Experiences of home care workers caring for people living with palliative and end of life care needs at home

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

Acknowledgments

This is dedicated to the memory of my Papa, Philip John Cassidy who always believed in the power of education and distilled in me from a very young age the importance of always trying to make a positive difference. It is also dedicated to my Mum, Jackie Terry and my step dad, Mark Terry who always made me believe that I could be anyone I wanted to be and achieve anything I set my mind to. I could not have finished my thesis without the unwavering love and support of my husband Neil Cardwell who is my biggest supporter, and kept our home life together when I had to concentrate on other things. I would like to thank my mother-in-law Linda Cardwell for all the additional childcare support that she lovingly provided to enable me to study. The fact my three-year-old son Flynn can say “Mummy doing PhD today” is a testament that it truly takes a village to reach the finish line.

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Abstract

Background

Home care workers are often required to provide physical and emotional support to people living with palliative and end of life care needs at home. Despite home care workers playing a vital role in ensuring people can remain at home to die, if this is their preference, not enough is known about the experience of this workforce from their own perspective. Many developed countries rely on home care workers to deliver end of life care in the community but these roles continue to offer poor financial benefits with variable access to training and support. This hermeneutic literature review and interpretative phenomenological analysis (IPA) study explored home care workers' lived experiences of caring for people approaching the end of life.

Aim

The aim of this hermeneutic literature review and IPA study was to examine the lived experience of home care workers who are delivering care to people with palliative and end of life care needs in the community.

Methods

A literature review was conducted using a hermeneutic framework to explore the experience of home care workers caring for people with palliative and end of life care needs in their own home. The findings of this review informed the qualitative IPA study. IPA methodology, which is informed by phenomenology, hermeneutics and idiography, was selected as it enabled in-depth analysis of transcripts. Eight home care workers from community care providers in Scotland were recruited and interviewed. All home care workers had cared for people approaching the end of life at home over the previous twelve-month period.

Results

Four master themes arose from the IPA analysis. (1) “You are really on your own”: Coping with isolation when providing care in the community. (2) “You just treat them, you know, like they're still alive”: The value of ritual for home care workers when caring for the dying and the dead. (3) “I wait and cry most times in the car”: Understanding the impact of grief and bereavement for those delivering care. (4) “These are the rules, no matter how frustrating you just have to follow”: Frustrations with organisational influence and control within community care settings. The notion of being unseen or invisible was reflected across participant accounts and can be found in all four master themes.

Conclusion

IPA allowed an in-depth exploration of home care workers' lived experiences of caring for people with end of life care needs. Home care workers were geographically, professionally, and emotionally isolated but remained overwhelmingly positive around their perception of being privileged to care for people at the end of life. Their experience of grief and bereavement was seen as an expected part of their role. Conservation of resource theory enabled home care workers occupational stress and risk of burnout to be further explored. The results of the study add to existing evidence that clarity on organisational support and access to education focused on palliative and end of life care would be meaningful for this workforce.

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Chapter One: Introduction

In 2015, I was asked to contribute to a palliative care workshop aimed at health care assistants and home care workers working predominantly with elderly clients in either home care or care homes. I had recently returned from working in Australia for almost a decade, where I was used to delivering postgraduate palliative care education and education programmes in care homes, so I was pleased to attend. As part of the workshop, attendees were encouraged to ask questions based on their own clinical experiences. As I stood and listened to some of their questions, I became acutely aware how shocked I felt hearing what they had faced in their caring role. Indeed, for many in the room it was the first time in their caring career they had attended any sort of palliative care training. For those attendees who were community based their experiences sounded particularly harrowing.

As the experience had really resonated with me, I was keen to explore whether research could improve this. Their experience felt very disconnected from the specialist palliative care environment I was used to working within, at the same time, it felt extremely relevant for me to consider in-depth the workforce upon whom we rely to deliver end of life care in the community, and so chose it as the area of study for my PhD at Lancaster University. I focused on the experience of home care workers rather than care home staff because when I began to explore the published literature it became clear that there was less research available which examined the experience of this workforce.

1.1 Aims of Research

The aim of this study was to explore the lived experiences of care workers supporting people at home with palliative and end of life care needs; this was also the focus of my literature review. Interpretative phenomenological analysis (IPA) was used to gain an in-depth understanding of their lived experience. The main research question was:

> **What is the lived experience of home care workers caring for people with palliative and end of life care needs?**

1.2 My Background

I am a registered nurse with 22 years' experience working in oncology and palliative care settings both in the UK and in Australia. While in Australia, I developed a passion for education and undertook my Masters in Palliative Care before moving into an education and project management role at the Centre for Palliative Care, Melbourne, Australia. This role enabled me to develop my education and research skills with the support of nurse leaders, medical researchers and passionate palliative care professionals. The gift of having time and support to be involved in state-wide projects and hone my education skills was professionally life changing. It altered my view on the world, which resulted in me undertaking the PhD. I now lead the specialist palliative care community services within an independent hospice in Scotland. My role also encompasses education, research, strengthening relationships with other health and social care providers, and representing the hospice on a variety of different steering groups.

1.3 Definitions of palliative and end of life care

There is no agreed single definition of palliative care (Hui et al., 2012). The International Association for Hospice and Palliative Care (IAHPC) defines it as "the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers "(IAHPC, 2018, para. 1). Following the release of the IAHPC definition, the World Health Organization (WHO) updated their definition of palliative care in 2020. The WHO outlined that "palliative care is an approach that improves the quality of life of patients (adults and children) and that of their families who are facing challenges associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychological, social or spiritual." (WHO, 2020, para. 1). Due to the lack of a singular definition, the IAHPC have argued that it has then caused challenges in agreeing what defines palliative care, how palliative care is implemented, the timing of the implementation and who delivers it (IAHPC, 2019). In 2022, the European Association of Palliative Care (EAPC) also revised their definition of palliative. The EAPC completed a Delphi study in an attempt to gain consensus on various standards and norms using online survey rounds across 52 European organisations affiliated with the EAPC (Payne et al., 2022). This study updated research already undertaken in 2009. The definition of palliative care which had an agreement rate of 93% within the study described palliative care as “the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.” (Payne et al., 2022, p.685).

In the IAHPC definition of palliative care, end of life care seems to be an important component that is not as evident in the WHO definition of palliative care. The EAPC defined end of life care as “comprehensive care for dying patients in the last few hours, days or weeks of life” (Payne et al., 2022, p. 685). This ambiguity is also reflected in how individual countries define end of life care and sometimes this differs even in the definitions used by institutions working in those geographical areas. For example, end of life in England has been defined as the last year of life (NHS, 2023). However, the National Institute for Health and Care Excellence (NICE) defined end of life for adults as “adults in the final weeks and months of life, although for people with some conditions, this could be months or years (NICE, 2021, p. 8). In Scotland, the location for this study, the Scottish Government combine palliative care and end of life care definitions without clearly detailing a time period for either: “palliative and end of life care are integral aspects of the care provided by health or social care professionals to people living with and dying from any advanced, progressive and incurable condition" (Scottish Government, 2023). The Scottish Government definition goes on to emphasise that palliative care is not just end of life care but is about ensuring quality of life at every stage of a life-limiting illness from diagnosis. For the purposes of this thesis, I will be using the term end of life care to encompass people receiving care who are thought to be in the last days, weeks and year of life, recognising that this can also be described as palliative care in some published literature.

1.4 Overview of thesis

As part of the thesis, I conducted a literature review using a hermeneutic approach based on a framework by Boell and Cecez-Kecmanovic (2014). The literature review enabled me to explore the experience of home care workers in the wider literature. Areas for further research were identified. My main focus of the thesis is an Interpretative Phenomenological Analysis (IPA) study exploring and understanding the lived experiences of home care workers caring for people with palliative and end of life care needs in the community. Data were collected using semi-structured interviews and analysed using IPA (Smith et al., 2012). The thesis is arranged into six chapters (including the current chapter) followed by references and appendices.

1.4.1 Chapter Two: Background

Chapter two provides relevant background as to why the study is important in relation to what is already known. It also positions the study, relating it to both the current clinical context within community palliative care and government policies and priorities in this area. The home care worker role is introduced with acknowledgement of how essential it is to the delivery of palliative care. Despite this, some of the challenges this workforce face, such as inconsistency in job title, mean they often do not have the opportunity for their voice to be heard.

1.4.2 Chapter Three: Hermeneutic Literature Review

Chapter three is the literature review, entitled ‘The experience of home care workers caring for people with palliative and end of life care needs living at home: a hermeneutic review.’ The literature review enabled me to explore what was known, where there were gaps in knowledge, and areas where further studies would help contribute to the existing knowledge base. Findings from this review assisted me to formulate my research question and my interview topic guide. The review of the literature was also helpful when discussing my research findings in comparison to published literature.

1.4.3 Chapter Four: Methodology

Chapter four outlines the methodology and methods used in the study. The philosophical underpinnings of the study and the methodological choices made as a result are explored. It examines why IPA was selected to investigate this research question. The methods section describes how the study was carried out in terms of design, population, sampling, recruitment, data collection, and data analysis. Relevant ethical considerations related to undertaking the study are also outlined.

1.4.4 Chapter Five: Findings

Chapter five outlines the study findings. Four master themes are presented, demonstrating the depth and richness of the data and subsequent interpretations. The four master themes are “You are really on your own”: Coping with isolation when providing care in the community; “You just treat them, you know, like they're still alive”: The value of ritual for home care workers when caring for the dying and the dead; “I wait and cry most times in the car”: Understanding the impact of grief and bereavement for those delivering care; “These are the rules, no matter how frustrating you just have to follow”: Frustrations with organisational influence and control within community care settings.

1.4.5 Chapter Six: Discussion and Conclusion

Chapter six discusses the key findings of the study in relation to published literature and existing theory. It explores the overarching issue of visibility, which is a thread through all four master themes: coping with isolation, the impact of grief and bereavement, and organisational and sector wide influences. Despite challenges, people dying well remains the key priority for these participants. The significance of the study and the clinical and methodological implications are explored, alongside the study limitations and considerations for future research. The contribution to knowledge that this study has made is also explored. Finally, I offer some personal reflections about undertaking the study and the journey to completion, prior to final conclusions being made.

Chapter Two: Background

2.1 Introduction

In this chapter the background as to why the study is important is explored in relation to existing published literature. The chapter will set the context for the study, with consideration given to the impact of UK government policy on community palliative care and how this influences clinical care. The home care worker's role in delivering end of life care is explored, including the job title variation that exists within this workforce both nationally and internationally. Finally, a consideration of this role within the Scottish context is examined as this is the setting for this study.

2.2 Models of palliative and end of life care

Historically palliative care services were initially focused on caring for people with a cancer diagnosis who were approaching the end of life, rather than being available for anyone requiring palliative care regardless of a cancer diagnosis (Clark, 2007). Over recent decades, significant work was undertaken in developed countries to address this, to try and ensure palliative care is available to anyone who requires it, however inequity still exists (Dalkin et al., 2016; Murray & Sheik, 2008). Across the world the need for palliative care far exceeds its provision (Clark, 2007). The UK, as with many other developed countries, has an ageing population who are living with increasingly higher levels of chronic and long-term health conditions (Gomes & Higginson, 2008). This will continue to significantly impact the demand on not only specialist palliative and end of life care services but broader primary care and community services who support people in their own homes. The question of who is going to deliver this type of care within stretched healthcare systems remains an issue. In the UK, the National Health Service (NHS) has always relied upon independent hospices and charities external to the NHS to provide the majority of palliative care provision (Clark, 2007).

Critically, considering the increasing demand on palliative care services (Etkind et al., 2017), there needs to be consideration around who needs access to specialist palliative care services, and who can be supported by other health and social care professionals who are already caring for people at the end of life. The WHO (2020) suggested that an interdisciplinary approach is required to provide effective palliative care, highlighting that multiple professionals are involved such as allied health professionals, nurses, pharmacists, physicians, and support workers. In addition to the multi-disciplinary team working in palliative care services and hospices, there is also a heavy reliance on volunteers (Bloomer & Walshe, 2020). Considering end of life care can be delivered in a variety of settings, such as care homes, hospices, hospitals, prisons, and in people's own homes, in reality there is a need for a broad range of health and social care professionals in different settings to have skills to enable them to adopt a palliative approach when caring for people living with palliative care needs (Carey et al., 2019; Quill & Abernathy, 2013).

Many developed nations have published government strategies which recognise the importance of having appropriately trained healthcare staff in different settings. For example, in England the Ambitions for Palliative and End of Life Care national framework detailed this in ambition five, aiming for all staff to be prepared to care, setting out that all health and social care staff, regardless of setting, should have the skills and expertise to provide a competent level of care (National Palliative and End of Life Care Partnership, 2021). In Scotland, the Palliative and End of Life Care Strategic Framework for Action included clear acknowledgment that palliative care can be delivered in any setting and that all health and social care staff were required to have an appropriate knowledge and skills in caring for people living with a life limiting illness (Scottish Government, 2015). The framework attempted to provide greater clarity for generalists and specialists into their different roles and responsibilities in delivering end of life care in Scotland (Scottish Government, 2015). Quill and Abernathy (2013) explored the issues of palliative care delivery from a generalist and specialist perspective in the US, concluding that to ensure people can access palliative care when they require it, a care model would need both generalist and specialist elements.

2.3 Delivering end of life care in a community setting

Models of community palliative care can vary but many developed countries rely on general practitioners (GPs) and district nursing services to support people approaching the end of life at home (Goldschmidt et al., 2005; Johansen & Ervik., 2018; Koper et al., 2018), with specialist palliative care services supporting them with more complex patients where these services exist. Critically, these models can work less well in rural areas where there is access to fewer health care professionals (Weng et al., 2022). Extended nursing roles, such as advanced nurse practitioners, were developed in many countries to try to bridge the gap, with nurses who have undertaken additional training working autonomously assessing, diagnosing and prescribing within agreed boundaries (Mitchell et al., 2016). These extended nursing roles were developed due to doctor shortages, as a way of improving timely access to medication for patients, and to ensure nursing skills were maximised to their full potential (Kroezen et al., 2012).

In the UK, as with other developed countries, we have increasing numbers of both nurse practitioners and nurse prescribers working within the community setting (Laurant et al., 2018). The impact these roles have on palliative care can be dependent on how these roles were developed, what working agreements are in place within generalist settings, and whether the vision for the roles was made clear (Kennedy et al., 2015). In primary care these extended nursing roles have resulted in the community nurse moving away from longer term support to focusing on acute episodes of care and the delivery of health promotion (Keleher & Parker., 2013; Kemp et al., 2005; Roden et al., 2016). This shift has altered how much physical care community nursing teams can provide including to those approaching end of life. There was some criticism that this more task focused approach has resulted in the loss of traditional community nursing roles and impacted the quality of care provided (Morris, 2017). As a result of such changes, home care workers are now largely responsible for providing the daily physical care to people approaching the end of life at home (Herber & Johnston, 2012). Home care workers are not qualified nurses but their role is to provide physical care and emotional support with absolutely minimal training to people living in their own home (Lovatt et al., 2015). Arguably as more people choose to die at home, the amount of practical care district nursing teams can provide will continue to reduce.

Published data have shown an increase in home deaths in countries such as Canada, the United Kingdom (UK) and the United States (US) (Shepperd et al., 2021). For a number of years, the focus of UK policy was to enable people to die at home where this was their preference (Marie Curie, 2023). However, hospital remains the most common place of death (Public Health England, 2018). A recent study from Ali et al. (2019) examined the deaths of 2176 patients in the UK who were known to a community palliative care service over a five-year period. Around 73% of people had expressed a preference of where they would like to die. Of the people who wished to die at home, 69% did so. From the participants in the sample, 9.5% changed their preferences throughout the course of their illness. However, people with no documented preference were more likely to die in hospital. van Doorne et al. (2021) found that individuals who had previously been admitted to hospital, who had a long-term condition, or were living alone were more likely to have a preferred place of death recorded. The findings highlighted that many people had not considered their preferred place of death until the idea was introduced to them by a health care professional (van Doorne et al., 2021). This emphasised the need for health professionals across different health care settings to be able to take a palliative approach putting the individual and their family at the centre of their care, and have the ability to have skilled conversations with people around death and dying in order to be able to identify their preferences around care and where they would like to die (Sawatzky et al., 2016). For those who wish to be cared for or die at home then there is a need to revisit this as their illness progresses as preferences can change (Evans et al., 2014).

2.4 Community end of life care in Scotland

Community palliative care models are dependent on the structure of the health service in a particular country. Despite these differences, many issues around the delivery of end of life care in the community can be similar. In Scotland, the government launched its Strategic Framework for Action on Palliative and End of Life Care in December 2015 with the aim of opening up access to palliative care by ensuring anyone who required support could access it. There was also acknowledgement of the significant pressure placed on health and social care services related to an ageing population and increasing numbers of people living with multiple co-morbidities resulting in complex health care needs (Audit Scotland, 2016).

As a way to address this, the Scottish Government implemented health and social care integration in April 2016 with the aim of bringing together health and social care into a single connected system (Scottish Government, 2022). Within the UK, health and social care arrangements differ according to each country, however what is consistent is that people can also self-fund, paying for their own care which can then be tailored to their individual needs. However, many people are reliant on the care provided to them through publicly-funded services and how this is managed is dependent on where an individual is based. For example, in England health and social care remained separate entities with health being the responsibility of the national government and social care sitting with the local authority (Shuttleworth & Nicholson, 2020), until integrated health care systems were formed on the 1st July 2022 with the purpose of bringing health and social care together (NHS England, 2022). Scotland created 31 integration authorities who work with local communities and care providers, with the aim of better meeting the needs of the local communities they serve (Scottish Government, 2023). As part of this, an attempt was made to integrate palliative care services in relation to their planning, designing and commissioning (Scottish Government, 2019). The challenges around this model are where and how the NHS and community services connect effectively, and the degree of partnership working that the integration authorities do with third sector partners (Griesbach, 2019). Moreover, at the time of integration, there was some recognition from the government that improvements in recruitment and retention of the health and social care workforce would be required (Scottish Government, 2017).

Across the country recruitment and retention of staff remains a major challenge especially in social care, which appears to be worsening after the pandemic (Edwards et al., 2022). Government policy continues to support people to die at home. However, caring for people at home can be impacted by issues wider than health and social care, including housing, employment, and financial security for people living with a life-limiting illness and their informal carers (Marie Curie, 2023). Research has highlighted the significant financial burden faced by people who are caring for someone at the end of life and who often struggle to access government income support (Gardiner et al., 2014). Bindley et al. (2020) found the experience of attempting to access welfare was burdensome for carers, with processes inconsistent and at times inequitable. Therefore, ensuring people can access support whether they are being cared for by their primary care team or a specialist palliative care team is crucial.

Variation exists within the literature when examining published studies around what defines a palliative care service and who ultimately provides the care (Bennett et al., 2016). In clinical practice there was acknowledgment that not everyone who is dying requires input from specialist palliative care services (Gardiner et al., 2012). Many specialist palliative care services in Scotland are run by independent hospices, palliative care charities and, in some cases, the health and social care partnerships. Across the UK, including Scotland, generalist palliative care is delivered in the community by general practitioners, primary care teams and home care workers who may access specialist palliative care services for advice and support when required. However, challenges exist within generalist and specialist services partnership working, including difficulties around perceived roles and responsibilities, and for generalist services how the demands associated with caring for someone approaching the end of life can be integrated into their existing workloads (Gott et al., 2012).   The delivery of physical care at the end of life, regardless of whether specialist or generalist services are leading the care, often sits with home care workers as they are the workforce who delivers hands-on care to people in the community who are approaching the end of life.

2.5 Home Care Worker Role

Herber and Johnston (2013) conducted a systematic review of the literature which focused on the role of the home care worker in the provision of palliative and end of life care in the community. Their findings suggested that the provision of personal care, emotional and social support, and enabling family carers to have periods of respite were all central components of the home care worker role. Role clarity was highlighted in the review as an issue, with home care workers assisting with domestic tasks despite it not being part of their role. Herber and Johnston (2013) positioned the home care worker role between that of a professional role and that of an informal carer, which appeared to hint at some of the potential difficulties in how and where the role relates to the wider multi-disciplinary team. They highlighted that collaboration and communication could be more challenging as a result. This review, like others (D’astous et al., 2019; Devlin &McIlfatrick, 2009), mentioned the issue of inadequate training, resulting in home care workers’ being unprepared for the role. Tsui et al. (2020) completed a scoping review which focused on attempting to identify published studies which explored what training options were available to reduce home care aides’ work related stress. Findings suggested most training programmes targeted broader health care audiences.

Devlin and McIlfatrick (2010) examined the role of the home care worker in the provision of palliative and end of life care in the community in the UK. Within their sample of 69 participants, the main reason home care workers selected this career pathway was simply they wanted to care for people. Findings also suggested that after personal care, they viewed talking and listening to the individuals they were caring for or their family as the main aspect of their role. In the community, this emotional support can be crucial for families and friends to feel able to support people with a life limiting illness at home. Herber and Johnston (2013) highlighted in their review that the emotional support provided by home care workers was thought to be more ad-hoc. Arguably emotional support at moments of crisis could prevent an unnecessary admission to hospital for someone who is at the end of life. Further exploration of a home care workers' role could increase understanding of the impact of this type of support. The home care worker is an established role in many developed countries, providing both physical care and emotional support to people in the community and is a crucial part of the health and social care team.

Fleming and Taylor (2006) highlighted that, despite this workforce being essential to delivering community palliative care, working hours, low pay, and workload issues result in difficulty retaining staff in these roles. They surveyed 45 home care workers in Northern Ireland and their survey findings suggested that home care workers could feel more supported to remain in their role if staffing levels improved, if they had access to increased support out of hours, and if they were allowed to feel more included within the wider health care team. Studies which have examined care workers across different care settings have suggested altruistic motivation, gendered social norms and their sense of fulfilment in the type of work undertaken as reasons why job satisfaction remains high regardless of poor pay and conditions (Hebson et al., 2015). Studies which include home care workers have identified that this is a largely female workforce. Palmer and Eveline (2012) linked the notion of altruistic motivation and gender in their article focusing on the Australian aged care sector, highlighting that organisations have a role in upholding a narrative that care work is unskilled and aligned to women and as a result not deserving of higher pay. Indeed, it was argued that through using the term 'care' it orientates it to being 'love-centred' as opposed to 'money-centred' despite organisations often aiming for high quality care provision (Palmer & Eveline, 2012, p.254).

The influence of organisations can be seen in Atkinson and Lucas (2013) study, which examined human resource practices and worker responses within the adult social care sector in England. Their findings highlighted attempts to normalise low pay and financial insecurity by relating this to social norms within the care sector. This workforce was perceived as largely female and poorly educated who valued job security, flexibility and opportunities for training above financial gains. For the home care worker this highlights how employers can influence them in regards to their need for job security and attachment to the role, to encourage them to set aside issues related to financial security (Hebson et al., 2015). Looking more broadly at studies which have examined group identity and organisational theory, Lammers et al. (2013) found that a group of workers' professional identities is fostered from an activity, for example caring, as opposed to their identity being defined by the group or organisation. Their findings suggest that it is the attachment to the activity, for instance caring, which can create a 'sense of accomplishment' for the home care worker where the value is placed on the activity rather than how they identify with the organisation (Lammers et al., 2013). Therefore, if organisations employing home care workers emphasise the value of caring, this enhances the home care worker's identity in their role encouraging productivity without focusing on their working conditions such as poor pay and long hours, which could be perceived as exploitative.

2.5.1 Job title variation

Across organisations home care workers have different job titles, therefore challenges do exist in identifying this workforce. Variation in job titles have occurred as different organisations and different countries have opted for differing job titles despite roles often being very similar. A scoping literature review identified that multiple job titles existed which described this group of workers (Devlin & McIlfatrick, 2010; Herber & Johnston, 2013). However, despite variation in job title, the role of home care workers is consistent; that is part of their role is to support people with palliative and end-of-life care needs in the community through the provision of personal care and emotional support. Some of the job titles noted in the literature included assistant nurses; health care assistants; health care workers; healthcare support workers; health and social care staff; home care workers; home health aides; home care workers; nursing aides; nursing assistants (D'Astous, et al., 2019; Devlin & McIlfatrick, 2010; Herber & Johnston, 2013; Jansen et al., 2017). This will be explored further as part of the literature review in Chapter 3, section 3.3.1 in relation to published studies. ‘Home care workers’ is the term used by UNISON Scotland, the trade union which represents the workforce and also Scottish Care, a membership organisation and the representative body for independent social care services in Scotland. Therefore, for the purposes of this study the term ‘home care worker’ will be used to describe this workforce.

2.6 Home Care Workers in the Scottish context

In Scotland, the Scottish Government created the Scottish Social Services Council (SSSC) to regulate the social service workforce in 2001. It was not until 2017 that all home care workers had to be registered with the SSSC and hold or be working towards a relevant qualification such as a Scottish Vocational Qualification SVQ in social services and healthcare (SCQF Level 6 which is the equivalent to a ‘Skills for work higher’). Commonly SVQs related to health and social care are delivered by colleges in Scotland and involve attending study days or online lectures, and working towards completing a portfolio of evidence to demonstrate knowledge and understanding of relevant theory, principles and practices (Glasgow Clyde College, 2023). The SSSC set standards for their practice through their codes of practice document, setting a national standard for both conduct and clinical practice (SSSC, 2020). Employers also have legal responsibilities to ensure anyone they appoint is registered with the SSSC or is registered within six months of employment. Employers have the responsibility to support their home care workers with adequate access to post registration training and learning opportunities (SSSC, 2020), although how this occurs in practice is unclear and is not monitored in terms of how the training is delivered. Research has highlighted that in other countries with no mandatory registration process in place, such as England and Ireland, a large proportion of home care workers do not hold formal training qualifications (Devlin & McIlfatrick, 2010; Fleming & Taylor, 2006).

NHS Education for Scotland (NES) and the SSSC released the Palliative and End of Life Care Education Framework in 2017 (NES, 2017). The purpose of the framework was to enable a consistent approach to identifying the level of knowledge and skills required by staff who are involved in caring for people with palliative and end-of-life care needs (NES, 2017). It was intended to be used by individuals, service providers and at an organisational level. The framework was advisory with no formal training opportunities attached to it. Palliative care training for home care workers is not mandatory and it is unclear whether the framework is actively used in any clinical settings. As part of the home care worker registration they are required to complete a set number of hours of continuous professional learning (SSSC, 2023). However, it is currently unknown what time if any is dedicated to education with a palliative or end-of-life care focus.

2.6.1 Home care workforce in Scotland

The Scottish Government (2022) published figures about the adult social care workforce in Scotland in 2020, which highlighted 80% of adult social care staff were female, with 74,870 individuals employed in care at home services or housing support. Unfortunately, there is no specific figure for care at home services. Voluntary organisations employed 34,910 workers, which was then followed by the private sector (*N* = 20,280) and finally the public sector (*N* = 19,680). The median age range for the workforce was 46 years old. Ethnicity and Disability data collected were incomplete. The SSSC Workforce Skills Report (2021) highlighted that 48% of adult social care workers did not hold the required qualifications or were working towards a qualification. Moreover, the least qualified group of workers fell into the care at home/housing support category which also has the highest level of vacancy. In 2021, The Independent Review of Social Care in Scotland (2021) highlighted that workers employed in this sector remain undervalued and poorly paid. Despite the Scottish

Government providing additional funding to ensure people are paid the living wage, these uplifts in pay are accessed through local government contracts, therefore this relies on care providers accepting changes to their contracts to access additional funding (Scottish Government, 2022). Despite making steps forward in recent years in attempting to register this workforce, to describe accurately who they are and to try and improve their conditions at a policy level, significant challenges remain for them as a collective and for them as individuals working in these roles currently.

Given the climate in which they are working, I was aware from the outset that home care workers who wanted to be interviewed may have an existing interest in caring for people approaching the end of life, and may not be entirely representative of the entire home care worker population. The participants who sought to take part in the study worked a variety of shifts, including night shifts, which meant they had longer periods with the individuals and the families for whom they were caring. It is important to recognise that not every home care worker may be as supportive or positive about caring for people approaching the end of life. However, exploring the home care worker's individual experiences could assist us in considering how we support home care workers to be aspirational in this area.

2.7 Conclusion

In summary, palliative care should be available to anyone who needs it but, as the need for palliative care increases, the challenge as to who should provide this care intensifies. Specialist palliative care services are unable to care for everyone, so focus their efforts on people living with the most complex issues. In developed countries there is an expectation that a range of health and social care professionals should have some basic knowledge on how to care for people approaching the end of life in their own care setting. In the UK, as in other developed countries, the model of palliative care depends on having both specialist and generalist services involved. In the community delivering end-of-life care relies on GPs, district nursing services and home care workers who can be supported by a specialist palliative care service depending on their geographical location. In Scotland, who provides this specialist support varies depending on geographical location with independent hospices, palliative care charities and health and social care integration boards all providing palliative care services in different parts of the country. Challenges exist in navigating effective partnership working between generalist and palliative care services.

In primary care, extended nursing roles and a population of people living at home with increasing complex needs has shifted the district nursing role to become more task focused, leaving the delivery of regular physical care for people approaching end of life to the home care workers. Home care workers can provide vital physical care and emotional support for people and their families approaching end of life. The impact of their role within the multi-disciplinary team has not been fully explored. Despite the system relying on this population of workers to deliver hands on care, poor pay, long working hours and workload issues make it difficult to attract and keep people in these roles. This largely female workforce has reported high job satisfaction despite these financial challenges, which were linked to both altruistic motivations and associated with gender social norms. Through aligning care work as a vocation, organisations can foster this notion and influence how home care workers identify themselves, placing value on the act of caring rather than what they are paid or the broader benefits they receive.

As a way of regulating this workforce in Scotland the Scottish Social Services Council was established which now also maintains a mandatory professional register for this workforce. Education is key component of this registration, with requirements for the home care worker and their employers around access to continued professional learning. However, it is unclear if as part of their role they could access palliative care training, and who would provide this training. Despite this national registration there continues to be variation in job titles regardless of their roles being very similar. For the purposes of this study, the term home care worker was used to describe this workforce. As home care workers underpin both generalist and specialist palliative care delivery in the community and this is only set to increase, it is essential to explore their experiences of caring for people approaching end of life at home. In Chapter 3, published studies on home care workers' experiences in caring for people at end of life in the community are systematically reviewed.

Chapter Three: Review of the Literature

3.1 Focus of the review

In this chapter, a hermeneutic review is presented exploring the experience of home care workers caring for people approaching the end of life at home. The results of previous published systematic reviews which have focused on this area were explored in the Background Chapter (Chapter 2, section 2.5). The published reviews differ from this hermeneutic review in a number of ways. D'Astous et al.'s (2019) systematic review focused only on people living with dementia. Therefore, the range of included studies differ significantly, with only three studies being included as part of each review. D'Astous et al. (2009) also included quantitative and systematic reviews as part of their included studies, which differs from the qualitative focus of this review.

Herber and Johnston's (2013) systematic literature review focused on the role of the home care worker including what tasks the workers carried out when caring for people at end of life; they also attempted to explore the challenges and supporting influences that impacted their role. The review included both quantitative and qualitative studies published between 1990 and 2011, and studies which were carried out in nursing homes and the community, therefore only one study is included across both reviews. My hermeneutic review focuses entirely on home care workers caring for people in the community. Devlin and McIlfatrick (2009) conducted a literature review also focusing on the role of the home care worker in delivering palliative and end of life care in the community, however their search was limited to studies published between 2004 and 2009. As a result, only two studies were included in both reviews.

Fee et al.'s (2020) scoping review focused on the role and responsibilities of home care workers in out-of-hours' community palliative care. As their focus was out-of-hours this meant studies were included which focused on out-of-hours teams which may have included a home care worker as part of that team and also included studies undertaken with hospice teams. Due to these differences only one study was included across both reviews. Tsui et al (2020) published a scoping review focusing on training needs of home care workers following the death of an individual they were caring for. Six studies were included in the review which included both quantitative and mixed methods studies. Therefore, only one of those studies were included in both reviews. Training may be an important issue for this workforce, but the hermeneutic review aimed to have a broader focus to attempt to understand what has been published that explores the home care worker's experiences within the role.

This hermeneutic review aimed to explore the subjective experience of home care workers in the context of caring for people approaching the end of their life in the community. This review takes a different approach as it uses Boell and Cecez-Kecmanovic's (2014) hermeneutic framework for conducting a literature review and incorporates a more systematic mapping of the search strategy. Boell and Cecez-Kecmanovic (2010) argued that a more traditional systematic review could be systematic but could not claim to be a complete picture of the literature, due to issues around variability in databases as well as the seemingly unachievable task of including all synonyms. They argued that this often resulted in a low precision search where only some of the articles are relevant. Instead the hermeneutic approach focuses on the re-interpretation of included papers which may then increase a reader's understanding of the broader topic area, without claiming that this understanding is complete (Boell & Cecez-Kecmanovic, 2010). With these limitations in mind, and also acknowledging the sparsity of literature reviews in this area and indeed research focusing on this particular workforce, I believed it important to outline the search strategy taken prior to using the hermeneutic framework to deepen my understanding of included literature. Through searching, analysing, and interpreting individual studies, as the number of studies expand then the researcher's perspective may also alter, enabling them to go back and engage with individual studies differently. This iterative process is based on the hermeneutic circle. The review synthesises themes found in qualitative studies which focus on or include home care workers caring for people with end of life care needs at home as part of their sample, using the approach and structure of Boell and Cecez-Kecmanovic's (2014) hermeneutic framework. The literature review findings provided a base of knowledge for the thesis and were also used in the discussion chapter to compare against the empirical findings of this study.

3.2 Methods

Through critically assessing existing knowledge, and identifying where the phenomena could be greater understood, literature reviews can not only challenge what is known but also identify areas that require research or areas where the strength of evidence could be challenged (Boell & Cecez-Kecmanovic, 2014). Literature reviews play a key part in demonstrating a cohesive summary of what is known about a particular research topic in context, while informing the methodological direction of future research and minimises the risk of duplicating studies that have already been undertaken (Maggio et al., 2016). However, there are a number of ways in which literature reviews can be done. Khoo et al. (2011) examined published literature reviews and recognised that they fall in a continuum between descriptive and integrative, with most having elements of both. Descriptive reviews spend time describing individual studies and their findings, compared to integrative reviews where the emphasis is on synthesising a summary of key trends and milestones across the entire body of work. There is criticism of descriptive reviews. Thorne (2017) argued for the need to be clear on the type of knowledge that qualitative evidence synthesis yields. Implying that the description and the aggregation of findings alone is insufficient, instead there is a need for greater interpretation to expand on the understanding from study findings. However, synthesis can be used to demonstrate to the reader what was uncovered and allow them to follow the researchers' thinking and decision making. More importantly, it also enables readers to form their own view of the information that was presented (Green et al., 2006).

Hermeneutics was described as the theory of interpretation (Smith et al., 2012). The hermeneutic circle is a central idea in hermeneutic theory and focuses on "the dynamic relationship between the part and the whole" (Smith et al., 2012, p.28). A hermeneutic approach to reviewing literature is based on the idea that understanding the individual text can increase understanding of the wider context but also a deeper understanding of the wider context can increase understanding of the individual text. Boell and Cecez-Kecmanovic's (2014) conceptual models are based on the hermeneutic circle, enabling the researcher to deepen their understanding of a particular area of interest, whilst acknowledging that new and emerging theory will continue to be unearthed. The knowledge and understanding gained very much depends on the individual's viewpoint or horizon (Boell & Cecez-Kecmanovic, 2014).

The Hermeneutic Framework for literature reviews is shown as two intertwined circles, one outlining the search and acquisition process, and the second outlining the analysis and interpretation process (Boell & Cecez-Kecmanovic, 2014). This is replicated below in Figure 3.2. By identifying the phenomenon of interest or review question the search and acquisition cycle can commence. The smaller '**Search and Acquisition**' circle outlines seven clear processes – searching; sorting; selecting; acquiring; reading; identifying and retaining. Linked into this is the larger '**Analysis and Interpretation**' circle which contains four steps, mapping and classifying; critical assessment; argument development and research problems. Both cycles in the process require balance, "overemphasizing the searching for literature will lead to increasing confusion, while overemphasizing the literature analysis and interpretation at the expense of searching will lead to ignorance" (Boell & Cecez-Kecmanovic, 2014, p.264). By undertaking the hermeneutic approach in this way, the researcher has to remain reflective, and consider when to stop which can be guided by the reducing amount of new findings that they uncover.

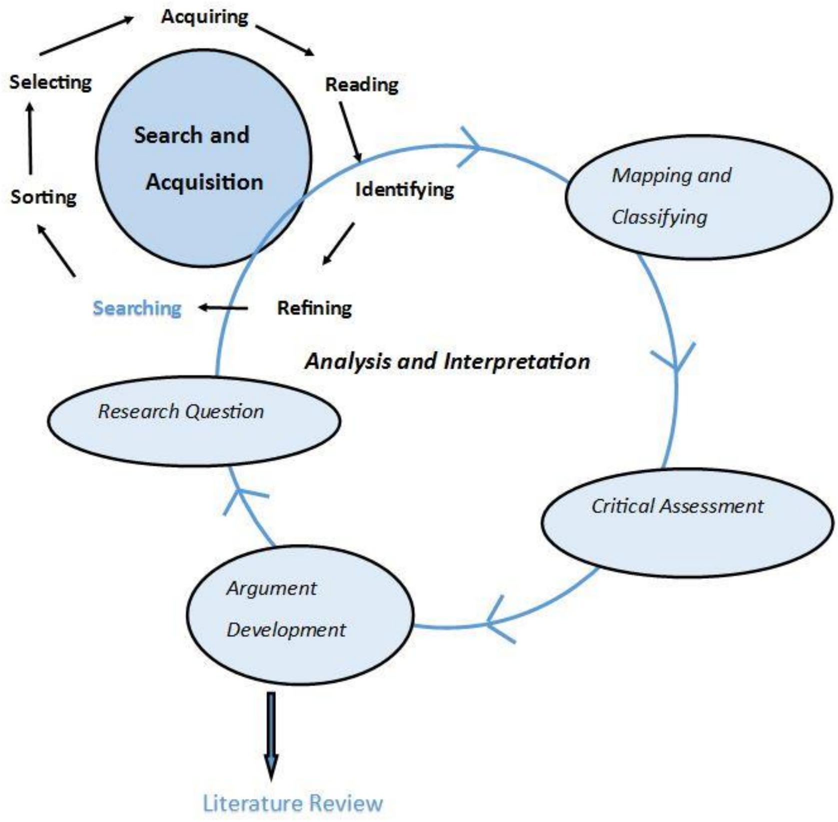

Figure 3.2 Hermeneutic framework (adapted from Boell & Cecez-Kecmanovic, 2014)

This literature review incorporated a hermeneutic approach, it does not purely describe the knowledge that was gained through published studies focusing on a specific phenomenon, and it is not a complete summary of everything that was published on that topic (Smythe & Spence, 2012). Instead, it stimulates thinking (Chester et al., 2020), enabling me to delve into the experiences of home care workers' caring for people at the end of life, and attempting to gain a deeper understanding of that experience through examining published studies. A hermeneutic approach is also congruent with my primary research methodology.

3.2.1 Review Question

The review question was:

What are the experiences of home care workers caring for people with palliative and end-of-life care needs living at home?

The initial search and systematic review were undertaken in 2018 which informed the study specifically the methodology and data collection. This was then updated in 2023 to ensure it was current which informed my entire thesis and used to gain greater understanding of my study findings.

3.3 Search and Acquisition

3.3.1 Searching

In September 2018 the following databases were searched CINAHL (nursing), PuBMeD and MEDLINE (Biomedicine, Health, Life and Behavioural Science), Social Care Online and Social Services Abstracts. The search was then updated in September 2023. These databases were selected to ensure both health and social care studies were captured that could include relevant data on home care workers experience of caring for people approaching the end of life in their own home. The purpose of the search strategy was not to be exhaustive but to be comprehensive. That is to enable an in depth exploration of studies relating to home care worker experience in caring for people approaching their end of life. Subject heading terms were used where available. Boolean Operators were used to focus the linked search terms and increase the likelihood of locating relevant published research; these are outlined in Table 3.3.1. Due to the limited amount of data published, conducting a forward and backward citation search of relevant articles was necessary.

The search acronym Population, Issue, Context and Outcome (PICo) (Fineout-Overholt & Johnston, 2005) was used to structure the search terms for the review and is outlined below in Table 3.3.1. This approach assisted in clearly defining the scope of the search. The PICo Framework was selected as it best fitted the qualitative nature of the question. The PICo Framework was selected as it is included within the National Institute for Health and Care Excellence (NICE) tools and resources, and it is suggested as an appropriate framework when developing evidence reviews seeking information around experience (NICE, 2018). The PICo framework also related to the hermeneutic approach taken within the literature review. It was intended that the experiences of home care workers were the main focus of enquiry, and that the content of studies were adequate to explore this in depth, all within the particular context of community care. It should be noted that there is no single framework that exists that allows for complete sensitivity when using a framework to structure a search strategy (Booth et al., 2016; Methley et al., 2014).

Discussion with a specialist librarian helped inform search terms, alongside a recommendation to examine job titles and roles for home care workers from published literature to ensure these were appropriately captured. The term home care worker is discussed in greater depth in section 3.

Table 3.3.1 Search Terms Used including Boolean Operators

Population	Health and Social Care Personnel	Healthcare support workers OR Adult social care workers OR Social care practitioners OR Social care staff OR Social care OR Support workers OR Council staff OR Council workers OR Health care assistants OR Nursing assistants OR Nursing associates OR Home Care Workers OR Community Health Workers
		AND
Issue	Identification of Palliative Care	Palliative care OR Palliative approach OR Palliative OR Terminal Care OR Terminally Ill patients OR Terminal OR End of Life OR Supportive care OR Continuing care OR Care of the dying OR Dying OR Death OR life limiting OR hospice
		AND

Context	Location of Care	Community OR Home OR Home care OR Primary care
		AND
Outcome	Experience	Experience OR Support OR Needs OR Education OR Training OR Health Personnel Attitudes OR Attitude OR Perception OR View OR Belief OR emotion

3.3.2 Sorting and Selecting

Only studies that met the inclusion criteria were included within the review. The inclusion and exclusion criteria are outlined below in Table 3.3.2

Table 3.3.2 Inclusion and Exclusion Criteria

Inclusion	Exclusion
Studies that have been reported in the English language	Studies which have not been reported in the English language
Studies which included home care workers as part of their sample.	Studies which focused on health and social care workers employed in care homes, nursing homes and other in-patient settings or did not include home care workers as part of their sample.
Qualitative Studies or Mixed Methods studies describing the experience of home care workers caring for people living with end of life care needs at home, even if the topic is not the main focus of the study.	Quantitative studies were not included as the focus is on the lived experience of home care workers caring for people at end of life. Grey literature including articles published consisting of expert opinion or commentary only,

	editorials, newspaper and magazine articles, and theoretical papers were also excluded.
Studies published from 2003 to 2023 were included.	Studies published prior to 2003.

Only studies that were reported in English were included. As I was attempting to gain some understanding about the home care workers' experience of caring for people with end of life care needs, it was essential that included texts had home care workers in their sample. Studies which had samples consisting entirely of home care workers, and studies which included home care workers as part of their sample where results could be clearly attributed to them, were included. Studies which focused on health and social care workers employed in care homes, nursing homes and other in-patient settings were excluded, as they were working in a different care setting and as part of a team. As my focus was on studies that explored the experiences of home care workers when caring for people approaching end of life, qualitative studies and qualitative data from mixed methods studies which illuminated their experience were included.

The search was limited to studies published since 2003. Studies undertaken over the last two decades are more reflective of the current home care worker role and the evolving health and social care sectors in which they work. Examining studies that are more contemporary ensures those which are included have some relevance to the current home care worker role and their experiences of caring for people approaching the end of life. The role that these workers had prior to 2003 has changed significantly in developed countries due to changes in national policies which resulted in structural changes in the primary care system between 1983 and 2003. Such changes occurred across a number of developed countries including Denmark, Finland, Italy, Norway, Spain, Sweden, and the UK (Macinko et al., 2003). Primary health care reform in Canada and the UK resulted in a change of focus to delivering more care in the community, with increased use of multidisciplinary primary health care teams with changes to how services were commissioned and their governance structure (Campbell et al., 2010). This also resulted in significant change in health care roles. In Scotland for example the Community Care and Health (Scotland) Act 2002 saw local authorities moving away from home helps to instead focus on free personal care at home and increasing wider support services to ensure people could remain at home. Due to these international and national sector changes research published prior to 2003 was not included.

3.3.3 Acquiring

Quality Appraisal

There is some debate around what the best approach is for quality assessment of qualitative research (Booth et al., 2016; Carroll & Booth, 2015; Hannes & Macaitis, 2012), with no one tool being singled out as optimal. Hawker et al.,'s (2002) critical appraisal tool was chosen as it had been developed and validated (content) to be used across all research designs, and is used widely in palliative care reviews (Crowe & Sheppard, 2011).

Hawker et al‘s (2002) critical appraisal tool has nine elements to score against. These cover the abstract/title; introduction and aims; method and data; sampling; data analysis; ethics and bias; results; transferability; and implications and usefulness. Scoring ranges from very poor (1) to good (4) for each section, therefore a total quality score for an individual study can range between very poor (9) to good (36). The tool was used to assess the quality of each study included within the review (Appendix 3.3.3a). Following completion of the appraisal tool by the reviewer, an overall score was given. An example of a completed quality appraisal tool on an included study is provided in Appendix 3.3.3b. No studies were excluded from the review on the basis of quality, due to the limited amount of published data available in this area. However, the quality score highlights the assessed methodological rigor of the study.

The quality scores from the twenty-four studies ranged from 19 to 34, and are included within the data extraction table (Appendix 3.4). The majority of quality scores were in the mid to high twenties, with only six papers scoring below 25. Despite the scores providing an indication of quality and aiding the critical appraisal process, the scores are subjective. It is also argued that critical appraisal tools can lack the depth required to truly determine the quality of the study (Crowe & Sheppard, 2011). They also do not take into account the various ways in which studies can be reported and written up for publication (Crowe & Sheppard, 2011).

3.3.4 Reading, Identifying and Retaining

The screening of studies, the quality appraisal of included studies and data extraction was undertaken by one reviewer, in line with the hermeneutic approach taken. This meant that all reading and subsequent interpretation was carried out from a single perspective. The data extraction tool (Appendix 3.3.4) had six categories which included the author(s) alongside the year and country of publication, the quality score, and the research question the researchers were attempting to answer. It allowed a way to examine the population studied including job title of the home care worker and setting the research took place in. The key findings of each study were documented that were relevant to the research question. These findings informed the analysis and interpretation phase of the review, and allowed me to develop themes. Finally, any implications for practice made by the researchers were recorded, to assist in identifying further gaps in the literature.

Data synthesis

A hermeneutic approach to data synthesis was taken following Boell & Cecez-Kecmanovic (2014) hermeneutic model of analysis and interpretation. Firstly, critical reading of all included studies was carried out. Described as '**analytic reading**' this enabled me to gain a fuller understanding of the fundamental findings, the methodology used and what interpretations or assumptions had been made, if any, across the studies (Boell & Cecez-Kecmanovic, 2014, p.265). Secondly, **Mapping and Classification** which is a “distinct activity in the analysis and interpretation hermeneutic circle which provides a systematic analysis and classification of relevant findings” (Boell & Cecez-Kecmanovic, 2014, p. 265). Mapping and classification aided analysis of not only connections and disconnections within the body of literature, but also highlighted potential gaps in knowledge. This was then followed by **Critical assessment**, examining the literature through a broader lens and exploring what type of knowledge was generated, how helpful the type of knowledge is in relation to the review question and where the current limits of knowledge are relevant to that particular body of literature (Boell & Cecez-Kecmanovic, 2014). By highlighting the limits of this knowledge, it then can challenge people to consider what more needs to be understood.

As this process is cyclical, it enabled me to consider more than just the study findings. Consideration of studies following deeper reading and engagement with how meaning had been expressed, followed by stepping back and considering it as part of a body of knowledge, provided me with different insight. Acknowledging and remaining aware that I was conducting this process as an experienced community palliative care nurse was important to keep a check on my own assumptions and how they were influencing my interpretations. This self-awareness was important if I was going to engage with the literature as openly as I could to broaden my view of what was known. The context for me was especially important in relation to the workforce where the experience of community-based working is unique. Therefore, understanding the studies in relation to time, place and culture was essential (Smythe & Spence, 2012). Smythe and Spence (2012, p. 23) noted that “*Literature acts as a dialogical partner to promote thinking*” and through using a hermeneutic method I was able to engage with the literature and view it differently, gaining knowledge in an enriching way.

3.4 Mapping and Classifying - Results

The search resulted in 16525 studies, with an additional fourteen studies found in citation searching of key articles. Following the removal of duplicates, 14061 studies were screened against the inclusion/exclusion criteria. 13588 studies were removed based on the title demonstrating that the study did not meet the inclusion criteria, leaving 473 studies to proceed to abstract screening. Following examination of each abstract, 48 papers were then read in full and assessed against the inclusion/exclusion criteria. 24 studies met the inclusion/exclusion criteria and were included in the review. Data from the 24 included studies were extracted onto the data extraction table (Appendix 3.4). Studies were excluded for a variety of reasons such as issues around the care setting with only workers from residential care included; community health professionals included within the sample but no home care workers; health care assistants from inpatient settings included within the study alongside health and social care professionals such as community nurses, social workers and so forth based in the community but no home care workers; variation from what the study aimed to examine which included home care workers to what was achieved and published; and quantitative studies which provided no insight into the lived experience of home care workers caring for people approaching the end of life. The PRISMA Flow Diagram for this review is detailed in Figure 3.4. As there were limited studies that focused exclusively on home care workers, if the workforce was included as part of the sample, and the study was relevant for the review question then these data were included.

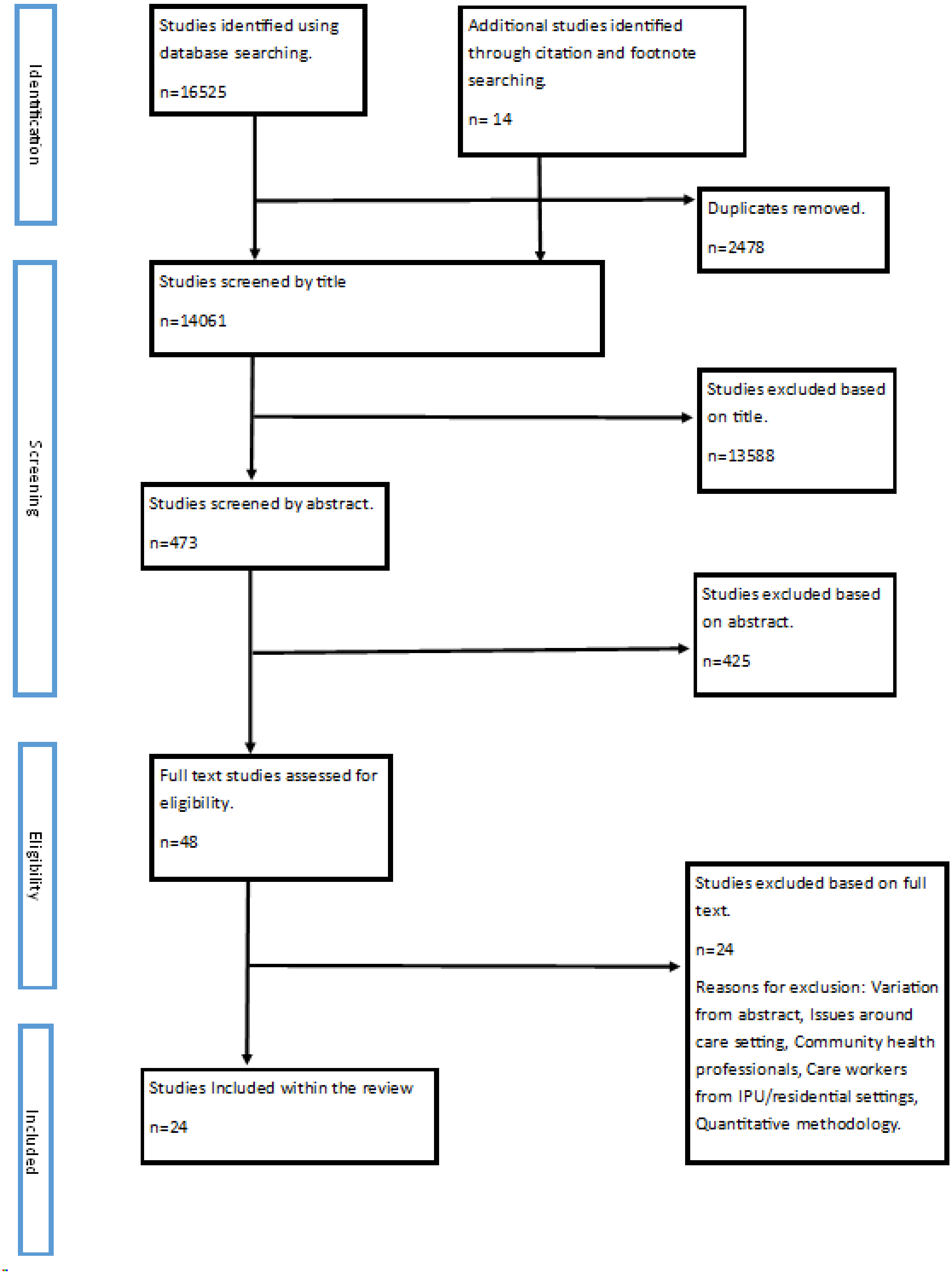

Figure 3.4 PRISMA Flow Diagram

3.4.1 Overview of the findings

Of the twenty-four studies included within the review, nine studies were conducted in the USA, eight studies in the UK, three studies from Canada and the remainder were from Australia, Japan, and South Africa. The included studies had taken a mixed methods (*n* = 15) or qualitative (*n* = 7) approach. The remaining two studies used a secondary data analysis from data taken from the 2007 National Home and Hospice Care Survey in the USA.

The way in which participants were described in terms of their job title within the studies varied, these are outlined below in Table 3.4.1. There was little consistency even when the studies were conducted in the same country; the greatest consistency came from US studies where the term Home Health Aides was used in six out of the eleven US studies.

Table 3.4.1 Variation in job titles of included studies

Job Title	**Author**	**Country**
Community Care Workers	Poulos et al., (2018)	Australia
Community Health Workers	Campbell & Baernholdt, (2016)	South Africa
Community Support Team	Noble et al., (2015)	UK
Direct Care Workers	Kemper et al., (2008)	USA
Generic Care Workers	Holme & Hart, (2007)	UK
Health Care Assistants	Lovatt et al., (2015) Pesut et al., (2015)	UK Canada
Head Care Workers	Fujita et al., (2019) Fukui et al., (2019)	Japan Japan
Home Care Workers	Baik et al., (2021) Devlin & McIlfatrick, (2010) Manson et al., (2020)	USA UK UK

	Sims-Gould et al., (2013) Yeh et al., (2019)	Canada England
Home Health Aides	Bercovitz et al., (2011) Boerner et al., (2015) Boerner et al., (2016) Boerner et al., (2017) Gleason et al., (2016) Riesenbeck et al., (2015)	USA USA USA USA USA USA
Nursing Assistants	Reimer-Kirkham et al., (2016)	Canada
Personal Assistant Workers	Butler et al., (2010)	USA
Personal Care Assistants	Ingleton et al., (2011)	UK
Support Workers	O'Sullivan & Harding, (2017)	UK

The research question or aim of the studies were outlined in the Data Extraction Table (Appendix 3.4). In summary, seven studies examined or partly examined the role and experience of home care workers. One study examined how to implement a palliative approach. Three studies focused on their experience of grief in caring for people living with a terminal illness and how prepared the home care worker felt when the patient died. One study took a slightly different approach and focused on the emotional labour of direct care workers, which included home care workers who were caring for people in the community with palliative care needs. One study as part of their aim, explored community nurse's perception of the home care workers' role when supporting them to deliver palliative and end of life care in the community.

Seven studies considered the learning and training needs of this workforce. Six evaluated a palliative care training intervention. The remaining study as part of its aim included examining the training, support and supervision needs of home care workers across two integrated NHS trusts. Two studies were service evaluations, one from Australia, which evaluated a new palliative home care support program and the second evaluating a specialist palliative care service in the United Kingdom.

Three studies considered the demographics of home care workers who provide palliative and end of life care as part of their role. A further three studies considered management and employment factors of home care workers in some depth. One study considered these factors from the perspective of a home care worker and questioned if specific restrictive policies were linked to their level of job satisfaction.

3.4.2 Methodological Considerations

Mixed methods methodology (*n* = 15) was the most common design used within the included studies. The qualitative studies (*n* = 7) and the qualitative components of the mixed methods studies used interviews, group interviews and focus groups to collect data. Secondary data analysis (n=2) included in the review used surveys conducted over the telephone as methods of data collection. The surveys used were mostly cross-sectional, where the research team collected data from the relevant population at one-time point (Bowling, 2014). However, Butler et al. (2010) used a longitudinal approach and collected data across two time points. As this study examined staff turnover it was appropriate, as the longitudinal approach is used commonly to study trends in behaviour or attitude over time (Bowling, 2014). For the purposes of this review, I only included the qualitative elements of the studies.

3.5 Critical Assessment of the literature – developing themes

Following the hermeneutic approach, it was important to consider how each study added meaning to our knowledge in relation to home care workers' experience of caring for people with end of life care needs in the community. This sense of whether it added meaning or not was an important prompting question, which had been used effectively in other hermeneutic reviews (Greenhalgh et al., 2017). I read and re-read included studies and began to identify and refine ideas and findings as I considered each study individually and then as part of a larger body of knowledge. The data extraction tool enabled me to summarise key findings and any relevant themes that emerged from further interpretation. Following this process, findings fell under four broad headings. The matrices below were designed to provide a visual demonstration of some of the connections and disconnections across the literature, alongside the detail found in the text.

3.5.1 Feeling paralysed – Female labour and financial vulnerability

'Feeling paralysed – Female labour and financial vulnerability' refers to sector wide factors which seem to impact the home care workers' broader working environment and their limited ability to influence change. The impact of what is known around the financial vulnerability of home care workers and how this largely female workforce has been unable to negotiate better conditions is considered. Table 3.5.1 provides a visual aid as to where the connections across the literature were.

Table 3.5.1 Matrix of themes identified in analysis of published findings: Feeling Paralysed - Female Labour and Financial Vulnerability

Themes		**Bercovitz et al (2011)**	**Butler et al (2010)**	**Kemper et al (2008)**	**Boerner et al (2015)**	**Boerner et al (2016)**	**Boerner et al (2017)**	**Gleason et al (2016)**	**Riesenbeck et al (2015)**
	Low Income	*	*	*					
Financial Burden	Lack of employment benefits		*	*					
	Inconsistent working hours		*						
Workforce	Largely female workforce	*			*	*	*	*	*
	Minority background				*		*		

Firstly, financial vulnerability was experienced across the sector for people choosing to work in these roles. These financial risk factors were not only related to low salary but also the lack of employment benefits for workers in these roles. Issues such as a lack of travel allowance despite relying on their own means of transport to carry out the role, and a lack of health insurance for those workers employed in developed nations such as the US created further financial instability (Butler et al., 2010). Inconsistent working hours with contracts either on an as and when required or part time basis were common, resulting in the home care worker risking receiving no income at all when no work was offered (Butler et al., 2010). Interpreting this further, there is a risk that the home care worker would be disempowered to influence financial change as the financial picture across the sector appears similar. There would be limited options to increase financial resources whilst remaining in the home care worker role. Butler et al (2010) found that financial instability contributed to high levels of staff turnover. Financial factors could in turn make it increasingly difficult to attract people into this workforce, despite it being vital to the delivery of care in the community. All three studies that explicitly discussed this were conducted in the United States, so further knowledge around how these financial factors influence the home care worker in other parts of the world is needed. From the findings, financial vulnerability not only disempowers home care workers as individuals, but the financial limitations of the role and the lack of alternatives can mean they feel unable to challenge these poor conditions.

Moreover, there are other factors that could also contribute to the home care worker's ability or not to inspire change within the sector. Some studies examined the demographics of the home care workforce (Table 3.5.1). Six studies highlighted that home care workers were predominately female (Bercovitz et al., 2011; Boerner et al., 2015; Boerner et al., 2016; Boerner et al., 2017; Gleason et al., 2016; Riesenbeck et al., 2015). Most studies were from the United States. However, other studies included details of sex and ethnicity within the demographics table of their findings but did not comment or expand on it further. All of these samples were predominately female, which appeared to indicate that there was an assumption that this type of role would be one that is delivered by women. This largely female workforce employed in key worker roles, appear to be disproportionately financially vulnerable and have limited ability to influence change in relation to working conditions. This lack of power appears embedded within the sector in a way that may not be the case for industries with a better gender ratio. Both of these external factors -financial vulnerability and a workforce that is not gender diverse - creates a sense of paralysis for the individual home care worker. For some this leaves them with no option but to abandon the role.

3.5.2 A lack of management support and a complex working environment: the organisational impact on home care workers

This section explores the organisational influences that affected home care workers when caring for people approaching the end of life in the community. The complexity of the work environment faced by home care workers, from the logistics of undertaking home visits to the environment they were working within, resulted in a stressful place of work. Moreover, home care workers also perceived a lack of management and organisational support. Table 3.5.2 outlines some of the connections found across the literature relating to this, which is explored in greater depth below.

Table 3.5.2 Matrix of themes identified in analysis of published findings: A lack of management support and a complex working environment: the organisational impact on home care workers

Themes	"	Poulos et al (2018)	Sims-Gould et al (2013)	Devlin & McIlfatrick et al (2010)	Kemper et al (2008)	Gleason et al (2016)	O'Sullivan & Harding (2017)	Boerner et al (2017)	Boerner et al (2016)	Noble et al (2015)	Yeh et al (2018)
Working environment	Complex work environment	*	*								
	Significant travel			*							
	Lack of time			*							
	Experience of patient/family aggression		*								
	Experience of crisis		*								
	Fluctuating levels of care needs		*								
	Sense of isolation										*
	Working with no breaks										*
Management and Organisational Support	Need for better relationships with managers				*						
	Lack of support by supervisors					*					*
	Lack of organisational policies		*				*				
	Management support reducing experience of burnout							*			
	Restrictive polices impacting experience of grief								*		
	Flexible working improving working environment									*	
	Seeking more colloboration between services						*				

Table 3.5.2 highlights that the home care workers working environment was a focus for a number of studies and the organisational influences that affected their experiences. Home Care Workers experience a complex working environment (Poulos et al., 2017; Sims-Gould et al., 2013), often spending significant time travelling to patients' houses, with little time assigned to delivering the care when they arrive (Devlin & McIlfatrick, 2010). Due to the changing clinical care needs of the patients who were dying (Sims-Gould et al., 2013), being able to plan visits can become challenging. This changing picture can result in home care workers experiencing patients in crisis, either through rapid deterioration or acute events such as strokes. There can be increased levels of carer strain in the home often due to increased caring responsibilities of family carers as people deteriorate. Home care workers can find themselves having to navigate and cope with episodes of severe distress and

aggression from patients and their families (Sims-Gould et al., 2013). The negative impact of this unstable working environment could be significant, as workers attempt to cope with increasing uncertainty and changing care needs.

Perhaps because of their working environment, a lack of management and organisational support became a clear theme across seven studies (Table 3.5.2). Home care workers perceived a lack of support from their supervisors when caring for someone approaching end of life (Gleason et al., 2016). Kemper et al., (2008) reported that relationships between home care workers and management needed to improve. Gleason et al. (2016) highlighted ways in which home care workers would like managers to improve which included someone to check in on them and give them time and space to talk, to provide appropriate end of life care training for them to attend and informing them when someone has died. This could be viewed as vital for this workforce as an initial study by Boerner et al. (2017) found that the provision of appropriate management support for these home care workers reduces burnout.

Two studies highlighted that a lack of organisational policies available to home care workers, in relation to clearly defining their role (Sims-Gould et al., 2013) and a lack of providing clear policy guidance for them to work within when caring for people at end of life (O'Sullivan & Harding, 2015). Restrictive policies in other areas such as not allowing funeral attendance were seen as detrimental to the experience of grief for home care workers (Boerner et al., 2010). Instead, studies which highlighted supportive policies to enable funeral attendance (Yeh et al., 2019), flexible working environments (Noble et al., 2015) and collaboration between services (O'Sullivan & Harding., 2010) were viewed more positively and strengthened the home care workers' connection to the organisation. In organisations which have supportive policies in place, the home care workers experience of grief could be interpreted as more humane and may also be less likely to be hidden. Consideration should be given as to whether organisations that have supportive policies in place around grief and bereavement for example, have staff that are less likely to experience disenfranchised grief, as they are able to mourn in a more open way. Disenfranchised grief occurs when an individual's grief is not recognised by society, therefore there is a lack of empathy or even validation that a loss has occurred (Weiss & Oman, 2023).

3.5.3 Being in the role and working alongside others

This theme highlights findings which focused on or included the role of the home care worker, both the experience and responsibilities of the role together with being in the role and working alongside others. The role of the home care worker from their own perspective and the home care worker role in relation to the multi-disciplinary team appeared to differ. This difference in perspective appeared to play a part in how people interpreted the home care worker role, contributing to the issue of role ambiguity. Other key findings which are explored is the strength of connection between the home care worker and the family which appeared to be important for them and one that they prioritised. Table 3.5.3 provides a visual aid of the connections and disconnections across the literature which is explored further below.

Table 3.5.3 Matrix of themes identified in analysis of published findings – Being in the role and working alongside others

Themes	.	Boerner et al (2016)	Lovatt et al (2015)	O'Sullivan & Harding (2017)	Reimer-Kirkham et al (2016)	Devlin & McIlfatrick (2010)	Poulos et al (2018)	Bercovitz et al (2011)	Butler et al (2010)	Pesut et al (2015)	Sims-Gould et al (2013)	Ingleton et al (2011)	Holme & Hart (2007)
Experience of HCW role	Close relationships	*	*	*	*								
	Provision of emotional support		*			*	*						
	Provision of personal care					*	*						
	Sense of reward					*	*	*					
	Positive attitude to caring												
HCW as part of the MDT	Lack of value in role by others				*			*	*				
	Unclear role boundaries		*			*				*	*		
	Reliance on DNs for care planning											*	
	Training improved working relationships and professional status												*

The close relationship that is built between the home care worker, the patient at the end of life and their family is viewed as an important element of the role (Boerner et al., 2016; Lovatt et al., 2015; O'Sullivan & Harding., 2017; Reimer-Kirkham et al., 2016). Perhaps as a result of this close relationship, the provision of emotional support is seen as a crucial part of the home care workers' role (Devlin & McIlfatrick., 2010; Lovatt et al., 2015; Poulos et al., 2018). Emotional caring is referenced more than the provision of personal or physical care (Devlin & McIlfatrick, 2010; Poulos et al., 2017). Interpreting this further, it demonstrated from the perspective of the home care worker how, instead of being task focused, the journeying alongside someone providing support and reassurance on a regular basis in a much more reactive way was viewed as an important part of their role. It also highlighted that they understood it was both the individual and their family carers who required additional support to remain at home. Regardless of the external and organisational challenges home care workers face, they report a sense of reward from their role in caring for people with end-of-life care needs (Bercovitz et al., 2011; Devlin & McIlfatrick, 2010; Poulos et al., 2017; Stone et al., 2013).

Despite this personal sense of reward in their role as a home care worker, there is a perception that there is a lack of value placed on their role from other members of the multi-disciplinary team (Bercovitz et al., 2011; Butler et al., 2010; Reimer-Kirkham et al., 2016). Role ambiguity could influence how the home care worker is perceived within the multi-disciplinary team. Various job titles given to this workforce further complicates this (Bercovitz et al., 2011). Four studies found that home care workers had unclear role boundaries (Devlin & McIlfatrick, 2010; Lovatt et al., 2015; Pesut et al., 2015; Sims-Gould et al., 2013). This can cause challenges for patients and families in regard to what they expect the home care worker to do (Sims-Gould et al., 2013), and for the home care workers themselves, with some reporting that they are unclear about how to best meet the needs of patients with end-of-life care needs within their role. In Holme & Hart's (2007) explorative qualitative study, looking at the experience of one team of home care workers, it was perceived that training can assist home care workers to strengthen relationships with district nursing teams and to recognise their professional status within the wider team.

3.5.4 Limited education and a lack of support: the home care workers’ experiences of caring and grieving

This finding summarises the experience of support and education which relate directly to home care workers caring for people approaching the end of life. The lack of access to relevant education, which could assist them in the part of their role which involved caring for people approaching the end of life, coupled with limited support options, appeared to impact their level of preparedness for carrying out this type of work. How prepared the home care worker felt for the patient’s death and what their experience of grief was like impacted on levels of burnout, and their ability to continue to work in the role. Table 3.5.4 provides a visual demonstration of some of the connections across the literature which will be explored further below.

Table 3.5.4 Matrix of themes identified in analysis of published findings – Limited education and a lack of support: the home care workers’ experiences of caring and grieving

Themes	Sub-themes	Bercovitz et al (2011)	Devlin & McIlfatrick (2010)	Gleason et al (2016)	O'Sullivan & Harding (2017)	Reimer-Kirkham et al (2016)	Pesut et al (2015)	Holme & Hart (2007)	Campbell & Baernholdt (2018)	Riesenbeck et al (2015)	Boerner et al (2015)	Boerner et al (2017)	Butler et al (2010)	Fujita et al (2019)	Fukui et al (2019)	Manson et al (2020)	Yeh et al (2019)	Baik et al (2021)
Experience of Education and Training	Lack of university education	*																
	Lack of end of life & grief and loss training		*	*	*	*												
	Lack of communication training		*				*											
	Training improves clinical skills							*										
	Training improves collobarative working													*	*			
	Difficulty in attending training															*		
	Peer learning reduced isolation															*		
Clinical supervision and debriefing	Debriefing reduces stress								*									
	Support through talking			*														
	Lack of support available			*														
	Lack of clinical supervision		*		*				*								*	
	Lack of formal support																*	
	Reliance on peer support																*	
Preparedness for patients death	Clincial experience increases preparedness for patients death									*								
	Patient acceptance increases staff preparedness									*								
	Avoidance negaticely impacts HCW preparedness for death									*								
	HCW reluctance to seek support			*														
	Lack of preparedness for patients death										*						*	
Experience of grief and bereavement	Time to grieve is important			*													*	
	Experience of grief symptoms		*		*						*	*						
	Experience of burnout											*	*					
	Supervisor support reduces risk of burnout												*					
	Coworker support increases risk of burnout												*					
	Emotional exhanustion is lower than residential care workers												*					
	Fear of patient death																	*
	Sense of being overwhelmed																*	
	Patient death links to personal experiences																*	

The studies which examined how prepared home care workers were for the death of individuals they were caring for found that they were not prepared (Boerner et al., 2015). Findings also highlighted there was reluctance to seek support prior to the patient's death, even when they had recognised feeling unprepared (Gleason et al., 2016). If the patient themselves openly acknowledged that they felt they were dying and had input into their own care, this increased how prepared the home care worker was for their death (Riesenbeck et al., 2015). One study also highlighted the importance of clinical experience in terms of how informationally prepared a home care worker was where those with more clinical experience of caring for people at the end of life, felt more informationally prepared (Riesenbeck et al., 2015). Boerner et al. (2015) in their mixed methods study found that home care workers not only lacked preparedness for the patient's death, they also went on and experienced symptoms of grief.

Home care workers experience grief after the death of the person they were caring for (Table 3.5.4). Two studies highlighted that having time to grieve should be seen as a priority in terms of supporting this workforce (Gleason et al., 2016; Yeh et al., 2019) and ensure organisational policies support the opportunity for workers to attend funerals should they wish to (Yeh et al., 2019). One simple recommendation from Gleason et al. (2016) was to have a procedure in place to ensure staff are notified when someone dies. There was no evidence available which evaluated any practical applications in how grief and bereavement support could be provided at scale. The onus appears to be very much on the worker to seek support, rather than the organisation offering or putting in place support measures.

Two studies also highlighted that home care workers experience a higher risk of burnout after a person they were caring for died (Boerner et al., 2017; Butler et al., 2010). Boerner et al.'s (2017) mixed methods study found that high levels of supervisor support can reduce the risk of burnout for home care workers. However, environments where there are low levels of supervisor support and the home care workers are reliant on co-worker support alone, increases the risk of emotional exhaustion and risk of experiencing burnout. Consideration around the benefits of providing more formal support options either through line managers or other leaders within the organisation could be beneficial. Access to line managers in a timely manner would also be important but may be more challenging for those working remotely. However, the findings suggest that home care workers do value management support when it is available.

The need for appropriate support for home care workers is noted within some of the background literature as a central issue. However, there is a gap in the literature as to what home care workers view as support. Gleason et al.'s (2016) mixed methods study examined the perceived availability of support for home care workers in New York caring for people at the end of life. Their findings suggested support was defined as being able to talk about their feelings. Debriefing was found in the study by Campbell and Baernholdt (2016) to reduce the emotional impact associated with caring for people with end-of-life needs. The need for home care workers to access formal support such as debriefing or clinical supervision was also highlighted (Devlin & McIlfatrick, 2010; Campbell & Baernholdt, 2016; O'Sullivan & Harding, 2017; Yeh et al., 2019). This could suggest that a lack of formal support such as debriefing or clinical supervision is an issue across different developed countries and different health care systems.

The need for education and training continues to be a central finding in papers which include home care workers as part of their sample (Table 3.5.4). This is also a reoccurring theme highlighted in the background literature (Chapter two). The challenge appears to be understanding what type of education and training would best support this workforce and would be sustainable. Devlin and McIlfatrick (2010) suggested the need for a joint approach to the delivery of end of life care training programmes including a period of preceptorship to gain experience and competence and the opportunity to work alongside other professionals such as community nurses to improve skills in physical care at the end of life. Manson et al. (2020) suggested the challenges this workforce face in even attending training can be significant such as shift work and being asked to attend training on days off to ensure they can be released; therefore, organisational support is crucial for education programmes to be successful.

There appears to be a lack of consistency across the workforce around what formal and informal education can be accessed. Despite home care workers delivering crucial physical and emotional care to people with end-of-life care needs, a lack of training in end-of-life care, grief and bereavement and communication skills were reported (Devlin & McIlfatrick, 2010; Gleason et al., 2016; O'Sullivan & Harding, 2017; Pesut et al., 2015; Reimer-Kirkham et al., 2016). More understanding is required into what types of education and training pathways best fit the needs of this population.

3.6 Discussion

I conducted this hermeneutic review using Boell and Cecez-Kecmanovic (2014) hermeneutic framework for literature reviews, to synthesise study findings which explored the experiences of home care workers caring for people approaching the end of life in the community. Following data synthesis and critical assessment of the literature, four key themes were explored.

3.6.1 Feeling paralysed – Female labour and financial vulnerability

Some of the external factors that influence the home care workers experience in their role and their ability to influence meaningful sector wide change may be related to who makes up this workforce. Home care workers are a predominately female workforce, and due to the remuneration associated with the role they are at risk of being financially vulnerable (Butler et al. 2020). The Royal College of Nursing (RCN) in the UK released a report examining gender and nursing as a profession and found that as nursing in the past was seen as a vocation usually undertaken by women, this notion still persists and can be seen in a variety of ways such as nursing staff working beyond their contracted hours in challenging environments without any financial reward (Clayton-Hatchway et al., 2020). The authors argued that care is viewed as a feminine skill and ignores the skills required to undertake nursing roles, devaluing core aspects of caring roles such as emotional labour and not rewarding roles in terms of remuneration appropriately.

Hussein (2017) attempted to examine the scale of 'poverty pay' within this largely female workforce. She defined 'poverty pay' as an hourly rate below that of the national minimum wage and found that up to 13% of care workers were being paid below the national minimum wage in England. Cominetti (2023) in the Resolution Foundation Briefing, examined the experience of social care workers and the enforcement of employment rights in the sector. Social care was noted as one of the largest low-paying sectors in the UK. They found that the median hourly rate was below the economy wide average and below other low paying jobs such as those in call centres, offices and transport, making it increasingly difficult to attract people into these roles. Smith (2012) examined the American experience and found that home care workers had higher poverty rates, worked fewer hours each week and did not receive additional benefits such as health insurance when compared to care workers in hospital and nursing home settings. Therefore, when it comes to home care workers caring for people approaching the end of life as part of their role, the financial constraints may continue to affect recruitment and retention of new staff and the competition in other job markets with better paying roles which offers less responsibility could impact this further. There may be a gender assumption around who should be in these caring roles, and what the value of these key workers are. But from the perspective of the home care worker themselves, there may be a risk of feeling disempowered. The perception of feeling powerlessness to change important aspects in your life such as financial security could impact whether someone remains in the home care worker role.

3.6.2 A lack of management support and a complex working environment: the organisational impact on home care workers

This theme focused on the working environment and organisational influences of the home care worker. Poulos et al. (2017) identified the complex working environment home care workers face. The changing clinical needs of people approaching end of life at home alongside distressed family carers can result in home care workers feeling alone and underprepared for supporting people at end of life. Wider literature which examined preparedness of care workers in a care home setting found the majority of care workers felt under prepared to deliver the complex care they perceived was required to support someone well at the end of life. Moreover, they also relied upon their own self-care strategies, as there were inadequate organisational resources available to support them (Booi et al., 2023). Riesenbeck at al. (2015) also examined the experience of care staff and their preparedness for residence death in long term care where they felt greater support from colleagues and the hospice teams resulted in increased preparedness for the resident's death. This external support was viewed as positive for both emotional and informational preparedness. The need to explore the home care workers views further around what constitutes organisational support would be valuable. If home care workers felt able to access management support, then this may also have a positive impact on their ability to remain and thrive in the role.

3.6.3 Being in the role and working alongside others

This theme explored the role of the home care worker and the connections they formed with those around them. Their own perspective of their role and the perspective of other health professionals appeared to differ. Role ambiguity appeared to complicate this further. A lack of role boundaries resulted in home care workers facing challenges around role expectations. Herber and Johnston (2013) also highlighted role ambiguity as an issue within their systematic review which focused on the role of the home care worker, noting that the additional duties they chose to undertake resulted in confusion for family carers around the boundaries of their role. Devlin and McIlfatrick (2009) in their review of the literature commented that unclear role boundaries increased confusion for other health professionals working alongside home care workers caring for people approaching the end of life. Gaining a clearer understanding around the issues of role ambiguity from home care worker and health professionals’ perspectives could assist in developing strategies to strengthen their professional connections. O’Neill and Cowman (2008) investigated community nurses understanding of an interdisciplinary team-based approach to community care and found that clarity around individual contributions and level of knowledge resulted in more effective teamwork. Role clarity was a central component of this.

Home care workers perceived their role to be rewarding, and the emotional support they provided to people with end-of-life care needs and their families was at the heart of this. Earlier research highlighted that home care skewed the boundaries of public and private, with public services delivering care in private settings (Martin-Matthews, 2007). Ayalon and Roziner (2016) examined the satisfaction of family carers using family systems theory and viewed the individual receiving care, the family carer and the home care worker as a triad in Israel. They found the role of the home care worker contributed significantly to how satisfied both family carers and the individual receiving care felt. The home care worker role when carried out well was central to the family member being able to step back from some of their caring duties. Shaw et al. (2021) examined both the benefits and challenges of home care workers from the perspective of family carers in New York. They found that home care workers did provide both functional and emotional support. However, there were logistical issues in coordinating care and the relationship was dependent on how well the person fitted into the home and the family. Much of the published literature from family carer perspectives focuses on caring for older adults across a spectrum not only at end of life, therefore further exploration into the home care worker role at end of life from the perspective of the home care worker and family carer may be useful. It may also assist in identifying how best to support home care workers and to tailor education that aligns to their role in the community environment.

3.6.4 Experience of support and education

This theme brought together the support and education needs of the home care worker caring for people with end-of-life care needs, the dying and the dead. The onus appeared to be placed with the home care worker in both seeking and navigating support options when an individual had died, rather than providing this to them. Formal management support and connection to management appeared to be valued by home care workers. Other formal talking support such as debriefing and clinical supervision, if available may be examples of organisational provided support. Beavis et al. (2021) carried out a literature review examining clinical supervision for support workers in paediatric palliative care and noted that supervision needs for support workers in a variety of settings are neglected. Their findings highlighted that staff working in emotionally difficult situations appreciate access to clinical supervision as a method of support, however further research was needed to link clinical supervision to stress reduction and reduced risk of staff burnout. Clinical supervision is a formal process used by health professionals for clinical reflection, learning and development (NHS Employers, 2023). Masamha et al. (2022) carried out a scoping review of clinical supervision literature published over the last thirty years and found that there are persistent barriers to implementing clinical supervision despite it being well regarded as a form of formal reflection on clinical practice. They highlighted the difference between the belief in clinical supervision to the reality of its poor implementation and uptake. So although clinical supervision may be beneficial for home care workers, further exploration is needed into what they themselves may perceive to be helpful in regards to more formal support options.

The need to provide support for home care workers through end of life care training programmes was viewed as important. Lack of access to palliative care training was highlighted consistently in other reviews featuring home care workers (Devlin & McIlfatrick, 2009; Herber & Johnston, 2013). This has also been noted in government policies with aims of how this may be improved (Scottish Government, 2022). The reliance on end of life care training provided by peers, whilst on shift, risks unsafe working practices being replicated (Herber & Johnston, 2013). End of life care training for this workforce and how it could be rolled out at scale requires further consideration and action. However, identifying what was most helpful for existing home care workers providing end of life care could help inform larger pilot projects. Ensuring sustainability and a combined education approach may require further research.

3.7 Strengths and Limitations

No additional reviewers were used to assist with quality appraisal or data extraction. However, as a hermeneutic approach was taken, this allowed interpretation and questioning where ideas were refined as understanding about the experience of home care workers grew. The phenomenological approach taken, incorporating the hermeneutic framework strengthened the method of the review. Supervisors were involved in terms of guidance and advice on the process of the review. But it is acknowledged that as a result this was completed from a single reviewer's perspective. Data extraction and analysis focused on the published studies and their findings only. No authors were contacted for clarification or to examine raw data.

A strength of the review is that areas which require further exploration in the literature were identified. The literature review included all available studies that met the inclusion criteria, which resulted in international studies being included. All of the findings from these international studies may not apply in Scotland, however it does demonstrate the complexity that exists in research focusing on home care workers.

3.8 Conclusion

The hermeneutic review highlights that despite home care workers providing both physical and emotional care for people living with palliative and end-of-life care needs, they feel undervalued by the wider multidisciplinary team. Role ambiguity could be contributing towards how the home care worker role is viewed by the wider team. Further exploration of this is needed.

The studies that were undertaken suggest that this largely female workforce are working in a complex working environment for low pay with inadequate management support. Due to the population of patients they are caring for, studies have found that home care workers are experiencing symptoms of grief and bereavement, and are at risk of burnout. Home care workers have little to no access to clinical supervision and debriefing.

A lack of support was a recurring finding across the existing literature; however, a clearer understanding of what home care workers view as support is needed. A lack of training has also been noted across the existing literature as an issue in relation to this workforce, despite a small number of published studies evaluating specific training programmes which were designed to increase home care worker’s knowledge of end-of-life care. There appears to be a lack of clarity as to what type of education and training is seen as most valuable by the home care workers themselves. This hermeneutic review demonstrates there is a need to further understand what the experience of caring for someone at end of life from the perspective of a home care worker is like, and for them to consider and reflect on their experience of accessing support and training and perhaps consider what elements of that may be most valuable.

In this chapter I have conducted a hermeneutic literature review to examine the published studies which focused on the experience of home care workers caring for people with end of life care needs in the community. These findings were explored and summarised. I have demonstrated that a study exploring the experiences of home care workers is needed. Therefore, in Chapter Four I will outline the methods for the empirical study.

Chapter Four: Methodology

4.1 Introduction

In this chapter the research question is presented, alongside a rationale and justification for the research approach. The philosophical underpinnings of the study are explored and the methods of the study including sampling, the inclusion and exclusion criteria, and data collection are presented. The Interpretative Phenomenological Analysis (IPA) methodology is outlined, including how this was implemented throughout the study and how data analysis was conducted. Throughout data collection and data analysis, consideration was given to my own reflexivity and positionality within the research, so this is also explored. Ethical considerations such as informed consent, non-maleficence, and confidentiality are outlined in relation to how the study was planned and conducted.

4.2 Research Aim and Question

The research aim evolved from both my own clinical experience as a community palliative care nurse and educator, and from undertaking a literature review. Findings from the literature review suggested home care workers were a largely female workforce, often working in challenging environments for poor financial reward with inadequate management support. Further exploration is needed into the home care worker experience of caring for people with end of life care needs, to gain a deeper understanding from their perspective around the challenges they face and what support and training is open to them. Therefore, the primary aim of this qualitative study was to examine the lived experience of home care workers who are delivering care to people with end of life care needs in the community.

The study was conducted in Scotland, at a time when the Scottish Government had implemented health and social care integration, bringing together health and social care into a single integrated system (Scottish Government, 2019). Scotland is a devolved nation, with its own health and social care system which differs from England, Wales, and Northern Ireland. All policy decisions regarding health and social care are made by the Scottish Government.

4.3 Research Methodology

4.3.1 Philosophical Underpinnings of the study

A paradigm is connected assumptions made about the world, also known as a world view (Slevitch, 2011). Our ontological positioning determines the scientific paradigm we are working within (Sale, Lohfield & Brazil, 2002). Ontology is the study of the nature of reality (Lincoln & Guba, 1985). Ontological positions outline whether there is a single confirmable reality or whether it is socially constructed with multiple realities (Patton 2002, p.134). Different ontological positions outline what exists, what can be assumed to exist, and what the relationships between these categories are (Guba & Lincoln, 1989; Slevitch, 2011). Epistemology is the theory of knowledge, and considers how we create knowledge, the nature of that knowledge and as a researcher how we contribute to knowledge (Lincoln & Guba, 1985; Okesina, 2020; Slevitch, 2011). The epistemological assumptions made by a researcher informs the research questions we attempt to answer, and the methodological approach taken to answer them. Objectivism and subjectivism are at two ends of the epistemological spectrum. The objectivist believes the world can be observed and knowledge created (Moon & Blackman, 2014). A subjectivist concludes that observations are theory dependent (Fryer, 2022), that meaning exists within the subject and meaning is placed on the object (Moon & Blackman, 2014). There are a range of positions across the epistemological spectrum that fall in between objectivism and subjectivism.

From my own ontological perspective, a world does exist which is independent of myself as a researcher. When considering epistemology, forming knowledge is more than purely observing this world, instead I believe it is theory-dependent. Therefore, when viewing the research problem through this lens, it was essential to ensure the methodology of the study was congruent to these core principles. It was important that the research approach chosen enabled me to gain a deeper understanding of the home care worker in context. As I was seeking to deepen my understanding, I chose to take a qualitative approach to explore the research question. Bazeley (2013) highlighted that researchers who take a qualitative approach focus on the description, interpretation and analysis of people's experience, actions or reflections on themselves, and the world in which they inhabit.

There is not a standard definition of qualitative research. Aspers and Corte (2019) carried out a systematic review of the literature attempting to encapsulate the core elements of qualitative research. They highlighted four key areas. Firstly, being able to make new distinctions enhancing data through in depth analysis; secondly, a research process which includes iteration; thirdly, closeness to what is being investigated; fourthly, seeking an improved understanding of what was studied rather than a correlation or explanation alone (Aspers & Corte. 2019). Qualitative research enables people's life experience and perceptions to be described, explored, and, depending on the type of qualitative approach taken, interpreted (Cuthbertson, Robb & Blair, 2020). Taking a qualitative approach enables researchers to use both their interpersonal and subjectivity skills within the research process (Alase, 2017). Qualitative research in health and social care is often used to gain further understanding into patients and families' experiences of care, health care professionals' clinical decision making or to explore the experiences of health and social care professionals in particular settings (Denny & Weckesser, 2019). To answer the research question posed, it is essential for me to deepen my understanding of the experiences of home care workers caring for people with palliative and end of life care needs in the community, therefore a qualitative approach was an appropriate pathway to take. However, by choosing a qualitative approach I acknowledged that the research undertaken would be subjective, and it was essential I avoided making assumptions that my own beliefs were the reality (Bowling, 2014).

4.3.2 Methodological choices - Interpretative Phenomenological Analysis (IPA)

Interpretative phenomenological analysis (IPA) is a qualitative research approach which is informed by phenomenology, hermeneutics and idiography. Phenomenological research arose out of what was originally a philosophical tradition (Vagle, 2018). Phenomenology was described as a way of seeking insight into the "phenomenality of lived experience" (Van Manen 2017, p.779). It originally focused on understanding individuals' subjective experiences and subsequently also considered how people make sense of those experiences from the world in which they live (Bryman, 2015). Published literature has argued IPA explores the meaning, structure, and essence of the lived experience of a phenomenon for an individual or group of people (Patton, 2002).

Smith et al. (2009) described hermeneutics as the theory of interpretation, with hermeneutic theorists historically focusing on the method and purpose of interpretation. Martin Heidegger (1889-1976), connected both hermeneutics and phenomenology. Heidegger's phenomenology treated the mind and the world as interconnected (Vagle 2018). Heidegger's approach to phenomenology advocated the concept of Dasein, a German term which translated as 'being there' or 'being in the world.' Importantly, Dasein acknowledges the influences of the world in which people inhabit (Flood, 2010; Van Manen, 1990). This can mean that people are attempting to make sense of their lived experience in the world through the meaning they place on the people, objects, relationships, and language (Bazeley, 2013) and in turn researchers are attempting to 'make sense' of the participants 'making sense' of their experience (Bazeley, 2013; Smith et al., 2009). Heidegger recognised that interpreting how a person attaches meaning to a phenomenon is central to the interpretative process of hermeneutic phenomenology (Smith et al., 2009). Therefore, when considering the phenomenon, such as a home care worker with a dying patient, the question may be: how is it to experience being with and caring for someone who is dying?

Idiography is focused on the particular. IPA aims to understand how an individual has experienced a particular phenomenon in a specific context and this is achieved through detailed analysis (Smith et al., 2009). IPA attempts to show the complexity within people's individual experiences and indeed their reflections of it (Murray & Wilde, 2020).

IPA enables researchers to consider how a lived experience can hold significance for people as they begin to reflect on this lived experience and try to make sense of it; researchers can draw on these reflections (Smith et al., 2009). IPA enabled me to not only gain insight into the home care workers' lived experience when caring for people approaching the end of life but allowed me to identify shared experiences across the sample, alongside points of difference within home care workers' accounts. Meaning was particularly important as when caring for people at end of life, the context in which they care and the reflections they make on where they placed value provided insight into their lived experience. It also enabled exploration around how this was embedded in the world of people, objects, relationships, and language (Bazeley, 2013). IPA as a methodology closely aligned with how I believe knowledge can be created, having outlined the theoretical underpinnings of IPA above -phenomenology, hermeneutics and idiography. Debate exists within the literature around where IPA should be positioned within particular ontological and epistemological positions, and whether this needs to be explicit or not (Dennison, 2019). However, IPA studies can be undertaken from a number of different epistemological perspectives depending on the researcher and the research question that is being asked. Those who elect to explicitly position themselves within a particular epistemological or ontological position such as critical realism for example, acknowledge that a complex reality exists independent of human knowledge and experience, where reality is knowable although only partially (Brunson et al., 2023). In critical realism reality cannot simply be observed; instead, attempting to gain understanding of its complexity can be done through rich exploration of the phenomenon (Lawani, 2020). Others adopt a social constructionist approach, where knowledge is built through co-production between the participant and the researcher through interpretation (Urcia, 2021).

When exploring phenomenology, I originally considered taking a hermeneutic phenomenological approach to the study. As a methodology it relies on 'cultivated thoughtfulness' rather than any formal process of analysis (Bynum & Varpio, 2018, p.253). The hermeneutic circle is a way in which researchers can consider how the data (the parts) advance their understanding of the phenomena (the whole) (Bynum & Varpio, 2018). This cycle of thinking, reflecting, and writing is thought to uncover a deeper meaning that was perhaps previously unexplored. As a novice researcher this approach seemed overwhelming. I was keen to explore other methodologies which incorporated hermeneutics but also provided clearer structure in its implementation. IPA provides a methodology which is iterative; it incorporates a method of examining the data as a part and a whole and this process enables the researcher to examine data in a nonlinear fashion (Smith et al., 2012, p.28). The sense that being in the world is always 'perspectival' (Smith et al., 2012, p.18) and that our 'horizon of understanding' is what we view from our perspective incorporating our own pre-judgements (Gadamer, 1979) are important for both the researcher and the research participants. IPA's focus on idiography means that the depth of analysis is key, alongside how the individual has experienced the phenomenon. IPA allows the researcher to focus on the individual and how that individual makes sense of their experience (Finlay, 2011). The idiographic account enables the researcher to answer exploratory research questions which are focused on meanings and processes rather than outcomes (Finlay, 2011). Therefore, IPA was thought to be congruent with the study aims.

4.4 Study Design

This study used IPA to explore the lived experiences of home care workers caring for people at home with end of life care needs. The research design included purposive sampling, recruitment of participants, data collection through semi-structured interviews and data analysis. Ethical approval was sought and granted from the Faculty of Health and Medicine Research Ethics Committee at Lancaster University (Reference: FHMREC17048) and the Marie Curie Research Committee.

4.4.1 Population Setting

Purposive homogenous sampling is used within IPA studies to gain a particular perspective on the phenomena being investigated (Smith et al., 2012). The study population were home care workers who worked in the community, caring for people living with end of life care needs in their own homes. Home care workers who met these criteria can be employed by different health and social care community services depending on who is contracted to deliver care in particular geographical areas. Therefore, participants were recruited from councils delivering home care services, independent community service providers and Marie Curie community services based in Scotland. From a homogeneity perspective the importance was the home care workers all shared a common experience of caring for people at home approaching the end of life. Murray and Wilde, (2020) highlighted that at a *"fundamental level, participants in an IPA study are homogenous because they are all bound by the experience of a similar phenomenon."*

4.4.2 Inclusion and Exclusion Criteria

The table below outlines the inclusion and exclusion criteria used to guide recruitment. All participants were over the age of 18 and employed to care for people in their own home. All participants had cared for people living with end of life care needs in the last 12 months. People who were employed as a registered nurse were also excluded as the research question focused on home care workers only.

Table 4.4.2 Inclusion and Exclusion Criteria

Inclusion	**Exclusion**
Participants who were over 18 years old	People under 18
Participants who had cared for a patient with end of life care needs in the last 12 months	People who have not cared for palliative patients within the last 12 months
Participants who are employed to care for people in their own home	People employed as a registered nurse
	People who are not English speaking, as there is no resource available for translation.

4.4.3 Sampling

A purposive sampling method was used. In qualitative research purposive sampling is commonly utilised as it enables the research team to gather in depth understanding of the phenomenon being investigated (Patton, 2002), through focusing on participants who have had experience in the area of interest. The study initially aimed to recruit up to fifteen Home Care Workers. However, the sample size of studies using IPA is influenced by idiography, the focus on the particular. By intentionally using smaller homogenous sample sizes, in some instances a single case, a greater depth of analysis can be achieved. Studies using an IPA approach in health and social science research have commonly ranged between four to ten interviews (Ablett & Jones, 2007; Muishout et al., 2018, Saarelainen et al., 2020; Smith et al., 2009). The active decision to have a smaller sample size related to the openness of the participants to spend time sharing their experiences. By purposely gathering this in-depth data, which was created jointly by the involvement of both participants and the researcher, a smaller sample size was appropriate and congruent with an IPA approach. Eight home care workers participated in the study which is usual in IPA. Everyone who expressed interest after reading the study information and who met the inclusion criteria consented to take part. As noted earlier, the home care workers self-selected to take part in the study, therefore may have a more positive perspective of caring for people at the end of their life or at least an interest in the area.

4.5 Recruitment

4.5.1 The process of recruitment

Managers who led care at home services provided details of those services and in what context the care was delivered to ensure the inclusion/exclusion criteria could be met. Email was the central form of communication within councils and Marie Curie, therefore managers of community services were forwarded the study information which included a study flyer (Appendix 4.5.1a), participant information sheet (Appendix 4.5.1b) and an Expression of Interest Form (Appendix 4.5.1c). They then shared this with their frontline staff. This ensured that, as the researcher, I was not directly contacting potential participants unannounced which avoided any risks of coercion. For those organisations where email was not the central form of communication for home care workers, the researcher attended team meetings to publicise the study and left paper copies of the study information in the home care offices. Participants were not contacted by myself directly until they had contacted me either to express an interest in taking part or to request further information. At that stage I ensured they met the inclusion criteria and that all their questions were answered. The right to withdraw was outlined to them at that time, highlighting that it would be difficult to withdraw once the data had been analysed and synthesised. If they were happy to proceed, interviews were arranged at a time and place convenient for the participant and written consent was completed on the day of interview (Appendix 4.5.1d).

Participants were recruited from a range of community home care providers which included two council community teams, two independent community service providers and the Marie Curie Nursing Service. All participants were home care workers caring for people with end of life care needs in their own home.

4.5.2 Recruitment Challenges

There were recruitment challenges related to accessing managers and home care workers from independent service providers. Managers employed by independent care providers tended to gate keep, declining to share information about the study. A gatekeeper in relation to research was defined as someone who controls access to a particular organisation or care setting (Singh & Wassenaar, 2016). Therefore, home care workers employed in these companies were difficult to access and even to provide them with study information to publicise the study was a challenge. They did not tend to have regular team meetings so even attending these to publicise the study was not an option available to the researcher.

4.5.3 Sample Demographics

Recruitment commenced in May 2018 and was completed in February 2020. Immediately following data collection, I had a period of intercalation due to maternity leave and a second period due to my clinical responsibilities during the COVID pandemic. I have explored the impact of this further in section 4.9.

This produced a reasonably homogenous sample of eight female participants, who all shared similar experiences of caring for people living with palliative and end of life care needs at home. All participants had recent experience of providing such care and did so as part of a home care worker role. All participants had worked in a home care setting for at least five years, two participants requested their information around this was withheld. Participants' ages ranged from 25 to 29 up to 70 years' old which would be expected within a normal workforce. One participant declined for their demographic information be included apart from their gender but was happy to proceed with interview.

Table 4.5.3 Sample Demographics

Participant Alias	Gender	Age	Ethnicity	Qualifications	Length of employment in home care
Mary	Female	70 and over	White British	SVQ/NVQ	Information withheld on participant request
Patricia	Female	65 to 69	White British	Bachelor's Degree	5 years
Jacqueline	Female	Information withheld on participant request	Information withheld on participant request	Information withheld on participant request	Information withheld on participant request
Mairi	Female	25 to 29	White British	SVQ/NVQ	6 years
Tracey	Female	55 to 59	White British	SVQ/NVQ	25 years
Josie	Female	45 to 49	White British	SVQ/NVQ	7 years
Karen	Female	30 to 34	White British	SVQ/NVQ	12 years
Ruth	Female	40 to 44	White British	Standard Grades/GCSEs/ Equivalent	6 years

4.6 Data Collection

In depth semi-structured interviews were used to collect data from home care workers. Interviews are a key method of data collection used in IPA studies (Smith et al., 2012). Interviews are used as a way to explore and collect the participants' reflections of their lived experience in their own words (Ajjawi & Higgs, 2007). In semi-structured interviews an interview schedule is used which includes a list of topics or questions that the interviewer wishes to cover, however the questions do not need to be asked in a specific order depending on the interviewee's responses. It is a flexible approach, and it ensures that the researcher can ask questions not included on the interview schedule depending on the participants' replies (Bryman, 2015). When using semi-structured interviews in IPA it is essential the questions are open and enable the participant to talk extensively (Smith et al., 2012). In line with the IPA phenomenological approach, interviews enabled home care workers to discuss topics around their experience of caring for people with palliative and end of life care that were most relevant to them.

The interview schedule was constructed to ensure there was adequate flexibility for the participants to explore and reflect on any unanticipated issues or experiences that arose. I was also mindful of the topic area, and therefore attempted to put participants at ease, to ensure they felt comfortable to provide an open and detailed account of their experience in caring for people with end of life care needs. My initial question was an open question exploring their role, designed for them to start talking about something reasonably descriptive that they felt at ease with. From that opening question, there were four areas outlined within the schedule which included their experiences of caring for people with end of life care needs, exploring their support needs, interprofessional relationships and education and training. Which specific questions were asked in each area was wholly dependent on the participant's narrative and what experiences or reflections they focused on. The final question sought their opinion around something they felt was important in relation to caring for people with end of life care needs that they would want to share with new home care workers about to embark on their career. This was designed intentionally to end the interview with a future gazing approach, especially important due to the topic area covered.

The interviews were conducted in private meeting rooms close to the participants' community base, which minimised travel. Interviews were arranged for a time that was most convenient for the participants. Participants signed the consent form on the day of interview, prior to data collection.

Demographic information including age, ethnicity, gender, level of education, qualifications and number of years worked in home care were also collected from each participant to aid with overall sample description (Appendix 4.6). To ensure data protection and anonymity was maintained, demographic information about the participants were stored on a password protected Excel spreadsheet, in a secure Lancaster University Filestore system. The spreadsheet was used to generate pseudonyms and was kept separately from the transcripts and audio recordings.

In-depth face to face semi-structured interviews were conducted. The median interview time was 50 minutes, with the longest interview taking 71 minutes. There is no specific guidance on the length of interviews required in IPA. Smith et al. (2012) suggested that it is dependent on the number of questions within the interview schedule, with six to ten questions taking a suggested 45 to 90 minutes. Instead, the focus should be on the quality of engagement across the interview, where fewer questions could still result in participants providing a full and detailed response (Larkin, 2005).

The interviews with home care workers aimed to explore the lived experience of home care workers caring for people with palliative and end of life care needs. The interviews were recorded on a password protected encrypted device which I then transcribed verbatim. I also kept a research diary to document the process and any key reflections throughout the research process.

4.6.1 Informed Consent

As outlined in section 4.5.1, prior to consenting to take part in the study, all participants received a participant information sheet (Appendix 4.5.1b), a study flyer (Appendix 4.5.1a) and an expression of interest form (Appendix 4.5.1c). This was shared with them either via email by one of the service mangers in their organisation or they received a paper copy at one of their team meetings. The participant information form was discussed with them once I had received an expression of interest form, and then again prior to completing the consent form (Appendix 4.5.1d). This was to ensure they had adequate opportunity to ask any questions. The participant information sheet clearly outlined the study aims, how the study would be conducted, what their role would be if they decided to take part and how their data would be managed. It also provided contact details where they could seek further information from myself or from my supervisory team.

4.7 Data Analysis

Data were analysed using Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003; Smith et al., 2009). There are now a number of approaches and the reasons why this version was used are outlined in greater depth in section 4.7.2. The process outlined below was followed.

4.7.1 Reading and Re-reading

Verbatim transcription is word for word transcription of spoken language including pauses, use of minimal encouragers etc. In IPA a verbatim transcription is needed as the aim is to interpret the meaning behind the content of the individual's narrative (Smith et al., 2009). Therefore, transcripts were intentionally transcribed verbatim to allow time to immerse myself within that particular individual's narrative. Each transcript was read and re-read several times alongside listening to the recording of the interview. This enabled me to consider what parts of the interview had more depth, where the transcript had reoccurring narratives or contradictions (Smith et al., 2009).

4.7.2 Exploratory Comments

At the point I commenced data analysis, I used the most recent version of Smith et al. (2012) IPA to guide my analysis. Data analysis in IPA studies can be time consuming, and prior to my completion of the thesis an updated version was published in December 2021, which was not readily available until 2022. The majority of my data analysis had been completed at this point. The updated version included new terminology, however the analytic process remained largely unchanged. Therefore, I believed it to be appropriate to continue to use the Smith et al. (2012) version which used exploratory comments as the second stage of analysis.

Analysis was undertaken in the order in which the interviews had been conducted. Analysis of each individual transcript was completed prior to moving onto the next. When conducting analysis, I also ensured there was a gap of time between analysing each interview, to ensure my focus could be placed entirely on the individual case. This was a method I used to try and bracket emerging ideas from the previous case as much as possible. Bracketing in IPA analysis is connected to its idiographic commitment, despite acknowledgement that a researcher would be impacted by what has already been found, it is an attempt to try and ensure new themes can arise in subsequent cases is important (Smith et al., 2012).

The second stage of analysis involved reading through the transcript and making exploratory comments. These focused either on descriptive comments around the context of what had been said, linguistic comments which noted the type of language used by the participant or conceptual comments which had a more inquiring focus (Smith et al., 2009). At this point I also documented any personal reflections or reactions that I had to the transcript. These comments were all documented on the right margin of the transcript.

4.7.3 Emergent Themes

Emergent themes attempt to capture both descriptive elements of the individual's words and views but also my own interpretations. This was done through examining exploratory comments and considering the connections, patterns, and contradictions between them (Appendix 4.7.3). This process ensured complexity was maintained but the volume of data reduced (Smith et al., 2009).

These emergent themes were then written down individually to enable consideration of how they could connect. To aid this process, all emergent themes were then spread out on a table to allow me to consider any patterns, differences, and contextual factors (Appendix 4.7.3b). Other aspects such as how frequently the participants revisited an experience or a reflection (numeration) within the account could suggest this was particularly important or meaningful for them. The function of the language used was also considered carefully, as it could be connected to the thoughts, or the meaning placed on certain experiences by the participants. I also recorded in my research diary why I had made certain decisions when going through this process. Once I had grouped these emergent themes, I was able to move towards developing super-ordinate themes for one participant. Super-ordinate themes enable the analyst to demonstrate how the themes could fit together, highlighting the most interesting and important areas of the transcript (Smith et al., 2012). This process was then repeated for all eight participants. On average there were eight super-ordinate themes per participant.

4.7.4 Identifying patterns across cases

Once all cases had been analysed individually, I then used an Interview Theme Matrix to enable me to examine the similarities, differences, and connections across the super-ordinate themes. An interview theme matrix was a table which listed all participants and the corresponding super-ordinate themes that had developed from analysis of each individual transcript, enabling a visual representation of some of the connections and differences across individual narratives. Smith et al. (2012) explained that when a pattern or connection between emergent themes are identified, then a superordinate theme can be created. This part of the analysis enabled me to gain a deeper understanding both of the individual participant's experience but also the wider group experience across the sample. The theme matrix included nine superordinate themes which following further analysis focused on the convergence and divergence of these superordinate themes (Smith et al., 2012). Following an extended process of really considering what and where the connections were, four master themes emerged. These four master themes encompassed a number of connected super-ordinate themes within them (Smith et al., 2009). A descriptive summary paragraph of each master theme was written. This enabled me to scrutinise that the themes had been developed in a coherent way, and still represented the findings from each of the home care workers' accounts. These master themes are outlined in the Results Chapter.

4.8 Quality

There is no single agreed method of assessing quality within qualitative studies, as qualitative research can be positioned within a range of different paradigms, each with their own perspective of reality and knowledge, and their own approach to defining and reporting quality (Stenfors et al., 2020). Nizza et al. (2021) suggested four quality indicators that could assist readers to assess the quality of an IPA study. The four indicators are as follows, firstly, constructing a compelling narrative which is coherent and unfolds. Secondly, the account is experiential and adds depth to the analysis. Thirdly, the analysis and interpretation of participants quotes provides additional meaning for the data and the experience. Fourthly, that there is adequate convergence and divergence to demonstrate idiographic depth (Nizza et al., 2021).

Ensuring my study was trustworthy and the reader engaged with the study and its findings were of paramount importance. Using these four indicators, I have outlined below how I considered these four quality indicators in relation to my own study.

- Compelling narrative and close analytic reading

  I used the hermeneutic circle carefully in my analysis, through transcribing the data independently and analysing each transcript in great depth, immersing myself in the participants' words and reflections of their lived experiences. This intense focus on the individual cases (the part) enabled me then to interpret at both the individual basis but also to consider the whole sample. Each theme was developed using meaningful quotes alongside analytic interpretation to build the narrative (Nizza et al., 2021). The organisation of each theme has been intentional to build and progress the narrative, the themes together then aim to demonstrate depth and cohesion.

- Developing an experiential or existential account

  High quality IPA studies are usually focused on things that are important for participants and they are encouraged to reflect on their experience to try and make sense of it (Smith et al., 2009). Arguably due to the significance placed on the experience, interpretation can result in experiential or existential themes (Nizza et al., 2021). The significance participants placed on caring for people at the end of life resulted in them reflecting on the care rituals they rely on from their own beliefs around death, and their sense of responsibility to deliver a 'good death'. As the narrative develops, their isolation, disempowerment, and grief created a sense of invisibility and of disconnection from health and social care colleagues and the organisations in which they were supposed to belong.

- Convergence and Divergence

  Convergence and divergence demonstrate similarities and differences between study participants (Nizza et al., 2021), illustrating what makes an individual's experience extraordinary and what connects the participants' experiences across the sample (Smith et al., 2011). Throughout my results and discussion chapters I aimed to demonstrate how the idiographic nature of participants' narratives enabled a greater depth and sense of understanding of the lived experiences of home care workers caring for people with end of life care needs. For example, demonstrating both similar shared experiences such as their experience of cumulative loss impacting on their own grief and bereavement, whilst also considering how particular individual's experiences of traumatic death shaped how they coped and sought support.

These quality indicators enable me to articulate how I have considered and demonstrated quality throughout my study. Through immersing myself in the data and following IPA methodology I believe I have remained true to the participants' accounts and used interpretation to gain a fuller understanding of the home care workers' lived experience.

4.9 Reflexivity and Positionality

Reflexive experience with the data is a key component when conducting IPA research. Engward and Goldspink (2020) have highlighted four areas where the researcher can demonstrate their reflexivity. Firstly, for the researcher to see themselves as part of the research at every stage, and then to ensure that each 'discovery' from each participant account is captured using reflexive awareness and being open to hearing each story. It was essential that my positioning within the research was adequately captured. Positionality relates to identifying the researcher's place in relation to the phenomena being investigated, the participants taking part in the study and the research design (Holmes, 2020). I have worked in a variety of specialist palliative care settings both in the UK and Australia for over twenty years. It was important for me to acknowledge this experience and carefully consider how it could impact assumptions I made whilst conducting interviews and when analysing the data. My current role focuses on leading specialist palliative care services in an independent hospice. Although the role of specialist palliative care is important, it was not the focus of this study. I have much clinical experience in caring for people with complex end of life care needs, but not as a home care worker, so I was aware my experience would be substantially different from theirs. I have delivered education to similar groups of staff both here in Australia and in the UK so on reflection this also shaped my understanding of their role, and some of the challenges they may face in the community although I was mindful to not make any presumptions. I also have not had a clinical role for a number of years, so I acknowledge that my perspective would be quite different from those working with patients on a daily basis. This enabled me to step back and focus on the individual home care worker's experience, while remaining highly cautious of any assumptions I was making. I did feel that my knowledge of working within this area could help in regard to the terminology used by participants, not just in terms of increased understanding but also in having an awareness of when to challenge or explore topic areas in greater depth. The only caution with this is I had to remain mindful that my understanding in regard to terminology could differ from the participants, therefore I was very aware of this and explored any terminology used by the participants in interview very carefully. Smith et al. (2012; p.36) described the IPA researcher as attempting to see what the experience was like from the individual's perspective 'standing in their shoes' while also considering their experience from a different perspective, interpreting it by 'standing alongside' them. I felt my background and experience enabled me to do this.

To assist with this, a reflective research journal was kept, which assisted with my reflections prior to, during and after each interview along with the interpretations that I was making. I reflected immediately prior to each interview detailing everything from the setting of the interview and the impact that may have, to any reflections I had prior to conducting the interview such as was anything that was happening for me on a personal or professional capacity that could impact the interview in anyway.

Immediately after each interview, I reflected on not only how it had gone from my perspective, but also anything I felt was important to note including any incorrect assumptions I had made, or why I had felt a certain way as they were answering, for example anger, sadness, and happiness. I also noted non-verbal behaviours that could be important for the transcript. My post interview reflection really considered any learning from how the questions had been asked, and the depth of responses that the participants felt they wanted to focus on. I also reflected once I had completed each transcription of the interview as, at that point, it was clear to see areas of deeper exploration compared to more superficial answers and, in some cases, how I had contributed to this. Using this reflexive approach meant that, although I could not bracket off my experience entirely, I was able to ensure as far as possible that through this engagement I was more informed about what my preconceptions were. My research journal also enabled me to recognise and discuss some of these issues with my supervisors.

Engward and Goldspink (2020) highlighted the need to be reflexive at each stage of data analysis, ensuring analysis across cases is anchored in what each participant has shared through direct examples from their account. My own reflective research journal also enabled me to reflect on the decisions that I made during analysis and consider carefully why these decisions were made. Alongside this was some of the challenges and burdens that I faced and worked through, including time spent with the data and the hours of analysis to ensure participants' voices are heard.

I had a long period of intercalation following data collection due to maternity leave which coincided with the global pandemic. Due to that, I felt distanced from the data on my return and took time to reacquaint myself with all the interviews and my research journal. However, I felt this period of distance strengthened my data analysis. I was able to step back and consider it more thoughtfully than had I started analysis immediately after completing the interviews. Despite the community landscape changing over that period due to the pandemic, the experiences of the participants were just as relevant. When I returned from intercalation, I also had a change in one of my supervisors as a result of retirement. As part of the change in supervisory team I did a short presentation of my progress to date and my considerations for how I would approach analysis. Through preparing for this presentation and the ongoing discussion with my supervisory team, it became clear that a broader hermeneutic phenomenological analysis may not be the best approach to take. I knew why phenomenology was the right approach to answer the research question but within my research proposal I had not considered in adequate depth how I would approach analysis. This was a particularly challenging time; however, it allowed me some space to carry out substantial background reading into different phenomenological approaches which may better suit the interviews that had been collected and the overall sample. IPA provided a structured approach to phenomenological analysis which enabled me to delve deeply into each participant's narrative, and the meaning that people placed on their experiences, their expression of feelings and thoughts, or the value they placed on a relationship.

4.10 Ethical Considerations

Ethical considerations which arose during the planning of the study or while undertaking the study will now be explored. These include non-maleficence, confidentiality, anonymity, and lone working.

4.10.1 Non Maleficence

Non-maleficence is to protect the participants from harm as a result of taking part in the research study (Gelling, 1999). Due to the study focusing on home care workers experience of caring for people with end of life care needs, the potential risk to the participants was around emotional distress during and after the interview. Therefore, a Distress Protocol (Appendix 4.10.1) was created which was adapted from two other protocols (Draucker et al., 2009; Haigh & Witham, 2015). A two-stage response involved firstly stopping the interview and providing immediate support, then establishing if the participant wanted to resume the interview or to stop. The second stage if the participant was unable to carry on, would be to encourage the participant to contact one of the support services listed on the Participant Information Sheet. In practice, the distress protocol did not need to be implemented during data collection.

Interviews were conducted at the most convenient location and time for the participant to minimise the burden of cost, travel, or disruption to their routine as most participants were shift workers. Participants were informed of their right to withdraw prior to written consent being completed.

4.10.2 Confidentiality and Anonymity

Confidentiality is important for the relationship between the researcher and participant, to ensure honest and open responses are given during data collection (Gelling, 1999). Confidentiality creates safety for the participant and ensures autonomy is maintained. However, the need to maintain confidentiality is not absolute, and can result in ethical dilemmas if not carefully considered (Bryman, 2015). For example, there are limits to confidentiality if someone is at risk of harm. No participants in this study disclosed anything during the interview process that resulted in confidentiality having to be broken.

All identifying details were removed from transcripts to protect anonymity in both the thesis and future publications. All demographic information was stored on a password protected excel spreadsheet and kept separately from the interview responses, this will be destroyed at the completion of the PhD. Interviews were recorded on an encrypted MP3 device. Once each interview had been completed, the recording was transferred on to the Lancaster University Cloud Storage. Interviews were deleted from the MP3 device. Electronic copies of transcripts will be kept for ten years and deposited in the Lancaster University institutional data repository. The data repository holds, manages, preserves, and provides access to datasets produced by Lancaster University research.

4.10.3 Lone Working Risks

During data collection interviews were held in meeting rooms owned by the council or Marie Curie. The Lancaster University – Guidance for Lone Working (2007) was followed which included carrying out a risk assessment. Interviews were conducted during the day and a checking in and out process was used. A local emergency procedure was put in place using a nominated emergency contact. This person was contacted post each interview at an agreed time. They also had a copy of my location and could contact the venue manager if concerned and escalate as appropriate.

4.11 Conclusion

In this chapter the rationale for taking a qualitative approach and using IPA to explore the meaning home care workers place on caring for people with end of life care needs is presented. IPA enabled me to do an in-depth exploration of a small sample of home care workers who to date have little voice within published research. This population of health and social care staff are more frequently included as part of a wider group of health and social care professionals.

Purposive sampling was used to recruit home care workers providing care in the community to people living with end of life care needs. Participants were recruited from councils, independent providers, and Marie Curie. Semi-structured interviews were conducted with eight participants. IPA was used to analyse these transcripts. Ethical guidance was considered and followed throughout.

Chapter five will outline and explore the findings.

Chapter Five: Findings

5.1 Introduction

Chapter four outlined the methodology and methods used to undertake the study. A qualitative approach was taken using IPA to explore the experiences of home care workers' caring for people approaching the end of life at home. In this chapter the key findings of the study are presented. An overview of the findings will be provided and the four master themes which arose from the data are explored.

5.2 Overview of the Findings

Interpretative phenomenological analysis (IPA) of the eight semi-structured interviews enabled four master themes to be developed. The four master themes are outlined below and the contrast between visibility and invisibility is threaded through all four themes in some way.

These four master themes will be explored in this chapter. Each theme will include relevant verbatim extracts from participant interviews. All extracts were anonymised and pseudonyms used to ensure anonymity for the participants. It is acknowledged that the themes do not include all components of a participant's experience in caring for people with end of life care needs but were created to answer the specific research question: what is the lived experience of home care workers caring for people with palliative and end of life care needs?

5.2.1 Cross case analysis and development of Master Themes

The process of analysis that was undertaken is presented in Chapter Four (section 4.7). The cross case matrix below (Table 5.2.1) highlights the superordinate themes developed following analysis of each individual case. By setting them out in this way, it enabled me to explore the similarities and differences across the cases, and assisted in developing master themes which represented the experiences of the whole sample. Examining these in depth enabled me to understand in detail where the connections and disconnections were, resulting in four master themes being developed. The first master theme, *"You are really on your own": Coping with isolation when providing care in the community* explores home care workers experience of isolation which was significant across all participant transcripts, and the strategies they used to cope. The second theme *"You just treat them, you know, like they're still alive": the value of ritual for home care workers when caring for the dying and the dead* developed as, across all transcripts, the importance placed on rituals as a way of managing emotional distress when journeying alongside families at the end of life was clear. These informal practices were often relied upon by home care workers and based upon personal beliefs. Of the participants who explored grief and bereavement, this was viewed as an inevitable part of their role and that the responsibility to cope rested with them as individuals. From analysing these transcripts, the third master theme *"I wait and cry most times in the car": Understanding the impact of grief and bereavement on those delivering care* developed. Organisational influence in terms of how it made people feel to work within an organisation echoed across all transcripts. There was a strong sense of unclear role boundaries creating disempowerment, resulting in a loss of professional identity. The organisational culture for all participants contrasted between the perception of strong organisational control in certain areas but in others a perceived lack of organisational support. The fourth theme *"These are the rules, no matter how frustrating you just have to follow": frustrations with organisational influence and control within community care settings* explores this in greater depth.

Table 5.2.1 Cross Case Analysis

	The burden of Isolation for the HCW	**How people coped with isolation?**	**Bearing witness to people's death story - the importance of care rituals and informal practices in managing emotional distress**	**Emotional avoidance and coping**	**The unaddressed impact of grief & bereavement for the HCW – inevitability and a personal responsibility to cope**	**How an organisation disempowers**	**Self as a 'nurse' - Lost Identity**	**The unwritten rule book – working in a culture of organisational control contrasting with a lack of organisational support**	**The contradiction of age and ageing – navigating the role and the workforce**
Mary	Emotional impact of lone working	Wanting connection through shared learning and peer support Seeking professional connection	The story of dying – the intimate observer Navigating unanswerable questions Care Rituals	Reluctance to face or explore emotional response to death	Emotional labour Compassion fatigue	Preparedness in response to role uncertainty Negotiating the balance between knowledge and unclear role limitations	Loss of identity Attachment to nursing role Nurse as expert Unsupported	Public image of professionalism and competence vs private persona Sense of powerlessness and organisational control Inauthentic and authentic self Lack of organisational support	Age impacting perception of self

	The burden of Isolation for the HCW	**How people coped with isolation?**	**Bearing witness to people's death story - the importance of care rituals and informal practices in managing emotional distress**	**Emotional avoidance and coping**	**The unaddressed impact of grief & bereavement for the HCW – inevitability and a personal responsibility to cope**	**How an organisation disempowers**	**Self as a 'nurse' - Lost Identity**	**The unwritten rule book – working in a culture of organisational control contrasting with a lack of organisational support**	**The contradiction of age and ageing – navigating the role and the workforce**
Patricia	Geographically, professionally and emotionally isolated	Wanting connection through shared learning and peer support Disconnection vs need for proximity -the need for connection with management	The story of dying – the intimate observer Navigating unanswerable questions Caring across a trajectory The weight of responsibility Care Rituals	Balancing emotional self protection and self-care The need to access external supports	Emotional labour The need for mourning and participation in death traditions Cumulative loss Compassion fatigue Gagged	Preparedness in response to role uncertainty Negotiating the balance between knowledge and unclear role limitations Role ambiguity Overwhelmed	Loss of identity Attachment to nursing role Professional pride in the HCW role	Public image of professionalism and competence vs private persona Sense of powerlessness and organisational control Rule breaking Hostile learning environment Lack of organisational support	Age impacting perception of self Age aligned with perceived experience

	The burden of Isolation for the HCW	**How people coped with isolation?**	**Bearing witness to people's death story - the importance of care rituals and informal practices in managing emotional distress**	**Emotional avoidance and coping**	**The unaddressed impact of grief & bereavement for the HCW – inevitability and a personal responsibility to cope**	**How an organisation disempowers**	**Self as a 'nurse' - Lost Identity**	**The unwritten rule book – working in a culture of organisational control contrasting with a lack of organisational support**	**The contradiction of age and ageing – navigating the role and the workforce**
Jacqueline	Emotional impact of lone working Geographically, professionally and emotionally isolated	Wanting connection through shared learning and peer support Trust strengthening connection to management	The story of dying – the intimate observer - "I bore witness to it." Burden of doing the right thing Care Rituals	Balancing emotional self protection and self-care "There is too many people to remember them all."	Emotional labour The need to mourn and participate in death traditions Disconnection between grief and mourning	Preparedness in response to role uncertainty Negotiating the balance between knowledge and unclear role limitations Role ambiguity		Sense of powerlessness and organisational control Perception of lack of organisation support	
Mairi	Professionally isolated	Seeking professional connection	The story of dying – the intimate observer Caring across a trajectory Care Rituals	Reluctance to face or explore emotional response to death	Experience of trauma	Preparedness in response to role uncertainty Role ambiguity		Organisational control	

	The burden of Isolation for the HCW	How people coped with isolation?	Bearing witness to people's death story - the importance of care rituals and informal practices in managing emotional distress	Emotional avoidance and coping	The unaddressed impact of grief & bereavement for the HCW – inevitability and a personal responsibility to cope	How an organisation disempowers	Self as a 'nurse' - Lost Identity	The unwritten rule book – working in a culture of organisational control contrasting with a lack of organisational support	The contradiction of age and ageing – navigating the role and the workforce
Tracey	Emotional impact of lone working decision making	Seeking professional connection across organisational divisions Placing importance on shared learning and experience Connection through proximity to management	Caring across a trajectory Contradiction in caring for and journeying alongside at end of life	Emotional distancing through language "Death of a service user"		Dual roles creating confusion Replacing a professional role – a balance between knowledge and role limitations		Unmanageable organisational expectation A culture of compliance – organisational narrative Attachment to organisation Importance of public image	

	The burden of Isolation for the HCW	How people coped with isolation?	Bearing witness to people’s death story - the importance of care rituals and informal practices in managing emotional distress	Emotional avoidance and coping	The unaddressed impact of grief & bereavement for the HCW – inevitability and a personal responsibility to cope	How an organisation disempowers	Self as a ‘nurse’ - Lost Identity	The unwritten rule book – working in a culture of organisational control contrasting with a lack of organisational support	The contradiction of age and ageing – navigating the role and the workforce
Josie		Seeking professional connection across organisational divisions Connection through proximity to management Reliance on peer support	The story of dying – the intimate observer Care Rituals	Emotional distancing through language	Experience of trauma Emotional labour	Replacing a professional role – a balance between knowledge and role limitations	Loss of identity Identity aligned with AHP	Sense of powerlessness and organisational control Attachment to organisation The need to be compliant	

	The burden of Isolation for the HCW	How people coped with isolation?	Bearing witness to people's death story - the importance of care rituals and informal practices in managing emotional distress	Emotional avoidance and coping	The unaddressed impact of grief & bereavement for the HCW – inevitability and a personal responsibility to cope	How an organisation disempowers	Self as a 'nurse' - Lost Identity	The unwritten rule book – working in a culture of organisational control contrasting with a lack of organisational support	The contradiction of age and ageing – navigating the role and the workforce
Karen	Preference of working alone contradicted by the emotional impact of lone working Professionally isolated – value not recognised by the MDT	Disconnection from management Trust in management	Caring across a trajectory The story of dying – an intimate observer Care Rituals	Emotional distancing through language	Experience of trauma - "It was horrific" The need for being able to participate in death traditions Emotional labour - "I wait and cry most times in the car" Attachment	Overwhelmed Role ambiguity ensures organisational compliance Frustration around role limitations – "I feel stupid"	Nurse as expert Lack of professional identity	Sense of powerlessness to impact organisational change Organisational control Disconnection from organisation due to poor working conditions Rule breaking Awareness of public image of the organisation Perception of lack of organisational support	

	The burden of Isolation for the HCW	**How people coped with isolation?**	**Bearing witness to people's death story - the importance of care rituals and informal practices in managing emotional distress**	**Emotional avoidance and coping**	**The unaddressed impact of grief & bereavement for the HCW – inevitability and a personal responsibility to cope**	**How an organisation disempowers**	**Self as a 'nurse' - Lost Identity**	**The unwritten rule book – working in a culture of organisational control contrasting with a lack of organisational support**	**The contradiction of age and ageing – navigating the role and the workforce**
Ruth	Emotional impact of lone working and individual decision making Professionally isolated	Disconnection from management Lack of trust in management	Caring across a trajectory The story of dying – an intimate observer The weight of responsibility Care Rituals	The need to access external supports	Cumulative loss Attachment Emotional labour	Negotiating the balance between knowledge and unclear role limitations Role ambiguity suits organisation		Public image of professionalism and competence vs private persona Disconnection from organisation due to poor working conditions Hostile learning environment Hidden policies Rule breaking Perception of lack of organisational support	

5.3 Master theme one: “You are really on your own”: Coping with isolation when providing care in the community

In this master theme participants felt that they were not only geographically isolated in terms of their working environment but also emotionally and professionally marooned. The emotional impact of lone working led to feelings of being burdened especially around decision making at the end of life. Professional isolation increased with a sense of their role not being recognised by other external health professionals. Participants actively sought connection with peers as a way of combating the perception of isolation.

All participants commented on aspects of their role as home care workers which resulted in them feeling isolated in some way. Geographical isolation was a particular issue for those participants who were based in a rural setting and were remote workers. Patricia provided an account which highlighted her reality of rural working when caring for people at end of life. “*Basically, there’s quite often an on-call district nurse or the GP. And you have to call them really, but they don’t help with last offices and things; you’re really on your own there because it is so remote.”*

Jacqueline also provided an account of her geographically isolated experience as a lone worker in rural Scotland. Due to her location, she could only access a limited amount of out of hours’ support. Moreover, she felt that, even when it was available, there was a reluctance on the part of the health professional to provide that support. Participants perceived this reluctance from other health professionals as a lack of trust in their role as a home care worker and their judgement.

> *“The GPs do come out if you call them out of hours, but it’s not every area* [that] *does it. If it gets to the point that I have to call them, yes, it [is] terrible. But I have to say they don’t seem too keen to come”*

Both accounts highlight how this geographical isolation often led to professional isolation, with a perceived lack of access to multi-disciplinary support for all the participants who worked rurally.

Even for those workers who were based in more populated areas, they also described feelings of isolation due to both their geographical location and at times fears for their own safety. As Karen was describing her experience of lone working, her tone and pace of language changed, suggesting a heightened level of anxiety.

> *"Personal safety for the carers at night [is important]. We've only got torches but a company I worked for previously, they gave you a rape alarm because there is some houses that I come out of and it's nowhere near the road, and it's dark. Obviously, key safes; trying to see a key safe in the dark. I sometimes don't feel safe when I'm at work."*

Fears around lone working and personal safety were common across both rural and urban areas. For some participants this was heightened when they had limited transport options. Karen discussed her peers who could not drive and therefore walked to people's homes and her feelings around this.

> *"They walk between it. They'll get a set rota and it's probably a couple of miles [in all] they walk. I'll never do this job if I couldn't drive because I wouldn't feel safe walking* [*at] ten o'clock, eleven o'clock at night."*

The emotional impact of lone working resulted in a feeling of fear and helplessness for some participants. Mary, who had previously been a registered nurse, described an experience of caring for someone who was experiencing significant levels of pain as they approached end of life. The reality of working within the limitations of the role with little access to prompt medical support could at times seem overwhelming for the participants.

> "*[The main symptoms that we struggle with are] usually pain, although sometimes secretions and agitation. And then you're into your other 'what can we do' which you've already tried beforehand anyway. [We use] distraction and heat and any oral medication that you may have that one can give. But, so I would say probably about half an hour to three quarters of an hour is pretty average [time we would have to wait for nursing support]. I mean I think [this]*

> *is one of the things I have probably found the hardest. In my previous life, I'd have administered symptomatic relief. And I can't do that."*

Patricia in her account repeated the phrase 'you're on your own' throughout the interview, as a way of emphasising the isolation she felt. This was interpreted as her perception of a lack of understanding by others around the challenges associated with working in this way and a sense of abandonment.

The experience of decision-making at end of life was described by participants, their need to make care decisions with little or no input from other health and social care professionals while trying to ensure the needs of the individual's family were met. The burden of this heightened the feelings of isolation. A perception of striving to do the right thing was common across the participants' experiences. Patricia highlighted this when describing a common decision with which she regularly grappled, deciding when and if to wake family members up when their relative was dying, making this decision in isolation without input from others resulted in Patricia feeling she was responsible if the relative was not present when their loved one died.

> *"Most relatives do want to go to bed even when the patients [are] very very ill. And they'll say can you wake me if there's any change. Most times we do it in time. But sometimes people can actually pass away very quickly, literally you turn your head and they are gone… [sigh and long pause]"*

For some of the participants this geographical isolation and emotional burden experienced as a result of lone working led to a perception of professional isolation. Karen described her experience of caring for a person with organ failure when she had no access to professional or peer support. Despite witnessing an event she perceived to be traumatic and experienced feelings of being overwhelmed with no access to immediate support, she was able to reflect on what decisions she was able to make in the moment which could provide some comfort.

> *"[I told them] he was actually drowning in fluid, so it was horrible. Honestly, it was horrific to just watch. I've never seen that before. I'm so used to different life-limiting diseases whereas I'd never seen that, and you can't even touch him he was in so much pain... although we are not trained nurses, we actually helped a lot. I gave my personal input and it made him comfortable."*

Karen's account repeatedly highlighted the professional isolation felt by home care workers when attempting to communicate with other health and social care professionals. All participants appeared to align their role more with family carers. Mary described her perception of this: "And we are…taking over the care that the family would otherwise provide." A clear sense emerged that they were working on the periphery rather than being viewed as an essential part of a professional health and social care team. Karen shared her experience of this, where she perceived her skills, knowledge and expertise to be ignored by the wider health care team.

> *"[Health Care Staff are] not there all the time, whereas we are. With my other job, I'm with some of my service users for hours on end. I know when their behaviour's changing, I know if there's a UTI, I know something's wrong. I might not be medically trained for that, but I know something's wrong."*

This sense of not being 'heard' by community health and social care colleagues or in some cases not being seen was echoed in Josie's account. She recalled trying to source additional support through a GP for a person for whom she was caring.

> *"There was a lady who was end of life, we weren't able to provide the care that she needed, because she needed more, and we didn't have capacity. This lady was in bed. She was just not*

> *getting enough. We tried to get her GP involved and his response was, "What would you like me to do about it?" [adopts dismissive tone]*

For all participants the desire to gain some recognition of their role from other professionals held some value and provided them with a sense of legitimacy. However, for most participant's appropriate external acknowledgement of their role was directly related to how connected they felt to the wider community health care team.

Due to the burden of isolation, all participants actively sought connection with their peers, usually through sharing their learning or seeking peer support in other ways. Jacqueline reflected on both the formal and informal ways in which she tried to connect with her peers for support.

> *"Well we have quarterly peer, well clinical supervision with a supervisor leader and then other colleagues. So that's peer supervision. And I would say maybe twice a year we have team meetings. But that's the sort of formal part. I believe you know there's a couple colleagues that I talk to quite regularly…"*

Participants focused on the need to seek connection through learning with others. Mary discussed styles of learning at length and expressed anger about the move to online courses. The need for her to remain connected to her peers was clear. Throughout the interview she used the collective opinion, for example "*from what I hear from other people*" and "*you know people are feeling...*" to demonstrate that her view was commonly shared by her peers. Her view of self was as a leader within the team due to her years of experience. This rhetoric against online learning appeared to mask an anxiety around this type of learning. The value of education, from her perspective, was based on being able to access peer support and to seek connection with a team with whom she would otherwise not be able to connect. Mary also seemed to be aware of the importance of being visible, and as a group attending education in this way emphasised their visibility. Other participants echoed this sense of needing to connect through learning. Mairi reflected on this in her account. *"I like face to face training. I hate the online, you can just skip it. You just click the answers and stuff like that. It's not real. [It is not] learning with real people."*

The need for social interaction with peers was viewed as difficult by most participants due to geographical isolation. Patricia described a rare social event on which she placed significant value.

> *"Even though I'm not much of a party person but if they're doing something I'll go. Because that's the only time we actually really get to… because we're lone workers. So really we don't see each other. So it's quite nice to get together and people have a laugh, they're a great bunch, a great team."*

Despite the nature of lone working, some participants still viewed themselves as being part of a team. Throughout the interview Patricia continued to use language such as "we try", "we're not prepared for" and "we're not really meant to." The pronoun use of 'we' indicates her sense of belonging and that she views herself as part of a community and professional group. This connection is at odds with some of the realities of the role, however seeing herself as 'we' again provides them with a place and a voice.

Participants also sought connection with external teams when trying to connect with their own team was perceived to be too difficult. They valued the support from other health professionals with whom they came into contact and placed themselves more centrally within a wider multi-disciplinary team rather than just the organisation for which they were working. This broader sense of belonging seemed to improve how they viewed their own role and increased their perception of feeling supported. By seeking support in this way, it again ensured they had some visibility and connection within the wider healthcare group.

> *"The hospice nurses, they've been great. If we need any support for whatever reason or any advice, we know that we can get in touch with the local hospice...I haven't had any issues with getting any support or help when it comes to anybody who is very end of life, it's normally quite good."*

In this theme, geographical isolation led to home care workers perceiving a lack of understanding and awareness from health care professionals around their role and the challenges they faced. This experience of professional isolation was evident through their perceived lack of access to out-of-hours support and a (perceived or actual) lack of willingness by other health professionals to provide support even when it was available. The emotional impact of lone working led to participants experiencing anxiety and fear in response to specific clinical situations related to geographical and professional isolation. Lone workers experienced a sense of burden and responsibility when delivering end of life care. However, how people coped with this isolation was also evident; recognition of their role by the wider health care team provided them with a sense of legitimacy and connection. Contact with peers through education and support also had a positive effect on easing the burden of isolation. Visibility is threaded through this theme, with a perception of invisibility when their role and contribution has not been acknowledged and the lack of immediate support options open to them left them feeling disconnected. However, this contrasted with their need to be visible, they sought connection through education, or sought connection with other professionals, being seen as an individual as well as a professional group held importance.

5.4 Master Theme Two: "You just treat them, you know, like they're still alive": the value of ritual for home care workers when caring for the dying and the dead

The theme brings together the value that participants placed on performing care rituals to demonstrate respect for the people and families for whom they were caring. Participants relied on these informal practices and their own beliefs about death to enable them to cope in the absence of formal training. Participants perceived that the burden and responsibility of the patient 'dying well' rested with them. The need to achieve this for every individual all of the time, resulted in people holding themselves to an impossibly high standard that could not always be met.

Participants described feelings of privilege in being able to care for people at end of life. Their accounts detailed the moments of intimacy they observed between the people approaching end of life and their family and friends. Being present for these moments, alongside the individual's family and in their home, created a sense of shared experience. This shared experience appeared to result in the participants placing great importance in showing respect for the individual but also in enabling them to be perceived as respectful by the family; moreover, care rituals were used as a way to demonstrate such respect and promote coping. Examples of care rituals varied between participants, but some were consistent across all participants such as 'last offices'. The ritual of last offices occurs when health care staff wash, dress and reposition people after they have died. Patricia described an experience she had had when doing this.

> *"Actually, the guy that I told you about that was you know cuddling his wife when she died. He went outside, and I said 'Would you like me to put her new jammies on and stuff like that?' And he said 'Yeah.' After I'd done all that, it took me about half an hour, he came in and he said. "Were you on your phone?" And I said no. He said "well who were you talking to?" I said 'I was talking to your wife'. [laughs] "*

Patricia laughed after this statement and humour was used by several participants when describing these rituals which appeared to highlight their discomfort when talking openly about this with someone they perceived not to be a peer. The use of ritual appears almost a private part of their care. They appear to use most of these rituals at the time of death or just after someone had died. The use of rituals seemed to form an important part of their coping strategy, it appeared to be considered and deliberate, assisting them with both their emotional coping and as a way for them to release tension. The repetitive nature of these rituals is what they found comfort in, reinforcing their feeling of remaining in control. This differed to humour which was used in a more reactive way, a coping mechanism home care workers appeared to use in the moment which varied in effectiveness.

Other examples of ritual included positioning of people after death, opening windows and doors to facilitate their soul to leave and placing flowers or certain complementary oils on the person's pillows. All rituals seemed well known within the participant group, learned from peers, or based on their own life experience rather than formally taught. It was interpreted that being able to complete these rituals brought comfort to the participants, thus improving their ability to cope.   Mairi reflected on this in her account. *"We don't really understand. All we're using is our own knowledge of it [death]. You're using your own knowledge to work it out pretty much. It can be quite hard. But these things help."*

The participants' accounts detailed a perception of feeling burdened with a responsibility of ensuring the person they were caring for died well. This sense of responsibility seems to be influenced again by the connection the home care worker had to the individual and their family, rather than an actual expectation of their employer. Mary reflected on her feelings of responsibility.

> *"Dreadful thing to say but you know we die once. Most things they have a second chance at improving even birth they [can] have a second birth [a second child]; you know it's a lot better. You die once and the person that dies, you want it to be as comfortable, peaceful as we possibly can but their relatives live with that for years. And you know we have a huge responsibility to ensure they're cared for and what they're seeing is not going to haunt them for years."*

The use of the term 'haunt' by Mary may have indicated a belief that a traumatic image at the end of life could result in feelings of anxiety and guilt for both the family carer and for herself, ultimately affecting the families' grieving process.

For one participant this sense of responsibility had an impact on her personal life. In her account, Ruth described that her decision around when to take leave was based predominately on the person for whom she was caring.

> *"The couple that I've been with, it's only me that's ever been in, and I've always worked my holidays. I was excited that at the beginning [because] he's like, I don't want anybody else to...I would rather it was just one person. I do two [night shifts]. He asked that I split them up, and I said I couldn't because it's hard enough getting back to a sleep pattern after. I haven't been able to do every single night, and he doesn't want to be left on his own, so he has had some days off in this week. He's had to accept some days off. I had to promise him [that it would only be me]. I said, I promise you. He's lovely. [laughs] I just worked my holidays round them, so instead of just starting on a Monday, I would start the holiday on Wednesday, or took like just the Saturday, or something, because I feel too bad for them."*

Ruth's commitment to her role seemed to influence her sense of self and self-worth. She felt valued by the people for whom she was caring, however this notion of exceeding expectations also implied that Ruth's own needs were not being met. Ruth appeared attached to the people she was caring for, to the extent of compromising time in her personal life to ensure she could meet the needs of the individual. In her account Ruth used different examples of how she demonstrated empathy to the patients and families for whom she cared. As in the example quoted above, there was an implication that due to her connection with the family carer, she would have to be the one to support the person to die well. It could be hypothesised that putting patients' and family carers needs ahead of her own to this extent could increase the risk of burnout.

5.5 Master theme three: "I wait and cry most times in the car": Understanding the impact of grief and bereavement on those delivering care

The theme aims to explore home care workers' reflections on their lived experience of grief and bereavement and the impact of the coping strategies they used. Participants commonly did not show emotion whilst delivering care; instead, this was done privately, if at all. Cumulative loss and experience of trauma brought a disconnection between their experience of grief and their ability to mourn. There was a perception that this was an inevitable part of their role, with the responsibility of coping placed solely with them.

All participants reflected on or described an experience of wanting to go back to visit the family after the person had died. Participants identified the needs of the families as a justification for these bereavement visits in most cases, however there also appeared to be a clear need of the home care worker to have some closure to enable them to cope and move forward. The implication through non-verbal communication was that participants were carrying out bereavement visits regardless of their organisational policy on it, sometimes in their own time. Jacqueline described her experience as to why this was important for her.

> *"But what I find lacking is a follow up when the person dies. And I just kept thinking, why can't we offer a cup of tea? And I know the reasons why but I think [I am] still robust enough to not get drawn into the family dynamic. I'd be happy to go have a cup of tea with someone after their loved one died. This, kind of, just acknowledges, we just went through this thing together. Or you just did and I bore witness to it. I was there part of the time or whatever. I feel in the human world of empathy and compassion, possibly some words of comfort these days. That to just walk away is not really compassionate."*

The connection that home care workers most valued was often the one they made with the family carers. Home care workers in the community appeared to struggle to break that connection with family carers in the early part of their bereavement, hence they placed importance on ongoing visits or attending funerals and memorials. This also appeared to support them in their own expression of grief, offering them an opportunity to share bereavement customs and provide them with a sense of closure. However due to the ongoing emotional labour in their role there was a limit as to how long they could journey alongside bereaved family carers. Jacqueline provided an example of this.

> *"I remember this one man. I never actually talked to him. He was completely unconscious on a syringe driver but I spent a lot of time with his wife. But I can't place her face in my head now, I can't remember her name but I remember making a connection. And the warmth towards her. You know there is too many people to remember them all."*

Throughout the transcripts participants detailed their physical reactions such as having a "tightness in my chest" and "a feeling of heaviness" as a more immediate reaction to grief. They also described experiences related to emotional labour, where they were surface acting while performing their caring role, and then had an outpouring of emotion when in private. Karen describes her experience of this.

> *"I found it really, really upsetting. I would have to take myself away and I would actually probably cry most times in the car driving to my next client. There was one day, it just got too much and my senior phoned me and she's like, "Come in the office so we see you," and they did, they made me a cup of tea, they gave me a cuddle. They were there."*

Interpreting this further visibility was important, in this experience Karen felt seen by the management team, and hence she then felt well supported. She placed value on this, reflecting on this as a positive experience where she was given space to express grief.

The shock experienced by home care workers when they felt a death was unexpected, in some cases resulted in an experience of trauma. Josie's experience of this had remained with her over a year after the event.

> *"The woman actually hung herself, and left a note to say that she was in her shed or her garage, it was actually. She had bled. That wasn't a very nice thing. On our keys and things, we've all got a little key thing (points to her keys) that we can phone up if we need any [help]..."*

In her reflection Josie appeared to downplay this experience to enable her to cope with what she had seen, and potentially what she could encounter again. Instead of exploring the emotions attached to this experience, Josie used avoidance to instead focus on something more tangible, the safety alarm.

The participants also touched on their longer-term experiences describing both personal accounts and experiences shared by their peers. An excerpt from Mary's transcript below detailed her perception of the cumulative loss experienced by home care workers over an extended period and how providing training could help with coping.

> *"Because people can tick along very nicely and then suddenly for some inexplicable reason they hit a brick wall with dealing with bereavement. And there's no formal path, and if it's raised then it's you know, 'they can come and talk to us.' You know there's this person, there's that person but I feel we could equip people better with coping mechanisms and skills in how to not desensitize, because my goodness that's the last thing you want, uncaring people".*

The effects of this type of loss over time could not only result in psychological crisis for the individual but also lead to burnout. Patricia provided a personal reflection of her own experience of cumulative loss.

> *"It is challenging. I mean just after Christmas I think I got too many sad cases and they all died. There are times when you think 'can I do this?' I haven't got a big enough heart to hold all of this and you can get really really sad and feel really down... I still find, I still find it, a lot of it quite painful and quite difficult to cope with. I do cope with it but it tells on you."*

Patricia may have used the term “big enough heart” to indicate her emotional connection with patients, the grief and loss she experienced when people died was therefore felt very personally. This grief appeared to be cumulative in nature and not openly acknowledged within society. The use of repetition throughout seemed intentional as Patricia’s non-verbal communication- including her tone, rapid speech at times when becoming distressed and then using extended pauses to regain control of her emotions - mirrored the intensity in which she had struggled with the effects of cumulative loss.

Participants believed that experiencing grief and bereavement was an inevitable part of their role, with the responsibility of how to cope placed with them. Patricia reflected on this in her narrative.

> *“You actually do go through a sort of degree of grief with some of these patients. It's just really sad. It just is. And you just sort of feel like I can't, that's why I don't do any more than about four or six shifts a month because I just get too, I’ve got over involved once or twice and that’s a big mistake. A big mistake. You know I think a lot of us are guilty of that.”*

Ruth repeats the term “big mistake” to emphasise her perception of the gravity of the situation they could face should they become overly involved with the person for whom they were caring. She alluded to this throughout her narrative to signify she had previously experienced significant distress or burnout from which it was difficult to recover. This was also evident in Ruth’s reflection of her own experience of attachment, where, again, she lay fault exclusively with herself. From the extract she also used repetition to emphasise the time spent with the person as a way of having to justify the connection.

> *“I was with him for a year and a half. It was like, I think it was three shifts a week at night. It was like quite a lot...quite a lot of time I was with him. That was really hard. I do get attached to them. That's my problem. I think I'm just that person that gets attached to folks.”*

Ruth viewed her connection to individuals she was caring for as problematic as opposed to being a more normal part of her role, and a quality the individuals and their families may have valued most. Ruth expressed feelings of guilt over her attachment to people and viewed her experience of grief as a personal issue, placing all of the responsibility with her.

Home care workers' experience of grief and bereavement appears to be significant. They tried to cope through taking part in bereavement customs such as funeral attendance and seeking ongoing connection with family carers through the provision of bereavement support visits, often done in their own time. The emotional labour experienced while providing end of life care results in the individuals often only expressing emotion either in private or with their peers. The cumulative loss experienced by the participants resulted in them reflecting on the limited access to formal support that is available to them. This sense of grief and bereavement, as an inevitable part of their role, placed the responsibility for coping and seeking help solely with the individual.

5.6 Master theme four: "These are the rules; no matter how frustrating you just have to follow": frustrations with organisational influence and control within community care settings

Participants perceived a lack of access to organisational support for key aspects of their role. This contrasted with the level of organisational influence and control felt by home care workers from the organisation. The theme highlighted the perceived disconnection between the public image of the organisation and its workforce with the participants' reality of working within it. Participants described their perception of their organisation's public image as caring, person centred and professional. Participants provided accounts of ways in which they had become disempowered by their organisation. Role ambiguity created confusion and a sense of being overwhelmed, at times resulting in a loss of professional identity.

The perceived lack of organisational support across a variety of areas central to the home care worker role resulted in a perception that they were undervalued or, for some, invisible within their own organisations. Participants provided examples across transcripts relating to access to education and training, and management support.

All participants reported good access to online mandatory training, however recognised a lack of access to in-person education that would support them to care for people with end of life care needs. The strongly held perception among participants was that the organisational focus on training was solely linked to regulatory requirements, rather than supporting them in their role. This was evident in Karen's account.

> *"All we've got is, from another company we've got an online training programme. You've got nine mandatory trainings that you need to do. There's your course, your health [and] safety, fire, moving and handling, all that, infection control. Then you've got another 25 that are up to you if you want to do them. I always choose the grief and loss and the palliative care ones because I've always been interested in palliative care so I always do them. That training, it's only online, there's nothing [face to face]. Nothing. You never get sent on courses or anything like that."*

"Nothing" was repeated for emphasis to highlight how limited her training options were. Karen's tone underlined her frustration. Interpreting this further, there was a sense that this was another way in which the organisation had demonstrated how undervalued this group of staff were, through their lack of investment in them.

For some participants the need for further education in palliative care resulted in them self-funding this and completing it in their own time. Jacqueline described the financial implications associated with this.

> *"Because I've done quite a lot off my own back recently. But that was right for myself [but] I'm not going to do any more for a while. I went out of my own interest which is fine but, you know, it is expensive!"*

The need for compliance in completing mandatory training and the perceived lack of access to in-person education resulted in participants feeling under-supported in their development and at times undervalued as employees. Some participants also reported that the internal training that had been provided around palliative and end of life care was not perceived to be of an adequate standard. Mairi explored her experience of this.

> *"We've got [name of team member] who is doing a training thing on palliative care. We're doing that now. We've had one session of that already. But that's just another girl on our team, who's went on a course who's doing it so she's not actually [got a] palliative care background. So, it's not as if we're getting proper…specialist training which would be better."*

There was a reliance on peer learning rather than being able to access appropriate training, which appeared to leave the home care worker feeling vulnerable and underprepared. Mairi reflected on this:

> *"When the families are upset, depending on how the relationship is with you, how to speak to them, to keep them right and then somebody else had said they know exactly what to say. They know the things to say. Whereas we were like, well we sometimes copy what you're saying, to reassure them [the patient or family carer], because we don't have a clue what to say. We're just kind of learning off each other. Yes, we're kind of just learning off each other."*

Participants reported access to clinical supervision as a positive support. For those who were able to access this, they reflected on their belief that clinical supervision could be time-limited or precarious in some way due to their organisation prioritising other projects or staff groups financially. This perception of a lack of ongoing monetary investment by the organisation in this type of support was outlined in Mary's account.

> *"So I personally enjoy that but, also if I had to stop tomorrow, I am accepting of that. Because again, it's an intrusion into my own time as well. So, we always got paid for it, even when it became non-mandatory they continued to pay. And I don't know if they'd have said 'you're not going to be paid', I don't know what the take up would have been. But two hours of an auxiliary's pay is not very much anyway. You know for the inconvenience. But anyway, that's the stage it's at just now, they're asking staff if they wish to continue with clinical supervision."*

Participants seemed to have a level of mistrust around clinical supervision provision but appeared to find this difficult to articulate. Their non-verbal behaviour, such as eye rolling, hushed tones, and other facial expressions, appeared to indicate they were hesitant to criticise their organisation openly.

Management support was perceived as important for participants, despite many describing feelings of disconnection from their leadership team. Participants desired proximity, a wish to be physically close to their manager to access support however, this was not always achievable. Jacqueline discussed this aspect in her account.

> *"[The registered nurse] is highly valuable to the whole operation. She's one step below [the Manager] in my area. I can contact the [Manager] as well but I try not to as she's so busy. I can contact [the Registered Nurse on the phone] when I need to. Unfortunately, we do not have a base [close by.]"*

Some participants tended to refer to their manager using part of their role title rather than their name. Terms such as "Senior", "Sister" and in some cases "the office" gave them a distinct remote status, emphasising the lack of any meaningful relationship with them, in a way dehumanising them by only acknowledging their role or seniority. The culture within the organisations they were working could have contributed to this or normalised it in some way.

Participants reported that trust strengthened their connection to management but for some a lack of trust distanced them further from their organisation. Ruth described her lack of trust in her managers.

> *"I don't really speak to my office much at all. Every time I go in for a supervision, we just kind of get on with it. [laughs] I'm glad that I've never needed to be in the office. They'll just bring you in and ask if everything is all right [for a courtesy short visit]. Usually, it's more for the Care Inspectorate [national regulator for care services in Scotland]. I think, I guess because they have asked them to do it."*

This experience was common among participant accounts where relationships with management appeared to be distant, with little trust placed in them. These accounts often aligned the manager firmly with the organisation, rather than connected in any meaningful way to them or their team. The care for the home care worker in these cases appeared inauthentic and driven by a different agenda.

There was a perception that some of the information technology systems used by organisations also appeared to distance home care workers from their managers and in turn their organisation. Karen described the electronic system that her organisation had in place to manage her schedule via an app. This resulted in her not having daily contact or support from her management team unless she actively sought it out.

> *“We’ve got an online system where they just send your rota to an app so that I know where I'm going. If I'm doubled up with another member of staff, it's got the staff's phone number and it's also got the service user's address on it so that obviously we can meet with key safes and a list of really what you've got to do... [I only go into the office] if I'm going to dip my nose in and annoy them, but other than that, no, you're on your own.”*

For Karen this way of working created a greater disconnect between her and her line manager and the broader organisation. When interpreting this further, her sense of seeking connection even for brief periods meant the onus was placed on the individual home care worker to seek out management rather than the other way around. However, some participants did acknowledge a greater connection to their line manager and recognised the support they provided to them on an individual basis. Elizabeth provided an example of this, “the senior nurses talk to the staff quite a lot and pick up on, how you’ve been after maybe you’ve had a couple of deaths, maybe after the death they know there has been a difficult situation. So they are really good…”

All participants were shift workers who required some management support out of hours to be available in case organisational assistance was required; this differed from seeking support for clinical advice which they would seek from other channels as outlined in the earlier theme. The level of support available from the organisation compared to how comfortable the participants felt accessing it appeared to differ. Patricia explained this in her account.

> “[There are] all sorts of strange things that there are rules and regulations [for]. But yes, I mean, usually yes, they're there if we need advice. But usually, they don't really like being woken up (laughs) to be quite honest.”

The implication was that despite overnight management support being technically available to them, they were reluctant to access it and there was a perception that calls for support to managers were not encouraged.

This perception of feeling unsupported by their organisation was contrasted at times with the level of organisational influence and control felt by home care workers. Rules and regulations were referred to by all participants alongside language such as “we are allowed to” and “we are not allowed to.” Participants often described organisations as “strict”. Josie used this terminology when discussing training. *“[Anyone that] starts will get their basic moving and handling, as I say the [organisation] are really quite strict with their training, [it] has to be all up to date, always!”*

However, rule breaking was implied through language by all participants, for instance “we are not supposed to” was used across a broad range of subject matter, from bereavement support to clinical care. Examples given by participants included additional or extended visits or contact which was done outside of working hours or at personal financial cost.

For those participants who worked day shifts there was a perception of organisational control in relation to length of visits with little regard for the person or their condition. Participants reported feeling anxious and frustrated at having to work under such strict time restrictions, given how unwell the people for whom they were caring were. Karen reflected on her own experience of this.

> *“I'm set to a time limit. I've got 15-minute calls, I've got half-an-hour calls, 45-minute calls, or whatever... I'm constantly rushing about and then if you run into traffic, it's ridiculous. Then you get to the service user's house and they're angry because you're late, but you've then got to then leave early because you've then got to get back on to [Scottish Town] and into the car for the next one. There's a lot of pressure.”*

For some participants there was a clear contrast in how they perceived their organisation. In one sense the organisation was deemed as ‘other’; it had overall awareness and they perceived that organisational rhetoric had to be followed. This was despite their narratives highlighting that the organisation was blind to the challenges of their role. At times it felt in the early part of some of the interviews participants were following a script as their responses seemed inauthentic and contrasted what was said later in the account or after the audio recording had stopped. However, there appeared to be a sense of organisational attachment, which is highlighted in Tracey’s account.

> *“We've had catheter training, we've had stoma bag training, you name it we've had it. We do, do online training as well, our fire awareness is online at the moment and we do bits and pieces... The backup is excellent with the [organisation]... You would get support straight away; you would get the support straight away.”*

The terms “support straight away” was repeated to emphasise this point. At the end of the interview once the audio recording had stopped Tracey then highlighted areas where accessing support may be more difficult, and what additional training and support was required, contradicting her earlier statement. She alluded to this later conversation in the recorded interview when she stated *“Is this on tape? Because I want to tell you this one off-tape.”*

In Scotland, home care workers have to be registered with the Scottish Social Services Council (SSSC) or working towards registration with support from their employer. Participants perceived this to be an additional layer of control implemented by both their employer and also the SSSC. Participants expressed both anger and frustration related to their perception that value was being placed on qualifications above experience. For example, Mary commented:

> *“Well I’ve been doing this job 15 to 20 years, are they not satisfied? You know, I’ve got an SVQ 2 at the age of 58, I don’t want to embark on this. Are they going to make me? So there’s*

> *a bit of frustration and you know people are feeling that, you know, why now? Really what difference is it going to make to their practice? And there's a lot of feeling that, because in [organisation], there a huge number of (I suppose they're everywhere) mandatory training but tick boxing, tick boxing, that this is another. You know actually our practice is good. It's not going to make any difference to how we perform, it's just so somebody can tick a box."*

The level of anger directed at the organisation from Mary possibly indicated a fear around loss of status and a perceived lack of control over change in relation to the new role requirements. Her perception of feeling undervalued is heightened by what she perceived to be bureaucracy. The use of repetition around the term "tick boxing" highlighted her anger, and her voice was also raised and the pace of her speech was fast. This appeared to cement her view that the organisation did not value people, but rather the systems in which they worked.

The accounts of the participants highlighted a perceived disconnection between the public image of the organisation for which they were working and the participants' reality of working within it. Patricia was one of the participants who openly reflected on the feeling of organisational pressure she experienced when trying to uphold the positive public image of her organisation.

> *"Because [organisation] has got a good name, so far, we've got to be careful we don't mess that up. People trust the uniform, they trust the people and so they just relax when we arrive."*

Despite often receiving limited grief and bereavement support from their organisations, there was an overwhelming sense of responsibility to represent their employer well. A need to protect the bereaved families from the lack of corporate response resulted in home care workers taking on this responsibility personally. Karen described this in her account of why she believed attending funerals was important.

> *“We all get information about the funerals, and it's up to us if we go. I always think somebody should go to represent the company because they've invited us into their house. We've got that rapport, somebody should go. It's a bit of respect, so I go to them. I still go and visit some of the families outwith my own time just because you get used to people.”*

Participants reported having to work multiple jobs due to minimal hour job contracts and poor conditions around benefits. Participants reflected on the need for organisations to maintain a caring public image, however the staff working within them did not feel particularly cared for or treated fairly for the role they performed. In her account Karen provided an example of this as she reflected on why she felt claiming for travel expenses to be too difficult.

> *“In our company, the drivers only get 50 pence an hour extra than the walkers and we don't get any travel time and you don't get any mileage. You only get mileage if you take a service user out. Even then, you've got to claim it. By the time you get it.... so I never ever claim it. The person who takes me usually buys me a cup of tea or something and that's just the way I do it. I never claim mileage. It's just rather than all the paperwork and then that person will get an invoice for the mileage but it's more expensive than what I get. The company takes a certain percentage and gives me a certain percentage of it. I would rather they just bought me a cup of tea or something. The girls that are walking, they don’t get paid for that time that they're walking either.”*

Organisational procedures were perceived to intentionally discourage home care workers from accessing the benefits they could claim. Onerous procedures, together with additional charges for the people for whom they were caring, created a sense that the organisation was deliberately obstructing people from their financial benefits associated with their role.

Most participants were trying to balance multiple jobs due to the poor salary associated with these roles. Karen explained in her account why she felt over stretched.

> *"I know that it's always good to have the extra training, but right now between obviously my two jobs, I don't really actually have a lot of time to fit all that in. I do about ten a week here and about 20-odd in my other job, but my husband works shifts and I've got three kids."*

There was a perceived lack of understanding by the public around the reality of the pay conditions within these caring roles. Participants appeared frustrated and angry at not feeling seen or heard by their employers. Ruth articulated this in her account.

> *"They have meetings every so often asking how we can keep staff and that's the problem that comes up every time is pay, mileage because they don't pay anything like that...That's how I ended up getting nightshifts because I told them I wasn't doing [day shifts] anymore because I was running my car into the ground. It was [the] petrol costs and just the timescale of being out. I worked all day and all night and getting rubbish pay for it."*

In addition to frustrations around salary and travel costs, participants also explained ways in which they felt they had become disempowered by their organisation. Individuals who had joined organisations with both experience and qualifications reported feeling unable to develop in the role or use existing qualifications, Mary reflected on the conversations she had had with some of her peers.

> *"Speaking to my colleagues, there's a lot of frustration because some of the girls have SVQ 3's. And when they came here with that qualification, they weren't allowed to do anything with it. So, this is a qualification that they maybe got ten years ago, they have it on paper. But they are doing exactly the same work as somebody who hasn't got anything, sort of…just the [organisational training]."*

For those employed in larger organisations there was frustration at the lack of consistency in policies and procedures across different sites. The participants felt this created a sense of imbalance around similar roles. However, there seemed to be a clear sense of powerlessness within their place in the organisation with no real ability to influence change. Mary discussed a clinical example of this.

> *"We are in this [service] not allowed to push the [syringe pump] buttons at all. It's just a visual inspection, which I take great…If [another service] can do this and get a very accurate recording.... But anyway (you know) being 'good girls' we just [do the] visual assessment and the usual checks of the content of the syringe."*

From Mary's use of "good girls," there is a lack of power associated with the feminine language she has used. It also infantilises them, children with no power. Her words and tone indicated begrudged compliance with the organisational policy rather than acceptance, and there was some fear of punishment.

Role ambiguity created confusion and a sense of being overwhelmed, at times resulting in a loss of professional identity for the participants. Patricia reflected on how she introduced herself to the person and family that she was visiting, in relation to distinguishing herself from a registered nurse.

> *"I mean it's one of these we're very very heavily drilled on, is to introduce yourself and say who you are and what you are. And you know I mean obviously a lot of the patients have got some degree of dementia as well, so they'll just say 'it's a nurse'. Often these patients have had so many people in, they've had carers and they're in uniforms, and we're in uniforms so usually you say "This is Patricia and she's the nurse that's going to be with you tonight. And that's enough for them."*

This reflection demonstrates a perceived lack of identity around the home care worker role and the challenges the public perception of the role causes. Jacqueline also reflected on where these boundaries must be made plain.

> *"Often they think I'm a nurse. I always remind them when it comes to medication. I can only do [prompting] because I am not a nurse. Well, they call us nurses, which is fine but, you know there is a line, there's a line here. And I think they're always a bit surprised."*

Participants reflected on how they attempted to work within boundaries of a role that was not always made clear to the public by their organisation. However, two participants also reflected on how their roles had been broadened and adapted to encompass previous allied health professional tasks. Josie reflected on her experience in her role replacing registered staff.

> *" It is a big job. It was very daunting. A few years ago, when we were asked to do it, but we've actually done it, and it's really enjoyable. We've had support from obviously, managers within the social work team. It is, it works. It's been working. Nobody's thrown us out just yet anyway (laughs)."*

Josie seemed connected to her role and proud of the change, however there appeared to be little consideration of any training needs that may be required since the change in her role. Expanded roles could be a cost-effective option for the organisation, however they could also add to a sense of lost identity, with people feeling isolated with limited peer support. Competence and how competence was assessed for roles which were ambiguous, created challenges for the home care workers and their service leads.

There seemed to be an unspoken expectation that home care workers would do more. Ruth reflected on having to care for a married couple, despite only supposed to be caring for the elderly lady. She was able to reflect on and articulate this sense of burden. *"She's actively dying now. This past week we've been in quite a lot. The husband was just diagnosed with Parkinson's as well. It's like we've got it all."*

The lack of access to organisational support for key aspects of their role created a sense of feeling undervalued. Participants held a level of mistrust against their employers related to an assumption that decisions around training and support were made for bureaucratic or financial purposes. The perception of their organisation having control and being inflexible was highlighted by participants, which sometimes resulted in rule-breaking. However, there remained a strong attachment to their employers which at times resulted in participants providing inauthentic responses which they later contradicted. The sense of anger and frustration directed at employers as a result of sector-wide governance changes was evident. Despite this, participants had a clear sense in needing to maintain the public image of the organisation for the sake of the people for whom they cared. Some participants clearly expressed in their accounts why working for these organisations did not feel caring and compassionate. The lack of financial benefits and the need to work multiple jobs to stay in the role resulted in participants feeling unheard and unseen. Participants appeared disempowered within their organisations, unable to develop fully in their role unless the organisation required their role to expand to include new tasks. This sense of role ambiguity created confusion and a sense of not having any reliable boundaries within which to work. Organisational power and the limited ability of home care workers to influence or contribute to change resulted in them feeling part of an invisible or forgotten workforce.

5.7 Chapter Conclusion

Four master themes were explored within this chapter, firstly “You are really on your own”: coping with isolation when providing care in the community. Through this theme the notion of geographical, emotional, and professional isolation experienced by home care workers was explored. Out of hours’ support was viewed as precarious, with the perception of a reluctance by other external health professionals to provide support and the perception they were not trusted by them which resulted in experiences of fear and helplessness. Decision making in isolation contributed to the sense of feeling unseen. The competing elements of connection and disconnection were pronounced throughout this first master theme. Their self-worth and their professional self both appeared to be influenced by how they were seen and valued by others.

The second master theme “You just treat them, you know, like they're still alive”: the value of ritual for home care workers when caring for the dying and the dead explored the value participants placed on performing care rituals when people were dying or had died. Within this theme the strong notion of the home care worker perceiving that they had done everything possible to ensure the individual died well and their family were supported was explored. There was a sense of privilege and pride in their caring role which positively influenced their self-worth and sense of self. Caring was interpreted as a shared experience with the family, and the connection to the family of the individual they were caring for held significance and importance for all participants.

The third master theme, “I wait and cry most times in the car”: Understanding the impact of grief and bereavement on those delivering care, examined grief and bereavement and the impact of coping strategies used by home care workers. Participants often waited until they were in private before they displayed any distress. Emotional expenditure was perceived to be an expected part of the role by the participants which could increase the risk of fatigue and burnout. The experience of cumulative loss described by participants was evident. Interpreting this further home care workers’ grief could be viewed as disenfranchised as it was often not formally recognised, resulting in variation in their ability to mourn. Examples such as funeral attendance and ongoing contact with family members which was often hidden were explored. Support for grief and bereavement was largely viewed as the responsibility of the individual, therefore there was an expectation that they would rely on their own self-care strategies, if they had any. The notion of connection to surviving family members was viewed as important, but for some who recognised the ongoing emotional labour related to their role there was a clear need to disconnect at some point.

The fourth master theme, “These are the rules, no matter how frustrating you just have to follow”: frustrations with organisational influence and control within community care settings, explored the experiences and challenges participants had while working within their organisation. For many there was a sense of a lack of organisational support, despite there also being a perception of organisational control and influence. There was a sense of mistrust for many of the participants in their organisations across a variety of areas. For example, there was a perception that the mandatory training offered was offered to meet regulatory requirements rather than increase or support the knowledge of individual workers or teams. Similarly, it was considered that formal support, such as clinical supervision or one to one support was conducted to meet the standards of national regulators rather than support them as home care workers. Participants reflected on the poor pay, challenging job contracts, lack of benefits and the need to work in multiple jobs resulted in them feeling disempowered but also unable to influence change from their position within the organisation. Role ambiguity was evident from each individual participant's account, which seemed to result in home care workers doing more than what would be expected by their employer not less. Despite any frustrations expressed, participants' concerns always remained with the people and families they cared for. In this theme this can be seen in their concerns around time limited visits for people who are living with end of life care needs and require additional support.

In the next chapter, the findings are discussed in relation to published literature and theory.

Chapter Six: Discussion and Conclusion

In this chapter the key findings of the study are outlined and discussed in relation to the literature review included in this thesis and wider published literature. The study focused on the individual experience of home care workers caring for people approaching the end of life. Consideration of what the study has contributed and how it relates to theory will be explored. The chapter concludes with the study limitations, consideration of future research opportunities and my own reflections on the study.

6.1 Overview and Significance of the Study

This IPA study aimed to explore and understand the experience of home care workers caring for people living with end of life care needs at home. Data collection was undertaken using semi-structured interviews. The hermeneutic literature review (Chapter Three) highlighted the limited amount of published research available which focused specifically on this workforce and their experiences of caring for people with palliative care needs. To my knowledge, this study is the first in-depth qualitative study examining the lived experience of home care workers caring for people with end of life care needs. Previous studies in the area included home care workers as part of a larger sample of health and social care professionals, thus conflating their role with others, or have examined their role using a different methodology and have not taken an in-depth qualitative approach. This IPA study, due to its idiographic focus, allows the home care worker's voice and experience to be heard and acknowledged. In the UK, home care workers are central to delivering end of life care in the community (Hanna et al., 2021). Gaining further understanding into their role is crucial. There is a care crisis across the UK (Age UK, 2023), so understanding the home care worker's experience and how they could be better supported is essential to ensure people die at home with support.

The primary aim of the study was to examine the lived experience of home care workers who are delivering care to people living with end of life care needs in the community in Scotland. Chapter five presented the findings of the study. The four master themes were:

- “You are really on your own”: Coping with isolation when providing care in the community
- “You just treat them, you know, like they're still alive”: the value of ritual for home care workers when caring for the dying and the dead
- “I wait and cry most times in the car”: Understanding the impact of grief and bereavement on those delivering care
- “These are the rules, no matter how frustrating you just have to follow”: frustrations with organisational influence and control within community care settings

The four master themes of the study will now be explored by relating these to the aims of the research and considering how these findings relate to published literature and theory. Exploring the experience of home care workers caring for people at home with end-of-life care needs was a central aim of the study. All participants in the study reflected on their experiences of isolation, working in the home environment, and how this had impacted them.

6.2 “You are really on your own”: Coping with isolation when providing care in the community

My findings suggested home care workers were geographically, emotionally and professionally isolated. Geographical isolation associated with rural working was common across the sample. Rabbetts et al. (2020) carried out an integrated literature review focusing on nurses’ experience of providing home based palliative care in a rural setting. They identified that the wellbeing of nurses working in rural areas due to geographical and professional isolation needed to be carefully considered, with calls for awareness raising around the signs of burnout. However, as with other generalist services, the infrequent nature of delivering palliative care made predicting the timing of delivering additional support such as debriefing challenging. Reid (2023) examined the experiences of adult community nurses delivering palliative care to children in rural areas of Scotland. She highlighted that the limited support mechanisms that were in place for nursing staff could lead to nurses becoming disenfranchised. In my study, Patricia highlighted in her account that even in locations when there was a doctor or nurse to call out of hours, her perception was they were reluctant to provide support. So for her she was somewhat accepting of the geographical isolation; however, it was the professional isolation which left her feeling deserted.

Professional isolation was prominent across participant accounts, and was not just related to those working in rural locations (Chapter Five, Section 5.3). O'Donnell et al. (2010) published a study examining practice nurses' and the impact of professional isolation. They found nurses who worked in GP practices with no wider nursing team around them were isolated. Their findings indicated that practice nurses who believed their training and qualifications were not being used to their full potential felt increasingly isolated. Some professional groups have managed to implement strategies to combat professional isolation. Barnett et al. (2013) found in their Australian study that there were benefits for GP trainees to join a virtual community of practice, which reduced their professional isolation and enabled them to share knowledge with their peers. Mwape et al. (2018) examined a WhatsApp discussion group for HIV nurse practitioners in Zambia, which they found was used effectively for both rural and urban based nurses as a way of sharing best practice and preventing professional isolation. Consideration of how home care workers could be effectively supported in the community to reduce professional isolation is required, peer support networks may be one of a number of strategies to consider. Patnowska et al. (2023) attempted to explore lone working practices for health care assistants in hospice at home services within one palliative care organisation in the UK; they highlighted that lone working could not only impact wellbeing but also the retention of health care assistants.

Carson et al. (2024) in their scoping review examined the workforce crisis in rural social care settings. Their findings highlighted that instead of focusing on recruitment and retention of staff within existing service models, greater innovation was needed in terms of how care is provided in rural areas. Edwards et al. (2022) echoed the need for a transformation across multiple social care settings. They highlighted some examples such as apprenticeships, care work ambassadors and the use of values based recruitment as ways to retain staff in these roles. Two participants within my study were working in roles that had been broadened to include previous allied health professional tasks and they reflected on the positive aspects of this, however their salary and benefits had not altered (Chapter 5, section 5.6, p. 116). Arguably being able to retain staff under such conditions is not viable. By asking home care workers to do more, increasing role ambiguity further, without addressing sector wide issues and exploring how resources could be used differently, is unsustainable. Critically for those working with people approaching end of life, it is unclear whether increased job satisfaction due to the type of care they are delivering positively influences staff retention. In my study, despite participants finding caring for people approaching the end of life one of the most rewarding parts of their role, the financial pressures associated with pursuing a career in home care resulted in them having to work across multiple jobs due to issues related to low salaries and minimal hour job contracts.

A workforce strategy for adult social care was developed by Skills for Care alongside the adult social care sector in England. Similar to the systems in other developed nations social care in England is complex. The purpose of developing a workforce strategy was to unite key stakeholders such as national and local government, care providers, regulatory bodies and organisations, which support the social care workforce (Skills for Care, 2024). One of the key themes explored in their strategy related to the recruitment and retention of staff, through the call to improve pay and working conditions, workplace culture and the wellbeing of people delivering care (Skills for Care, 2024). Presumably, due to the number of stakeholders involved across social care in England, a range of job titles are used when describing this workforce within the framework. Arguably, this is an ongoing obstacle for home care workers as there is a challenge to harnessing a collective voice in the way in which other professional groups can (Johnson et al., 2021). Pay, working conditions and workplace culture have also been uncovered within the literature review as significant for home care workers (Chapter 3, section 3.6.1 & 3.6.2) and the study findings (Chapter 5, 5.3 & 5.6). Bottery and Mallorie (2024) highlighted in their article for the King's Fund, a third sector organisation based in England trying to improve health and social care, that vacancies across social care dropped as a result of international recruitment. However, due to high levels of inflation across the UK, this ultimately meant a pay cut for many working in the independent sector (The King's Fund, 2024). The lived experience highlighted by some of my study participants of having multiple roles across different sectors has also been highlighted by The King's Fund in their example that people working within social care can be better paid in the retail sector doing entry level roles (The King's Fund, 2024). Given the complexity of caring for people at end of life, the home care workers' lived experience of isolation and the challenges they face more broadly in my study, it is no surprise that retaining people in these roles is extremely challenging. Arguably it makes studies which focus on home care workers' perspective important, highlighting not only their lived experiences of caring for people approaching end of life but also the emotional impact of the role.

6.2.1 Emotional Isolation and decision making

The emotional impact of lone working caused feelings of fear and helplessness related to the limitations of the role. This was especially evident when participants reflected on experiences of caring for people approaching the end of life who were in distress and their decision making around trying to manage this. Edberg et al. (2008) examined nurses' experiences in caring for people living with dementia. In their study, nurses experienced increased strain as a result of being unable to provide effective symptom relief or due to communication challenges when delivering physical care that inadvertently increased patient distress. Challenges in balancing the competing needs and priorities of the individual and their family also added burden. Although these findings are aligned with some of the experiences of home care workers, very limited published literature has included the concept of burden leading to isolation in relation to decision making by home care workers, making this a novel finding for this study. The burden of decision making around assisting with symptom control to alleviate suffering, enhancing quality of life through holistic care and providing family support to ensure the patient died well were expressed by all participants. It was notable from participant interviews that the sense of responsibility in relation to decision making came from the participants themselves. These decisions also had a longer-term impact for some participants, reflecting back on these decision-making moments which they perceived were made in isolation as the only health professional in the home connected them with their experience of grief for the people for whom they had cared. From my interpretation, there was no expectation or awareness from the participants that the burden they described could be improved or indeed reduced by their organisation or the wider care system, instead they believed they needed to bear this burden alone. Perception of job stress, experiences of grief and type of coping strategies used were all factors which resulted in increased risk of burnout in nursing home and residential home staff in Harrad and Sulla's (2018) systematic review of the literature. Mockli et al. (2020) examined how the demands of the home care worker role influenced their levels of burnout in Switzerland. Findings suggested that work stressors strongly correlated with emotional exhaustion (Mockli et al., 2020). Judd et al. (2016) explored workplace stress and coping in a sample of Australian disability support workers and found that despite the perceived challenges of their role, if positive aspects could be celebrated this could help mitigate the risk of burnout in some way. Arguably, as a result of the emotional isolation experienced by home care workers in my study, they could also be at risk of burnout.

Burnout comprises of emotional exhaustion, depersonalisation and feelings of lack of personal accomplishment (Maslach et al., 2001; Maunder et al., 2022). Burnout not only affects the individual but also has wider organisational consequences. People who experience burnout have increased rates of error and deliver poor quality care (Vahey et al., 2004; Welp et al., 2015). Lammers et al. (2013) examined group, organisational and professional identities and their relationship to burnout in the IT sector. They found that people who felt they could be their authentic self within their work group had lower depersonalisation scores (Lammers et al., 2013). As home care workers can be isolated from their peers and other community professionals, this may increase their risk of burnout further. Findings suggested that even though the role was rewarding, the responsibility of someone 'dying well' and the need to hold themselves to account for this made this experience of care burdensome at times. Informal care rituals learnt from peers and their own beliefs around death appeared to strengthen their ability to cope with delivering this type of care.

6.3 "You just treat them, you know, like they're still alive": the value of ritual for home care workers when caring for the dying and the dead

This theme brings together the value that participants placed on performing care rituals to demonstrate respect for the people and families for whom they were caring. Participants relied on these informal practices and their own beliefs about death to enable them to cope in the absence of formal training.

The use of rituals by nurses were explored in other studies. Benbenishty et al.'s (2019) qualitative study on nursing rituals in the intensive care setting found that these practices were perceived by the nurse as personal and individual, however there were similarities in these rituals across the international sample. Benbenishty et al. (2019, p.289) described care rituals as the "inner world of nursing" which was also reflected in the findings of this study with home care workers. This private part of their care was held almost out of view. Other published literature around care rituals have both a cultural and spiritual care focus (Quartier, 2010; Maitland et al., 2012). Myerhoff (1984) highlighted the repetitive aspect of care rituals could provide an aspect of cultural order, giving meaning to adults and their families as they move through older age to death. For the home care workers who placed value on care rituals, there may also be an element of them trying to find meaning in death. Balmer et al. (2022) examined social practices and rituals of death in residential care and found there remains a notion that death marks a spiritual passing on, and the staff used these rituals to support each other and process this loss. Rituals can assist nurses when they face uncertainty which challenges them in their everyday world, and provides them with a sense of maintaining control even in situations where there is none (Strange, 1996). In my study care rituals were used as a way to demonstrate respect and dignity not only for the patient but also their family. Participants felt that family members were comforted in the care rituals that were carried out. Patricia highlighted this in her account when discussing her personal experience of a friend dying and the comfort those rituals had brought to her.

6.3.1 The burden of dying well at home

When home care workers reflected on their experience of caring for people with end-of-life care needs, all participants perceived caring for people in the last days to hours of life to be the most rewarding part of their role. This was echoed in the literature review findings and previous published studies conducted with home care workers where there was a sense of privilege in delivering this type of care (Bercovitz et al., 2011; Devlin & McIlfatrick, 2010; Poulos et al., 2017; Stone et al., 2013). The participant's role as a home care worker appeared to have a positive impact on how they viewed themselves. They viewed the role as important and this was supported by the families with whom they were working, which in turn increased their sense of self-worth. Pelham and Swann (1989) identified people's view of self and how they are framed, as contributing factors to an individual's global self-esteem. However, despite this, there was also a clear sense of burden in ensuring the person died well, both for the individual concerned but also their family. This perception of responsibility seemed to be directly related to the high standards home care workers had set for themselves, however these self-imposed standards could not always be reached.

Moreover, the findings highlighted that because of their awareness of the challenges of coordinating care in the community, and at times the limited number of people involved in care provision, for the home care workers themselves there was a real sense of responsibility on achieving a 'good death' not only for the individual but especially for the family carers. There was a feeling of being 'let in' to a family and so the onus was on them as individuals to ensure someone died well, in a way that it would not be if the person being cared for was in an inpatient setting. Due to the place of care, this close supportive relationship, which was built with not only the individual but also their family, was seen as a central component of their role. This sense of connection to family was found across all participant interviews in the empirical study.

The provision of emotional support has also been highlighted in the literature review findings (Chapter Three) as an aspect of care which is as important as the physical care provided by this workforce (Boerner et al., 2016; Lovatt et al., 2015; O'Sullivan & Harding., 2017; Reimer-Kirkham et al., 2016). Despite emotional support being central in their role, most participants in this study had not received any formal communication training, therefore were relying on their own clinical and personal experiences and skills and techniques that they had taken from peers to inform how they communicated with family members. This adds to the findings from the literature review, which highlighted home care workers experiencing a lack of access to formal end of life care training (Devlin & McIlfatrick, 2010; Eriksson et al., 2014; O'Sullivan & Harding., 2017; Reimer-Kirkham et al., 2019). The participants in the study appeared to value their self-sufficiency in terms of being able to fulfil their role in supporting the person to die well, often carried out using their own resourcefulness and in isolation from others.

6.4 “I wait and cry most times in the car”: Understanding the impact of grief and bereavement for those delivering care

All participants reflected on the impact of grief and bereavement in their accounts and this was also echoed in the findings from the literature review (Chapter Three). They collectively placed value on expressing grief through the ritual of mourning, even when this had to be done in their personal time. Participants described the importance of funeral attendance and bereavement visits, connecting and sharing this experience with the individual’s family. It appeared, in some cases, participants were seeking a sense of closure. In Zambrano et al.’s (2019) study examining funeral attendance of health care professionals in Australia, nurses were more likely to attend funerals for individuals they had cared for to gain closure. Another reason given was to show respect and support for the bereaved family. MacConnell et al. (2012) examined nurses’ experiences of providing bereavement support following the death of a child, and the need for closure for the nurse and the families they were caring for was perceived to be important. Participants in that study felt funeral attendance and bereavement visits carried with them a sense of closure. The experience of grief in the workplace can contribute to health professionals experiencing burnout (Lathrop, 2017).

Home care workers, as with other health and social care professionals, are also at increased risk of disenfranchised grief, as their experience of grief is not openly acknowledged and may not be viewed as significant by wider society (Tsui et al., 2019). Disenfranchised grief can be self-imposed or be influenced by societal or organisational norms (Bento, 1994). Doka (2005) defined disenfranchised grief as a grief that is experienced by the individual but is not openly acknowledged in society, affecting how publicly the individual can mourn. This manifested in different ways within my study. Participants described their experiences of grief, however their ability to express this grief was limited. Some participants attended funerals but often they had to do this in their personal time. Bereavement support visits carried out by most participants in the sample were often hidden from their employers and also arranged in their own time. This shared connection, and need to connect with the family who were also mourning, was viewed as important. An added issue for these participants was the cumulative nature of their grief, so the experience of disenfranchised grief could occur many times. Despite this, they were still attempting to support families informally after someone had died.

6.4.1 Home care workers experience of providing bereavement support to others

Chang et al. (2012) examined community palliative care nurses' experience and perceptions of bereavement support in Australia. They found that although bereavement support was viewed as part of their role, over fifty percent of the sample found it challenging due to excessive personal identification with the family, the emotional intensity often present and a lack of confidence or skill to manage the bereavement visit despite training. The experience of home care workers navigating this, with no training and little access to support, is alarming for the home care workers' themselves but also for their employer and potentially for the bereaved relatives for whom they are trying to care. Studies focusing on bereavement support in the community have highlighted that clinicians do not feel prepared to support bereaved relatives even when training was provided (Birtwistle et al., 2002; Morris et al., 2018; O'Connor & Breen, 2014; Pearce et al., 2021). Health professionals with personal experience of bereavement felt more confident in demonstrating empathy and providing support (Birtwistle et al., 2002; Chang et al., 2012; Johnson 2015). Home care workers who had personal experience in caring for friends and family who were dying did express more confidence in being able to provide bereavement support subsequently. However, the personal cost to their own emotional wellbeing is unknown. Emotional labour appears to be perceived as an accepted part of the home care worker role.

6.4.2 Experience of emotional labour

Emotional labour is defined as the management of an individual's emotions while in a work role (Gabriel et al., 2015). Emotional labour is the perception of when emotions should be shown and in what context, which is influenced by an individual’s workplace setting (Gabriel et al., 2015; Tsai, 2001). Surface acting and deep acting are two strategies used to manage emotional labour (Grandey, 2003). Surface acting occurs when an individual’s emotions are hidden while in a work environment, as outlined in the findings of the study by the home care workers. Deep acting occurs when an individual alters their feelings to conform to what they perceive to be acceptable (Gabriel et al., 2015, Grandey, 2000).

From my interpretation of the home care workers’ accounts, all participants seemed to accept that emotional labour was an inevitable cost of the job. Participants would surface act while performing care and only express their emotions in private. Surface acting and emotional labour was found to reduce an individual’s cognitive and emotional reserves, causing emotional exhaustion and leading to feeling discontent within their role (Grandey, 2000). Consideration should be given by employers around what support home care workers may need for the benefit of both the individuals but also the people for whom they are caring. Established social support, including an appropriate forum to share their feelings with peers and encouragement of self-care strategies, are some of the examples that were effective for other health care groups (Bush, 2009; Back et al., 2014).

6.5 “These are the rules, no matter how frustrating you just have to follow”: frustrations with organisational influence and control within community care settings

In this theme, a lack of access to organisational support and a sense of feeling invisible within their organisation was described. Interpreting this further, participants appeared to feel disempowered, especially in relation to their ability to influence or be part of any meaningful change. An example of this would be the perceived need for access to clinical supervision by some of the participants within the study. However, home care workers reflected on examples that seemed to indicate to them that there was little commitment to support clinical supervision due to the cost and the logistics of arranging it for such a dispersed staff group. The participants who explored having access to a safe shared space did not believe their views around whether it should continue would be ‘heard’ by their employer.

Clinical supervision has been established in the UK for over thirty years (Masamha et al., 2022). Clinical supervision is defined as a formal process of support and learning, achieved through reflection, to develop knowledge and competence which ultimately improves patient care (Masamha et al., 2022). Driscoll et al. (2019) highlighted that, despite challenges around implementation in the UK, clinical supervision in theory is still valued. Clinical supervision and debriefing have both been found to reduce the emotional impact of caring for people with end of life care needs (Campbell & Baernhodt, 2016). A call for more structured support such as clinical supervision for home care workers was also noted in the literature review findings (Campbell & Baernhodt, 2016; Devlin & McIlfatrick, 2010; Eriksson et al., 2014; O’Sullivan & Harding, 2017). These current findings suggested that clinical supervision was not widely accessed or available by the participants but, when it was offered, generated mistrust towards the organisation around how and when it was used.

6.5.1 Mistrust of the Organisation

The mistrust of employers was a common thread across the study findings, which also extended to some of the organisational policies including the lone working policies. There appeared to be mistrust from participants that these processes would be effective in keeping them safe. For example, participants had little training around risk management and had minimum accurate up-to-date information shared with them prior to their visit. Safety concerns for community-based staff are reported in the literature (McPhaul et al., 2007). Brennan (2010) published a rapid risk assessment tool that could be used by lone workers in community health care settings, which was developed following the murder of a mental health support worker in Newcastle, England.

International studies highlighted risk factors that were also explored in my study such as limited street lighting, people loitering and working in areas with illegal drug activity (Maneval & Kurz, 2016; Fazzone et al., 2000). Fazzone et al.'s (2000) qualitative study with fifty home care workers in the US found that from an organisational perspective, more robust enforceable policies were required to improve workplace safety. This sense of requiring more robust safety procedures indicated not only a lack of trust in their organisations, but also that they felt undervalued as employees.

This mistrust and perception of not being valued was also noted when some participants reflected on their experiences in accessing education. Participants reported a lack of accessible palliative care education, so for some this resulted in self-funding education which they attended in their own time. Participants' perceived education offered tended to align with regulatory and sector wide requirements of the organisation such as mandatory training, rather than reflecting the individual learning needs of the staff. Online mandatory training programmes had largely replaced in-person education. The standard of training on offer, when it was available, was deemed variable, with some examples of peers attending training and then being expected to deliver that training to their wider team. This emphasised the notion of feeling invisible within their role, with a perception that the organisation failed to invest in them therefore did not value them.

Despite home care workers perceiving themselves to be unseen by the organisation for whom they worked, conversely, there was also a sense of organisational control in certain areas of their role. This can be seen in the findings chapter (Chapter Five, section 5.6) where all participants referenced the rules and regulations they were required to follow. This was evidenced in both their reflections and also in the language they used such as "we are not allowed…" were commonplace. This created a culture where participants tried to circumnavigate particular rules or did not apply them in certain clinical situations. Rule breaking appeared common but appeared not to be used in a way that was deviant. Instead it was often used to try and assist the individual and family, or to minimise work for others. This finding is similar to studies undertaken in organisational research. Dahling et al. (2012, p.21) named this type of rule breaking *Pro-social rule breaking* and defined it as “a form of constructive deviance characterised by volitional rule breaking in the interest of the organization.” Rule breaking is commonly carried out in these circumstances to enable employees to assist their peers, to work more efficiently or to improve the service they offer (Dahling et al., 2012; Ghosh & Shum, 2019). In my findings, this can be seen in a variety of accounts, including Karen’s description of her attendance at funerals as a way of representing the company she worked for, despite her attendance not being entirely encouraged by her employer. Another example from my study came from Patricia who chose when she contacted the out-of-hours manager to ensure she could remain in a home to support an individual when the social circumstances were less than ideal. She prioritised the person approaching the end of their life above everything else. From the perspective of the home care workers, this type of rule breaking was perceived to be acceptable, however, there was acknowledgment that the perspective of their manager and the organisation would differ.

6.5.2 Organisation as Other

The notion of ‘othering’ the organisation was evident across all interviews. Othering can involve individuals or groups of people being viewed as different, it often involves an in-group viewing an out-group and attributing negative traits to them (Cherry, 2023). This can then result in distrust, reluctance to interact and the out-group being viewed as a group as opposed to individuals. In my study, the participants reflected on and discussed clinical experiences and their peers as distinct from their organisation. They discussed their organisation as an entity in itself; this was especially evident when related to how the organisations were perceived by the public.

For some participants their accounts highlighted a disconnection between the public perceptions of an organisation and their lived experience of working within it. There was clear organisational messaging in the early part of some of the interviews, which signalled some organisational attachment, but as the interviews progressed, arguably responses that were more authentic emerged focusing on individual or peer experiences. This was interpreted as the home care workers appeared to identify and align with their peers and their role rather than with their organisation. Lammers et al. (2013) study examined group, organisational and professional identity. They found that connection to the organisation was not as important as belonging to a "work group" and having a shared commitment to a specific activity (Lammers et al., 2013, p. 529). In the case of home care workers this would mean a connection to each other and a shared commitment to providing care to people at home at the end of life would be more significant than their connection to the organisation.

One way of strengthening a connection to an organisation is to examine work place culture. Work life models have been suggested as a way of developing a healthy workplace culture (Montgomery et al., 2019). One such model outlined six areas of focus which included workload, ability to influence, recognition and reward, feeling part of a community, fairness and values (Leiter & Maslach, 2003). When considering this in relation to home care workers, their workload can be significant and the study findings suggested they did not feel able to influence decisions out-with their own practice. Home care workers feel their role is rewarding but receive little reward or recognition for the job they do, outside of the praise received at times from the individuals they are caring for and their families. Their perception of being an invisible workforce does not suggest they recognise equity or shared values broader than their immediate peers. Models are often aimed at the professional workforce; however, there is a real need to examine the experience of other staff groups such as home care workers who are essential to the delivery of care.

6.6 Introduction of Conservation of Resource Theory

The four master themes from my study were explored in this chapter and related to published literature and literature review findings. The findings outlined the home care workers experience of geographical, professional and emotional isolation while working in the community. I also explored the burden experienced by home care workers in delivering end of life care and the value they placed on care rituals to enable coping. An examination of how delivering this type of care impacted their own experience of grief and bereavement was discussed. Their attachment to the organisations in which they worked varied, affecting not only their sense of connection to the organisation but also their trust in it. The next section considers these findings in relation to a relevant established theory to uncover if theory can contribute to our understanding of how the home care worker can maintain themselves and thrive in this role despite all of the challenges they face. Conservation of resource theory may help to develop understanding on how individual home care workers can aim to protect and build resources to assist them to cope with stress and build well-being.

6.6.1 Conservation of Resource Theory

Conservation of Resource Theory is a theory that examines stress; it describes how individuals maintain their current resources and seek to acquire additional resources on which they place value, such as professional recognition (Hobfoll, 1989; Prapanjaroensin et al., 2017). The theory outlines an individual's reaction to environmental threats, either when existing resources are under threat, when resources are lost or when an individual is unable to increase resources despite investing time or knowledge (Hobfoll, 1989; Prapanjaroensin et al., 2017). Hobfoll (1989) categorised these resources as *objects, personal characteristics, conditions* and *energies*.

Objects

From a home care worker perspective 'objects' represent physical resources such as the ability to provide shelter. Due to financial challenges associated with the home care worker role individuals could feel diminished in this area, for example relying on limited contracted hours or having to work multiple jobs. Participants reported poor pay and conditions alongside onerous procedures in place to claim travel expenses. This resulted in participants becoming disempowered.

Conditions

‘Conditions’ have been associated with health, relationships and status (Hobfoll, 1989). Professional isolation with a lack of support was described by all participants, alongside home care workers perceiving there to be a sense of reluctance from other professionals to provide them with assistance when they sought help. This was interpreted that this group of staff were very much an invisible workforce. They appeared to be on the periphery and actually aligned themselves with the patient and family rather than the health and social care team. Despite this they continued to seek connection with their manager and organisation, however their narratives described a disconnect from their employers.   This could suggest that home care workers perceive themselves to have a lack of status within their own organisation and the wider professional team.

Personal Characteristics

‘Personal Characteristics’ relate to coping as home care workers’ ability to cope could be influenced by their access to peer support and the social support structure around them. This type of support is said to impact an individual’s sense of self (Prapanjaroensin et al., 2017). Findings suggested that participants sought professional connection and approval from the wider multi-disciplinary team; this provided them with a sense of legitimacy, often in a situation where role ambiguity was present. Role ambiguity created a sense of uncertainty around the boundaries of their role which was perceived at times to suit the organisation and sector, despite resulting in personal cost for the individual.

Energy

Finally, ‘energy’ resources centre on someone’s skill set. This can mean what they can offer in regards to employment or through their time and knowledge (Alvaro et al., 2010; Hobfoll, 1989; Prapanjaroensin et al., 2017). This theory suggested that when under such threats then the individual is at risk of burnout, which affects performance (Alvaro et al., 2010) and, ultimately, the quality of patient care (Prapanjaroensin et al., 2017). Findings suggested that participants’ knowledge and skills in caring for people approaching the end of life were undervalued and at times not recognised at all by either the wider health and social care team or their employers.

6.6.2 Review of Conservation of Resource Theory in relation to study findings

Conservation of resource theory has been used most often when exploring organisational behaviour including exploring motivation (Halbesleben et al., 2014). At its centre, the theory proposes that people try and protect their existing resources while trying to grow and develop new ones. Hobfoll (1988) has broadly outlined what constitutes resources as objects, conditions, personal characteristics and energy. However, which resources people place value on differs depending on the individual and their own set of personal beliefs (Halbesleben, 2006). When examining home care workers’ individual accounts, there is a sense of a struggle in trying to increase certain resources across all four categories. There are financial limitations in carrying out such a role and for some a sense of invisibility within their organisation resulting in a lack of status. However, motivational factors, resources that are particularly valued by the individual such as their skills and knowledge or their social support, may mean that despite being depleted in other areas these resources enable them to cope with the stress and impact of their role. The idiographic nature of this theory enables the individual aspect to be considered in detail and in some depth, which is also congruent with the IPA methodology used to conduct this study. For those who attempt to invest and gain resources in other areas, they ultimately may feel more protected and able to recover from depleted resources (Halbesleben & Wheeler, 2008). In comparison, for some individuals, the lack of resources can lead to them feeling the need to conserve everything they have which could result in not only a lack of motivation, but also a feeling of disempowerment and emotional exhaustion. This could in turn increase their risk of burnout (Halbesleben & Bowler, 2007).

Conservation of resource theory enabled me to explore how individual home care workers caring for people at the end of life may have unique and individualised resources that can change over time, to better enable them to cope with the stress of their experiences as a home care worker or not. However, they will still experience threats to resources such as financial challenges. The theory appeared to be a good fit to explain the home care workers experience of occupational stress and their subsequent risk of burnout when they are not able to protect or gain additional resources. It incorporates individual, social and environmental elements, which is also in line with the holistic nature of the palliative approach that is often taken by home care workers with the people they are caring for. Acknowledgment and consideration would need to be made around cultural variations, where certain resources may hold higher value depending on cultural factors alone (Theory Hub, 2023). For example, certain cultures may place a higher value on conditions such as status rather than the social support structure around them. Hobfall (2001) also highlighted that conservation of resource theory details how known resources may operate and how these resources contribute to coping.

6.7 Recommendations for clinical practice, policy and research

6.7.1 Clinical Recommendations

The findings of both the hermeneutic review and the study assisted in formulating clinical recommendations, which could improve home care worker support and reduce the perception of geographical, professional and emotional isolation. The table below summarises the findings from the hermeneutic review, the study findings, and the clinical implications.

Table 6.7.1 Clinical Implications from findings

<table>
<tr><th>Hermeneutic Review Findings</th><th>Study Findings</th></tr>
<tr><td>Feeling paralysed – Female labour and financial vulnerability</td><td>“You are really on your own”: Coping with isolation when providing care in the community</td></tr>
<tr><td>A lack of management support and a complex working environment: the organisational impact on home care workers</td><td>“You just treat them, you know, like they're still alive”: the value of ritual for home care workers when caring for the dying and the dead</td></tr>
<tr><td>Being in the role and working alongside others</td><td>“I wait and cry most times in the car”: Understanding the impact of grief and bereavement on those delivering care</td></tr>
<tr><td>Limited education and a lack of support: the home care workers’ experiences of caring and grieving</td><td>“These are the rules, no matter how frustrating you just have to follow”: frustrations with organisational influence and control within community care settings</td></tr>
<tr><td colspan="2">Clinical Recommendations
Fairer employment contracts and terms of conditions that reflect the complexity of the role, which could aid in staff retention and connection to their organisation
Employers to provide clear role descriptions which would reduce role ambiguity, and may strengthen the home care worker role within the wider multi-disciplinary team.
Grief and Bereavement policies to support staff to attend funerals, conduct bereavement visits safely, reimbursement of their time and provide accessible staff support
Access to formal peer support networks through the use of clinical supervision or by alternative methods
Palliative, end of life care and bereavement training for all staff who care for people approaching the end of life at home
Personal safety - appropriate risk assessments and policies and procedures, and pathways to access assistance that have been informed by the staff themselves</td></tr>
</table>

The impact of poor terms and conditions and uncertain employment contracts was evident across the sample, with not only people having to work in multiple jobs but also struggling to access benefits such as travel or not having access to any additional job benefits at all. Fairer employment contracts could not only improve staff retention but also provide people with a sense of being valued in their own organisations. The study adds to peer reviewed studies from the US calling for fair employment contracts and improved terms and conditions for these essential workers (Bercovitz et al., 2011; Butler et al., 2010; Kemper et al., 2008; Stone et al., 2013). Clearer role descriptions would reduce role ambiguity, which could empower home care workers to more readily carve out a place within the wider multi-disciplinary team, reducing their professional isolation. The findings are consistent with other international and UK peer reviewed studies, which outlined the need to reduce role ambiguity through clearer job titles and job descriptions (Devlin & McIlfatrick, 2010; Lovatt et al., 2015; Pesut et al., 2015; Sims-Gould et al., 2013). Worldwide the number of job titles used for home care workers removes their ability to be seen as a collective, effectively silencing them and removing their visibility.

The findings highlight that home care workers' experiences of cumulative loss and emotional labour increased their risk of burnout. These findings further support the need for organisations to update their grief and bereavement policies to enable staff who wish to attend funerals to do so. Organisations should consider offering bereavement support visits, ensuring staff are appropriately trained to carry these out and management support is available should they need to access it. The findings highlight the value of formal peer support for home care workers and clinical supervision may be a good approach to formalise this. Concerning education and training, the findings add to the call for end of life care training for this group of staff. Moreover, the study highlights the need to move away from focusing on mandatory training alone; instead, asking organisations to consider the skillset that this workforce requires and including them in deciding around how this could be delivered.

In the study, geographical isolation was a major issue for both home care workers in rural areas and those working in towns and cities. This left some participants feeling unsafe at work. Consistent with published studies in this area, organisations employing community-based staff should consider their personal safety carefully, putting in place appropriate risk assessments, options to access assistance especially outside of working hours, and appropriate policies and procedures that have been informed by the staff themselves.

6.7.2 Recommendations for government policy

For most developed countries, including Scotland, the current health and social care system are reliant on home care workers to support people approaching end of life who wish to remain at home. Despite this they appear to be completely undervalued with little means to influence change. For this model of health and social care to remain sustainable in any way, government intervention is required to:

- Legislate to ensure home care workers receive a fair living wage and that any job benefits for which they are entitled are easily accessible
- Update safe staffing legislation to ensure appropriately trained home care workers are supported through consistent job titles and grading, appropriate skill mix and access to trained staff for support in a timely manner
- Clarifying job titles and grades would also enable the workforce to have a collective voice

For too long government policy has supported home care above admission to acute and secondary care settings where appropriate, without also providing clear policy in support of the workforce that we rely upon to deliver this care.

6.7.3 Recommendations for future research

The study findings have highlighted a number of areas that future research could explore, as the research focusing on the population of home care workers is limited. As the demand for palliative care in the community increases across the world, and here in the UK the care crisis deepens, further research may be able to assist in building a future workforce. In considering how best to support home care workers in the future, consideration should be given to:

- the experiences of grief and bereavement in this population and how they could be better supported
- further exploration around the incidence, the causes and the effects of burnout in home care workers

- intervention studies focusing on identifying effective education programmes for this population of workers would could be delivered at scale
- exploring and developing progressive health and social care delivery models that improve joint working

6.8 Strengths and Limitations

The strength of conducting an IPA study is that it enables in-depth analysis of a small number of participants who have experience in caring for people with end of life care needs in their own home. This demonstrated idiographic commitment as I sought extensive understanding of the phenomenon (Smith et al., 2012). Considerable time was spent on each transcript to ensure depth of understanding and meaningful insight could be drawn from the analysis. My own understanding played a part in making sense of the participants' experiences. The results aimed to be meaningful given the subject matter and the time generously given by the participants. Their experiences shared were extremely moving, challenging at times, and insightful, so it was essential the methodology enabled this to be captured effectively. The double hermeneutic process of IPA, whereby the researcher is attempting to make sense of the participants making sense of their experience (Smith et al., 2012) was achieved in this study. The idiographic nature of IPA enabled me to hold on to the individual analysis longer, really exploring the participant's reflections on their experiences and where they placed meaning. This benefited my interpretation and ultimately my study findings.

I had never conducted an IPA study before and vastly underestimated the time that it takes to grasp the methodology and then analyse the data. As a novice IPA researcher, I had to spend considerable time reading about IPA, seeking information through IPA forums and seeking knowledge and advice from my supervisory team. The process of analysis can seem overwhelming at times but making the decision to transcribe interviews myself enabled me to feel grounded in the data, and really aided me as I worked through all the steps of analysis. The balance of interpreting the data while remaining true to the home worker's experience was a challenge. I reflected on this considerably in my research journal. Trying to ensure I was remembering each decision and why I had made it, felt important.

I have attempted to contribute meaningful knowledge of home care workers' experiences in caring for people approaching the end of life, highlighting the complexity, their sense making and the personal meaning they place on caring for the dying and the bereaved.

6.9 Reflections on the study

I changed significantly as a researcher throughout this study. I moved from Melbourne, Australia to the UK to undertake my PhD. Although I am from the UK originally, my perspective of palliative care is an international one, albeit in developed countries with well-established health care systems. I was very mindful of this as I undertook the study and reflected on the impact of having that wider lens. I had come from a background of working in community palliative care services, before moving on to a university based palliative care education and research programme. Returning to the UK, I moved from education into palliative care leadership roles so my experience is varied. As a result of this, I had to remain extremely vigilant of any pre-conceived ideas I had especially during the interview process, and any assumptions that I made throughout the analysis process. I do feel my broad experience in the field of palliative care has ultimately assisted me in my analysis. Reflecting back on the process, I also think it assisted me in my data collection as I was not known to any of the participants within the study, therefore I did not feel compromised in any way. Due to my accent at the time of data collection, I was viewed as an outsider which resulted in participants feeling safe enough to be very open, in most cases. Accents can be fundamental in how someone is perceived and categorised (Pietraszewski & Schwartz, 2014), therefore my mixed Australian and Scottish accent very much placed me as external to their local community and in some ways their work communities also.

During the study, I intercalated for an extended period (12 months) due to maternity leave. I had completed data collection prior to maternity leave which was fortunate from a research perspective, as the COVID-19 pandemic occurred over this period. However, returning to start data analysis post the extended break was challenging. It took me some time to reacquaint myself with the data and feel fully immersed. I also felt the natural progress of the study had been lost or at least stalled. Reflecting on these periods were important in terms of how I went on and approached my analysis using IPA.

During this period one of my original supervisors retired. I felt the relationship and trust I had in my supervisory team was altered, and the change was a challenging period within the study. At the time I felt frustrated that previous discussions and decisions had to be revisited and in some cases decisions had to be revised. On reflection, I now view that as a positive step; it enabled me to re-focus, re-consider methodological decisions and really explore whether IPA was the most appropriate route to take. I also now feel the benefit of being gifted three supervisors in a way, to support and guide me through the PhD journey.

The study has also positively impacted my leadership role. I am an advocate for research, quality improvement projects and audit across all hospice services. I am involved in research steering committees, conference planning groups and other national groups. My everyday thinking around research has changed as a result of this process.

Because of my background, I am passionate about community palliative care and recognise and live in the crisis we now face in health and social care. The findings of this study can inform future research and can hopefully go some way of improving the visibility of this workforce.

6.11 Conclusion

The study aimed to explore the experience of home care workers caring for people living with end of life care needs at home. IPA enabled an in depth analysis of home care workers' reflections on their experience of caring for people with palliative and end of life care needs.

Interpretative phenomenological analysis (IPA) of eight semi-structured interviews found four master themes.

- "You are really on your own": Coping with isolation when providing care in the community
- "You just treat them, you know, like they're still alive": the value of ritual for home care workers when caring for the dying and the dead
- "I wait and cry most times in the car": Understanding the impact of grief and bereavement for those delivering care
- "These are the rules, no matter how frustrating you just have to follow": frustrations with organisational influence and control within community care settings

Poor visibility ran through each theme; home care workers were geographically, professionally and emotionally isolated. Emotional labour was viewed as an inevitable part of their role, with cumulative loss placing them at greater risk of disenfranchised grief or burnout. Education focused on mandatory training, instead of areas where there were clear learning needs such as end of life care and bereavement support. Home care workers appeared disconnected from their organisations although were keen to maintain the organisations reputation externally. Role ambiguity, contracts and conditions and organisational support were all areas that required clarity. Despite this, home care workers reported feeling privileged to deliver end of life care and sought to support the individual and their family to die well.

This study enabled the home care workers voice to be heard. Hopefully in the future, more research will be undertaken with this workforce to strengthen their voice as a collective. The study highlights that the health and social care system is letting this workforce down. Meaningful change is required to improve not only their pay and conditions, but to ensure home care workers are appropriately supported and trained to provide this vital care at the end of life for those who choose to die at home.

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Appendices

Appendix 3.3.3a Quality Appraisal tool

Adapted from Hawker et al. (2002)

Author and Title					
Date					
	Good (4)	Fair (3)	Poor (2)	Very Poor (1)	Comments
Abstract and Title					
Introduction and Aims					
Method and Data					
Sampling					
Data analysis					
Ethics and Bias					
Findings/Results					
Transferability/Generalizability					
Implications and Usefulness					
Total Score					

Appendix 3.3.3b Example of Quality Appraisal Scoring from one paper

Author and Title	**Yeh, I.-L., Samsi, K., Vandrevala, T., & Manthorpe, J. (2019). Constituents of effective support for homecare workers providing care to people with dementia at end of life**				
Date					
	Good (4)	Fair (3)	Poor (2)	Very Poor (1)	Comments
Abstract and Title	X				Clear and title links to study aims
Introduction and Aims	X				Sets the scene of the situation in England where the study is based. Aims and focus of paper is clear.
Method and Data	X				Methods clearly described and appropriate for aims of the study. Face to face interview used for data collection.
Sampling	X				Purposeful sampling
Data analysis		X			Data analysis described and appropriate for study methods.
Ethics and Bias			X		One sentence outlining where ethical approval had been sought. No exploration of bias included in the article.
Findings/Results	X				Themes explored in depth with quotes from the participants to illustrate points made included.
Transferability/Generalizability			X		Findings cannot be generalised although can inform future studies in this area and add to knowledge.
Implications and Usefulness		X			As noted above.
Total Score	30				

Appendix 3.4 Data Extraction Table

Author	Quality Score	Research Question	Participants	Methods	Relevant Themes on Review
Baik et al (2021) USA	28	To elicit the educational needs and priorities of home care workers on end of life care for patients with heart failure.	Home Care Workers (41)	Semi-quantitative structured group interview process	*HCW expressed challenges handling their feelings (fear, distress, shock) when a patient died * Feelings of helplessness when someone was dying at not being able to 'heal' the patient *Challenges in how to express empathy
Bercovitz et al (2011) USA	24	National estimates on home health aides demographics and employing agency characteristics	Home Health Aides and Hospice Aides (160700)	Secondary Data Analysis - Data from the 2007 National Home and Hospice Care Survey - original data set developed using interviews, using computer-assisted telephone interviewing	*Lack of university education within the workforce. *Financially vulnerable - low income. *Largely Female Workforce. *Perception there is lack of value in their role by others *Sense of reward in their role
Boerner et al (2015) USA	27	1. Grief symptoms experienced amongst direct care staff 2. How prepared staff members were for the patient's death 3. Factors related to workers grief levels	Certified Nursing Assistants (143) Nursing Home, and Home Health Aides (80)	Study part of a larger mixed methods study. This study used 1:1 interviews, lasting approximately 80 minutes. Texas Revised Inventory of Grief used to assess grief symptoms.	*Largely female workforce *Primarily workers from a minority background *Home Health Aides experienced grief symptoms *Lack of preparedness for the patients death, both from an information and emotional perspective.

Boerner et al (2016) USA	29	Home Health aides employed by agencies with restrictive policies are more likely to consider career options, and less likely to be satisfied with their job.	Home Health Aides (78) working in the community	Study part of a larger mixed methods study. This study used 1:1 interviews, lasting approximately 80 minutes. Job Description Index used to measure job satisfaction.	*Largely female workforce *Home Health Aides developed close relationships with the patient and family *Home Health Aides expressed lower job satisfaction when working in agencies that prevented funeral attendance or for them to express condolences *Restrictive polices resulted in less time to process grief
Boerner et al (2017) USA	28	Primary aim to investigate staff, institutional, relational, and grief factors as predictors of burnout dimensions among direct care workers who had experienced recent death of a patient in their care.	Certified Nursing Assistants (143) in a nursing home, and a sample of Home Health Aides (80) in the community.	Study part of a larger mixed methods study. This study used 1:1 interviews, lasting approximately 80 minutes. Texas Revised Inventory of Grief. Maslach Burnout Inventory.	*Primary female workforce *Minority Background *Home health aides experience grief and burnout when caring for dying patients *Home Health Aides had lower levels of emotional exhaustion when compared to frontline workers in residential care *High supervisor support can reduce likelihood of burnout *High co-worker support could increase the likelihood of burnout
Butler et al (2010) USA	27	1. Factors influencing turnover among home care workers 2.Recently terminated home care workers describe their work and reasons for leaving	Personal Assistant Workers (261) working in the community	Mixed Methods Study. Survey mailed to workers at 2 time points. Grau Job Satisfaction Scale and the Maslach Burnout Inventory used in the survey. Telephone Interviews used also.	*Lack of Benefits contributed to high staff turnover (low pay and no health insurance) *Coordination of care led to inconsistent hours being available & slow patient replacement *Burnout related to stress and lack of appreciation for their role

Campbell & Baernholdt (2018) South Africa	21	1. Identify palliative care learning needs of community health workers working in South Africa 2.Community health workers perception of the training	Community Health Workers (29) working in a rural community organization in Mpumalanga Province	Focus Group Interviews and a five item questionnaire	*Debriefing identified by community health workers as an unmet need. *Debriefing seen as important to reduce emotional impact of palliative care
Devlin & McIlfatrick (2010) UK	28	1. Role & experiences of home-care workers in palliative and end-of-life care 2. Explore the perceptions of community nurses on the role of home-care workers in palliative and end of life care 3. To identify the training, support and supervision needs of home-care workers in palliative and end-of-life care	Home Care Workers (236) working for two integrated NHS trusts in the UK.	Mixed Methods Study. Cross Sectional Survey - self completion postal questionnaire based on Fleming and Taylor (2007). Qualitative and Quantitative Questions included (236 questionnaires completed). Phase 2 - Focus Group with 6 community nurses.	*Provision of emotional support to patient and family central to role, alongside personal care *Lack of time to complete patient visits *Travel time significant *Caring for palliative patients seen as rewarding *Psychological concerns in terms of coping with clients death and loss *Communication Challenges in answering difficult questions *Unmet training needs reported in communication, end of life care and dying & loss *Need for clinical supervision *Unclear role boundaries

Fujita et al (2019) Japan	26	Evaluation of an interprofessional education program for home based end of life care health and welfare professionals.	291 (64 homecare nurses, 129 care managers, and 98 head care workers) consented to participate in the study and completed the questionnaires twice.	Cluster randomised clinical trial. Questionnaires at two time points. Education group completed a qualitative feedback questionnaire also.	*HCW valued learning about different professional roles. In practice, their main relationship was to the Care Managers. *HCW gained confidence in communication skills following training
Fukui et al (2019) Japan	25	The study aimed to assess the effect of a multidisciplinary end-of-life educational intervention program on confidence in inter-professional collaboration and job satisfaction among health and social care professionals in Japan.	291 (64 homecare nurses, 129 care managers, and 98 head care workers) consented to participate in the study and completed the questionnaires twice.	Cluster randomised clinical trial. Confidence in improved interactions among professionals and job satisfaction were assessed with the Face-to-Face Cooperative Confidence Questionnaire and the Minnesota Satisfaction Questionnaire at T1 (before intervention) and T2 (7 months after the intervention).	*Education programme improved communication and aided relationship building between health professionals. *Participants were able to increase understanding of community resources and community networks

Gleason et al (2016) USA	26	Examine the perceived availability of supervisor and co-worker support, during the time leading up to their client's death and after.	Home Health Aides working in the community service division of an elder care system in New York City. 80 HHA.	Mixed Methods Study. Interviews conducted with HHA post the death of a client.	*Largely Female Workforce *Lack of support from supervisors felt by Home Health Aides *Lack of support from co-workers felt by Home Health Aides *Few sought support prior to the patients death *Support identified as talking about their feelings *Time to Grieve seen as support *Training needs on coping with clients death identified
Holme & Hart (2007) UK	19	Explore the reaction and responses of Generic Care Workers being trained to undertake limited health care tasks alongside home care tasks to terminally ill clients.	9 Generic Care Workers who provided a package of care over 9 months, to 33 home care clients.	Small explorative qualitative study. Focus Group and Questionnaire.	*Development of new clinical skills *Ability to work more closely with district nursing teams *Recognition of professional status and the role of care worker
Ingleton et al (2011) UK	26	Examine the role of trained and personal care assistants in supporting district nurses and family carers in providing palliative and end of life care in the community.	District Nurses and Nurse Managers (6), Administrators (3), Commissioners (2), Personal Care Assistants (2), Other Health Care Professionals (4), Bereaved Carers (6)	In depth semi structured interviews.	*Reliance on District Nursing staff to provide up to date care plans in the home to guide care delivery

Kemper et al (2008) USA	23	To understand what changes in management practices would most improve the job of frontline workers , and to analyse the differences across settings.	3468 direct care workers, employed in nursing facilities, assisted living facilities and home care agencies in 5 US states.	Survey - 8 page self-administered written survey	*Poor pay for home care workers *Better fringe benefits required *The need to improved working relationships with home care managers seen as important
Lovatt et al (2015) UK	34	Explore the emotional labour undertaken by health care assistants working in community palliative care, from the perspectives of both HCA's & bereaved family carers.	8 Health Care Assistants, working in 3 community services and 33 bereaved family carers.	Qualitative Study using semi structured interviews.	*Forming and maintaining relationships with patients and family was central to the role *Role ambiguity meant they had some flexibility in how they support the family *Health Care Assistants worked hard to fit into the patients home environment *Health Care Assistants supported family carers without excluding them from hands on care *Emotional Labour seen as key part of their role

Manson et al (2020) UK	23	To test the acceptability of Project ECHO to domiciliary care workers as a means of increasing their knowledge of, and confidence in, delivering palliative care, and its effectiveness in reducing isolation by developing a community of practice.	25 home care workers who attended part of a 12-week education programme.	A mixed-methods service evaluation of one domiciliary care agency.	*Project ECHO was an accessible way to join training *Staff shortages resulted in non-attendance * Project ECHO can help to reduce home care worker isolation
Noble et al (2015) UK	27	To evaluate the Midhurst Specialist Palliative Care Service	Midhurst Staff and Volunteers (30) including community support team (9), Patient and Carers (21), 18 external staff including 2 agency care workers	Mixed Methods Study - financial evaluation, postal survey, qualitative interviews	*Positive working environment - non-hierarchical and flexible working *Willingness to learn from each other
O'Sullivan & Harding (2017) UK	26	Explore support staffs' experience of caring for people with a learning disability at end of life	13 support workers employed by 3 independent care providers in London. Participants had to have cared for a service user who had died in the last 3 months.	Qualitative Study using focus groups.	*Forming and maintaining strong emotional bonds with clients *Collaboration of other services essential to support care workers to deliver end of life care *Lack of end of life care training *Lack of organisational policies and procedures for provision of end of life care *Experience of grief when client dies *No access to clinical supervision or other support mechanisms

Pesut et al (2015) Canada	27	To pilot a clinical placement for RN and HCA students, caring for people with advanced chronic illness in their home.	21 RN students and 21 HCA's completed the questionnaire. 8 RN's and 13 HCA's were interviewed.	Mixed Methods study using a pre and post questionnaire at 3 time points, and a qualitative semi structured interview.	*Health Care Assistant's highlighted the value of communication training *Role clarity - identifying their role in caring for patients with terminal and chronic disease was challenging *Limited long terms benefits to teaching programme in some areas, as the health care assistants had a heavy workload, which became increasingly task focused.
Poulos et al (2018) Australia	23	To evaluate the *Palliative Care Home Support Program*	Family care givers who received at least 2 hours of the service (n=128 survey, n=20 interviews). Community Palliative Care Teams working with these workers (n=9 interviews). The Specialist Community Care Workers (n=26 surveys, n=10 interviews).	Mixed Methods study involving a survey and interviews.	*Complex working environment related to supporting family carers with little experience in caring for someone at end of life *Provision of both physical and emotional support central to the care worker role *Greater job satisfaction for care workers working with palliative patients
Reimer-Kirkham et al (2016) Canada	25	How do nurses and nursing assistants enact a palliative approach in a variety of nursing care settings?	25 nurses and 5 nursing assistants from British Columbia, Canada working with patients with chronic life limiting conditions	Qualitative study using interviews and focus groups.	*Building relationships with patients and their family improves communication *Nursing Assistants role within the MDT can be negatively perceived *Further education in the palliative approach required *Further education for nursing assistants in the provision of psychological, social and spiritual support

Riesenbeck et al (2015) USA	27	To identify characteristics of the Home Health Aide and the client that may influence the HHA's emotional & informational preparedness for the client's death.	Home Health Aides working in the community service division of an elder care system. 80 HHA took part in the study.	Part of a larger mixed methods study. Semi-structured interviews were used. Interview included open ended questions, and standardised measures.	*Largely female workforce *Client awareness of dying - Home Health Aides felt more prepared for client's death in this circumstance *Experience of palliative symptoms, Home Health Aides informationally felt prepared for client's death *Avoidant attitude of Home Health Aides resulted in them being less prepared for a client's death
Sims-Gould et al (2013) Canada	27	To understand the nature of crises faced by home support workers.	Home Care Workers working in British Columbia, able to complete and interview in English, which were employed by home care agencies who provided non-medical services to patients over 65 years. (n=118)	Qualitative Research using in-depth, semi structured interviews.	*The majority of home care workers have experienced crisis when providing care *Crisis involving the patients physical condition was the most common *Verbal aggression by patients and family most common relational crisis experienced *Role ambiguity and organisational policies contribute to relational crises, family expectation not met *Stressful working environments *Unpredictable care provision due to deteriorating patients
Yeh et al (2019) England	30	1.What are the challenges and their impact experienced by homecare workers caring for people with dementia at end of life? 2. What sources of support do they use and need?	29 homecare workers and 13 homecare managers.	Semi structured interviews.	*Time – inadequate visit times to deliver personal care * Care at end of life emotionally draining and overwhelming *Lone working over an extended time causes psychological and physical fatigue *Reliance on peer support

Appendix 4.5.1a Study Flyer

Lancaster University

Would you like

to participate in research?

What is the study about?

The study is aiming to help understand your experience of caring for people living with a life-limiting illness in their own home.

You will have the chance to talk about your role as a carer from your viewpoint, and think about the education and support that can help you to provide care to palliative clients and their families.

Could I take part?

We would like to talk with you because you are employed to care for people living at home who have a life limiting illness.

For more information, please contact:

Name: Lyndsay Cassidy

Email: l.cassidy@lancaster.ac.uk

Appendix 4.5.1b Participant Information Sheet

Participant Information Sheet

What are the Experiences of Home Care Workers caring for people living with palliative and end of life care needs at home?

My name is Lyndsay Cassidy and I am conducting this research as a student in the PhD in Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to gain better understanding of the experience of home care workers caring for people living with a life-limiting illness at home. The study will examine the complexities of their role from their perspectives and identify the education and support needs that they feel could help them to support their palliative clients better.

Why have I been approached?

You have been approached because the study requires information from people who deliver health and social care to people living with a life limiting illness in their own home. Or you are a Manager or Service Director for a service which delivers care to people at home with a life limiting illness.

Do I have to take part?

No. It’s completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to speak to me on the phone so I can tell you more about the study and answer any questions you may have. You will be asked to sign a consent form. We would then arrange a time for you to come in for an interview. The interview will take approximately 30 – 90 minutes. The interview will take place somewhere convenient to you, at a time most suitable to you.

You can withdraw your participation from the study at any time. You can withdraw your data up to four weeks after you have been interviewed. After the four weeks your data will have been anonymised and incorporated into themes, and it might not be possible for it to be withdrawn, though every attempt will be made to extract the data, up to the point of publication.

Will my data be Identifiable?

The information you provide will be anonymised, which means identifying features such as names, locations and organisation names will be changed. The data collected for this study will be stored securely and only the researcher conducting this study (and her supervisors) will have access to this data:

- Audio recordings will be destroyed at the completion of the research study. Transcripts will be kept securely for 10 years then destroyed
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected. The files will be kept for 10 years then destroyed.

- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses and will be destroyed at the completion of the project.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to an appropriate person about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a PhD thesis and may be publicised in academic journals or at professional meetings and conferences.

Are there any risks?

There are no risks anticipated with participating in this study. However, as we will be talking about your experience of caring for people with palliative and end of life care needs there is a possibility this could upset you. If you experience any distress during or following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Name: Lyndsay Cassidy Email: l.cassidy@lancaster.ac.uk Tel: 07715 812108

The supervisors for this study are:

Name: Dr Sean Hughes Email: sean.hughes@lancaster.ac.uk Tel: 01524 593722

Name: Dr Nancy Preston Email: n.j.preston@lancaster.ac.uk Tel: 01524 592802

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Catherine Walshe
Tel: (01524) 593382
Email: c.walshe@lancaster.ac.uk
Division of Health Research
Lancaster University
Lancaster LA1 4YG

If you wish to speak to someone outside of the Blended Learning PhD Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

- Cruse Bereavement Care Scotland. 0845 600 2227. Cruse is a charity, staffed by volunteers, to give bereavement support to people throughout Scotland. Their telephone support line is open from Monday to Thursday 10am – 8pm and Friday 10am – 6pm. http://www.crusescotland.org.uk/

- Macmillan Cancer Support Line. 0800 808 00 00. Macmillan can provide information and support to those affected by cancer. Their telephone support line is open Monday to Friday, 9am -8pm. You can also visit the website https://www.macmillan.org.uk/

- Marie Curie Helpline. 0800 090 2309. Marie Curie can provide information and support to those who have a life limiting illness or are caring for someone with a terminal illness. Their telephone support line is open Monday to Friday 8am – 6pm, and Saturday 11am-5pm. You can also visit the website https://www.mariecurie.org.uk/help/marie-curie-support-line

- Samaritans. Samaritans are open 24 hours a day, 365 days a year, to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of suicide and self-harm. Their national free-phone number is 116 123. You can also visit the website: www.samaritans.org

Appendix 4.5.1c Expression of Interest Form

Expression of Interest Form

Project: What are the experiences of Home Care Workers caring for people living with palliative and end of life care needs at home?

I have read and understood the 'Participation Information Sheet'. ☐

I am interested in taking part in this study because I have cared for at least one client in the last 12 months who is living with a life limiting illness. I am also employed to care for clients in their own home. ☐

I am a service manager or director, whose service provides care at home to people with palliative and end of life care needs. ☐

Please return this form either by post via the stamped addressed envelope or by email to the researcher at the address below. The researcher will be in contact via telephone and/or email to discuss the study, answer any questions you may have about the research and establish if you would like to take part.

Please complete the following but only provide contact details that you are happy to share with the researcher:

Name:
Mobile phone:
Home phone:
Work phone:
Email:
Postal address:

Researcher contact details:

Lyndsay Cassidy RN, MPallC, PhD Student
Division of Health Research
Faculty of Health and Medicine
Lancaster University

Email Address: l.cassidy@lancaster.ac.uk
Address: Strathcarron Hospice, Randolph Hill, Denny, Stirlingshire, FK6 5HJ

Appendix 4.5.1d Consent Form

Consent Form

Study Title: What are the experiences of Home Care Workers caring for people living with palliative and end of life care needs at home?

We are asking if you would like to take part in a research study that aims to gain better understanding of the experience of home care workers caring for people living with palliative and end of life care needs. The study will examine the complexities of the role of a home care worker from their perspective, and identify the education and support needs that they feel could help them to support these clients better.

As part of this study, service managers will also be asked to provide contextual information about the service and the policies in place to support home care workers to provide such care.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Lyndsay Cassidy.

	Please initial each statement.
I confirm that I have read the information sheet and fully understand what is expected of me within this study.	
I confirm that I have had the opportunity to ask any questions and to have them answered.	
I understand that my interview will be audio recorded and then made into an anonymised written transcript.	
I understand that audio recordings will be kept until the research project has been examined.	
I understand that my participation is voluntary and that I am free to withdraw my participation at any time without giving any reason, without my legal rights being affected.	
I understand that four weeks after my interview, my data will have been anonymised and incorporated into themes and it might not be possible for my data to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.	
I understand that the information from my interview will be pooled with other	

participants' responses, anonymised and may be published.	
I consent to information and quotations from my interview being used in reports, conferences and training events.	
I understand that the researcher will discuss data with their supervisor as needed.	
I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others. In which case the principal investigator will need to share this information with an appropriate authority.	
I understand that the data will be anonymised and securely stored on an encrypted Lancaster University server for ten years. The data will then be destroyed.	

Name of Participant: **Signature:** **Date:**

Name of Researcher: **Signature:** **Date:**

By proceeding to the survey you confirm that:

- You have read the information sheet and understand what is expected of you within this study
- You confirm that you understand that any responses/information you give will remain anonymous
- Your participation is voluntary
- You consent for the information you provide to be discussed with my supervisor at Lancaster University
- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished

Appendix 4.6 Demographic Information

Demographic Information

Thank you for taking part in the study. Please complete the following form. All the questions are optional.

1. **Gender – are you: (please circle)**
   - Male
   - Female
   - Transgender

2. **Age – which age group do you belong to? (please circle)**
   - 18 to 24
   - 25 to 29
   - 30 to 34
   - 35 to 39
   - 40 to 44
   - 45 to 49
   - 50 to 54
   - 55 to 59
   - 60 to 64
   - 65 to 69
   - 70 and over
   - Prefer not to say

3. **Ethnic Details - (Please tick)**

- White
  - ☐ English/Welsh/Scottish/Northern Irish/British
  - ☐ Irish
  - ☐ Gypsy or Irish Traveller
  - ☐ Any other white background, please state……………………..

- Mixed\multiple ethnic groups
  - ☐ White and Black Caribbean
  - ☐ White and Black African
  - ☐ White and Asian
  - ☐ Any other Mixed\multiple ethnic background, please state …………..

- Asian/Asian British
  - ☐ Indian
  - ☐ Pakistani
  - ☐ Bangladeshi
  - ☐ Chinese
  - ☐ Any other Asian background, please state………………

- Black/African/Caribbean/Black British
  - ☐ African
  - ☐ Caribbean
  - ☐ any other Black/African/Caribbean background, please state…….

- Other ethnic group
  - ☐ Arab
  - ☐ Any other ethnic group, please state…………….

4. Qualification– what is the highest level of qualification you have completed? (please circle)

- Standard Grades/GCSE’s or equivalent
- Highers/A-Levels or equivalent
- SVQ or NVQ or equivalent
- Apprenticeship Scheme
- Certificate of Higher Education
- Diploma of Higher Education
- Bachelor’s Degree
- Graduate Diploma or Graduate Certificate
- Honours Degree
- Master’s Degree
- Doctoral Degree

Please state if you have a qualification relevant to your current role:
…………………………………………………………………………….

5. Length of employment in the home care setting

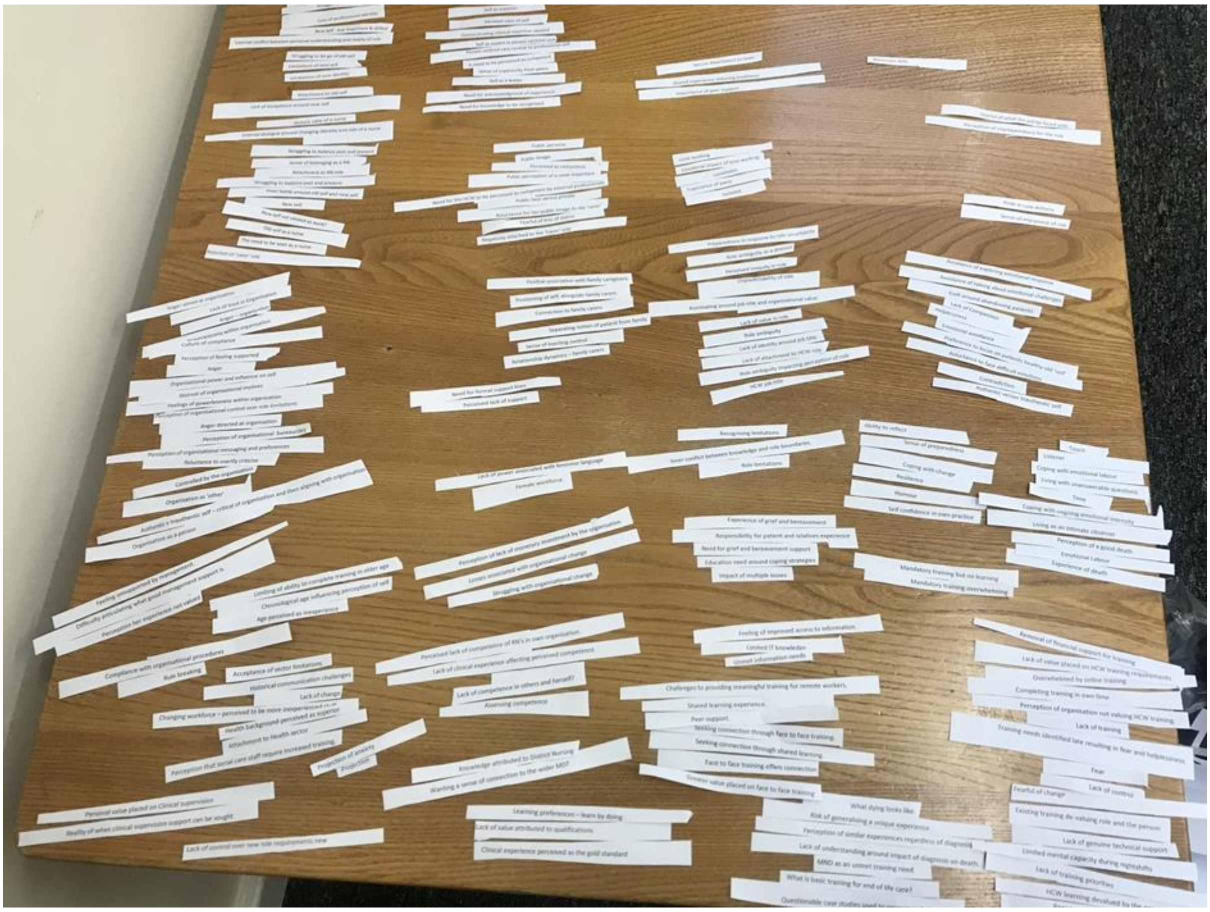
How many years have you been employed as a home care worker?.........

Thank you for taking the time to complete these questions.

Appendix 4.7.3 Sample of transcript – analysis

Coping with ongoing emotional intensity Reluctance to face difficult emotions Preference to focus on patients healthy old 'self' Struggling to balance past and present Need for acknowledgment of experience	just not happening. And somebody may have said 'oh a couple of days.' Two days have passed and they're still sitting there. And so they feel, they want them to die. And then that's their Mum, how can they want their Mum to die? You know it's that sort of…these awful emotional dilemmas that they have. And that's the sort of thing that I find people talk about. Also (you know) the happy times, and, you know sort of triggering really great memories. I'm a great one for getting them to tell me stories about all the photographs that they have, and because we meet people when their really poorly and it's so nice to see, to be able to see what somebody was like when they were fit and well. If they can't, the patient can't communicate to you about their life, their spouse might be able to. And to talk about their life together, which (you know) hopefully it's been good. And so there's not too much, I think if, it's difficult again because my experience and knowledge is a bit different. But I	Reality of dying – complex emotions that Mary is supporting families with. Object of concern – an event that Mary revisits multiple times a month. *Deliberate use of 'Also', strong certain tone signifying moving away from the emotional dilemmas onto a more positive and comfortable topic.* Is there reluctance to face the reality of what they are having to cope with? Comfort and positivity to focus on the past – Looking back at their 'healthy self' Photographs used as windows to their past life Separated into 2 different people HCW as a Nurse Separating herself from the HCW role or her colleagues? Is she find it challenging to know where her knowledge and skills sit within this 'new' role? Balancing past and present self? Indicating experience and perceived skill through extended role.

Appendix 4.7.3b Photograph – Part of the analysis process



Appendix 4.10.1 Distress Protocol

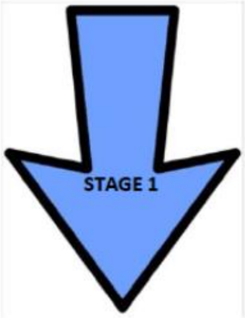
Distress Protocol – Managing Distress in the Context of a research interview
Modified from Draucker, Martsolf & Poole (2009)

Distress

A Participant indicates they are experiencing high level of stress or emotional distress.

OR

Exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying and shaking.



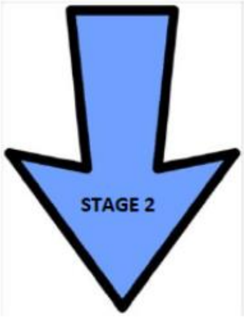
Stage 1 Response

- Stop the interview
- One of the researchers (who is a health professional) will offer immediate support.
- Assess mental status—Tell me what thoughts you are having, Tell me

  how you are feeling, do you feel able to go on about your day? Do you feel safe?

Review

- If the participant feels able to carry on, resume interview.
- If participant is unable to carry on, go to stage 2.



Stage 2

- Discontinue interview
- Direct participants to the list of support services listed on the Participant Information Sheet, should they wish to seek further support.