CARING FOR CHILDREN AND YOUNG PEOPLE WITH LIFE LIMITIING CONDITIONS; COPING STRATEGIES AND IMPACT ON WELLBEING AMONG QUALIFIED SOCIAL WORKERS WORKING IN CHILDREN'S HOSPICES

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ABSTRACT

Introduction: Research is sparse regarding the wellbeing of hospice staff, particularly child hospice staff. Research suggests that health and social care professionals are unlikely to provide high-quality care if they feel under pressure, dissatisfied with their working conditions and poorly supported. The focus of the current literature is often on nursing and medical staff, and very little is known about Social Workers. This study had two aims; 1). To gain an understanding of the impact on wellbeing for Social Workers working with children/young people with life limiting conditions in a hospice setting, and 2). To explore the factors that affect wellbeing in this group, including the coping strategies they employ.

Method: A qualitative approach was undertaken interviewing eight participants (qualified Social Workers). The semi-structured interviews explored participant experiences of supporting children/young people living with life limiting conditions and their families in hospice settings. Thematic Analysis (TA) was used to analyse interview data.

Results: Three superordinate themes were developed following analysis; ‘my work life balance: sources of support’, ‘doing hospice work’, and ‘what I bring to the role’. Participants acknowledged in recent years that their role has become varied and one that has seen extensive change and transition in light of the national government hospice guidelines. Each of the participants described experiencing generally high work satisfaction and felt privileged to work in their role. Participants discussed the rewards and challenges of their role, and how this impacts their wellbeing. Participants particularly shared insight into working with children/young people at risk of death and those who die, and the barriers in access to services this group may experience. Participants also highlighted protective factors including the importance of work life balance, building positive relationships with colleagues and utilising skills developed from prior hospice experiences.

Discussion: Results were discussed in relation to current models of wellbeing and with reference to the literature base. The study provides insight into the workplace culture of a children’s hospice setting. Participants highlighted how they feel supported individually by their hospice colleagues but identified areas of improvement with regards to external support and profession specific supervision. Participants also raised clinical implications for staff support, training and the clinical care provided by children’s hospices.

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CHAPTER ONE – Introduction and Literature Review

Chapter one aims to provide the reader with an overview of the current study. It begins by introducing the background to the study in terms of the wellbeing of staff in health and social care more generally. Chapter one will also introduce the concept of wellbeing as the focus for the research, and more specifically in hospice settings, before it will outline the relevant definitions to the reader, provide a brief history of Paediatric Palliative Care (PPC) and the hospice movement, consider the potential impact of the work and introduce models of wellbeing. Chapter one continues by presenting a detailed scoping review that will summarise and critique the existing literature related to the impact of working with children/young people with life limiting conditions, and how children's hospice staff manage their wellbeing and utilise support. The next section will then present an overview of research specific to Social Workers within a hospice setting. This chapter ends with a critique of the presented studies, potential clinical implications of this study and concludes with my proposed aims and objectives.

Introduction

Staff wellbeing

In recent years the government has set initiatives to improve the quality of National Health Service (NHS) care by putting the patient first. To that end, it has been recognised that health and social care professionals are unlikely to provide high-quality care if they feel under pressure, dissatisfied with their working conditions and poorly supported (Department of Health, 2021). The most recent NHS staff survey collected data in 2020 (NHS Staff Survey, 2021) and received approximately 595,270 staff responses from over 280 NHS organisations across England and Wales. Ten key themes were reported: Health and wellbeing; Morale; Staff engagement; Immediate management; Team working; Equality, diversity and inclusion; Quality of care; Safety culture; Safe environment (bullying and harassment); and Safe environment (violence). Several of these themes relate to wellbeing and 44% of NHS staff reported feeling unwell as a result of work-related stress, an increase on 2019 (40.3%) and a figure that has been rising steadily since 2016 (NHS Staff Survey, 2021). The negative impact is widely known and includes staff sickness/absences which can inevitably impact patient treatment and care (Firth-Cozens & Payne, 1999).

These results however did not detail the nature of the stressors experienced among healthcare professionals, and also give no information on groups that may be vulnerable due working in settings that are challenging in terms of emotional impact, such as palliative care. In particular, as hospices are not part of the NHS, their staff were not included in this survey.

The little that is known about the wellbeing of hospice staff suggests similar concerns around wellbeing. In a national annual hospice staff survey, hospice staff across all departments reported low morale, poor communication, and negative impacts to their wellbeing (Smits & Tomsett, 2017). The literature is sparse and the focus is often on nursing and medical staff - very little is known about Social Workers. Similarly, there are few empirical studies on the wellbeing of staff in PPC and how they may be best supported. What is recognised, however, is that there are risks associated with staff who report poor wellbeing and feel unsupported.

Burnout and compassion fatigue

The current study is focused on the experiences of Social Workers in a children's hospice who are working with children/young people with life limiting conditions and their families. As such, they are regularly exposed to emotions and situations that would be seen as potentially distressing. An initial consideration in the current study, therefore, was burnout, a concept defined by Maslach (1982) as 'emotional exhaustion' characterised by symptoms such as emotional numbing and psychological distress and associated with extreme workplace related stress. This has been studied particularly in the helping professions. The field has grown and encompassed several additional concepts, including 'vicarious traumatisation' and 'secondary traumatic stress disorder' but many terms are used interchangeably and are not well defined (Sprang, Clark & Whitt-Woolsley, 2007).

Amongst the most useful developments has been the identification of compassion fatigue and compassion satisfaction (Figley, 2002; Stamm, 2002). Compassion fatigue refers to the emotional exhaustion described by Maslow (1968), exposure to distress at work causing those in the helping professions to become overwhelmed themselves and unable to care. Compassion satisfaction, on the other hand, refers to the positive, protective effects that working in challenging situations can confer on staff – that they experience rewards from caring for others. This appears to counterbalance compassion fatigue (Stamm, 2002). At the very least the literature suggests that focusing exclusively on burnout may be misguided, which led to a wider focus on wellbeing within the current study. Though it is important that negative events in the workplace and their impact are acknowledged, it is also important that this is set in a wider context; both to map potentially positive impacts from similar events and also to better understand how wellbeing works on a larger scale. In the section below, two models of wellbeing with good empirical support are described.

Models of wellbeing

Self-Determination Theory (SDT). SDT, proposed by Deci and Ryan (1985), is a macro-theory that explores human functioning: wellbeing, motivation and the development of personality (Ryan, 2009). The focus of this theory is how factors such as culture and society influence an individual's self-determined behaviour (Ryan, 2009). SDT proposes three basic psychological needs (autonomy, competence and relatedness) as being vital to supporting and fulfilling healthy human functioning. It suggests that when each of the three basic psychological needs are met, an individual may experience greater wellbeing, vitality and motivation (Ryan, Deci, Grolnick, & LaGuardia, 2006). Thus, if the three psychological needs are not satisfied, wellbeing, vitality and motivation will all be diminished. This model has been researched in the context of cultural dimensions and the lifespan (Hahn & Oishi, 2006; Kasser & Ryan, 1999). Deci and Ryan (2008) cite a number of studies that support the model across a number of life domains. The SDT framework has been developed from five mini-theories that are proposed to explain how psychological needs can affect optimal human functioning (Ryan, 2009). These five mini-theories are: The Basic Psychological Needs Theory (BPNT), which suggests individual basic needs directly impact wellness; The Cognitive Evaluation Theory (CET), which is concerned with how interpersonal interaction and social context influences intrinsic motivation; The Causality Orientations Theory (COT) which explores how individual differences can affect how people regulate their behaviour in differing environments; The Goal Contents Theory (GCT) which suggests that the concept of materialism and other extrinsic goals can negatively impact an individual's wellbeing; and finally, The Organismic Integration Theory (OIT), which explores how extrinsic motives are internalised by individuals. There is a wealth of empirical support for SDT when exploring wellbeing (Deci & Ryan, 2000; La Guardia, Ryan, Couchman & Deci, 2000; Reis, Sheldon, Gable, Roscoe & Ryan, 2000; Ryan & Deci, 2000). Ryff (2004) further argues that several other theories of psychological wellbeing have shown an association with elements of SDT, for example, autonomy, environmental mastery, building positive relationships with others, personal growth, purpose in life and self-acceptance.

The Dynamic Equilibrium Theory (DET). Headey and Wearing (1989) proposed that DET (also referred to as the Set-Point Theory) balanced an individual's personality against life events, which has the potential to impact their wellbeing. Headey and Wearing (1989) developed DET from Brickman and Campbell's (1971) work, which suggested that following the experience of major life events individuals will always return to their baseline of happiness (Dodge, Daly, Huyton & Sanders, 2012). Headey and Wearing (1991; 1992) developed a Stocks and Flows Framework proposing that stocks and flows - psychic income and subjective wellbeing - is best understood as a dynamic equilibrium, in which an individual's subjective wellbeing is consistently stable. Headey and Wearing's (1991; 1992) focus on equilibrium reflects Herzlich's (1973) work and refers to an equilibrium as a state of mind that individuals aim to sustain. Herzlich (1973; p.60) explained equilibrium as comprising the following: *"physical well-being, plenty of physical resources; absence of fatigue; psychological well-being and evenness of temper; freedom of movement and effectiveness in action; good relations with other people"*.

Headey and Wearing's (1991; 1992) overall aim was to understand how individuals cope and adapt to change, as well as how this impacts on their levels of wellbeing. They suggest that when an individual experiences change to their wellbeing; this is in response to the individual's equilibrium being disrupted by external forces. They therefore experience a negative impact to their functioning (Dodge et al., 2012).

Headey and Wearing's (1989) theory has been extensively researched and has gained empirical support (Ormel & Schaufeli, 1991; Ormel & Wohlfaryh, 1991; Suh, Diener, & Fujita, 1996). Research supporting the theory has linked changes to an individual's equilibrium caused by current life events with an impact on subjective wellbeing, and also showed that an individual's state of equilibrium quickly returns to baseline (Dodge et al., 2012).

Though there is limited knowledge of the application of the two models to understanding palliative care staff experiences, they do offer a broader perspective of wellbeing, rather than a focus on burnout or compassion fatigue, whilst also highlighting the complexity of the construct of wellbeing. Please note these models are explored in more detail in chapter four.

Defining wellbeing

Over the past four decades, interest into what 'wellbeing' means and how the term is understood has steadily grown. It has been argued that wellbeing tends to be described in terms which are too broad or vague to be helpful (Dodge et al., 2012). Dodge et al., (2012) however, present a paper offering a new definition which they argue is simpler, more universal in its application, and as such offers optimism and a basis to explore measurement.

To truly understand wellbeing, Dodge et al., (2012) propose that researchers familiarise themselves with the history of the concept and the emergence of two approaches in antiquity; hedonic and eudaimonic. The hedonic approach emphasises the importance of happiness, life satisfaction, and the development of positive affect, and sees wellbeing as the presence of these factors and the absence of negative affect (Bradburn, 1969; Diener, 1984; Kahneman, Diener, & Schwarz, 1999; Lyubomirsky & Lepper, 1999). On the other hand, the eudaimonic approach is more concerned with the presence of meaning and purpose, which it sees as creating and enhancing psychological functioning (Rogers, 1961; Ryff, 1989a; 1989b; Waterman, 1993). This approach was originally proposed by Aristotle who believed human action is underpinned by this common goal to achieve meaning (Dodge et al., 2012).

As research on wellbeing has grown, researchers have increasingly supported the idea that wellbeing is multi-dimensional (Diener, 2009; Michaelson, Abdallah, Steuer, Thompson, & Marks, 2009; Stiglitz, Sen, & Fitoussi 2009). Dodge et al., (2012) argue that this has contributed to the complexity and development of inconsistent literature, and prompted a need for a new definition (Dodge et al., 2012).

Dodge et al., (2012) describe Bradburn's (1969) research as one of the first to explore and actively define wellbeing, specifically psychological wellbeing. Bradburn (1969) explored the relationship between negative and positive affect, stating that feelings of happiness are one of the primary and most important elements when understanding wellbeing. However, Shah and Marks (2004) argue wellbeing is not only underpinned by feelings of happiness but is achieved when an individual feels fulfilled through actively contributing to society. Dodge et al., (2012) suggest that this principle of eudaimonia does not offer a definition of wellbeing in itself though adds further to the description of what wellbeing may represent.

Dodge et al., (2012) point out Ryff (1989a) critiques Bradburn's (1969) work as lacking definition and structure and is limited in taking into account aspects which they argue promote wellbeing, such as positive relationships, environmental mastery, having life purpose, self-potential and acceptance. Diener and Suh (1997) introduced the concept of three interconnecting components: satisfaction with life, unpleasant affect, and pleasant affect.

As wellbeing research progressed, a shift took place to incorporate aspiration and self-development, with researchers also exploring the achievement of goals (Felce & Perry, 1995). Furthermore, the term 'quality of life' began to be used interchangeably with 'wellbeing', further adding to the difficulties associated with defining wellbeing (Dodge et al., 2012).

Stratham and Chase (2010) argue that psychologists need to challenge common constructs of wellbeing and shift the focus away from a medical model to incorporate 'positive functioning'.

Carl Rogers (1961; p.186) discussed positive functioning in relation to wellbeing, using the term *"the good life"* (Dodge et al., 2012). Rogers (1961) stated that individuals aspire towards becoming fully functional, and in order to achieve this they are required to be open to experiences, be trusting and practice existential living (Dodge et al., 2012).

Dodge et al., (2012) further discuss how research on wellbeing has impacted clinical psychology, with the profession extending research to explore how to measure positive functioning. For example, Keyes (2002) explored the frequency with which youth reported the symptoms of emotional, psychological and social wellbeing; leading to the notion of 'flourishing', a term used within the positive psychology movement (Dodge et al., 2012).

Seligman's (2011) work presented a new concept of wellbeing, in which rather than defining it as the presence of happiness, it is seen as a state of being. Dodge et al., (2012) argue that this does not provide a universal definition, and reaffirm the usefulness of wellbeing as a construct.

Finally, Dodge et al. also highlight the idea that wellbeing exists as an equilibrium, altered when an individual is faced with challenges that may disrupt their wellbeing (Tomyn & Cummins, 2011; Headey & Wearing, 1991).

In light of the above, Dodge et al., (2012; p.230) offer their definition of wellbeing as being *"the balance point between an individual's resource pool and the challenges faced"*. This definition suggests wellbeing occurs for individuals when there is a balance between resources and the challenges they may experience. Both resources and challenges in this definition are suggested to impact psychological, social and physical factors. Figure 1 is adapted from Dodge et al., (2012) and visually represents their proposed definition. Dodge et al., (2012) suggest there are three key areas that their definition of wellbeing acknowledges: that wellbeing has a set point, the inevitability of an equilibrium, and fluctuation between two states (resources and challenges).

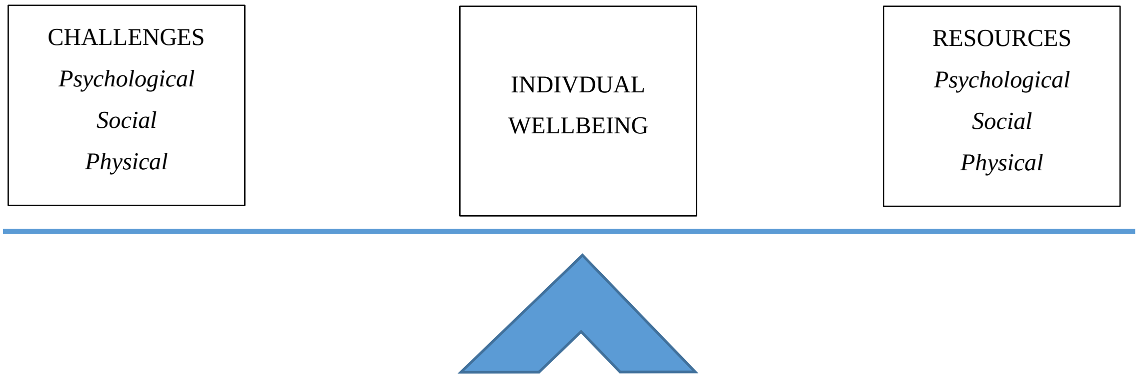

Figure 1. Adapted from Dodge et al., (2012) a proposed definition of wellbeing.

The definition states the balance of wellbeing is best described as a see-saw effect. If an individual's experience of challenges outweighs their resources this will inevitably create an imbalance to their wellbeing. According to Dodge et al., (2012) an individual's purpose is to maintain a balance between resources and challenges. The same can be argued for an individual's resources. Dodge et al's (2012) definition of wellbeing shows support for the Stocks and Flows Model of Wellbeing by Headey and Wearing (1992), discussed previously. Furthermore, Dodge et al., (2012) suggest their definition provides simplicity, a universal application and a basis to measure wellbeing. That being said, this definition describes wellbeing in terms of general wellbeing and therefore further consideration is needed in order to focus on employee wellbeing. Krishantha (2018) explains employee wellbeing can be assessed in terms of three dimensions: happiness, health and relationships.

In summary, wellbeing provides a focus for this research, and Dodge et al's (2012) definition is a useful way to operationalise the concept so that factors that increase and decrease wellbeing may be considered.

Palliative care and children's hospices

This section presents the context for the current study in terms of the setting: children's hospices. This includes defining palliative care, differentiating between adult and child palliative care, and providing a brief history of child palliative care within the hospice movement.

Palliative care

Palliative care for adults and children is a form of mainstream healthcare that aims to ensure patients have the best quality of life for as long as possible. This is delivered by treatment that focuses on the management of symptoms (both physical and psychological) rather than curing disease (World Health Organisation [WHO], 2021). Palliative care provides prevention and relief of suffering through the means of early identification, assessment and treatment of pain and other problems, such as physical, psychosocial and spiritual (WHO, 2021). Palliative care is provided in hospitals, community services, and in the hospice organisation.

Paediatric palliative care

Despite some similarities, there are significant differences between child and adult palliative care. Together for Short Lives (2018) states there is a smaller number of children who die from life limiting conditions compared to the number of adults who receive palliative care. Many conditions with diagnoses specific to childhood or young adulthood are extremely rare. Often many of the illnesses are genetic and there may be more than one affected child in the family (Together for Short Lives, 2018).

PPC often involves the whole family with a strong emphasis on organisations to provide bereavement support to the immediate family, a role that Social Workers can specifically undertake (Together for Short Lives, 2018). The WHO defines PPC as "*the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease"* (WHO, 2021). This definition suggests a child's social distress, psychological, and physical care needs are to be considered and must be supported by a multidisciplinary approach to paediatric care. The WHO also recommend PPC patients should start to receive such treatment from the moment they have been diagnosed (WHO, 2021). Some children/young people diagnosed with life limiting conditions may live only for a few weeks or months, whereas others may live longer for years or possibly even decades after a diagnosis (Hain, Heckford, & McCulloch, 2011).

The hospice movement and the development of PPC

Dame Cicely Saunders pioneered the hospice movement in the 1960s. Dame Saunders trained initially as a nurse and then a Social Worker, before training as a medical doctor, beginning each training in an effort to increase her capacity to influence the development of hospice care in the UK. She developed the culture of palliative care in hospices, as well as introducing effective pain management, and advocated compassion, dignity and respect for those dying from life limiting and threatening conditions (Hunter, 2017). Dame Saunders also promoted the idea that not all patients are curable and those who are not are not a sign of failure.

In 1967 Dame Saunders founded St Christopher's Hospice in London, the first in the UK, still a leading service within the palliative care discipline (Hunter, 2017).

In the late 1970s following the development of adult specialist palliative care units, there was a growing recognition among paediatricians for the need to provide specialist palliative care services for children/young people (Chapman & Goodall, 1979, 1980; Cotton, Cotton & Goodall, 1981). In the UK, Helen House was built as the world's first children's hospice and opened in 1982 (Dominica, 1982). Since 1986, Great Ormond Street Hospital has also been providing specialist palliative care to children. Craft and Killen (2007) state the overall aim of PPC is to improve and sustain the quality of life of children before their death from a life limiting condition and recommend that no timeframe is placed on such care. Currently in the UK there are 49 children's hospices that provide various levels of specialist care for children and young people with life limiting conditions (Together for Short Lives, 2018).

Though there are very close links with the NHS, all adult and children's hospices in the UK are independent charitable organisations generating their own income through donations and fundraising events (Hunter, 2017). Each children's hospice is unique with regards to the services that are offered, but all broadly follow the guidelines set by the WHO. There are six general principles that children's hospice services are required to adhere to when providing paediatric palliative care: communication, best interest decision-making, continuity and co-ordination of care, diversity and cultural issues, consent, confidentiality and capacity, advance care planning and anticipatory care planning (Together for Short Lives, 2018).

Life limiting conditions in children/young people

A life limiting condition is an umbrella term used to *"describe diseases with no reasonable hope of cure that will ultimately be fatal"* (Fraser, Miller, Hain, Norman, Aldridge, McKinney & Parslow, 2012; p. 923). Life limiting conditions are defined by Musgrave (2017; p.138), as "*those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers*". Together for Short Lives (2018) presents life limiting conditions in four categories, summarised in Table 1. These groups are illustrative of the wide range of conditions likely to benefit from a palliative care approach and support from children's palliative care services (Together for Short Lives, 2018). The four categories summarised in Table 1 are not fixed and children can move between them.

Table 1. The four categories of life limiting conditions in children. Adapted from Together for Short Lives (2018).

Category	Description	Conditions
One	Life-threatening conditions. Curative treatments are available but there is a chance these may fail.	Cancers, failures of major organs (heart, liver, kidney).
Two	Unavoidable premature death. Category two conditions may involve intensive treatment to prolong life.	Cystic fibrosis, Duchene muscular dystrophy.
Three	Conditions where there is no cure. Treatment is exclusively palliative.	Batten disease, mucopolysaccharidosis
Four	Non-progressive conditions resulting in severe disability with complex health care needs and a high risk of premature death.	Cerebral palsy (severe), multiple disabilities such as following brain or spinal cord injury.

Epidemiology of life limiting conditions in the UK

In England in 2017, approximately 3,000 child deaths were the result of medical conditions; 2,351 child deaths were reportedly due to a neonatal death or a life limiting condition (Together for Short Lives, 2018). In the UK research has estimated that 49,000 children aged 0-18 years are living with a life limiting condition (Fraser et al., 2012). In addition, Fraser et al. (2012) reported that in England in 2012 approximately 55,000 young adults aged 18-40 were diagnosed with a life limiting condition; 13,000 of these were aged 18-25. This number is much higher when compared to previous estimates of 20,000 in 2007 (Cochrane, Liyanage & Nantambi, 2007). 50% of childhood deaths are suggested to be among those who have life limiting conditions (Cochrane et al., 2007; Hain et al., 2011). It is estimated children's hospices in the UK care for approximately 7000 patients every year, of which, 15% are diagnosed with a life limiting condition (Blackburn, Devanney & Bradley, 2012; Fraser et al., 2012). When these figures are compared to other Western countries, like the USA, a similar proportion of children/young people require hospice care. However, there are smaller numbers of paediatric hospices in the USA and as such, care is largely delivered by children's hospitals and adult hospices (Friebert & Williams, 2015).

Palliative care: hospice professionals

UK children's hospices provide around the clock care tailored to patient and family needs and delivered by a Multi-Disciplinary Team (MDT) of trained health and social care professionals. As well as in the hospice, this care can also be delivered within the patient's home or other appropriate settings. In a hospice setting, the MDT approach involves supporting children/young people with life limiting conditions from diagnosis, through to end of life care and can extend beyond the patient's death by supporting families in bereavement (Connor & Bermedo, 2014; Knapp, Woodworth, Wright, Downing, Drake, Fowler-Kerry, Hain, & Marston, 2011).

The MDT will vary according to the needs of the patient and family, as well as the available resources of the organisation. Professionals can include - but are not limited to - doctors, nurses, paediatricians, psychologists, Social Workers, physiotherapists, occupational therapists, counsellors, teachers, dieticians, child life specialists, play therapists, spiritual leaders, music and art therapists (Bowden, Mukherjee, Williams, DeGraves, Jackson, & McCarthy, 2015).

The role of the social worker in paediatric palliative care

The Social Work profession historically has held a pivotal role within the hospice movement. The philosophy and principles of Social Work are asserted to providing holistic care that involves the whole person, valuing respect, dignity and difference and aligns with the six hospice care principles (Earnshaw-Smith, 1990; Sheldon, 2000). Social Workers aim to promote the wellbeing and safety of both vulnerable children and adults by promoting them to: have control in their lives, social justice and human rights (International Federation of Social Workers, 2014; Social Work Task Force, 2010).

Currently, there are over 300 Social Workers attached to palliative care services in the UK (Association Palliative Care Social Workers [APCSW], 2019), with many others encountering people receiving palliative care in non-specialist settings such as hospitals and nursing homes (Small, 2001b). While the role of the Social Worker varies between service providers, a fundamental attribute of palliative care Social Workers includes supporting individuals and their families to manage change and loss at every stage of the illness trajectory (Bosma et al., 2010). Palliative care Social Workers specialise in working with children and adults who are at the end of their lives, as well as with their families, those they are close to and with their communities (APCSW, 2016). They use their skills and knowledge to support individuals to help cope with the impact of what is happening to them, including loss and bereavement, and to have a good life and a good death (APCSW, 2016). The palliative care Social Worker works in hospices or hospitals, in the community, or in prisons, alongside other professions, agencies, organisations and as part of the wider community in which they are based to ensure people get the support they need (APCSW, 2016). '*Supporting people to live and die well: a framework social care at end of life'* (National End of Life Care Programme [NEoLCP], 2010) recognises that social care services are "*predominantly located in community settings*" therefore having an important role in "*promoting supportive communities through engagement with a wide range of community services*" (NEoLCP, 2010; p.30). The significance of Social Workers, specifically in end of life care, is addressed in the '*Route to Success in End-of-Life Care: Achieving Quality for Social Work'* document (NEoLCP, 2012). This guide highlights key issues across the six steps of the end-of-life care pathway and highlights the fundamental role and specialist skills Social Workers have in "*maintaining a focus on the dying person in their family, community and cultural context"* (NEoLCP, 2012; p. 36). It asserts that a focus on end-of-life care should be an everyday part of practice for all Social Workers, not just palliative care Social Workers (NEoLCP, 2012). This confirms the idea that openness around death and dying is positive, serving to increase awareness and develop resilience (Kellehear, 2005). Specialist palliative care Social Workers are highlighted as a potential "*resource to social workers in other settings through the provision of consultation, education and training*" (NEoLCP, 2012; p. 36).

Having set the context in terms of wellbeing, child hospice settings, and the role of the Social Worker, the next section will report a detailed scoping review.

Literature Review

Introduction - staff wellbeing in palliative care

In the healthcare context, several factors have been found to negatively impact staff wellbeing. These factors have been identified as either organisational and/or staff demographic factors. Organisational factors include long hours, a large workload, inadequate staffing, and limited resources (Dougherty et al., 2009). Staff demographic factors have been commonly related to years of experience, being younger in age and single (Graham, & Ramirez, 2002).

With regards to palliative care, a substantial amount of research has explored the psychological wellbeing and quality of life of palliative patients and their families (Harding, List, Epiphaniou, & Jones, 2012; Harrop & Edwards, 2013; Jaiswal, Alici, & Breitbart, 2014). Research has also begun to explore the experiences of professionals within adult palliative care settings. Initial findings suggest professionals often report positive experiences, such as building rewarding relationships with patients and their families and making a difference in terms of reducing physical and psychosocial suffering to patients (Klassen, Gulati, & Dix, 2012; McCloskey & Taggart, 2010; Plante & Cyr, 2011; Reid, 2013).

In comparison, PPC is a relatively new area of research and so far the focus has largely been limited in regards to the experiences of PPC staff (Hill, Dempster, Donnelly, & McCorry, 2016; Wolfe, Hinds & Sourkes, 2011). A child's death within a Western culture is considered hugely traumatic and unexpected, particularly as a widely held belief is that children will outlive their parents (Melin-Johansson, Axelsson, Grundberg & Hallqvist, 2014). Staff who care for children with life limiting conditions reportedly experience similar negative impacts on their wellbeing to those of the patient's family members, in turn, impacting upon their personal and professional lives (McConnell, Scott & Porter, 2016). Such impacts have been reported to leave professionals with feelings of frustration and guilt around their perceptions of providing inadequate care for PPC patients and support to the patients' families (Bergstraesser et al., 2013;

Papadatou, Bellali, Papazoglou, & Petraki, 2002; Papadatou, Martinson, & Chung, 2001). The potential challenges and negative impacts of the work on staff wellbeing may also affect their performance and there is a growing body of evidence that shows a link between staff wellbeing and patient experience, including patient outcomes (Francis, 2013; Franco, Bennet, & Kanfer, 2002; Firth-Cozens & Cornwell, 2009; Maben et al., 2012; Udipi, Veach, Kao & LeRoy, 2008; Wallace, Lemaire, & Ghali, 2009; West & Dawson, 2012). Furthermore, impacts on individual staff can affect their team members negatively in terms of workload and wider team morale (Westman & Bakker, 2008). As well as being problematic to individual staff members, and the wider team, it can also negatively impact at a broader organisational level in relation to the cost of sickness absence and presenteeism, further risking patient safety and care (Van Wyk & Pillay-Van Wyk, 2010).

The following section reports the scoping review methodology prior to outlining a detailed discussion and presentation of the literature on staff experiences within children's hospices. The remainder of the literature review will outline what we currently know about Social Workers' experiences in palliative care.

Scoping review methodology

The following literature review took the form of a scoping review, also known as a 'mapping' review (Peters, Godfrey, Khalil, McInerney, Parker, & Soares, 2015). A scoping review was chosen for the current study in order to accurately summarise the current literature base and to identify gaps (Arksey & O'Malley, 2005; Tricco et al., 2016). This scoping review will follow the five-stage methodological framework as proposed by Arksey and O'Malley (2005). The five stages are: 1) Identifying the research question; 2) Identifying relevant studies; 3) Study selection, 4) Charting the data; and, 5) Collating, summarising and reporting the results. Arksey and O'Malley's (2005) methodological framework for conducting a scoping review is underpinned by the transparent and rigorous methods often used within systematic reviews (Arksey & O'Malley, 2005). The current study undertook this process as a means to increase the reliability of the literature review and to ensure methodological rigour (Mays, Roberts & Popay, 2001).

The methodological framework stages

Framework stage one: Identifying the research question. Chapter one concludes with a summary of the current study's research questions and objectives (see page 52).

Framework stage two: Identifying relevant studies. Three electronic databases (EMBASE, Medline and PsycINFO) were searched in January-February 2021, with date restrictions 1986-2021. The start date of 1986 was chosen due to the hospice movement expanding to provide services for children and young people with palliative care needs at this time. It was accepted that there was likely little literature specifically on Social Workers in paediatric hospices, so studies in related areas were included (e.g., focussing on other professions). The key search terms used when searching the online databases were: paediatric/pediatric hospice; child and young person hospice; children's hospice; child hospice; hospice staff experience/practice/involvement/wellbeing/coping; Social Worker experience/practice/involvement/wellbeing/coping; hospice experience; hospice Social Worker; paediatric/pediatric Social Worker; and palliative care Social Worker. Search terms allowed for language variances in spelling (e.g. paediatric and pediatric). Please refer to Appendix J for full list of search terms with Boolean operators. In addition to the database searches, the reference lists of relevant articles were also checked.

Framework stage three: Study selection. Titles and abstracts were screened using eligibility criteria (inclusion criteria) to ensure only those studies meeting the aims and objectives of the current study were examined. The following eligibility criteria were employed: paediatric professionals and / or Social Workers working within hospice settings; studies that specifically explored staff/professional/ Social Worker experiences and / or perceptions of working with children / young people with life limiting conditions.

Framework stage four: Charting the Data. Searching electronic databases yielded a total of 2,952 articles, with the removal of 435 duplicates leaving 2541 articles to screen titles and abstracts. After the removal of ineligible titles, a total of 70 articles for which abstracts, and papers were read. Of these, 52 were rejected for not meeting the eligibility criteria, leaving a total of 18 studies included in the scoping review.

Figure 2 illustrates the process used when identifying and selecting articles to be included in the literature review. Table 2 lists a summary, critical appraisal and evaluation of relevance in context to the current study of all the papers included in the scoping review, in date order.

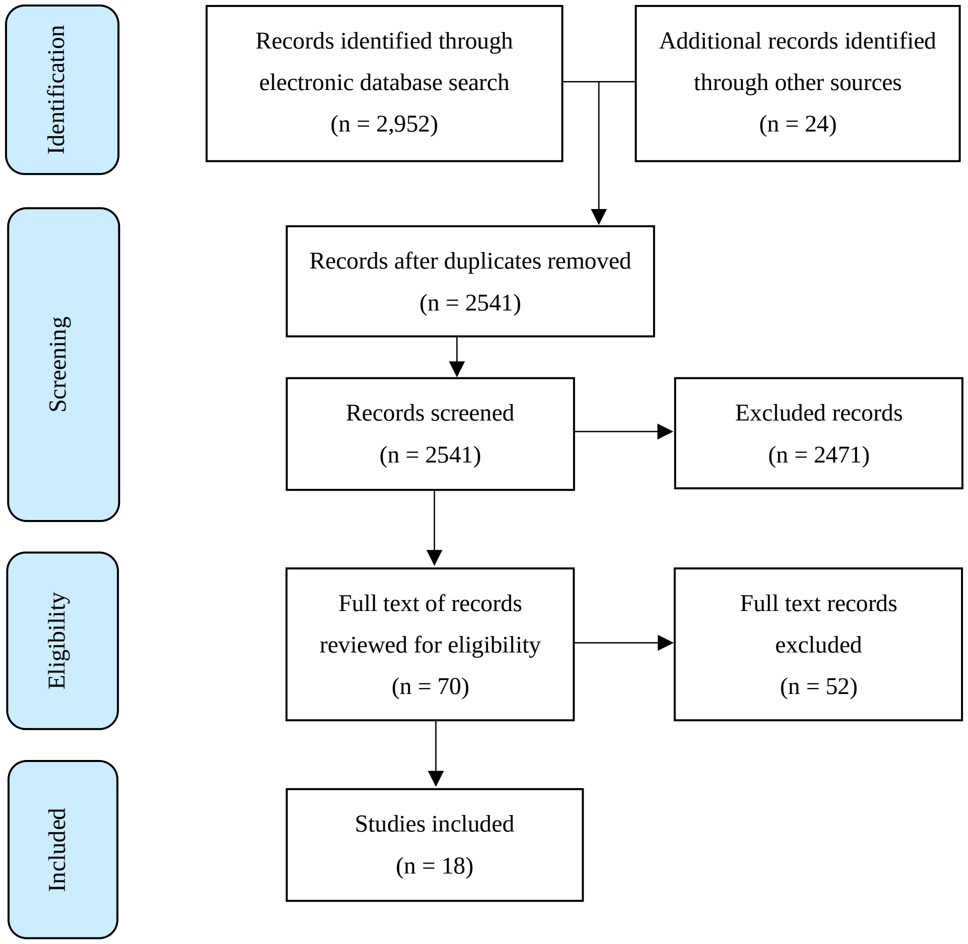

Figure 2. A PRISMA flow diagram of the scoping review process adapted from Peters et al. (2015)

Table 2. A summary, critical appraisal and evaluation of relevance of papers included in the scoping review.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
Woolley, Stein, Forrest & Baum (1989) UK: England	1) To explore the degree of stress experienced by staff caring for children and their families; 2) Examine the factors staff found stressful, and those which helped them to manage in difficult circumstances; 3) Explore the degrees of and factors associated with job satisfaction.	12 Nurses; five members of staff with qualifications in social work, teaching, physiotherapy; Six members of staff had no formal qualifications. Total: 24.	Mixed methods: Participants underwent a semi-structured interview to explore aspects of hospice life and were asked to complete a self-report questionnaire on general health. Job satisfaction was explored using a 7-point Likert scale.	The findings suggest that sources of stress were connected to feelings of ineffectiveness amongst staff when unable to relieve patient needs/distress, managing negative feedback from families, conflicts within the staff group. Mitigating factors that helped staff were informal staff support, hospice home from home environment and the variety and	Communication and inter-relationships were an important contributor to staff stress in this study with participants reporting high levels of job satisfaction – it will be interesting to explore how the participants in the current study perceive and experience relationships within their team and job satisfaction, in particular what they use to support their wellbeing and what keeps them in their role. Limitations: small numbers of male participants and the study did not document how many Social Workers took part. It is also a study that took place over 30 years ago – hospice policy etc. has since moved on although it will be interesting to identify if participants in the current study have the same / similar / different experiences for comparison.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
				diversity of professional and personal skills sets amongst the participants.	
Vachon (1995) Canada	International literature review focussed on staff stress in hospices.	No data on number of papers included found.	Narrative literature review.	Found staff stress/burnout to be a major feature of early work. Though there is evidence of hospice staff suffering from anxiety, depression, drug abuse and ‘difficulties with dealing with issues with death and dying’, later studies found this was not always true. Notes importance of social support,	26 year old review; includes all child and adult hospice staff but interesting background in terms of staff stress/burnout not being universal and importance of support mechanisms.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
				involvement in work and decision making and realistic workload.	
Barnes (2001) UK	A Narrative literature review examining the causes and effect of staff stress within children's hospices. This review also considered factors that staff reported as supporting them to cope within a hospice environment.	This review did not state how many papers were reviewed in the article, however Barnes (2001) acknowledged there have been relatively few studies that examine staff experiences within a children's hospice setting and the literature has been presented on staff experiences from the wider	Narrative literature review.	Findings conclude that the main causes of stress were related to communication difficulties, conflicts within the staff group, limited relationships with the child's family, struggling to accept a child's distressing symptoms. The following was identified to help staff cope better with their working environment: good communication	The findings highlight two key factors promoting good coping: hospice characteristics and impact of staff who have a number of years of experience. Furthermore, at the time of the study, children's hospices were stated to be in their infancy in terms of number and service evolution, therefore a number of the study's reviewed were not conducted within a children's hospice. However, the findings presented in this study and wider literature suggest future research is still required.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
		palliative care area.		and the home-like atmosphere of the hospice and teamworking.	
McCluggage & Elborn (2006) UK: Northern Ireland	The aim was to identify the symptoms which cause staff anxiety who work within children's hospices.	A total of 10/23 children's hospices approached returned at least one questionnaire (43.47%) Participants: 10 hospice administrators, 10 doctors and 18 nurses Total: 38.	Mixed methods postal questionnaire – qualitative and quantitative items.	The doctors reported five symptoms whereas nurses reported six symptoms that are likely to cause them anxiety.	Conducted a thorough recruitment process through the Association of Children's Hospices website. The use of a mixed method questionnaire has been useful to demonstrate factual information about the hospice as well as gathering clinical staff experiences and allowing the voice of participants to be heard. This study's findings are interesting in terms of how symptom management and identity contribute to the emotional impact of working within a children's hospice for its staff, however there is very little in the way of how this impacts the participants' wellbeing, support professional identity, work etc. It is very much focused on medical staff perspectives. Limitations: Respondent bias, small sample and age of the study.
McCloskey & Taggart (2010) UK:	To explore the experience of occupational stress of nurses across three	Healthcare professionals: nine hospice nurses; seven	A qualitative study using focus groups (four). Newell & Burnard's (2006) Content Analysis.	Four key themes emerged: work demands; nurse/child &	Despite this study being conducted within a specific geographical location/profession without the representation of hospice Social Workers, it presents a robust design and sense of 'fit' between

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
Northern Ireland	services providing children's palliative care (hospice care, hospital care and community care).	community children's nurses; two hospital nurse specialists working in the children's hospital. Total: 18.		family relationships; maintaining control; and support and roles-related stressors. Participants reported the main consequences of stress included compromised family relationships, sleep disturbance, irritability, and having to take sick leave.	the findings and those of previous studies, which gives credibility to the results. This study does not mention the use of researcher reflexivity, the current study aims to explore this (See chapter two).
Remke & Schermer (2012) USA	Explores themes related to team development within child palliative care.	Review of the literature and contains three case study examples from the Social Worker perspective.	Narrative review and case examples.	The three case examples from Social Worker practice: Team member relationships; collaboration; and communication.	The literature review does not detail the method undertaken when searching and presenting the literature. Lacks scientific rigour with limited base to generalise the findings to hospices based within the UK. The case examples presented may be influenced by researcher bias due to presenting subjective accounts.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
				This paper put forward recommendations for effective teamworking and collaboration.	
Price, Jordan & Prior (2013) UK: Northern Ireland	This study aimed to investigate health and social care professionals' perspectives on developing services for children with life limiting conditions at the end-of-life using issues identified by bereaved parents.	Health and social care professionals (n=35) recruited from a children's hospice and palliative care ward.	A qualitative study using focus groups with a nominal group technique (NGT). Thematic analysis.	Six key themes: truth telling; symptom management; communication with and relationship between families and professionals; emotional impact; the withdrawal of feeding or treatment; and sibling support. Professionals in this study were noted by the authors to have a strong resonance with parent experiences from previously	This study ensured each of the focus groups had between 6 and 9 participants. A limitation of the focus groups is they tended to be conducted in the same setting whereby only issues relevant to that setting were discussed/prioritised. Focus groups were facilitated by the same researcher, who is experienced within children's palliative care. Despite the researcher having likely been known to many of the participants, the authors aimed to reduce researcher bias through the fact they had no managerial or other responsibility over participants. Further to this, the researchers used as 'second researcher' taking notes during the group interviews was unknown to the participants. This study used a NGT during group interviews to provide structure and to reduce disproportionate participant contribution particularly as the study recruited from both health and social care professionals. Despite these efforts the authors reported nurses predominated focus group

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
				conducted studies on issues related to decision-making about/withdrawal of treatment and when talking about death (to child and siblings) (Price, Jordan, Prior & Parkes, 2011; 2012).	participants but did not explain why this was (e.g. due to larger numbers of nurses being recruited, group dynamics etc.) Furthermore, this study failed to note the specific roles of the health and / or social care professionals that took part. This study made reference to the emotional impact and briefly discussed direct links of this to staff wellbeing. The findings however do not go any deeper than specifying that staff from a hospice setting feel they have support to manage and support their wellbeing through reflection and group support, this was found to be the opposite in child palliative hospital settings. Therefore, little is known of exactly how such work and which elements of the work may impact/influence wellbeing.
Maunder Z. (2016) UK: Wales	Conference abstract reporting on an ethnographic study of 'emotional labour' experienced by nurses in children's hospices and	No details of numbers given; children's nurses providing palliative care for children/young people and their families within community and	Ethnographic study: non-participant observation followed by qualitative interviews; focus group to test interpretations.	Emotional labour influenced by work; nurses required to form emotional connections with families and adopted informal personas in the	This was a conference abstract so had little detail; no publication identified. Interesting notion of 'emotional labour' and suggestion that in children's palliative care – and particularly the hospice – this forms a major part of the work to form connections with families.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
	community services.	children's hospice settings in Wales.		hospice to make families feel as if they were at home.	
McConnell, Scott & Porter (2016) International systematic review	To explore the experiences of healthcare professionals who provide care to children with life limiting conditions as a means to inform the development of interventions to support professionals, thus improving the palliative care quality for both children and their families.	Papers reviewed included: 16 qualitative; six quantitative; and eight mixed methods; total: 30. Across a range of settings and professions.	Mixed methods systematic review.	Key themes identified rewards and challenges of providing care to children with palliative care needs, the impact on staff's personal and professional lives, coping strategies, and key approaches to help support staff in their role.	The results highlight and provide recommendations for practice. Only two of the 30 studies focused on children's hospice work and included a number of different child healthcare settings, making it difficult to apply the findings to the current study.
Hunter (2017) UK	Reflective paper on experiences of a paediatrician in a children's hospice.	Reflections of one paediatrician.	Reflective piece.	Includes background to development of paediatric palliative care,	Limitation: paper focuses on one person's reflective account, though it is interesting to hear the perspective of a doctor. There is acknowledgment that medical care is actually one small part of the

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
				alongside personal reflections of work in a children's hospice.	care offered in the hospice; also use of phrase 'privilege to work in hospice care'. Could be interesting to think about in terms of the hospice movement and five-year strategy.
McConnell & Porter (2017) UK: Northern Ireland	To investigate the impact on staff who provide end-of-life care to patients in a children's hospice. This study also aimed to understand how staff cope, and draw recommendations for improving staff wellbeing, with the objective to improve paediatric care for both children and their families.	15 healthcare staff from a children's hospice. Participants were mainly from nursing backgrounds.	A qualitative study: interviews (n=12) and a focus group (n=3). Thematic Analysis.	Three themes: rewarding experiences; challenges; and recommendations.	This study offers insight into the wellbeing of staff providing end-of-life care to children within a hospice setting in the UK. This study explored how the participants felt their role was rewarding in terms of the meaningful relationships developed with children and their families. This study also demonstrates the impact and use of multiagency working. Interesting points to review in terms of the current study. Evidence presented is robust and has scientific rigour. Authors used a reflexive journal throughout data collection and analysis to record decisions and their reasoning. An approach adopted in the current study. Limitations: The findings were investigated within a single hospice and mainly comprised the experiences of nurses, limiting transferability to other settings, in particular children's hospices and other child hospice professions. Nonetheless, many of the findings substantiate results from

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
					previous research in a range of settings. However, future research conducted across different children's hospices would be useful to triangulate this study's findings. Overall, these results are interesting when exploring wellbeing and coping in Social Workers in the current study. Social Workers have unique experiences which the current study aims explore further. Nonetheless, this study adds to the limited understanding of staff experience of providing end-of-life care within a children's hospice.
Pelon (2017) USA	This study explored the prevalence of compassion fatigue and compassion satisfaction among hospice Social Workers.	55 participants from 34 hospices.	Quantitative: Online survey.	Findings suggest compassion fatigue is a concern among participants although compassion satisfaction may act as a protective factor.	The quantitative design did not offer the researcher the opportunity to explore the participants' responses to gain an understanding of the positive and negative experiences of their work and how such work may impact their wellbeing and coping skills. This study did not specify whether the research conducted was within adult/child hospices.
Taylor & Aldridge (2017) UK: England	To explore work-related challenges and rewards, support and development	Focus groups with healthcare professionals (doctors and	A qualitative study using semi-structured interviews and focus groups. Thematic Analysis.	Seven themes identified: making a difference and getting it right; a	Scientific rigour demonstrated: using several criteria to ensure credibility, dependability and authenticity: Utilised a good sampling strategy. This study assessed data saturation during data collection as a means to

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
	needs in a multi-disciplinary care team in a children's hospice.	nurses): 10; allied health professionals (nursery nurses, therapists, and care staff with other qualifications and skills): 7 Total:17 Semi-structured interviews with health professionals (doctors and nurses): 10; allied health professionals (nursery nurses, therapists, and care staff with other qualifications and skills): 20 and managers		multi-faceted role; complexity of children's care; team functioning; being valued; individual coping; and job motivation.	determine the final sample size for interviews supporting credibility. This study employed a standardised approach to data collection as well as completing an audit of the study processes for study dependability. The study sought respondent validation to assure authenticity regarding study findings. Furthermore, the findings have been discussed with other hospices and presented at national conferences. Limitations: No inclusion of Social Workers. Failed to discuss the potential limitations of the study: focus group design, participant demographics (e.g., gender, experience in role) as well as only exploring the experiences of professionals from one children's hospice. To that end, future recommendations were also not outlined.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
		and other hospice staff: four Total: 34 A children's hospice. setting.			
Marmo & Berkman (2018) USA	This study aimed to examine: 1) job satisfaction associated with interdisciplinary collaboration and their perceptions of hospice leaders; 2) To investigate if these associations differed by the hospice profit status.	Total: 203 Social Workers.	Quantitative: Cross sectional study – online questionnaire.	Findings explored: Interdisciplinary collaboration, servant leadership, job satisfaction, profit status, perception value & professional characteristics. nursing over social work.	Adds to the limited evidence base on Social Worker perceptions within hospice settings. Ensured rigour and utilised a four-method recruitment strategy. Limitations: Findings are of interest to the current study, though it is difficult to make direct comparisons due to differences in hospices practices between the UK and USA and this study being limited specifying whether participants were recruited from either child/ or adult hospices. Sampling protocol may have led to selection bias.
Pentaris, Papadatou, Jones & Hosang	To explore palliative care professionals' perceptions of the barriers and	Five participants from nursing and social care backgrounds.	A qualitative study: Semi-structured interviews. Content Analysis.	Three themes emerged from the data: availability and adequacy of	Limitations: sample size of palliative care professionals recruited through this study's convenience sampling were all female. Therefore, the results may present with bias. Such limitations have been

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
(2018) UK: England	challenges that prevent or delay families from using palliative care services in London, UK. This study also aimed to extend on previous research by exploring palliative staff perceptions rather than general healthcare professionals.			palliative care for children; obstacles to accessing and benefitting from palliative care; and cultural and religious resources in black minority ethnic communities.	considered in the current study. The authors argue that despite the limitations, this study has sparked a dialogue among professionals and researchers concerning the issues raised and possible solutions to the barriers highlighted. Only two of the five participants worked in a children's hospice, therefore, limited insight into how the hospice environment impacts the professionals, an area the current study aims to pursue.
Price, McCloskey & Brazil (2018) UK: England	To explore parent and professional perspectives from a UK children's hospice regarding step-down care as part of the hospital transition to home.	Parents: five Professionals: 26 Total: 31.	Parents: Interviews Professionals: Five Focus groups. Thematic Analysis.	The overall findings discovered similar results reported by parents and hospice professionals: they believe the hospice setting had much to offer children and	This study focused on both parent and professionals' perspectives of a new aspect of care within paediatric palliative care. However, the data is only collected from one UK hospice and the perspectives of the professionals does not detail the impact of the work on them and their wellbeing and coping.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
				families in terms of step-down care.	
Tatterton, Summers & Brennan (2019) UK: England	To explore the experiences of nursing staff supporting families of deceased children and young people who have been cared for in children's hospice cool rooms.	Six nurses.	A qualitative descriptive study: a focus group interview.	Five themes were identified: barriers to care; bereavement care for families; impact on families and staff; influencers and enablers of change; and sustainability of new practices. The findings further concluded that participants viewed the long term and responsive approach to supporting bereaved families as a strength of	The three researchers ensured research rigour, each had analysed the focus group transcript and fieldnotes independently before discussing constructs prior to agreeing the thematic framework. Following data mapping, the authors ensured all relevant data featured in the framework, and that the map represented the data derived from the transcript. Despite parallels being drawn from the wider literature, this study was confined to a single partnership between two hospice organisations, therefore results should be generalised with caution. Although the authors of this study state they considered that the opinions of more forceful or articulate participants may have contributed to the findings gathered from the focus group, the experiences of the participants will be useful to explore in relation to the current study's findings.

Author (Date) Country	Aims of Study	Participants and Setting of Study	Approach: Method and Data Collection	Findings	Appraisal: Usefulness of Findings for the Current Study
				the hospice model.	
Cappi, Riboni, Grana, Pierotti, Ravelli, Sutti et al. (2020) Italy	To explore the perceptions of doctors, nurses and psychologists working within Italian paediatric hospices with regards to ‘appropriateness of care’. Secondly, the perception of non-appropriateness on the individual and at team level.	Total: 17 professionals.	A qualitative study: semi-structured interviews.	The findings show participants did not refer to a common concept of appropriateness.	The findings are useful for the current study as this study explores the experiences of staff within a child’s hospice. Although no Social Workers participated it will be interesting to compare the current study’s findings to this European study. This study is based in Italy therefore the findings may be limited to the cultural contexts and the professionals involved.

Framework stage five: Collating, summarising and reporting the results. The majority of the studies included in this scoping had taken place in the United Kingdom (n=11). Others were conducted in: United States of America (n=4), Canada (n=1), Worldwide (n=1) and Italy (n=1). Studies were conducted in the following settings: children's hospices (n=10), child hospice/community/hospital (n=2) with three studies not specifying whether findings were gathered from either a child and / or adult hospice. In terms of study design: qualitative (n=8), quantitative (n=2), mixed methods (n=4), narrative review (n=2), reflective article (n=1) and a systematic review (n=1) were included in the scoping review. Excluding participants from the two narrative reviews (Barnes, 2001; Vachon, 1995) and a systemic review (McConnell, Scott & Porter, 2016), studies featured a combined total of 498 participants with a variation in individual sample sizes (5-203, median=18).

The remainder of chapter one will present the results from the scoping review.

The scoping review

Introduction

The following scoping review is organised under subheadings derived from themes from the literature.

The review will firstly summarise and discuss the findings from the two narrative reviews (Barnes, 2001; Vachon, 1995) followed by the systematic review conducted by McConnell, Scott and Porter (2016).

The scoping review will continue by outlining the wider literature base on the child hospice setting, rewards/challenges of the work and the direct impacts on hospice staff. The scoping review will also present the research that is more specific to Social Workers and their experiences within a hospice setting.

Findings from the reviews

Two narrative reviews (Barnes, 2001; Vachon, 1995) outline a summary of the research published at that time on the causes and impact on staff stress within children's hospices. The older of the two narrative reviews presents the earlier research specific to staff stress and burnout in adult and children's hospices (Vachon, 1995). Though there is evidence in this review of hospice staff suffering from anxiety, depression, drug abuse and "*difficulties with dealing with issues relating to death and dying*", later studies have found such accounts are not necessarily a widely held experience. Although this 26 year old review by Vachon (1995) does not report data on the number of studies included, the review does however illustrate the importance of social support, involvement in work and staff decision making while having a manageable workload.

Similarly, Barnes' (2001) review also failed to state how many studies were included. Barnes' (2001) review did however present the factors that staff described as supportive and beneficial to their coping within a hospice environment. The review concludes that the main cause of hospice staff stress were related to communication difficulties, conflicts within the staff group, limited relationships with the child's family, and staff struggling to accept a child's distressing symptoms. Factors that promote staff coping within a hospice environment were suggested to be good communication amongst staff teams, the home-like atmosphere of the hospice and teamworking. Additionally, at the time of the study, children's hospices were in their infancy in terms of number of hospices and service provision. Therefore, a number of the studies presented within this review were not conducted within a children's hospice, an area Barnes (2001) suggested required further research. These findings are therefore difficult to generalise to hospice staff experiences and so the current study will treat these findings with caution.

Each of the reviews provides a summary of earlier research. Although both focus on stress they are limited with regards to the direct impact to the wellbeing of hospice staff.

A more recent systematic review conducted by McConnell, Scott and Porter (2016) explored staff experiences across a range of paediatric palliative care settings and presents the factors staff find rewarding and challenging when providing end-of-life care.

The key reward that PPC staff identified was the deep and meaningful relationships they developed with the children and families they were caring for. As for the key challenges for staff, they reported the following: experiencing feelings of grief when a child dies, maintaining appropriate boundaries, having demanding caseloads, limited staffing levels and communication problems with families/colleagues and/or management. The systematic review also reported palliative care staff who had greater experience or a particular expertise within palliative care were more likely to feel comfortable when providing end of life treatment. While these findings provide more insight into what it is like for staff working in PPC, it is worth noting that only two studies out of the 30 presented within this review had focused on staff experiences within a children's hospice setting (McCloskey & Taggart, 2010; Woolley, Stein, Forrest, & Baum, 1989). These studies were also extracted in the current study's database search and will be discussed at a later point in the literature review. These are interesting results and highlight the need for additional research, further supporting the current study's exploration, with the particular focus on Social Workers. In addition, this review noted that in comparison to community and hospital settings, children's hospices are the most optimal environment when carrying out palliative care. The review reports that staff prefer the 'home from home'-like qualities, as well as the emphasis on providing emotional, social and spiritual support – services hospital wards and community settings did not always offer. This is an area within paediatric services that requires further exploration.

The next sections outline a summary of the individual articles identified in the scoping review.

The child hospice setting

Hunter (2017) presented a reflective paper on their experiences as a paediatrician in a UK children's hospice. Though this is just one person's reflective account, it is interesting to hear the perspective of a doctor. Hunter (2017) also discussed the background and development of children's hospices specifically within the UK. Reflections were shared on a number of aspects of their work and highlights the differences from an NHS setting: NHS work is heavily governed by guidance and regulations, which Hunter (2017) explains hospices have historically been free from. However, this has changed in recent years as hospices increasingly aim to meet the statutory requirements set by the Care Quality Commission and government bodies. Hunter (2017; p. 525) described the hospice setting as *"pleasant with lots of light, space and outdoor areas"*. Hospice work in comparison to NHS work was noted as being more relaxed with the aim of working in a reflective approach encompassing MDT working. Hunter (2017) further reported that the focus of hospice work did not centre around their medical role, which they explained was difficult at times as this left them unsure on their role within the hospice setting. A further comparison between hospice and NHS work was that although a hospice setting is flexible, they experienced professional isolation, with difficulties accessing peer support or supervision as well as seeking appropriate professional development to meet appraisal requirements. Hunter (2017) argues that children and families seek hospice intervention for one of two reasons: psychosocial support for children with life limiting conditions, or children being referred for end life care and symptom management. Hunter (2017) also explains their role mainly entails symptom management and they support children and families to make informed choices about their treatment and care, such as the location of receiving care and types of medication. Making predictions and plans were also discussed as part of their role and they explained how medical staff are often asked questions that they cannot answer, such as when certain events are likely to happen (i.e., when a child may die). Hunter (2017; p.526) suggests hospices may wish to find ways to *"increase access to specialist medical input and to increase working across the boundaries between NHS and hospices"*.

Price, McCloskey and Brazil's (2018) qualitative study explored parent and professional perspectives from a UK children's hospice regarding step-down care for children and their families as part of the hospital transition to home. Although this study is particularly interested in the perspectives of the professionals (of which two were Social Workers), and acknowledges the perspectives are limited with regards to how the work may impact their wellbeing and coping, it does offer an insight into how the professionals view a children's hospice setting. Five themes emerged from the professional data: The long road home; Living again; Learning to care; Developing professional partnerships; and, Best place-best care. Professionals reflected they felt the step-down care offered by the hospice was empowering to the patients and their families and offered them the opportunity to *"live again"* (p. 404) as the setting was described as a home from home.

The two studies present an overview of a children's hospice setting and the way hospices tailor care to the needs of the patient and their family (Price et al., 2018). Hospice staff experience a hospice setting as one that offers more than just medical care (Hunter, 2017) and that working in children's hospices brings with it rewards and challenges.

The rewards and challenges of hospice work

The literature discusses what it is like for hospice staff when providing palliative care to children/young people, as well as supporting families. The literature specifies these experiences as 'rewards' and / or 'challenges' when working in a children's hospice.

Taylor and Aldridge (2017) conducted a qualitative study using focus groups and individual semi-structured interviews with children's hospice staff (n=34). This study aimed to explore work-related challenges and rewards, support and the developmental needs in an MDT in a UK children's hospice. It is unclear whether this study included Social Workers as the authors stated they recruited participants across health and social professions within the hospice. The authors identified seven themes: Making a difference and getting it right; A multi-faceted role; Complexity of children's care; Team functioning; Being valued; Individual coping; and Job motivation. Taylor and Aldridge (2017) found a number of factors that contribute to hospice staff experiencing both rewards and challenges in their work. In particular team functioning was discussed by participants as being both a reward and a challenge in their hospice work. Some of the challenges specific to team functioning were identified and described when the team functions poorly. Instances of when they felt their team functions poorly were reported by some of the participants as handover where the allocation of work was noted on occasion to cause team conflict and colleague isolation. The authors discussed this as being related to some participants having low confidence in aspects of their role and they worried about being tasked with responsibilities out of their comfort zone and felt other team members were better suited. Team functioning on the other hand, was reported to create a happier and a more relaxed atmosphere between the team. Participants noted at the end of their shift they were able to 'switch off' from their work, bring a greater work/life balance and experience more positive attitudes towards their work, feeling valued by their colleagues and positively impacting on the quality of care participants felt they were providing. Similar results were reported in the Cappi et al., (2020) qualitative study that explored the perceptions of Italian hospice professionals (medical staff and psychologists). This study reported teamwork as being fundamental to PPC and was "essential to harmonize any differences of views" (Cappi et al., 2020, p. 5-6).

Further, Taylor and Aldridge's (2017) study raises the importance of individual factors, coping skills and resilience, revealing participant differences with regards to workplace motivation in a children’s hospice, participant relationships with the hospice organisation and participants’ perceived risk of burnout. However, there are potential limitations: the focus group design, participant demographics (e.g., gender, experience in role) as well as only exploring the experiences of professionals from a single children’s hospice. Despite these critiques, Taylor and Aldridge’s (2017) findings demonstrate scientific rigour using several criteria to ensure credibility, dependability and authenticity. These findings are further supported by a number of the studies included in McConnell, Scott and Porter’s (2016) systematic review; that staff are committed to provide high standards of care is in keeping with the philosophy of a children’s hospice.

A similar UK qualitative study conducted by McConnell and Porter (2017) also investigated the impact on staff (n=15) who provide end of life care to patients in a children’s hospice using a focus group and individual interviews. This study also aimed to understand how staff cope, and drew recommendations for improving staff wellbeing, with the wider objective to improve paediatric care for both children and their families. McConnell and Porter (2017) identified three themes: Rewarding experiences; Challenges; and Recommendations. Rewarding experiences were identified by participants feeling they make a difference. Participants acknowledged that providing palliative care was among the most difficult of experiences for families to endure. Participants felt satisfaction from the meaningful relationships developed with children and their families, providing individual care packages aimed to manage the child’s symptoms. Also associated with the work were the challenges participants experienced: communicating with families, symptom management through medication and relieving child and family distress, difficulties managing grief and finding ways to coordinate respite care alongside end of life care for patients. Participants in this study also reported a number of coping strategies and specific aspects of the hospice setting that were felt to alleviate some of the challenges experienced in their role. The authors discussed these as recommendations for the child hospice setting and the wider considerations within children’s palliative care. These recommendations are: Self-care and building resilience, Dissemination of specialist skills and experience, Peer support and Organisational support. McConnell and Porter (2017) report robust findings through the use of a reflexive journal and rigorous data collection and analysis. Despite this, the study’s limitations are that findings were investigated within a single hospice and mainly comprised the experiences of nurses, limiting transferability to other settings and professionals. Nonetheless, many of the findings substantiate results from previous research in a range of settings (McConnell, Scott & Porter, 2016), though future research conducted across different children’s hospices would be useful to triangulate this study’s findings. This study does add to the limited understanding of staff experience of providing end of life care within children’s hospices, which are interesting to consider when exploring wellbeing and coping of Social Workers in the current study. However, as Social Workers have unique experiences, the current study aims to explore this further.

Research from Tatterston, Summers and Brennan (2019) support the findings with regards to some of the challenges experienced by staff as discussed in the above two studies. Tatterston et al's., (2019) study explored the experiences of six nurses supporting families of deceased children and young people who had been cared for in children's hospice cool rooms. The five themes that emerged from the focus group interview identified the following: Barriers to care; Bereavement care for families; Impact on families and staff; Influencers and enablers of change; and Sustainability of new practices. The findings further concluded that participants viewed the long term and responsive approach to supporting bereaved families a strength of the hospice model.

In Pentaris, Papadatou, Jones and Hosang's (2018) study, five participants from nursing and social care backgrounds shared their perceptions of the barriers and challenges that prevent or delay families from using child palliative care services in London. Three themes had emerged from the semi-structured interview data: Availability and adequacy of palliative care for children; Obstacles to accessing and benefitting from palliative care; and Cultural and religious resources in black minority ethnic communities. This study's findings should be interpreted with caution, and conclusions considered tentatively in light of the current study. Firstly, this study is a qualitative study exploring the perceptions of staff who work in children's hospices, however, the study does not explore how it directly impacts them as individuals. Secondly, the study only interviewed and gained perceptions from white female participants from two boroughs of South East London, leading to a narrow set of experiences, based on a patient population from a very specific demographic and socio-economic background. Therefore, this study's findings may only be relevant to areas with children and families of a similar demographic and socio-economic background. Furthermore, only two of the five participants worked in a children's hospice. The authors argue that despite the limitations, this study has sparked a dialogue among professionals and researchers concerning the issues raised and possible solutions to the barriers highlighted. Moreover, it offers some limited insight into how the work/hospice environment impacts staff, an area the current study aims to pursue.

Overall, these studies offer insight into the rewards and challenges hospice staff experience as part of their role within children's hospice care, and how these experiences may impact their wellbeing. Challenges to the role are often related to barriers in patient care, conflicts within relationships: staff teams and between staff and families (McConnell & Porter, 2017; Taylor & Aldridge, 2017; Tatteron et al., 2019; Pentaris et al., 2018). Rewards were linked to team functioning (Taylor & Aldridge, 2017) and feeling that the work they do makes a difference (McConnell & Porter, 2017). Factors such as staff resilience, self-care, support from peers and the organisation they work for were considered factors that enhance wellbeing in a children's hospice setting. It will be interesting to compare these findings with the results of the current study.

The impact of working in children’s hospices

A number of the studies included in this scoping review discuss the impact of the work on children’s hospice staff, including both negative and positive impacts which will be discussed below.

Negative impact - emotional load

The literature describes the emotional impact that children’s hospice staff commonly report. Emotions that are frequently reported among staff are anxiety (McCloskey & Taggart, 2010; McCluggage & Ellborn, 2006), ineffectiveness, (Woolley et al., 1989), grief (McCloskey & Taggart, 2010), and sadness (Price, Jordan, & Prior, 2013). These emotions were often reported as a response to feelings of frustration at the challenges faced in attempting to reduce suffering in their patients and distress in the families.

A study conducted by Woolley et al., (1989) was the first in the UK to explore the experiences of staff working in a children’s hospice interviewing a range of health and social care professionals from doctors to non-qualified hospice staff (n = 24). Although the primary aim was to explore the degree of stress experienced by staff, this study also examined factors associated with job satisfaction. The findings suggest that sources of stress were connected to feelings of ineffectiveness amongst staff when unable to relieve patient needs/distress, managing negative feedback from families, and conflicts within the staff group. Limitations of the study include few male participants and the study did not clearly document whether Social Workers took part. In addition, it is noted that the study is 30 years old and hospice policy and practice has changed.

McCluggage and Elborn (2006) recruited participants from medical (doctors and nurses) and non-medical roles (hospice administrators) (n=38) from 10 out of 23 children’s hospices through the Association of Children’s Hospices website within the UK. This mixed methods study examined the symptoms suffered by children with life limiting conditions that cause hospice staff anxiety. Doctors in the study report five child life limiting symptoms (seizure control, spasms, pain assessment, vomiting and unidentified distress) that cause them anxiety, whereas the nurses reported six (distressed non-verbal, psychological difficulties, pain assessment, seizures, pain management and vomiting). Though this study focusses on medical professionals, it does offer insight into how symptom management and hospice role may contribute to the emotional impact of staff working within a children’s hospice. A limitation of this study is potential respondent bias which may limit the study’s findings as only those staff who had anxiety may have responded, though the authors argue this is not case because this was minimised by content and face validity pilot studies that had been conducted prior to questionnaires being administered to the participants (McCluggage & Elborn, 2006). The authors report this study recruited a small sample, however at the time of study there were only

23 children’s hospices compared to 54 in 2020, again meaning the study may be less relevant now.

A qualitative study conducted by McCloskey and Taggart (2010) used semi-structured interviews to investigate the experience of occupational stress in nurses (n=18) across three services providing children’s palliative care (hospice care, hospital care and community care) in Northern Ireland. The qualitative results report four key themes: Work demands; Relationships; Maintaining control; and Support and roles. The emotional impact of the work was mainly discussed under the theme of ‘work demands’ and presented within the subtheme of ‘emotional load’. This subtheme highlighted that the emotional load of the work greatly impacted the nurses across each of the three services. The main negative emotional impact reported were feelings of anxiety and loss and grief that were particularly experienced when children in their care had died. This study found nurses felt they had to behave in a way that ignored their feelings of grief as a way to cope at work. Participants reflected on the emotional impact they felt was a result of the particularly strong relationships they had formed with the children and their families, also noted by the participants as going *“beyond the expected nurse-patient dynamic”* (McCloskey & Taggart, 2010; p. 236). Although this study did not discuss the impact of the nurses’ work directly on their wellbeing, the findings do suggest participants had been carrying feelings of anxiety that they reported impacted other areas of their lives outside work, as illustrated in this quotation: *“you absorb a lot of families’ distress and it just wears you down.”* (p. 236). Though this study focussed on 10 nurses in one geographical area, it could offer an insight into some of the negative experiences experienced by other children’s hospice staff. In terms of methodological limitations, there is limited discussion of researcher reflexivity and participants were recruited from a small geographical region.

Price, Jordan and Prior (2013) were also interested in understanding the experiences of staff who provide PPC staff across multiple palliative care units (a UK children’s hospice and a regional children’s cancer unit). They carried out a qualitative study using five focus groups to collect data from a range of health and social care professionals (n=35). Thematic analysis identified six key themes: Truth telling; Symptom management; Communication with and relationships between families and professionals; Emotional impact; The withdrawal of feeding or treatment; and Sibling support. Though many of the participants had reported they experience work satisfaction, they did share they also experience a number of negative emotions. These emotions were commonly reported as sadness and frustration along with feelings of inadequacy. Such emotions and feelings were primarily noted by participants when caring for children who were receiving end of life treatment. The findings of this study highlighted the gaps in collaborative working between UK hospice staff and external agencies. This was particularly evident with regards to late referral procedures and limited bereavement care available to families. Such experiences were reported as creating difficult relationships between professionals and families and further manifesting feelings of guilt amongst professionals.

Although the authors brought attention to how the emotional engagement of the work may compromise clinical care as well as participant wellbeing, opportunities to manage and support staff wellbeing did not feature in their post study recommendations.

Maunder (2016) reports similar findings from an ethnographic study exploring factors influencing the emotional labour nurses reportedly experience while working in children's hospices and community palliative care services. Although data was extracted from a conference abstract with limited detail on the participants and no identified publication, it does however report the interesting notion of 'emotional labour' and the suggestion that in children's palliative care - particularly the hospice setting - this forms a major part of the work when forming connections with child patients and their families.

The findings from these studies illustrate some of the emotional impacts staff in children's hospices may experience. Reflections from Hunter (2017) reinforce the idea that staff often experience higher levels of anxiety, which they argue is due to the fact that most health professionals have little experience of children dying and it is clearly a highly emotional experience. Hunter (2017) also argues that the anxiety can have an impact on the professionals' ability to care for the child and their family effectively. These studies also highlight the gaps in the current literature, with poor representation of the wider hospice workforce, particularly Social Workers.

Positive impact

There are very few studies exploring the positive impact that working in a children's hospice can have on its staff. A number of these have already been highlighted in the above section titled 'The rewards and challenges of hospice work'.

As discussed above, Woolley et al., (1989) explored factors associated with job satisfaction in hospice staff. Communication and inter-relationships between hospice staff were identified as an important contributor to the stress staff were experiencing, but despite this, participants reported high levels of job satisfaction. Woolley et al., (1989) highlighted some of the mitigating factors: the hospice's 'home from home' environment, receiving informal support and how varied and diverse the hospice staff team were with regards to experience and skill mix.

The current study aims to explicitly explore factors that influence wellbeing in children's hospice staff, which is contemporary, and a topic mostly absent from previous research.

Palliative care Social Workers

The scoping review also searched for research specific to the experiences of hospice Social Workers. Only three out of 18 papers included in this review focused on the experiences of Social Workers who work in hospice settings.

Remke and Schermer's (2012) paper offers a narrative review of the literature and provides three case examples that explore themes related to team development from a Social

Worker perspective within child palliative care. Three case examples were also presented on the following themes: Team member relationships; Collaboration; and Communication. Within each theme Remke and Schermer (2012) proposed a number of recommendations.

For instance, Remke and Schermer's (2012) case study that explored hospice collaboration highlighted the differing perspectives of a Social Worker while supporting a family with a child's imminent death when compared to a physician's. The Social Worker's perspective, through their counselling work with a family with a terminally ill child, had understood that the family were managing well with the child's health deterioration, the family's preference was to be alone (without medical staff) in the child's last days and the Social Worker aimed to empower the family and support this. However, the physician felt a medical presence was required to manage the child's pain and symptoms. Through collaborative working the Social Worker and physician identified that although they were working from different perspectives, sharing their perspectives with one another had helped to defuse any tensions that had been building between the two professions. Remke and Schermer (2012) suggested that teams follow Blacker and Deveau's (2010) seven recommendations for effective interprofessional team collaboration. Remke and Schermer (2012) emphasised the importance of building trust between child hospice team professionals and that trust is strengthened when teams work together that helps to create a shared vision and approach to care for children and their families. Remke and Schermer (2012) discussed when teams work collaboratively that communication is vital, specifically the quality of this communication is key to fostering team problem solving, particularly when faced with the emotional pressures of rapidly changing situations professionals may face in a child's hospice setting.

Although Remke and Schermer (2012) present the perspectives of Social Workers from children's hospices this paper is not without limitations. Firstly, the paper is limited with regards to how the work may impact the wellbeing of the Social Workers. Secondly, the literature review presented in this paper does not detail the method undertaken when searching and reporting the literature, lacking scientific rigour with limited base to generalise the findings to hospices within the UK. Thirdly, the case examples included may have been influenced by researcher bias due to presenting subjective accounts.

A quantitative study by Pelon (2017) explored the prevalence of compassion fatigue and compassion satisfaction among hospice Social Workers through an online study. The study findings suggest compassion fatigue was a concern among the participants, though compassion satisfaction may act as a protective factor. Though Pelon's (2017) findings demonstrate Social Workers are at risk of compassion fatigue, the quantitative design did not allow further exploration into the positive and negative experiences of their work and how they may impact their wellbeing and coping skills. A further criticism, and relevant to the current study, is that Pelon (2017) did not specify the hospice setting (adult and / or child) from which the Social Worker data had been collected.

Marmo and Berkman (2018) conducted a quantitative cross-sectional study using an online questionnaire with palliative care Social Workers to examine two aims: 1) Job satisfaction associated with interdisciplinary collaboration and their perceptions of hospice leaders; 2) To investigate if these associations differed by the hospice profit status. The findings indicate Social Workers reported experiencing job satisfaction, though this was only slightly higher than those found in a previous study of hospice Social Workers (Coopman, 2001) and compared to other professions (e.g., nurses). With regards to the findings exploring profit status, lower retention of hospice Social Workers was reported at for-profit hospices. Marmo and Berkman (2018) suggest these findings are possibly due to the greater emphasis on the medical model approach and placing primacy on physical symptoms over psychosocial needs, suggesting the nursing profession has been prioritised over social work. This study adds to the limited evidence base on Social Worker perceptions within hospice settings, particularly Social Worker experiences of interdisciplinary relationships and how valued they feel within the hospice environment. Although this study ensured rigour and utilised a four-method recruitment strategy it is limited with regards to the sampling protocol that may have led to selection bias due the lead researcher having emailed Social Workers. This study is US based with a focus on profit status. Hospices in the UK are typically charities, therefore a non-profit organisation, meaning some of this study’s findings are not applicable to the current study. The emphasis on the medical model reported by the participants is an interesting element to consider in relation to the current study’s findings.

The findings from these studies are interesting with regards to how the participants in the current study may report on their experiences of working in a setting supporting children with life limiting conditions, medical needs and the emphasis of the medical model (Remke & Schermer, 2012). Furthermore, two studies identified the importance of team collaboration from the Social Worker perspective within a hospice setting (Marmo & Berkman, 2018; Remke & Schermer, 2012). However, all of these studies present limited research exploring Social Worker perspectives specifically from a children’s hospice setting, further supporting the requirement for the current qualitative study to investigate this.

Limitations of the scoping review studies

The existing research as presented in the above scoping review illustrates that the overall literature base is limited with regard to exploring the experiences of children’s hospice staff, especially the experiences of Social Workers. The existing research has predominantly recruited participants from a medical background (i.e., doctors and nurses) (Hunter, 2017; Maunder, 2016; McConnell & Porter, 2017; McCloskey & Taggart, 2010; McCluggage & Elborn, 2006; Tatterton et al., 2019; Taylor & Aldridge, 2017; Woolley et al., 1989). Although it is insightful to learn of the experiences of medical staff who work with children/young people with life limiting conditions, it is likely that through their different training, practices and hospice roles that their experiences are difficult to generalise to those of Social Workers.

Furthermore, two out the three studies that focused on hospice Social Workers used quantitative designs that are particularly lacking when exploring and understanding the lived experiences of child hospice Social Workers (Marmo & Berkman, 2018; Pelon, 2017). Moreover, the three studies included in the scoping review that specifically report data from Social Worker participants were conducted within the USA. While the results from these studies are of interest to the current study, again these will be used with caution in respect to the fact the USA and UK have differing health and hospice practice systems. For example, USA hospices are either for-profit or not for-profit, whereas hospices within the UK are predominately self-funded through charities. Thus, operating under different government guidance, policy and protocol.

Additionally, a number of the studies are limited with regards to their sampling. Several studies have reported having recruited from one hospice or had mainly recruited female participants (Hunter, 2017; McConnell & Porter, 2017; Pentaris et al., 2018; Price, McCloskey & Brazil, 2018; Woolley et al., 1989). Again, these limitations create difficulties with respect to generalisability of the findings. Studies conducted from one hospice may limit our understanding of overall hospice experiences, particularly as these studies will be heavily influenced by that particular hospice's ethos, services and practices, further creating room for bias and potentially polarised viewpoints. Similar concerns are held with regard to those studies having only successfully recruited from female populations. Additionally, some of the studies discussed recruiting participants across multiple palliative care settings (i.e., hospital, community and hospice settings), in these studies the smallest group of participants were from a hospice setting. For example, in one study only two of the five participants worked in a children's hospice, giving limited insight into how the hospice environment may truly impact its staff, an area the current study aims to pursue (Pentaris et al., 2018). Furthermore, several studies indicate that hospice work has an impact upon their staff but fails to offer an understanding as to how this impacts their wellbeing.

Finally, a number of the studies discussed span between the years 1989 to 2017, which may not reflect current thinking, especially as governmental guidelines on how hospices should practice has greatly changed (Barnes, 2001; Hunter, 2017; Maunder, 2016; McCloskey & Taggart, 2010; McCluggage & Elborn, 2006; McConnell & Porter, 2017; McConnell, Scott & Porter, 2016; Pelon, 2017; Remke & Schermer, 2012; Taylor & Aldridge, 2017; Vachon, 1995; Woolley et al., 1989), particularly in light of the hospice movement five-year strategy launched in 2017 (Hospice, UK).

How the current study will address previous study limitations

A number of gaps remain within the current literature, with limited research exploring Social Worker experiences of working within a children's hospice and how such work impacts their wellbeing. The current study will make a qualitative exploration into the experiences of Social Workers to gain a better understanding of how they cope and manage their wellbeing when supporting children/young people with life limiting conditions. This will add to the existing research as well as address some of the gaps within the literature base. The current study aims to invite participants through the APCSW, which will allow recruitment from more than one hospice, from around the UK, as well as aiming to recruit male and female participants from differing backgrounds ensuring as broad-a-representation as possible.

Clinical implications raised in scoping review

As discussed at the beginning of chapter one when reporting data from the most recent NHS staff survey (NHS, 2020), there is growing concern and priority to explore, understand and support the wellbeing of healthcare staff in the NHS. However hospices, specifically children's hospices, were not included in this. The scoping review has found several relevant articles; however, the focus remains wide, with no relevant studies specifically investigating the wellbeing of children's hospice Social Workers in the UK. The current study will utilise the definition of wellbeing provided by Dodge et al., (2012) and two models of wellbeing, the SDT and DET, to understand and explain the current study findings.

Research has highlighted the importance of hospice staff to be thoroughly and appropriately trained to carry out their role in order to provide exemplary care and support to patients and their families. It is hoped that the current study may enable hospice organisations, as well as other agencies responsible for training and supporting palliative care Social Workers, to widen their understanding of Social Worker experiences and to review the support and developmental pathways they provide to hospice Social Workers, as well as provide insight into retention rates of Social Workers in children's hospices.

Team relationships had often been reported impacting staff abilities within a child hospice setting in the present literature, particularly with regard to MDT collaboration and communication. One study made specific reference to the importance of child hospice teams enabling communication and sharing of patient practice to ensure MDT were working together (Remke & Schermer, 2012). This study also reported that improving communication and collaborative ways of working can reduce and eliminate potential issues between MDT members (Remke & Schermer, 2012). The current study may provide ways for children's hospice teams to engage in reflective team practice with the view to improve hospice team communication and collaboration, which could address Smits and Tomsett's (2017) hospice staff survey, which identified morale and communication as being low and negatively impacting hospice staff wellbeing.

Research aims and objectives

The research question for the current study is: What are the experiences of hospice Social Workers who care for children and young people with life limiting conditions?

There are two aims for the study that will consider the participants' experiences:

1) To gain an understanding of the impact on wellbeing for child hospice Social Workers.

2) To explore the factors that affect wellbeing in this group, including the coping strategies they employ.

In order to investigate these aims, the following objectives will be explored:

- Impact of the work
- Coping skills utilised within their practice
- Organisational impacts; support systems available to participants and the impacts on staff retention rates

CHAPTER TWO – Methodology & Method

Chapter two is presented in two parts. The first discusses the current study's methodology, including the design, rationale for utilising a qualitative approach, the researcher's ontological and epistemological stance, and overall methodological approach. The second presents the study's method and details the sampling procedure, recruitment process, semi-structure interview procedure, ethical clearance, and closes with a statement of reflexivity.

PART ONE - Methodology

Design

The current study utilised a qualitative approach to explore the experiences of qualified Social Workers from child hospice settings using Thematic Analysis (TA; Braun & Clark, 2006). A convenience sample was recruited through the Association of Palliative Care Social Workers (APCSW) via email advertisement (Appendix D). Data was collected through eight semi-structured telephone interviews that were audio-recorded and transcribed verbatim. This falls within TA recommendations for qualitative research projects (Braun & Clark, 2013). A topic guide was used in each interview and participants were asked a variety of open-ended questions to promote conversation between the researcher and the participants in order for them to share their experiences (Appendix H). Each recorded interview was listened to and transcribed, with the transcript being reviewed prior to conducting the TA analysis.

Methodology

Adopting a qualitative approach

A qualitative approach is simply analysing *"words as data, collected and analysed in all sorts of ways"* (Braun & Clarke, 2013, p.3). Qualitative methodologies (e.g., interviews) enable researchers to explore the subjective experiences of individuals, and in turn generate data that is rich in detail, which is advantageous when researching areas where little is known (Braun & Clarke, 2013). Furthermore, a qualitative approach can contribute significantly to research by enhancing understanding of the context of events as well as the actual events themselves (Sofaer, 1999). The current study is written from the perspective of psychology and understands qualitative research as an approach that allows for the discovery of new scientific knowledge especially where this is limited knowledge on a subject matter (Denizen & Lincoln, 2005; Robson, 2011). Consequently, a qualitative approach was considered more appropriate as there is a lack of previous research in this area and this study's aim was to explore the experiences of Social Workers in children hospices and how the work impacts their wellbeing and coping, that are not easily quantified (Barker, Pistrang, & Elliott, 2015).

Ontology and epistemology assumptions

Qualitative research examines *“the richness of the worlds we all exist in”,* and is underpinned by various theoretical positions (Braun & Clarke, 2013, p. 26). Elliott, Fischer and Rennie (1999) state qualitative researchers are required to maintain an awareness of their own theoretical positioning and reflect upon this whilst considering their relationship and understanding specific to their area of research. Methodological considerations, such as data collection and analysis, rely on ontological and epistemological assumptions (Ramazanoglu & Holland, 2002).

Ontology assumptions

Ontology is defined as the ‘science of being’ and explores the relationship between human interaction and the world in which we live (Braun & Clarke, 2013). Ontology varies along a spectrum with realism (a realist) and relativism (a relativist) at either end. Realists interpret *“a knowable world”*, assuming there is only one truth and forms the basis of most quantitative research (Braun & Clarke, 2013, p. 27). Whereas relativists assume several realities exist, that change across a variety of contexts and time and underpins some qualitative methodologies (Braun & Clarke, 2013). At the centre of this spectrum sits critical realism. A critical realist assumes a knowable and real world does exist; though, this is typically influenced by a researcher’s context (Braun & Clarke, 2013; Madill, Jordan, & Shirley, 2000).

Epistemology assumptions

The philosophy of epistemology is interested in *“the study of the nature of knowledge and the methods of obtaining it”* (Burr, 2003; p.202). Although epistemology, like ontology, is understood along the spectrum of realist-relativist, there are stark differences between ontology and epistemology assumptions (Harper, 2012). Ontology is concerned with what there is to know in the world, while epistemology investigates what it is possible to know (Braun & Clarke, 2013). Various epistemological assumptions exist, three will be outlined here: constructivism, positivism, and contextualism.

Constructivism examines how societies develop constructs of reality and explores how these are perceived and lived by individuals (Braun & Clarke, 2013); this contrasts with positivism/empiricism, concerned with seeking definite truths (Clark, 1998; Guba & Lincoln, 2005). Constructivist theory suggests that what someone understands the world to be does not always reflect the true nature of the world in which someone lives (Braun & Clarke, 2013). Furthermore, constructivism aims to understand and explore a person’s individual experiences as their truth, rather than an objective.

Positivism argues that the relationship between perceptions and the world is a simple one (Harper, 2012). Positivism is mostly aligned to that of empiricism and suggests valid knowledge is gathered through *“the application of established scientific methods”*, thus reduces bias and contamination, enabling the discovery of the truth (Braun & Clarke, 2013; p. 29). Recently, post-positivism (a form of positivism - viewed as being less pure) dominates. Post-positivism acknowledges that the truth is attainable, however, post-positivists consider the influence their contexts may have on their research (Braun & Clarke, 2013). While others disagree, some argue qualitative research can be undertaken whilst adopting this position (Michell, 2004).

Contextualism is suggested as being similar to critical realism in that it is positioned between positivism and constructivism (Henwood & Pidgeon, 1994). Contextualism can be seen as a version of constructivism, in that a contextualist researcher does not assume a single reality, instead they see knowledge as emerging from contexts while reflecting on their own positioning (Braun & Clarke, 2013). Contextualism, however, retains the notion of truth seeking often refuted by constructivism (Braun & Clarke, 2013) and claims no single method can explore ‘the truth’, and that knowledge is valid to specific contexts (Tebes, 2005).

My positioning as researcher for the current study

My positioning and the current study is orientated towards a contextual critical realist stance. This position assumes data (i.e., interview data) can tell researchers about reality, without surmising a direct mirroring of that data (Harper, 2012). A contextual critical realist understands research data will not tell us directly what is experienced by those being interviewed, and thus I aim to move beyond the interview content. I acknowledge participants in the current study will be influenced by their social context, individual differences, and experiences, that I believe is difficult to separate from. I feel a contextual critical realist stance aligns with my study’s question, aims and objectives and ensures my research goal of staying close to the participants’ experiences, as well as being aware of the wider socio-contexts at play. As much as is possible, as the researcher, I am mindful of my own reality and experiences and how my own social context may impact the analysis (Braun & Clarke, 2013) (please refer to my statement of reflexivity p.66).

Methodological considerations

Data collection – rationale for semi-structured interviews

Several data collection methods can be used within qualitative approaches (including TA), for example: focus groups, a form of group interview that generates data by capitalising on the communication between participants (Kitzinger, 1995); ethnography, which involves long-term exposure to a setting or a group of people (Lincoln & Guba, 1985); and case study research, which is often fairly long-term and tends to be conducted with one person and involves interviews which help researchers to explore an individual’s perspective on a particular idea or situation (Boyce & Neale, 2006). For this study, individual interviews were selected as the most suitable data generation method.

Qualitative interviews are the primary method of data generation used within qualitative research as well as within the social sciences (Briggs, 1986). These allow researchers to collect direct responses from participants in relation to specific research questions (Bradford & Culen, 2012; Stuckey, 2013). Individual interviews have been defined as a ‘professional conversation’, with the overall aim of encouraging participants to talk about their perceptions and experiences (Braun & Clarke, 2013; Kvale, 2007).

There are three types of individual interview commonly used within qualitative research: structured, semi-structured and unstructured (Green & Thorogood, 2018). Although these interview types share similar characteristics, such as asking people questions about their feelings, thoughts, beliefs and behaviour; it is acknowledged that these interview types are also widely different, particularly with regard to the amount of control the researcher has over the interview structure and process (Grant, Rohr, & Grant, 2012; Stuckey, 2013). Braun and Clarke (2013) define the three interview types as: 1) Structured: the researcher offers predetermined questions or response categories – this type of interview is typically used in quantitative research; 2) Semi-structured: the researcher is guided by a list of questions, with the flexibility for participants to discuss topics the researcher may not have anticipated – this type is mostly used within qualitative research; and 3) Unstructured: At most, the researcher will be guided by a list of themes or topics of discussion, though the interview is typically participant led – this type of interview is used in some, but not all qualitative research projects. When conducting TA, the use of semi-structured interviews is the preferred method when collecting data on individual experiences as they allow researchers to explore and understand participants’ meanings of their ‘reality’, assumptions, discourse, or ideas that exist within their society (Braun & Clarke, 2006). This method of data collection also strongly aligned with my positioning.

The semi-structured interviews used in the current study ensured an in-depth subjective view of the participants’ experiences was obtained, following a series of open-ended questions, that prompted interviewees to give detailed responses. Closed questions would have produced limited responses as they tend to prompt yes or no answers (Flick, 2018). The use of semi-structured interviews in the current study allowed rapport to be built with each participant, leading to discussions of detailed and meaningful personal experiences. These discussions provided the participants a voice, one that is not always heard. The discussions also allowed the participants’ world to be explored and offered some understanding of what it is like to care for children/young people with life limiting conditions (Denzin & Lincoln, 2005; Reid, Flowers & Larkin, 2005; Smith, 2007).

Though virtual interviews (e.g., telephone, video conferencing or email) have previously been perceived as *“a poor substitute”* in comparison to face to face interviews - that are often viewed as the ‘gold standard’ way of collecting interview data (Braun & Clarke, 2013, p. 79; Novick, 2008) - they have also been suggested to be an effective tool when generating data

(Sturges & Hanraham, 2004). Telephone interviews can offer participants flexibility, convenience and accessibility as they are not restricted by geography (Sturges & Hanraham, 2004). The current study offered participants the choice between face-to-face and telephone interviews.

Despite the advantages semi-structured face to face and telephone interviews provide researchers, this form of data collection is not without limitations. Face to face interviews have been deemed as time consuming for researchers and a method that may lack breadth due to smaller sample sizes in comparison to qualitative surveys (Braun & Clarke, 2013). This method has also been argued to limit participant empowerment (less participant control over produced data) or anonymity and may deter participants who wish to disclose sensitive information within a group setting (Braun & Clarke, 2013). Some of the limitations associated with telephone interviews are technological problems and issues of confidentiality (i.e., others being during the interview without the researcher's knowledge). Additionally, researchers may have difficulties verifying participant identification as well as limited observation of participants in comparison to face to face interviews, whereby interviewers/researchers can observe the emotional state and wellbeing of participants more closely (Braun & Clarke, 2013).

Choosing a data analysis methodology

When selecting a qualitative methodology it is important that researchers select the most appropriate approach that will best explore the research question of inquiry and gain desirable results (Starks, Brown & Trinidad, 2007). Choice of data analysis and methodological decisions are noted to be influenced by the researcher's epistemological positioning. Qualitative methodologies, such as TA, Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA) are argued as being underpinned by critical realism in the way they are normally applied (Braun & Clarke, 2013). TA is the chosen methodological approach for the current study, however, prior to this decision being made, the below methodologies had been reviewed and eliminated as they were thought unsuitable regarding the current study's research aims and objectives.

IPA (Smith, Flowers & Larkin, 2009) aims to explore an individual's experience of a phenomenon from a particular viewpoint, to understand the ways in which an individual makes sense of their experiences and the meanings they attach to particular life events (Smith et al., 2009). It remains a popular method amongst psychologists but it has been argued that IPA explores an individual's opinion rather than the meaning associated with a particular lived experience (Tuffour, 2017). IPA is theoretically bound (theory of hermeneutics), an approach that is heavily influenced by a researcher's interpretation. In aiming to conduct a dual focus on individual cases and superordinate themes across datasets, it has been suggested that it lacks the substance that TA analyses can offer (Braun & Clarke, 2006; Braun & Clarke, 2013).

GT (Glaser & Strauss, 1967) aims to create psychological theory from qualitative datasets. Until theoretical saturation is met, GT suggests data collection and analysis should continue (Braun & Clarke, 2013; Glaser & Strauss, 1967). The current study aimed to detect patterns across the dataset and was not focused on producing psychological theory in relation to qualified Social Worker experiences, consequently GT was thought inappropriate.

Rationale for using TA

This approach was first developed in the 1970s by Gerald Holton and has been recognised since as a distinctive method (Braun & Clarke, 2006). TA is now a well-established qualitative approach that is widely utilised within the discipline of psychology; it is a qualitative approach that provides a method for analysing data (Braun & Clarke, 2006). TA was chosen for use in the current study for its pragmatic and flexible approach, a key strength and one that can be used to explore a range of research topics and questions (Braun & Clarke, 2013). It is a methodology that is not constrained by preferences of data collection, one specific epistemological position or theory when identifying, analysing and reporting patterns (superordinate themes) across qualitative datasets (Boyatzis, 1998; Braun & Clarke, 2006). Boyatzis (1998) argues that TA can go much further than this and states it can interpret several aspects related to the research area in question. TA also has a variety of analyses that can be conducted (discussed below). A further strength of TA is that it aims to listen to an individual’s story and tries to understand how they make sense of their lived experience, an aspect that is key to the current study (Braun & Clarke, 2013). Also, TA is underpinned by the critical realist position and aligns with my own positioning to the research. For these reasons, TA was deemed a sound approach for the current study.

Despite the advantages of using TA for the current study, several limitations had also been considered. For instance, TA is suggested to have a limited literature base when compared to other methodologies, for example GT and IPA (Guest, MacQueen & Namey, 2012; Holloway & Todres, 2003). TA is also argued by some to have limited interpretative power when the approach is not used within a theoretical framework and lacks concrete guidance when a more interpretative analysis is required (Braun & Clarke, 2013).

It is important to note the above limitations may occur due to inappropriate research questions or poor researcher analysis rather than TA itself (Javadi & Zarea, 2016). Notwithstanding, to assist and address these potential limitations, I sought training and practical support from internal (tutors and fellow trainees) and external (TA discussion groups and training workshops) resources. I also followed the TA six-phase procedure and 15-point checklist developed by Braun and Clarke (2006; 2013) whilst reflecting on my experiences throughout.

TA: The considerations

Once TA has been decided upon as the chosen data analysis approach, Braun and Clarke (2006) suggest the researcher has further considerations to make. The first consideration is the type of TA analysis to be undertaken. There are two ways in which TA can identify patterns and superordinate themes within a qualitative dataset; either an inductive, i.e., a 'bottom-up' approach (Braun & Clarke, 2006) or a deductive/theoretical i.e., a 'top-down' approach (Boyatzis, 1998; Hayes, 1997). An inductive TA analysis is data driven and is therefore not shaped by existing theory or by the analytic preconceptions of the researcher (Braun & Clarke, 2006). A deductive TA analysis is developed by the researcher's theoretical interest and thus is driven by the analyst identifying patterns and superordinate themes within qualitative datasets (Braun & Clarke, 2006).

The current study employed an inductive approach. The aim was to be led by the data and thus the analysis was not driven by a theoretical interest in the topic area, an approach that in some cases may limit or risk collecting data that is less detail rich (Braun & Clarke, 2006; Braun & Clarke, 2013). It is however acknowledged that *"researchers cannot free themselves of their theoretical and epistemological commitments"* (Braun & Clarke, 2006; p. 12). This was considered throughout and managed by providing a statement of reflexivity, attending regular supervision and keeping a reflective journal.

A second consideration researchers need to address is the level at which themes will be identified from the dataset, using either semantic or latent interpretation (Braun & Clarke, 2006). A semantic level analysis involves the pattern of themes focusing on the explicit meanings of the data, whereby the researcher organises the pattern of themes by summarising and interpreting the significance of the patterns, their broader meanings and the implications that are important when answering the research question (Patton, 1990). A latent level of analysis is argued to go further than semantic, whereby underlying assumptions and ideas are identified that inform and shape the data's semantic content (Braun & Clarke, 2006).

The current study aimed to be data led and chose to conduct a semantic level of analysis to address the research question, aims and objectives. Data was excluded that was deemed to not be relevant to the research question, aims and objectives.

TA: The procedure

The following section presents the six-phase procedure of TA (Braun & Clarke, 2006) as well as detailing criteria advised in Braun and Clarke's (2006) 15-point checklist. The below section demonstrates how I applied this within the current study.

Phase one: Becoming familiar with the data. Braun and Clarke (2006) advise that for researchers to become familiar with qualitative datasets they engage in the process of reading and re-reading interview data, as well as recording their initial thoughts. In phase one of the current study, I became familiar with the interview data by listening back to each of the interviews prior to transcription. This was repeated following transcription in order to review for errors within each text and to immerse myself in the data. I transcribed four of the eight interviews, while the other four interviews were transcribed using approved transcription services. Once the transcription process was complete, each interview transcript was read, and preliminary notes were written based on any initial ideas about the data. This process ensured that any emerging patterns from the dataset were captured prior to starting the initial coding phase.

Phase two: Initial codes. Phase two involved reading through each interview transcript several times, line-by-line, while referring to the preliminary notes made during phase one. This process helped me to develop the initial codes. Codes are features of the dataset, as Boyatzis (1998, p.63) states, they are *"the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon".* I gave equal attention to the eight transcripts; this was to ensure the coding was comprehensive. The data was coded manually by hand, whilst constantly referring to the preliminary notes I made on each transcript. Data that was not relevant to the research question or study objectives was not coded. The initial codes were then categorised in preparation for phase three. An example of the coding process is in Appendix I.

Phase three: Searching for initial superordinate and subordinate themes. Phase three began by reading through the initial codes, before organising these into groups, identifying patterns within the dataset and reviewing any relationships between the codes (Braun & Clarke, 2006). The initial codes started to form the superordinate and subordinate themes, with interview extracts attached from each of the eight interviews. At this stage, it was useful to present the initial superordinate and subordinate themes using a thematic map, Figure 3 shows this in detail. This led to an early understanding of the emerging superordinate and subordinate themes and how they related to each other. Care was taken at this stage to ensure no data relevant to the research question or study objectives was disregarded; supervision was utilised to regularly monitor this.

Phase four: Reviewing superordinate and subordinate themes. In phase four, the initial superordinate and subordinate themes generated in phase three were reviewed, as recommended by Braun and Clarke (2006). The initial superordinate and subordinate themes, as well as the thematic map and the relationship between superordinate and subordinate themes were reviewed between myself and my project supervisor in meetings and email exchanges. This process helped me to form a sound idea of the different superordinate and subordinate themes that were emerging and ensured the true narrative of the Social Workers' experiences was reflected.

Phase five: Naming and defining superordinate and subordinate themes. Once satisfied with a the thematic map, the names of the three superordinate and subordinate themes were finalised. During this process, it was useful to refer to the participant interview extracts and reorganise them into a coherent story that related to the research question, aims and objectives. The aim of phase five was to ensure that the superordinate and subordinate themes were concise and were presented as participant thoughts. This provides the reader with an overview of what the superordinate theme was presenting (Braun & Clarke, 2006).

Phase six: Writing the report. This phase involved telling a story of the participants' experiences (Braun & Clarke, 2006). The report presents the superordinate and subordinate themes along with extracts of interview data of the overall experiences of the eight participants working with children/young people with life limiting conditions in a hospice setting and is illustrated in chapter three. When writing chapter three, I ensured I presented a balanced use of participant extracts. I also applied my own analytical interpretation and completed appropriate quality checks, outlined later in this chapter.

PART TWO - Study method

Sampling procedure

Sample size

In comparison to quantitative research, qualitative research collects data from much smaller samples (Braun & Clarke, 2013). Patton (2002) suggests that qualitative inquiry is not restricted with meeting certain rules regarding sample size, however, guidelines for TA (Braun & Clarke, 2013) categorise suggestions on sample size by the type of data collection and the size of the project ('small', 'medium', or 'large'). For small projects utilising interviews to gather data, Braun and Clarke (2013) recommend sufficient data can be gathered from 6–10 participants.

The current study interviewed eight qualified Social Workers employed in children's hospices who had agreed to take part in the current study. Please refer to chapter three regarding participant demographic data and participant pen portraits.

Inclusion criteria

The following inclusion criteria were adhered to when recruiting participants for the current study:

- Participants were required to be a qualified Social Worker employed within a children's hospice setting that supports children/young people with life limiting conditions
- Participants had to have been employed within the hospice for a minimum of six months
- Participation was encouraged from participants of any age, gender, sexual orientation, and religion.

If potential interviewees did not meet the above inclusion criteria, they were not eligible to participate.

Sampling strategy

The current study utilised a convenience sample and I approached recruitment of participants through the APCSW, a professional association for Social Workers working in palliative care and hospices. Not all of the participants who took part in the current study were members of the APCSW. These participants were recruited through APCSW members sharing the study details with non-APCSW members within their local regions.

Recruitment

I attended an APCSW study day in January 2020. This was a useful opportunity to be introduced to the APCSW members, become more familiar with the Social Worker role within a palliative care setting and to promote the current study. Following the APCSW study day, also in January 2020, an email advertisement (Appendix D: e-mail advertisement) was shared with APCSW members by the APCSW chair. This email contained the participant information sheet and consent form (Appendix E and F). I asked participants who were interested in taking part in the current study to send me an email. The advert was disseminated twice more in both February and March 2020. Participants who expressed an interest were invited to interview and were asked for their preference of a face-to-face or telephone / skype interview and a convenient interview date and time. Once participants had agreed to take part in the current study and prior to their interview, they were asked to read the participant information sheet and sign and return both the consent form and participant demographic questionnaire.

Eight participants came forward: six were interviewed prior to the first COVID-19 lockdown (dated March 2020) and a further two participants were interviewed in June 2020 upon their return to hospice employment following a period of furlough.

Ethical clearance

Ethical clearance was granted for the current study by the University of Leeds School of Medicine Research Ethics Committee (SoMREC) in February 2018 (Appendix A: Ref: MREC16-043). A further two amendments were submitted and approved by SoMREC. The first amendment informed the ethics committee on changes to the recruitment process, in particular that I initially hoped to recruit healthcare professionals from three paediatric hospices within the Yorkshire region (Appendix B: MREC 17-043 Amd 1). The second amendment occurred because of a change in research supervisor, and, after a review of the existing literature, I decided to focus the current study on the experiences of Social Workers employed within children’s hospices (Appendix C: MREC 17-043 Amd 2). The following ethical aspects were considered:

Informed consent. Written informed consent was obtained from all participants. Each participant electronically signed and returned their consent form via email prior to the commencement of interview. Participants were informed that their participation was voluntary and that they were able to withdraw, and request removal of their interview data, at any time. It was possible to withdraw anytime from the interview itself up to a maximum of two weeks following the interview date (Appendix F).

Confidentiality. Telephone interview data was collected in line with the Data Protection Act 1998 and was kept confidential throughout the current study. Participants were given a participant number and informed prior to their interview that no identifiable information would be kept. Participant numbers were used during data analysis and the report write up. All the telephone interviews took place in a private and confidential room. Interview recordings, transcripts, participant consent forms, demographic questionnaires, the participant key (linking participant names to the data) and interview transcripts were password protected and stored on a secure drive (M Drive) at the University of Leeds.

Participant wellbeing. Participant wellbeing was sustained throughout the current study. The research could have caused participant distress as they were being asked to share sensitive and distressing experiences from working with children/young people with life limiting conditions within a hospice setting. Participants had been informed of this potential risk to their wellbeing prior to agreeing to being interviewed. Risks had been outlined in the participant information sheet and was further discussed at the start of each interview. For information on the support offered to participants, please see the participant information sheet for details (Appendix E). Although the content discussed in the interviews by participants had induced negative feelings for some, no lasting signs of distress have been identified by either myself, research supervisor or by the participants.

Topic guide

Semi-structured interviews should resemble a ‘flowing conversation’ and aid the development of rapport suited to in-depth and detailed personal discussions (Choak, 2012; Reid, Flowers & Larkin, 2005; Rubin & Rubin, 2005). Therefore, semi-structured interviews were conducted in the current study using a topic guide that was informed and developed by the existing literature, and discussions had with my research supervisor. Following the initial development of the topic guide, but prior to recruiting participants, the topic guide was reviewed by an APCSW member in December 2019. This individual has been a qualified Social Worker for over 20 years and had worked within the local authority and a children’s hospice for over five years. This process allowed the interview questions to be refined and developed my understanding of the role of a Social Worker working with children/young people with life limiting conditions. The topic guide explored the following: the impact of the work on Social Workers’ wellbeing, organisational impacts, and their coping strategies (Appendix H).

Semi-structured interview procedure

Interviews. The first six participants were offered either a face-to-face interview (at the University of Leeds or their place of work) or a telephone and / or skype interview. Participants seven and eight were only offered a telephone or skype interview due to the UK Government's social distancing rules during the COVID-19 pandemic. Each participant was interviewed individually, and they each chose to be interviewed via telephone. Prior to the interviews, each participant had electronically signed the informed consent form and completed the participant demographic questionnaire. Smith (2007) stresses the importance of establishing a good rapport with participants when conducting one-to-one interviews, therefore at the start of each interview there was a period of general conversation (e.g., brief discussions on the weather / COVID-19 virus). Following this, the participants were reminded of the current study's purpose, expected interview time (approximately 30-60 minutes), the fact the interview would be recorded and a summary of the ethical considerations (e.g., participants could terminate the interview or withdraw their interview data up to 14 days after their interview date). I used the topic guide in a flexible manner, for example, I did not use all the prompt questions with each participant as this was dependent on the detail provided in their answers. Furthermore, some questions were asked in a different order to that originally proposed. This approach was taken to encourage conversation and build rapport with participants to gather rich and meaningful data (Choak, 2012; Smith, 2007). I used a Dictaphone to audio-record each of the eight interviews. Following the completion of each interview, a summary of the discussion and any initial reflections were captured in my reflective journal.

Transcription. Four out of the eight interviews were transcribed by me and the remaining four were transcribed using approved transcription services. Interviews were transcribed verbatim. I listened to all eight of the interviews to check for transcript accuracy. This process helped with the familiarisation of data in preparation for the data analysis stage. Braun and Clarke (2006) state there is no set way to transcribing qualitative data, I however used a transcription key suggested by Braun and Clarke (2013).

Scientific rigour: quality checks

Qualitative research requires quality checks to ensure scientific rigor (Elliott, Fischer & Rennie, 1999). As well as following Braun and Clarke's (2006) six-phase TA procedure I also used their 15-point checklist to ensure a standardised TA procedure was adhered to (as discussed above). In addition, I was guided by Elliott et al's., (1999, p. 220) seven quality checks for conducting qualitative research. Below I outline how I met each of Elliott et al's., (1999) guidelines to ensure the current study met methodological rigour:

Owning one's perspective. When conducting qualitative research, it is important for researchers to engage in the process of reflexivity and outline their theoretical position (Braun & Clarke, 2006). I was mindful of being a Psychologist in Clinical Training (PICT), the lead researcher, and a new mother throughout the project. This was monitored by recording any initial thoughts I had following each interview in my reflective journal and exploring them within research supervision. Discussing and reflecting on the impact of the interviews, and throughout each stage of analysis, was helpful and contributed to greater developing my awareness of my own assumptions and beliefs in relation to the current study. Please see below for my statement of reflexivity (p.66) detailing my values and interest in the topic area.

Situating the sample. Elliott et al., (1999) state researchers are required to be transparent about the study participants recruited and to include a summary of their context and experiences. I did this by providing individual participant pen portraits (please see chapter three). This quality check also aligns with my contextual critical realist position and informs the current study.

Grounding in examples. This quality check encourages researchers to provide examples of their data to validate the analytical processes undertaken and the understanding that is created by the researcher (Elliott et al., 1999). This also allows readers to conceptualise alternate meanings from the data. I met this quality check by providing participant interview extracts throughout the TA analysis (please see chapter three).

Providing credibility checks. Credibility is sought through varying methods. I did this primarily using research supervision. Throughout each phase of the current study I sought regular meetings with my research supervisor, particularly after each interview and throughout the analysis stage. The experience of each interview was discussed and I made a record of our discussion and my reflections. These enabled me to reflect on the experiences of each interview and to discuss the impressions of the participants whilst being mindful of my own values and assumptions. During analysis I discussed my superordinate themes with my supervisor as they emerged and were revised to incorporate new data. My supervisor provided a different perspective on the data, encouraging me to reflect on the links being made between participants, and to test the emerging thematic map. Again, I kept a record of the discussions and my thoughts regarding data analysis. Keeping an audit trail using a reflective journal was invaluable. This process allowed me to reflect on experiences and responses in relation to the research, in particular the participant interviews and data analysis. This was often shared during supervision.

Coherence. Coherence is the understanding that is reached from the data. I did this by presenting a narrative of the participants’ experiences using superordinate and subordinate themes supported by data extracts and is presented in chapter three.

Accomplishing general vs. specific research tasks. This quality check is to ensure researchers present a general understanding of the intended phenomenon. I demonstrated an understanding of how qualified Social Workers experience supporting children/young people with life limiting conditions and the impact of the work on their wellbeing and coping, identified from eight participant accounts. Chapter four discusses the limitations of the findings.

Resonating with readers. Resonance with the reader is achieved when, conscious of all other guidelines, the research material is presented accurately. I did this by seeking feedback from my research supervisor on how I had presented the research data. Equally, I gained resonance from seeking participant feedback once data analysis had been completed; a summary of the superordinate themes had been emailed (with participant consent) to each of the participants for their feedback and comments (please see chapter four).

Reflexive research

The term 'reflexive research' relates to the process researchers engage in that is essential to conducting sound qualitative research (Braun & Clarke, 2013). This process expects researchers to reflect on their involvement throughout each stage of their research project while considering their own role, positioning, beliefs and assumptions and how this may influence interpretation of the findings (Gallais, 2008; Finlay, 2002a; 2002b).

I implemented the methodological approach of TA and throughout the research I acknowledged the importance of situating myself within each part of the research process. When conducting qualitative research, I was mindful of the difficulty to adopt a 'blank slate' approach (Braun & Clarke, 2013). I aimed to remain as self-reflexive as possible using a reflective journal, attending research supervision, and documenting a statement of reflexivity to explore my own experiences, beliefs and values and how this may influence my understanding of the participants' experiences and study results.

Statement of reflexivity

I'm a PICT with an interest in wellbeing and coping, particularly in the workplace. My interest in this area first formed when I was in my first Assistant Psychologist post where I experienced an imbalance in my own work-life balance, which had impacted my mental health. Through my experience I have remained committed to ensuring I engage in healthy self-care and wellbeing practices.

Prior to conducting the current study, I have always respected those who work in roles where they are regularly faced with the balance of life and death. A few years ago I asked my sister, a qualified children's nurse, what it was like to care for children/young people with life limiting conditions in a hospice setting. I discovered that her experiences were filled with anxiety that had negatively impacted her wellbeing and coping skills. My sister shared that she did not feel she had received adequate support from the hospice or her supervisors. She noted how her limited experience and being newly qualified at the time in such a setting had possibly contributed to her feeling inadequate and had subsequently resulted in her resigning from her post. I was shocked to hear of my sister's experiences, and, upon reflection, I felt a sense of guilt that I did not recognise her distress and the impact this had on her wellbeing and coping. I found myself reflecting that I too may have experienced a similar emotional response when children/young people die. I also felt I too may have tried to hide my distress, especially if I felt colleagues were not experiencing similar pressures, as I was worried about how my colleagues may perceive me. My reflections of working with such patients made me reflect much more on the support for staff wellbeing within a hospice setting. Wanting to know more and with a limited evidence base, I was inspired to explore the impact on qualified Social Workers in relation to their wellbeing and coping within the current study. When entering this research, I acknowledge I held the assumption that children's hospices are emotionally demanding and can hinder the wellbeing and coping ability of its staff.

Throughout my thesis journey and especially during the data analysis stage, I have noticed I have shared similar experiences to those of the participants. There were times I too felt a great sense of sadness and frustration, particularly when participants shared experiences that involved the death of a young infant or when a participant discussed a family's experience of a stillbirth. Part way through my thesis journey I took time out on maternity leave to be with my daughter, Charlotte. Certainly, since returning I feel the research has touched me on a much more personal level, whereby I have found myself reflecting more on my own family's health and wellbeing. Hearing the experiences of the participants, and the children/young people and the families that they support, has instilled in me a greater appreciation for life and living in the moment. This journey has also reminded me of how privileged myself and my young family are to live a healthy life.

I am aware my prior experiences, assumptions and being a novice qualitative researcher may have impacted my data analysis and the overall findings. I feel I have managed this through my research supervision and keeping a reflective journal. Throughout my thesis journey I have aimed to stay close to the participants' experiences by regularly reflecting upon my own experiences, assumptions, and values. The one thing that has stuck with me from interviewing the current study participants is that working within a hospice setting and supporting children and their families is not about death, it's about living.

CHAPTER THREE - Results

In chapter three, I present the results of the Thematic Analysis (TA) with participant extracts that demonstrate the superordinate and subordinate themes. Please note that participant extracts have been edited for readability, for example, repetitions of words and hesitations have been removed. Participant extracts are labelled with a participant number and line number to identify the participant and location of the extract from the interview transcripts. A thematic map illustrates the superordinate and subordinate themes that have emerged from the dataset. Participant demographics followed by participant pen portraits are also provided.

Participants

The current study interviewed eight qualified Social Workers regarding their experiences of working with children/young people with life limiting conditions within a hospice setting. All participants reported their gender as female with each describing their ethnicity as white British. The participants all reported having previously worked within local authority and children's services. Participant ages ranged between mid-thirties to late-fifties. Participants had been in their roles between three and a half to 10 years, all stating this was their first position within a children's hospice setting. Participants had been qualified as a Social Worker for between five and 26 years. Recruitment for participants had taken place via the Association of Palliative Care Social Workers (APCSW) or through APCSW members' colleagues. Participants were allocated a participant number in the analysis to maintain confidentiality and anonymity.

Participant pen portraits

Participant One

Participant One has been a qualified Social Worker for approximately 10 years. She has been working in her current role at the children's hospice for approximately three and a half years. She conveyed that her role as a Social Worker within the hospice has been varied and was ever evolving.

Participant Two

Participant Two has worked as a qualified Social Worker for approximately 13 years, and for seven and a half years she has been employed as a Social Worker at a children's hospice. She explained her role at the hospice involves leading the hospice's family support and safeguarding team. Participant Two expressed her interest to participate in the current study was to help promote the Social Worker role within the hospice setting.

Participant Three

Participant Three has worked within social care services for over 25 years and has been at the hospice for approximately five years. She shared that her reason for joining the hospice was to gain a healthier work life balance, one she felt had not been achieved when working for a local authority. She shared her motivation to take part in the current study and explained she hoped to *"debunk the stigma"* that surrounds what it is like to work in a children's hospice - views that she had once shared. She also hoped that her involvement in this study would promote the Social Worker role within her hospice setting.

Participant Four

Participant Four was keen to take part in the current study and expressed she has a strong interest in research and hoped her role in the future would incorporate research opportunities. She has been working in her current hospice role for approximately three years and has been a qualified Social Worker for five years.

Participant Five

Participant Five was enthusiastic to participate in the study as she felt it would be of value to her service. She has worked as a Social Worker for 10 years and had been at a children's and adult hospice for approximately five and a half years.

Participant Six

Participant Six has been working as a senior Social Worker and clinical lead at a children's hospice for five years. She was motivated and passionate to participate in this research and she spoke of her interests to promote the role of the Social Worker within palliative care.

Participant Seven

Participant Seven has been a qualified Social Worker for over 26 years. She was the most experienced Social Worker I interviewed. Her current role is split between both an adult and children's hospice where she has worked for the past three years. Participant Seven is the manager of the family support team and she spoke about how rewarding she finds this role and described it as one that she felt helps to *"empower"* children and their families. Participant Seven also presented as committed and eager to further develop the role of the Social Worker within children's hospices.

Participant Eight

Participant Eight has been a qualified Social Worker for over 20 years. Participant Eight has worked in an adult and children's hospice for the past 10 years. Prior to this, she worked as a qualified learning disability nurse before retraining as a Social Worker. She shared that she has always had an interest in health and her last placement during her Social Worker training inspired her to apply for her current role. Participant Eight had great enthusiasm for her role expressing "*I love it. I really like it*".

The findings

This study investigated the experiences of hospice Social Workers who support children/young people with life limiting conditions. In addition, the current study aimed to gain an understanding of the impact on their wellbeing and the factors that affect this, including the coping strategies they employ.

This section presents three superordinate themes that emerged from the semi-structured interview data using TA that investigates the research question, aims and objectives (please see chapter one). The three superordinate themes are 'my work life balance: sources of support', 'doing hospice work' and 'what I bring to the role'.

A thematic map featuring the superordinate themes and the subordinate themes is shown in Figure 3. It illustrates the interaction between the superordinate themes and subordinate themes in relation to the research question, aims and objectives. At the centre (presented as the larger blue circle) of the thematic map is the focus of the current study – the wellbeing of children's hospice Social Workers and how they cope. The three superordinate themes (presented as the three smaller circles) represent the areas that influence wellbeing. They are interlinked and influence one another. First, 'my work life balance: sources of support'- participants naturally separated sources of support into those important at home and at work. Second, 'doing hospice work', which featured participant descriptions of the types of work they undertake and the challenges they experience as part of their role, including working with death on a daily basis and conflict between a medical and social model of care. Third, 'what I bring to the role' featured participants' reflections on the qualities and skills that they felt they bring to the role, suggesting a confidence and pride in their work that supports their wellbeing.

The superordinate and subordinate themes are described in detail below with participant extracts.

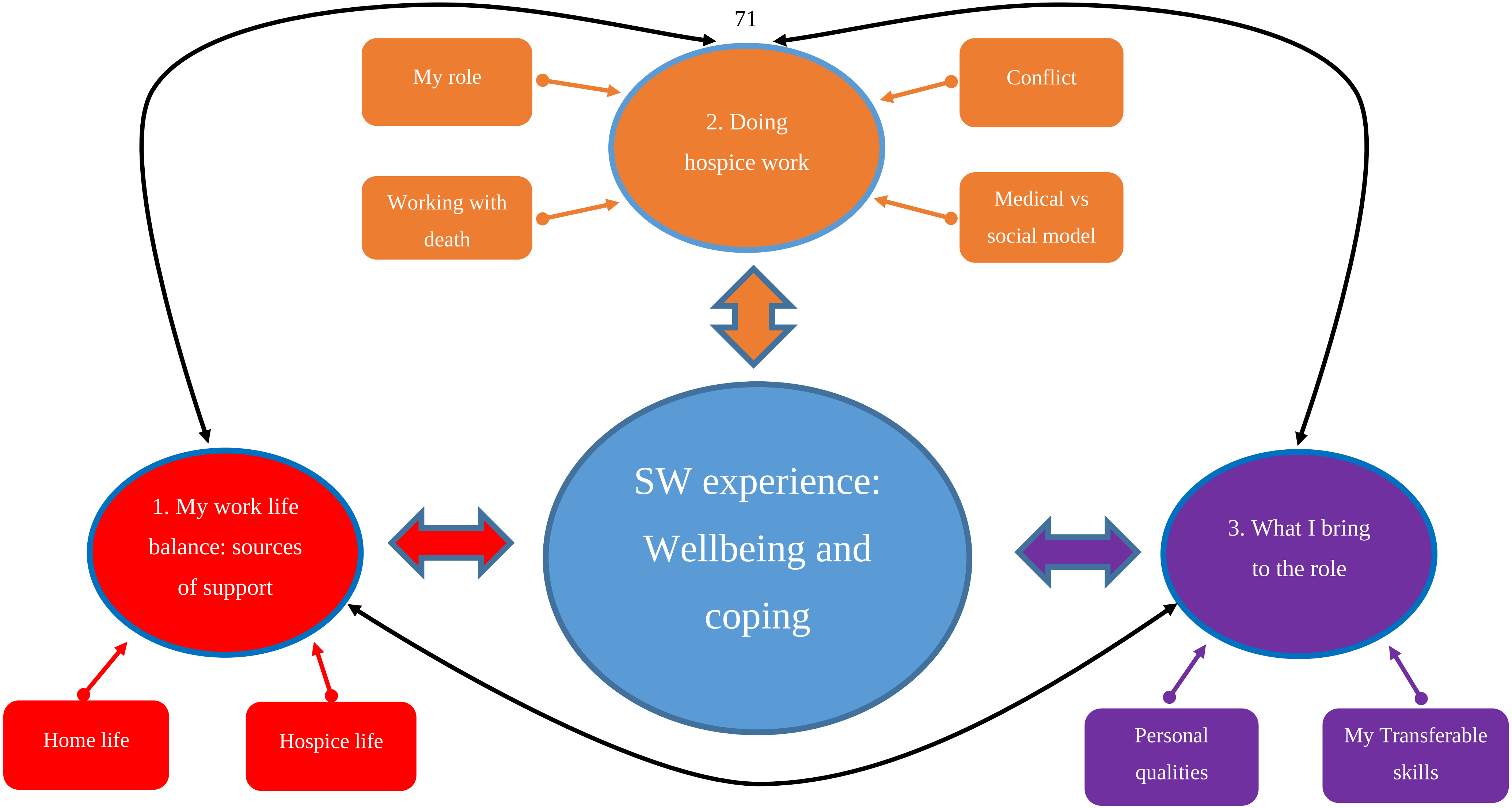

Figure 3. Thematic Map

Superordinate Theme One: ‘My work life balance: sources of support’

Participants described and articulated factors and sources of support they experience that they felt contribute positively to their work life balance as well as being fundamental to supporting their overall wellbeing in their role. This superordinate theme has two subordinate themes: ‘home life’ and ‘hospice life’. The subordinate theme ‘home life’ depicts the factors participants hold in high regard from their personal lives, whereas the subordinate theme ‘hospice life’ presents those associated with the hospice setting.

Throughout this theme, participants emphasised the importance of these factors and how they contribute to their ‘survival’ at the hospice. Each of the participants recognise their work life balance can range along a continuum. For some, they felt that over their social care career they had managed to develop and sustain a healthy work life balance through the process of trial-and-error; others felt that they continued to struggle - they acknowledged barriers such as difficulties finding time to establish a healthy work life balance, and not always viewing this as a priority, alongside competing personal demands and commitments. Participants recognised that management of their work life balance is their own responsibility and acknowledged it is important that they continue to sustain and develop this. Some felt that improving work life balance was one of the incentives for working at the hospice; despite the common view that hospice work is emotionally overwhelming they felt this was easier to achieve in the hospice:

> *“Well, I find that much easier to do since coming to work in a hospice. The stress level that I experience in this job and the effect on my wellbeing is much less actually, when this may be viewed by others as being a more kind of taxing emotional role and having an effect on your wellbeing, I find it the opposite.” (Participant Four, L314-319)*

Participants demonstrated self-awareness by acknowledging their needs and what felt helpful and unhelpful to their work life balance and overall wellbeing.

Subordinate theme: ‘Home life’

This subordinate theme presents the factors that participants felt have helped to support and promote their work life balance from within their personal lives. Common factors discussed were spending time and connecting with friends and family and engaging in their hobbies and interests. The benefits associated with these factors were also discussed and highlighted below.

Friends and family. Participants discussed spending time with friends and family as a helpful distraction and also identified them as an important source of support. They helped participants to focus their minds and give them opportunities to escape from their hospice work. Participant Three in the following extract acknowledges how conversation and quality of time spent with her friends and family helps her to better manage her own physical health condition:

> *"I go and see my own mother, I get a lot of support from her. I look after me by doing that. You know, I have to look after me cause of my mobility issues, the arthritis I suffer from impacts on me emotionally as well and that's where I fall back on friends who are really good* and *supportive." (Participant Three, L553-558)*

On the other hand, some participants felt that when it came to their wellbeing and sustaining a healthy work life balance, this was much more difficult to achieve due to limited opportunities resulting from personal commitments (e.g., childcare needs, health of their own child, dependants – elderly parents). Participants illustrated that they hoped to open up and have conversations with their friends and family about their work, though they were bound by the constraints of confidentiality, which makes it difficult for them to actually share their experiences. The other constraint was not wanting to shock or upset friends - *"it's never gonna be a happy conversation" (Participant One, L313-314).* This had left participants feeling isolated, as though they had no one to turn to in their home life to reflect with or offer an escape. The need to protect others was also emphasised by several participants who talked about trying to protect their friends and families by not talking about their experiences of hospice life, assuming their family and friends would not want to listen to difficult experiences (e.g., child death) the participants encounter as part of their hospice role. It seems the barriers of maintaining professional boundaries and adhering to confidentiality may leave the participants feeling short of support within their home lives. This leads to participants ruminating on events, and negatively impacts their wellbeing. The following extract captures participants' experiences:

> *"I see friends in the evening but again I can't talk about my job really because of confidentially and because it's not something people generally want to talk about, nobody wants to talk about children dying." (Participant One, L311-313)*

Hobbies and interests. Participants discussed having hobbies and interests that support their work life balance. The hobbies and interests participants shared were exercise/outdoor pursuits, walking the dog, arts and crafts, engaging in psychological / holistic therapies, and taking time out for oneself. Participants reported when engaging with hobbies and interests that *"it's switching off and being creative" (Participant Five, L198)* that provides them a sense of escape, creating and allowing them space and clarity from their hospice work. This was noted to be particularly important at times when participants are exposed to emotionally challenging experiences, such as the death of child/young person whom they supported, and when working with conflict in the hospice setting. Some participants felt that the more they engaged in their hobbies and interests, the better they maintained boundaries with work, reaching a sense of equilibrium between their home and hospice life:

"Work is work and home is home. And I've always, always throughout my social work career been very good at leaving work at work and home being home and my family being important for me and my hobbies, and different things like that. So, I try to apply that in everything I do." (Participant Seven, L203-206)

When discussing hobbies and interests, some participants acknowledged their journey to discovering healthier ways to better support their work life balance since joining the hospice. They shared how their ways of managing their wellbeing had changed, sometimes dramatically, and they felt this had become more sustainable and healthier over time. When discussing the benefits of exercise, some participants commented on increased feelings of relaxation and improvements in their quality of sleep:

"I run when I get home because I find that's a healthier option than having a bottle of wine, which I was doing a little bit at the end of last year. Not saying I was a raving alcoholic but just having a couple of glasses to relax after tea. That's not a path I wanted to go down, so I try to have a run now after I've put the kids to bed before having my tea. Just to let go of work really, just to relax really and sleep better, so that's kind of my coping mechanism." (Participant Two, L316-323)

Participants reported how slowing down and making sure they "*take time out" (Participant Three, L551)* allows them the opportunity to reflect and process their experiences and to feel contented. Participant Three shared even the smallest of things like attending to her personal hygiene helped her to create a sense of calm and restoration:

"I now live on my own so I can go home have a shower and relax." (Participant Three, L553)

Engaging in holistic therapies and / or mindfulness was reported by some participants to promote their wellbeing and create a better work life balance. Participant Six in particular expressed that through her positive experiences of not feeling judged and gaining support from the hospice she works to engage in holistic therapies and mindfulness - not just at home but also within the hospice setting - she felt her experiences and the positive effects this brought her would be welcomed and thus recommended this to her hospice colleagues. There was a sense that given her leadership role at the hospice that she may have felt a duty of care to share her experiences with her colleagues and support the wellbeing needs of others, also creating a sense of satisfaction for Participant Six:

"I'm a great believer of mindfulness and acupuncture but I did all that before I came here so I don't think those have really changed. I think these are really important. When I talk things

through with other colleagues, I recommend these. I say go and give it a go! If it doesn't work for you, try something else." (Participant Six, L574-580)

Subordinate theme: 'Hospice Life'

Participants also discussed experiences within the children's hospice environment that they felt has helped to promote their work life balance and overall wellbeing. Each participant emphasised job satisfaction that working in an environment that is non-judgemental, supportive, and compassionate can have. The two below extracts capture this:

"The whole environment, it is a lovely place to work, everyone supports each other and you just feel like, I go home every day feeling like I have achieved something and that is what most social workers get into social work for isn't it, is to feel like they are doing something, and I do that without question most nights." (Participant One, L32-37)

"The hospice is a really happy place. You walk in and you smile, and the staff are brilliant, and we all support each other." (Participant Eight, L120-121)

As a result, participants reported feeling that their role and contribution to the children's hospice is valued by the hospice and their hospice colleagues. Participants felt a sense of belonging, that they are understood professionally by those they work with, thus positively impacting service user experiences.

Participants noted the hospice environment was also actively encouraging of its staff to engage in activities that promote their wellbeing and self-care. Participants commented on the importance of taking regular breaks and how hospice work was not driven by targets - unlike in previous roles. Participants stated they each preferred this way of working and felt it had helped to create balance between their home and hospice lives, as well as feeling they had acceptance to ensure their wellbeing was a priority and is important to maintain:

"So, I have very good work home life balance so I don't ever feel the need for example to take work home with me or you know to be kind of worrying about work when I'm not here and that that was a big difference for me after coming from a local authority where there never seemed to be enough time to do everything that was needed." (Participant Four, L321-326)

The subordinate theme 'hospice life' further delineates both informal and formal channels within the hospice that participants felt promotes their work life balance.

Informal. All participants reported receiving 'informal' support at their hospice. This ranged from ad-hoc chats with their line manager to conversations with Multi-Disciplinary Team (MDT) colleagues over cups of tea in the staff kitchen. Some felt such conversations were non-judgemental and had allowed them time to reflect and open-up to their colleagues to discuss their experiences across all elements of hospice work in ways that were closed outside the hospice because of confidentiality. These participants also commented on how such conversations encourage them to be more explorative and curious in their work, which they felt had helped them in their career development, such as finding new ways to promote their own ethical practice. Participants described this level of informal support as being more important to them during challenging times than the formal support they receive (e.g., supervision/ MDT meetings) as this creates a space to be heard in a compassionate manner.

Some participants commented on the benefits of having informal conversations with their colleagues. They expressed that this encouraged them to build meaningful relationships with their colleagues whom they considered "*good friends within the hospice" (Participant One, L145).* Informal conversations also highlighted a number of commonalities amongst participants and their colleagues (such as, being of a similar age, stage of life and have similar hobbies and interests) and reduced the 'clinicalness' of the hospice environment. There is a sense that having mundane conversations with colleagues provided participants with a sense of informal support and peer connection they reported as being an important aspect to their professional wellbeing:

> *"I suppose it's just more informal support, it's the kind of peer support. We have a community nursing team we work closely with and if I'm having a difficult day, I will just go into their office and they are usually talking about Love Island or something like that and I just have 10-15 minutes with them, I find that useful." (Participant One, L276-282)*

Participants also spoke of experiencing positive relationships with their line managers and senior hospice managers should they find themselves needing to discuss their work. They felt this approach had an open-door policy of support allowing them to not feel constrained to wait for planned support forums (e.g., supervision/MDT meetings etc.) and if additional support and meetings are required that participants can action this. There was a real sense of teamworking that captured the participants' experiences of informal support; they felt valued and appreciated by their colleagues. This support was viewed by the participants as promoting their ability to work flexibly, not only contributing to their wellbeing and coping, but also supporting the development of their professional autonomy. This is captured in the following two extracts:

> *"Internally there are managers within the hospice that I feel quite happy to go to and either just offload or get advice on where they think I should go with a problem. Or, I will call a MDT and then it is not just my decision it's a joint decision, it's a hospice decision so it's not solely my responsibility then. Even if we can't come up with any further plans, I just generally feel better knowing that I'm not in it alone." (Participant One, L127-133)*

> *"The team I sit in is really supportive. My line manager, I literally feel that I could go to her at any time with anything and she would kind of sit down and go through with me and be supportive. So, I think knowing that you have that I think that's really positive, and I think as a social worker you need to have a good relationship with your line manager to be effective." (Participant Four, L147-152)*

Again, the above two extracts demonstrate the positive impact on participants' work life balance and the skills they utilise to achieve this: being proactive, exploring and searching available resources that they felt helped them to deliver and complete a good job. Such skills will be explored in further detail in superordinate theme three 'what I bring to the role'.

Informal support was reported by each of the participants as occurring frequently, *"supervision goes on everyday" (Participant Three, L538).* There was a sense that participants preferred to seek informal support or peer supervision, particularly from colleagues who were of a similar professional level, as this reduced feelings that they may increase the burden on less experienced staff and was viewed by participants as being professionally appropriate:

> *"I make sure one of my colleagues who I work with. We kind of manage similar teams and we use each other as sounding boards so we kind of have daily off loads which help really rather than something more formal." (Participant Two, L313-316).*

Participants also reported the informal support they receive helps them to feel they are part of a supportive team at their hospice. Sharing the difficulties they experience in their hospice work is something participants felt they were more able to do with their hospice peers and can help them to promote and maintain their wellbeing – in comparison to friends and family as discussed above. What appears to foster a sense of comradeship between the participants and their colleagues is that they felt they are all working towards the same goals within the ethos of the hospice in which they are employed. All of the participants acknowledge this is to support patients and families to live in the present moment:

> *"That's how it works here at the hospice, it's very much teamwork." (Participant Four, L346-347)*

Participants disclosed feeling safe emotionally and supported within their hospice team when facing barriers to their work or challenging experiences:

> *"We all support each other. It's ok to be sad and it's ok to cry and nobody's going to blink twice if you have a cry. Having a very good team who recognises very quickly if you need a*

break, that's caring for each other. It really helps tremendously." (Participant Three, L414-421)

Working as a part of a team and experiencing informal support was reported by participants to allow them opportunities to openly express their honest reflections and opinions about their work and the impact this may have to their personal lives. Some of the participants shared the ways their colleagues have supported them and have shown their appreciation when experiencing difficulties in their personal lives:

"The ethos is very much about supporting members of staff throughout the hospice ... when my father died a couple of years ago I got a big bouquet of flowers sent from the hospice team, those little touches mean an awful lot. I also have tomorrow afternoon off to have some castings done on my arthritic leg ... it's not an issue to take the time off." (Participant Three, L446-452)

Formal. The participants also illustrated the formal support they receive at the hospice. This level of support consists of management supervision, training/teaching, support from managers and MDT meetings. Each of the participants seemed grateful and appreciative of the level of support and dedication they felt they each receive from other professionals who support them at the hospice. Participants felt that line management, and seeking professional advice and support, had been crucial in supporting them in making difficult decisions, reviewing their professional practices and contributing to a healthier work life balance and maintaining their wellbeing. The support they received meant they are more able to leave work at work:

"I will go to my manager or my supervisor just to say, 'look I've done this, this and this, what more do I need to do?' Or, 'is there anything else I can do?' Then, once I've kind of got that okay in my head, then I can de-stress then if that makes sense." (Participant One, L156-159)

Participants expressed their gratitude towards other professionals at the hospice who offer them regular and consistent management supervision. They reported having additional support from management to access an in-house counsellor for emotional support. Participants felt fortunate that this hospice support was provided and that it was their choice should they feel they required more. There was a sense this level of support contributed to them feeling respected in their role and validated their experiences within the hospices, particularly around experiences they found challenging:

"I get supervision kind of 4-6 weekly off my line manager and then the staff counsellor I... we're advised to see every 6-8 weeks but if I wanted to see her more frequently, I could make a request for that." (Participant Two, L297-300)

Though participants predominantly felt the hospice and their colleagues were supportive of them and their role, some highlighted a gap that they were surprised by, such as a lack of clinical supervision from a qualified Social Worker. Participants voiced how they had expected this to be standard in their role at their hospices. Further to this, participants acknowledged feeling that without this the work can be professionally isolating as a lone Social Worker at the hospice. Some participants discussed the difficulties they have experienced in finding suitable external supervision and highlighted experiencing possible negative impacts to their skills and wider professional development. There was a sense these participants may have felt as though their practices were not 'current', which professionally disadvantages them:

> *"I've really struggled to access any social work supervision since working here and so I know even though I keep up to date with training and legislation and things like that, though actually having reflective supervision with a social work team or with another social worker, I think that is the one thing that I'm missing." (Participant Four, L156-161)*

For those who had external hospice Social Work support, participants felt professional reassurance through gaining external supervision and peer contact. In comparison to those who did not have external supervision with a Social Worker they felt they were able to discuss social work matters and keep up to date with current practices. Such support was also discussed amongst the participants as being important for them to remain professionally connected, up to date with training and in touch through general networking:

> *"We do have contact with other hospices where I can talk with other colleagues outside of here who are in similar roles. I think that's good as well, having that learning and conversations with other colleagues in similar roles." (Participant Six, L581-583)*

Some form of supervision outside of the hospice was viewed as an essential requirement for participants to feel they were able to conduct their jobs effectively:

> *"I get clinical supervision outside of the hospice which has been invaluable I don't think I could do my job effectively without her." (Participant One, L122-127)*

For some, a lack in Social Worker specific supervision was their rationale for joining professional organisations such as the APCSW as a means to seek what they felt they miss from clinical supervision:

> *"For me, being part of the Association of Palliative Care Social Workers is really good because we do conferences and training." (Participant Eight, L234-236)*

Summary of Superordinate Theme: ‘My work life balance: sources of support’

This superordinate theme captured elements from the participants’ ‘home life’ and ‘hospice life’ and ways of coping they felt are important in obtaining a healthy work life balance. Some participants felt they still had not achieved this, noting challenges and also the impact of getting the balance wrong with their wellbeing. Participants recognised the importance of the support received from their friends and family, as well as having time to complete hobbies and interests, creating a life and identity separate from the hospice. When discussing friends and family, some participants recognised the difficulties in receiving emotional support at home whilst being unable to talk in detail about their work because of the need to ensure confidentiality. The participants also made reference to their ‘hospice life’ and discussed informal and formal forms of support they felt enabled them to better manage their wellbeing. Overall, participants emphasised the hospice as a supportive and happy environment, one that is felt to be non-judgemental and compassionate towards its employees. This links with the following superordinate theme ‘doing hospice work’.

Superordinate Theme Two: ‘Doing hospice work’

Superordinate theme two, ‘doing hospice work’, attempts to capture the participants’ experiences of what it’s like to be a Social Worker employed within a children’s hospice. Throughout, participants discussed how their experiences have challenged their preconceptions of the role. Participants discussed several shared work experiences and the emotional impacts they felt both positively and negatively impacted their wellbeing and ways of coping. Participants reported that during their hospice role they have experienced a mixture of both positive and negative emotions that are presented throughout superordinate theme two. It seems these emotional impacts are linked to experiences participants felt were either rewarding or challenging and are captured in the subsequent subordinate themes.

When reporting positive emotions associated with their role, the participants shared experiences that brought them a sense of job satisfaction, with feelings of pride, joy and achievement. With regards to some of the more negative emotions experienced by participants, these were reported as being helplessness, angry, and frustrated. These negative experiences were often brought about by participants witnessing the harsh realities of life limiting conditions on the children and young people they support. Despite experiencing negative emotions, participants always maintained positivity for their role:

“It’s emotionally draining but very rewarding.” (Participant Five, L27)

This superordinate theme delineates the participants’ common work experiences in the following subordinate themes: ‘my role’, ‘working with death’, ‘conflicts’, and finally provides an insight into the ‘medical model vs social care approach’ from the participants’ viewpoint.

Subordinate theme: 'My role'

Each of the participants reported enjoying their work at the hospice:

"You know what I absolutely love it in terms of it is the most rewarding and fulfilling job I have done to date without question." (Participant One, L31-32)

"I love my job." (Participant Eight, L99).

Participants discussed the aim of their role as a Social Worker is to empower and promote service user independence and to bring communities, professionals, and families together under a common goal. Each of the participants acknowledged, and felt pride, that at the centre of their work they are determined to ensure their involvement encourages a person centred and holistic approach that promotes quality of life and the best interests of patients and their families:

"It's about achieving peace for people and giving them a good quality of life even if it's only for two days. If two days is all they've got then let's make it as good as we can. If you can do that then it gives you job satisfaction that you've done that." (Participant Eight, L99-102)

Participants also explained that they aim to use their hospice role and position as a Social Worker in a children's hospice to break down the public perception and stigma that often surrounds the profession. This provides participants a sense that they are in the role to 'do good', that they can affect positive change – participants also felt their role goes beyond the hospice's traditional medical support to patients and families:

"It's about reassuring families I wasn't here to take children away which is the image that a lot of families have about social workers, they're 'gonna watch us, gonna take children', not about that. So it was about breaking down that myth that's what I was about and actually helping people to understand that here in the hospice I will take my lead from you what do you want from me and that the social work service will be very much needs led." (Participant Three, L66-73).

Though some participants discussed their role and responsibilities within the hospice setting as being no different to those they had experienced in previous settings or roles (e.g., local authority):

"I don't feel that I necessarily work any differently with the children and young people who have palliative care needs than I worked with those who don't." (Participant Four, L60-62)

Many participants did however acknowledge the hospice environment allowed them the freedom and time to be more flexible within their role and offered them the opportunity to work without experiencing the constraints and pressures that they reported to have regularly experienced in previous roles (e.g., local authority). Factors such as service deadlines, budget cuts, working in understaffed/under-resourced services, and working beyond their role capacity were often felt to be limitations in their previous roles but not in the hospice setting. This is captured in the two below extracts:

"I definitely wanted to work here. They said 'you can work with families for as long as is necessary. Your visits can last for as long as is necessary and you can be out there for hours if you have to be'. There has never been that kind flexibility in local authority, you are always too stretched to do that kind of thing." (Participant One, L73-77).

"What I have found is that I have more time to do a better job I think." (Participant Four, L70)

The above two extracts also demonstrate a sense participants thrive on this level of autonomy within the hospice setting and further portrays the pride they experience in their work. The freedoms participants experience to do their hospice role their way makes a positive impact to their wellbeing. In addition, participants reported the hospice environment gives them the opportunity to build meaningful relationships with the children/young people, and families they support. The hospice environment appears to also provide participants with a sense that this way of working supports them in being more likely to achieve their own professional aims, further creating a sense of job satisfaction (the impacts of job satisfaction to participant wellbeing and coping are discussed in more detail below). Participants also reflected that such experiences had reminded them of their initial desires to join a hospice setting.

Overall, participants view their role as being purposeful:

"*If I can make anything within their situation better for them then that's a job worth doing." (Participant One, 267-270).*

I took this to mean they felt they fulfil their role potential. There was a sense this outlook is helpful to participants when navigating through challenging situations and possibly aids their problem-solving skills and ability to promote the use of healthier resources when supporting their wellbeing. These factors are acknowledged by participants to contribute to the low staff turnover rates within their hospice setting and subsequently increases their commitment to their role. Participant Three shares their role within a hospice environment has increased their motivation and commitment to their position:

> *"Well, it keeps me coming in every day that's what it does. Like I say I'm actually, I'm just about to turn 60 and not so long ago I'd be retiring this year. It's given me the impetus to keep coming to work really." (Participant Three, L491-494)*

When participants discussed their role in further detail, they noted that it does not mean they are involved with every child/young person and family that uses the hospice and they will only become involved if there is a social care requirement (e.g., bereavement support, housing issues, and signposting families to support services). Participants discussed this as a protective factor to their wellbeing and emphasised the detrimental effect to their mental health if they were involved with each patient, particularly when working with those at end of life / those who die:

> *"You would go quickly, and you wouldn't last very long." (Participant Two, L226)*

Participants also felt that their current role allowed them to become more widely and actively involved within the hospice, thus creating a greater impact and acceptance by their colleagues, as discussed above. Participants described their role as *"very varied" (Participant Two, L117)* and multifaceted. They noted it as having evolved and allowing them to continuously develop. They acknowledged too that the setting and role is *"not mundane" (Participant Two, L115)* though this was a common preconception they held before starting at the hospice:

> *"I think there was a preconception that it was quite a sedate role and not as interesting as working within mainstream childcare and I quickly learnt that that was not the case." (Participant Six, L33-38)*

Participants also shared that they felt their hospice's values and ethos are closely aligned with their own values and those that underpin their social work profession (see superordinate theme three: 'what I bring to the role').

Despite the above findings illustrating positive aspects of the participants' roles, some participants also discussed negative aspects they have experienced. Some participants reported occasions in which they have felt there are limits to their hospice role as a Social Worker. Experiences which had left them feeling a lacking in professional direction - how or what their position can bring the hospice - potentially impacted their levels of productivity within the hospice. Some participants acknowledged these feelings were more likely to have occurred in their earlier years at the hospice and have since subsided, once they became accustomed to the hospice environment and how their role can be used effectively. On the other hand, others discussed still experiencing these feelings when their hospice adjusts to new ways of practice, typically following changes to government guidelines and / or hospice policy and procedure. Participants explained that such experiences motivated them to be determined to further promote what their Social Worker role has to offer within the children's hospice, allowing them agency in choosing the type of social care support they can offer the service users and families. This sense of control seems to support participants' wellbeing. Participants also reported this to successfully enable them to use skills to diversify within their work and thus find new ways of working with hospice professionals and service users (see MDT team under superordinate theme 'conflicts'). Overall, participants felt that their role is fundamental and integral to the wider hospice functioning and the services that are offered to service users, their families, as well as supporting their colleagues:

> *"I suppose it made me feel more valued, that I was doing things right and that I was doing a good job and that they know they can turn to me." (Participant Five, L133-134)*

Participants also disclosed some of the preconceptions and expectations they held prior to the assumption of their hospice roles. Many shared that although they were prepared to support patients with housing and benefit issues, they were unsure exactly what to expect from the hospice setting itself, especially as this was the first time they had worked within a medical setting. Participants expressed concerns that they would be constantly surrounded by sadness with *"emotions flying about" (Participant Four, L384),* when in reality what they experienced is a happy place to work (see the superordinate theme one 'my work life balance: sources of support'), and that there is not the *"doom and gloom" (Participants Eight, L120)* they feared. As presented in superordinate theme one, participants spoke positively about the hospice setting and that supporting children/young people and their families through their saddest moments can be some of their most rewarding experiences:

> *"You walk in and you smile and the staff are brilliant and we all support each other. I didn't expect the satisfaction you'd get from working with people that are dying." (Participant Eight, L120-123)*

Participant expectations and preconceptions surrounding their experiences of working with death and dying is captured in more detail in the below subordinate theme and presents the impact to participant wellbeing and coping.

Subordinate theme: 'Working with death'

A common theme in each of the participants' accounts of 'doing hospice work' related to their experiences of endings. Participants discussed endings as an aspect of their Social Worker role that they had long become accustomed to prior to joining the hospice but gained a different dimension in the hospice. Each of the participants spoke about ‘working with death’ as being the most paramount within the hospice setting when referring to endings. Though participants experienced a sense of mixed emotions, they also explained that due to medical treatments and advances, death does not always occur in a children’s hospice, challenging their initial expectations:

> *“I expected there to be grief, I expected there to be more than we actually see. I think my preconception was that children are dying pretty regularly, weekly and that’s not the case at all. There’s been a move anyway over recent years, so that children who even 10 years ago would have been expected to die sooner, are actually living into adulthood. So, with medical advances etc. a lot of our young people are surviving longer.” (Participant Three, L250-257)*

For those participants who work across both child and adult hospices they had emphasised this being a stark contrast to when adults use hospice services – usually at the end of life – whereas children are more likely to live into their early adulthood with life limiting conditions. Each of the participants emphasised the inevitability of encountering ‘working with death’ in their role evoking the assumption participants felt ‘prepared’ for such events. In contrast, many participants expressed the notion that this was not necessarily them being ‘ill prepared’ but the experience of ‘working with death’ in children/young people as one that continues to instil both shock and disbelief:

> *“It’s not something that you particularly get used to.” (Participant Five, L204-205).*

Participants portrayed feelings of anger, shock and disbelief as being widely experienced by other hospice colleagues from differing professional disciplines (inclusive of medical staff). Although the participants expressed concern around their responses being interpreted as unprofessional, as though not equipped to manage such situations, their response is better related to being human and encompasses compassion for themselves and others. These experiences reinforce the sense of unity that is illustrated in the previous superordinate theme ‘my work life balance: sources of support’ under the subordinate theme ‘hospice life’. Participants also portrayed the widely held opinion that it is against human nature to not be shocked or experience disbelief when a child/young person dies and suggest that any other reaction would mean they would not be suited to their role:

> *“I mean you are a human being at the end of the day you can put all these structures and things in place to help you deal with your day to day work but you are still a human being and if I*

didn't get .. if it didn't bother me when I found out a child had died, I think it right it's time for you to move on." (Participant Two, L166-172)

When discussing their experiences of 'working with death', some participants explained their disbelief in what is expected as part of their role:

"I never thought that I would be seeing so many dead children, I know that's being blunt but if you'd have asked me when I was doing my social work degree 'would I be working somewhere where I would have to go check on dead children?' I would be like 'what the hell, no'." (Participant Two, 344-348)

Participants expressed anger at the unexpected and disruptive nature of life limiting conditions in children/young people and their families. Participants portrayed a sense of injustice for families. This was particularly evident when participants spoke of experiences that resulted in unexpected baby deaths. Participant Seven described this as being "*robbed from the word go" (Participant Seven, L216).* Or when healthy children with no prior health concerns are diagnosed with a life limiting condition:

"There have been families who have been in the most awful situations. I had one family with an eight-year-old, new diagnosis, brain and spinal tumours, perfectly healthy up until that point." (Participant One, L198-201)

Participants expressed their sadness of an unexpected diagnosis and they acknowledged the need to manage their own emotions as a means of supporting the needs of families:

"It can be emotional, but you try not to show because it's not your child, it's not your grief." (Participant Five, L235-237)

Participants discussed their experiences of 'working with death' at the hospice in more detail and described experiencing the death of a child/young person as a *"difficult situation" (Participant Seven, L73)* and one they experience as being overwhelming. Participants also reported factors that contribute to them being more likely to experience feelings of difficultly and becoming emotionally overwhelmed when 'working with death'. For some, there were occasions when medical staff had instructed that their role was no longer required once a child/young person reached the latter stages of their life limiting condition or following the sudden death of the child/young person. Though this experience was commented on by the participants as being rare, I sensed they felt excluded, as though their involvement with the child or young person and their family was redundant (participant experiences in relation to working with medical professionals is captured in more depth in the subtheme ‘medical model vs social care’). There was also a sense participants felt that a consequence of such experiences was they were unable to say their goodbyes and meant they did not experience closure. Participants shared that although such endings can be unavoidable, there was however a sense that an abrupt ending may create feelings of loss, resentment and rejection for participants. Participants’ felt there was a missed opportunity to process the emotional impact of the work, and this may result in them denying themselves the opportunity to grieve or be sad for the child or young person. I wondered if denying their feelings may also be a way participants cope to survive this type of ending.

Another factor participants discussed when ‘working with death’ that would contribute to feelings of difficultly and intense negative emotions (sadness, frustration, and helplessness), was if they knew the child/young person and their family well. Participants emphasised finding it difficult to ‘switch off’ from the job, impacting participants’ sense of work life balance as discussed in the previous superordinate theme. Participants suggested this was typically related to the length of time in which they have been involved in supporting the patient and their family. Participant Two described such deaths as being *“a significant death” (Participant Two, L182-183).* Participant Two further discusses their experiences:

> *“I don’t mean that any one child is more important than another but like there are some kids or young people who have been with us for years and we’ve had a lot of work with them and there are some children who we might only know for like a day and then they come and it’s an emergency and they die so for me it kind of depends on the level of involvement.” (Participant Two, L183-188)*

Time of year and when taking annual leave were also discussed by participants as a factor more likely to increase feeling overwhelmed. This was more likely at festive times of the year, when they are more likely to experience feelings of shock and disbelief when a patient dies. Participants disclosed feelings of dread about returning to the hospice in the event of discovering whether a child/young person they have worked closely with has either deteriorated in their condition or died. Participants reflected on times when this had caught them off guard emotionally and consequently feeling hesitant in the future to be absent from the hospice. Participants also disclosed these experiences of ‘working with death’ had reminded them of the stark reality and tragedy of life limiting conditions and the general sense of unfairness this brings (as discussed above). As well as portraying empathy for the families who have experienced a sudden death of a healthy child, participants recognised during these experiences that they reassessed their own lives and what’s important to them and their wellbeing - reminding them to be more mindful and grateful. For some participants this reinforced the fragility of life, creating anxiety that this could be their child:

> *"You know a lot of us have got kids and you know, I know my kids, touch wood, haven't got any kind of illness or condition. But my kid could get sepsis, my kid could get cancer, so you generally find the oncology cases, or like the sepsis ones, have like a ripple effect because they can effect anybody." (Participant Two, L204-209)*

Though this subordinate theme predominantly discusses participants' negative experiences of 'working with death', there was a sense that for some participants they felt death had brought some element of relief to the child/young person and their family:

> *"It's just the fact they haven't had much of a life. However, saying that, when you look at the quality of life they've got when they're coming up to the end of life you wouldn't want it to drag on. Grateful is not the right word, but you think it's the right thing that they are dying, what quality of life have they got at the end? Some of these kids? They are in and out of hospital, on a ventilator, on machines, and you think 'that's no quality of life for anybody'. So they may only be 10, and they've had 9.5 really good years, but what's the point carrying on if it's not great quality of life." (Participant Eight, L110-117)*

Again, when participants reflected on a child/young person's quality of life and the suffering they may experience, participants showed an acceptance, a 'weighing up' of a child's/young person's prognosis. I wondered if this acceptance may be a form of coping for participants when 'working with death'. This may have helped participants to find acceptance and bring them closure, particularly when a child/young person they know well has died unexpectantly. Participants acknowledged that acceptance is a widely held way of coping in the hospice environment. Participants know they are unable to change a patient's diagnosis or prognosis:

> *"I have to get my head around the fact that I couldn't fix the situation. The children are coming here because they've got a life limiting condition or a terminal illness, I can't change that." (Participant Two, L70-73)*

This acceptance and putting on a 'brave face' had helped participants when supporting families to keep their emotions under control and remain professional whilst finding ways to help families following a patient death. Participants also spoke of how acceptance and being brave is not a means to ignore or diminish their experiences and feelings but rather them being professional and creates a sense for them that they are doing a good job and putting the needs of family first and supporting them through their child's death:

> *"I told myself that I can't change what patients and families are going through but if I can make anything within their situation better for them then that's a job worth doing." (Participant One, 267-270)*

Participant Two also reported how acceptance of a death can subsequently create achievement and pride through team working. This support is reported to enhance a team's productivity in meeting the needs of the families:

> *"I realised that no matter what I did these children were going to die and that is something I always tell my staff is that we can't change that. That's the bit that we can't change. But what we can change is the bits from now until that time and after." (Participant Two, L77-80)*

Subordinate theme: 'Conflicts'

Each participant spoke about the 'conflicts' they experience when 'doing hospice work' that they felt have at some point impacted their wellbeing and ways of coping. Participants acknowledged workplace 'conflicts' as an experience that is often opposed to their values and professional ethos (more detail in the superordinate theme 'what I bring to the role') and practices that lack being centred around the needs of the child/young person and their families. The 'conflicts' participants discussed were often associated with their involvement with external agencies, the hospice multi-disciplinary team (MDT) and the families they support.

External agencies. Some participants shared their experiences of working with external agencies (e.g., local authority, housing associations, and other charitable/third sector organisations) and discussed some of the barriers they have faced. They shared feelings of anger and frustration when describing gaps in the 'system' when working with external agencies that they felt contributed to delays in receiving support for children/young people who required external social care support. Participants who experienced 'conflict' with external agencies noted this was often in relation to issues of safeguarding within a child's or young person's family or inappropriate housing/housing difficulties. They discussed how such experiences created feelings of helplessness that their concerns had been ignored or not taken seriously. Participants' position as a Social Worker is to advocate for others (see the subordinate theme 'my role'), yet participants felt they may have not had a voice and thus were not 'heard' by their external professional peers as a result of working in a hospice setting. This in turn may leave them feeling they are not delivering in their role subsequently lacking professional control and negatively impacting their wellbeing. Participant One summarises the sense of lack of control and helplessness they felt in their role when advocating for service users when liaising with external agencies:

"When you suspect that there is high levels of child abuse continuing and you can't get anywhere with local authority social workers then it becomes very frustrating and very difficult to kind of marry that in your head as a qualified social worker. It's kind of the helplessness of the situation, I don't have any authority any more to progress those things so I find that very challenging." (Participant One, L92-97).

Participants also referred to how they did not anticipate such barriers with external agencies, particularly agencies they were familiar with and had been employed with prior to working at the hospice. Such experiences generated feelings of anxiety amongst some of the participants, with some noting this had caused them distress in their role. Participant Four shares the impact to her mental wellbeing when feeling their concerns were not validated by an external agency:

"It had a bit of a negative effect on my confidence. I started to doubt myself cause I started thinking ok this young man has got to the age of 17. Why has no one flagged this up before?" (Participant Four, L105-108)

Participants acknowledged their response to finding ways to support patients had helped them to manage their feelings associated with a lack of control and authority when working with external agencies. Some participants wondered if their experiences were linked to external agencies lacking an awareness of how child hospices operate, the services they provide, as well as having a limited understanding into the Social Worker role at the hospice. They acknowledged this lack of awareness of hospice work when liaising with local authority Social Workers. Participants further reflected on feeling removed and professionally isolated from their local authority Social Worker peers. Repeated exposure to such experiences may impact participants' wellbeing, feedback their role does not make a difference and in turn may supress their pride in their work and risk quality of care and productivity:

"I found the opposite is true they're often .. quite anti my involvement and will not invite us to meetings, not share information with us we are on different systems so we can't see when CINs are going on or anything else." (Participant One, L105-109).

Some participants also acknowledged positive aspects to working with external agencies, acknowledging the disadvantages of working with external agencies as an opportunity to pursue more proactive and innovative ways to overcome the difficulties discussed above. These participants reported finding ways to better support and advocate for patients and gave examples of having helped promote their role as a Social Worker more widely within a child's hospice. Participants also found this helped them to develop knowledge and understanding across external agencies, as well as to improve their own professional practice skills to enact positive change for the children/young people, and families they support:

> *"I thought we needed to speak with some people who can affect some change so I got in touch with all the directors of housing from the local authorities we cover, the three local authorities, and got in touch with all the housing associations and on the back of doing a lot of researching about housing and the housing need I … spoke to the quality and human rights commission who in 2018 were doing an inquiry into housing people with disabilities a nationwide inquiry and we were stakeholders in that inquiry. I spent a long time speaking to them … I used the inquiry as the basis of my presentation to them and what we've now got is a situation where, so far 3 housing associations have agreed to build a bungalow." (Participant Three, L109-125).*

This portrays participants exercising autonomy and links with the freedom they felt they had in their role, as discussed in subordinate theme 'my role'. A sense of achievement and accomplishment was also noted and further provides participants with a sense of professional growth.

MDT. Some participants discussed experiencing 'conflict' with some of their hospice colleagues and explained they had occasionally witnessed difficult team dynamics similar to those they have experienced in roles prior to working at the hospice. Participants recalled examples, such as: MDT staff being dismissive of their professional views or decisions; MDT staff appearing to be naive and refusing to appropriately challenge parents with teenage children in matters concerning mental capacity; and MDT staff responses to families who are struggling with mental health and using unhealthy means to cope with their child's prognosis. Participants spoke of these as some of the main difficulties they faced:

> *"What challenges me is, is your team's response and staff's response to situations that we face." (Participant Six, L352-354).*

When discussing conflict with MDT staff, participants commented on their experience of negative emotions. Participants experienced feelings of anger, frustration and confusion and some discussed experiences where they were 'in the dark' with cases that involved risk and safeguarding. There was a sense there was a lack of communication on roles and responsibilities within the MDT:

> *"I think everyone might of thought everyone else was doing it or no one had the confidence to speak out because no one had before it was kind of a vicious circle really." (Participant Four, L117-120)*

When participants reflected on their experiences with their MDT working and some of the challenges, they noted how change was required from the hospice in order to meet the needs of the children/young people and their families. They spoke about offering MDT staff training and reflective practice groups to understand the dilemmas they face. Participants also reflected on how they were able to gain a sense of reward and achievement from such challenges. It seems that this change was gradual and without persistence from participants the positive influence on MDT practice, perspective and culture would not have occurred. These experiences provided participants a voice and one that they felt has ultimately been heard and respected by the MDT. One result is a sense of professional achievement and enhanced wellbeing at work. There was a sense of such experiences lifting morale, participants felt they have made a difference to the quality of life of patients through promoting empowerment and independence:

"Most of them are a bit better now I've nagged them! I just think that staff think 'we are at a children's unit, so we ring the parents' and I've started working over there now and I've started advocating that they are young adults and if they have capacity then you contact them and not the parents. And you address the letters to them. It has changed, which is good." (Participant Eight, L155-159).

Families. 'Conflicts' were also acknowledged by participants to occur with the families of the children/young people they support. Participants - and in comparison with some of their MDT colleagues - when engaged with families with complicated social care needs, were prepared to 'go to places others weren't':

"It's all about having difficult conversations with adults and with children, whether they are clients or family members." (Participant Eight, L238-240).

I understood this to mean participants were solution focused, they felt equipped and confident that they had the skills to be able to have the more difficult conversations with patients and their families. When the family situation was complex, interventions often went beyond the focus of life limiting conditions to take on the wider context, with the aim to empower, advocate and nurture.

Participants discussed the numerous complexities surrounding families - particularly those from poorer socio-economic backgrounds - with difficulties regarding family dynamics, issues of risk and parents struggling with mental health. Participants acknowledged the added difficulty when working with vulnerability and expressed their compassion, and concern, to those they deemed to be in this position:

> *"Obviously, our children are the most vulnerable, they couldn't be more vulnerable, and when you suspect that there are high levels of child abuse continuing … I find that very challenging." (Participant One, L91-97)*

Participant One also spoke of the increased level of complexity to their work when supporting hospice patients who also experience abuse:

> *"It's very complex and my caseload is very complex and most of my cases have that level of complexity within them." (Participant One, L246-248).*

Participant Four reported one of her most challenging times at the hospice had been when working with complex family dynamics, in particular supporting parents who struggled with their own mental health difficulties. Participant Four may have felt professionally torn; recognising that mental health support was needed for the family member whilst understanding that this would inevitably have an impact on their patient's palliative care needs. This may have impacted them to feel limited in their resources, not knowing which direction to take, thus lowering their morale and confidence:

> *"I felt a little bit uneasy with some of the things which had happened to him historically. There were factors that, as a social worker, made me question things because what his mum was saying how his disability was affecting him wasn't what we were seeing at the hospice. She said he was dependent, that he was having hundreds of seizures a day, that he needed very close monitoring and a high level of care, when actually that wasn't what we were seeing at the hospice." (Participant Four, L77-85)*

Participants shared their experiences of supporting families in conflict who had experienced relationship breakdowns as a result of the challenges that come with caring for sick and poorly children. Participants reported feeling as though they have acted as a mediator between families, whereas others experienced hostility and that their input was not well received. Participant Five shared their involvement and how their role was used with mediating between family members and the positive impact they felt their role had to this family:

> *"There was a time, about six months after the death, where the dad of the child was really struggling. He found that his trigger was his brother and they worked together in a family business. So, he asked if he could come in for an appointment and bring his brother with him because he wanted to tell his brother how he as feeling. And we had quite a few sessions with the dad and his brother, and they eventually talked things through by giving his brother the understanding of it wasn't him that was the problem but for some reason he was the trigger to*

dad’s anger. And they worked through, and the business is thriving now.” (Participant Five, L134-143)

Participant Five also disclosed the outcome of their involvement and the impact this experience had on them personally:

“A sense of achievement, that I’d enabled them to deal with their issue. And that we’d done it in a calm manner, and I was able to encourage them to speak and to give their own point of view. And they started having, afterwards they started having family nights, they both had daughters of similar ages, so they started spending time together just them and their daughter.” (Participant Five, L154-159)

Many of the participants discussed experiencing feelings of frustration and anger when ‘conflicts’ occurred between the child/young person and their parent(s). Participant feelings were compounded by a sense of the injustice they felt for the child and / or young person that disagreed with their professional values:

“I was cross. Because I still think he wasn’t listened to. And yes, his sister probably could do his care but why as a 21-year-old boy would you want your 23-year-old sister to come and wash you and bath you? I just didn’t think he’d been given a voice, but it’s difficult because he has capacity and he just said, “if that’s what my mum says that’s what we’ll do”. So, there’s not much you can do.” (Participant Eight, L138-143)

In this extract, Participant Eight also explained how such an experience did not influence her moral or professional compass, and that she was determined to listen to the young person, to ensure her role empowered and gave the young person a voice while respecting their views and wishes. There was sense Participant Eight felt a sense of accomplishment and their experience in this instance shows a parallel process to that of the young person, they experienced the power of having a voice and being heard, a factor that supports participants’ ability to build trusting relationships with their clients:

“I would still do the same again. I would still talk to the young adult without the parent again if they have capacity and ask them what they really want. Because I don’t think that happens enough. Even some of the staff on the unit would say “oh we’ll have to ring his mum”, but I’m like, “why? He’s 19, he’s got capacity, why are you ringing his mum? Why aren’t you ringing him?” And they just look at me. I know it’s a children’s unit, but we’re up to 25, he’s over 18, and he has capacity, he has a mobile phone, ring him! If he then says “speak to my mum”, then

> *fair enough but you don't go to mum first. You wouldn't if he didn't have a disability, would you?" (Participant Eight, L146-154).*

Subordinate theme: 'Medical vs social care approach'

When discussing 'doing hospice work', participants also shared their experiences of what it's like to be a qualified Social Worker working in a predominantly medical setting. They reflected on their role and noted that they felt there had been a shift in the overall culture of the hospice in comparison to when they first started. They discussed how the profession of Social Worker is utilised and viewed positively within the hospice setting. Some participants emphasised that they were recruited to their role to replace medical staff with the goal to modernise the hospice and its practices in line with changes in government guidance and hospice standards, to enhance MDT ways of working. Many reflected on feeling they have become more involved in the running of the hospice in recent years, such as decision making and service development opportunities, for example, through becoming directly involved in leaderships roles, and supervising and training staff. These experiences portrayed participants felt appreciated by their colleagues and the hospice and creates a sense of belonging and team unity. Participant Four details how the hospice has encompassed her role and presents that the diversity her role brings has offered hospice staff the opportunity to also grow professionally. The subsequent impact to participant wellbeing I sensed instils purpose and meaning, a product of motivation:

> *"I feel that the wider kind of hospice work force has really embraced my role because, you know this is a children's hospice and I am kind of taking them out of that zone working with young people from 16 and above who they have to consider different aspects of the law and things like that." (Participant Four, L297-301)*

Some participants acknowledged their position has brought opportunities to promote the Social Worker approach amongst their medical colleagues. They felt this offers hospice staff new ways of approaching the care of the children and young people and provides collaborative health and social care. While some discussed the positives of health and social care models working in parallel, others shared occasions in which their experience was not as collaborative as they had hoped, and left them with negative feelings that their role had limits in a medically dominated setting. There was a sense that these participants felt at a disadvantage not being medically trained, as though the hospice movement had not progressed at the rate expected, that their role is not a good fit in a world that predominately focuses on physical health conditions and disease. They also highlighted their views that the medical model at times is misaligned with social care, particularly as the values and principles that underpin social care entail thinking holistically to incorporate the mental, physical, and spiritual needs of patients:

> *"I work directly with young people using the social model of disabilities whereas hospices tend to be focussed on a very medical model, so I tend not be focussed on the things that's wrong with them or the diagnosis or any of those things. I tend to be focussed on a person-centred way looking at them as a person, how they are within their own family how they see themselves in society, what their aspirations and dreams are looking at the legal aspect of moving from a child to an adult." (Participant Four, L30-38)*

> *"I just think sometimes that traditionally the health perspective is maybe quite clinical, and patient focused, and I think social work perspective is much broader and more holistic. I think with the challenges and the changes of health and social care working together better, it's a long, long process but I do think the MDTs and that do make a real difference." (Participant Seven, L181-185)*

Participants felt that although there has been some change, working in a hospice dominated by the medical model is still a daunting experience, particularly the focus on diagnosis rather than viewing patients holistically:

> *"In a hospice environment you're surrounded by that medical knowledge and world and that can be difficult, it can be a lonely place to be if you're the only person with that background and that qualification and that role, it's very lonely." (Participant Six, L789-793)*

Despite this, there is also a sense of perseverance and commitment to promoting newer practice in the interviews, the importance of challenging the dominant medical culture through MDT working.

Participants reflected further on their experiences in relation to the hospice organisation and described it as one that exists within its 'own world'. They referred to the ways in which a hospice is self-contained outside the NHS and social services, governed by its own timeframes and scales, and possessing a distinct culture. In fact, hospices are often distinct from each other. Participants reported that this left them feeling sometimes 'out of kilter' or removed from the 'real world', external to the NHS and local authority services. Participants also noted feeling that the historical dominance of the medical model in the hospice still influenced hospice culture, in some ways making it feel old fashioned compared to NHS settings. Therefore, some discussed how their role as a Social Worker was one that required them, at times, to change so that they 'fit' in with the hospice world. The impact to participants' wellbeing may risk a loss of identity and possibly create uncertainty in their position within the hospice that if it were to continue may create further disparity between the social care and medics. The following quotes captures participants' views of the hospice world:

"The hospice world is different than any other kind of sector. It's a very quirky kind of world. I don't know if other people who have worked in hospices have said that. I've worked in social care, I've worked in business, I've worked with colleagues who have come from health and they all say, "the hospice world is very strange, the hospice world is a very strange bizarre world."
(Participant Two, L108-114)

"Hospice world can be a bit of a time warp, like we've got to March and I'm thinking how did we get to March? As you feel like you're in a protective bubble. What is going on out here?"
(Participant Six, L589-593)

Summary of Superordinate Theme Two: 'Doing hospice work'

The superordinate theme 'doing hospice work' presents the participants' experiences of their day-to-day work in the hospice and the responsibilities of the role. It was often not what they originally expected but one that all participants identified as giving a great deal of job satisfaction.

Participants spoke of experiences they found both rewarding and challenging, and discussed the impact on their wellbeing and ways of coping. Of note, alongside the descriptions of the role and the significance of working with death, participants detail role conflicts and a 'culture clash' between the medical model – long dominant in hospice culture – and a social model brought by the participants, an approach they identified as being more modern and particularly important in their MDT work. Superordinate theme two included four subordinate themes: 'my role', 'working with death', 'conflicts', and 'medical vs social care approach'.

Superordinate Theme Three: 'What I bring to the role'

This superordinate theme captures the participants' views of the skills, experiences, and characteristics that they bring to their role, and the impact of this on their wellbeing. When discussing these, participants also emphasised the importance their prior work experience has had on their current learning and how this has harnessed their development in the hospice setting. Participants also disclosed some of their qualities and interpersonal skills they felt also contributes to sustaining their wellbeing and coping. This superordinate theme has two subordinate themes, 'my transferable skills' and 'personal qualities'.

Subordinate theme: 'My transferable skills'

This subordinate theme is further separated into resilience and reflective practitioner.

Resilience. In the previous superordinate theme 'doing hospice work', participants spoke about their expectations and preconceptions. In particular, participants shared their initial anxieties and preconceptions regarding their own resilience prior to taking their hospice role.

They reflected on how their preconceptions of a hospice setting had led to them questioning their ability to manage the emotional impacts of the role prior to accepting it. There was a sense many required time and careful consideration on whether a hospice role was right for them:

"The job came up at (names hospice) and I kind of um'd and ah'd for a long while about whether that was something I was emotionally resilient enough to do." (Participant One, L15-17)

When discussing their resilience, the participants gave examples of prior experiences before working in a hospice setting that reassured them that they could manage the suspected emotional load they expected while working at the hospice:

"I think that the resilience of the work of a social worker that you actually get from doing a lot of safeguarding work over the years, I sort of built up that internal resilience. Particularly that internal resilience when it comes to distress and difficult situations that you work in. That, to me, helped too, like…almost like prepared me for some of the sadness that comes around with hospice work at times." (Participant Three, L48-53)

Overall, when sharing their experiences, there was a sense participants were surprised at how well they coped, what Participant Three termed above as *"internal resilience" (L50).* They specifically emphasised that they have harnessed their prior learning experiences to enable them to overcome the challenges and barriers that a hospice setting can present to one's resilience. They described these prior experiences as the foundation to their resilience, and is captured in the below two extracts:

"My resilience and coping ... I do put it back to the grounding I had working in the local authority, I put it back to that. Reflecting on this, I do believe that gave me the grounding to cope and gave me the resilience." (Participant Six, L552-555)
"Having done work with children with disabilities on a local authority team, I felt that equipped me to work in a hospice because obviously a lot of their young people obviously have palliative conditions but have serious disabilities as well, so I'd already got that experience." (Participant Three, L56-60)

Participants also spoke about their resilience having a positive impact on their work life balance, which links with superordinate theme one. There was a consensus amongst participant accounts that resilience in this context described experiences relating to their use of self-awareness, reflection, self-care strategies, engaging in positive relationships (both professional and personal), feeling they have a purpose, and that they are practicing in ways that meet their professional goals and values. This is a continuous process, and taking time to reflect on past successes helps participants manage stressful times:

"Throughout my career really, they are the things that kind of propel you, to keep on moving forward and they build that resilience because when you know things are not going so well you still have those kinds of positive experiences to remind you that it's all worthwhile".
(Participant Four, L343-347)

In conjunction with the notion that previous experience was the basis for developing resilience, they also discussed training and career development opportunities they have sought. Participants that qualified as a Social Worker in the last decade spoke about their training modules that provide teaching on resilience and coping skills. These participants reported feeling that this teaching had also provided theoretical knowledge that they have been able to apply in their practice. They also emphasised that this had contributed to better developing their own personal coping strategies when faced with hospice challenges:

"A couple of years ago I did a degree in health and social care and stress and resilience was one of the main sort of modules. So I think my own personally coping mechanisms that kind of really helped me. But also I think it was previous experiences of working out in the community." (Participant Seven, L100-104).

Reflective practitioner. Participants described themselves as a reflective practitioner and discussed this as a process that involves developing their professional self-awareness, harnessing a willingness to learn and maintaining an open mind. Participant Six reflected on times when things did not go well and how they aimed to learn from these experiences:

"And sometimes we get it wrong, but you know we're open and honest and say 'right, if that's not working for you, what do you need from us? what do you feel you need?' It is being open and honest." (Participant Six, L303-307)

Participants prided themselves on practicing reflection and shared that they felt this is an essential coping skill to their role. They expressed the importance of maintaining reflective skills, and shared that having space and time to reflect is significant in promoting the care of service users and service delivery:

"I'm a very reflective practitioner, I always take time out to think about situations, how I felt, is there any learning that I can take from it. At the end of the day I think when you are in practice

you will always learn and maybe do things differently, so I think being reflective really helps." (Participant Four, L140-146)

The same participant explained the ways in which they engage in reflective practice, such as keeping a reflective journal:

"If I've got any worries or niggles or anything like that, I keep a journal. I can write something down and it's out of my head." (Participant Four, L337-340)

They also demonstrated some of the reflective questions they ask themselves:

"Reflect on what you are doing, could you do something differently? You know? could there be a better way of supporting a young person, you know? Do you need to stop and take stock? So, I think it just helps with that reflection what went well? Could any of those experiences be transferred, you know? Can I use those again? So, it's all just positives and it helps you to stay buoyant on the days when things aren't going so well actually." (*Participant Four, L350-357)*

Participants also spoke about offering reflective practice sessions and promoting reflective practice skills across their MDT. This seemed to be a unique contribution in the hospice, and also offers the opportunity to learn with others and to engage in discussion that promotes the sharing of team knowledge and support. Engaging in team reflective practice often increased the likelihood that meaningful and positive change can occur within team dynamics, thus positively impacting hospice care. Participants spoke in more detail of the positive impact of their role in team reflective practice. There was a sense that supporting their team to think more reflectively had enhanced their team to adapt collaboratively and effectively when facing adversity, and enhanced the MDT's understanding of their role. Flexibility with reflective sessions and a non-judgemental approach was reported to work well amongst participants:

"Staff can just talk about low level niggles that they are experiencing but don't want to formally bring anything." (Participant One, L49-51)

Reflective practice groups were also useful in enhancing communication and sharing information – participation led to participants feeling better informed about hospice events and this positively impacted their own practice and thus their coping and wellbeing:

"The reflective sessions are really useful as you can have those as an when needed basis and for me I'm a reflector by style and personality, so you know when I'm craving that space those

are the times when I really need those sessions and they really help me make sense of whatever's going on at the time." (Participant Seven, L196-200)

Subordinate theme: 'Personal qualities'

Participants reflected on the character qualities and interpersonal skills that they saw as protective factors in supporting their wellbeing and coping. The two most common personal qualities cited were having commitment and motivation, and humour. This subordinate theme closes with the participants' advice to others that they emphasised as supporting their wellbeing that they have learnt through their experiences at the hospice.

Commitment and motivation. Each participant demonstrated their commitment and motivation to their role and wanting to do a 'good job' for the children/young people and families, which links with the subordinate theme 'my role' under superordinate theme two 'doing hospice work'. Participant Eight in particular explained how their commitment to social care and their hospice role gives them a duty of care. Participant Eight alludes to being a particular 'type of person' - social care is not about making substantial amounts of money but rather empowering and promoting individuals:

"It isn't something you do for the money, you do it because you like the job so I don't think you would stay in it if you didn't like it". (Participant Eight, L248-250)

Some felt that the longer they work in a hospice setting the more they felt committed to their role and determined to make positive changes to the lives of the children/young people and families they support. This was particularly evident in those who worked across both adult and children's hospice settings. Participant Seven specifically shared their experience:

"I think it's helped me to feel more committed to the children's side of things." (Participant Seven, L173-174)

Participants demonstrated commitment to their role through their motivation to seek additional and career development opportunities. They discussed their hopes of continually developing within their practice and seek to widen their skills and knowledge base to ensure they are practicing as innovatively as possible (e.g., specialist safeguarding training):

"I'm the safeguard lead as well for adults and children, and again it's about making sure you are up-to-date with your safeguarding stuff". (Participant Eight, L243-245)

Participants also shared experiences that demonstrated occasions where they have gone 'above and beyond' to support the children/young people and families that use the hospice.

They explained that this often means being involved ‘without limits’ for as long is necessary to the service users:

> *“There is no cut off point for our support afterwards so once a child has passed away we will continue to support the family holistically. So that is parents, grandparents, siblings, we will support them all for as long as they need. There is no cut off. So, they can come back a number of years later and say ‘look I’m really struggling’.” (Participant Six, L148-154)*

Humour. Participants acknowledge that having humour with their hospice colleagues was also an important aspect to supporting their wellbeing, particularly when navigating some of the difficult elements of their hospice work and role:

> *“It’s being able to have a laugh at work, which sounds a bit bizarre, but humour is a big part of our working life. If you couldn’t laugh, if you couldn’t have a bit of a joke with your colleagues, you’d go stir crazy because you are dealing with awful stuff.” (Participant Two, L212-215)*

Participant Two went on to comment on the impact having humour with hospice colleagues has to her overall wellbeing:

> *“So, for me it’s the people like my team and the people I work with that kind of help keep you afloat really because you can have a bit of a laugh a bit of a kind of a debrief and wind down in a very unformal way and it just helps you just to say and you know we say we say you know it’s awful.” (Participant Two, L215-220)*

Advice to others. Each participant spoke of the advice they would like to give to Social Workers considering a role within a children’s hospice, as well as to their fellow staff currently employed within a children’s hospice to support their wellbeing. They highlighted the factors most important in promoting wellbeing in the hospice setting: supporting their own mental health and ensuring they had their own coping strategies in place before they are able to support others and emotionally manage when ‘working with death’:

> *“I think my advice would be to make sure you’ve got your mechanisms in place for keeping yourself ok because if you’re not ok you can’t help anybody else and it can be tough you know. We’ve got people who have come here and they’ve not been able to cope with death. Basically you’ve got to be able to cope with death because it’s part and parcel of our world and we’ve got to be able to deal with that.” (Participant Two, L333-339).*

They also reflected on the importance of approaching situations with an open mind and having a willingness to adapt to the demands of the situation, acknowledging the need for self-care:

> *"Your coping strategies can change all the time, something that used to work might not work now." (Participant Six, L780-782)*

Some participants also discussed having appropriate expectations and accepting that it is impossible to *"solve all problems" (Participant Two, L329).* Participants spoke about approaching the work without judgment of self, skills and knowledge. Participants also discussed the importance of building relationships and utilising support networks, they empathised the importance of these particularly if others discover they are the lone Social Worker in a hospice:

> *"It's about your coping and your resilience but for me it's always been surrounding myself with those people who are your go tos, whether its people in the hospice or people outside of the hospice. It's making sure that you have got that network or those go tos where you can emotionally offload or if you need some practically advice which I think is key. In a hospice environment you're surrounded by that medical knowledge and world and that can be difficult, it can be a lonely place to be if you're the only person with that background and that qualification and that role, it's very lonely". (Participant Six, L782-793)*

Participant One shared feelings of isolation. There was a sense too that the role carried a risk of being vulnerable to developing 'blind spots' through working closely and intensively with families and lacking Social Worker colleagues with whom to discuss cases increased this. Participant One also reflected upon the importance of keeping professional boundaries and creating space between 'hospice life' and 'home life':

> *"I suppose my number one piece of advice would be to build your relationships, build those links as quickly as you can because you can become quite isolated and because of the nature of the work it can become .. I don't even know what the word is quite draining I suppose .. so you have to you almost have to have something that is going to take you mind of it when you get home .. and don't take things home with you would be my advice. And it's a lot of the work it's about boundaries as well it's very difficult to maintain to keep and set up very professional boundaries when you are dealing with the situations that were dealing with and you are seeing the families so often and you are so heavily involved in every aspect of their lives but you are there do you job aren't you." (Participant One, L326-336)*

Participant Eight discussed the need for Social Workers to ensure they practice in the best interests of the young people to empower and promote choice and independence, specifically those of consenting age:

"Bear in mind that young people have a voice, if they are over 18 with capacity then they are a young adult not a child." (Participant Eight, L219-220)

Summary of Superordinate Theme Three: 'What I bring to the role'

This theme captures the personal qualities and skills participants felt that they bring to their role. Acknowledging this, particularly during challenging times, was felt to be an important aspect of coping, building resilience and supporting wellbeing. This superordinate theme was made up of two subordinate themes: 'my transferable skills' and 'personal qualities'. Transferable skills described the participants' application of Social Worker skills in the hospice setting, and pride in doing this well. This professional pride was important to maintaining wellbeing. Participants also discussed the importance of reflective practice and briefly shared the benefits to MDT working. In the subordinate theme 'personal qualities' participants shared their thoughts about what they brought to their role as a person, particularly those qualities that they thought adaptive to the setting, for example the importance of having humour in their role and how this helps to keep them "*afloat" (Participant Two, L216)*. They noted too the importance of their commitment to their role. This subordinate theme closes with the advice participants would give to other child hospice Social Workers and staff either considering joining a hospice setting or currently employed in how to maintain or improve their coping and wellbeing.

Summary of findings

This analysis was guided by Braun and Clarke's (2006) six phase guideline for TA and presents three superordinate themes following the eight participant interviews. Each participant contributed to each of the three superordinate themes. Throughout, the superordinate and subordinate themes have been illustrated as if they were the participants thoughts and perceptions. Participant extracts have been presented throughout and provide transcript lines for reference. The semi-structured interviews explored participants' experiences of working as a qualified Social Worker within a children's hospice.

The overall findings illustrate how the participants experience their role in a hospice setting, the impacts to their wellbeing and ways of coping. The findings will be discussed further in relation to the current literature and theory in chapter four.

CHAPTER FOUR - Discussion

I open chapter four by reviewing the study question, aims and objectives, prior to discussing the study findings in relation to the theoretical models and literature base. I will then present the current study's strengths and weaknesses, followed by the clinical implications and areas of potential future research. I close this chapter with my own reflections.

Reviewing the study question, aims and objectives

A qualitative approach was used to explore the experiences of eight qualified Social Workers working with children/young people living with life limiting conditions in a hospice setting. I conducted eight semi-structured interviews and used Thematic Analysis (TA) to analyse the interview data to explore the research question, aims and objectives.

The research question for the current study is: What are the experiences of hospice Social Workers who care for children/young people with life limiting conditions?

Two aims were set:

1) To gain an understanding of the impact on wellbeing for child hospice Social Workers.

2) To explore the factors that affect wellbeing in this group, including the coping strategies they employ.

To investigate the study aims the following objectives were also explored:

- Impact of the work
- Coping skills utilised within their practice
- Organisational impacts; support systems available to participants and the impacts on staff retention rates

The qualitative analysis identified three superordinate themes; 'my work life balance: sources of support, 'doing hospice work', and 'what I bring to the role'.

Discussion of results

The discussion of results section begins by revisiting the models of wellbeing described in chapter one, followed by reviewing the superordinate themes in relation to existing literature and theory.

Revisiting the models of wellbeing

In chapter one, I outlined two models of wellbeing to support an understanding of factors that may impact wellbeing of the participants in the current study. I chose the Self Determination Theory (SDT) and the Dynamic Equilibrium Theory (DET) as these models offer a broad perspective of wellbeing whilst also highlighting the complexity of the construct. This section revisits the two models in more detail. I will firstly discuss the SDT, followed by the DET. I will further refer to how these theories may explain the wellbeing of the current study's participants in relation to the existing literature in the subsequent section 'reviewing the superordinate themes'.

Self Determination Theory (SDT). SDT is a theory that aims to understand social and cultural contexts that can either facilitate or hinder an individual's wellbeing/personal growth (Ryan & Deci, 2017). SDT has two key principles, 1) an individual's need for growth that drives their behaviour, and 2) interaction between extrinsic factors and an individual's intrinsic motives.

Though SDT may be criticised for focusing on motivational states, this theory has three basic needs (autonomy, competence, and relatedness) that are referred to *"as nutrients that are essential for growth, integrity, and well-being"* (Ryan & Deci, 2017; p.10). Accordingly, for wellbeing to be sustained SDT suggests these basic needs should be met and thus may offer insight into the experiences and wellbeing of the participants in the current study – for example, the satisfaction expressed when managing (or attaining mastery over) situations that anyone would find challenging. The first basic need, autonomy, is acknowledged by SDT as how well an individual functions and is related to feelings of congruence, decision making and integrity (de Charms, 1968; Friedman, 2003; Ryan, 1993; Shapiro, 1981). Ryan and Deci (2017) state the hallmark of autonomy is how an individual's behaviours are self-endorsed and are congruent with their own values and interests, a theme that emerged throughout my interviews. The second basic need, competence, describes the qualities (judgement and skill) an individual may use when performing certain tasks. SDT notes individuals need to feel they are functioning as effectively as possible within their current context and this is manifested in their curiosity and motives (Ryan & Deci, 2017), experiences participants had also reported as impacting their wellbeing. Relatedness is the third basic need that SDT proposes and acknowledges as an individual's ability to feel a sense of belonging and relational connection to another person or social group. Relatedness is also when an individual feels they are contributing to the care and belonging of others (Deci & Ryan, 2014a), an obvious connection to the participants in the current study.

Dynamic Equilibrium Theory (DET). DET explores subjective wellbeing (SWB) influenced by an individual's relationship between their life events, personality, wellbeing, and ill-being (Headey & Wearing, 1989). Headey and Wearing (1989; p731) state *"only when events deviate from their equilibrium level does SWB change. Unusually favorable events enhance SWB; usually adverse events depress it",* suggesting people's levels of wellbeing is impacted by external factors (known as flows). DET proposes SWB is impacted and experienced differently by individuals with each experiencing their own level of equilibrium. DET proposes when this equilibrium fluctuates that an individual's personal characteristics (known as stocks) can re-balance their equilibrium. Participants demonstrated negative impacts to wellbeing when facing challenges or barriers to their role.

I will discuss the usefulness of the wellbeing models in relation to my findings later in this chapter, however, to summarise, SDT could be used to explain several of the participants' experiences whereas DET was found to be less relevant.

The findings: superordinate themes

My work life balance: sources of support

This superordinate theme captured factors and sources of support that were thought by the participants to contribute positively to work life balance, from both their personal lives and those associated within the hospice setting. A good work life balance was important to the participants of this study in relation to their wellbeing and ability to continue in post.

Work life balance has not been widely discussed within the existing hospice literature. Taylor and Aldridge (2017) reported the experiences of children's hospice staff who described using individual coping strategies that they indicated had helped to create a balance between their home and work life, reducing the emotional impact of the work and supporting their wellbeing. Similarly, in the current study participants reported on the importance of creating a separation between their home and work life. When discussing factors from their personal lives, participants spoke of the importance of friends and family, and their hobbies and interests outside of work that positively distract them from thinking about their work. Likewise, participants from the McConnell and Porter (2017) study also spoke about the importance of having an outlet outside of work they reported to maintain energy for both their work and home life, further reporting this helped to clear their heads supporting their emotional and psychological needs.

Participants in the current study also described going 'on a journey' with their work life balance since joining their hospice and this had led them to seek healthier alternatives in their coping behaviours; for some participants this has meant engaging in physical exercise rather than consuming alcohol. Similarly to the participants in Taylor and Aldridge's (2017) study, participants in the current study discussed issues around confidentiality when seeking support outside of the workplace – they did not feel able to share their hospice experiences with friends and family and felt a need to protect them from the emotional impact of their experiences in the hospice.

When participants in the current study discussed their experiences in the hospice, each identified a difference between informal and formal sources of hospice support. They perceived the hospice environment as actively encouraging them to engage in activities that promote their wellbeing and self-care. Overall, participants reported feeling valued in their role by their hospice colleagues, with a sense of belonging that they noted positively impacted service user experiences and helped them to feel more able to continue in their job. Similar findings were also noted by Aldridge and Taylor (2017) and McConnell and Porter (2017).

Participants also emphasised the significance of having positive relationships with colleagues in sustaining their wellbeing. Participants spoke of how informal conversations and having an ‘open door policy’ with colleagues had enabled them to feel connected to others. Participants felt that working in a supportive hospice team had promoted their abilities to safeguard their work life balance. Participants also spoke of this resulting in them making meaningful friendships with colleagues and meant they were able to have the difficult conversations they felt they could not have with their friends and family. The results in the current study are further supported by McConnell and Porter (2017) whose participants had found peer support and ‘open doors’ a key element of support and felt this contributed to them attending work with a positive attitude and helped to release any pressure felt during challenging times. Several findings support positive professional relationships can enhance workplace productivity, job satisfaction, service quality and reduced staff absences and rates of turnover (Sheng, Tian & Chen, 2010).

SDT explains the closeness and belonging the participants report in the current study as experiencing ‘relatedness’. Participants experience the hospice environment, and their colleagues, as caring and supportive and they acknowledge this enhances their wellbeing. ‘Relatedness’ is also apparent in the participants’ experiences, particularly as they reported feeling their role and teamworking is significant to hospice care (Cappi & Artioli, 2020). The participants note they too contribute compassion towards their colleagues. McConnell, Scott and Porter’s (2016) review propose colleague support is a commonly known strategy used to help staff cope when providing end-of-life care to children.

When discussing formal forms of support, participants in the current study felt grateful and appreciative of the level of support they receive from line management that they note is particularly crucial when making difficult decisions, a finding echoed in McCloskey and Taggart’s (2010) study. Participants however acknowledged a significant gap in formal support, receiving no clinical supervision from a qualified Social Worker. This was important to them and some were shocked that this was not standard practice in a hospice as it is something they experienced in previous roles; this was also seen in Aldridge and Taylor’s (2017) study. Additionally, participants discussed difficulties in finding suitable external supervision. They acknowledged that a lack of clinical supervision created feelings of professional isolation and were concerned with how this may impact their clinical practice. McConnell and Porter (2017) acknowledge the importance of clinical supervision in the hospice; though focussed on nursing staff, clinical supervision was thought beneficial to reflect upon end of life matters and was a source of reassurance that they had done everything within their ability to support child and family. Further, research by Pelon (2017) suggests supervision is a protective factor against compassion burnout and assists hospice Social Workers in enhancing their coping skills within the hospice environment.

SDT predicts that when individuals do not feel self-determination, that their basic need of ‘competence’ is depleted, thus hindering their wellbeing and professional growth. This explains participants’ concerns that they are not doing a good job and not following current professional practice (Ryan & Deci, 2017). SDT suggests that when individuals feel competent they experience a sense of mastery and thus are more likely to feel they have the skills to achieve their goals, especially when facing tasks that challenge. DET here would suggest that although such events would initially be negative to an individual’s wellbeing, that participants’ ‘stocks’ would quickly return their state of equilibrium to a stable baseline (Dodge et al., 2012). Though SDT states this experience would negatively impact individual’s personal growth, it is unclear how or when participants’ self-determination would later improve. Though the two theories offer insight to some of the participants’ experiences, it is difficult to comment more fully, especially as participants’ own definition of wellbeing did not feature, which may be considered a weakness of the current study. Furthermore, DET includes an important role for personality traits, something again not investigated by the current study.

An interesting difference in the results between the current study and the Taylor and Aldridge (2017) study is participants in the current study saw their work life balance as being their own responsibility. Though some reported that personal demands (such as childcare, family health needs and dependant elderly parents) may impact their ability to attain a reasonable work life balance, in Taylor and Aldridge (2017) they felt pressing priorities of their children and families meant a work life balance was impossible. Participants in the current study noted how the hospice environment was encouraging of its staff to engage in activities that promote their wellbeing and self-care and feeling this support had helped them to create more of a sustainable balance. Participants recognised their wellbeing was a priority. Participants reported this being a positive aspect of hospice working with most commenting on this being a marked improvement in comparison to previous positions held in local authority settings. The difference in participant experiences between these two studies maybe that my study collected data from Social Workers whereas Taylor and Aldridge’s (2017) participants were mainly from medical backgrounds, the impact of professional training and role involvement may influence experiences.

Doing hospice work

This superordinate theme highlighted the participants’ experiences of what it’s like to be a Social Worker employed within a children’s hospice. This superordinate theme reflects the participants’ shared work experiences and the emotional consequences of the work that they feel both positively and negatively impacts their wellbeing and ways of coping.

My role. Participants in the current study experienced a mixture of both positive and negative emotions associated with their role. When they discussed their positive emotions, they shared experiences that have given them job satisfaction, pride, joy, and a sense of achievement. Participants also experienced the negative emotions of helplessness, anger, and frustration in response to witnessing the harsh realities of life limiting conditions on the children/young people they support. Research conducted in UK children's hospices support the current study findings and reports others experiencing similar positive and negative emotions to the participants in the current study (Taylor & Aldridge, 2017; Woolley et al., 1989). Research by Marmo and Berkman (2018), that specifically explored job satisfaction and job retention levels in 203 hospice Social Workers, found those who felt valued by their hospice colleagues were more likely to report job satisfaction and less likely to leave their role. Although this study explored Social Workers employed in American for-profit and non-profit hospices, similar findings were reported by the participants in the current study. Job satisfaction is typically found when work is perceived as meaningful and aims to advance social cause, providing accomplishment (Marmo & Berkman, 2018). This is consistent with the participants' experiences in the current study and thus the values of Social Work. DET theory proposes favourable events that create a sense of achievement yield satisfaction, positively affecting participants' subjective wellbeing suggesting participants equilibrium is stable. Job satisfaction brings a sense of accomplishment, recognition from others and perceptions of shared values with colleagues (Marmo & Berkman, 2018).

Although these findings are positive from the current study and provide insight into the experiences of Social Workers within a children's hospice, it is important to note research by Korzeniewska-Eksterowicz et al. (2010) that contradicts the current study's findings. Korzeniewska-Eksterowicz et al. (2010) evaluated the level of job satisfaction in paediatric home hospice staff in Poland, Social Workers were included in the sample. The findings reported low levels of satisfaction were felt by staff in relation to their professional relationships with the home hospice staff team. These results are interesting in comparison to the current study, however direct comparisons are difficult as the settings were not the same. In addition, the quantitative study of Korzeniewska-Eksterowicz et al. (2010) used a questionnaire to collect data that was neither standardised nor validated.

Overall, the participants spoke highly of the hospice environment as highlighted above. Participants discussed that the pace of work takes a more relaxed approach and offers them more freedom in the sense of being able to take the time to build positive relationships with the children/young people and their families, to ensure their needs are met, in comparison to previous positions outside of the hospice. One of the current study's objectives was to gain insight into why staff might stay in role. Each of the participants expressed no wishes to leave their post. The participants' experiences of the hospice environment echo those illustrated by

Hunter (2017) and follows the end of life care for infants, children/young people with life-limiting conditions: planning and management guidelines (NICE, 2019).

Interestingly, participants in the current study did not report physiological impacts of hospice work such as burnout, compassion fatigue, feelings of irritability and / or physiological effects e.g., headaches, noted by other research (Pelon, 2017; Woolley et al., 1989). There are several possible reasons these were not reported by the participants in the current study. They may not have experienced them or were reluctant to share them. Equally, the questions that were asked in the topic guide focused more on the participants’ experiences and how their work impacted their behaviour and emotional wellbeing, as such, specific questions on physical wellbeing were not directly asked. It is also the case that not all the existing literature included Social Workers, many focused on experiences from different professional disciplines. Participants in the current study emphasised their training, years of experience, in-hospice supervision and support they received as part of their role. These attributes may have developed participants’ coping skills so they can manage workplace stressors in such a way that they may not have been affected by some of the physical impacts discussed within the existing literature.

Working with death. Another area of the participants’ work associated with mixed emotions is the death of a child/young person. They experienced different kinds of endings but referred to the death of a child/young person as the most common form of ending within the hospice environment. They did however note death being a rare event experienced in a children’s hospice, a difference between child and adult hospices. Though participants explained they feel professionally prepared to manage death, they did acknowledge that when a child/young person dies they noticed fears of being overwhelmed, anger, shock and disbelief. The anger was conceptualised as being related to the unexpected and disruptive nature of life limiting conditions and the injustice of a shorter life for children/young people and their families. Participants experienced sadness at a young life ending, too. Death was not an experience that they become accustomed to, and they acknowledged factors that can contribute to them feeling even greater sadness, such as knowing the child/young person and their family well, time of year (e.g., Christmas), and the sudden death of a healthy child. These findings support those of McCloskey & Taggart (2010) who reported the emotional load following a child/young person’s death was greater for hospice nurses if they had developed deep-seated attachments with the patients and families, resulting in them experiencing feelings of loss and grief when a child/young person died. Participants in the current study, despite the sadness, acknowledged the need to manage their own emotions to support the needs of families. Some wondered whether this was a missed opportunity for them to process the emotional impact of a death, as though they were denying themselves to grieve for the child/young person. Research by Price, Jordan and Prior (2013) highlighted frictions between family and professional approaches around when to inform children/young people of impending death, that their participants noted as a contributor of stress. This was not raised in the present study, perhaps because Price et al's. study recruited medical staff. Participants in the current study spoke of having greater involvement with a family following the death of a child/young person and therefore questions surrounding medical treatment and prognosis are more likely to have occurred with medical staff. When discussing death, participants also alluded to the relief this may bring the child /young person and their family, particularly when weighing up quality of life. They spoke about acceptance as a form of coping that brought them closure. They felt acceptance of a death improved team productivity and thus increased participants' feelings of achievement and pride when meeting the varying needs of families. Similar results were reported by participants in the Tatterton, Summers and Brennan's (2019) study, whereby child hospice staff aim to provide family-focused bereavement care. They reported this approach not only has a positive impact on the families but also hospice staff, similar experiences were noted by the current study participants. Though SDT and DET can offer an insight into how a child/young person's death may impact participant wellbeing, it is worth noting that the experiences of death and the direct impact to wellbeing may move beyond that of the wellbeing models, thus making it difficult to fully comment on.

Conflict. Within the current study, the concept of conflict was reported by participants in relation to working with external agencies, the hospice Multi-Disciplinary Team (MDT) and the families they support. Little existing research has commented on the impact of barriers when working with external agencies within the child hospice environment and the impact of this on staff wellbeing. Participants reported feelings of helplessness when raising concerns, that stemmed from feeling ignored or not taken seriously. These experiences led to participants not feeling 'heard' by their external professional peers, with some commenting on the negative impact to their mental health. They deemed that working in a hospice was a key factor and felt that the charity sector was somehow dismissed by other services. Participants illustrated difficulties working with external agencies and service inequality was compounded if the child/young person they were supporting fell between service provision (McCloskey & Taggart, 2010). Research by Pentaris, Papadatou, Jones and Hosang (2018) support the current study's findings, they also found that child hospice professionals had regularly experienced barriers in accessing services for patients and families, though these were more related to transport issues rather than housing/safeguarding as reported in the current study. Interestingly, participants in both studies emphasised the difficulty such barriers have on ensuring a child/young person's medical equipment meets their needs. Although participants reported several positive experiences and good relationships with colleagues, they also discussed experiences of team conflict that had brought them feelings of anger, frustration and confusion. Participants spoke of the lack of communication amongst the MDT impacting team functioning. The current study findings are similar to those presented by Taylor and Aldridge (2017). Unlike that study however, the participants in the current study were able to discuss strategies within their MDT that they reported had improved team functioning, such as delivering training and leading reflective practice groups to help understand dilemmas within the MDT. Participants reported their commitment to improve team functioning brought them feelings of achievement. They also highlighted that such changes were gradual and required constant influence from participants to ensure MDT practice changed. Such achievement was noted to enhance their wellbeing, further resulting in participants commenting on this making a positive difference to patients and families. The SDT would suggest participant experiences correspond with their own interests and values proposing ‘autonomy’ (Deci & Ryan, 1985). A criticism of SDT and DET is they don’t offer an in-depth understanding of group processes, with a particular focus on conflict. Remke and Schermer’s (2012) research explored team development in child palliative care specifically analysing this from the perspective of Social Workers. To safeguard team wellbeing, Remke and Schermer (2012) propose teams adopt the view that team dynamics will constantly change and unfold. As Remke and Schermer (2012; p.294) explain, team functioning can be understood as taking *“two steps forward, one step back”.* This summarises the participants’ experiences in the current study and may be explained by traditional group process models such as Tuckman (1965; 2001). Though unlike the traditional ‘forming, storming, norming, and performing’ stages the Tuckman model prescribes, in the current study participant experiences seem to be better aligned to them forming, storming, norming, performing, reforming, and storming again, then norming and performing, until they experience themselves as forming again (Remke & Schermer, 2012). An example from the current study was illustrated by Participant Eight surrounding issues of consent and capacity: discussions held with hospice staff/participant providing training to establish appropriate boundaries and expectations (forming); reflective groups to discuss new skills (storming); staff practice their new skills (norming); staff practicing skills at team level (performing); feedback on progress from participant (reforming); team learning from participant feedback (storming); new hospice policy (norming); team working cohesively in light of new skills (performing); team adopt new skills and becomes daily practice (forming). Participants noted such experiences brought them a voice and ensured they were heard and respected by their MDT. Further, Blacker and Deveau (2010) state there are seven recommendations teams should consider to engage in effective team functioning. Although participants did not directly quote Blacker and Deveau (2010) they illustrate some of their recommendations in their practices, such as working with person/family centred goals, expecting MDT difficulties, seeking MDT professional developmental and having processes, protocols and processes for sharing information with internal and external care providers.

Medical vs social care approach. Research exploring workplace culture has predominantly examined NHS hospital settings, with a particular interest in how workplace culture impacts practice, patient care and hospital outcomes (Mannion & Davies, 2018). Another interesting finding within the current study demonstrated participants' experiences of working as a Social Worker in a medical dominated setting. Though making positive change with regards to workplace hospice culture is high on the agenda for Hospice UK (2017), hospice workplace culture has rarely been explored within the current literature. The current study offers a unique contribution to this gap in the literature and provides an insight into hospice workplace culture from a Social Worker perspective. Participants reported they felt there had been a shift in the overall culture of the hospice in comparison to when they first started, specifically noting the profession of Social Work is utilised and viewed more positively. These results are interesting and offer some insight into the effect of the five-year strategy launched in 2017 to improve the hospice workplace culture across both adult and children's hospices (Hospice UK, 2017). This five-year strategy aims to improve collaboration and harness a multi-disciplinary approach as opposed to a hospice workforce that is medically driven (Hospice UK, 2017). Although participants in the current study described working within a medically led setting as daunting, some noted they had been recruited to replace medical staff. They discussed the hospice's approach to modernise practice in line with changes in government guidance and hospice standards, to enhance MDT ways of working. SDT would propose participants' experiences here meet each of the three basic needs (autonomy, competence, and relatedness) and thus experience self-determination, suggesting personal growth and wellbeing are strengthened. Participants expressed this opportunity has meant they are more involved in the decision making and management of daily practice, feeling valued and belonging by their MDT. Hunter's (2017) reflective paper supports this change as they discussed difficulties of their work not being centred around a medical role. Although research specifically exploring hospice workplace culture is limited, the current study echoes previous research that has reported on the atmosphere of a children's hospice (Barnes, 2001). Earlier research commented on hospice staff's preferences for a non-hierarchical and non-rigid hospice system often associated with medically led settings, as well as staff having reduced caseloads (Woolley et al., 1989). Combined with a hospice's home-from-home approach, these factors have been reported to enhance staff wellbeing thus improving workplace culture within hospice settings (Barnes, 2001; Woolley et al., 1989; Zimmerman, 1981).

What I bring to the role

This is the final superordinate theme and captures the transferable skills and personal qualities participants felt that they bring to their role. Participants spoke of transferable skills such as resilience and being a reflective practitioner, plus personal qualities such as boundaries, having humour and advice to others.

Transferable skills – Resilience. Participants in this study reported their resilience and reflective practitioner skills were protective factors to maintaining their wellbeing and coping. When discussing resilience, participants discussed the length and breadth of their experience, often from previous local authority roles, which they felt was a contributing factor in the development of their resilience. Research is limited with regards to exploring Social Worker experiences of resilience and what contributes to this in a child hospice setting. Despite this, these findings do however concur with previous research on nurses working in child palliative care services (Feudtner et al., 2007; Quinn & Bailey, 2011; Reid, 2013). Conversely, it is difficult to directly compare the current study findings to the above studies due to the different professional background and varying child palliative care settings reported upon. DET proposes an individual's prior experiences is a protective factor for their wellbeing and suggests this may reduce the fluctuation of an individual's equilibrium by supporting quicker stabilisation when facing challenging situations. Participants reported their prior work experiences were fundamental to their learning that they felt had better enabled them to navigate themselves through challenges.

Transferable skills - Reflective practitioner. Another important finding from the current study raised by the participants is the importance of reflection in practice. Participants spoke of delivering reflective practice sessions and skills in their MDT Team. Butterworth, Bell, Jackson and Majda (2007; p. 270) state *"Employees who are supported and are allowed time to reflect and develop will make a significant contribution to patient wellbeing and safety, and employers bear a considerable responsibility in sustaining and developing this activity in their organisations."* This mirrors the participants' experiences where they reported reflective practice with their MDT as significant in promoting meaningful and positive change to service delivery and care. Positive changes to team functioning were also noted as highlighted in the above Tuckman model example (Tuckman, 1965; 2001). Furthermore, participants prided themselves on practicing reflection and shared that they felt this is an essential coping skill to their role.

Personal qualities - Commitment and motivation. Participants' accounts conveyed a commitment and motivation to undertake their role. They discussed the importance of duty of care and ensuring they were doing a 'good job' for the children/young people and their families. Other studies have also demonstrated hospice staff commitment to deliver high quality clinical and holistic care (McConnell, Scott & Porter, 2016; Taylor & Aldridge, 2017). The SDT differentiates between types of motivation along an autonomy–control continuum (Ryan & Deci, 2017). Being autonomously motivated is to be value driven, the more an individual engages along this continuum the more they find their three basic needs (autonomy, competence, and relatedness) being satisfied (Ryan & Deci, 2000). In the current study, participants reported that the longer they worked at their hospice, they had noticed they had become more committed and motivated to fulfilling their role and driven to make positive changes to the lives of the children/young people and families they support.

Personal qualities – Boundaries. Boundaries are designed to ensure the protection of service users, families, and professionals (Homan, 2006a; 2006b). Homan (2006b) states if professional boundaries are not endorsed this increases the risk of negatively impacting staff wellbeing and creating negative implications for patients and families. The hospice setting is a likely environment where many professionals are engaged in intimate relationships with patients and families (Homan, 2006b). Participants in the current study acknowledged their resilience and commitment to their role related to their ability to maintain appropriate professional boundaries with patients and families.

Humour and advice to others. A further noteworthy finding from the current study is the participants' reports of using humour and the positive impact this has in supporting their own wellbeing and the wellbeing of their colleagues. A systematic mixed methods review found several studies had noted maintaining a sense of humour was vital to self-care of professionals when working with dying children (McConnell, Scott & Porter, 2016).

Participants in the current study were also asked about the advice they would give to other professionals new to working in children's hospices. Participants spoke of the importance of ensuring they protect their mental health through appropriate coping strategies, approaching situations that challenge with an open mind and practicing in the best interests of the children/young people.

Reflections on the wellbeing models

In this section I offer a summary of my reflections on the usefulness of the wellbeing models in relation to the findings of the current study.

SDT appeared to be helpful in identifying the importance of personal growth and the positive and negative impacts of the work on participants and how this impacts wellbeing through the three basic needs in the model (autonomy, competence, and relatedness). SDT also highlighted the dichotomy experienced by many participants: on the one hand the hospice promotes a modern, person-centred approach in how it treats staff – it encourages staff to engage in appropriate practice to support wellbeing and participants generally feel very well supported by their hospice colleagues (e.g., relatedness); on the other hand this support seems more focussed on the personal than professional level, with participants sometimes frustrated that their professional role was not properly understood. The lack of specific social work/clinical supervision was a particularly important issue, leading to many feeling professionally isolated, reinforced by what they saw as a medically dominated culture in the hospice environment (e.g., competence).

In terms of the DET, though this model offers an overview of the functioning of wellbeing, it perhaps offers little in this context beyond the obvious, that difficult experiences can disrupt/alter wellbeing and good experiences enhance it. A further reflection on the DET model is that it does usefully highlight individual differences, social background, and social networks as an individual's stocks/protective factors. The DET however - unlike the SDT - makes no account for change over time. The DET would assume that each challenge or barrier experienced by participants had briefly altered their equilibrium before returning to baseline, allowing for no long-term effects on participant wellbeing. Additionally, it was difficult to identify each of the participants' 'baseline' and this was not a focus of the current study.

In summary, I feel the SDT was a useful model that offered insights for each of the superordinate themes, whereas it was not always clear where the DET would enhance interpretation.

Study strengths and weaknesses

Strengths

Qualitative approach. A qualitative approach enables researchers to capture the complexity, perspectives and understanding of the world for the participants in question (Braun & Clarke, 2013). The current study captured this for Social Workers employed within children's hospices, an area where there is limited existing research. Semi-structured interviews were used to encourage participant conversations and supported the collection of data rich participant accounts, allowing participants to openly discuss and reflect on their experiences in a meaningful way (Braun & Clarke, 2013). This would not have been achievable if a quantitative approach was utilised. In addition, as a Psychologist in Clinical Training (PICT) and lead researcher I feel utilising several transferable skills such as: presentation, interviewing and consultancy skills (developed through clinical training) further supported the gathering of rich and meaningful participant data. I applied these skills to each of the eight participant interviews, when presenting at the APCSW study day, and consulting with a qualified Social Worker prior to participant interviews that also aided participant recruitment and participant rapport. I feel these skills allowed me to gain a deeper understanding of what it means to be a Social Worker within a hospice setting.

Adding to the evidence base. A key strength of the current study is that, to my knowledge, this is the first study of its kind on Social Workers in children's hospices. This study also provides initial insights into the progress of Hospice UK's five-year strategy launched in 2017 that aims to move towards an MDT culture within hospices (Hospice U.K., 2017).

Scientific rigour. I ensured the current study was conducted rigorously by implementing qualitative guidelines outlined by Elliott et al., (1999), and Braun and Clarke's (2006) six phase TA guidance and their 15-point checklist for conducting TA, as specified in chapter two. Therefore, I believe my research provides credibility of the current study when sharing the participants' story as Social Workers who support children/young people and their families in a hospice setting.

Participant feedback. Though the analysis has since been further refined, I gathered participant feedback on the superordinate themes, offering a further strength of the current study. Each of the eight participants expressed an interest to comment on the overall study findings following their interview. Once analysis had been completed, I emailed participants individually (maintaining confidentiality) a summary of the superordinate themes. I managed to receive responses from three participants, their comments are as follows:

> *"I would concur with the common themes…as I read them, I could definitely identify with each one in some way. For me, taking part in this research has strengthened my view that it is important to ensure adequate professional supervision and continuing professional development opportunities are available to social workers, often working in isolation in hospices. This is something that I have taken forward with the senior management team here and hopefully I will be given the time to pursue this." (Participant Four)*

> *"This is very interesting and, in my opinion, accurate." (Participant Five)*

> *"I am happy with the content and feel there is nothing that is inaccurate regarding the responses given." (Participant Six)*

Reflexive research and supervision. Reflexivity enables researchers to reflect upon their research experiences (Braun & Clarke, 2013). I engaged regularly in research supervision, sharing my experiences and reflections at each stage of the research process. The process of supervision supported my development and confidence as a qualitative researcher, especially as the current study was my first time conducting qualitative research using TA. Supervision also enabled me to remain objective and reflect on the breadth of participant experiences ensuring the validity of superordinate themes as they emerged from the analysis findings.

Limitations

Data collection method. I conducted each of the eight participant interviews via telephone upon participant request. Despite the flexibility telephone interviews can bring (Block & Erskine, 2012) I experienced limitations of their use. Firstly, I felt the telephone interviews did not allow for the communication of body language or visual cues that face-to-face interviews may offer (Braun & Clarke, 2013). This was particularly evident when participants had paused in their speech when thinking of their response to interview questions that encouraged me to unnecessarily interrupt them. I also experienced technological difficulties, for example, in interview four I experienced noise interference in a University interview room when conducting the call that I felt had disrupted the flow of conversation. This meant that I found myself checking-in more regularly with Participant Four, aiming to ensure she was still able to hear. Additionally, during interview eight, the telephone connection had unfortunately cut out due to the participant's mobile signal. Each of the incidents I describe may have impacted on the depth of meaningful data gained. Despite my experience I continue to support the use of telephone interviews in the current study. This form of data collection remains the most accessible and practical method for the current study participants who were recruited from across the UK. If I relied upon face-to-face interviews this may have impacted recruitment. Moreover, telephone interviews allowed Participant Five to be interviewed the same day in which she had expressed her interest to take part.

Participant demographics. A limitation of the current study is the sample includes only white British female participants, despite recruitment of participants being open to any Social Workers in children's hospices across the UK. It is possible that the results may have been different if data included male perspectives and / or participants from differing ethnicities. However, without understanding the overall demographics of the population group, this is difficult to assess.

Recruitment and sampling. I sought recruitment from the APCSW and utilised a convenience sampling procedure. Though convenience sampling means participants are accessible and meet the study's population of interest, recruiting from one group this way means the target population was nonrandomised and is likely to be subject to bias (Etikan, Musa & Alkassim, 2016). This may limit the findings and I acknowledge this is not representative of the population. The below limitation, 'respondent bias', outlines this further.

Respondent bias. I am mindful that the current study may be impacted by respondent bias. It is possible that only positive and motivated participants responded to the study email advert. All the participants reported a positive perception of working in a children's hospice and collectively they described hospices as a *"happy place" (Participant Eight, L146)* bursting with life. As I did not hear of any opposite experiences, this may further suggest that only positive participants responded and took part as well as the fact some participants were recruited using a convenience sample. It could be the case that Social Workers who are less positive or have had more negative perceptions/experiences of the role chose to not take part or have left children's hospices and were therefore unable to be recruited. Whilst acknowledging that this was out of scope for this study, an opportunity for further study on the experiences of Social Workers who have recently left children's hospices as well as recruiting Social Workers outside of the APCSW could contribute to this research area.

Researcher bias. It is acknowledged that there will always be some level of researcher bias, although I aimed to minimise this as much as possible. I followed Elliott et al.'s (1999) guidelines for qualitative research, utilised a reflective journal, defined my role as the lead researcher and was guided by Braun and Clarke (2006) when conducting the TA. I feel my dual identity as both a PICT and lead researcher actually gives great benefit to this study – for example my ability to draw on my prior professional experiences, develop real rapport with participants, and conduct interviews. Despite this, I acknowledge that my experiences may have shaped how I interacted with participants during the interviews themselves and throughout the analysis stage.

Future research

The following recommendations for future research are suggested based on the current study's findings and limitations.

Despite recruiting participants from across the UK, the limited demographics of the sample and the differences in the way hospices are organised could limit the generalisability of the findings. The current study only included the accounts and experiences from eight qualified Social Workers who are all white British females. There is a possibility that if the current study had recruited participants from different ethnicities and genders that different results may have been yielded. It is difficult to draw upon these inferences without knowledge of the demographics of the entire population group but further research may uncover this and add to the current literature base.

Despite obvious challenges, the participants in the current study appeared positive and motivated. There would be value in conducting similar research with Social Workers who have recently left their roles and those who may have had a more negative experience of the hospice setting. These individuals may ultimately provide a different perspective on experiences as a Social Worker in a children's hospice.

I explored the experiences of eight qualified Social Workers and what it is like to support children/young people with life limiting conditions in a children's hospice. Future research may wish to explore from the patient and family perspectives, specifically their experiences of receiving care and support from Social Workers within a children's hospice setting. Additionally, future research in this area may find value in comparing the experiences of Social Workers who support children/young people in a hospice setting with those of Social Workers from adult hospices. Exploring these experiences would provide an interesting comparison given that the nature of the work, and level of family involvement, is often very different between the two. This recommendation is inspired by two of the participants from the current study who split their role across both a children's and adult's hospice.

The findings of the current study offer insight into the world of a children's hospice and the workplace culture within it from the Social Worker perspective. These findings add to the limited literature base on hospice workplace culture. To that end, a final recommendation for future research is to further explore hospice culture and how this is experienced across the professional disciplines within a children's hospice with the specific focus of wellbeing.

Clinical implications

The current study's findings provide insight into the participants' experiences specifically related to factors that impact their wellbeing when supporting children/young people with life limiting conditions. The findings have raised important implications for practice and have been written with a focus to enhance wellbeing for child hospice Social Workers and other hospice staff. I have written the following section from the perspective of clinical psychology and what the profession may contribute to children's hospices. The role of clinical psychology is to work with individuals as well as teams and organisations to develop and support psychological practice, wellbeing, and coping. Russell and Fountain (2018) conducted a survey on Clinical Psychologists (CPs) in UK hospices and although this paper did not differentiate between CPs input across child or adult hospices, it does conclude that the roles of CPs, and levels of input from CPs, can be considerably varied. This paper further demonstrates the wide contribution that CPs can have, for example: consultation, staff support, supporting organisational change and clinical work (Russell & Fountain, 2018).

I have also included recommendations for CPs based on findings from the current study. Although not exhaustive, it is hoped these will stimulate discussion and encourage thoughts on what might be helpful.

Clinical supervision. It is clear from the findings that participants value supervision and view this as an important element to their role, particularly to support their professional and personal wellbeing. Although most of the participants felt satisfied with the level of in-hospice management supervision and colleague support they receive, findings indicate that many of the participants lacked clinical supervision, specifically from their peer Social Workers. Participants expressed two factors that may have contributed to this: 1) they are the only Social Worker employed within the hospice setting, and / or 2) participants were unsuccessful in seeking external support from peer Social Workers. Participants stated a common reason was there are usually no other children's hospices within their locality and participants also reported APCSW members as being predominantly employed within adult hospices. Participants noted involvement of Social Workers from adult hospices are not specific to their role and they felt this would not address their supervision requirements. Participants felt limited clinical supervision can result in them feeling professionally isolated and thus may negatively impact their wellbeing.

Difficulties surrounding issues of supervision not only impact the participants but also other professionals employed within a children's hospice setting. These findings highlight potentially wider consequences for clinical practice, such as the quality of patient care, issues related to risk and safeguarding and the wellbeing of staff in general, for example, the ability to manage and reflect upon the emotional load of the work. Supervision is an essential requirement within the helping professions to enhance their professional development and learning (Fleming & Steen, 2012). Rothwell, Kehoe, Farook and Illing (2019) wrote a report for the Health and Care Professions Council (HCPC) and presented a wealth of research that supports the need of clinical supervision for the helping professions. Rothwell et al's. (2019) report summarises the literature on the effective use of clinical supervision and states improvements have been found in job satisfaction (Bethell, Chu, Wodchis, Walker, Stewart & McGilton, 2018; O'Donoghue & Tsui, 2015;Pohl & Galletta, 2017) staff retention rates (Brunetto, Farr-Wharton & Shacklock, 2011; Brunetto, Shriberg, Farr-Wharton, Shacklock, Newman & Dienger, 2013; Chiller & Crisp, 2012; Rodwell, Brunetto, Demir, Shacklock & Farr-Wharton 2014; Rodwell & Martin 2013; Rodwell, McWilliams & Gulyas, 2017), better management of mental health and leadership skills (Koivu, Saarinen & Hyrkas, 2011). The report highlights effective clinical supervision can improve working environments and increase delivery of quality care (Davis & Burke, 2012; Koivu, Saarinen & Hyrkas, 2011). The report also outlines some of the barriers to effective clinical supervision, such as: limited time and resources, experiences of non-supportive organisation/management, limited supervisor supervision skills and training, lack of trust within supervisory relationship, limited understanding of supervision and its purpose as well as contextual factors (Rothwell et al., 2019). Though the HCPC no longer regulates Social Workers, Rothwell et al., (2019) include data from social care populations in their report.

The role of clinical psychology may be helpful with addressing some of the difficulties of supervision raised by the participants in the current study. CPs are trained in various models of supervision (such as, Functions Model; Inskipp & Proctor, 1993; Kadushin, 1992a, Developmental Model; Stoltenberg & Delworth, 1987, Key Issues Model; Gilbert & Clarkson, 1991, Systems Approach Model; Holloway 1995, Process Model: Hawkins & Shohet, 1989; 2000, Integrative Models and therapy specific models) and thus may be able to provide training on supervision, promote the importance of supervision and its impacts to clinical practice for wider professions in the hospice sector. It's important to note CPs may not address the issue of professional isolation, however CPs with experience of paediatric settings would be a good fit for clinical supervision here. An advantage of supervision with a CP may be the different professional perspectives. Finally, the role of Social Workers in hospices is quite different from roles of other Social Workers in local authorities, with the work involving more therapeutic content, therefore, support offered by CPs may prove a better fit

Special Interest Group (SIG). My own contribution as a PICT is to present my findings from the current study at the next available APCSW study day. I will propose the participants' suggestion to form a Special Interest Group (SIG) to connect Social Workers employed within children's hospices. It might be helpful if this SIG could be open to all Social Workers employed within a children's hospice rather than a closed group exclusive to APCSW members. Further, the SIG could be used as a networking forum for Social Workers to share career development opportunities, promote good practice, offer peer supervision and provide an opportunity to discuss clinical supervision needs. SIGs are typically held quarterly throughout the year with a SIG chair, someone who guides the group through an agreed agenda, with another person as minute-taker to provide a meeting log. To establish group responsibility, it may be useful for the SIG chair and meeting minute taker responsibilities to be shared on a rota based system to accommodate for absences and to allow for diversity within the group. SIGs can be conducted face to face, virtually or a combination of both, what is important is members have the flexibility to choose.

It is hoped that raising the concern of limited clinical supervision and proposing the development of SIGs may promote the wellbeing and coping strategies of Social Workers in children's hospices and reduce feelings of professional isolation reported by participants in the current study. It is also hoped that presenting my findings to the APCSW will encourage its members to discuss, and raise awareness of, clinical supervision within their hospice reflective practice groups and consider their existing supervision practices.

Reflective practice groups (RPGs). Participants in the current study noted their use of reflection, whether in a group forum or individually, and emphasised the importance of having time to process and make sense of their work and the positive impact this may have on their wellbeing and clinical practice. In addition to clinical psychology promoting clinical supervision, it can also encourage the use of RPGs. Notably, all participants in this study reported they engaged in RPGs but it is unknown if this is common for all children's hospices in the UK. This could be an important forum for children's hospices to consider using to ensure staff wellbeing. Research supports the use of RPGs to improving team working and staff wellbeing, clinical psychology has been identified as a profession to best deliver this type of work (Heneghan, Wright & Watson, 2014). It is recommended RPGs follow a set format and are held monthly for one hour with clinical psychology support. RPGs should commence in a quiet room away from ward/patient activity, be open to all hospice staff and ensure ground rules have been established with attendees. It is hoped RPGs provide an opportunity for staff to open their communication, evaluate/explore ways of coping for individual staff to support wellbeing and team functioning.

Collaborative working. A further implication raised by the current study is from the participants' experiences of working with external agencies (e.g., local authority, housing associations, and other charitable/third sector organisations). Though in recent years the APCSW has attempted to improve collaborative working by promoting the role of the Social Worker within palliative care services, the participants in the current study reported experiencing barriers to working with external agencies that had created feelings of frustration and helplessness when participants raised issues related to safeguarding, best interests, and risk. This is a clinical implication that can impact many professions within the health and social care system and has implications for wider clinical practice and service delivery. Healthcare research has demonstrated collaborative working can yield improvements to services and service user outcomes through efficiency, utilising an improved skill mix and creating a person centred and innovative approach (Green & Johnson, 2015; Littlechild & Smith, 2013). Participants in the current study felt external agencies had little understanding of the role of a Social Worker within a children's hospice. Further, improvements in collaborative working with external agencies has the potential to improve the wellbeing and experiences of the wider hospice staff team and thus improve the outcomes for children / young people and their family in a hospice setting.

CPs may support children's hospices in this area as they are equipped to consult with organisations to explore strategies to enhance service development (BPS, 2011). CPs may be able to recommend improvements that promote collaborative ways of working through education and training, team working, regular meetings between children's hospices and external agencies as well as children hospices and external agencies establishing working towards common goals. CPs can help to address issues with team functioning to support positive change, as well as offering external consultancy. This might be useful in a medical dominated setting. It is hoped these practices may improve relationships between child hospices and external agencies that ensures services retain the child/young person and their family at the centre. Further, it has the potential to reduce Social Workers from experiencing negative working relationships and support their overall wellbeing. The DET theory would support this and suggests when good relationships are established this creates an equilibrium for an individual and enhances their psychological wellbeing (Headey & Wearing, 1989).

Reflections

Personal reflections. At the beginning of my thesis journey I had a limited understanding of what it is like for professionals to support children/young people with life limiting conditions in a hospice setting. I was saddened to hear of my sister's experience as a nurse in a similar setting and was surprised the existing literature is predominantly based on the experiences of medical professionals (mainly nurses). This drove my curiosity to learn more about the hospice environment and as a PICT my aim is to understand the experiences and stories of those who may not be regularly heard. Upon reviewing the existing literature exploring the experiences of Social Workers in a children's hospice was a natural fit for the current study.

Prior to conducting the interviews I assumed Social Workers would be at breaking point and would struggle to maintain a healthy work-life balance, and thus I was primed to hear about some very difficult experiences. I also assumed the participants' workload to be unsustainable, both emotionally and physically taxing, with participants experiencing long lasting and detrimental effects e.g., vicarious trauma and emotional pain. Throughout the participant interviews and data analysis I was struck my preconceptions of the stigma of hospice work was akin to those held by the participants before they assumed their roles. To my surprise, and again similarly to the participants' experience, my preconceptions were challenged. Even in the face of some very difficult experiences, the participants were able to point out the ways they had impacted positively on the lives of families. They talked about their hospice experiences, their skills and the factors that support their wellbeing and coping at the hospice, and in their personal lives. I have since been amazed by how much enthusiasm, joy and love the participants have for their role and the positive impacts their role can bring to the lives of the children/young people living with life limiting conditions and their families.

This project has prompted me to pause and think more about my own wellbeing and coping in relation to my work and how I engage with my own self-care routine. I have noticed I now have a greater awareness of this in my clinical practice, not just for myself but also for the team in which I work.

Overall, it has been a pleasure to complete this research and learn of the participants' experiences. I have found this research humbling and I end this journey feeling privileged to have captured the participants' accounts. I aim to share the findings with wider audiences.

Reflections on my researcher development. My experience of qualitative research was limited before undertaking my thesis project. My research has taught me of the advantages that utilising qualitative methods can bring to under-researched populations. My research has also given me a greater appreciation of qualitative enquiry and the importance to reflect upon this, and I feel I am more mindful of the contexts in which may influence this. I feel this approach is more akin to the CP I aim to be and best suits my contextual critical realist position, that has been strengthened in clinical training and is cemented in this thesis submission. My research has also taught me to reflect more on how clinical psychology can contribute to this area of research and is a factor I will continue to pursue in any future research opportunities and clinical practice. Overall, I feel this meets my clinical training goal of becoming a scientist-practitioner.

Conclusion

The current study explored the experiences of eight qualified Social Workers supporting children/young people with life limiting conditions and their families in a hospice setting, an area limited in the existing research literature. The current study highlighted three superordinate themes following participant interviews: 1) my work life balance: sources of support, 2) doing hospice work, and 3) what I bring to the role. This research adds to the existing literature base and offers some insights into the working experiences of hospice Social Workers, their wellbeing and ways of coping. Though the participants reported their experiences as being broadly positive, the findings did demonstrate some of the challenges of working in a hospice environment as well as identifying implications for clinical practice.

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LIST OF ABBREVIATIONS

APCSW	Association of Palliative Care Social Workers
CPs	Clinical Psychologists
DET	Dynamic Equilibrium Theory
GT	Grounded Theory
IPA	Interpretive Phenomenological Analysis
MDT	Multi-Disciplinary Team
NHS	National Health Service
PPC	Paediatric Palliative Care
PICT	Psychologist in Clinical Training
RPGs	Reflective Practice Groups
SDT	Self-Determination Theory
SIG	Specialist Interest Group
TA	Thematic Analysis
UK	United Kingdom

APPENDICES

Appendix A: Ethical approval

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)
Room 9.29, level 9 Worsley Building Clarendon Way Leeds, LS2 9NL United Kingdom
& +44 (0) 113 343 1642 14 February 2018

Rhian Lloyd
Psychologist in Clinical Training
Clinical Psychology, Leeds Institute of Health Sciences Faculty of Medicine and Health
Level 10, Worsley Building
University of Leeds
Clarendon Way
LEEDS LS2 9NL

Dear Rhian,

Ref no: MREC16-043

Title: Caring for children and young people with life limiting conditions; coping strategies and impact on wellbeing of staff working in children's hospices

Your research application has been reviewed by the School of Medicine Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documentation received from you and subject to the following conditions, which must be fulfilled prior to the study commencing:

- C15 – presumably this should have been ticked 'no' – please amend and submit for file
- Consent form –please update the date in statement one for the Participant Information Sheet (as the PIS is dated November, not October) and submit for file
- Participant Information Sheet – please add a version number and submit for file

Document	Version	Date Submitted
Thesis Ethics Form Rhian Lloyd final signed	1.0	08/12/2017
Lone_Working_RA_Nov_15 (1) JH	1.0	08/12/2017
Interview Topic Guide Sections	1.0	08/12/2018
Participant Demographic Questionnaire	1.0	08/12/2017

Rhian Lloyd Participant consent form final	1.0	08/12/2017
Thesis Information sheet for participants final	1.0	08/12/2017
Participant Email Invitation and reminder	1.0	08/12/2017

Please notify the committee if you intend to make any amendments to the original research ethics application or documentation. All changes must receive ethics approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two-week notice period if your project is to be audited.
It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you every success with the project. Yours sincerely
Dr Naomi Quinton, Co-Chair, SoMREC, University of Leeds
(Approval granted by Co-Chair Dr Naomi Quinton on behalf of the committee).

SoMRECApproval letter v2_0
September 2013

Appendix B: Ethical approval amendment 1

UNIVERSITY OF LEEDS

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)
Room 9.29, Level 9 Worsley Building Clarendon Way Leeds, LS2 9NL United Kingdom +44 (0) 113 343 1642 22 February 2019

Rhian Hudson
Psychologist in Clinical Training
Clinical Psychology, Leeds Institute of Health Sciences Faculty of Medicine and Health
Level 10, Worsley Building
University of Leeds
Clarendon Way
LEEDS LS2 9NL

Dear Rhian

Ref no: Title:
MREC 17-043 Amendment 1 December 2018
Caring for children and young people with life limiting conditions; coping strategies and impact on wellbeing of staff working in children's hospices

We are pleased to inform you that your amendment to your research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documents received from you:

Document	Version	Date submitted
MREC 17-043 amendment December 2018 Thesis Ethics Form Rhian Lloyd final signed	1.0	19/12/2018
MREC 17-043 amendment December 2018 Version 1 Recruitment poster (1)	1.0	19/12/2018
MREC 17-043 amendment December 2018 Version 2 Interview topic guide questions(1)	2.0	19/12/2018
MREC 17-043 amendment December 2018 Version 2 Participant demographic questionnaire(1)	2.0	19/12/2018
MREC 17-043 amendment December 2018 Version 2 Participant email invitation (1)	2.0	19/12/2018
MREC 17-043 amendment December 2018 Version 2 Participant Information Sheet_(1)	2.0	19/12/2018

MREC 17-043 amendment December 2018 Version 2 Participant informed consent form(1)	2.0	19/12/2018
MREC 17-043 amendment December 2018 Version 2 Participant reminder email invitation(1)	2.0	19/12/2018

Please notify the committee if you intend to make any further amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please contact the Faculty Research Ethics & Governance Administrator for further information (fmhuniethics@leeds.ac.uk)

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

SoMREC Amendment approval letter vs2_0 September 2013

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two-week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you continued success with the project. Yours sincerely

Dr Naomi Quinton

Co-Chair, on behalf of the SoMREC, University of Leeds

Appendix C: Ethical approval amendment 2

Rachel De Souza [Medicine] on behalf of Medicine and Health Univ Ethics Review

Wed 20/11/2019 12:49

To: Rhian Hudson

Cc: Gary Latchford

+1 other

Hi Rhian

MREC 17-043 Amd 2 Nov 2019 - Caring for children and young people with life limiting conditions; coping strategies and impact on wellbeing of staff working in children’s hospices

Many thanks for submitting the above amendment, which is under consideration of approval with a SoMREC co-Chair.

I hope to have the outcome in approximately 7 working days.

Best wishes
Rachel de Souza

~~~~~~

Rachel de Souza Research Ethics & Governance Administrator, The Secretariat, Room 9.29, Level 9, Worsley Building, Clarendon Way, University of Leeds, LS2 9NL, Tel: 0113 3431642, r.e.desouza@leeds.ac.uk
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Appendix D: Email advertisement

Participant email invitation to take part in the study: Caring for children and young people with life limiting conditions; coping strategies and impact on wellbeing among social workers working in children’s hospices.

Dear Social Worker,

My name is Rhian Hudson. I am a third year Clinical Psychology trainee at the University of Leeds studying for a Doctorate in Clinical Psychology. I am conducting a research project on the experience of social workers that work in paediatric palliative care services. This email is an invitation to take part in this project. I am interested to learn more about the experiences of social workers working in paediatric palliative care services, their role and their wellbeing, and thoughts about the factors that help or hinder how you cope.

Participation in this research includes taking part in a one-to-one interview with me where you will be given the option to be interviewed at your place of work (or the University of Leeds) or over the telephone or Skype, which will take approximately one hour. It’s important to note that all interviews will be confidential, and participation is completely voluntary. Should you decide not to take part in this project I would like to clarify there will be no consequences to your work.

I have enclosed a Participant Information Sheet that provides more detail about the project and what taking part in this study would involve. Should you require any further information please do not hesitate to contact me on the following email umrkl@leeds.ac.uk

Thank you for taking the time to read this email invitation and the Participant Information Sheet. I look forward to hearing from you.

Best wishes,
Rhian Hudson (Psychologist in Clinical Training).

Participant reminder email invitation to take part in the study: Caring for children and young people with life limiting conditions; coping strategies and impact on wellbeing among social workers working in children's hospices.

Dear Social Worker,

Thank you very much to those who have already taken part in the study and contacted me. This is an email reminder for those who have not yet taken part to inform you that there is still time to become involved in the study.

My name is Rhian Hudson. I am a third year Clinical Psychology trainee at the University of Leeds studying for a Doctorate in Clinical Psychology. I am conducting a research project on the experience of social workers that work in paediatric palliative care services. This email is an invitation to take part in this project. I am interested to learn more about the experiences of social workers working in paediatric palliative care services, their role and their wellbeing, and thoughts about the factors that help or hinder how you cope.

Participation in this research includes taking part in a one-to-one interview with me where you will be given the option to be interviewed at your place of work (or the University of Leeds) or over the telephone or Skype, which will take approximately one hour. It's important to note that all interviews will be confidential, and participation is completely voluntary. Should you decide not to take part in this project I would like to clarify there will be no consequences to your work.

I have enclosed a Participant Information Sheet that provides more detail about the project and what taking part in this study would involve. Should you require any further information please do not hesitate to contact me on the following email umrkl@leeds.ac.uk

Thank you for taking the time to read this email invitation and the Participant Information Sheet. I look forward to hearing from you.
Best wishes,
Rhian Hudson (Psychologist in Clinical Training).

Appendix E: Participant information sheet

Study Title: Caring for children and young people with life limiting conditions; coping strategies and impact on wellbeing among qualified social workers working in children hospices

You are invited to take part in a University of Leeds Clinical Psychology Doctoral thesis research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read through the following information.

Who is conducting the research project?
This study is being conducted by Rhian Hudson, Psychologist in Clinical Training as part of her Doctorate in Clinical Psychology at the University of Leeds.

What is the purpose of this research project?
This study aims to investigate how qualified social workers perceive work stresses within a paediatric palliative setting, and what helps them to continue to work within this setting.

Who should take part?
We would like to invite qualified social workers who patients and their families within paediatric palliative care services. You must have been in post for a minimum of six to take part in a one-to-one interview with the researcher.

Do I have to take part?
No. It is up to you whether or not you decide to take part. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. You will still be free to withdraw from the study at any time until the analysis takes place (14 days post interview).

What will be expected from me?
If, when you have read the Participant Information Sheet and have had the opportunity to ask any questions about the study, you would like to take part, the researcher will discuss with you a convenient date and time for the interview to take place. The interview will be held at a place convenient to you, usually your normal workplace or over the telephone. The interview will be audio recorded and will last approximately one hour. Before the interview, you will be asked to sign a consent form which gives your permission to take part in the project and for the interview to be recorded. Prior to the interview you will

also be asked a series of demographic questions. Interviews are scheduled to take place between January – March 2020.

During the interview, you will be asked questions about your perspective and experiences of working within paediatric palliative care services, with particular focus on what you find helpful to manage effectively within your role, particularly when you are faced with stressful or rewarding situations. Interviews will be transcribed verbatim within a month of the interview-taking place and any identifiable data will be removed. It is important to note that the researcher may be interested in using quotes from the interview. The researcher will ensure participants are not identifiable and will only include these with participant consent.

What happens if I decide I no longer want to take part?

Prior or during the interview if you decide that you no longer wish to take part in this study you can withdraw at any time and your data will be destroyed. If you decide that you no longer wish to take part in the project following your interview you will have two weeks following your interview date to withdraw and for your data to be excluded and destroyed from the study.

What are the benefits and risks of taking part in this study?

It is hoped that the information collected from this study may contribute to the knowledge of how health and social care professionals working within paediatric palliative care services manage stress and maintain their wellbeing and resilience when faced with stressful and rewarding working environments. It is envisaged that there will be no risk to you taking part in this study. It is important to inform you that the information discussed during interview will be kept confidential and no one participating within this study with be identifiable. This study is strictly confidential and therefore the interview data will be recorded and stored on a secure drive at the University of Leeds.

How to get involved

If you are interested and would like to take part, please contact Rhian Hudson on umrkl@leeds.ac.uk

Please contact Rhian Hudson if there is anything that is not clear or if you would like more information about the study. Please take the time to decide whether or not you would like to take part and thank you for taking the time to read about the study.

What if I need support after participating?

If at any time during or after the interview you feel distressed for any reason, please contact Rhian Hudson who will consult with her research supervisor (contact details at the end of the information sheet) to identify the best person to support you.

If you have a concern about any aspect of this study, you should ask to speak to Rhian Hudson or the research supervisor (contact details at the end of the information sheet).

Who has reviewed the study?
This study has been reviewed by the School of Medicine Research Ethics Committee (MREC 17-043) and has been approved by them.

If at any point you have questions or concerns regarding this study, please contact:
Rhian Hudson (Lead Researcher); umrkl@leeds.ac.uk

Research Supervisor Contact Details:
Dr Gary Latchford
Address: Level 10 Worsley Building, University of Leeds
Tel: 0113 343 2736
Email: G.Latchford@leeds.ac.uk

Thank you for considering taking part in this study!

Appendix F: Consent form

Consent to take part in Caring for children and young people with life limiting conditions; coping strategies and impact on wellbeing among qualified social workers working in children's hospices.	Add your initials next to the statement if you agree
I confirm that I have read and understand the Participant Information Sheet (dated October 2019) explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time during the interview without giving reason and without there being any negative consequences. In addition, should I decide to withdraw from the study after my interview I understand that I have until two weeks following my interview to do so. If you decide to withdraw please contact the researcher Rhian Hudson at umrkl@leeds.ac.uk	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses and any quotes included in the study write up will be kept strictly confidential.	
I agree for the anonymised data collected from me to be stored and used in relevant future research.	
I understand that other researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	
I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change during the project and, if necessary, afterwards.	

Name of participant	
Participant’s signature	
Date	
Rhian Hudson (Lead Researcher)	
Signature	
Date*	

A copy of the signed and dated consent form will be kept with the project’s main documents and will be stored on the M drive, which is a secure drive at the university.

Appendix G: Demographic questionnaire

The purpose of this questionnaire is for you to provide some basic background information about yourself and your experience in working within a paediatric palliative care service. The information you provide in this questionnaire and during the interview will be kept confidential and no one participating within this study with be identifiable.

Please complete the following demographics questionnaire and circle below

Age:

21-24 25-34 35-44 45-54 55 and over

Gender: Female

Ethnicity:

Length of years qualified:

How long have you worked in this paediatric hospice (*minimum 6-months*)?

How were you recruited to take part in this study?

Thank you for answering the above questions. You will now take part in a one to one interview that will ask you questions about your experiences of working within a paediatric palliative care service.

Appendix H: Topic guide

1. Tell me about your professional background.
   How did you come to work in paediatric palliative care and the hospice?

2. Can you tell me about your role as a social worker in the hospice?
   a. Prompt – Do you work as part of a team/ Social Worker team and if so, what is your role within the team?
   b. Prompt – How long have you been in this role?
   c. Prompt - How are you finding it so far?
3. What is it like to work with children and young people who have life limiting conditions?
   a. Prompt – Is it what you expected?
   b. Prompt – If no, what did you expect it to be like?
4. Can you tell me about a time which you have found particularly challenging whilst working here?
   a. Prompt – Can you talk me through what happened?
   b. Prompt – Did you anticipate feeling like this when you first started your role?
   c. Prompt – How does that compare to now/What about now?
   d. Prompt – How do you think your peers found this?
   e. Prompt – What helps you manage when X occurs (Are there any professional, organisational or personal factors that help you to manage)?
   f. Prompt – How does this make you feel? In what ways does X impact on your behaviour? If your behaviour does change who notices it? Is it you or someone else?
   g. Prompt – Can you think of anything more that could be offered to help you manage situations like this? Do you think this would be beneficial to others?
5. Can you tell me about a time in which you have found particularly rewarding whilst working here?
   a. Prompt – Can you talk me through what happened?
   b. Prompt – Did you anticipate such an experience when you first started your role?
   c. Prompt – How does that compare to now/What about now?
   d. Prompt – How do you think your peers found this?
   e. Prompt – How does this make you feel? In what ways does X impact on your behaviour? If your behaviour does change who notices it? Is it you or someone else?
6. What support (if any) do you receive as part of your role at the hospice?
   a. Would you like more or less support
   b. What would this look like?
   c. How do you manage your wellbeing/ look after you?
7. What would your advice be to someone (another social worker) starting out in paediatric palliative care?
8. Is there anything else you would like to add?

Appendix I: Coded transcript example

Interview Data	Codes
I: Okay. What would you say helps you to manage when you find yourself experiencing those moments of helplessness? So, are there any professional, organisational or personal factors you find help you manage in those situations?	
P: Yeah, I get erm clinical supervision outside of the hospice which has been invaluable she is a very experienced err social work manager and I have a great respect for her so she if I have any real concerns or don't know where to go with something then I find my supervisions with her incredibly useful and I've always said that I don't think it could do my job effectively without her and her support erm so I will go to her erm also internally there are managers within the hospice that I feel quite happy to go to and either just offload or advice on where they think I should go with it or I will call a MDT and then it is not just my decision it's a joint decision it's a hospice decision so it's not .. solely my responsibility then and then even if we can't come up with any further plans I just generally feel better knowing that I'm not in it alone.	(Lines 121-125) Professional development and support – feeling grateful and fortunate – appreciative of others investing in them. Importance of profession specific supervision- promote practice safeguarding/education. Outside confidant. Professional identify. (Lines 126-132) Professional wellbeing – Internal support from hospice managers – MDT meeting Social Workers are part of making decisions, shared responsibility, promotes value/ a healthy wellbeing relationship building – elevates feelings of isolation and pressure to get things right – sharing the burden
I: What about your own personal factors then? What do you think I guess you bring to help you manage in those situations?	
P: Erm … I have 2 very young children who keep me very busy at home so I don't have the capacity once I'm home to then think about or worry about or do anything about any kind of situation unless it's a real emergency but even then it's never my responsibility its always gonna be a local authority social worker responsibility so as long I know I've done my bit I do find it quite and I say quite easy it's not quite easy but I can switch off from the job because as I say my sons got his own health needs so that keeps us very busy and I have an 11 month old daughter who also now keeps me very busy so I just don't have the capacity to take ta .. to kind of those things home with me and I do have very good friends within the hospice I have very good friends outside the hospice when I don't want to talk about work .	(Lines 135-141) Work life balance? Home distractions – limited distance from home life and work. Personal responsibilities - childcare Accountability falls to other professionals – sense of helplessness? Boundaried – separate home/ work life – a balance? Healthy factors to support wellbeing. (Lines 144-146) support in personal and professional life – buoyant

Appendix J: List of search terms with Boolean operators

children's hospice.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
paediatric hospice.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
p?ediatric hospice.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
child hospice.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
(child and young people's hospice).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice staff experience*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
Hospice staff experience.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice experience.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice staff practice.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice staff involvement.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice staff relationship*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
p?ediatric hospice social worker.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
palliative care social worker.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice social worker wellbeing.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism

supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice social worker health.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice social worker.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
child hospice social work.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
social worker wellbeing.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
social worker health.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
social worker welfare.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
paediatric social worker.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
children's social worker.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
1 and 6
1 or 7
1 or 8
1 and 8
1 or 6
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1 or 10
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1 and 22

1 or 22
2 or 6
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2 and 12
2 or 13
2 and 13
staff experience.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
hospice staff.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
1 or 63
2 or 16
2 and 16
2 or 18
2 or 19
1 or 62
1 and 62
2 or 62
2 and 62
2 or 63
2 and 63
3 or 16
3 or 62