonstrated practice of providing continence care must be integral to gaining status.

4.9 COVID-19 and the Impact on Methods

As previously stated, almost the entirety of this research took place during the COVID-19 pandemic. The initial plans for the research project varied considerably from what was possible, and consideration needed to be given to the importance of reducing burden for the participants and ensuring physical safety of both the researcher and participants (Vindrola-Padros et al., 2020). As such, the methods that would have been previously used to aid interviewing techniques and collect data had to be adapted to adhere to social distancing regulations stipulated by both the government and the University of Southampton. This study had both the benefit and curse of being planned before the onset of the pandemic, meaning that a lot of the theoretical considerations were already in place. However, the methods chosen before COVID-19 were no longer viable.

4.9.1 Initial Research

The initial research proposal aimed to investigate how episodes of faecal incontinence affect the provision of dementia care. This was to be explored in a three-phase study. Phase one included a four week “hangout” period in which I would spend time in the residential care setting without collecting data to facilitate trust between the researcher and the participants. This would have then been followed by an eight-week period where participant observations were carried out. Participant observations would have involved myself working alongside care workers and assisting with the provision of continence care to reduce disruption and distress for the individuals being supported. Only individuals who had consented to take part in the study would have been observed in this manner.

Phase two of the study was a proposed documentary analysis of care records pertaining to provision of continence care. This was to establish what information was recorded about episodes of incontinence, as exploring the information would suggest what was deemed important about the interactions.

The final phase of the study was to involve focus groups with staff members and in-depth interviews with residents with dementia and/or their friends or family members. The schedule for these focus groups and interviews would have been outlined based on the participant observations carried out in phase one of the study. At the time of the first COVID-19 lockdowns in March 2020, a protocol for the above-described study had just been submitted to the Integrated Research Application System (IRAS) for ethical approval. At this time, all individuals were required to work from home where possible and care homes (the target population for this research) were ordered to close their doors. Non-essential visitors were not permitted, meaning that the proposed study was not possible (DHSC et al., 2020).

The initial study would have produced rich data about experiences of continence are that could have been analysed in tandem to triangulate the experiences of both care workers and people living with dementia. This study would have explored how societal meanings around continence change how care is experienced for all parties involved. However, the context in which social care was being provided changed drastically in this time. Even if it had been physically possible to enter care homes and carry out participant observations, this would have been unethical due to the additional stresses and pressures on care workers and the extreme health concerns experienced by individuals with a dementia. Carrying out the participant observations would have also meant exposing myself to infection, or potentially exposing individuals with compromised immune systems to infection. Participant observations were therefore not feasible, and it was not possible to contact individuals living with a dementia in a care setting in an ethical or reliable manner.

The inability to conduct the participant observations meant that a change in research question was needed. It was not possible to explore the experiences of individuals with a dementia; and therefore, not appropriate to include that as a focus in the research question. I was able to conduct the document analysis and interviews (with adaptions to accommodate social distancing) with care workers of people with dementia, meaning that the focus needed to be only on the experiences of said care workers. The focus of the document analysis needed to change from care records to guidelines and reports as the care records would need to be analysed within the care setting, which was not possible. COVID-19 restrictions therefore limited the research methods available, which dictated the types of data that could be gathered and the knowledge generated.

4.9.2 Challenges of Socially Distanced Methods

The use of remote interviews created challenges. As I was working from home due to the pandemic, the interviews were not necessarily conducted in an ideal environment that is free from distractions. I had to contend with interruptions from pets and postal workers which sometimes disrupted the flow of the interview. Many of the participants were also in disruptive environments due to the digital nature of the interviews and we were frequently interrupted by their own children, pets, and disturbances. However, the presence of my two dogs did have some unexpected benefits. In many of the video call interviews, I found that when either of my dogs presented on screen or began playing in the background, it always seemed to have a positive effect. For example, this interaction from an interview with Olivia:

Interviewer: *Yeah. Sorry, that's my dogs growling in the background; they've decided to start.*

Olivia: *Yeah, that's alright; don't worry about it. My kitten has decided to curl up in her box for now.*

Interviewer: *Cats and boxes; they're obsessed with them, aren't they?*

Olivia: *And bags. You can't go shopping and come back without a cat in your shopping bag.*

Discussing or seeing animals gave participants an opportunity to bring up their own pets and adapt the dynamic of the interview. By acknowledging the distractions and at times, awkwardness of the context, participants were able to see that I was present in the interview and focused on the interaction. Introducing references and conversations about common environmental factors, for example owning and caring for pets, aided in developing a rapport outside the typical "researcher and participant" relationship. This rapport building led to more authentic relationships with participants which in turn led to more honest and rich interviews. Whilst the presence of pets during remote interviews requires further research, previous studies show animals; particularly dogs; often act as “social catalysts” and help to create a relaxing and therapeutic environment (Olsen et al., 2019, p. 255, Beetz et al., 2012)

In the context of the telephone interviews, I did have trouble in not being able to see the individual I was talking to. The lack of physical body language cues meant that I did not feel able to recognise when the participant was feeling uncomfortable or if they felt they were making a particularly salient point (Farooq, 2015). I felt I had to try harder to develop a rapport with the individual, which on reflection likely led to me overcompensating with my language and tone to build a relationship. I found myself repeatedly uttering “acknowledgement tokens” (Irvine et al., 2013, p. 97) to demonstrate to the participant my presence in the interview. When reflecting on this, I was concerned these utterances could be interpreted as interruptions by the individual. However, these noises are evidenced as being more frequent during telephone interviews and appear to replace other physical cues that the interviewer is actively listening (Holt, 2010, Irvine et al., 2013, Farooq, 2015). Whilst I do not currently have experience of face to face interviews and how these may differ from telephone interviews, Irvine et al. (2013) found that the lack of visual cues did not result in a breakdown of conversation or a lack of rapport.

In the interviews I conducted, I felt that many of the participants based their answers on what they considered “best practice”; they presented the best versions of themselves in order to protect their identities and “save face”. Often, participants were much more open once I offered my own vulnerability and neutralised the power dynamic. Ezzy (2010) echoed this in his own experience of interviewing; “an emotionally neutral interview is also doomed to fail”. Sharing, acknowledging, and including the researchers own emotions and experiences helps to equalize the power imbalance, enable good interviewing practice and produce an environment in which the participant is more likely to comfortably share their experiences. This is particularly salient in health research, due to the likelihood that the researcher has life experience like that of the participant (Hiller and Vears, 2016). In the study reported in this thesis, the focus is on the doxastic experience of the participant in relation to episodes of incontinence. This is something I have experience and knowledge of in my previous work practice, therefore sharing my own emotional responses and feelings encouraged a co-constructed narrative to result from the interviews.

4.10 Summary

This chapter has outlined the methods utilised to undertake the research reported in this study, Qualitative, semi-structured interviews were used with documentary analysis to answer the question:

Interview based research is often used for exploratory topics and places a heavy responsibility for reflexivity on the researcher. To improve the validity of the research, the researcher completed a reflective diary and has included a reflective account in this thesis. Thematic analysis was used to synthesise the interview findings and documentary analysis findings together to give a holistic view of the data set. This research took place during a socially difficult period, namely the COVID-19 pandemic, which had a significant impact on the methods available. The next chapters go on to describe the participants included in the study and the themes resulting from the analysis.

Chapter 5 Qualitative Interview Participants

This study used convenience sampling and snowball sampling to recruit participants into the interview stage of the study. Initially, 51 individuals expressed interest in taking part in the study. After receiving the Participant Information Sheets and having time to consider their participation, 19 carers of individuals with a dementia consented to taking part in the study. One person withdrew their consent through lack of engagement with the study.

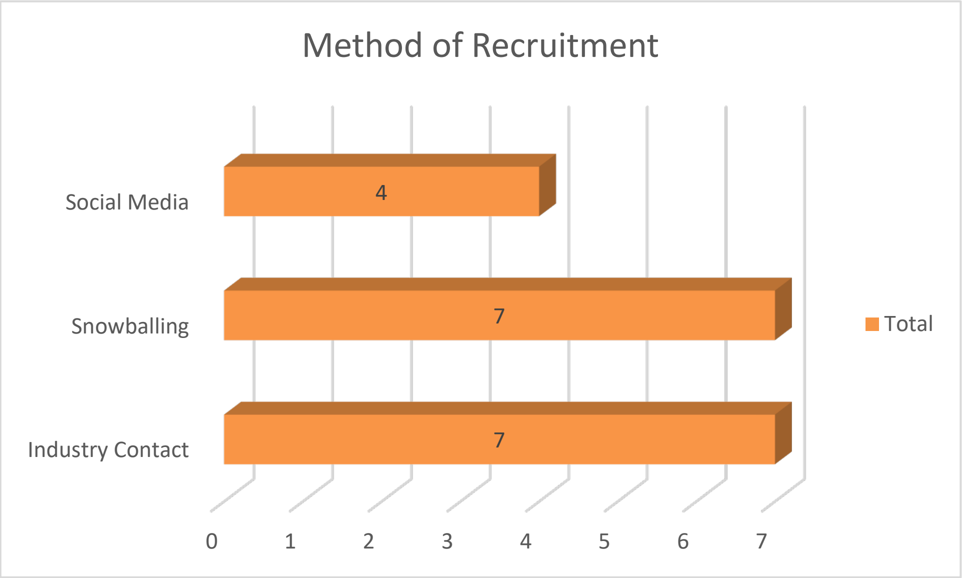

Figure 7 - Recruitment Method

Most participants discovered the study through their colleagues through snowballing or dispersal of the study through industry contacts, such as care home managers or commissioners (see Figure 7). Many of the initial contacts came from social media, however only four of these went on to participant in the study.

As shown in Figure 8, some of the participants worked together in the same settings or were employed by the same company. Participants were informed that their participation in the study was confidential and were encouraged to share the study details amongst their colleagues if they felt comfortable. All the settings in which participants were employed were registered care homes, providing either residential or nursing care to individuals living with a dementia. To be included in the study, participants had to provide personal or continence care to individuals with a dementia, although their job role did not have to require this. For example, it is common for individuals in management positions within care homes to be office based and not provide personal care, therefore it is likely that individuals in management positions who took part in this study may not be representative. For a breakdown of participants by job title, see Figure 9.

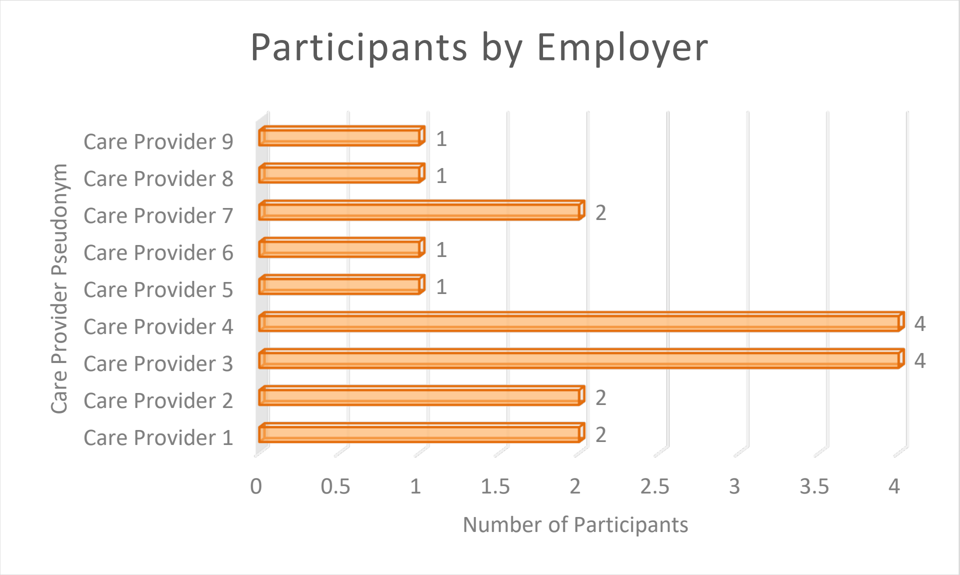

Figure 8 - Participants by Employer

In the social care workforce, male workers are the minority and account for only 18 per cent of the adult social care workforce (Skills for Care, 2021). Only one male participant took part in this study, accounting for only five per cent of the study population. As such, male care workers are under-represented in this study.

Participants had an average age of 37 with a standard deviation of 10.1. 11 per cent of participants were 25 or younger, 83 per cent were between 26 and 54 while only six per cent were over 55. 64 per cent of the adult social care population are between 26 and 54 (Skills for Care, 2021), meaning that in this study sample this age group is overrepresented while care workers over 55 are underrepresented.

Figure 9 - Participants by Job Title

Participants were given a choice of completing the interview via Microsoft Teams or by telephone. eight participants chose a video interview whilst 10 chose a telephone interview. The average interview length was 42 minutes and 53 seconds with a standard deviation of 11 minutes and two seconds.

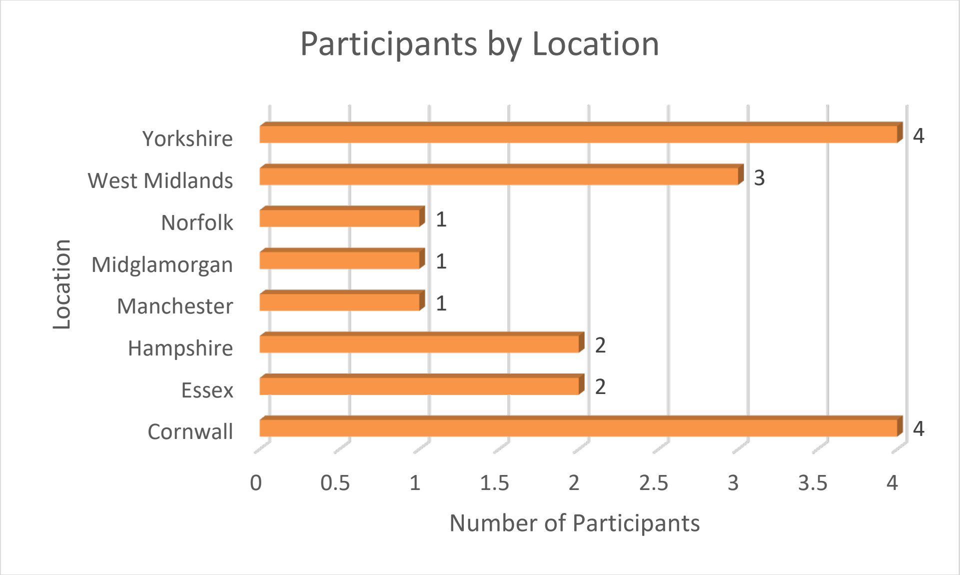

Figure 10 - Participants by Location

Care workers explained that from their perspective, continence care for people with dementias involved coming across faeces and individuals who had been incontinent in socially unacceptable areas, outside of the toilet or bathroom (see sections 6.3 and 8.2.2.2.1). They described the distress and difficulty that continence care can cause due to the reduced capacity of the individual and the difficulty of using equipment.

Writing the analysis formed the final stage in identifying the themes and interpreting data. During this process, analysis showed that participants in this study used membership within a legitimised group to provide themselves with the status and accreditation. Participants perceived themselves as being devalued in part due to their contact with faeces. All participants, despite originating from different areas of the UK and different care companies, presented as part of a group. Within this group, participants recognised the shared experiences and values of others and developed a strong sense of community.

Participants begin by perceiving their skills as “natural” facets of their personality, despite evidencing experiential learning and skill development throughout their lives. In addition, participants often had family members who were already care workers, leading to a perception of care work “running in the family.” Once they have this perception of being “naturally” caring, they are primed to enter the care community where they find mutual recognition and validation.

As participants begin working as carers, they report perceiving their role as actively stigmatised and devalued by non-care workers. They recall being labelled as “just a carer” and classed as an unskilled workforce, despite having collected several key skills and abilities to perform their role effectively. As participants have already extended their identity to include their caring role, the perception of the role being devalued means they also feel devalued and unrecognised as an individual.

To combat these feelings, participants in the caring community perform a rite of legitimacy to define the boundaries of their group and offer accreditation to members. This “rite” is an initiation ritual that not only cements membership within the group, but solidifies and legitimises the social boundaries that define the group (Bourdieu, 2005). The rite allows care workers to be respected and acknowledged within the group and ascribes value to the various actions they perform within their role.

Chapter 6 Responses to Continence and Incontinence

6.1 Introduction

This chapter reports on the first main theme identified from the document analysis and semi-structured interviews: shaping responses to continence. Firstly, this chapter discusses organisational factors that contribute to the responses of care workers. The documents analysed for this study identified how continence care was not considered a skilled activity but was conversely considered important enough to define the quality of care of an overall setting. Environmental factors associated with incontinence, such as odour, were associated with the success or failure of the setting.

When compared with care worker experiences of providing continence care, it became apparent that care workers employed dynamic responses to episodes of incontinence. The accounts given here describe highly skilled activities that were not acknowledged or recognised in the organisational documents.

6.2 Ignorance in Documents

The documents acknowledged that continence, specifically in the context of dementia, was an area that requires specialist knowledge and skills. Despite this, recommendations for continence training were few and far between. Very little attention was given to continence care unless viewed as an indicator of care quality.

6.2.1 Training Requirements

In the documents analysed for this study, continence care often referred to the actions taken by qualified continence specialists to plan and implement interventions to help manage an individual's continence. These continence specialists were often registered nurses who had undertaken additional training in the development, prevention, management, and treatment of continence. The way continence care was described varied depending on the source of the information. In the data resulting from the document analysis, the idea that continence care could be undertaken daily by "unqualified" care workers was conspicuous by its absence.

The NICE guidelines for Dementia (2018) and the NHS Enhanced Care Framework (2020) recommended that care workers for people with a dementia receive training on dementia specific continence issues, such as functional and cognitive causes of incontinence. The document therefore positions continence (rightly or wrongly) as a dementia specific issue.

The 22 frameworks and guidelines reviewed identified 56 areas care workers are expected to be proficient in, all of which they must achieve through training completed within 12 weeks of beginning their role (full table shown in Appendix D). Out of all these documents, only two made any reference to specific training around continence management and care. These were the NICE (2018) Dementia guidelines, which suggested care workers receive dementia specific training in the cognitive causes of incontinence, and the DoH (2013) infection control guidance, which suggested care workers receive training on the link between antibiotic prescriptions and *clostridium difficile* infections.

The inclusion of these two references is problematic. As the only explicit reference to continence training was in a dementia specific context, the implication is that only individuals with a dementia will experience incontinence and that only care workers in dementia care settings should receive training on this. While continence care remains incredibly important in the context of dementia, the ignorance of continence care outside of people with dementia may imply systemic agnoses around the provision of continence care.

In addition, these documents presented incontinence as resulting from a temporary infection and therefore being a short-term issue. This presentation ignores the experiences of individuals with incontinence and care workers alike, contributing to the systemic agnoses.

There were however training requirements mentioned that could be linked to continence care, shown in Table 8. The potential links were not described in the documents.

Table 8 - Training requirements in the context of continence care

Training Requirement	**Potential link to continence care**
Use of medication	How laxatives or diuretics may impact continence
Prevention and control of infection	Containment, cleaning and tidying after episodes of incontinence reduces spread of infection
Good nutrition for older people	Managing constipation or diarrhoea with diet
Initial wound care	Incontinence associated dermatitis
Experiences and needs of service user group	Service user group the care worker is supporting may experience incontinence

Training Requirement	Potential link to continence care
Physical activity assessment	Mobility may impact ability to access or get to the toilet in time
Understanding, reacting to and helping people living with dementia who experience agitation, aggression, pain, or other behaviours indicating distress	People with dementia may experience distress reactions due to bowel or bladder issues
Appropriate use of equipment	Using toileting slings, commodes, continence aids.

As such, it can be deduced that continence management was considered either a small part of the role or of little importance to policy makers and individuals regulating the provision of care. There were also no descriptions or explanations of what continence care entailed within these documents.

6.2.2 Finding Continence Care in Inspection Documents

References to continence and incontinence increased significantly in inspection documents.

> The service was visibly clean throughout, and no malodours were noted.
>
> ***(Care Quality Commission, 2019)***

The above phrase, or a slight variation of the above phrase, was found in 68 of the 108 CQC reports included in this study. While this may only be a very brief mention, the importance of noting a lack of malodour cannot be ignored. This was nearly always at the beginning of the report, before any mention of any other observations. As such, this implied that there was an *expectation* of a malodour and visible uncleanliness when entering a care home. The reports did not mention or discuss any other aspect of continence care.

There were four reports where malodours, or smells of urine and faeces, were detected. Of these four reports, three of the homes were categorised as “requires improvement”. In all reports for homes rated “Good” or “Outstanding” there was a notable absence of malodours. These reports therefore suggest that there was some correlation between a poorly performing home and the presence of malodours.

Despite the implied importance of this, continence care is not currently inspected within care homes. Inspectors often have “key lines of enquiry” (KLOEs) that structure their inspections, such as staff understanding of the Mental Capacity Act (2005). What falls under the remit of KLOEs changes frequently. Staff understanding of the provision of continence care, or experiences of individuals being supported, is not and has not been one of the KLOEs and is therefore not a routine topic for inspection. This is potentially as continence care is expected to take place in private and behind closed doors, and therefore out of sight of inspectors and regulatory bodies. Continence care, therefore, may fall into a lost realm of ignorance (Proctor and Schiebinger, 2008).

6.3 Care worker Accounts of Incontinence

This section reports on findings from qualitative interview participants. Continence care for care workers means supporting an individual to preserve their dignity when continence is difficult to maintain. In practice, this means cleaning up faeces and urine in socially unacceptable areas: outside of the bathroom. This can be particularly salient in providing continence care for individuals with a dementia, as the following accounts describe.

> “he was having a bit of a restless night and he was up and back, up and back from the toilet and his buzzer was going off so I kept going in, and then erm he was stood over his bed, and unfortunately he’d erm, yeah, opened his bowels and it was kind of down his legs and all over the floor and he was stepping in it and so, yeah I had to call someone else to help, he’s not normally someone you’d need two people with but it, sort of, I felt like there was too much for one person to deal with there because there was the cleaning and the cleaning of him, erm, I couldn’t find, there were no wipes in his room, so [laughs] then it’s like, OK what do I do now then? Sometimes I find it like, where do I start? Kind of, do I start, you know, do I, do I put something on the floor so he’s not stepping in all of that? Do I begin with cleaning the gentleman? Yeah. It’s a bit, a bit of the unknown sometimes.”

Linda, 38, Care Assistant, Care Provider 3

> “I can think of one gentleman who regularly will walk down the corridor and wee on a certain door, like urinate there, or he would erm, yeah, open his bowels in the corridor on the floor, so it’s really important to keep a watch on where he is at certain times. And you know you can try to encourage him into the toilet or to a commode or, erm, but he doesn’t want to do that. So it’s just a case of following him round really. Erm, you know within eyeshot, just to make sure you know that you clean up as soon as something’s happened, so that no one else falls over or steps in it or anything like that”

Linda, 38, Care Assistant, Care Provider 3

Linda's experience was representative of the experiences of other care workers interviewed for this study. She explained this individual was living with a dementia. To maintain his dignity and mitigate the stigma of incontinence, Linda had to "*keep a watch on where he is at certain times".* She described having to be constantly aware of the individual and what they were doing so she was ready to intervene if they were incontinent. They then had a messy accident that required Linda to step in and help maintain his dignity. She found the situation overwhelming and had to call for help but leaving the gentleman covered in faeces was not an option. Linda had to manage the individual's dignity, mitigate the stigma for the individual she was supporting, her own feelings of being overwhelmed, guilt about having to call another member of staff, along with uncertainty about what she needed to do first. In addition, she described an individual who does not appear to recognise the toilet or bathroom as a place to urinate or defecate. She explained he did not want to use the toilet or a commode. Because of this, she felt her only option to mitigate stigma was to monitor and clean up when an accident happened.

Linda was having to respond dynamically to the unique situation she found herself in. She had to quickly assess the physical needs (practical support), psychological needs (reassurance) and social needs (mitigating stigma) the individual had in that moment and then adapt her actions to meet those unique needs. The skills required to do this are complex, not covered in training, and call for considerable emotional labour.

> "but we quite often find her just standing up with her pants around her ankles with you know a nice bit of mess, sometimes her hand in the mess. That is the one that springs to mind (laughing), don't ask me why. Yeah, so she can still walk, she is able to walk with support, so we just take her off to the toilet. She does use the toilet when placed on there, but it has gotten a bit worse with her lately, I think it is just as the disease progresses. But for the most part she is alright....
>
> "…She is butt-arsed to the world then and you are like, "Oh, what are you doing?" and you have to run over, but yeah… "
>
> "…sometimes there is other residents in the room. Not that any of them mind, I mean they are all best mates, and they have all seen each other's bits in some way or another. But you know, she doesn't really seem to be very worried about it, she is very chilled. But yeah, I pull them up, either help her to her wheelchair to get to the toilet, or if it is too messy we can just walk her, because the lounge is really close to where the bathroom is anyway"
>
> ***Hannah, 26, Care Assistant, Care Provider 4***

Hannah described her experience of supporting an individual with a dementia who was unable to communicate when she needed the toilet. As a result, the individual was often incontinent in shared areas of the setting, in front of other individuals and at unexpected times. In Hannah's accounts of providing continence care, she also evidenced the need for dynamic responses. She had to consider the environmental and social circumstances, such as the location of the episode and whether there are other individuals around.

> "…he does have dementia. And he is extremely strong-willed so we would say to him sort of every three hours, 'Ooh, come on, shall we nip down to the toilet a minute? Shall we go and see if you need…?' 'I don't need the toilet, I don't need the toilet.' He effs and jeffs like a sailor as well. So it's difficult with him because we don't want to get him sort of heightened to the point that he's telling the whole dining room to fuck off. Because a lot of the ladies really don't like that when he gets going. And so we have to kind of gently, gently, 'Oh come and have a walk with me, come on, let's have a little walk'.
>
> So two of our carers were walking with him and right outside the office door where I was sitting, he passed an absolutely ginormous poo which hit the floor and I sort of sat there, I heard it drop and I looked, because he wears shorts because he's got dressings on his legs. And it literally came out the leg of his shorts and hit the floor.
>
> So I was just like, 'Oh my goodness'. So I just got up, I just got up, I went and grabbed a pair of gloves and a bag and a handful of wipes, picked it up, put it in the bag, put it in the toilet. They sort of carried on walking with him. He turned round and went, 'Well it's wasn't me'. (Laughter) I just thought, 'Oh God. Well it was you because I've actually just seen it leave your body. But…' Okay"
>
> ***Jennifer, 43, Senior Care Assistant, Care Provider 3***

Again, Jennifer described an experience of continence care for an individual with a dementia who defecated in a corridor. She explained how her response and approach had to consider his personality – "*he is extremely strong willed".* She also had to consider the social and physical environment, continence care for this individual could lead to distress reactions and "heightened" behaviour that impacted other individuals in the setting. Continence care in this example involves consideration of multiple factors and working as a team with her colleagues.

> "All the residents on all floors all have different incontinence pads and one thing and another. You've got your slips, you've got your pantyliners, you've got the wraparound pants, the pull-up pants, things like that, incontinence aids and things, so there's a variation. We've got ladies with stomas, the bag, I can't remember the name of it. I'm

> terrible, aren't I? For urinating, the catheter bags and things like that. There's a variation of different things that we do within the home across all floors. It's just making sure that it's in the care plan exactly what it is that they're using and being mindful of it…
>
> …You'll have one person, so for instance you'll have two carers, so one person is trying to hold that resident and you're putting the pad on, and it's just getting one side on. Once you've got one side on, it's not too bad, but it's getting it on properly to be able to then move around and do the other side without getting hit in the face or kicked in the face or kicked in the leg or whichever."

Susie, 50, Care Assistant, Care Provider 5

In this experience, Susie was discussing the type of continence aid she finds most difficult to use: the wraparound pad. In addition to the personality of the individual and the environment, Susie also had to consider the materials and technology in her response to incontinence. Susie explained that when supporting an individual with a dementia, aiding that person to put on the wraparound pad is physically very challenging. This is because it required two hands to fasten one side of the wraparound, and this causes the other side to fall down. If the individual is not able to actively participate in the action and hold one side themselves, simply putting on the wraparound pad becomes a job that requires two members of staff. In addition, Susie described an experience where the individual was distressed and exhibiting distress reactions. Susie therefore described a highly stressful moment.

> "his dementia is quite high, and he used to be a boxer. So we think his dementia is going back the other way, and he's going back to his old days. Erm, he'd only talk to me when he got to know me, and he was like 'oh I'm gonna fight everyone, they're all this they're all that' and he kept swearing and swearing and swearing at everybody that went near him. And we put a pad on him and I was like 'right, I'll be back in a little while [individual's name], I've just gotta go down and see somebody else and sort them out and get them out of bed and put them in their chair' and he was like 'OK', and then he started buzzing. I went 'what's wrong?' and he said 'my pads wet' and I went 'OK I'm coming, let me go and get my new gloves because I gotta put some new gloves on and then I'll come and see you' he went 'OK' and then by the time I've got round the corner he's taken the pad off and he'd launched it across the room."

Dorothy, 23, Carer, Care Provider 1

Dorothy highlighted the difficulty of providing responsive and timely continence care in a realistic care environment. Dorothy had to collect gloves to assist the individual to change his continence aid, not doing so would have contradicted policies and procedures implemented to maintain infection control. This caused the individual to behave in a manner they may not have done normally and added additional stress to the situation.

6.4 Summary

This chapter has highlighted the lack of consideration given to continence care in regulatory documentation. As there is a lack of training recommendations around continence care, this implies a belief that continence care is not a skilled activity and that it is something care workers should be able to do with no preparation. Despite this, the inspection documents show that care workers will have their quality judged on their ability to effectively contain episodes of incontinence. Failure to contain incontinence means care workers are occupationally derogated, but they are not supported to develop their skills in doing so. These organisational factors create a culture where continence care is not perceived as a skilled activity.

Contrary to this, participants in this study describe how they had to respond in increasingly dynamic and skilled ways to support individuals with a dementia who are incontinent. The accounts presented in this chapter come from a range of care workers of different ages in different settings; however, they all reflected having to consider the personality of the individual, their cognitive function, the social and physical environment, and the skill mix of the team around them. The consistency of these reported experiences implies the emotional labour being performed is present throughout residential dementia care provision. This emotional labour is not recognised in the documents reviewed. The care workers that participated in this study were not given the organisational opportunity to demonstrate their skills, as continence care had to take place behind closed doors.

Chapter 7 The Need for Community

The second theme identified was the collective sense of exclusion from wider society due to the role of care worker. Participants reported feeling judged and stigmatised because of their job role and choice to become care workers. Participants felt that their contact with faeces caused others without care experience to ignore all other aspects of the role, despite there being a considerable number of additional responsibilities and skills needed. The exclusion meant that the care workers interviewed felt the need to seek a sense of belonging elsewhere. These findings begin to explain the need for group formation.

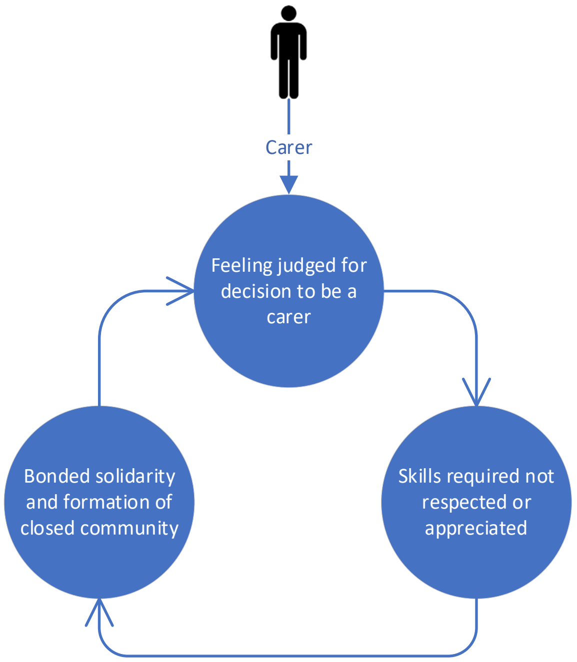

Figure 11 – Forming the group

7.1 Developing a Caring Identity

During the interviews, participants consistently referred to their skills and reasons for joining the care industry as being instinctual, natural, and part of their personal identity.

When describing how they initially made the decision to work in residential or nursing homes, many participants described having familial experience of care work; either through caring for family members or through family members that were already carers. For many participants, providing care for older adults was something they had already encountered before they started work in a care home. The skills required were already part of their history and identity before they began working in the care industry. In addition, some of the participants also specifically recalled caring for a family member living with a dementia. This experiential learning was often unrecognised but may have greatly contributed to the participant's decision to become a care assistant.

7.1.1 Familial Experience

Many of the participants in this study reported having prior family experience of caring, usually in childhood or very early adulthood. One participant, Emma, described how as a teenager she had begun caring for her terminally ill father.

> "my Mum has always worked in care, my sisters also worked in care, and then when we were, I was 14 so about 13 years ago, my Dad got really ill with cancer, and we didn't have enough time really to have any carers, so the family sort of took it on, and with so many of… everyone having to work it meant that even at 14 I had to start caring for Dad, and then once I'd finished school my Mum when she worked in a care home, again because I was the only one at home, I used to go and volunteer there a lot on any kind of summer fete and stuff, or whenever there was… Mum had no-one to baby-sit me, they'd let me go in and sit while she was working, so I just got used to the environment of care."
>
> ***Emma, 27, Care Assistant, Care Provider 8***

Emma explained that she was expected to support her father as she was *"the only one at home"*. The family did not have the financial means to pay for additional support, and Emma's mother and sisters likely worked in various shift patterns that meant they were out of the house when Emma was home. The lack of additional support and the physical absence of her other family members meant that Emma "*had*" to adopt the caring role at a young age in order to provide support for a close member of her family. If the family had been able to organise outside support in the form of palliative care nurses or paid carers, Emma may never have adopted this role and gone on to identify as "naturally" caring.

Once Emma gained this care experience, she likely found this encouraged and recognised by her mother and sisters who were also carers. Emma states "*Mum had no one to baby sit me",* implying that her mother either did not have the financial capital or the social capital to leave Emma at home unsupervised. As a result, Emma would spend time at the care home her mother worked in, whereas other children of higher socio-economic status may have been cared for by a guardian or child minder. This experience meant Emma "*got used to the environment of care".* She was exposed to, and accepted, aspects of caring from a young age. The environment and actions were all familiar to her, so that when she was eventually deciding what career path to follow it made sense to enter a caring profession. She already had experience and had developed some skills that would support her in this role.

Emma's story was representative of other participant experiences shown in Table 9. The prior experience of care, often with other close family members, led to a tight knit and closed familial group with shared experiences.

Table 9 – Developing a caring identity

Quote	**Participant**
"I have a, a sister who was into care, so she talked to me about going into care about, you know, and, also, in the past, I've had a son who needed care, and I had to learn, because I had no experience in care, so I had to learn, you know, to care for my son. He's, he's passed away now … it was four years of care, and, in that time, I gained some, some unprofessional experience in caring"	*Jacob, 41, Care Assistant, Care Provider 4*
"I have been the main carer for my grandparents for the last 17 years and have cared for my granddad right up until he passed away two years ago"	*Lucy, 38, Head of Services/Care Assistant, Care Provider 3*
"My grandad had Alzheimer's but I was quite young then, I was about 12 so it was watching my mum care, and then my mum became a carer and she really enjoyed it. So, it was watching them really that made me like it."	*Molly, 26, Care Assistant, Care Provider 9*
"I first sort of went into care at the age of 18, worked in my first care home for three years – days and nights – then went off to do my first degree and ended up having a little boy with profound disabilities so I was also caring for him."	*Olivia, 48, Care Assistant, Care Provider 4*
"I started care because of my granddad going into a care home, erm, and I was in childcare beforehand, and of course him being in a care home he was like "oh you should be a carer, you'd love it" I was like "granddad I'd love to be a carer, let's try it and see what they say" and then obviously he passed away so I started my care job, at his care home"	*Dorothy, 23, Carer, Care Provider 1*
My parents and one of my grandparents worked at this big psychiatric hospital in Bristol and they used to have a Tuesday evening club where … they were obviously called patients at the time, the patients had a little social club where you could play darts, pool, have tea and coffee and biscuits, and as part of my voluntary work, I went along and helped and I enjoyed doing that. I think I was about	*Mia, 55, Care Assistant, Care Provider 7*

Quote	Participant
16 then. Then when I was about 18, I applied for a job and I got a job.	

As many of the participants had experience of caring outside of their occupation and paid role, the idea of being a "carer" was more than just a job that took place only during working hours; it was something they portrayed and enacted outside of their working role. Therefore, it became part of their personality and part of their individual identity, shown in *Table 10*.

7.1.2 Care as Identity

The familial experience of many of the participants had led to them adopting caring behaviours and traits into their identity. The skills learnt and developed during their personal experience were perceived as instinctual, natural, and part of them. Participants frequently described their role as *"part of my fabric"* or *"who I am"*, going as far to say that becoming a carer was not a choice, rather the only option due to their personality and identity (see *Table 10*). Additionally, this perception was consistent across participants from various locations, ages, and care providers.

Whilst this was the perception of the majority of participants, one participant stood out as having a different route into the caring profession. Linda was 38 years old at the time of interview. Linda became a carer during the height of the COVID-19 pandemic when she was furloughed from her "*normal"* job at the age of 37. Prior to this, and unlike the other participants, Linda had no informal experience of providing care. She already had a full-time job and was not financially struggling. She had other opportunities but felt the need to "*help out in some way".* Her desire to help individuals and a community she perceived to be in need implies a caring and empathetic nature; Linda was already a "caring" person before she became a carer. While Linda's entry into care presented as very different to most participants in this study, Linda had many similarities. Linda showed caring is inherent in her personality and she was recognised as a "natural" carer. Despite joining the workforce at a later age than other participants, she easily joined the "carer" community due to her shared values of empathy and kindness. Being caring and nurturing was part of her identity.

Table 10 – Care as Identity

Quote	Participant
"I think with elderly people I've always had that kind of nurture instinct"	*Jennifer, 43, Senior Care Assistant, Care Provider 3*

Quote	Participant
“you do get natural carers, you do get people who are just, I believe, you can see a spark”	
“like well what else would I do, it’s part of my, it’s part of my fabric”	*Bella, 45, Registered Manager, Care Provider 2*
“It gets in your bones doesn’t it, I think it’s just in your bones anyway if you’re a carer.”	*Emma, 27, Care Assistant, Care Provider 8*
“I think you have to be a different kind of person to be able to deal with that, don’t you?”	*Terri, 29, Registered Manager, Care Provider 7*
“I’d prefer to clean a dirty bum than I would paperwork. As bad as that sounds, that’s how I feel. That’s who I am.”	*Lucy, 38, Head of Services/Care Assistant, Care Provider 3*
“for some reason I’m made to look after people; It’s not a choice it’s just how I’m made”	*Olivia, 48, Care Assistant, Care Provider 4*
“It’s almost like I was meant to be a carer”	*Susie, 50, Care Assistant, Care Provider 5*
“I think some people can do it and some people can’t. And I get that, you know it’s not everybody’s cup of tea. You have got to be in the right mind to be a carer. You have got to have the right way about you” **“I think it’s something that’s in you”**	*Ruth, 48, Care Assistant, Care Provider 4*

Regardless of how participants entered the caring profession, they all self-identified as having “*naturally”* caring traits, skills and experiences. The term “*naturally”* is problematic here, as by identifying this way the participants were already disregarding and devaluing their prior experience that led to the development of these skills. As such, many of the participants had entered the caring community with the perception that this is what they were meant to do, what they are built for. Being caring and being a carer was an intrinsic part of their identity, rather than an aspect that was refined and developed.

7.2 Mutually Recognising Identity

Once participants had incorporated being caring into their identity, they then reported experiencing a need to cement this identity and find mutual recognition in other individuals who defined themselves by their caring nature. This resulted in a tight knit community where carers were able to develop mutually beneficial bonds.

7.2.1 Shared Understanding

Within this tight knit community, individuals reflected the need to have shared understandings that solidified the bonds between them. Participants in this study highlighted shared understandings in their experiences of continence care.

Whilst relaying an experience where he had contact with faeces, Jacob related it to bonding with his colleagues. Jacob explained that after such experiences, he would make light of it with other carers to "*relax"* and "*ease off the stress of the day".* In Jacob's recollection, these conversations were always away from the individual he was supporting to maintain their dignity and show respect. In addition, any comments Jacob may make were only with other carers. This shows that the purpose of the interaction was purely to bond with the other carer. Jacob rationalised this by saying it's "*because we [carers] understand".* If these comments were made to someone outside the caring community, they would be perceived as unprofessional and as if Jacob was degrading the individual he is supporting. Jacob explicitly stressed that making light of the situation was not the same as making a joke. He seemed to interpret the idea of making a joke as disrespectful of the individual he was supporting, something that clearly violated his values and intentions as a carer. To Jacob, being perceived as disrespectful would contradict his core identity as a carer, but he does not run the risk of being perceived this way by other carers when he is making light of an experience.

Jacob's experience demonstrated an intrinsic understanding and recognition that this was just "*sharing an experience"* and there were no ill intentions behind the humorous comments. When he made light of contact with faeces to other carers, there was an instant mutual recognition of the experience and an understanding of his intentions behind talking about it. Jacob's identity as a carer who respects the dignity of the people he supports was affirmed and reaffirmed with every discussion. Jacob felt a sense of belonging as he was surrounded by other carers who have shared his experience and immediately validate it.

> "a carer would understand, you know. If, if, if you're talking about poo to a carer, we understand, you know."
>
> *Jacob, 41, Care Assistant, Care Provider 4*

> "so because we understand, but if it was someone else, it, it would, it would be unprofessional, because they, they might think it's like a joke, which it's not, which is really not… We're not trying to make a joke about anybody, but we're just, you know, having, you know, we're sharing an experience"
>
> *Jacob, 41, Care Assistant, Care Provider 4*

> "But I won't, I won't say that to someone who's not a carer, who didn't experience it with me. I wouldn't come back the next day and, like, make it a discussion. No. No, not like that, no. No, it was between me and my partner"
>
> *Jacob, 41, Care Assistant, Care Provider 4*

Jacob's experiences were particularly interesting as he was the only male care assistant in the participant sample. Despite this, Jacob's experiences were consistent with that of the female participants. This suggests that in this specific context, gender may not influence how an individual mitigates incontinence related stigma. Further research would be required to explore this.

Through these experiences of dealing with incontinence, participants' experiences and identity were repeatedly validated and affirmed. Carers in this study simultaneously provided this service for other carers, and so a network of mutual understanding is developed.

Once the participants in this study established a group dynamic, they reported feeling able to develop mutually supportive relationships that helped them to deal with the emotional labour of their role. Molly (Table 11) described contacting colleagues outside of work after what she identifies as a "*really hard shift".* The only purpose of this contact was to ensure both individuals had an opportunity to reflect on their shared experience and talk through any issues they may have. This reinforced their bond and solidified their status as members of the community, as individuals outside that group would not have the required understanding to provide emotional support.

> "we all recognise our strangeness in each other if you like; we're like a huge dysfunctional family"
>
> ***Olivia, 48, Care Assistant, Care Provider 4***

Oliva describes herself and her colleagues as a "*huge dysfunctional family"*. The label of "family" shows that Olivia viewed herself and her colleagues as sharing an unconditional bond that is difficult to sever. In addition, by saying "*we all recognise our strangeness in each other*", Olivia shows that there was an unconditional acceptance of the community members' personhood. Traits and characteristics that would otherwise label the individual "strange" were accepted and acknowledged without qualms.

Table 11 – Community

Quote	Participant
"Unless you do care, they don't realise what you actually do … I mean, to be fair most of the people I am friends with actually work in care. All my family, my mum was a nurse, my sister was a nurse, my other sister a social worker." **"we all recognise our strangeness in each other if you like; we're like a huge dysfunctional family"**	*Olivia, 48, Care Assistant, Care Provider 4*
"Sometimes I go home and talk to the person I was on shift with and say that was a really hard shift, and we will just check we are both okay or if we want to talk about it, we will just chat on the phone to make sure we are alright."	*Molly, 26, Care Assistant, Care Provider 9*
"they thought it was hilarious that the Deputy Manager had her foot weed on. I guess also remembering that I am as much one of them as well"	*Terri, 29, Registered Manager, Care Provider 7*
"we all work together and that's just the way that we do it."	*Dorothy, 23, Care Assistant, Care Provider 1*
"A carer will understand, but someone who's not a carer won't understand."	*Jacob, 41, Care Assistant, Care Provider 4*
"My son lives here and he's 30, he works in care so he probably would know exactly what I would be saying and not bat an eyelid … I think people in care know what the job entails"	*Mia, 55, Care Assistant, Care Provider 7*
"I'd say about 70% of my friends are all in care"	*Lucy, 38, Head of Services/Care Assistant, Care Provider 3*

7.3 "Sometimes it feels almost taboo to tell someone that you're a carer"

After explaining her perception of how the caring role is devalued, Emma described how she feels reluctant to tell people she is a care worker.

> "Sometimes it feels almost taboo to tell someone that you're a carer"
>
> ***Emma, 27, Care Assistant, Care Provider 8***

By saying it feels "almost taboo", she showed she felt reluctant to associate herself with the label of care worker. While she knew that a care worker was much more than this, she felt that other people view care assistants as people who just "wipe bums". Despite having already established herself as a naturally caring person and incorporated this into her identity, she feels that other people associate being a care worker with contact with faeces (see section 7.2.1). She perceived there to be a stigma linked to faeces and did not want her contact with faeces to result in courtesy stigma for her.

This experience was echoed by Linda, who was from a different locality and care provider. Linda explained that when she told other people what her job was, she also found they focused primarily on continence care.

> "they're like 'oh you clean old people's bums'"
>
> ***Linda, 38, Care Assistant, Care Provider 3***

Again, Linda recalled that the care worker role was reduced to *"clean[ing] old people's bums".* Linda did not seem to recall any other understanding or perception of what being a care worker entailed. Linda also seemed to be feeling angry and frustrated when explaining this.

> "Same as if you're a nursery worker you have to change children's nappies, but you don't do the job because you want to change nappies, do you? No one would say 'oh you change nappies for a living' but they would say to me 'oh you wipe old people's asses'"
>
> ***Linda, 38, Care Assistant, Care Provider 3***

Linda compared her role to that of a nursery worker. Linda explained that nursery workers also have contact with bodies and effluent, however, they are not characterised by this contact as care workers are. In Linda's view, nursery workers are not positioned as performing their role solely because they wish to change children's nappies. This implies that Linda feels care workers are accused of performing their role because they wish to assist with continence care. A nursery workers role outside of continence care is valued and acknowledged, whereas a care workers role is reduced simply to continence care. She highlights the disparity between nursery workers and care workers: nursery workers contact with infantile incontinence is not important, but a care assistant's contact with adult incontinence is. In this comparison, Linda highlighted that despite both roles having contact with incontinence, they are viewed and treated differently.

> I think you know they go "oh how can you do that?!" and erm, so I just tend to, yeah, I just tend to keep that to myself really.
>
> ***Linda, 38, Care Assistant, Care Provider 3***

Much like Emma, Linda was not comfortable sharing her job role because of how she perceived other people to feel about care work. She related this directly to contact with faeces and adult incontinence, as non-carers questioned her specifically about how she can provide continence care. Being repeatedly asked how or why one chooses to do something suggests disbelief on the part of the questioner, there was little Linda felt she could say to convince the questioner that the role is enjoyable and satisfying due to the widespread devaluation and misunderstanding of what care work entails. Therefore, Linda chose to just "*keep that to myself*". This experience was not unique to Linda and was described by many of the participants (see Table 12).

Table 12 – Perceptions of Others

Quote	**Participant**
"he's just like 'I can't imagine, I could never do your job' he always says that to me, I could never do your job"	*Caitlin, 33, Unit Manager, Care Provider 2*
"the only job where once I tell people, people instantly tell me they'd never do it" **"care and nursing people love to tell me that they'd never do it"**	*Emma, 27, Care Assistant, Care Provider 8*
"some people are just like, 'Ugh, why do you do that for a job?'"	*Hazel, 25, Care Assistant, Care Provider 6*
"I mean my husband's heard it all. And he will say to me, 'I don't know how you do that'"	*Jennifer, 43, Senior Care Assistant, Care Provider 3*
"I think if I was speaking to my husband about it he would be thinking 'Oh my god, how do you do that?'"	*Mia, 55, Care Assistant, Care Provider 7*

Quote	Participant
"Everyone goes, you know, and who would want to do it?"	*Sinead, 44, Dementia Specialist Tutor/Care Assistant, Care Provider 3*
"Even my best friend is like, 'I could not do what you do'" **"But, yeah, an awful lot of people go, 'There's no way I could do that'"**	*Olivia, 48, Care Assistant, Care Provider 4*
"because I work night shifts as well I get 'oh I don't know how you do nights, I don't know how you just go into these places and just clean up after them'"	*Molly, 26, Care Assistant, Care Provider 9*

These feelings are summarised by Bella, a mental health nurse who is the registered manager of an 84-bed residential, dementia and nursing care home. Bella explained that people outside the care industry do not understand why anyone would choose to become a care worker. She echoed the experiences of other participants by describing the role as perceived as unskilled and closely associated with unpleasant tasks.

> "I think that, I think that people are, I think people are amazed that people choose to do this job … I still think people think care is just an unskilled job that does a really awful set of tasks."
>
> ***Bella, 45, Registered Manager, Care Provider 2***

Furthermore, Bella went on to define this separation of care work and wider society. Bella stated that the care worker role is stigmatised, before going on to say that most people who stigmatise the role would not be able to do it anyway.

> "there is a huge stigma attached to a profession that actually 98% of the population couldn't do."
>
> ***Bella, 45, Registered Manager, Care Provider 2***

As a registered manager and a registered nurse, Bella represented a minority in this participant group. However, her perceptions still supported the experiences the rationalisations of care workers. For Bella, the allocation of a stigma shows an entrenched difference between those who can and those who cannot. This difference becomes a boundary that defines carers as those who can.

7.4 “You’re just a carer”

Emma worked in a bank before deciding she wanted to study nursing at university. To gain some experience before she began her degree, Emma worked part time in a care home for individuals with a dementia. Emma described telling her manager at the bank that she was leaving to work in care.

> “When I first got in, first left to go into care, I remember going downstairs and telling my manager, and he just looked at me blank and said, ‘What do you want to do that for?’
> And I said, ‘But I’ve always wanted to,’ and he was like, ‘What… so you just want to wipe bums for your life?’”
>
> ***Emma, 27, Care Assistant, Care Provider 8***

Emma was faced with someone in a senior position to her who had no understanding of her life choice or her desire to work in care. Emma described her manager as looking *“blank”,* indicating bewilderment and incomprehension. She recalled him questioning her choice, as if it was beyond belief that she would choose to work in care. The final question she recalls, *“so you just want to wipe bums for your life?”,* explained her managers reasons for the bewilderment and confusion. In addition, his disbelief regarding what she wants to “*do”* implies a lack of recognition of her personhood. Her manager did not understand why she would choose to leave a bank and work in care as he believed a care assistants sole role was to “*wipe bums”.*

It is possible her manager had other understandings of what care work entails; however, Emma specifically recalled this being his primary concern. This means her managers’ focus on “wiping bums” had a significant impact on her. Emma sounded very angry and frustrated when relaying this story. She went on to explain that when other people focus on “wiping bums” as part of care work, it *“diminishes our role”.*

From the 22 guidelines and standards reviewed for this study, 56 key skill areas were identified that care workers are expected to be proficient in. As previously mentioned, only one of these documents explicitly referred to continence care as a necessary skill (see section 6.2.1). By focusing on “wiping bums”, Emma’s previous manager disregarding the many other key skills and abilities demonstrated by care workers and identifying the role by one act.

In Emma’s mind, her manager’s focused response meant he disregarded all necessary skills that were desirable and crucial for being a successful care assistant. Her valuable skills were deemed unimportant in comparison to contact with faeces and incontinence. Emma was angry because a role she feels is important and part of her identity was devalued. Her life choice was not validated.

Emma explained that distilling a care worker down to “someone who just wipes bums” would be akin to saying a mechanic only plays with spanners.

> “Because I just think there’s so much to the role that it’s completely diminished, and I think, ‘One day you’re going to need that help potentially,’ and I just don’t get people’s mindsets with it. I can understand obviously not everyone would want to do it, and that’s fine, I don’t [want] to be a mechanic, I don’t want to be a nail technician, and I don’t want to be a brain surgeon, but I wouldn’t ever knock that, you know, that one thing, go and fail and sit spinning spanners all day or, because that’s not their job, that diminishes our role, and it diminishes mine completely … really angers me because that’s constantly the response I get is, ‘Well you’re just wiping bums’”
>
> ***Emma, 27, Care Assistant, Care Provider 8***

In the previous quote, Emma went on to explain that she understands not everyone would “*want to do it”,* meaning care work. She then listed several jobs she would not like to do but explained that her lack of interest in these jobs did not diminish their importance. In contrast, she felt that other people’s lack of interest in her job, along with their focus on continence care, actively diminished her role. There was a disparity in how other people treat Emma compared to how she treats them.

She then went on to say she was angry because other people vocalised these points consistently in response to her job. Emma felt she was respectful, whereas others were not respectful to her. Therefore, when other people focused overly on continence care Emma felt that she was not being respected. The work she carried out that was not continence care is ignored and devalued. The focus on assisting with continence care separated Emma from her other important responsibilities and devalued her effort, hard work and emotional labour. Emma was angry because she felt undervalued, unrecognised, and unacknowledged.

Table 13 – Devaluation

Quote	Participant
“’oh you’re just a carer’” **“carers are so underrated for the job that they do”** **“a healthcare professional would rather talk to a nurse or a manager about that person than a carer**	Caitlin, 33, Unit Manager, Care Provider 2

Quote	Participant
that actually knows them really really well… 'cause they're 'just a carer'"	
"It's just, it's just, it's just unfortunate that it's not paid, a, kind of, paid job that people say it's a good job."	Jacob, 41, Care Assistant, Care Provider 4
"You know, there's no way that it reflects the skills and knowledge that you need. However, I think there's value in… it's about being valued, isn't it, you know, for the job that you do."	*Sinead, 44, Dementia Specialist Tutor/Care Assistant, Care Provider 3*
"I think people think that carers are really untrained people" **"care home managers are seen to be failed nurses"**	*Bella, 45, Registered Manager, Care Provider 2*
"What does annoy me is the fact that we are classed as an unskilled workforce. You know as well as I do, jeez Louise. Mandatory, statutory, just induction, training, competencies, your monthly reviews – wow."	*Lucy, 38, Head of Services/Care Assistant, Care Provider 3*

Throughout the participants interviewed, there was a consistent theme of the role being devalued by wider society. Participants frequently referred to feeling as though they were unskilled and untrained, despite having a wealth of experience and training that enabled them to effectively do their job (see section 6.2.1). The perceived devaluation of the caring role causes carers in this study to feel unimportant and angry.

7.5 Summary

Participants in this study had similar experiences before they began working in the care industry despite originating from different localities and working for different care providers. Many of them had prior experience of providing care for family members or had close family members that were already carers, participants that did not have this experience still identified naturally caring aspects of their personality. These experiences and personality traits contributed towards participants' decisions to become a carer.

Once a participant began their role as a carer, they found that they are surrounded by individuals who have similar experiences, personalities, and identities. The mirrored caring traits reinforced the idea of these attributes being natural rather than learned. The participants in this study felt that being caring is a natural part of their personality, rather than a set of skills that have been carefully adopted and constructed over many years of experiential learning. They also found that this was consistently reinforced by those around them.

Participants reported feeling stigmatised and marginalised because of their choice to become care workers, as they perceived that people in wider society directly associated a caring role as having contact with faeces. Participants viewed this external focus on continence care and contact with faeces as the reason people in wider society ignored other important aspects of the role, therefore devaluing the work participants did daily. This perception was consistent across job titles and roles within care. For the participants, this then meant that the only other people who recognised the intensity of the role are other care workers, leading to a closed community of care workers who were subjected to courtesy stigma by anyone outside of that group.

Chapter 8 Group Boundaries

The final overarching theme identified within the data was the initial experiences of faecal incontinence for care workers in this study. It was found that almost all participants had vivid recollections of their first exposure to faeces. Participants then used these experiences to define a boundary between themselves and the "uninitiated", therefore giving credit and importance to experiences that are generally devalued and ignored.

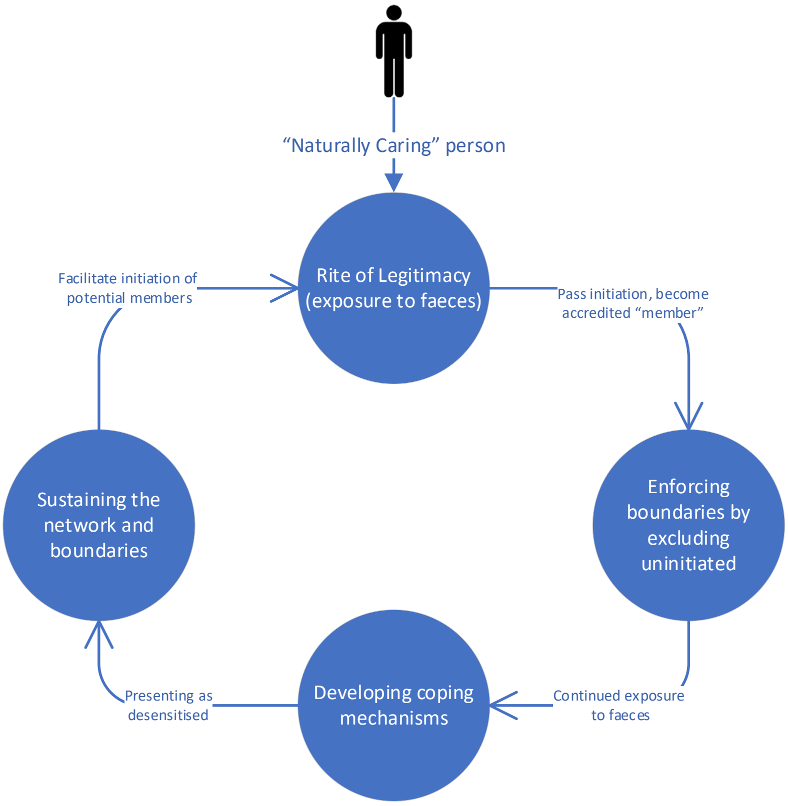

Figure 12 – Creating and Sustaining Boundaries

8.1 Initiation

The accounts relayed in this section were all told by the participants themselves but did not necessarily relate to that individual. Some participants discussed their colleagues first exposure to faeces and how that was managed. These experiences of exposure focused on how the individual was feeling at the time, and what their initial reactions to exposure were. Data is also presented here from documentary analysis regarding prior training or preparation for dealing with incontinence.

8.1.1 Preparation

When recalling and describing their initial experiences of exposure to faeces, participants spoke about not knowing that contact with faeces might be necessary prior to commencing the care worker role.

> "I just didn't realise some of the stuff they had to do"
>
> ***Linda, 38, Care Assistant, Care Provider 3***

> "Nobody asked me how I felt about wiping a bum"
>
> ***Olivia, 48, Care Assistant, Care Provider 4***

Both participants here were from different localities and different care providers, however both expressed not knowing that exposure to faeces would happen. Here there was also an implication that during the interview or job application process, exposure to faeces was not discussed or acknowledged. Therefore, these participants did not consider exposure to faeces as a possibility.

As discussed in section 6.2.1, there was no expectation or requirement for continence training to be completed before a carer began actively working within the role, and so it could be expected that care workers were not adequately prepared for this aspect of care provision. It was also not specified how care providers should deliver this training, which is reflected in participants' recollections of continence training.

> "I have never come across any specific training, apart from anecdotal and experiential"
>
> ***Bella, 45, Registered Manager, Care Provider 2***

> "We had a classroom based [continence training session] one when I first started in care, and we had to sit in a pad to know what it feels like, and we had to try on different ones to understand what it is like."
>
> ***Molly, 26, Care Assistant, Care Provider 9***

Above, Bella explained that continence care was often learned through the experiences and anecdotes of colleagues, while Molly was able to attend a specific training session. Molly specified that this training took place *"when I first started in care",* however she did not explain whether this was before or after she began her role, reflective of the lack of specificity in guidance documents.

Regardless of if or when participants completed continence care training, they still expressed uncertainty about their ability to cope when the moment came.

> “I think the first thing that went through my mind was, ‘I can’t do this’. I was literally thinking, because the people I was shadowing were like, ‘Yeah, just get on with it,’ and I was just like, ‘What? Am I going to be able to do this?’ “

Hannah, 26, Care Assistant, Care Provider 4

> “I think before like when I had my interview and stuff I hadn’t done it before, and in my training they were like, ‘Well you will have to do this,’ and I was like, ‘Oh, I hope I’m okay when it comes to it’. You don’t know, do you, until you do it?”

Hazel, 25, Care Assistant, Care Provider 6

Hannah and Hazel’s uncertainty seemed to stem from not knowing if they would be able to cope with the presence of faeces when the moment comes, as it was not something they have experienced before. Hazel also explained that *“you don’t know, do you, until you do it?”,* meaning that even if an uninitiated carer had been warned about what they may experience, that did not mean they will be able to cope with the situation.

8.1.2 The Rite

A process of initiation into interacting with another person’s faeces or “rite” was consistent throughout all the participants’ accounts. When recalling their own initial experiences of faecal incontinence, participants expressed feelings of being overwhelmed and being uncertain about their ability to continue in the role. Participants repeatedly described thinking “Can I do this?”

> “genuinely when I first went in, and our first day of shadow, because we had three shadow shifts[i], our first day was literally just watching, you are not allowed to do anything, you have just got to watch, and yeah they were chatting away to the residents, changing them, there was shit everywhere, and I just thought, “Can I really do this?””

Hannah, 26, Care Assistant, Care Provider 4

Hannah described a situation in which she did not physically have to provide any support to the individual who had experienced faecal incontinence. In this scenario, the simple presence of faeces outside of a socially appropriate receptacle (*“everywhere”*) caused the participant to doubt whether she could perform the role.

> "it was definitely hard when you go in your first care shift and you come across it because there's no getting away from it"

Emma, 27, Care Assistant, Care Provider 8

During the initial exposure, participants felt as though there was no escape from the situation. In the above quote Emma clearly stated, "*there's no getting away from it*". Uninitiated carers did have the physical ability to remove themselves from the environment and situation. They were not physically constrained or restricted from leaving the room, however Emma felt that the only acceptable outcome was to cross this arbitrary boundary. Emma considered herself as naturally caring (see 7.1.2) and was seeking mutual recognition and validation from other individuals labelled caring. Her intrinsic desire to belong and have her personhood recognised caused her to complete a task she was not necessarily comfortable with. For her caring nature to be recognised, she had to complete her initiation.

Hazel, from a different care provider, echoed this experience, going on to explain that once she had completed the task, she found it *"wasn't as bad"* as she expected it to be.

> "And I was like, I remember just being like, 'Yeah,' because I didn't even want to like give myself time to think about it. I was like, 'Yeah, yeah,' and I like cleaned his whole room, and I was like, 'I've never done that before,' but it was not as bad as I was thinking, so, 'Maybe I'll be like alright at this'."

Hazel, 25, Care Assistant, Care Provider 6

Here Hazel explained that she did not want to give herself time to think about what she was about to do, implying that if she had time to think about it, she may have decided she was unable to complete the action. She was aware that she did not want contact with or exposure to faeces, however due to her need to belong and become a member of the "in" group, she performed actions with obverse values: cleaning faeces. She then felt surprised that the reality was better than her expectation. This then validated her choice to become a care worker and confirmed her ability to perform her role, "*'maybe I'll be alright at this'".*

The rite appears to be consistent throughout the care industry, as all the participants described their initial experience in this way. Firstly, feeling uncertainty, trepidation, and reluctance before consciously forcing themselves to complete a task they knew they may not like. Once the task was completed, they found their decisions and choices validated by their ability to complete the task.

> “it was a real eye opener to me, I think it could have been kill or cure”
>
> ***Linda, 38, Care Assistant, Care Provider 3***

Participants frequently described these initial experiences as being a crossroads in their progression as a care worker. Phrases such as “*kill or cure”* highlighted how the ability to cope with exposure to faeces was a defining moment in a participant’s career. When Linda used this phrase, she implied there are only two possible outcomes. If they found the experience traumatising and were unable to rationalise the experience, it would be the death of their career as a carer. They would have failed their initiation and no longer be able to label themselves as “caring”. If they found themselves capable, they also found themselves able to enact their “naturally” caring personalities and fulfil a role they have adopted from a young age. In addition, when capable they found a group of like-minded individuals who provided mutual recognition and validation.

Linda’s *“kill or cure”* moment referred to her self-esteem built around the concept of being caring. Failing the initiation by faeces would mean that the identity she has developed throughout her life would collapse. Passing initiation means she was validated, and she was a carer.

8.2 Legitimising the Rite

Once the rite had been established, participants then demonstrated a need to maintain the boundaries of the group defined by the initiation. The established boundary was that individuals who could not cope with exposure to faeces could not become members of the group, therefore it fell to initiated members to perpetuate this to legitimise their own membership. Without excluding the uninitiated, their own achievement had little value.

8.2.1 Excluding others

For the initiation ritual to have credibility and meaning, there had to be ramifications for individuals who did not pass. The following quotes describe how participants responded to uninitiated carers who struggled with their first exposure to faeces. The participants had identified ability to cope with faeces as a crucial characteristic in their occupational role and now perpetuated that belief amongst uninitiated carers.

> “And I always say to the new starters, “Give yourself a week, but I will tell you now, this job, it goes one of two ways. You can either do it or you can’t”. Because there’s no in-between. There’s no kind of, “Ooh, well, maybe, maybe I could if I give it a bit more time”. If you can’t get your head around what you’re doing, it’s not for you.”

Jennifer, 43, Senior Care Assistant, Care Provider 3

Jennifer described giving uninitiated carers a way of abandoning the career without fault: she told them "*if you can't get your head around what you're doing, it's not for you."* By doing this, she was warning uninitiated carers that if they could not cope with exposure to faeces then they would not be able to continue in the role. She gave a time limit, implying that ability to cope with faeces was not a behaviour that could be learned; but rather an intrinsic part of a carer's personality that made them able to perform their role. Jennifer believed that if the uninitiated carer was not able to pass their initiation, they would not be able to succeed as a carer. This was a belief that was echoed amongst many of the participants (see Table 14).

> "But I'd be getting the phone out if I was in the staffroom going, 'Let's have a little look for another job'. And they'd be going, 'What do you mean?' 'Well, you're not happy here, are you? Let's have a see if there's something down the local wherever, because you're not happy in this job, are you?'"
>
> "I just want to go, "Why are you here? Why don't you just go and work somewhere else?" How about Tesco or Asda or go and do something else. Because that's not the attitude we need."

Sinead, 44, Dementia Care Specialist Tutor/Care Assistant, Care Provider 3

Not only did initiated carers adopt this belief, but they also actively attempted to exclude uninitiated carers that failed the initiation. Sinead explained that in her role managing the inductions of uninitiated carers she often experienced individuals who could not cope with exposure to faeces. In these events, she would independently begin searching for a new job for the uninitiated she had deemed incapable of assimilating. While she initially rationalised this action as in the uninitiated carer's best interests (*"you're not happy in this job, are you?"*), she then went on to say, *"that's not the attitude we need"*. This demonstrated an awareness of how the uninitiated carer may be feeling when they found they were unable to cope with faeces and a continuation of her "caring" nature. Sinead felt she was supporting the uninitiated carer to find a role that better suited them. However, she also identified the difference in values that prevent an uninitiated carer from being included in the "in" group. The uninitiated's inability to cope with faeces would not be beneficial to the team. Therefore, the uninitiated carer was actively excluded and ostracised, becoming part of the "out" group of "civilians" who did not have the ability or defining characteristic that made them able to cope with exposure to faeces.

Table 14 demonstrates that the active exclusion of individuals who fail their initiation was practiced by participants regardless of age, location, care provider, or job title. This indicates that all initiated carers, regardless of official job title, are responsible for supporting and giving meaning to the rite.

Table 14 – Excluding the Uninitiated

Quote	Participant
“I had one girl that was, she was a bit younger than me when I started, I think she was straight out of school, and a lady had done a bowel movement, and it was a particularly smelly one, but you know, just grin and bear it, and once the lady, we’d hoisted her and got her back into her chair and she’d left the room, we were just tidying round, she’d, she was like, ‘Ooh, ooh,’ and I was like, ‘She can probably still hear you, you can’t,’ and she couldn’t, she went, ‘Ooh,’ she couldn’t get used to it. I don’t think she stayed in the job too long.”	*Emma, 27, Care Assistant, Care Provider 8*
“I remember she said to me, she was like, ‘I didn’t think the job was going to be this,’ and I just said, ‘Maybe you should just have a think if it’s suitable for you or not, you could maybe do something else within the home,’ because those are the situations but you have them a lot.” **“I found that quite weird because when she said afterwards, ‘I didn’t think the job was going to be like that,’ I did ask her, ‘Well, what did you think it was? Did you think that you weren’t going to do that? Did you,’… like she had an interview, so I don’t know whether she meant, ‘I didn’t think it was going to be that messy,’ or, ‘I didn’t think we were going to do that at all,’”**	*Hazel, 25, Care Assistant, Care Provider 6*
“I think within a few days of having new people on the shift, you can tell who is going to last. So, you know, the ones that are willing to get their hands in, the ones who aren’t afraid to get on and do the job and do it well.”	*Jennifer, 43, Senior Care Assistant, Care Provider 3*
Some carers have actually come in and done that job and then they’ve left because they’re like, ‘Can’t do it anymore’.	*Susie, 50, Care Assistant, Care Provider 5*

By excluding individuals who failed their initiation, the boundaries that defined “carers” are solidified, consecrated, and legitimised. Transforming the daily act of continence care into a credit-giving rite increased the self-esteem and occupational value of those who had passed the rite. Being part of the “in” group was an achievement that was attained through adversity. Recalling one’s own ability to pass their initiation compared to those who did not became a source of pride. A task that elicited disgust in non-carers was repurposed as a meaningful and valuable undertaking.

8.2.2 Sustaining the Network

Once carers had passed their initiation, they then became active members of a larger network of carers. New carers were constantly being initiated into the role through their first exposure to faeces, pre-existing carers were expected to continue these initiations to sustain the boundaries of the network. To do this, carers adopted coping strategies to manage prolonged exposure to faeces.

8.2.2.1 Desensitisation

One mechanism employed by participants was presenting as desensitised. Participants frequently described being *"used to it"* (Table 15). This phrase implied that over a period of time, the participants had been repeatedly exposed to something that previously may have caused a negative emotional response. However, the continued exposure had eroded this emotional response and the participants no longer felt sensitive to it.

Table 15 – Desensitisation

Quote	Participant
"Well, it happens every day, so we're used to it."	*Jacob, 41, Care Assistant, Care Provider 4*
"I have got used to it"	*Molly, 26, Care Assistant, Care Provider 9*
"I guess you kind of become immune to it, after you've done it for so long" **"I think I've got so used to that that that kind of [pause] that kind of aspect of the job is just second nature now"**	*Sadie, 28, Care Team Manager, Care Provider 1*
"I think I'm just used to it."	*Emma, 27, Care Assistant, Care Provider 6*
"I think you get to a stage where you don't think of it as what it is, you just, it's your job isn't it, it's supporting someone to manage it and you don't think about it. " **"You deal with it on a daily basis, it's one of those things isn't it."** **"That would be more important to me than anything else, but that's part of being a carer. It can be**	*Terri, 29, Registered Manager, Care Provider 7*

Quote	Participant
detrimental to you, but as long as the person you are supporting is happy, that's what you're there for"	
"I think you do, I think erm, I think you just don't even think about it"	*Linda, 38, Care Assistant, Care Provider 3*
"It is just funny how things just completely change from, "Oh, I don't think I can do this," to, "Oh yeah, look at that one, amazing, good job". It is so strange." **"You just become used to it, I think."** **I'm like, "It's just poo, it's fine, just get on with it". But yeah, I think it just becomes second nature, doesn't it?**	*Hannah, 26, Care Assistant, Care Provider 4*
"It's the norm. If you work in this sector, it really doesn't – you don't even bat an eyelid." **"I think I'm just desensitized to that element"**	*Lucy, 38, Head of Services/Care Assistant, Care Provider 3*
"there is no point being not happy about doing cleaning up or whatever, it's a job you have to do."	*Ruth, 48, Care Assistant, Care Provider 4*

The frequency with which participants were dealing with incontinence gave them reason to believe they were desensitized or immune to the difficulties of providing continence care, despite participants also describing feeling disgust and anxiety when having contact with faeces (Table 16). What many participants initially presented as a passive process and "*one of those things"* was soon explained to be the result of deliberate actions and choices.

> "I don't think about what I'm doing, and then that makes it a lot easier. It gets me through it [laughing]. Everyone has their own ways. Yeah, that's mine."
>
> "I'd probably think about, I don't know, what we have been doing at work, or what I have been doing at home. If I've been out with my daughter, whatever, I'll probably think about something like that."
>
> "It's not easy to do, don't get me wrong, but it is a lot better for us and them if we do that."
>
> ***Ruth, 48, Care Assistant, Care Provider 4***

Ruth explained here how she deliberately did not think about what she was physically doing to make the task easier to manage. Ruth acknowledged how difficult it was to not focus on what she was doing and to instead send her mind elsewhere, but stated *"it is a lot better for us and them if we do that".* Thinking about other things and distracting from the task at hand allowed both the care assistant and the individual being supported to pretend continence care was not happening, meaning no moral injury took place for either person.

Mia explained this more explicitly. Not thinking of or acknowledging the incident allowed normal routine to continue. Deliberately not drawing attention to any mess or products of incontinence decreased the likelihood that the individual being supported feeling embarrassed, upset, or ashamed. By ignoring the "mess", participants in this study were protecting the people they were supporting and themselves from experiencing the emotional impact of incontinence.

> "In my mind it's almost like trying to ignore that that had happened and just try and get on with the normal routine which is, 'Let's go in for a nice shower and let's get you dressed. Let's pick your clothes out,' and do the normal routine without drawing any attention to any of the mess that has been caused."
>
> ***Mia, 55, Care Assistant, Care Provider 7***

Table 16 – Disgust

Quote	Participant
"I hate it. I hate it, it stinks. It's just abhorrent" **"They're horrible, aren't they? Somebody else's poo, if I may say that, it stinks. It's not nice."**	*Sinead, 44, Dementia Specialist Tutor/Care Assistant, Care Provider 3*
"I'm not gonna say I haven't come out of a room and gone '[retches] god, that was strong'"	*Lucy, 38, Head of Services/Care Assistant, Care Provider 3*
"you know no matter how much you wash your hand after that it just like, I felt like oh I can't wait to get home and have a shower"	*Linda, 38, Care Assistant, Care Provider 3*
"oh my god have I trodden in something, is it still on me, have I sat on a chair perhaps?"	*Caitlin, 33, Unit Manager, Care Provider 2*
"it's even worse I think if you accidentally get it on your skin or whatever. Like, I had someone, I was cleaning them and just a little plop went on my arm and I was like, "Oh no," and literally went and scrubbed my arm with like any chemical I could find, "Get it off". Yeah, horrible."	*Hannah, 26, Care Assistant, Care Provider 4*

Quote	Participant
"I just remember thinking the smell was so bad!"	*Molly, 26, Care Assistant, Care Provider 9*

Actively concealing their disgust and presenting as desensitized to contact with faeces maintained the boundary established by their initiation rite. Presenting as desensitized sustains their position in the network and continues to separate them from individuals who have failed to gain membership. Equally, claiming desensitisation illustrated to new potential initiates what is expected of them and how they need to behave to gain membership.

8.2.2.2 Bonding through incontinence

Another mechanism employed by participants was to view contact with faeces and continence care as opportunities to bond with the individuals they were supporting. By thinking about the positive outcomes of these interactions, participants were changing the focus of their recollection.

> "So [individual] was walking down the corridor and I just started walking with her, we were talking about her daughter because we both have the same name so that's often quite a good in road for [individual], erm and she was laughing 'cause she told me that I spell my name wrong because there's so many different spellings, and as we carried on walking I mentioned that she looked like she was a bit uncomfortable and would she allow me to show her where the toilet was?"
>
> ***Bella, 45, Registered Manager, Care Provider 2***

Bella explained she had noticed that an individual seemed to have been incontinent of urine. Bella described how she could see that the individual's continence aid was full through her trousers as it was hanging down to one side. Instead of approaching with the sole intention of assisting the individual with continence care, Bella instead used conversation to put the individual at ease before suggesting continence assistance. While this conversation may have been brief, it involved a light-hearted exchange of comments about a topic that is familiar to both Bella and the individual. Not only did this respect the dignity and personhood of the individual being supported, but it also acknowledged Bella's own personhood. The conversation gave Bella an opportunity to be herself before she enacted her caring role; it put her at ease as well as the individual being supported. By bonding with this individual, she reduced the potential moral injury of providing continence care. This experience occurred because Bella noticed the individual had been incontinent, therefore incontinence offered Bella an opportunity to bond with the person she was supporting.

> “one of my favourite things there is to learn about their professions and their lives”
>
> ***Linda, 38, Care Assistant, Care Provider 3***

Linda stated that learning about the people she supported was one of her favourite aspects of her role, showing that she placed a high value on the people the is supporting and their individual characteristics.

> “the friendship we form with them over something like a pad change – I can stand there for like an hour changing them and have a nice, detailed conversation while changing them”
>
> ***Dorothy, 23, Carer, Care Provider 1***

While the language Dorothy uses suggested a task orientated mindset, she showed here that providing continence care gave her the time to communicate and develop relationships with the people she was supporting. This highlighted that one of the enjoyable aspects of being a carer could be achieved through providing continence care, meaning that only individuals who can cope with exposure to urine and faeces are able to access the enjoyable parts of the role.

8.2.2.2.1 Presents

Participants also described specific experiences when supporting people with a dementia. Supporting people with dementias could mean carers are exposed to faeces outside of the typical continence care interaction. Hannah (Table 17) described a situation where an individual with a dementia had been incontinent of faeces but had not recognised the faeces. She instead believed they were Maltesers and placed them in the box, which was then offered to staff. Describing faeces presented in this way as *“presents”* acknowledged that the individual likely did not intend to offer an offensive product to the staff, but instead wished to share something she particularly enjoyed with people around her.

Table 17 – Faeces as Presents

Quote	Participant
“that is what a resident did, she loved Maltesers, all that sort of thing, and took the time to carefully roll her presents into little balls, put them back in the Malteser thing and offered them to a member of staff”	*Hannah, 26, Care Assistant, Care Provider 4*

Quote	Participant
“he loved to hold your hand, and take you for a walk, so walking up to George, “hi [individual] sweetheart how are you?” “oh, oh oh!” like that with his hands and I thought oh he wants to hold my hands, put my hand out and he dropped two handfuls of poo in my hand, I had no gloves on” **“so you have getting given presents of love”**	*Lucy, 38, Head of Services/Care Assistant, Care Provider 3*
“we did have a resident who used to be here who would actually [laughs] it’s awful, but would bring you her faeces and hand them to you”	*Caitlin, 33, Unit Manager, Care Provider 2*
“From under the bed cover, handed me it, can you hold that? Lovely, thank you!”	*Molly, 26, Care Assistant, Care Provider 9*
“And she did one day offer me. I said, “Oh no, I’m alright thanks,” and she was really insistent. I’m like, “I’m diabetic, I can’t eat chocolate”.”	*Ruth, 48, Care Assistant, Care Provider 4*

Hannah also stated, “*she took the time”*; meaning that despite the potentially offensive nature of the gift Hannah could recognise the thought and connotation of it. Participants frequently referred to being given faeces in this way, referring to this as being given “presents of love”. Reframing these unmanaged episodes of incontinence as gift giving and expressions of affection allowed care workers to feel valued for their role.

8.3 Summary

As with the previous findings chapters, the experiences and rationalisations of the participants in this study were consistent regardless of age, gender, location, care provider, or role within the care setting. Participants demonstrated that when they entered the care industry, they were subjected to a rite of legitimacy that they were not prepared for. To become a fully accredited and respected member of the care community they had to pass this initiation, which meant having to cope with their exposure to faeces without expressing negative emotions. Once they had passed this initiation, they had to solidify their position by enacting the initiation ritual with others and excluding those who fail. Simultaneously, the participants reported having to develop coping mechanisms to manage their prolonged exposure to faeces. Participants in this study presented as desensitised despite also communicating their disgust and concern. Presenting as desensitised and reframing incontinence as bonding episodes contributed to their position within the group whilst also dictating to new potential initiates what behaviour was expected of them.

Chapter 9 Discussion

9.1 Introduction

This thesis privileges the voices and experiences of care workers working in care homes. Research and theory show that the dirty work of care is delegated to those with a perceived moral taint, or people of low socio-economic status, to maintain the cleanliness of wider society (Hughes, 1962, Hughes, 1958, Brittain and Shaw, 2007). Their continued subservience in providing care, along with a potential perception of being deviant in their support of individuals with reduced capacity, confirms their moral and social taint and separates them further from society (Ashforth and Kreiner, 1999, Hughes, 1962, Rothman, 1987). This continued taint validates the allocation of dirty work and contributes to a societal system where the label of dirty work keeps individuals in devalued roles of low socio-economic status. Dirty work means the individual is perceived as having a moral, physical, and social taint, therefore further dirty work is allocated to them. This has negative consequences for maintaining a positive perception of identity for the dirty worker (Ashforth and Mael, 1989). Therefore, they must develop strategies to mitigate this (McMurray and Ward, 2014).

Continence care for people with a dementia is heavily researched, however the experiences and perceptions of formal care workers and the impact these may have on the success or failure of continence interventions are not always given adequate consideration (Dubeau et al., 2007, Lekan-Rutledge et al., 1998). If care workers are having to implement strategies to maintain a positive identity whilst carrying out a role that is perceived to be “dirty” and “tainted”, then it is likely that this would impact on care provision in some way. Research shows that continence care interventions often have low rates of adoption or success amongst care staff. Exploring their experiences helps to identify why this may happen, how policies around training can be adapted to improve practice, and improve the care provided for individuals living with a dementia and incontinence.

This study used qualitative, semi-structured interviews and document analysis to explore how care workers mitigate or reproduce stigma associated with continence care for people with a dementia and what organisational factors shape this. Chapter 6 demonstrated the disconnect between organisational documents and the experiences of care staff in relation to continence care. Considerable training was recommended, however participant experiences showed this was not always provided or appropriate. The organisational documents, and the training they recommend, did not acknowledge the emotional labour and dynamic social skills involved in supporting people with a dementia and faecal incontinence. Conversely, failure to achieve desired organisational outcomes was used as a “benchmark” for quality of care due to observable factors such as odour.

As shown in Chapter 7 , care workers adopted the label of “naturally caring” from a young age and used this to validate their ascension into a formal caring role, despite there being other possible reasons for their choice. This demonstrated the societal system of delegating dirty work to a passively pre-determined group of individuals: those who believe they are “naturally caring”. Individuals then found themselves feeling the effects of the societal separation through “othering” of their role and continued devaluation of the dynamic skills they employed, primarily in relation to their proximity to incontinence. Surrounded by individuals with similar experiences and values, participants found that this community reinforced their identity and fulfilled the intrinsically human desire to belong to a group.

The group must be legitimised. For the group to have social value, it must be exclusive in some manner (Amiot et al., 2017, Bourdieu, 2005). The in-group members must have a characteristic that differs from others outside of the group. As participants perceived proximity to faeces as the reason behind their “dirty” labels, they reframed this as the criteria that legitimised them as accredited group members (McMurray and Ward, 2014). Care practices such as continence care for people with a dementia became a solid wall on an arbitrary boundary, legitimising and consecrating the group as real. This mitigated the stigma and taint perceived by care workers as they then had a group in which they were included; while others who failed the rite were actively excluded. This then gave them a perception of power and autonomy over their own lives and the care they provided.

While the sample for this research was relatively small and no claims for representativeness are being made, the experiences and recollections described by these participants were consistent across the participant group. Participants in this study were located in various areas across the U.K. and worked in a variety of different settings. Their experiences mirrored each other’s and related to wider theory as described in this chapter.

9.2 Self-categorisation

Self-concepts of social identity and their meaning contribute heavily to perceptions of social status and permeability. The ability of oneself to join different social groups and take part in social activities depend on our concept of social identity. Social identity theory (Ashforth and Mael, 1989) stipulates that our social identities are formed based on the groups we are members of, whether these are chosen or “mandatory” such as family groups (Ellemers et al., 2002). However, it is difficult to accept that social identity is formed in such a linear way. For this thesis, “social groups” and “social categories” are used interchangeably as they are synonymous with each other (Abrams, 2001, Tajfel and Turner, 1979, Ashforth and Mael, 1989). One of the key tenets of this thesis is that this self-categorisation is crucial in the development of social identity (Ashforth and Mael, 1989, Ashforth and Kreiner, 1999, Abrams, 2001, Turner and Hogg, 1987).

Other factors that contribute to group membership must also be considered. Firstly, one must consider socio-economic factors and how they influence the availability of surrounding groups. If individuals self-categorise based on the ability to make use of other social categories, as described in theories of social capital (Bourdieu, 1986, Portes, 1998, Coleman, 1988) then geographical location and socio-economic “class” must be considered. Care workers often have a low socio-economic status (Bergman and Chalkley, 2007, Clarke and Ravenswood, 2019, Spellman, 2021, Twigg, 2000). As such, they are likely to come from “deprived” areas that are homogenous in nature; surrounded by others of low socio-economic status. They have an abundance of bonding capital but little bridging capital – the resources and connections generated by reciprocal relationships outside of their own homogenous group that enable social mobility (Bourdieu, 1986, Portes, 1998, Putnam, 2000).

As families are homogenous, these relationships result in bonding capital for each individual; their social capital is only valuable within that isolated group (Bourdieu, 1986). For participants in this study, self-categorisation as “naturally caring” cemented the bond between individuals due to shared values and experiences (Murray et al., 2020). Where participants had familial experience of care provision, the label “caring” became an additional name that cemented relationships within the family whilst providing a bridge to develop relationships outside of the family group (Bourdieu, 1986). This bridging capital allowed the individual to expand their social network and have meaningful interactions with other individuals labelled “caring” (Paxton, 1999). However, if family members lacked additional social labels that enabled the development of bridging capital, then individuals would only have access to others outside the family also labelled “caring”.

This social isolation means that the availability of other social categories is limited, suggesting that care workers have access to a minimal spectrum of social groups that they can adopt the categorisation of. Therefore, their social identity is shaped not only by the availability of categories but the wider socio-economic landscape.

In section 2.4, it was discussed whether Ashforth and Kreiner (1999) were accurate when asserting that occupational identity is formed as individuals made conscious decisions about which work groups or organisations to join. If individuals identify as “caring” due to family connections and experiences from childhood, then this identity label is developed before choosing occupational groups. This identity becomes the bridge that connects them to other individuals who are "caring" and gives them access to occupations that solidify that identity. Being accepted into such occupational groups reduces uncertainty (Hogg, 2021) and reinforces perceptions about ourselves (Valtorta et al., 2019b, Cheney et al., 2008, Berkman, 2014), therefore individuals may choose to join occupations that validate and support their pre-existing identity.

9.2.1 "Naturally Caring"

Participants in this study self-categorised as "*naturally caring"* based on their early life experiences or shared personality traits with others they categorised as the same. "*Naturally caring"* must be a contested term however, as it cannot be established in this study if the participants' *"caring"* nature is indeed natural, and not learned. Research suggests that caring personality traits are typically expected from and imposed upon women, with the associated social taint being allocated due to the servile nature of feminised, caring work (Drew et al., 2007). As such, it is likely that participants first self-categorised as "female" before self-categorising as "*naturally caring"* due to societal expectations and norms. This explains why Linda still categorised herself as naturally caring despite not having the same previous caring experience as other participants; she was first categorised as female, and therefore the "caring" category naturally followed.

However, Jacob's experience does not fit this theory. As Jacob is male, it is unlikely that Jacob self-categorised as caring to conform to societal gender norms, although it must be acknowledged that gender is also a contested term with many contributing factors that are outside the remit of this thesis. Jacob presented an interesting outlier case. He did not care for family members as a child or adolescent but did care for his child as an adult. This afforded him access to "caring" categories of people when he was older and highlighted similarities in experience and values. It is possible that Jacob was afforded access to "caring" individuals at a difficult time in his life where he felt an increased need for belonging, meaning that his desire to conform to in-group norms (being "naturally caring") would have been increased (Abrams, 2001). Therefore, Jacob adopted the self-categorisation of *naturally caring.*

Categorising being "caring" as a natural and intrinsic personality trait ignores any learning or development that have contributed to being a caring person. This ignorance of learning contributes to the lack of prestige afforded to "*naturally caring"* individuals as no effort is perceived to have been expended in reaching that status. Self-categorising as "*naturally caring"* therefore contributes to self-devaluation of the caring role through socially reproduced ignorance of how caring experiences develop one’s skills. Therefore, the individual needs to secure membership in another, likeminded group to achieve the acceptance and validation of choices that are necessary to human social interaction (Bernstein et al., 2010).

9.2.2 Societal Delegation of Dirty Work

As previous literature discussing dirty work states, dirty work is delegated to specific, underprivileged groups within society by those in privileged positions (see Chapter 2). This is a crucial part of functioning society that provides acceptable parameters within which to act (Goffman, 1963). If a societal group already exists with limited social mobility and access to bridging capital, it is logical that this “underprivileged” group would be designated agents of dirty work. In practice, this “delegation” operates by making the occupational group of “care worker” one of the few occupational groups available to the “underprivileged” group: there are no educational or experiential requirements for employment, making it accessible to those with low socio-economic status. Barriers that exist in other occupational groups such as education, geographic location, gender, race and ethnicity are absent when joining the care workforce (Brown, 2013, Li, 2017, Christie, 2016, Nunn et al., 2007, Mocca et al., 2019). The delegation of dirty work is therefore passive and happens as a result of societal systems.

The lack of opportunity afforded to individuals in these circumstances consequently means that their self-identity is based less on “self”-categorisation, which implies choosing an appropriate category from a range of options, and more on *obligatory* categorisation, where individuals have a limited selection. This presents difficulties for one’s development of a positive self-image as perception of autonomy and choice are key to psychological well-being (Gardner, 2020, Yong et al., 2019, Colakoglu, 2011). As previously discussed, Ashforth and Kreiner (1999) state that people inherently want to see themselves in a positive light. Research shows that increased perceptions of autonomy and freedom of choice are linked to psychological wellbeing. If these premises are accepted, it logically follows that care workers subjected to forced categorisation would attempt to reframe their career as intentional, rather than delegated. This is particularly relevant in the context of dirty workers, who frequently attempt to reframe, recalibrate or refocus the meanings associated with their tainted work and identity so that negative connotations are replaced with positive connotations (McMurray and Ward, 2014). Participants in this study perceived being “naturally caring” as a positive, autonomous reason to become a care worker.

Therefore, there is considerable emotional labour being performed by care workers before they have even begun supporting individuals within their care. To prevent the formation of negative concepts of identity, such as the perception of themselves as oppressed and restricted to specific paths within their own lives, care workers in this study reframe the pathway to their occupation as resulting from *naturally caring* characteristics. Instead of perceiving their role as resulting from social delegation caused by complex social systems. They construct a narrative where they became carers because it was something they were *created for.* They reframe their role as an autonomous choice to perform a civic duty and service, which gives them a positive social identity and higher occupational esteem (Ashforth and Kreiner, 1999, McMurray and Ward, 2014).

9.3 The Importance of Dementia

Participants in this study talked about their enjoyment of providing support for individuals with a dementia (see 8.2.2.2), however care in these contexts can also be extremely challenging. Incontinence is recognised to be difficult for both care providers and those who experience it (Butcher, 2020, Ostaszkiewicz et al., 2016d, Ostaszkiewicz et al., 2016a). There is considerable emotional labour and face work involved in managing one’s own reactions and emotions while providing continence care (Goffman, 1955). Participants in this study highlighted how this is exacerbated in the context of dementia.

McPherson et al. (2016) described how the challenges in providing care can negatively impact the capacity for compassion in formal care staff as it induced conflict between their desire to provide the best care possible and the practicalities of the role. This highlights that people with a dementia may require more compassion than those without, and care workers will have a more involved role in providing care (Schussler et al., 2016). It can therefore be accepted that providing care for individuals with a dementia may be more taxing and require more skilled labour from formal care workers. The data presented in this thesis demonstrate that participants must develop dynamic management skills when supporting individuals with a dementia with faecal incontinence, however the capacity for compassion in the participants was not impacted. Participants instead used their compassionate and caring identities to redefine the meaning of interactions involving dementia and continence care, interpreting the socially difficult presentation of faeces as developing their relationships with the individual.

9.3.1 Dynamic Management

In section 6.3, care workers demonstrated that creative and dynamic responses are required to effectively manage episodes of incontinence. For individuals with a dementia, this dynamic management becomes even more skilful as the care worker is not only assessing the physical, psychological and social needs of the individual in the moment but also the cognition of the individual being supported. Care workers described experiences where the individual did not understand what had happened or became significantly distressed due to their cognitive impairment.

In the care worker accounts of continence care described in this study, all participants described feeling overwhelmed and unprepared. Statements such as “I didn’t know what to do” recurred frequently, indicative of a stressful and traumatic experience (Kjoelaas et al., 2022). If it is accepted that these experiences can be interpreted as micro-traumas, it logically follows that care workers need a mechanism of some kind to rationalise and make sense of these experiences. Research shows that in other disciplines, debriefing and talking helps to diffuse emotional distress after traumatic experiences (Colville et al., 2017, Fillion et al., 2002, Wolfe et al., 2022). The dynamic management of incontinence in dementia care, coupled with the lack of preparation experienced by care workers, leads to experiences that can be emotionally traumatic and require significant cognitive or social processes to rationalise.

9.3.2 Moral Taint

Participants in this study also discussed their reluctance to mention their experiences with individuals outside of the initiated group of care workers, as they were concerned their remarks or experiences would be perceived as them laughing at the vulnerable individuals they supported (see section 7.2.1). This explains one of the reasons why so much “dirty” work takes place hidden away and behind screens, as described by Lawler (1991). The screens serve to protect not only the dignity of the individual, but also the social identity of the care worker.

As discussed in Chapter 2, moral taint can be applied to care workers deemed to be taking advantage of the people they are supporting (see section 2.3.1). Individuals with a dementia are often considered to be a group that is particularly vulnerable to abuse or control (Fox et al., 2020, Orme et al., 2015, Phillipson et al., 2019). The power dynamics that exist in relationships in dementia care exacerbate this, along with the physical support that is required during episodes of incontinence (Melheim and Hauge, 2010). Participants in this study felt that if they were to verbally attempt to rationalise their experiences with individuals outside of the care industry, they would be ascribed additional moral taint. In addition, care workers have a responsibility to maintain the confidentiality and dignity of the people they are supporting. As such, it can be argued that social and organisational factors mean that care workers cannot discuss their traumatic experiences without exposing themselves as “morally tainted”. Participants therefore developed a need to mitigate the negative impacts of moral taint.

9.4 Devaluation and group formation

Participants needed to rationalise these experiences in a way that did not compromise their social identity. Goffman (1963) argued that this is the function that social groups and categories provide. Membership in such a group provides parameters for how to act in given situations and offers validation of personal and social identity (Hogg, 2021, Goffman, 1963). Society has already delegated care workers to the societal group of “dirty workers”, however this group label continues the attribution of taint instead of mitigating it (Valtorta et al., 2019a).

Participants in this study described the importance of speaking to other carers, as there was a mutual understanding about the intentions and values of sharing their experiences. Whereas they felt unable to share their experiences with others due to the risk of additional taint being ascribed, sharing experiences within the “care worker” group strengthened relationships and provided them with a positive social identity. The social recognition of shared values and intentions promotes group membership and desire to contribute to said group (Renger and Simon, 2011).

9.4.1 Ingroup and Outgroup

The first boundary to be crossed for membership in the group is the perception of being “naturally caring”. Individuals who are not “naturally caring” cannot, from the perspective of the individuals in this study, become acceptable care workers. In the context of social identity theory (Tajfel and Turner, 1986) this constitutes the first step towards seeking a positive social identity: reinforcing identification of shared values with other “in group” members. Doing so reinforces the perception that discrimination against group members is justified, and enables members to rationalise perceived discrimination as resulting from ignorance or misinformation (Amiot et al., 2017). “Perceived discrimination” here refers to the labelling of care work as “dirty work” and the application of social, physical and moral taints to care workers (Valtorta et al., 2019b, Valtorta et al., 2019a, Ashforth and Kreiner, 1999). However, the degree to which individuals who are “naturally caring” are different from “civilians” is minimal – both can be considered naturally caring, therefore this does not fully mitigate the societal status of group members.

Hogg (2021) argues that for a group to successfully mitigate the uncertain social position of its members, there must be structured group rules and sharp group boundaries. “Naturally caring” is not a sharp enough boundary. Therefore, for membership in this group to be beneficial to its members there must be a sharper and more difficult boundary that must be crossed for admittance. In addition, the perceived difficulty of crossing the boundary is directly linked to the perceived benefits of group membership (Aronson and Mills, 1959, Bernstein et al., 2010).

9.4.2 Reframing, Recalibrating, and Refocusing

Ashforth and Kreiner (1999) argued that the stigma of dirty work causes ideological reframing: transformation of meaning attached to stigmatised acts or occupations. Participants in this study reported that their contact with faeces was often a reason for others devaluing their role and questioning their choices. Civilians deem contact with faeces to be a reason for physical taint and label it dirty work; and individuals who cannot control their bowels can be regarded shamefully (Ostaszkiewicz et al., 2016d, Valtorta et al., 2019b, Kyle, 2009). Out group members may have contact with other aspects of care work such as ageing bodies, cognitive decline and medical procedures; but they do not have contact with faeces, and they do not deal with the continence care of other people.

There is therefore a need to reframe the act which is a source of dirt and taint. If Hogg (2021)'s assertion that successful mitigation relies on the strength of the boundary, Ashforth and Kreiner (1999)'s discussion of ideological reframing, and that care workers perceive contact with faeces as being a source of dirt and taints are all accepted, then it follows that this act would be reframed in a positive light. Reframing continence care as a "rite of legitimacy" that gives accreditation and status to group members, while also excluding others, becomes a way in which care workers mitigate their "dirty" labels (see Figure 13).

It is important to explain here why the term "rite of legitimacy" is being used rather than the much more common "rite of passage". Both phrases have specific connotations. In the words of Bourdieu (2005):

> "by solemnly marking the passage across a line establishing a fundamental division in the social order, the rite attracts the observer's attention to the passage (hence the expression "rite of passage") whereas what is important is the line … every rite leads to the consecration and legitimisation of an arbitrary boundary".
>
> ***Bourdieu (2005, p. 81)***

Rites and ceremonies have long been used to legitimise boundaries between one group and another. In healthcare, rites and ceremonies are known to enforce barriers between different groups (Brooks and Brown, 2002, Tonuma and Winbolt, 2000). In the context of dirty workers of low socio-economic status, these rites can also contribute to maintaining the social systems that prevent social mobility.

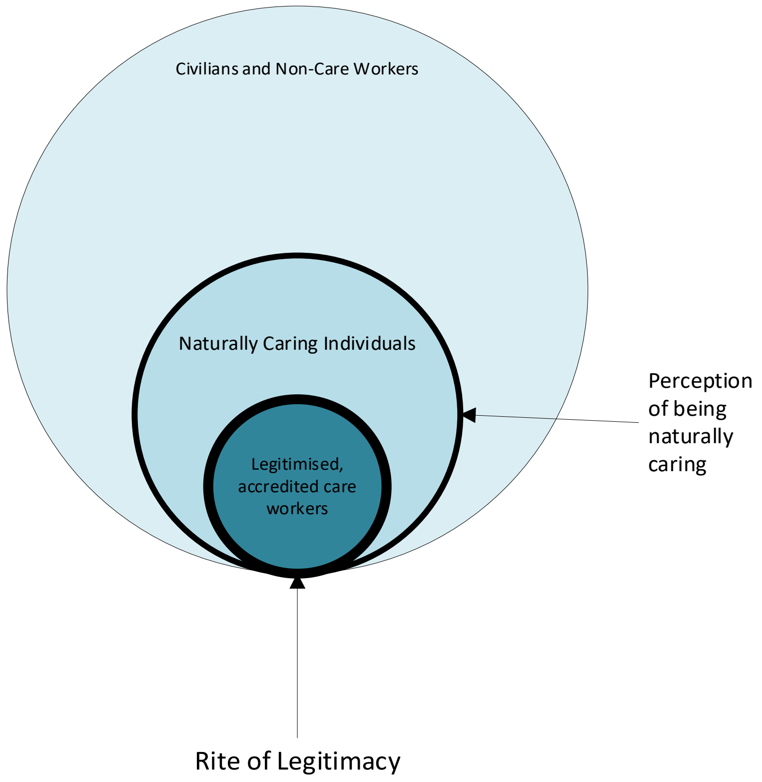

Figure 13 - Group Boundaries

Is the arguments made in section 9.2 are accepted, then individuals of low social standing are steered into "dirty", tainted roles through a social system of delegation and lack of opportunity. These dirty roles threaten the care workers status (Jervis, 2001), they then need to rationalise this by reframing their career as an autonomous choice based on their identity. However, this recalibration of the social world requires further embedding for positive self-identity to be maintained. This is achieved through the rite of legitimacy.

The rite of legitimacy for care workers involves having contact with faeces. Participants in this study described how difficult they found these initial experiences – feeling uncertainty and disgust at the task. However once complete, this became reframed in their minds as a normal experience that they were inherently good at. Once an individual completes their unpleasant initiation and gains membership in the group, they are more likely to have a strong sense of belonging and perceive the group as significantly more attractive (Aronson and Mills, 1959, Abrams, 2001, Hughes, 1962). In addition, their ability to cross the "difficult" boundary provides evidence for the skills they have developed to help manage dynamic and challenging situations. Group membership, therefore, accredits the individual and recognises their skills and abilities. This gives value to those skills and abilities, mitigating the perceived devaluation from wider society (Bourdieu, 2005, Bergman and Chalkley, 2007). Therefore, the rite of legitimacy not only legitimises the boundary between the group and wider society, but it legitimises their self-categorisation and concepts of identity. By focusing on the act of helping someone with incontinence, the individual is able to validate their self-categorisation of naturally caring and use this as a rationale for their career, rather than accepting societal assertions that they have chosen to "*just wipe bums*".

The rite of legitimacy enables membership in the care worker group to be secured without membership in the organisation itself being required. It has been shown that the attribution of moral taint to care workers is real and significant (see 2.3.1), but to maintain a positive social identity care workers must displace this taint, as it is difficult to coherently align a positive social identity with ownership of taints (Ashforth and Mael, 1989, Bentein et al., 2017, Valtorta et al., 2019a). The rite enables this by legitimising the "*naturally caring*" label within the group of others with the same categorisation. Legitimate membership in the group means that the care worker can evidence they *genuinely care* about the individuals they are supporting, as they can demonstrate their accreditation. However, there are other individuals within the care workforce who are not legitimised by contact with faeces, such as nurses, home managers, and those who influence policy.

It was established in the literature review that care workers often blame "illegitimate" individuals for inadequate resources and staffing (see section 3.6). The rite of legitimacy explains why this is: to reallocate moral taint. Legitimised care workers mitigate the moral taint attributed to them by focusing on altruism. Illegitimate workers have no proven justification for their career choice like legitimised members do, they cannot demonstrate their "naturally caring" accreditation. Therefore, their motivation in joining the care workforce is of dubious nature. They have dubious virtue, and can therefore be ascribed moral taint (Ashforth and Kreiner, 1999). Reallocation of moral taint enables care workers to blame illegitimate workers for care failures and maintain their positive social identity within their social group (Abrams, 2001, Bergman and Chalkley, 2007, Ashforth and Kreiner, 1999).

9.4.3 Solidarity

Research shows that when discrimination is experienced on a personal level, it often has negative effects on self-esteem (Jervis, 2001). However, when discrimination occurs on a group level it often has the opposite effect – the self-esteem of group members is positively impacted by the discrimination (Bourguignon et al., 2015). This has previously been explained by the discounting hypothesis (Crocker and Major, 1989) and social processes that allow different standards to be applied to personal and group discrimination (Taylor et al., 1990). This analysis offers an alternative explanation: solidarity.

The concept of solidarity is relatively new in occupational research, and mainly derives from definitions and explanations of social capital (Putnam, 2000, Portes, 1998). Definitions of solidarity vary depending on the context in which they are used. Although ambiguously defined, the concept of solidarity does exist in healthcare literature. This primarily refers to co-production and partnership between healthcare professionals and patients (Pot, 2022, O'Neill, 2022). In the context of social capital, solidarity refers to camaraderie, group strength and shared understandings (Murray et al., 2020). The two definitions describe solidarity as arising from different phenomena. Solidarity in the context of social capital is the result of recognising skills that are valuable to a particular community (Banks, 2018, Honneth and Farrell, 1997), whereas Pot (2022) argues that solidarity arises from social injustices.

If care workers are steered towards their caring occupation through the delegation of dirty work and reduced opportunity (section 9.2), and organisational and social factors mean that care workers are unable to discuss and rationalise their traumatic experiences outside of their occupational peers (section 9.4), then it logically follows that they develop group solidarity as a result of injustices placed upon them by wider society (Pot, 2022). By forming solidarity with other care workers, participants can mitigate the devaluation, taint and stigma applied to them by wider society by reinforcing their values and rationalising their experiences amongst their chosen group.

However, participants in this study also developed solidarity with their colleagues due to shared values that they defined as being useful for the group itself. As such, a new definition of solidarity in the context of care workers supporting individuals with a dementia can be proffered: *a complex, multifaceted process by which marginalised groups offer reciprocal support and acknowledgement to reframe societal devaluation.* Defining solidarity as a *process* rather than a semantic concept gives weight to the ongoing cognitive effort and labour that goes into maintaining group solidarity and the importance of this for individual social identity.

9.5 Summary

Participants in this study perceived themselves as being subject to devaluation by wider society due to the lack of accreditation given the skills and learning required for their role. Care work is accepted to be a role with low occupational status, however this study demonstrates that care workers believe this to derive from their close proximity to dirt and faeces. While research has extensively described the invisible labour and feminised nature of care work, this study identifies how participants are potentially delegated dirty work through their pre-existing low occupational status, which they then reframe as an autonomous choice due to their “naturally caring” self-categorisation. This is then reinforced by social systems that contribute to a lack of bridging capital that would enable participants access to different social groups.

This label is reinforced even more in the context of dementia care, which is accepted to require higher levels of feminised and devalued traits such as compassion whilst also putting the care worker at risk of additional moral, social and physical taints. Care workers develop solidarity with each other under key values, such as doing the best they can for the individuals they support. However, they continue to find themselves derogated and devalued by wider society.

To combat this, care workers reframe care practices when providing care for individuals with a dementia, specifically continence care. Care practices such as cleaning up after and supporting an individual with a dementia who has been incontinent outside of a socially acceptable venue become a rite of legitimacy that mitigates and legitimises their choices and occupation. The rite gives value and accredits the skills and behaviours care workers perceive as devalued by wider society, therefore validating their social identity and shifting the allocation of taints and stains to those who are “illegitimate”. The rite adds prestige and status to care workers who are “othered”. Passing this rite of legitimacy solidifies membership in the group and enables care workers to develop a positive self-image despite widespread devaluation and ignorance. The study reported in this thesis demonstrates that to mitigate perceived societal stigma, care workers undergo a complex social process by which “tainted” and “dirty” care practices are reframed and recalibrated to support and validate their social and group identity.

9.6 Contribution to Body of Knowledge

The literature review undertaken for this thesis discussed the prevalence of care worker perspectives in continence care research and found that this is often not considered. Research literature was mainly focused on care interventions for improving continence enacted by care workers, but often did not consider the difficulties experienced by the care workers themselves. This thesis privileges and provides a platform for the voices of marginalised and devalued care workers and has highlighted the importance of dementia specific continence care to combating this devaluation. The findings show how organisational ignorance around continence care (see section 6.2.1) and perceived societal othering (see section 7.3) have contributed to a need to seek belonging within a group with similar values, taints and stains (Hughes, 1962, Ashforth and Kreiner, 1999)(see section 7.3). As such, experiences of continence care have been reframed and reclaimed as a rite of legitimacy (see section 8.1.2) that solidify membership in an exclusive group. Interventions into continence care therefore present challenges for the group: seeking to change the qualifying experience risks damaging the safety that the group provides. This study therefore provides some evidence for why continence care interventions may have low rates of adoption amongst care staff.

Chapter 10 Conclusion

This thesis has reported on a qualitative study that aimed to explore how stigma around faecal incontinence was mitigated or (re)produced by formal care workers of people with a dementia in a residential care home setting.

10.1 Overview of Findings

The dirty work of providing care for people with a dementia is delegated to marginalised societal groups of low socio-economic status through reduced opportunities for social mobility. As humans intrinsically want to see themselves in a positive light, care workers must reframe this marginalisation as an autonomous choice (Ashforth and Kreiner, 1999, Hughes, 1962, McMurray and Ward, 2014). They do this by self-categorising as "*naturally caring"* (see Chapter 7).

This categorisation is reinforced as care workers find themselves surrounded by like-minded individuals who are also marginalised and have also mitigated the societal othering through self-categorisation. The mutual recognition between care workers validates their social identity.

Continence care for people with a dementia is widely ignored in policies and society alike, however care workers perceive this form of continence care as being the reason for their marginalisation and societal othering. This is because of the discrepancy between how continence care is viewed organisationally (see 6.2) compared to socially. Organisations do not recognise the skills and invisible labour that go into providing dementia specific continence care, whereas "civilians" use continence care to question and undermine the occupation and identity of formal care workers (see sections 7.3 and 7.4).

Therefore, when care workers then need to legitimise their identity and occupation, care practices like dementia specific continence care become reframed as a rite of legitimacy that mitigates the taints and stains attributed to them. Care workers focus on the positive aspects of continence care (see section 8.2.2.2) instead of the act itself. This enables them to redefine what continence care is. Instead of reproducing the societal view of care as "cleaning old peoples bums", care workers instead define their work in a way that reinforces their *naturally caring* identity.

Individuals working in the care industry who are not legitimised are deemed of dubious virtue. They have not been legitimised as naturally caring, therefore their motives for joining the care industry are uncertain. They are either expelled from the group (see section 8.2.1) or used as alternative targets for the societal taints and stains previously applied to care workers. This presents in practice as mistrust and wariness of “illegitimate” workers, such as managers that do not have contact with continence care.

Legitimate care workers are therefore individuals who are able to rationalise and evidence their occupation as stemming from their naturally caring identity, instead of wider socio-economic factors and societal delegation of dirty work. Providing continence care for people with a dementia is key to developing a positive social identity for care workers.

10.2 Strengths and Limitations of the Research

The study described in this thesis is subject to specific limitations that derive from the methods used. Firstly, as discussed in section 4.3, the sampling techniques utilised in recruiting interview participants will naturally skew the study population as only those who felt they had something to contribute on the subject will have volunteered. Recruiting care workers for research is notoriously difficult and this research took place during the COVID-19 pandemic. Care workers were under significant pressure in their working roles due to the risk of infection, and this may have had an impact on their capacity to participate in research. In addition, many participants were recruited through industry contacts and may have been preselected by these contacts to fit specific criteria that cannot be known.

It must be accepted that the views represented in this study cannot be transferred. However, the intention of this study was not to provide transferable knowledge, but to explore phenomena that could underpin further knowledge and research. In addition, the findings from this study were consistent across the participant group. Participants where from different geographical locations throughout the U.K. and of varying ages. Their perspectives and experiences were congruous regardless of care provider or job role, indicating that the findings are representative of the lived experiences of care workers.

An additional limitation is also in the method of analysis. As analysis was conducted by one researcher, it is likely that the researcher’s influence has resulted in the data being interpreted in a specific way that may not be repeated by others. However, significant steps were taken to improve the validity of the research through reflexivity. Sections 4.8.1 and 4.8.2 give an account of how my background and experience may have impacted data analysis. Equally, my background gave me the ability to make comparisons between my own experiences and those being reported to me. The reflective diary, along with supervision, reassured me that I was not lending too much weight to my own experiences.

Consideration must also be given to the methods used for data collection. Section 4.6.1 discusses how telephone interviews historically have a poor reputation in qualitative research due a perceived lack of contextual information that may aid in the interview process. However, recent research suggests that telephone interviews may be more effective. Although known to have a poor reputation, in this study I worked carefully to build rapport and overcome some of the reported barriers. The data collected for this study shows that participants did feel able to be open. The anonymity involved can facilitate discussion of sensitive topics and lead participants to be more open than they would be in person. This requires further research.

Finally, a strength of this thesis is that it captures in-depth, first-hand accounts of experiences that are often hidden behind closed doors. This research has given care workers the opportunity to discuss an aspect of their role that is heavily stigmatised and often invisible. Privileging the voices of a marginalised group contributes towards empowerment and improves the discourse around topics that can be under researched.

10.3 Implications for Research

It is notoriously difficult to recruit care workers to take part in research studies, possibly due to the marginalisation of aged care workers. Knowledge of what constitutes membership and acceptance within the caring community may help aid in recruitment and data collection. Evaluating interventions in care must also include an evaluation or consideration of the person delivering the intervention. The way in which that person is perceived will contribute significantly to whether or not the intervention is successful. If they are not legitimised by rites or shared experiences within the community, or if knowledge of legitimacy is not known throughout the group, this may result in interventions being rejected.

Further research is needed to establish the impact of legitimacy on the adoption of interventions. Additionally, further research and investigation is required to establish forms of training that would best prepare care workers for continence in dementia care environments

10.4 Implications for Practice

It is already understood that staff in residential care homes tend to have a pyramidical hierarchy with distinct differences between job roles and how they are perceived (Drew et al., 2007). This study adds additional understanding to the cultural structure of such facilities. While care workers are often resentful of the “higher ups” in their organisation, this study shows that they also seek to intentionally exclude them if they are not legitimised within the group. This implies that facilities where all employees have achieved and maintained their legitimacy through the rite described in this study will have improved workplace cultures and quality of care.

In addition, this study implies that opinions and knowledge from individuals who have not been legitimised by contact with faeces will not be incorporated into practice as effectively as that from individuals who have been legitimised. To contribute to improving dementia care practice, one must have experience of continence care for individuals with a dementia. One must have experienced faeces outside its socially accepted receptacle in a caring capacity.

Other aspects of this study have implications for care work policies and procedures. While current policies state that training in continence care is required, the participants in this study frequently reported receiving no training or training that did not effectively prepare them for the dynamic management involved. Organisational policies may therefore need to be adapted to incorporate the complex physical, social, and psychological aspects of continence care.

10.5 Final Reflection

To conclude, this thesis has expanded knowledge of group membership in devalued roles by demonstrating how care workers reframe continence care as an act that gives them prestige and status within their occupational group. By understanding how formal care workers situate continence care in the context of their role, and the factors that contribute to this, researchers and practitioners can begin to plan more effective interventions to improve continence care outcomes for people with a dementia in residential care. In addition, understanding the social complexities of group membership and formation within occupational care worker groups enables researchers and practitioners to facilitate improvements in cultures of care, which will inevitably improve the quality of care and support that people with a dementia receive.

Appendix A Records excluded at full text

Author/Year	*Reason for exclusion*
Aldridge and Harrison 2021	No care staff included
Andrews 2017	Non-research
Arnold-Long et al 2008	No care staff included
Bale et al 2004	Not continence specific
Barabas et al 2005	No care staff included
Bardsley 2013	Non-research
Black 2007	No care staff included
Blekken et al 2016	No care staff included
Bliss et al 2006	No care staff included
Boivin et al 2009	Non-Research
Booth et al 2019	Non-research
Bostock and Kralik 2006	No care staff included
Bradway et al 2010	Not care home specific
Brandeis et al 1997	No care staff included
Butcher 2019	No care staff included
Chang et al 2017	No care staff included
Cheater 2000	No care staff included
Colling 1996	Not care home specific
Cruise et al 1998	Not continence specific
Cummings et al 1995	No care staff included
Der Zijpp et al 2016	Not continence specific
Drennan et al 2011	No care staff included
Drennan et al 2012	No care staff included
DuBeau 2005	No care staff included
Dubeau et al 2006	No care staff included
Duff and Clarke 2010	Non-research
Dugan 1984	No care staff included
Dugger 2010	No care staff included
Durrant and Snape 2003	Non-research
Engberg et al 2002	No care staff included
Flanagan et al 2012	No care staff included
Flanagan et al 2014	No care staff included
Fox et al 2021	Not care home specific
Foxley 2008	No care staff included
Ganz et al 2007	No care staff included
Grant et al 2013	Not care home specific
Green 2012	Non-research
Halfens et al 2013	No care staff included
Hasegawa et al 2010	No care staff included

Holyrod 2018	No care staff included
Holyrod-Leduc et al 2004	No care staff included
Huang et al 2021	No care staff included
Huion et al 2021	No care staff included
Jerez-Roig et al 2015	No care staff included
Jumadilova et al 2005	No care staff included
Keegan 2012	Non-research
Klay et al 2005	No care staff included
Kyle 2012	No Care staff included
Lappen et al 2016	Not care home specific
Lim 2016	No care staff included
Lyons 2010	No care staff included
MacDonald et al 2007	No care staff included
Mangnall 2011	Non-research
McConnell et al 2004	No care staff included
McGrother et al 1990	No care staff included
Miu et al 2010	No care staff included
Mueller et al 2002	No care staff included
Murphy et al 2021	Not care home specific
Omli et al 2010	No care staff included
Ostaszkiewicz et al 2016	Non-Research
Ostaszkiewicz et al 2012	No care staff included
Ostaszkiewicz et al 2013	Non-Research
Ostaszkiewicz et al 2015	Non-Research
Ouslander et al 2001	No care staff included
Palmer 2021	No care staff included
Peet et al 1996	No care staff included
Pellatt 2012	No care staff included
Pinkowski 1996	No care staff included
Pinkowski 1996	No care staff included
Price 2011	No care staff included
Prosser and Dobbs 1997	No care staff included
Rahman et al 2012	Not continence specific
Rahman et al 2010	Not continence specific
Remsburg et al 1999	Not care home specific
Agency for health care 1998	No care staff included
Robinson 2000	No care staff included
Rodriguez et al 2007	No care staff included
Roe et al 2011	No care staff included
Roe et al 2013	No care staff included
Rose et al 2015	Not care home specific
Sanders et al 2012	No care staff included
Schnelle et al 2002	No care staff included
Schnelle et al 2003	No care staff included
Sgadari et al 1997	No care staff included

Shu-Yuan 2013	No care staff included
Simmons et al 2005	Not care home specific
Siswoyo et al 2021	No care staff included
Sublett 2010	No care staff included
Svedas and Wise 2012	No care staff included
Switzer 2006	No care staff included
Tanaka et al 2009	No care staff included
Taunton et al 2005	No care staff included
Temkin-Greener et al 2012	No care staff included
Thompson 2004	No care staff included
Thompson et al 1998	No care staff included
Valk et al 2002	No care staff included
Vinsnes et al 2007	No care staff included
Wagner et al 2003	No care staff included
Watson et al 2003	No care staff included
Woodward et al 2012	No care staff included
Woolridge 2000	No care staff included
Xu et al 2013	No care staff included
Yacintas et al 2021	No care staff included
Yap and Tan 2006	No care staff included

Appendix B Literature Review Data Extraction Table

STUDY	SETTING	PURPOSE	POPULATION AND SAMPLE	METHODS	MAIN OUTCOMES/FINDINGS	CONCLUSIONS/NOTES
CLARKE-O'NEILL ET AL. (2015)	UK, 2 NHs	Feasibility study of using IAD tools in clinical practice	6 RNs 10 non-RN caregivers (all female) 10 TVS nurses (gender not specified) 11 nursing home residents (8 female, 3 male)	Weekly photographs taken over 8 weeks with a subset of 10 representative photos taken. Staff participants graded IAD based on 3 instruments and a simple severity scoring system.	Current IAD instruments too time consuming and complex, particularly for non-nursing staff. Severity scoring system could be improved by adding reference photos.	Non-nurses in this study found text-based instruments harder due to English not being their first language. Non-nurses felt “unsure” what was being asked of them. RN’s did not have the time to complete the instruments due to the demands already on their time. Initial request to examine all 10 photos reduced to just 3.
DUBEAU ET AL. (2007)	USA, 358 NHs	Assessing NH staff’s knowledge and attitudes about UI, UI management and new federal guidance	500 NH staff and NH surveyors (*surveyors – 8%, NH administrators – 15.8%, directors of nursing – 27.6%, assistant DONs – 3.8%, staff nurses – 29%, nursing assistants – 1%,*	Questionnaires given to all NH staff who attended a workshop. NO data collected on personal information or employer.	Respondents had little knowledge about pharmaceutical treatment for UI. NH staff cited documentation as a problem 71% of all respondents felt that UI is one of the most	More intensive and quality-improvement-focused educational efforts needed Incontinence guideline efforts should focus on managerial structures and quality improvement Further research needed to define residents’ and

STUDY	SETTING	PURPOSE	POPULATION AND SAMPLE	METHODS	MAIN OUTCOMES/FINDINGS	CONCLUSIONS/NOTES
			nurse practitioners – 0.2%, nursing consultants – 2%)		bothersome problems for residents In free form answers, nurses were strikingly emotional, citing trust and paranoia about surveyors and researchers Significant gaps in basic knowledge about UI.	families' understanding/values regarding quality continence care
HÄGGLUND AND OLAI (2017)	Sweden, 1 NH	To describe staff perceptions of enabling and inhibitory factors that influenced implementation of EBP for UI	14 care staff (*6 auxiliary nurses, 4 RNs, 4 people in management positions)*	3 focus group interviews and 2 individual interviews (*due to inability to attend focus group)*	Clear and involved leaders with a continuous positive attitude helped implementation Inclusion of "continence agents" aided implementation Pad-weight tests before prescription of continence aids inhibited EBP	EBP for UI leads to increased quality of life and improved conditions. *Impact of providing continence care on staff not discussed*
JOHNSON ET AL. (2001)	USA, 4 LTCs and 2 RCs	To elicit preferences for UI treatments of proxy decision makers in care	403 family members 66 nursing staff 79 older adult residents	Survey with preference rankings between 7 paired combinations of UI treatments	Most participants preferred non-invasive strategies. Nursing staff preferred prompted voiding despite family members and older adults viewing it as embarrassing	Discrepancy between what different stakeholders prefer as treatment for UI. Different groups possibly have different preferred outcomes
LANCIONI ET AL. (2011)	Unspecified, 1 care centre	To assess whether 3 patients with Alzheimer's disease	3 older adults with Alzheimer's disease, 52	Body worn urinary alarm, social	Staff seemed to find the alarm system preferable to timed toileting	Encouraging findings but requires further research on a larger scale

STUDY	SETTING	PURPOSE	POPULATION AND SAMPLE	METHODS	MAIN OUTCOMES/FINDINGS	CONCLUSIONS/NOTES
		could learn to use alarms and prompts to eliminate large urinary accidents.	caregivers in residential and day care centres	validation assessment	Alarm system increased the incidence of self-initiated toileting Alarm system significantly reduced or completely ended episodes of urinary incontinence	No data to show if the residents preferred the alarm system, or how they adapted to it. No discussion of whether residents found the alarm embarrassing No data to determine actual preference of staff and families
LEKAN-RUTLEDGE ET AL. (1998)	USA, 23 LTCs	To investigate CNAs perceptions of incontinence causes and barriers to prompted voiding	141 certified nursing assistants	Workshop conducted by clinical nurse specialist Questionnaire	Reasons to begin prompted voiding include to improve resident care and satisfy expectations for quality of care, despite the intervention originating from corporate offices. Increased resident contentment was the 4th highest reported positive outcome Increased workload cited as highest reported barrier, absenteeism being the second highest	Increased staff, increased support, improved communication and ongoing education are necessary for long term success
MATHER AND BAKAS (2002)	USA, 2 LTCs	To examine staff perceptions about factors that	31 nursing assistants	Focus groups	Excessive workloads inhibit continence care, the training provided is not a	Most participants began working as a CNA due to personal experience

STUDY	SETTING	PURPOSE	POPULATION AND SAMPLE	METHODS	MAIN OUTCOMES/FINDINGS	CONCLUSIONS/NOTES
		promote or inhibit continence care			realistic representation of workload Cooperation: other staff do not make continence care a priority, some residents do not cooperate with continence care Inconsistent communication: not being given information about the person they are supporting, lack of nursing support Teamwork	Staff all want to provide good continence care Focus group interviews like those conducted in this study could help tailor continence programmes to specific concerns of caregivers.
OSTASZKIEWICZ ET AL. (2014)	Australia, 2 residential aged care facilities	Describe and explain how residents have their continence care needs determined, delivered and communicated	18 care staff (*6 RNs, 6 ENs, 6 PCAs)*	Semi-structured interviews Non-participant observations (*88 hours, all shifts)*	Caring against the odds - multiple constraints to care: *highly regulated environment, ethically challenging situations, high dependence, devalued role* Weathering constraints: staff responses to constraints of care: *accommodate the context of care, self-protective distancing strategies*	Residents have the right to independence, choice and control, but there are many factors inhibiting staff practicing this. The government must address these issues.
OSTASZKIEWICZ ET AL. (2016D)	Australia, 2 residential aged care facilities	Examine, describe and explain how continence care is	18 care staff (*6 RNs, 6 ENs, 6 PCAs)*	Semi-structured interviews	Occupational exposure to incontinence contributes	Socially constructed taboos about incontinence render care work a

STUDY	SETTING	PURPOSE	POPULATION AND SAMPLE	METHODS	MAIN OUTCOMES/FINDINGS	CONCLUSIONS/NOTES
		determined, delivered and communicated		Non-participant observations (*88 hours, all shifts)*	to the low occupation status of care work Care workers responses include: accommodating the context, dissociating oneself, distancing oneself and attempting to elevate ones status	stigmatised subject as well as a stigmatised occupation
OSTASZKIEWICZ ET AL. (2016C)	Australia, 2 residential aged care facilities	Describe care workers beliefs and experiences of providing continence care at night	18 care staff (*6 RNs, 6 ENs, 6 PCAs)*	Semi-structured interviews Non-participant observations (*88 hours, all shifts)*	Most residents checked at night. Staff concerned that residents were intractably incontinent and at risk of pressure injuries. Pads preferred containment method, mainly due to staffing ratios	Night-time continence care must be audited to ensure care is based on resident's preference
OSTASZKIEWICZ ET AL. (2022A)	Australia,	Establish expectations and preferences about continence care	Informal carers/family members, aged care staff members (quantity unreported)	Online survey with likert scale, qualitative interviews	Person centred care, practical assistance, knowledgeable and educated staff, adequate resources are all equally important for continence care	Conference proceedings so very brief.
OSTASZKIEWICZ ET AL. (2022B)_ENREF_163	Australia	Co-design and test best practice model of continence care	Online survey: 177 "aged care stakeholders" Interviews: 14 "aged care stakeholders"	Online survey, scoping review, qualitative interviews, co-design workshops	Developed best practice model of continence care. No statistically significant difference in staff knowledge before and after. Model helps to	Model represents best available evidence and incorporates lived experience.

STUDY	SETTING	PURPOSE	POPULATION AND SAMPLE	METHODS	MAIN OUTCOMES/FINDINGS	CONCLUSIONS/NOTES
			Co-design workshops: 5 care staff, 5 family members/informal carers.		support quality standards of care.	
PING ET AL. (2014)	Australia, 5 NHs	Explore UI assessment and management	121 care staff (*PCAs – 63%, ENs – 11%, RNs – 20%, managers – 4%)*	Questionnaire Interviews (23)	Care staff found that UI assessments were useful and contributed to care plans. Toileting time and frequency of continence aid change were most important aspects of management. Providing assistance *when requested* second most common strategy, although only practiced by about half of respondents	UI assessment and management can be improved. Results based on self-reporting, which may differ from actual practices.
RESNICK ET AL. (2006)	USA, 2 NHs	Consider beliefs of NAs and DONs about management of UI	11 DONs 27 NAs	Focus groups facilitated by 2 practice nurses. Separate groups for DONs and NAs	7 themes identified from NAs, 3 extra from DONs. Some NAs reported resident laziness as causing UI Staff level issues included conflicting demands and low priority of continence care, lack of staff, and just	Education about UI and realistic outcomes should be provided for staff Need to implement appropriate motivational techniques for residents

STUDY	SETTING	PURPOSE	POPULATION AND SAMPLE	METHODS	MAIN OUTCOMES/FINDINGS	CONCLUSIONS/NOTES
					not answering bells/buzzers/lights	
SAXER ET AL. (2008)	Switzerland, 10 NHs	Development and testing of knowledge scale as well as measuring practice and knowledge about UI	199 RNs 116 NAs	Questionnaire developed by the research team	NAs knowledge about UI is somewhat lower than that of nurses, which was considered satisfactory. When measuring practice, scores were almost identical between RNs and NAs, as both carry out practical tasks. For documentation, RNs scored surprisingly low considering this is one of their main responsibilities. NAs scored higher on support than RNs, likely due to providing more physical support.	Nurses need to be re-educated about UI. NAs do not require this knowledge to perform their roles. Both RN's and NAs need additional support with documentation as this is crucial for uniform and appropriate care.
SAXER ET AL. (2009)	Switzerland, 10 NHs	Examine relationships between knowledge, beliefs, attitudes and continence related practice	199 RNs 116 NAs	Cross-sectional survey, questionnaire developed by research team	Statistically significant relationship between knowledge and behavioural attitude, between emotional and behavioural attitudes but none between beliefs and knowledge or believes and behavioural/emotional attitudes.	Knowledge and attitude are related to self-reported practice. More research needed to investigate associations between knowledge, attitude and practice.

CASP Qualitative Research Checklist **Error! Not a valid link.**

Appendix C Study Protocol

FULL/LONG TITLE OF THE STUDY

Care practices and incontinence-related stigma for residents living with dementia in a care home setting: a qualitative interview study

SHORT STUDY TITLE / ACRONYM

Care Practices and Incontinence-Related Stigma

PROTOCOL VERSION NUMBER AND DATE

20/04/2021 Version 2.7

RESEARCH REFERENCE NUMBERS

IRAS Number:	N/A
SPONSORS Number:	N/A
FUNDERS Number:	Grant Reference Number 227

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: Date: ....../....../......

....

Name (please print):

....

Position: ....

Chief Investigator:

Signature: .... Date: ....../....../......

Name: (please print):

....

Appendix C

LIST of CONTENTS

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KEY STUDY CONTACTS

Chief Investigator	Jackie Bridges Jackie.bridges@soton.ac.uk
Lead Investigator	Leah Hewer-Richards l.hewer-richards@soton.ac.uk 07528538888
Sponsor	University of Southampton, represented by Dr Alison Knight 02380 598580
Joint-sponsor(s)/co-sponsor(s)	N/A
Funder(s)	Alzheimer's Society Katherine.Gray@Alzheimers.org.uk
Key Protocol Contributors	Leah Hewer-Richards l.hewer-richards@soton.ac.uk 07528538888
Committees	N/A

STUDY SUMMARY

Study Title	An exploration of the management of continence related stigma and how it impacts carer-resident relationships.
Internal ref. no. (or short title)	Stigma Management and Continence
Study Design	In-Depth Interviews
Study Participants	Care Home Staff
Planned Size of Sample (if applicable)	30

Follow up duration (if applicable)	N/A
Planned Study Period	18 Months
Research Question/Aim(s)	Q: How is stigma around faecal incontinence (re) produced or mitigated by care staff in care homes? Aims: To gather care home staff accounts of their interactions with residents living with a dementia related to faecal incontinence To develop an understanding of how staff understand their role in relation to continence care and managing associated stigma in these accounts To identify strategies that staff deploy to mitigate stigma and uphold dignity in these situations To identify the organisational factors that shape the practices of staff in these situations

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
Alzheimer’s Society Katherine.Gray@Alzheimers.org.uk	PhD Studentship Grant Number 227
University of Southampton	Supervisory Support

ROLE OF STUDY SPONSOR AND FUNDER

The study funder has no responsibility in this instance in regards to study design, conduct, data analysis, interpretation, or manuscript writing. The study will undergo an ethics review by the study sponsor to ensure it meets ethical regulations of the University of Southampton.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

This study has been reviewed by the Research Monitors employed by the Alzheimer’s Society to ensure that the area of research is of interest to stakeholders. Research Monitors are able to suggest changes and improvements to study design and research aims if they feel that an issue is not being fully addressed or there are other issues they feel need investigating. Currently, this research has been approved by the Alzheimer’s Society Research Monitors.

PROTOCOL CONTRIBUTORS

The main contributor to this protocol is the lead investigator, Leah Hewer-Richards. Advice will be taken from academic supervisors: Professor Jackie Bridges, Dr Ruth Bartlett and Dr Kellyn Lee.

The Alzheimer’s Society Research Monitors have reviewed this research proposal and agreed on the issues the research will be exploring but have not contributed to study design.

KEY WORDS: Stigma

Continence Care

Dementia

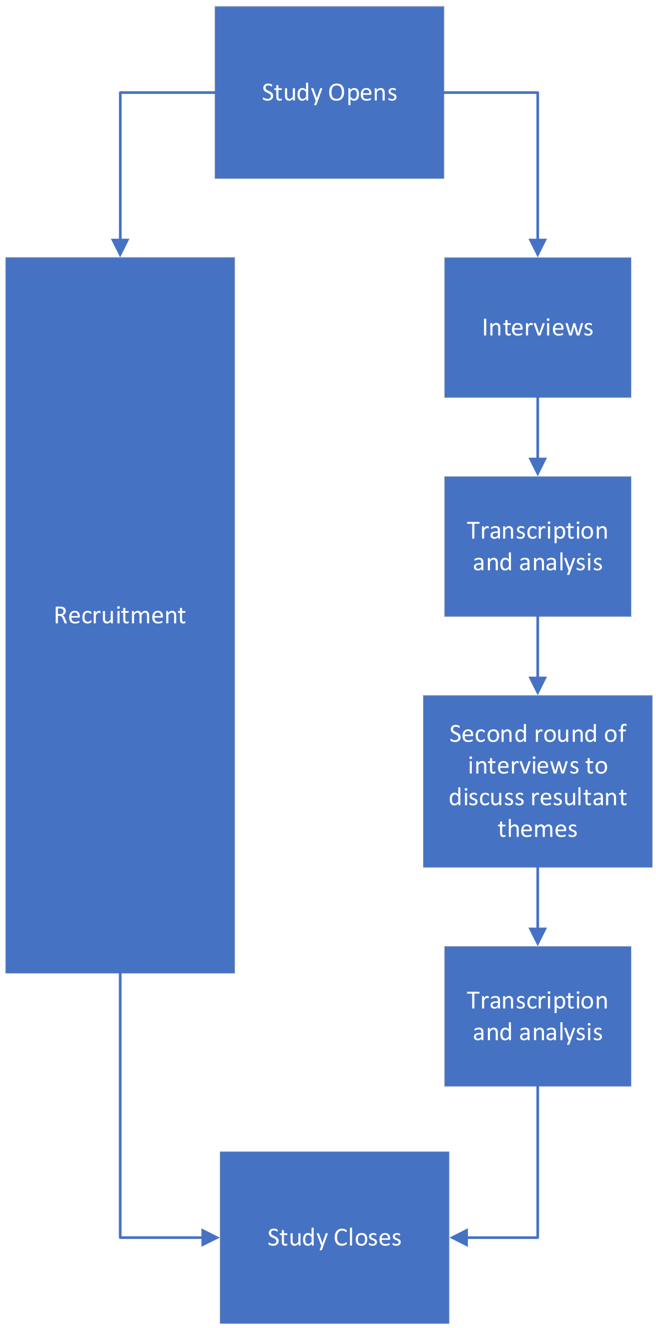
Relationships

Faecal incontinence

Care staff

Appendix C

STUDY FLOW CHART



STUDY PROTOCOL

BACKGROUND

Up to 77% of people living in care homes experience urinary incontinence (UI) (Damian et al., 2017). Between 30-50% of individuals will experience faecal incontinence (FI) (Goodman et al., 2017). The definition of incontinence generally includes the “involuntary” loss of faeces or urine (Drennan et al., 2011, Ihnat et al., 2016). For individuals with a dementia, incontinence often has more complicated contributing factors than when dementia is not part of the picture. It may be that people are voluntarily opening their bowels without realising it is socially inappropriate (Ihnat et al., 2016, Jerez-Roig et al., 2015). The various ways in which dementia affects the brain mean that ability to perceive one's environment may be reduced. The individual may not recognise situations where it is socially acceptable to defecate or urinate; leading to "inappropriate" voiding in areas outside of the norm. Individuals with a dementia may also have difficulty recognising the sensation of needing to defecate or urinate, this collection of symptoms is known as functional incontinence (Kyle, 2009). This can lead to conflict between the individual with a dementia and the individual providing continence care. Due to reduced understanding of cognitive deficits, incidences of incontinence can be labelled as "on purpose" by care workers providing support and cause resentment in the relationship between client and carer (van Dongen, 2001).

Individuals who experience faecal incontinence can be stigmatised. According to Becker (1963) they are known as "outsiders", this is due to the dirty and unhygienic breaking of societal rules. Many care workers have been socially conditioned to show embarrassment and disgust in response to faeces and therefore continue this line of assigning the individual an "outsider" label (Norton, 2004, Oaten et al., 2018, Norling et al., 2015).

In practice, this stigma manifests as a conflicting relationship between the care worker and the care recipient (Brunt and Rask, 2018, Byon et al., 2017, Kroeger, 2017). Whilst the care worker is outwardly providing supportive care, inwardly they are reluctant to be "contaminated" by another person's faeces. This can present as a reluctance to provide continence care, leading to a risk of the individual with a dementia being neglected (Ostaszkiewicz et al., 2016d, Ostaszkiewicz et al., 2016b).

Early evidence suggests that infection transmission for COVID-19 may be possible through the faecal-oral route (Heller et al., 2020). This knowledge, in addition to personal protective equipment (PPE) shortages in the care home sector in the UK, are likely to significantly increase staff stress over contamination and shape the provision of continence care to care home residents. Changes in the recommended uses of PPE, PPE shortages, increased death rates for patients and care workers, and heightened fears about contamination, infection and illness are likely to be causes worry and confusion in the care home workforce (National Care Forum, 2020, BBC, 2020, Hindson, 2020, Gordon et al., 2020).

Stigma is associated with both contagious diseases and bodily fluids. Care workers who support individuals who are confirmed to have Ebola have reported being subject to courtesy stigma as a result of their work (Gee and Skovdal, 2018). These findings are reflected in similar research into the SARS virus, which is similar in effect to COVID-19 (Nickell et al., 2004). This courtesy stigma seems to arise from media representations of the illness and wider society's concerns over the care workers infection status; they are avoided and ostracised as they are seen as a potential source of contagion. The same stigma exists for individuals supporting people with incontinence, particularly faecal incontinence. Society's distaste for faeces and fear of infection from faeces lead to care workers experiencing courtesy stigma; they are again ostracised as a result of their association with bodily fluids (Ostaszkiewicz et al., 2016d).

RATIONALE

This study has been formulated based on findings from a literature review focused on stigma around faecal incontinence and its impact on the delivery of continence care for people with a dementia in care homes. The study was adapted to include the ongoing COVID-19 pandemic, however following advice from academic peer review this has been consequently excluded to solidify the focus of the study.

Research currently exists discussing the impact of faecal incontinence on the personhood of individuals with a dementia, however there are few publications discussing the impact of supporting people with dementia and incontinence on the experience of staff. Issues that lead to incontinence such as constipation or diarrhoea can cause severe distress reactions which in this context refer to instances of "challenging behaviour" or "behavioural and psychological symptoms of dementia." The phrase distress reaction is used as it imparts less stigma on the individual. Distress reactions can include but are not limited to: episodes of aggression, frustration, depression, social withdrawal and anorexia (Fatania et al., 2019, Singh et al., 2019). In residential care, the individuals who are supporting people with distress reactions are often of low socioeconomic standing who are likely to have reduced training and experience in dealing with these issues. This is a leading cause of mental health problems in staff (Karlsson et al., 2019). The courtesy stigma associated with supporting these individuals is also likely to cause significant stress and burnout in staff (Kyle, 2009, Yeatts et al., 2018).

3 THEORETICAL FRAMEWORK

As previously discussed, faecal incontinence in relation to dementia care is defined as defecating outside of socially acceptable norms and locations. This is due to dementia limiting the skills needed to appropriately open one's bowels. Courtesy stigma for care workers can produce increased levels of staff turnover and risk of burnout. Episodes of incontinence add to already strict time pressure for staff, increasing the work load and stress levels within the workplace (Goodman, 2016, Ejaz et al., 2015, England and Dyck, 2011, Hilton et al., 2017, Jones and Moyle, 2016).

Despite awareness of cognitive difficulties in dementia that lead to faecal incontinence, healthcare professionals often blame the individual experiencing incontinence for not managing bowel movements in a way that conforms to societal expectations (Norton, 2004). Many care workers have been socially conditioned to show embarrassment and disgust in response to faeces and therefore label the individual they are supporting as an “outsider” (Norton, 2004, Oaten et al., 2018, Norling et al., 2015, Becker, 1963). This conflict between the care and affection staff often feel for the people they support and the frustration and disgust they may feel due to the lack of bodily control are likely to contribute towards emotional distress for the care worker. They may feel that they are not effectively performing the duties they are morally obliged to.

Wider society then applies this “outsider” label to care staff, due to the courtesy stigma of being associated with faeces and bodily fluids. Care workers are separated from society as a result of the duties they perform, leading to them being excluded from society due to fear of contamination. This separation of care workers from society is cemented by their current status as potential sources of contagion for COVID-19. Not only are they excluded due to their association with faeces, they are isolated and quarantined due to the perceived risk of them spreading infection.

To reduce this isolation of care staff and empower them to overcome barriers they may face, understanding of how these issues manifest is crucial.

4 RESEARCH QUESTION/AIM(S)

Q: How is stigma around faecal incontinence (re) produced or mitigated by care staff in care homes?

4.1 Objectives

To gather care home staff accounts of their interactions with residents living with a dementia related to faecal incontinence

To develop an understanding of how staff understand their role in relation to continence care and managing associated stigma in these accounts

To identify strategies that staff deploy to mitigate stigma and uphold dignity in these situations

To identify the organisational factors that shape the practices of staff in these situations

4.2 Outcome

To understand how care staff experience and understand stigma in relation to their work

To understand staff perceptions of the management of continence care

To understand how relationships between care staff and residents may be impacted by stigma

To provide recommendations which may help shape future continence care in dementia

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

This study aims to explore staff experiences of providing intimate continence care and discover how these may impact the development of carer-resident relationships. Due to COVID-19 the safest way to collect rich data is through an online telephone or interview method. Conducting this study as an interview-only design will enable rich, descriptive narratives of care workers daily experiences to emerge without the constriction of closed methods such as questionnaires (Noaks and Wincup, 2004).

In this study in-depth, semi-structured interviews will be conducted with care workers and registered nurses in care homes over a period of 22 weeks. Interviews will be conducted remotely using online video communication technology or telephone interviews. This will ensure the safety of the researcher and participants whilst adhering to social distancing rules. The lead investigator (LI) will use Microsoft Teams in order to comply with University of Southampton guidelines (Southampton, 2020).

Interviews will be audio recorded but not visually recorded. Audio recordings will then be transcribed and anonymised using pseudonyms, the key for which will be kept on a password protected document of the University of Southampton's secure server.

Data Analysis

A framework analysis method will be used to analyse all interview data. Framework analysis is a method that establishes and maintains connections between participants and their accounts to ensure the context of the individual's comments are not lost (Gale et al., 2013). This method has been chosen as it allows for relationships to be identified between different points in the data, therefore drawing explanatory and descriptive conclusions about what is being examined. It also allows policies and procedures to be assessed from the very people they affect. This means needs and wants of employees are more likely to be implemented in practice and result in greater compliance (Srivastava and Thompson, 2009). This method will aid the researcher in achieving the research objectives.

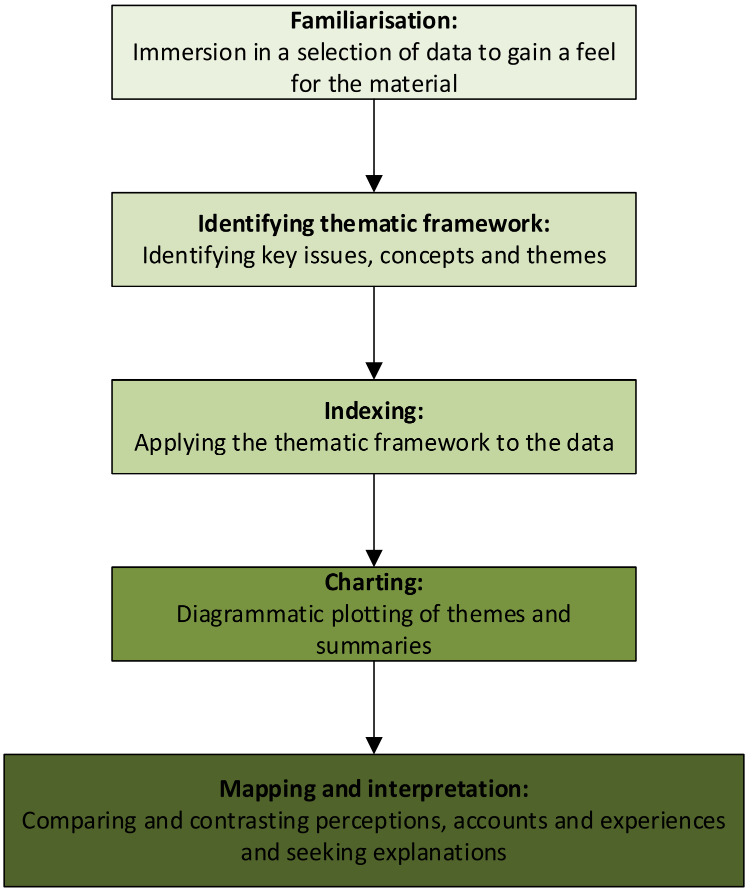


Diagram of Framework Analysis method (Ritchie and Spencer, 1994)

Familiarisation will begin with the LI reading through the transcripts from the interviews. It may not be possible at this stage to review all the material so the LI will select a sample of data that encompasses a range of different participants and time periods.

After familiarisation, the LI will use the original research aims to identify key issues, themes and concepts in the data sample and establish these as a thematic framework by which the data can be examined and sorted. This initial index is likely to be largely descriptive and will then be applied to further transcripts to be refined in an iterative process.

At this point, the LI will then begin indexing all of the data according to the thematic framework. In this stage it is possible that transcripts will be indexed with multiple themes and concepts, beginning to show associations between the data.

The following stage involves charting the data to group different themes together and demonstrate how the themes are building, meaning the charted will be carried out with a thematic approach. This is instead of a “by case” approach as the collation of themes will begin to show the prevalence of different attitudes.

Finally, the LI will begin mapping the data and interpreting it. Mapping and interpretation in this study will be used to provide explanations for the different themes and concepts that emerged in the previous stages of analysis. This will be done by finding associations between characteristics or experiences and behaviour or attitudes. This method will enable the researcher to achieve the objectives stated earlier.

6 STUDY SETTING

Participants in this study will be employed to work in a care home setting that provides intimate personal care for individuals living with a dementia in the UK. Within this environment, care home staff support individuals with a dementia to undertake activities of daily living such as washing, dressing, eating, socialising and maintaining relationships.

Potential participants will be accessed via online advertising, through relevant organisations (such as Royal College of Nursing, Care England, National Care Forum, ENRICH) and direct contact with registered home managers. When accessed via advertisements, interested parties will be encouraged to contact the LI by email or telephone to obtain more information about the study. Potential participants will then be sent a Participant Information Sheet (PIS) in their preferred format, either by e-mail or post. Where the LI makes direct contact with a home manager, the manager will be asked to distribute PIS's amongst their staff and staff will be encouraged to contact the LI via email or telephone to express their interest in the study.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

All care workers and registered nurses working within a residential or nursing care home who are able to speak and understand English will be available to join the study, regardless of location.

7.1.1 Inclusion and Exclusion criteria

	Inclusion Criteria	**Exclusion Criteria**
Care home staff	Working within a residential or nursing care home Working with individuals who have a dementia and experience incontinence Working in one or more of the following roles: care, domestic assistant, cleaning, administration, management, maintenance, registered nurse	Not working within a residential or nursing care home Not able to speak and understand English Not able to access the internet

	Inclusion Criteria	Exclusion Criteria
	Able to speak and understand English Living and working within the UK (Scotland, Wales, England, Northern Ireland)	

7.2 Sampling

7.2.1 Sampling technique

Participants will be selected for this study using accessibility sampling. All participants who are willing to take part and who meet the inclusion criteria will be recruited for the study to ensure the research outcomes are achieved. Accessibility sampling means that all care home employees who are willing to take part and meet the inclusion/exclusion criteria will be included in the study.

7.3 Recruitment

Recruitment in this study will continue throughout to ensure up to 150 participants are recruited. There will be various methods of recruitment used as follows:

Advertisements

The LI will share advertising on social media platforms with a budget of £50. These advertisements will be targeted at all individuals who have listed their occupation as a carer, care worker, residential care worker, domestic assistant or registered nurse. The generic term “care worker” or “carer” has been included here to increase the number of individuals the advertisement is visible to. There are a number of different job titles that encompass the role of “residential care worker”; the SC would like to ensure individuals who list variations of this as their job title are able to access the study. Advertisements will state that a study is taking place at the University of Southampton investigating the impact of COVID-19 and stigma on continence care practices and provide a link for potential participants to click to contact the LI. The advertisement will state that potential participants will be invited to take part in one or more remote interviews lasting about an hour at the time of their choosing.

The LI will also post the study information as shown in Appendix 9.1.2 regularly on Twitter and other social networks to increase the visibility of the study. Samples of these advertisements can be found in Appendix 9.1.1.

Research Ready Network

The LI will also attempt to utilise the NIHR ENRICH Research Ready Care Home Network, which comprises of a list of care homes that have self-nominated as willing to participate in research. Once registered with this network ENRICH research co-ordinators will contact enrolled care homes and distribute the study information amongst them. Members of staff within these homes will be encouraged to contact the LI to express their interest in the study.

7.3.1 Sample identification

This study will utilise accessibility sampling, meaning that all accessible individuals who meet the inclusion and exclusion criteria will be able to participate in the study. However, due to the excessive pressures that are being placed on care workers currently due to the pandemic, advertisements are being used in order to reduce additional pressure being place on employees to take part in research.

To incentivise participation, potential recruits will be offered a £10 Amazon voucher on completion of the research interview.

7.3.2 Consent

For individuals responding to advertisements:

If an individual contacts the LI after having seen an advertisement and requests more information about the study, the LI will provide this in the form of PIS’ via email or post. The LI will endeavour to answer any questions the individual has about the study and ascertain interest in the study, allowing more time if the person requires this. If the individual wishes to take part, they will be asked to complete a consent form. The consent form can be signed digitally and returned via email or physically signed and posted back to the LI. The LI will also send a how-to guide explaining how to digitally sign PDF forms. If the potential participant is unable to use either of these methods but would like to take part, the LI will arrange a telephone or video meeting and audio record the individuals consent and record this on a consent form for the individual.

When participants are initially contacted, they will be informed that the LI will contact them via email or their preferred method 7 days after the initial contact to ascertain interest in the study. If the individual does not respond to this follow up contact, their information will be permanently deleted, and they will not be contacted again. If an individual decides not to take part after receiving information about the study or after the follow up contact, their contact information will be permanently deleted and they will not be contacted again.

For individuals contacted through the ENRICH Research Ready Care Home Network:

Staff who wish to take part in the study will be asked to contact the LI to express their interest. The LI will then provide further information about the study and answer any questions they may have. At this point, the LI will ask if the individual would like to take part in the study and offer more time if the individual would like to consider it. If an individual declines to take part, their details will be permanently deleted, and they will not be contacted again.

Individuals recruited via this method will be informed that whilst their participation remains confidential, the LI will be reporting the number of people in each area recruited through the network to ENRICH. This means that the LI will be informing ENRICH that, for example, 6 people from enrolled care homes in the Hampshire area took part in the research.

All individuals who consent to take part in the study will be made aware that they can withdraw their consent at any time and cease participation in the study. Any data collected from them up to that point will be withdrawn from analysis and destroyed unless the data has already been analysed.

8 ETHICAL AND REGULATORY CONSIDERATIONS

There are a number of ethical issues to consider in relation to this study. Currently, care workers are under more pressure than usual due to the COVID-19 pandemic and are therefore at risk of increased stress levels and burnout (Röhr et al., 2020). Due to this, the LI is utilising passive methods of recruitment to ensure that only individuals who feel as though they have the time and energy to participate are included in the study. Using remote interviewing techniques means that potential participants will not have to complete any additional travel or work pressures to take part in the study. Participants will receive a £10 Amazon voucher as thanks for their participation in the study enclosed in a thank you card.

Some of the topics discussed during the interviews may be distressing to the participants, as they will be encouraged to discuss issues they are currently having whilst at work. The LI will include information on the participant information sheet on organisations that can offer support to staff.

There may be occasions where interviewees become upset and distressed during the course of an interview. All interviewers will be prepared in advance to manage such a situation sensitively and appropriately. Responses to distress will include stopping data collection, responding with empathy, and exploring the individual's options for accessing further support including furnishing them with contact details for relevant support services (these details will also be included on participant information sheets). If there is ongoing concern about the interviewee's distress, the interviewer will offer to contact a friend or family member on the interviewee's behalf if they would like that, and will follow them up in the next 24 hours to see how they are and to reiterate information about support that can be accessed. The interview may be resumed if that is what the interviewee would like, or an agreement may be made to discontinue them from the study or to reschedule the interview. The incident will be recorded in the research team’s log.

The researcher will also be completing a research diary after each interview to record their immediate feelings and views of the topics discussed. This will help to reduce any stress on the researcher.

8.1 Assessment and management of risk

This study deals with a marginalised group in society: care home staff. As a result of this, there is a potential for risk to be caused to participants.

For care home staff:

Data protection – all care home staff participating in this study will be referred to by pseudonyms in transcriptions; a key for which will be stored in a password protected Microsoft document on the University of Southampton’s secure file store to maintain confidentiality and continuity throughout the study.

Psychological harm – if at any point the LI believes a member of staff is experiencing psychological harm as a result of participation in the study, individuals will be asked if they would like to continue with their participation and the LI will signpost them to local services that may be able to help with any resultant emotional issues such as depression, low self-esteem, stress and guilt.

Safeguarding – the LI will inform all members of staff before the study commences that they have a duty to report any safeguarding issues they come across throughout the study. The LI will follow the University of Southampton’s safeguarding policy for reporting any concerns.

For the researcher:

Throughout the study, the researcher is likely to hear about issues that cannot be planned for or expected. The LI is likely to have a reduced ability to change practices they deem as “unacceptable” but do not pose a direct risk to residents or others. In this event the LI will use a “manager test” in order to determine how to proceed.

The manager test involves the LI considering if they were working as a healthcare practitioner in a care setting and observed the incident in question, is it of such severity that they would feel obliged to report the incident to the manager of the individual involved? If yes, the LI will follow safeguarding guidelines and will seek informal advice from their supervisory team. If no, no further action will be taken.

This could cause undue stress and psychological harm in the researcher. To help combat this, the researcher will be completing a research diary each day to record their own responses to the situation. In addition to providing insights to the research process, this will enable the researcher to work through personal worries that may arise during the course of the research. The LI will also have regular meetings at least every two weeks with their academic supervisors to discuss ongoing issues.

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

The study will be submitted via ERGO II to the research and governance office at the University of Southampton and a favourable opinion will be sought before data collection begins.

8.3 Regulatory Review & Compliance

Before any participants are recruited for the study the CI will ensure that approval has been received from the participating setting. Any amendments will be submitted to ERGO II.

8.4 Amendments

Any amendments will be submitted to the sponsors internal REC for review and approval before being carried out.

8.3 Patient & Public Involvement

The initial study was discussed with two Alzheimer’s society research monitors in November 2019. The discussion included the research question, background research, what is known and not known, research design, data collection methods, intended analysis methods and dissemination ideas. The monitors will review this study in subsequent years of the PhD. At the time of presentation, the outcome decision by the monitors was favourable.

As the research monitors only meet once a year, they have not seen the changes made in light of the COVID-19 pandemic.

8.4 Data protection and patient confidentiality

The is expected to adhere to the requirements of the Data Protection Act 1998 and the General Data Protection Regulation 2018 (GDPR).

All transcriptions will be stored electronically on the researcher’s laptop. Data will be encrypted and uploaded onto a secure server provided by the university. Data held on secure servers will be password protected.

All identifying details relating to participants will be anonymised using a pseudonym, a key for which will be kept on the secure server and password protected. This will be destroyed upon completion of the study.

The LISC will be using a dedicated mobile phone and pay as you go SIM card to contact participants if their preferred method of communication is telephone. Telephone numbers of participants will be stored on this device. This mobile phone will not be the LI's personal device and will be solely dedicated to the research study. The mobile phone will have a 6-digit numeric passcode and only the LI's fingerprint will be authorised to access the phone. At the conclusion of the study, the mobile phone will be factory reset and all data stored on the phone will be permanently destroyed.

Contact details for participants such as postal addresses and email addresses the LI may use to send documents will be stored on a password protected Excel document stored on the University of Southampton's secure server. Personal data will be stored for up to 1 year following completion of the study and will only be accessible by the SC. After this, data will be permanently destroyed.

8.5 Indemnity

Indemnity insurance will be provided by the sponsor.

9. APPENDICIES

9.1 Appendix 1- Interview Schedule

Introduction:

Hi, thank you for agreeing to take part in this interview. My name is Leah and I am undertaking a PhD in which I am researching how continence care is provided for people with a dementia, I am particularly interested in your experiences and opinions relating to this. A little bit about me: I started working in care around 10 years ago and worked in various roles such as domestic assistant, care assistant, senior carer and unit manager. However, we will be focusing on your experiences during this interview.

This interview will be audio recorded and transcribed, during the transcription I will remove all names mentioned and the recording will be subsequently destroyed. I will refer to you via a pseudonym to protect your privacy in any published texts and research reports. If you need to take a break at any time please let me know and I will stop recording – you are able to stop the interview at any time and you do not have to discuss anything you are not comfortable with.

Do you have any questions before we begin?

Daily work:

Tell me about your experience in care *(cover: how long, current role, any other roles, what made you decide to work in care)*

Tell me about where you are currently working and what you generally do throughout a shift *(cover: number of residents, type of residents, shift patterns)*

Continence

Focusing on residents with dementia, tell me about an incidence of faecal incontinence you've recently dealt with *(cover: what did you do and say from start to finish and why, how did you feel, your reactions, the person's reactions and how you think they were feeling, anything you did to help them feel better, type of incontinence, what sticks in your mind about the interaction))*

Can you tell me about another incident? (*what were you doing during this interaction? Why?)*

(keep asking for more stories)

Potential Improvements

Is there anything about the care home/team you work in that you think particularly influences the continence care you're able to give? *(cover: organisational, support from peers, what do you like most about where you work)*

Thinking about what we've discussed, is there anything you feel needs to be changed? *(cover: anything to make working life better, how do you think this could be enacted, how could care for people who are incontinence be improved)*

Closing:

Is there anything you would like to add/anything you feel is important but has been missed?

Thank you for your time and for taking part in the study

Appendix D Study Flyer

Call for participants – Experiences of Providing Continence Care

We are looking for people who work in care homes to take part in a research study exploring experiences of providing continence care

Participants will receive:

A £10 Amazon voucher

Participants will be asked to:

Take part in one interview via Microsoft Teams or telephone

Are you eligible?

- Living and working in the UK
- Residential care worker
- Domestic assistant
- Care home manager
- Care home deputy manager
- Registered Nurse in a care home
- Access to internet or telephone

If you're interested in taking part or would like more information, please contact Leah at:
l.hewer-Richards@soton.ac.uk
07506 647 264

Appendix E Participant Information Sheet

Employee Information Sheet for Remote Interviews

Study Title: Experiences of providing continence care

Researcher: Leah Hewer-Richards

ERGO Number: 55504

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. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether or not to take part. 7 days after you receive this information, the researcher will send you a follow up message to see if you would like any more information If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is about your experiences of providing faecal incontinence care and how they have impacted you and the people you support.

What will happen to me if I take part?

If you choose to take part, you will be asked to take part in a maximum of two remote interviews with the researcher. These will take place via telephone or video chat using Microsoft Teams.

Are there any benefits to my taking part?

There are no direct benefits to taking part in this research, however the aim of the research is to improve the overall provision of care and the working environment for employees in relation to continence care.

What data will be collected?

Interviews will be audio recorded with your permission and then transcribed for analysis. Interviews will not be visually recorded, and transcriptions will be anonymised. The interviews will discuss how you are experiencing continence care within your role in the care home and your general working life. You will be encouraged to discuss any issues related to continence care you feel have not been addressed and anything you feel may be relevant. This information will then be analysed to meet the research aims of the study and transcriptions of the interviews will be kept by the researcher to inform further research and learning.

If you agree, the researcher will also collect special category data from you in order to meet the objectives of the study. This is information such as your age, ethnicity and gender. This information will remain confidential and will only be accessible by the researcher. The data will be retained for a maximum of 1 year and will not be disclosed to anyone else unless the researcher is obliged by law to do so. You will be able to request a copy of special category data held about yourself at any time and withdraw consent for this information to be retained.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential. 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 these people have a duty to keep your information, as a research participant, strictly confidential. The only limitation to this confidentiality is the unlikely event that you tell the interviewer about something which indicates that residents or staff are at likely risk of harm. If this happens then the interviewer will inform you that they are reporting this as a safeguarding concern.

The researcher is required to feedback to ENRICH the number of participants recruited through the Research Ready Care Home Network. This means that if you work at one of the care homes in the network, the researcher will be informing ENRICH that someone in their area has participated. Your name and the name of your employer will not be shared with ENRICH, only the region in which you work. For example, the researcher will report back “6 care workers in the West Midlands participated in the study.”

All participants will be anonymised and referred to by pseudonyms in the resulting data. All confidential data will be password protected and stored on the University's secure servers. Physical documentation like consent forms will be stored in a locked filing cabinet within the residential home, only the researcher will have access to this.

What is ENRICH?

ENRICH, which stands for "Enabling Research in Care Homes", is an initiative developed by the National Institute of Health Research (NIHR) to encourage care homes and care home staff to influence, understand and take part in research. The Research Ready Care Home Network is a network of care homes nationwide that have agreed to take part in the initiative and be involved in research studies. If you are unsure if your care home is part of this network, please ask your care home manager. More information can be found at: https://enrich.nihr.ac.uk/

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 complete a consent form to show you have agreed to take part. If you decide to take part and then change your mind throughout the course of the study, you will no longer be included in the study. You are able to inform the researcher you no longer wish to take part via email, text, telephone or during your interview. The researcher will ask if you would like data collected from you prior to withdrawal to be removed from the study; this decision is entirely up to you.

Data Protection Privacy Notice

For any participants whose preferred method of contact is the telephone, the researcher will be using a mobile phone dedicated to the study to contact them. This mobile phone is not the researcher's personal device and will be encrypted following the University of Southampton's guidelines. At the conclusion of the study, any data stored on the phone such as telephone numbers will be permanently erased.

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 1 year 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).

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).

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.

What will happen to the results of the research?

The interview data will be transcribed for analysis and then used in the researcher's PhD thesis to contribute towards their PhD award. The results may also be used in academic publications and for educational purposes.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk)

Where can I get more information?

If you would like specific information about the study or have any questions please contact:

Leah Hewer-Richards
l.hewer-richards@soton.ac.uk
07506 647264

What can I do if I'm having difficulty at work or feeling stressed?

There are a number of organisations you can contact to help you through this stressful time

The Care Workers Charity www.thecareworkerscharity.org.uk Financial Support	SANE www.sane.org.uk support@sane.org.uk 07984967708 Emotional Support, Mental Illness

Anxiety UK www.anxietyuk.org.uk 03444775774 Emotional Support, Help with Anxiety	Mind www.mind.org.uk 03001232293 Emotional Support
Men’s Health Forum www.menshealthforum.org.uk 24/7 stress support for men by text, chat or email	Samaritans www.samaritans.org.uk 116 123 Support for people experiencing feelings of distress or despair

If you’re not sure how you are feeling, the NHS mood self-assessment tool can help you better understand how you have been feeling and point you in the right direction for helpful advice and information (https://www.nhs.uk/conditions/stress-anxiety-depression/mood-self-assessment/)

Appendix F Consent Form

CONSENT FORM

Study title: Experiences of providing continence care

Researcher name: Leah Hewer-Richards
ERGO number: 55504

Participant number:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet version number V1.4 dated 27/11/2020 and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw at any time for any reason without my participation 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 only.	
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 understand that my personal information collected about me such as my name or where I live will not be shared beyond the study team.	
I give permission for special category data about me as described in the participant information sheet to be collected for the purposes of this study	
I give permission for data that I provide during interviews to be held by the researcher as described in the participant information sheet so it can be used for future research and learning	
I agree to take part in a remote interview for the purposes set out in the participation information sheet and understand that this will be recorded using audio with my permission	

[Date: 27/11/20] [Version Number: 1.3] Name of participant (print

name)…………………………………………………………………………… Signature of

participant…………………………………………………………………………………….

Date…………………………………………………………………………………….. ………………….

Name of researcher (print name)……………………………………………………………………………

Signature of researcher …………………………………………………………………………………….

Date………..

Additional notes or comments (accompanied by date and signature):

Appendix G Training needs identified in document analysis

Theme	Individual Training Requirement	Document Reference
Medication	Use of Medications Recognition and management of problems Principles behind organisation’s policies Recording of medication	Dignity in Care National Minimum Standards
The Caring Role	Principles of Care Worker Role Duty of Candor Positive attitudes towards aging Equality and Diversity Person Centred Care Recording and Reporting Positive behaviour support	Dignity in Care National Minimum Standards NICE Safeguarding adults in care homes DoH National Service Framework Skills for care: core and mandatory training
Health and safety	Safe working Practices Fire Prevention Appropriate use of equipment Prevention and control of infection Links between antibiotic prescribing and *clostridium difficile* infections Food Hygiene Health and Safety Awareness Use of bedrails Assisting and moving people	Dignity in Care National Minimum Standards DoH National Service Framework DoH Prevention and control of infection in care homes DoH Guidance Bed rails: management and safe use Skills for care: core and mandatory training
Dementia	Identification, assessment and management of dementia and cognitive needs	NICE Dementia (Assessment, management and support for people

	Person centred care for people with a dementia Outcome focused care for people with a dementia Signs, symptoms and expected changes associated with dementia Identity, sexuality and culture for individuals with a dementia Needs of the person and their family or carers Communication for people with a dementia Understanding, reacting to and helping people living with dementia who experience agitation, aggression, pain, or other behaviours indicating distress Interventions and reducing the need for anti-psychotic medication Freedom of movement and minimising use of restraint Multi-sensory stimulation	living with dementia and their carers)
Physical Health	First aid Basic Life support Good Nutrition for Older People Oral Healthcare Initial Wound Care Physical Activity Assessment Falls Prevention Promotion and management of incontinence (including dementia and functional causes) Experiences and needs of service user group Palliative Care	Dignity in Care National Minimum Standards NHS Enhanced Care Framework DoH Prevention and control of infection in care homes Skills for care: core and mandatory training NICE Dementia (Assessment, management and support for people living with dementia and their carers)

	Testing residents with diabetes	
Mental Heath	Mental health needs Mental Capacity Act 2005 Deprivation of Liberty Safeguards	NHS Enhanced Care Framework NICE Dementia (Assessment, management and support for people living with dementia and their carers) Skills for care: core and mandatory training
Safeguarding	Safeguarding Children Prevention of abuse, risk of harm and suffering Recognising different forms of abuse Whistleblowing How to act on suspected abuse How to deal with and preserve evidence How to raise concerns How to escalate concerns Confidentiality and data protection Safeguarding and legal principles under the Care Act 2014	Dignity in Care National Minimum Standards NICE Safeguarding adults in care homes Skills for care: core and mandatory training

Glossary of Terms

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[i] Shadowing is a widely accepted training method which facilitates transition into a new workplace and role (García-Martín et al., 2021, von der Lancken and Gunn, 2019).