Exploring the Experiences of Hospice Healthcare Workers Caring for Adolescents and Young Adults with Advanced Cancer: An Interpretative Phenomenological Analysis

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

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Thesis Abstract

Title

Exploring the Experiences of Hospice Healthcare Workers Caring for Adolescents and Young Adults with Advanced Cancer: An Interpretative Phenomenological Analysis

Background and aim

Adolescents and young adults living with advanced cancer are a distinct population who require specialised care from healthcare workers. A thematic synthesis was conducted to conceptualise better the emotional experiences of healthcare workers who care for children and young adults living with life-limiting illnesses. The thematic synthesis resulted in eight descriptive themes and three analytic themes and highlighted that little is known about the experiences of hospice healthcare workers who care for adolescents and young adults. The aim of this study is to understand the lived experience of hospice healthcare workers who provide palliative care to adolescents and young adults living with advanced cancer.

Methods

This study was underpinned by interpretivism and constructivism. An interpretative phenomenological analysis was adopted, and phenomenology, hermeneutics, and idiography informed this methodology. Hospice healthcare workers from four paediatric hospices across Canada were recruited through purposive sampling. Semi-structured in-person interviews took place, and all interviews were transcribed verbatim. Interpretative phenomenological analysis was used to analyse all of the data.

Findings

Eighteen hospice healthcare workers participated. Two superordinate themes were generated – first, balancing on the tightrope of uncertainty and second, acting as a proxy. The superordinate theme, balancing on a tight and rope, the subordinate themes were related to healthcare workers doing their best and being heroes, with an emphasis on uncertainty and the fear of failure. This theme also focused on the role that time does not play in the development of attachments and the role that healthcare workers play in decision-making. There was a focus on healthcare workers taking the path of least regret while sometimes having to be uncomfortable with the decision being made. Within the second superordinate theme, acting as a proxy, the subordinate themes were focused on the importance of having honest and transparent conversations and the cycle of protection between adolescents and young adults, families, and healthcare providers. This theme also highlights the role that hope plays when caring for this population. The experiences of adolescents and young adults dying in a hospice versus a hospital are also discussed.

Conclusion

Within the subordinate themes there is a need for, or call to, action. The themes within this study demonstrate this action-focused orientation: the need to do and the need to

protect. Through this notion of doing and protecting, the hope for a good death, an exploration of decision making and building relationships, understanding the transitional hero narrative and advance care planning is imperative when supporting adolescents and young adults. .

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Glossary of Key Terms

adolescents and young adults	The World Health Organization describes adolescence as ages 10-19 and young adults as 19-24 (World Health Organization, 2021; Singh, Shirali, Chatterjee, Adhana, & Arora, 2016).
hospice healthcare workers	Paid healthcare professionals who work in an in-patient hospice setting.
advanced cancer	Cancer in which there are no curative options and cancer that cannot be controlled through treatment, also known as terminal cancer and end-stage cancer (NationalCancerInstitute, 2021).
In-patient paediatric hospice care	A facility which provides in-patient hospice palliative care to children, adolescents and young adults ages 0-19 living with life-limiting illness. Respite care and hospice care is provided through an interdisciplinary healthcare team.
Emotions	Physical arousal, mental perceptions and interpretations, based on feelings (Scheer, 2012). Emotions also include behaviour, cognitive and psychological changes and non-verbal expressions (Mordka, 2016).

Chapter One: Introduction

1.1 Background

Caring for adolescents and young adults dying from an advanced illness is a distinct experience. Adolescence and young adulthood are a time of emotional, social, and physical growth. However, when an adolescent or young adult is diagnosed with a life-limiting illness, it impacts their identity, relationships, and psychological, social, and cognitive development (Clark & Fasciano, 2015; Zebrack et al., 2013). The illness diagnosis may impact the usual growth of adolescents and young adults becoming more independent: The diagnosis of advanced illness causes further dependence on parents, disruptions in social lives, work, and school, and planning for the future is often distressing (Zebrack et al., 2013). Research into and about this population is essential, given their particular needs and their life phase (Pritchard, Cuvelier, Harlos, & Barr, 2011).

The care provided to adolescents and young adults with an advanced, life-limiting illness is often provided within paediatric palliative care services. Paediatric palliative care is an interdisciplinary approach to care for children, adolescents, and young adults living with life-limiting and life-threatening illnesses, supporting the physical, emotional, spiritual, and social needs of the patient and their families (Bergstraesser, 2013; Liben, Papadatou, & Wolfe, 2008). Paediatric palliative care begins from the moment of diagnosis, continuing through the trajectory of illness regardless of curative intent (World Health Organization, 2021). Paediatric palliative care is provided by physicians, nurses, personal support workers, social workers, child-life specialists, music and art therapists, and other healthcare disciplines (Cyr & Maisonneuve, 2015; Vadeboncoeur, Splinter, Rattray, Johnston, & Coulombe, 2010; Widger et al., 2016). Although there has been an increase in research in paediatric palliative care and paediatric end-of-life care, little is still known about healthcare workers who support adolescents and young adults living with advanced cancer (Nukpezah, Khoshnavay, Hasanpour, & Nasrabadi, 2021; Stevenson, Achille, & Lugasi, 2013; Tutelman, Drake, & Urquhart, 2019; Widger et al., 2007). To understand the care provided to adolescents and young adults, the experiences of healthcare providers must be understood.

The stage of adolescence: Oscillating between childhood and adulthood. A time of independence and autonomy

The stage of adolescence has been compared to a caterpillar transforming into a butterfly, a time of metamorphosis with major developmental milestones (Kapur, 2015). These developmental milestones are physical, emotional, mental, economic, and sexual, which often causes oscillation between childhood and adulthood (Havighurst, 1972; Parron, 2014). Understanding the wavering between two life stages that adolescents and young adults experience has been described as the concept of liminality (Charon & Montello, 2002). Liminality is related to uncertainty and worry due to the transitions in adolescence and young adulthood and their social position (Tierney et al., 2013). Autonomy and independence play a fundamental role in fostering the growth of these milestones as adolescents are at a stage in their lives where they become dependent from their parents (Dickey & Deatrick, 2000). Emotional, financial, and social dependence are transitions that adolescents and young adults experience, and these changes are often difficult (Sisk, Canavera, Sharma, Baker, & Johnson, 2019). The ability to make informed decisions is multifaceted (Dickey & Deatrick, 2000). Decision-making is dependent on multiple factors; both ethical and legal, as questions around adolescents' ability to engage in meaningful participation around their needs must always be considered (Chenneville, Sibille, & Bendell-Estroff, 2010). Parental support is vital when looking at autonomy, consent, and maturity outside of age should be considered as all adolescents develop differently.

1.2 The epidemiology of palliative care internationally for adolescents and young adults

The leading cause of death among adolescents and young adults is injury-related; however, the number one disease-related cause of death is cancer (Cunningham, Walton, & Carter, 2018; Nass et al., 2015). Among Danish and Canadian adolescents and young adults, cancer is the leading cause of non-accidental death and, in France the third leading cause of death (Cohen-Gogo et al., 2011; Dang-Tan et al., 2008; DePauw, Rae, Schacter, Rogers, & Barr, 2019; Desandes, Lacour, & Clavel, 2016; Wiener et al., 2012). This cause of death is similar for adolescents and young adults living in other high-income countries (Barr, Ferrari, Ries, Whelan, & Bleyer, 2016; van der Meer et al., 2020). In 2020 in the United States, 16,850 children under the age of 20 were diagnosed with cancer; death was expected for 1,730 of those diagnosed (Pyke-Grimm, Fisher, Haskamp, Bell, & Newman, 2021). Each year in Canada, 2,500 adolescents and young adults are diagnosed with cancer (DePauw et al., 2019). Adolescents and young adults account for approximately 2% of patients with a diagnosis of cancer (Ellison, De, Mery, & Grundy, 2009). Globally in 2018, 6.8% of all cancer cases were among adolescents and young adults (Trama, Botta, & Steliarova-Foucher, 2018).

Adolescents and young adults dying from cancer is rare compared to adults and supporting adolescents, and young adults who are dying is difficult (A. Bleyer, Choi, Fuller, Thomas Jr, & Wang, 2009; Tibi-Lévy, Le Vaillant, & de Pouvourville, 2006). In North America, 30% to 40% of the cases seen by paediatric palliative care medical teams are cancer-related (Siden, 2018). Yet, adolescents and young adults living with cancer have been described as a 'lost tribe' with no foundation of care in the paediatric or adult world (Burgers et al., 2021). When death is imminent, adolescents and young adults face development challenges that require special consideration (Bell, Skiles, Pradhan, & Champion, 2010). This population is less likely to access cancer services for medical and psychosocial care than any other age group (Bleyer, 2002).

1.2.1 Adolescents and young adults living with cancer

Young adulthood has been described as a time of excitement and challenge for adolescents and young adults as they transition from childhood into adulthood (Evan & Zeltzer, 2006). This stage of life comes with increased autonomy, independence, and developmental changes (Rahman, Nazri, Lee, Shamsuddin, & Yaakup, 2015). This stage of life is considered physically, spiritually, emotionally, and sexually complicated for adolescents and young adults (Wiener et al., 2012). Adolescents and young adults living with cancer are confronted with medical challenges while balancing developmental, emotional, psychological, cognitive, physical, and social transitions (Abdelaal et al., 2021; Baker et al., 2008; George & Hutton, 2003; Humphrey & Dell, 2015; Smith et al., 2013). Developmentally, cognitively, and socially, cancer impacts the ability for autonomy and to form intimate relationships, complete education, find employment, start a family, and have financial independence (Burgers et al., 2021). Physically, emotionally, and psychologically, cancer impacts body image and fertility, causes loneliness and isolation, and forces an early confrontation with mortality (D'Agostino, Penney, & Zebrack, 2011; Zebrack et al., 2013). Dealing with these issues compounded with transitioning to adulthood and coping with cancer is difficult (Cheung & Zebrack, 2017).

Adolescents and young adults are a distinct population whose care crosses two domains of care: paediatric and adult palliative care services (Pritchard et al., 2011; Saloustros et al., 2017). Adolescents under the age of 18 receive paediatric palliative care, and anyone older than 18 receives adult palliative care (Pritchard et al., 2011). At times transitioning from childhood to adulthood is an essential part of the human life cycle, and when living with advanced illness, transitions and development into adulthood can be challenging (Davies, Kelly, & Hannigan, 2015). This population's social and emotional needs are complex, and depending on the maturity of the adolescents and young adults, their health needs vary in terms of dependence and independence (Pritchard et al., 2011). Adolescents and young adults living with the illness have higher psychosocial and medical needs than children and adults, and these needs are not well addressed within either paediatric or adult palliative care services (Abdelaal et al., 2021; Fernandez et al., 2011; Pritchard et al., 2011). The lack of support for adolescents and young adults is attributed to this population being cared for in two systems – the paediatric and the adult world (Phillips, 2009).

Adolescence living with cancer has been described as being two stages, one being the transition to adulthood and the second being living with illness (Marshall, Grinyer, & Limmer, 2019). This population are at risk of emotional and psychosocial suffering attributed to dealing with these two transitional periods (Marshall et al., 2019; Thompson, Palmer, & Dyson, 2009; Trevino, Maciejewski, Fasciano, & Prigerson, 2011). There are multiple experiences that adolescents and young adults encounter throughout their cancer journey (Wilkins, D'Agostino, Penney, Barr, & Nathan, 2014). Through these experiences, a sense of imbalance, uncertainty, and confusion is often felt (Wilkins et al., 2014). The oscillating between child and adult has been described as challenging when transitioning to different care settings (Tierney et al., 2013). As adolescents experience cognitive and socioemotional development, their parents work towards a new relationship where they become independent and gain autonomy to make decisions (Butner et al., 2009; Steinberg & Silk, 2002). Autonomy has been viewed as playing an important role in oscillating; however, autonomy is often overshadowed by parents making decisions due to the cancer diagnosis (Tierney et al., 2013). The conceptualisation of dual liminality helps understand what adolescents are navigating through while living with cancer and also trying to balance autonomy, independence and consent (Marshall et al., 2019).

1.2.2 Adolescents and young adults living with advanced cancer

The cancer diagnosis often occurs at a challenging time when adolescents and young adults are at a stage of developing themselves and making a place for themselves in the world (Chen, Parmar, & Gartshore, 2014; Shaha & Bauer-Wu, 2009). Advanced cancer among this population impacts financial, social, and emotional dependence, higher academic goals and disruptions of achieving these goals, settling down, risk of infertility, autonomy around decision making, and developmental growth (Sisk et al., 2019). Adolescents and young adults fluctuate between independence and dependence while attempting to settle in a new world, although they are living with advanced illnesses (George & Hutton, 2003). Adolescents and young adults plan their lives uncertain about the future, with the knowledge that they will eventually die from their disease (Lundquist & Berry, 2019).

Adolescents and young adults have been described as an underserved and vulnerable population (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Phillips, 2009; Phillips, Haase, Broome, Carpenter, & Frankel, 2017; Smith et al., 2013). Social supports have been described as helpful in improving the quality of life of adolescents and young adults with advanced cancer; however, not many of these supports are available (Pritchard et al., 2011; Trevino, Fasciano, Block, & Prigerson, 2013). When finding ways of coping with the impacts of cancer, however, adolescents and young adults are hesitant about expressing their emotions to healthcare workers and try hard to maintain as much normalcy as possible (Lau et al., 2021; Lundquist & Berry, 2019). As maintaining normalcy is vital to this population, finding ways of addressing the stigma of accessing supports is important (Trevino et al., 2013).

1.2.3 The provision of paediatric palliative care for adolescents and young adults

Within the provision of paediatric palliative care, there is no equitable access across countries to this type of care. Paediatric palliative care is provided in various settings, including hospitals, outpatient units, free-standing hospices, and the patient's home (Boucher, Downing, & Shemilt, 2014). In the development of paediatric palliative care, Canada, the United Kingdom, Germany, and Australia have been leaders in growing these programmes (Ando, Nabetani, Yotani, Rin, & Sano, 2017; Cadell, Davies, Siden, & Steele, 2008; Gethins, 2012). In Canada in 2002, there was one free-standing paediatric hospice and seven hospital-based programs (Widger et al., 2016). There are now six paediatric hospices across Canada and 17 paediatric oncology centres (Pole et al., 2017). In 2012, 60% of children who received palliative for the last year of life received care within a free-standing hospice (Widger et al., 2016). In the United Kingdom in 2012, there were 44 free-standing paediatric hospice care homes, with 10% of the patients being served living with some form of cancer (Gethins, 2012). Within Asia, however, much of the continent does not have adequate paediatric palliative care programmes; the first paediatric hospice opened in Japan in 2012 (Ando et al., 2017). Equitable access to paediatric palliative care depends on whether the country is a high-income or low-income country, with low-income countries having less access to this type of care (Ando et al., 2017).

1.2.4 The provision of paediatric palliative care in Canada

This study is being conducted in Canada; therefore, it is important to understand the Canadian context. Canada has a current population of approximately 38.6 million people (Statistics Canada, 2022). In Canada, there are ten provincial and three territorial governments, and healthcare is a publicly-funded system that provides universal healthcare to all citizens (Bielska, Hampel, & Johnson, 2012). Provincial and territorial taxes fund 85% of healthcare, and 15% is covered by the federal government (Bielska et al., 2012). The Ministry of Health for each province and territory provides the direction for the primary jurisdiction over each healthcare system (Bielska et al., 2012).

In Canada, palliative care is delivered primarily in hospitals, where most Canadians die (Canada, 2019). In 2018, there were 88 free-standing in-patient hospices across Canada. Currently, across Canada, there are 13 paediatric palliative care programmes within a hospital setting and six free-standing in-patient paediatric hospices (Canadian Hospice Palliative Care Association, 2021). The in-patient paediatric hospices are located in the country's largest cities: Vancouver, Calgary, Toronto, Ottawa, and Montreal. Given that Canada is a multicultural country, the population served at each hospice is quite diverse and indicative of the community it supports. Hospitals across the country receive 100% funding, while the funding for each in-patient hospice differs depending on the province they are located in, as each province has their own healthcare system. In-patient hospices rely on donations and community support, as no hospice in Canada receives full funding from the government. Given the small number of in-patient paediatric hospices across Canada, additional paediatric hospices are needed. There are no in-patient paediatric hospices in Eastern Canada or the smaller cities and towns as in-patient paediatric hospices are only located in four of the ten provinces across the country. There are also no in-patient hospices specialising specifically in adolescents and young adults, resulting in this population being supported in both child and adult care facilities. Large parts of the country have no access to in-patient paediatric hospice care due to geographic availability (Widger et al., 2007). Hospice palliative care within Canada depends on where an individual lives creating equitable assess issues.

From 2002 to 2012, the number of children who received specialised paediatric palliative care in Canada increased; however, approximately 81% who would have benefitted from this care did not receive it (Widger et al., 2016). In 2012, 51% of children received specialised paediatric palliative care only 30 days before death (Widger et al., 2007; Widger et al., 2016). There is considerable variability provincially, and care provision depends on rural and urban settings (Fernandez et al., 2011). Coordinated paediatric palliative care programmes can improve quality of life and provide holistic support in the hospital, home, or hospice setting; however, equitable access is needed to improve care provision (Vadeboncoeur et al., 2010).

Within Canada, a limited number of programs and policies are specific to adolescents and young adults. There is also limited data on the needs of adolescents and young adults regarding palliative care. However the place of death indicator tells a story of how the palliative care needs of this population are not being met (Canadian Partnership Against Cancer, 2017). Less than 20% of adolescents and young adults living with cancer die at home, as most die in hospitals despite the desire to die at home (Canadian Partnership Against Cancer, 2017). The Canadian Task Force on adolescents and young adults with cancer was developed in partnership with the Canadian Partnership Against Cancer and the Canadian paediatric cancer centres in 2008 (Canadian Partnership Against Cancer, 2017). In 2019, a Canadian framework for the care of adolescents and young adults with cancer was developed through the Canadian Partnership Against Cancer (Canadian Partnership Against Cancer, 2019). This is because adolescents and young adults are described as a missed population who often receive palliative care too late in their trajectory of illness (Canadian Partnership Against Cancer, 2019). The purpose of this framework was to initiate future policies to ensure that this population has access to services and care that is appropriate to their needs based on best practices (Canadian Partnership Against Cancer, 2019). In 2014, the Princess Margaret Cancer Centre located in downtown Toronto established an oncology adolescent and young adult clinic focusing on fertility, coping with cancer, education, sexual and physical health and survivorship consisting of a medical team that works closely with psychosocial support and rehabilitation (Abdelaal et al., 2021). Each year approximately 750-800 adolescents and young adults are supported. Through this clinic, a gap was identified regarding the mental health and symptom management of this population living with advanced cancer. In 2017, an adolescent and young adult clinic specialising in advanced cancer, palliative care and psychiatry were established, the first of its kind in Canada (Abdelaal et al., 2021). Through the programs and services offered, significant impacts have been made on adolescents and young adults, and this program also highlights a need for more clinics like this across the country (Abdelaal et al., 2021).

In-patient admissions to most hospital-based paediatric care centres in Canada have age limitations of 16-18 as these ages are viewed as transitional ages to adulthood (De et al., 2011). The in-patient hospices are funded to support individuals up to a certain age; however, they often make exceptions and support adolescents and young adults who are older than 18 when they have been receiving care at the hospice to avoid transitions of care. When transitioning from paediatric care to adult care, collaboration amongst both teams is imperative (Greenberg, Barr, DiMonte, McLaughlin, & Greenberg, 2003). For the in-patient paediatric hospices across Canada, the support for adolescents and young adults is limited, and Canada would benefit from additional support (Klopfenstein, Hutchison, Clark, Young, & Ruymann, 2001; Whiteson, 2003).

1.2.5 Healthcare workers' role in caring for adolescents and young adults

Within the adolescent and young adult population, healthcare workers manage disease progression and support imminent death (George & Hutton, 2003). Healthcare workers manage pain and symptoms to ensure that adolescents and young adults have a 'good death' (Taylor, Barton, Kingsley, Heunis, & Rosenberg, 2020). Healthcare workers define a 'good' or 'bad' death based on the experiences of adolescents and young adults, and families (Taylor, Barton, Kingsley, Heunis, & Rosenberg, 2020). Death is considered good when suffering is decreased for adolescents and young adults and their families (Chong, Walshe, & Hughes, 2021). Healthcare workers should understand the biopsychosocial demands and transitions when supporting advancing illness and imminent death (Sisk et al., 2019).

Family involvement has been identified as challenging for healthcare workers supporting adolescents and young adults (Avery et al., 2020). Healthcare workers often witnessed family members not considering the viewpoints of their child and imposing their own opinions on their child’s care despite the child being able to decide on their own (Avery et al., 2020). This paternalism was described as difficult for healthcare workers as there were barriers and conflicts to their approaching topics like palliative care (Avery et al., 2020). From the adolescent and young adult perspective, there were times when healthcare workers would direct all questions and information to their families, resulting in them not feeling involved in their own care decisions (Gessler et al., 2019). Parents and healthcare workers need to treat adolescents and young adults as if they are in control and responsible for their care, as there was a tendency at times for healthcare workers to take on that parental role as well (Gessler et al., 2019). Families doing such things as sitting behind the adolescent and young adult as a way of illustrating their support and not taking the lead or healthcare workers directly speaking to the adolescent and young adult helped support an inclusive environment, which did not take away from the autonomy of the adolescent and young adult and respected the support of families (Gessler et al., 2019). Although challenging at times, it is important for healthcare workers to build strong relationships with families to provide support and guidance regarding end-of-life expectations (Taylor et al., 2020).

1.2.6 The emotional impact of caring on healthcare workers

Caring for adolescents and young adults has been described as emotionally taxing, with risks of emotional burnout underpinned by a sense of failure (Avery et al., 2020; Berger, Thompson, & Joubert, 2019). The anguish of supporting this population resulted in healthcare workers limiting the number of adolescents and young adults they supported to emotionally protect themselves (Avery et al., 2020). Emotional proximity was described when healthcare providers related to the adolescent and young adult whether through their age or by reflecting on their own experiences (Avery et al., 2020). The emotional proximity to adolescents and young adults resulted in difficulty caring for this population (Avery et al., 2020).

For many paediatric healthcare workers, when their patient is diagnosed with cancer and finding a cure is no longer an option, many emotions are experienced, including social, ethical, and existential issues related to impending death (Abdelaal et al., 2021; Avery et al., 2020; Johnston et al., 2017; Yoshida et al., 2014). The uncertainty of prognosis, communication, lack of collegial support, relationships with families, interinstitutional acceptance of care, information sharing, and conflicts with personal values and beliefs caused increased stress to healthcare workers (Hill et al., 2020). Due to the high levels of suffering and death, healthcare workers are at an increased risk for poor mental health and work-related stress (Bowden et al., 2015). There is a high burnout rate of healthcare workers supporting this population, as their emotional and mental needs are often missed (Pritchard et al., 2011). Healthcare workers often express feelings of loss, trauma, sadness, tragedy, and shock when caring for this population (Avery et al., 2020). They tend to experience increased emotional and personal deterioration due to balancing the need to do more and coming to terms with imminent death (Kenten et al., 2019). Understanding the emotional experiences of healthcare workers who support paediatric palliative care is important to understand how care is provided to adolescents and young adults. Given that there is little research on understanding the emotional experiences of healthcare workers who support adolescents and young adults with advanced cancer, the decision was made to interrogate emotions within the broader space of paediatric palliative care (Avery et al., 2020; Berger et al., 2019; Tutelman et al., 2019).

1.3 Researcher reflexivity

Having a social work background and working in the field of palliative care for the past 16 years, I have an in-depth knowledge of the provision of palliative care in Ontario. However, my experiences related to the phenomenon being explored is limited. Throughout this process, I was aware of the power and privilege that comes along with the knowledge and positions that I hold. I am a Senior Director of a long-term home and a community programme and an Executive Director of an adult in-patient hospice in Toronto, Canada. I am also an educator for various hospices across the province and a member of the board of directors of a community-based hospice programme in Toronto. I also sit on the accreditation review panel for Hospice Palliative Care Ontario. I am interested in researching the adolescent and young adult population as, over 10 years ago I had the privilege of supporting my first adolescent. Upon reflection, I realised that our needs as healthcare providers were never recognised, and many of the needs of these adolescents and young adults were complex and harder to meet. Reflecting on this case, the adolescent and young adult population became of great interest to me.

While obtaining my Master of Social Work, I was introduced to the work of Foucault. This challenged me to think more deeply about how I come to know what I know and critically look at the relationship between knowledge and power. Foucault viewed power as a constructive network that runs through the social body (Coopey & McKinlay, 2010). Foucault, therefore, challenged the nature of power and the power entrenched within knowledge (Wang, 1999). How individuals interpret, and experience reality is influenced by power, and therefore power should function by not imposing it on another (Wang, 1999). As Foucault placed subjectivity in the middle of power, it was important that throughout this study, I acknowledge the significance of this and the role that power played in my research (Wang, 1999). It is vital that I recognise the intersections of power and knowledge, coupled with my experience of working in palliative care.

Reflexivity is rooted in interpretivism, which was congruent with the philosophical underpinnings of this study. Understanding reflexivity's focus on the iterative evaluation of self was imperative throughout this research process (Shaw, 2010). Reflexivity allows for a holistic approach, in which the relationship between the researcher and the research are addressed (Shaw, 2010). During this process and throughout the data analysis process, I needed to practise reflexivity to ensure my personal biases and assumptions were managed. Looking inward allowed me to continuously do a self-check-in throughout the research process.

1.4 Overview of the thesis

This thesis is made up of 6 chapters. Tables and figures are used to explain the research process further. The references and appendices can be found at the end of the thesis.

Chapter One: Introduction

Here in Chapter One, the literature on paediatric palliative care of adolescents and young adults living with cancer with a focus on healthcare workers who care for this population is presented. The researcher's background is provided and a glossary of key terms.

Chapter Two: Literature Review

In this chapter, a thematic synthesis systematic review is presented (Thomas & Harden, 2008). This systematic review was conducted to contextualise better the emotional experiences of healthcare workers who care for children and young adults living with a life-limiting illness.

Chapter Three: Methodology and Methods

Within this chapter, the methodology that underpins this study is discussed. as well as the methods and ethical considerations. Constructivism and interpretivism provided the philosophical foundation of this study (Creswell, 2013; Willis, 2007). Interpretative phenomenological analysis was used in this study, which is informed by phenomenology, hermeneutics, and idiography (Smith, 2011).

Chapter Four: Findings

In this chapter, superordinate and subordinate themes are presented.

Chapter Five: Discussion

Within this chapter, the research findings are discussed in relation to theory and broader literature.

Chapter Six: Conclusion

In this chapter, the strengths and limitations of the study, policy implications, contributions to knowledge, recommendations for future research, and personal reflections are presented.

Chapter Two: Review of the Literature

2.1 Introduction

The aim of this review was to answer the following literature review question: “What are the emotional experiences of hospice healthcare workers who care for children and young adults living with a life-limiting illness?”. Although this study was focused on adolescents and young adults, I wanted to explore this in a broader context. Most adolescents and young adults are supported in paediatric settings and healthcare workers care for children, adolescents, and young adults. Limited research focuses specifically on the emotional experiences of healthcare workers who care for this population. Whilst the focus of the empirical work was expected to be the care of adolescents and young adults, there were concerns that existing research might largely address the care for all those cared for in paediatric settings. It was decided that looking broadly at the caring experience may help better contextualise the care for adolescents and young adults alongside what it is like caring for children to identify the broader research gaps. To ensure accurate reporting, the ENTREQ (enhancing transparency in reporting the synthesis of qualitative research) guidelines were used (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

2.2 Review methodology

Given that the purpose of this review is to understand the emotional experiences of healthcare workers who care for paediatric patients, a few key features of the systematic review approach were important in selecting a review method. Given the focus on lived experiences, it was important that a review method that demonstrated utility for qualitative research needed to be selected. The second key feature was a method that supported the synthesis of the literature to support an in-depth collective understanding of this phenomenon. The third element was to use a review method that supported the translation of concepts between various studies to gain an overarching understanding of how emotions are experienced (Thomas & Harden, 2008). Table 2.1.1 illustrates the methods that were considered for this review.

Table 2.2.1 Methods reviewed table

Method	**Method details**	**Suitability for this review**
Critical interpretative synthesis	Based on qualitative inquiry, this method synthesises literature and, through explanatory power, allows for the generation of theory (Dixon-Woods et al., 2006).	Meets the key element of being a qualitative review; however, the purpose of this review is not to generate a theory as the focus is on understanding experiences.
Meta-ethnography	A 7-step process with an aim of comparison and interpretation from one study to another (Britten et al., 2002; Noblit & Hare, 1988). This review is focused on understanding metaphors, which involves induction and interpretation with the aim of synthesis (Britten et al., 2002; Sandelowski, Voils, & Barroso, 2006)	Although this review method does not have to be used on ethnographic studies only, its focus on metaphors and the transferring of concepts and ideas did not fit with the aim of this review (Britten et al., 2002).
Narrative synthesis	The aim of this review is a focus on the development of a narrative summary of the findings (Cruzes, Dybå, Runeson, & Höst, 2015)	The focus of this review was not to create a narrative; it was to gain an understanding of experiences.
Thematic synthesis	A process for identifying, analysing, and reporting analytic themes across a data set (Cruzes et al., 2015). The reporting of findings are done in rich detail to demonstrate meaning and experiences	This review method was congruent with the key elements of this systematic review. Its focus on experiences underpinned by a

	(Cruzes et al., 2015; J. Thomas & A. Harden, 2008)	constructionist method demonstrated good utility for this review.

Thomas and Harden’s thematic synthesis draws on the principles of thematic analysis as well as other approaches to primary qualitative research (Cruzes & Dyba, 2011). The overall purpose of Thomas and Harden’s approach is to answer review questions by developing analytic themes through descriptive synthesis (Cruzes & Dyba, 2011; Snilstveit, Oliver, & Vojtkova, 2012). Thematic synthesis supports a close relationship with each study reviewed, supported the results of each study to be synthesised transparently, and facilitated the development of new analytic concepts therefore was utilised for this systematic review (Thomas & Harden, 2008).

This approach to thematic synthesis is focused on constructing interpretations (Cruzes et al., 2015). This thematic synthesis will be guided by a constructivist ontology and an interpretivist epistemology (Marshall, 2019). To understand the world, constructivist and interpretivist believe that one must first interpret it (Schwandt, 1994). Through this review, the data were interpreted in detail and utilised a constructionist approach, which examines how experiences, meanings, events, and realities impact the emotional experiences of paediatric healthcare workers (Cruzes et al., 2015). This philosophical underpinning is congruent with the methodology of thematic synthesis (Thomas & Harden, 2008).

2.2.2 Inclusion and exclusion criteria

The inclusion and exclusion criteria can be found in Table 2.2.3.

Table 2.2.3 Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Focus: Studies exploring the emotional experience of caring for children and young adults (up to 24 years old) who have a life-limiting condition, or where such data can be disaggregated from a wider study. Life-limiting conditions are defined as illnesses in which there is no cure and death is imminent (Fraser & Parslow, 2018).	Studies with an exclusive focus on neonates or infants, defined as those ≤ 2 years old.
Study designs: Any study design that includes the presentation of qualitative data. Published in a peer-reviewed journal.	Designs that present only quantitative data. Editorials, opinion pieces, grey literature, literature reviews, and dissertations and theses.
Population: Studies reporting the emotional experiences of health and social care workers, or where such data can be disaggregated from a wider study.	Studies that exclusively report on the experience of children, parents, family members, or other informal caregivers.
Language: English-language studies	Non-English-language studies

2.2.4 Approach to searching

Guides to structuring searches for systematic reviews include approaches such as PICO (population, intervention, comparator, outcome) and SPICE (setting, population/perspective, interest, comparison, evaluation), but these are primarily used to guide reviews focused on only quantitative or qualitative evidence (Cleyle & Booth, 2006; Eriksen & Frandsen, 2018). As the focus of this synthesis is on qualitative research or mixed methods in which the qualitative research would be synthesised, a more congruent approach was the SPIDER strategy. Table 2.2.5 provides a brief SPIDER strategy. A more detailed version of the SPIDER search strategy can be found in Appendix 1.

Table 2.2.5 SPIDER strategy literature search terms

S	Sample	Healthcare workers (may include students)
P I	Phenomenon of Interest	Emotional experiences of healthcare workers who care for children and young adults living with a life-limiting illness
D	Design	Interviews, questionnaires, focus groups, case study, observational studies
E	Evaluation	Their experiences
R	Research Type	Qualitative or mixed-method

2.2.6 Data sources and electronic search strategy

An in-depth systematic search was conducted between October 9 and 22, 2020. In consultation with the Lancaster Librarian, it was decided to search the three most relevant bibliographic databases – PsychINFO, MEDLINE, and CINAHL. In combination, MEDLINE, PsychINFO, and CINAHL were used, given their specialised subject database focused on nursing, behavioural science, and allied health (Bramer, Rethlefsen, Kleijnen, & Franco, 2017).

The healthcare worker was the concept, not only the search term. Boolean operators and truncation were used to help focus the search. Age limiters and terms relating to children and young adults were also used to help focus the search.

Abstracts and titles were also searched for each term. The identified search terms and the number of studies identified under each term can be found in Table 2.1.7. A complete search strategy, along with the Boolean operators and truncations, can be found in Appendix 1. No additional search parameters were added in terms of the publication date or country of origin to ensure that as much available evidence as possible was captured.

Table 2.2.7 Search terms and number of studies identified

	Search Terms	**MEDLINE**	**PsychINFO**	**CINAHL**
1	**Healthcare Worker**	996, 249	189, 452	784, 415
2	**Emotions**	1,412,623	130, 519	166,468
3	**Life-Limiting Illness**	169, 985	76, 286	18,664
4	**Child and Young Adults**	3,077,590	158, 381	605, 259
5	**1 AND 2 AND 3**		265	240
6	**1 AND 2 AND 3 (AGE LIMITERS)**	1,222	204	26
7	**5 AND 4**			32
8	**1 AND 2 AND 3 AND 4**	811	11	
9	**6 OR 8**	1,245	203	
10	**7 OR 8**			38

2.2.8 Study screening methods

I screened the titles and abstracts for all studies found to determine suitability against the inclusion and exclusion criteria. The inclusion and exclusion criteria were again used as a guiding factor, and the studies in which titles and abstracts met the criteria were read in full. The final studies identified were sent for verification to preclude any uncertainty via my supervisors.

2.2.9 Quality assessment

Thomas and Harden place importance on quality assessments and state that focus of quality assessments should be on quality issues, quality of the reporting, the sufficiency of the strategies, and assessment of the appropriateness of the study methods (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). All studies were assessed using the Quality Assessment of Research for Thematic Synthesis: Critical Appraisal Skills Programme (CASP) as it encompassed all of the areas of focus that Thomas and Harden explained as important (Thomas & Harden, 2008). The function of the quality assessment was to identify the strengths and weaknesses of each study and determine if it would be included in the review (Thomas & Harden, 2008). The studies were ranked as high quality, when: (a) there was a clear statement of the research aims; (b) there was congruence with the methodology and the research design; (c) data were collected rigorously in a way that addressed the research question; (d) ethical issues were considered; and (e) the findings of the data were sufficiently reported. All of the studies identified reported clear research aims with congruence with the methodology, recruitment, data collection, and analysis. None of the 17 studies had all of the items recommended by CASP. The 2 sections most commonly missed were the consideration of the relationship between the researcher and the ethical considerations. Given that all 17 studies had most of the reported items, which resulted in valuable contributions to research regarding this phenomenon, all of the studies were included in the review. An example of the quality assessments can be found in Appendix 3.

2.2.10 Data extraction and analysis

The data analysis for this review followed the stages of thematic synthesis as outlined by Thomas and Harden. This included a 3-step process, free line-by-line coding, the organisation of the free codes into descriptive themes, and the development of analytic themes (Thomas & Harden, 2008).

2.2.11 Steps one and two: Line-by-line coding and the development of descriptive themes

All the studies were uploaded into NVIVO, which helped with the organisation of the codes and themes. Each line of the findings and, when relevant, the discussion was coded according to its meaning and content (Thomas & Harden, 2008). A bank of codes was created; as new codes were developed, they were added to the bank (Thomas & Harden, 2008).

After all of the codes were developed for each study, the codes were examined to ensure there was the consistency of interpretation and to determine if more coding was needed (Thomas & Harden, 2008). After the codes for each study was developed, they were grouped into descriptive themes. This included reviewing each code for similarities and differences and grouping them into a hierarchical tree structure (Thomas & Harden, 2008).

2.2.12 Step three: The development of analytic themes

This stage of the analysis is based on the insights of the reviewer (Thomas & Harden, 2008). This stage involved going beyond the descriptive themes and developing analytic themes. Through the eight descriptive themes, three overarching analytic themes were generated. From these themes, the analytic themes were developed that described the most prominent aspects of the experiences of healthcare workers who care for children living with a life-limiting illness.

2.2.13 Review results

Throughout the study selection process, 73 of the identified studies were read in full. 25 studies were verified of any uncertainty via independent reviewers. 17 studies were identified. An example of the screening process can be found in Appendix 2. This stage of the data analysis process resulted in 111 codes, which generated eight descriptive themes and three overarching analytic themes.

The PRISMA diagram found in figure 2.2.14 presents the screening process of the studies included in this review. The study characteristics can be found in Table 2.2.1.

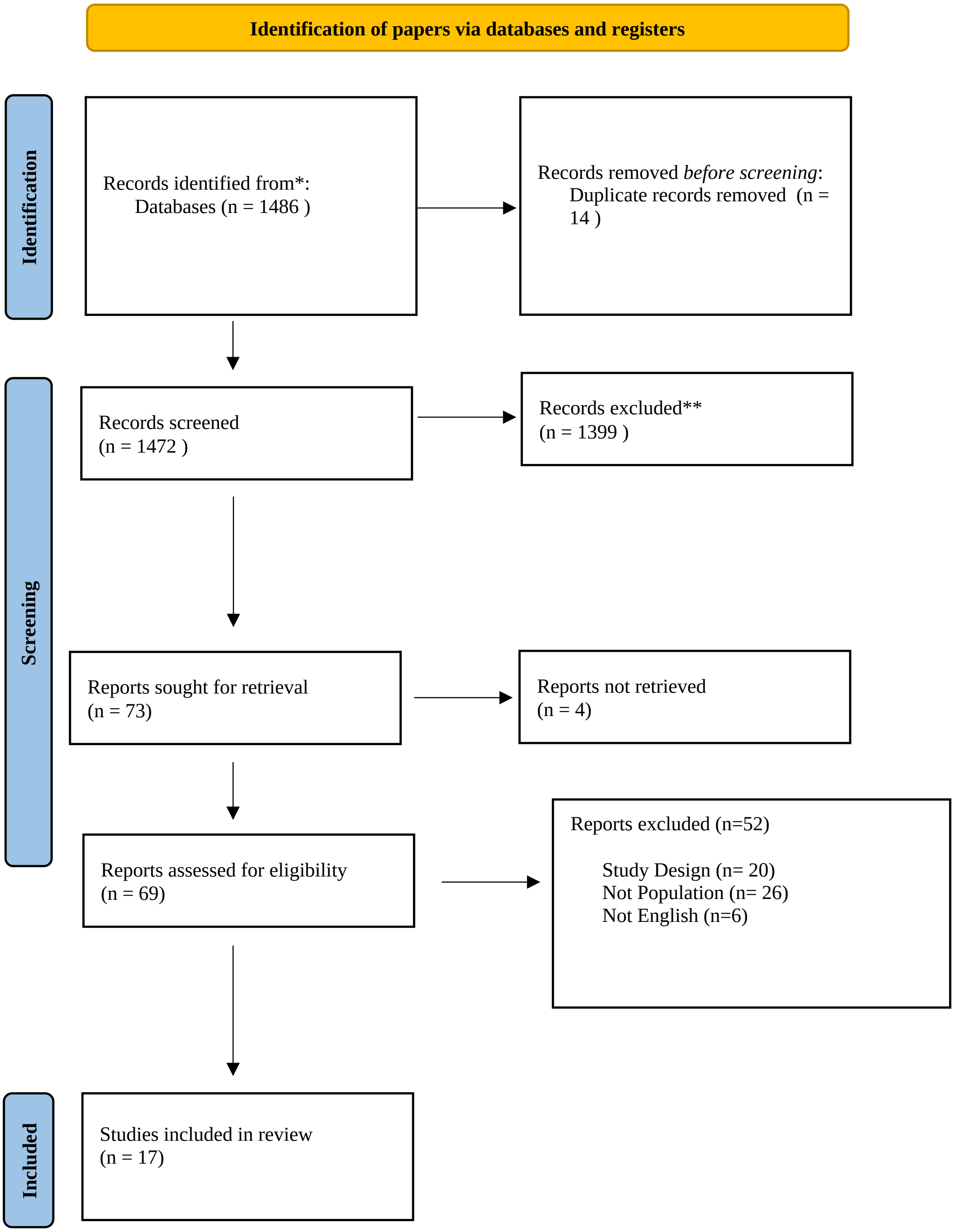

Figure 2.2.14 Literature Review PRISMA Diagram. Adapted from (PRISMA, 2020)

Table 2.2.15 Study characteristics. Adapted from Cooper et al. (2018).

Author and year	**Research question**	**Aim**	**Setting**	**Study population (number recruited)**	**Sampling strategy**	**Data collection method**	**Analysis method/ Conceptual framework**
Henao-Cstano, Quinonez-Mora, 2019	What are the feelings and attitudes towards the death of a child? What attitudes do you have towards the end-of-life care of a child in the PICU? What intervention do you provide a child's family at the end of life?	Explore nurses' coping strategies faced with the death of children in the PICU.	Paediatric intensive care unit in Colombia	10 nurses (n=10)	Convenience	Semi-structured interviews	Hermeneutical phenomenology
Cote, Payot, Gaucher, 2019	Not stated	Explore the challenges of providing paediatric palliative care in the ED and to describe the potential	Paediatric tertiary care centre in Montreal	ED physicians (n=58)	Theoretic	Semi-structured focus groups	Thematic analysis and methods from grounded theory

		roles for the ED in paediatric palliative care by the main services involved in the care of children with medical complexity. To propose concrete solutions to better implement paediatric palliative care in the ED.					
Beaune, Muskat, Anthony, 2018	Not stated	Explore the potential aim for personal growth in non-palliative care while caring for children with a wide range of life-limiting illnesses.	Hospital	9 social workers 8 nurses 8 physicians	Snow-ball	Semi-structured interviews	Thematic analysis
Donohue, Williams, Wright-	Is chronic critical care illness associated	To assess the clinical experience of burnout and	Neo-natal and paediatric intensive care	Physicians, nurses, social workers, and administrativ	Purposive and snowball	Semi-structured interviews	Content analysis

Sexton, Boss, 2018	with caretaker burnout?	clinical perception of family in burnout in caring for children with a chronic critical illness.	units, rehabilitation facilities, outpatient paediatric practices, and community care	e staff of a home healthcare company (n=44)			
Laryionava, Heubner, Hibbemann, Winkler, 2018	Not stated	Understand oncologists' and oncology nurses’ views on treatment decisions with young adult patients with advanced cancer to investigate the extent to which young age was a factor in cancer treatment decisions. To explore possible reasons that may hinder timely decisions and discussions of forgoing	Hospital in Germany	Oncologists (n=22) Nurses (n=7)	Purposive	Semi-structured interviews	Grounded theory

		treatment in young adult patients.					
Hendricks-Ferguson, Sawin, Montgomery, Phillips-Salimi, Haase, 2015	Not stated	To explore the palliative care and end-of-life care communication perceptions of 14 novice paediatric nurses.	3 paediatric hospitals in the US	Paediatric oncology Nurses (n=14)	Purposive	Focus groups	Qualitative empirical phenomenology based on the group-as-a-whole theory
Furingsten, Sjogren, Forsner, 2015	Not stated	To describe caring as represented in healthcare workers' experiences of caring for dying children in general, acute paediatric care settings.	One paediatric ward in Sweden	Registered nurses (n=2) Paediatric nurse assistants (n=2)	Purposive	In-depth interviews	Giorgi and Giorgi phenomenological approach
MacDermott & Keenan, 2014	Not stated	To explore the personal grief experiences of nurses who have cared for a child with an intellectual disability who has died,	Residential and school environment in Ireland	Nurses (n=8)	Purposive	Semi-structured interviews	A pragmatic approach to qualitative data analysis

		with a view to drawing awareness to this area, to potentially enhance the body of knowledge, and to develop a practice to improve this area of care and support.					
Citak, Toruner, Gunes, 2013	What are the communication difficulties of paediatric haematology/oncology nurses with the patients and their families in their care? How do these communications difficulties affect paediatric haematology/oncology nurses? What are the	Explore communication difficulties of paediatric haematology/oncology nurses with patients and their families, as well as their suggestions about communication difficulties.	Paediatric haematology/oncology hospital in Turkey	Paediatric haematology/oncology nurses (n=21)	Voluntarism	Semi-structured interviews	Content analysis

	paediatric haematology/ oncology nurses' suggestions about communication difficulties regarding themselves?						
Pearson, 2013		To explore the experience of nine children's nurses providing palliative care in the acute hospital setting to evaluate current support, educational, and pastoral preparation.	3 primary treatment centres in the UK	Nurses (n=7)	Purposive	Semi-structured interviews	Phenomenology/Strauss and Corbin qualitative analysis
Reid, 2013	Not stated	To highlight some of the challenges perceived by rural adult community nurses when delivering	Community program in Scotland	Nurses (n=10)	Non-probabilistic	Semi-structured interviews	Phenomenological thematic approach/ inductive content analysis

		palliative care to children or young people and their families in the home.					
Cook, Mott, Lawrence, Jablonski, Grady, Norton, Liner, Cioffi, Hickey, Reidy Connor, 2012		To describe and understand behaviours and coping strategies used by paediatric nurses caring for dying children on an in-patient acute care cardiology unit.	Children's tertiary-care centre	Staff nurses (n=17) Nurse practitioners (n=4)	Purposive	Focus groups	Qualitative content analysis
McCloskey, Taggart, 2010	Not stated	To explore the experience of occupational stress from the perspective of nurses contributing to the palliative care of children in	Paediatric hospice community children's nursing team paediatric hospital	Paediatric nurses (n=18)	Purposive	Focus groups	Thematic content analysis

		one region of the UK					
Fanos, 2007	Not stated	Identify early experiences with illness and death in the paediatrician's childhood and adolescence and identify coping strategies to manage the stress of caring for seriously ill children.	University and community hospital private practice pharmaceutical company blood bank no longer practising in paediatric care.	Paediatric oncologists (n=30)	Purposive	Semi-structured interviews	Not stated
Papadatous, Bellali, 2002	What motivates professionals to work with seriously ill children? What challenges do they encounter while caring for dying children? How are they affected by children's death? And	To further explore the grieving process and compare the subjective experiences of physicians and nurses who provide care to children dying of cancer in Greece.	Hospital	Oncologist (n=14) Paediatric oncology nurses (n=16)	Purposive	Semi-depth interviews	Strauss and Corbin qualitative analysis

	what are some of the factors that affect their desire to stay or leave this particular field of work in which exposure to childhood death occurs more frequently than in many other fields of nursing?						
Papadatou, Martinson, Chung, 2001	What motivates professionals to work with seriously ill children? What challenges do they encounter while caring for dying children? How are they affected by children's death? And what are some of the	To explore and compare the subjective experiences of nurses who provide care to children who are dying in an oncology versus a critical care setting in two different cultures.	Hospitals in Athens and China	Oncology and critical care nurses (n=63)	Purposive	Semi-structured interviews	Strauss and Corbin qualitative analysis

	factors that affect their desire to stay or leave this particular field of work in which exposure to childhood death occurs more frequently than in many other fields of nursing?						
Rashotte, Fothergill-Bourbannais, Chamberlain, 1997	What are the physiological, emotional, social, and occupational reactions of paediatric nurses to the death of a child in the intensive care unit? What are the factors related to a child's death that paediatric intensive care nurses perceive	To describe the grief experiences of paediatric intensive care nurses when their patients die.	Paediatric intensive care unit in a hospital in Canada	Nurses (n=6)	Non-probability purposive sampling	Semi-structured interviews	Heideggerian phenomenology/Colaizzi's method of phenomenology for data analysis

	facilitate or hinder their grieving? What are the coping strategies used by paediatric intensive care nurses to deal with their grief when their patients die? Are there developmental phases as identified by the participants through which paediatric intensive care nurses progress in response to their accumulated grief experiences?						

This thematic synthesis included 17 studies from 11 countries. The majority of the studies were located within a hospital setting. Nurses were the most included healthcare discipline, followed by physicians and social workers. Semi-structured interviews was the most common data collection technique used. Table 2.1.16 further describes the characteristics of each study.

Table 2.2.16 Characteristics of included studies (N=17)

Characteristics	**Number of studies ***
Country	
United States	4
Canada	3
United Kingdom	2
Greece	2
China	1
Sweden	1
Turkey	1
Ireland	1
Columbia	1
Scotland	1
Germany	1
Care setting	
Paediatric hospital (3 paediatric intensive care units)	13
Community care	2
School	1
Pharmaceutical company	1
Blood bank	1
Healthcare discipline	
Nurses	15
Physicians	6
Social workers	1
Study population	
Children	14
Adolescents and young adults	3

*1 study took place in two countries; 1 study took place in multiple settings; 4 studies included multiple healthcare disciplines; 2 studies included both children and adolescents and young adults.

2.3 Review findings

This thematic synthesis supported the development of three analytic themes: a rollercoaster of emotions; maintaining an equilibrium; processing grief and accepting death, and eight descriptive themes concerned with the emotional experiences of paediatric healthcare workers who support children and young adults living with a life-limiting illness.

2.3.1 A rollercoaster of emotions

This analytic theme consists of three descriptive themes: a range of emotions, emotional responses to caring, and intimate encounters. When caring for children living with a life-limiting illness, 28 emotions were identified. Stress, helplessness, and guilt were the most prevalent emotions identified; whereas passion, happiness, and trust were the least identified emotions within the analysis (see Table 2.3.2). The emotional responses to caring for this population also include feelings of detachment, emotional regulation, and fluctuation. The intimate encounters centre around relationship building and the emotions involved in building an attachment to patients.

Table 2.3.2: Emotions experienced

Author	Fear	Stress	Helplessness	Anxious	Worried	Suffering	Nervous	Powerlessness	Anger	Distress	Overwhelmed	Frustration	Upset	Sadness	Alone	Guilt	Crying	Rewarding	Gratitude	Passionate	Happiness	Denial	Uncertainty	Trust	Empathy	Hope	Love	Regret
Henao-Cstano, Quinonez-Mora, 2019		X	X														X											
Cote, Payot, Gaucher, 2019			X																									
Beaune, Muskat, Anthony, 2018								X						X				X	X	X						X	X	
Donohue et al, 2018		X	X	X	X					X	X	X				X		X					X			X		
Laryionava et al, 2018		X						X		X		X																
Hendricks-Ferguson et al, 2015		X					X								X	X										X		X
Furingsten, Sjogren, Forsner, 2015	X	X	X			X							X			X	X							X				
MacDermott & Keenan, 2014														X								X						X
Citak, Toruner, Gunes, 2013	X	X	X						X																	X		
Pearson, 2013				X			X			X					X									X				
Reid, 2013		X	X		X						X		X															
Cook et al,, 2012		X														X	X					X			X			
McCloskey, Taggart, 2010	X	X		X					X	X		X																
Fanos, 2007				X	X	X			X																X			
Papadatous et al, 2002		X	X	X				X	X	X	X				X	X	X	X									X	
Papadatou, Martinson, Chung, 2001		X	X													X	X	X						X				
Rashotte, 1997			X					X	X					X	X	X	X				X							X
	3	11	9	5	3	2	2	4	5	5	3	3	2	3	4	7	6	4	2	1	1	2	1	3	2	4	2	3

2.3.3 A range of emotions

Stress was identified as the most prevalent emotion in the studies reviewed. Stress was common when it came to goals of care conversations, ethical conflicts, lack of staffing, supporting a dying child, and when families asked questions that healthcare workers were unable to answer (Donohue, Williams, Wright-Sexton, & Boss, 2018; Laryionava, Heußner, Hiddemann, & Winkler, 2018; Papadatou, Martinson, & Chung, 2001; Reid, 2013). Stress experienced was also related to loss of control; and not being able to alleviate physical distress or not being able to stop the disease from progressing were also examples of loss of control, which resulted in stress (McCloskey & Taggart, 2010; Papadatou et al., 2001). Death was not something that could be controlled and, whether expected or unexpected, was described as causing high levels of stress. Discussions about progressive cancer illness with young adults were described as the most stressful situations within the clinical practice, as not being able to change the course of illness was stressful (Laryionava et al., 2018). Feelings of incompetence, desperation, and exhaustion resulted in stress that healthcare workers often reflected on (Citak, Toruner, & Gunes, 2013). These feelings relate to the concept of being in control, and when control was lost, stress was heightened.

Helplessness and powerlessness were described mainly around not being able to alleviate pain or change the trajectory of a child’s illness (Citak et al., 2013; Henao-Castaño & Quiñonez-Mora, 2019; Papadatou, Bellali, Papazoglou, & Petraki, 2002; Papadatou et al., 2001). The helplessness experienced was focused on not being able to provide quality care based on alleviating suffering and pain. Death resulted in helplessness and powerlessness when a provider was unable to manage the physical and emotional suffering of the patients (Papadatou et al., 2002). When the situation was unchangeable and the healthcare workers had nothing of value to offer their patients, emotions of uselessness were experienced (Henao-Castaño & Quiñonez-Mora, 2019; Papadatou et al., 2002; Rashotte, Fothergill-Bourbonnais, & Chamberlain, 1997). In contrast, one study described helplessness and powerlessness and explained them in a different way; these emotions were described as less of a weakness and more of a strength (Beaune, B. Muskat, & S. Anthony, 2018). Humility was explained as being important in cultivating this strength rather than viewing helplessness as a negative emotion attributed to caring (Beaune et al., 2018).

Nervousness was commonly felt around difficult conversations, uncertainty, imminent death, lack of training and education (Hendricks-Ferguson et al., 2015; Pearson, 2013). Nervousness was attributed to uncertainty, and this was felt in three ways – when supporting adolescents, when death was imminent, and when there was a lack of training (Hendricks-Ferguson et al., 2015; Pearson, 2013). Trepidation was described by healthcare workers in regard to supporting adolescents when they made unpredictable comments (Hendricks-Ferguson et al., 2015). Adolescents were described as having a better understanding of death and at times were more accepting, which led them to be more open to discussing their imminent death (Hendricks-Ferguson. et al., 2015). Healthcare workers felt nervous about saying the wrong thing or not having the right answer when supporting adolescents (Hendricks-Ferguson et al., 2015). The healthcare workers also felt exhausted and incompetent and at times circumvented communication with patients and families (Citak et al., 2013). When death was imminent, healthcare workers felt nervous when going into the rooms of their patients whose breathing had changed and not knowing if they were going to be alive when they entered the room (Pearson, 2013). Nervousness was related to uncertainty, death, and supporting adolescents (Hendricks-Ferguson. et al., 2015; Pearson, 2013).

There was a connection between anxiety, worrying, and suffering and the impacts of caring (Donohue et al., 2018; Fanos, 2007; Henao-Castaño & Quiñonez-Mora, 2019). Healthcare workers often reflected and worried about decisions that were made (Donohue et al., 2018; Reid, 2013). Feelings of constant worry and the emotional impact of taking those worries home were described (Fanos, 2007). Healthcare workers described carrying anxieties beyond their work and the impact that this had on their lives (Henao-Castaño & Quiñonez-Mora, 2019). It was felt that healthcare workers absorbed the distress experienced by families, and this takes a toll on them (Citak et al., 2013; Henao-Castaño & Quiñonez-Mora, 2019). This sometimes came through in intense dreams, which created anxiety (Fanos, 2007). Dreams of patients who had died or dreams of not being able to properly care for their patients and the powerlessness that this caused resulted in anxiety (Fanos, 2007). It was evident that by supporting this population, healthcare workers has difficulty separating their personal lives from their job and took the emotional aspects of their work home, which resulted in anxiety and overall suffering.

Emotions of anger, distress, being overwhelmed, and frustration were described (Cook et al., 2012; Papadatou et al., 2002; Rashotte et al., 1997). Anger was rooted in communication, memory recall, and death (Cook et al., 2012; Papadatou et al., 2002). Reflecting back on conversations with patients and families resulted in anger and frustration (Rashotte et al., 1997). There were times when healthcare workers did not feel as if they had the words to say, which were needed to support their patient or the family, and this caused distress (Pearson, 2013). When reflecting back on things said or memories of a patient's death, distress was experienced (Papadatou et al., 2002). Memory recall prior to death also caused distress when healthcare workers would see photographs of their patients prior to being ill (Cook et al., 2012). Seeing these photographs and the impact of the illness on the patient and their families was difficult (Cook et al., 2012). The past, the present, and the future all resulted in the emotions expressed above, most of which were rooted in death.

Emotions of sadness, grief, aloneness, guilt, and crying were experienced (Furingsten, Sjögren, & Forsner, 2015; Henao-Castaño & Quiñonez-Mora, 2019; Hendricks-Ferguson et al., 2015; Papadatou et al., 2002; Rashotte et al., 1997). Reactions to grief resulted in sadness and withdrawal (Papadatou et al., 2002). These emotions were connected around healthcare workers' need to do their best, the attachments made with patients and families, and the emotions experienced due to young people being robbed of their lives and dying at a young age (Furingsten et al., 2015; Henao-Castaño & Quiñonez-Mora, 2019; Laryionava et al., 2018; Papadatou et al., 2002). It was felt that healthcare workers try their hardest to do their best and when they perceive those efforts as failing, sadness and guilt were experienced (Henao-Castaño & Quiñonez-Mora, 2019). The depth and duration of this sadness often depended on the level of attachment between the patient and family and how visibly and audibly upset the family were at the time of death (Rashotte et al., 1997). When their patients died pain free, there was a sense of relief, which also impacted the duration of sadness experienced (Rashotte et al., 1997). Healthcare workers expressed feeling alone at the time of death in their patients' rooms (Hendricks-Ferguson et al., 2015). Healthcare workers found it difficult to come to terms with a life cut short, and the sadness this caused was described as intense (Laryionava et al., 2018; Papadatou et al., 2002). When all of these emotions were experienced, healthcare workers searched for explanations to make coping with the guilt and the other emotions experienced more tolerable (Papadatou et al., 2002).

Crying was described as a reaction to negative emotions, and the importance of self-regulating crying and the release that comes from crying was described (Furingsten et al., 2015; Henao-Castaño & Quiñonez-Mora, 2019; Papadatou et al., 2002; Papadatou et al., 2001; Rashotte et al., 1997). Crying was often experienced due to sadness, distress, anger, frustration, and guilt (Henao-Castaño & Quiñonez-Mora, 2019; Papadatou et al., 2002; Papadatou et al., 2001). Guilt was experienced in two ways: when a child died and healthcare workers felt as if they could have done more; and the guilt of not crying when a child died (Cook et al., 2012; Henao-Castaño & Quiñonez-Mora, 2019). The guilt of not crying when a child died was related to the connection between crying and maintaining control (Pearson, 2013; Rashotte et al., 1997). There was an importance placed on being able to control crying and needing permission to cry (Pearson, 2013; Rashotte et al., 1997). Some healthcare workers found it easier to laugh and be in control rather than crying and losing control (Pearson, 2013; Rashotte et al., 1997). On the contrary, crying was also viewed as a release, which was a natural reaction to sadness, and displaying emotions was explained as being an important part of coping (Furingsten et al., 2015). There were both a sense of control and a sense of relief that came from crying, and therefore finding a balance was viewed as important (Furingsten et al., 2015; Pearson, 2013; Rashotte et al., 1997).

Outwardly controlling emotions was related to losing control and maintaining control. It was viewed as a coping mechanism or as a weakness (Furingsten et al., 2015; Pearson, 2013; Rashotte et al., 1997). There was a need for healthcare workers to be able to separate and maintain distance between professional and personal boundaries as a way of protecting themselves (Pearson, 2013; Rashotte et al., 1997). It was found that healthcare workers needed support when coping with emotions, either through clinical reflection or debriefing as a team (Pearson, 2013). Given that team members' views towards outwardly expressing emotions differed, having these team debriefs were important (Furingsten et al., 2015).

Emotions were experienced related to the personal rewards that come from supporting this population (Beaune, Muskat, & Anthony, 2018; Donohue et al., 2018; Papadatou et al., 2002; Papadatou et al., 2001). There was a sense of reward and satisfaction felt when supporting this population (Beaune et al., 2018; Donohue et al., 2018; Fanos, 2007; Papadatou et al., 2001; Reid, 2013). Healthcare workers felt that although their job was difficult, it was also meaningful and unique in comparison to other units within the hospital (Papadatou et al., 2001). The rewards of their job resulted in healthcare workers feeling proud of telling others where they worked, as there was a perception that it is all sad (Beaune et al., 2018). The two factors that impacted healthcare workers wanting to continue doing this work were the meaning, which came from ensuring their patients died with dignity, and the nature of the work, which came from the relationships built with patients and families (Papadatou et al., 2001).

There were positive emotions experienced when supporting this population, which resulted in feelings of gratitude and hope (Papadatou et al., 2001). There was a sense of contribution felt towards ensuring that a child had a dignified death (Papadatou et al., 2001). It was also felt that when dealing with life and death issues, witnessing the strength of their patients evoked personal feelings of hope, inspiration, and privilege (Beaune et al., 2018). Observing this also led healthcare workers to experience gratitude for their health and the health of their children (Beaune et al., 2018).

2.3.4 Emotional responses to caring

Feelings of burnout were common among healthcare workers caring for this population. Death, time, and experience were described as attributing to burnout (Citak et al., 2013; Donohue et al., 2018; Furingsten et al., 2015; Papadatou et al., 2002). Burnout was attributed to patients dying (Donohue et al., 2018; Papadatou et al., 2002). The memory of the first death or cardiac arrest of their patient often impacted how they coped and dealt with situations afterwards (Cook et al., 2012; Hendricks-Ferguson et al., 2015). It was felt that a lack of training in supporting severely ill children contributed to feelings of incompetency and overall burnout (Citak et al., 2013; Fanos, 2007). Lack of time to build relationships was described as contributing to burnout as healthcare workers often felt as if they were unable to achieve what they would have if they had more time (Furingsten et al., 2015; Henao-Castaño & Quiñonez-Mora, 2019). Due to the lack of time and experience, feelings of drowning and not being able to cope were expressed, which often led to burnout (Henao-Castaño & Quiñonez-Mora, 2019; Reid, 2013).

The experience of emotional pain was prevalent in the studies, and emotional pain was described as an expression of hurting, which lasted for a couple of weeks (Rashotte et al., 1997). This hurt resulted in other painful emotions, such as anger, guilt, regret, and feelings of emptiness (Cook et al., 2012; MacDermott & Keenan, 2014; Rashotte et al., 1997). Healthcare workers found it hard to care when there were restrictions from their patients' parents and they were not able to care for the child as best as they could, which resulted in emotional pain (Furingsten et al., 2015). This was described as difficult; however, emotional pain was something that they learnt to adjust (Furingsten et al., 2015). Through the process of self-reflection, healthcare workers were able to come to terms with difficult situations and with their feelings of emotional pain (Rashotte et al., 1997).

Appreciation, benevolence, making a difference, and overall job satisfaction were commonly felt as a result of caring for this population (Beaune et al., 2018; Furingsten et al., 2015; Hendricks-Ferguson et al., 2015; Papadatou et al., 2001). Feelings of accomplishment was described as, despite the outcomes, knowing that their patient was helped made a difference (Beaune et al., 2018; Furingsten et al., 2015). Feelings of passion, motivation, and dedication were described in knowing that they helped improve the quality of life of their patients (Beaune et al., 2018). It was felt that valuable life lessons were learnt from caring for this population, and these life lessons provided meaning to this work (Donohue et al., 2018). The caring component of the job was described as the most fulfilling as healthcare workers found the connections that they built to be very meaningful (Beaune et al., 2018). Despite the pain and stress encountered each day, healthcare workers felt great reward and satisfaction knowing that they contributed to a dignified death, built meaningful relationships, and were strong advocates of care (Papadatou et al., 2001).

2.3.5 Intimate encounters

Professional attachment and relationship building were described as intimate encounters that contributed to the emotional experiences of caring for this population (Hendricks-Ferguson et al., 2015; MacDermott & Keenan, 2014; Pearson, 2013; Rashotte et al., 1997). Attachment led to becoming emotionally bound to patients, and the sadness experienced due to the emotional connection was often attributed to the level of attachment (Rashotte et al., 1997). This level of attachment led to either grief and upset or a sense of trust and personal reward from the contribution to care (Donohue et al., 2018; Furingsten et al., 2015; Papadatou et al., 2001; Pearson, 2013). There were times when the attachment was so strong that healthcare workers attended the child's funeral to gain a sense of closure (Papadatou et al., 2001). Attending the funeral of a patient often had to do with the attachment to the patient rather than the duty to attend. It was felt that when there was time to build relationships, healthcare workers felt more prepared, and stronger relationships were built (Côté, Payot, & Gaucher, 2019).

2.4 Maintaining an equilibrium

When caring for this population, maintaining an equilibrium was found to be very important. There was a consistent feeling of nurses having to be available 24/7, and therefore maintaining balance came from balancing their job, finding ways of managing a lack of resources, and dealing with role ambiguity (Citak et al., 2013; Cook et al., 2012; McCloskey & Taggart, 2010; Papadatou et al., 2001). There was also a need to serve and protect patients (Beaune et al., 2018; Hendricks-Ferguson et al., 2015; McCloskey & Taggart, 2010; Papadatou et al., 2002; Pearson, 2013; Rashotte et al., 1997). Emotional growth and emotional boundaries were described as a way of maintaining an equilibrium (Beaune et al., 2018; Papadatou et al., 2002; Papadatou et al., 2001).

2.4.1 The 24/7 nurse

Nurses felt that on top of their responsibilities, they at times had to provide the support that a social worker would provide (Citak et al., 2013; Hendricks-Ferguson et al., 2015). It was felt that juggling these multiple roles made defining the nursing role difficult (McCloskey & Taggart, 2010). There was a consensus regarding the lack of resources for supporting this population, which resulted in feelings of helplessness, frustration, dissatisfaction, exhaustion, mental depression, and overall stress (Citak et al., 2013; Furingsten et al., 2015;

Papadatou et al., 2002). This lack of support resulted in nurses feeling they had to be available 24/7, and it felt as if their jobs never ended (Henao-Castaño & Quiñonez-Mora, 2019).

As a result of juggling multiple responsibilities, role uncertainty was sometimes faced, especially around end-of-life care discussions (Hendricks-Ferguson et al., 2015; McCloskey & Taggart, 2010; Papadatou et al., 2001; Pearson, 2013). The role of the nurse did not end at the time of death as they were sometimes tasked with preparing the body for the morgue and transporting the body to the morgue, which was described as emotionally challenging (Rashotte et al., 1997). The administrative procedures of post-death care forced nurses to face the death of their patient before they were emotionally ready to let go (Rashotte et al., 1997). Taking on multiple roles also caused tension between nurses and physicians (Hendricks-Ferguson et al., 2015). As nurses were expected to wear both psychosocial and administrative hats, their juggling of roles resulted in their not being able to process their own emotions (Citak et al., 2013; Furingsten et al., 2015; McCloskey & Taggart, 2010).

2.4.2 Finding balance as a novice nurse

There was a high prevalence of nurses among the studies reviewed, and among the nurses there was a focus on novice nurses. Novice nurses found challenges with caring for this population and maintaining boundaries to protect themselves (Hendricks-Ferguson et al., 2015). These nurses often built emotional ties to families, which lasted after a child had died (Cook et al., 2012). It was felt that the continuation of the relationship with the family after death was for the gain of the healthcare workers and not for the benefit of the family (Cook et al., 2012). This sometimes resulted in a reversal of roles, in which the nurses had a hard time coping and the family would be consoling the nurse (Cook et al., 2012). Being there and being present was important; however, caution had to be exercised to ensure that healthcare workers did not have their emotions interfere with their relationship with the family or the relationship between the patient and the parent (Furingsten et al., 2015). It was found that if nurses had training in palliative care, they would better understand the balance needed to keep distance from patients and families to protect themselves and not interfere with the patient and nurse relationship (Cook et al., 2012; Henao-Castaño & Quiñonez-Mora, 2019).

2.4.3 Emotional growth

Emotional growth was important in maintaining an equilibrium. Emotional growth was explained as being able to share and express sadness while remaining calm and developing compassion (Beaune et al., 2018). This emotional growth assisted healthcare workers in finding ways of accepting the duality of their jobs: knowing that while supporting death and dying, they recognised that they could make a positive difference (Beaune et al., 2018). Accepting this duality helped healthcare workers cope with death while also being able to carry on with their day-to-day responsibilities (Papadatou et al., 2001). Recognising these dualities was described as healthy and necessary when supporting this population (Beaune et al., 2018; MacDermott & Keenan, 2014). Healthcare workers experienced emotional growth, and this helped with the challenges they experienced caring for this population and being able to stay in this work (Pearson, 2013).

2.4.4 Emotional boundaries

Emotional boundaries were described in two ways: personal boundaries and professional boundaries, in which both boundaries were somewhat fluid. Personal boundaries were described as healthcare workers having the ability to emotionally separate themselves from the patient to prevent burnout (Cook et al., 2012). This personal boundary ensured that professionally healthcare workers could do their job while keeping their emotions separate. This emotional separation was difficult and impossible at times, as healthcare workers often struggled, and letting go after death was one of the biggest struggles (Cook et al., 2012). Healthcare workers were described as going the extra mile for their patients, and some felt like they did too much at times (McCloskey & Taggart, 2010). This was often attributed to long-standing relationships with families in which personal connections were made, and personal and professional boundaries were often crossed (Donohue et al., 2018; McCloskey & Taggart, 2010). It was felt that healthcare workers gave resources emotionally and time-wise and often become overly involved by giving too much (Donohue et al., 2018). At times, healthcare workers believed it was unprofessional to become attached to a patient (MacDermott & Keenan, 2014). This was also felt around crying in front of a patient or family, as healthcare workers often wanted to appear as if they were coping well and were professional (Cook et al., 2012; McCloskey & Taggart, 2010). This, however, did not stop nurses from developing attachments, as it was viewed as being inevitable (MacDermott & Keenan, 2014).

It was found that healthcare workers sometimes viewed themselves as pseudo-family members, which caused challenges with maintaining professional boundaries (Reid, 2013). Family members often looked to healthcare workers for an answer, and this often caused stress when that view of pseudo-family members was held by the healthcare workers (Reid, 2013). Healthcare workers were left thinking they were doing too much for the family while also not wanting to upset the families (Hendricks-Ferguson et al., 2015). Therefore, being aware and establishing boundaries ensured that healthcare workers were protected and did not experience a flood of emotions, given the number of deaths they are exposed to (Rashotte et al., 1997).

Boundaries were viewed as an invisible line, and this line was different with every patient, whether it was due to a lack of experience or personal beliefs, which resulted in fluid boundaries (Cook et al., 2012). Healthcare workers needed to swiftly adjust boundaries and shift gears daily as they moved between patients based on their relationship with the patient and family (Cook et al., 2012). There were times when boundaries changed depending on how the healthcare provider viewed the patient who was dying, based on their own perceptions (Laryionava et al., 2018). Adolescents and young adults were described as a population, which was overtreated as a result of oncologists sometimes viewing dying at a young age as unfair (Laryionava et al., 2018). In some cases, when adolescents and young adults were dying, chemotherapy had been received two weeks prior to death (Laryionava et al., 2018) Having to accept that death was imminent was viewed as a personal failure, and therefore personal boundaries at times were crossed to avoid feelings of guilt and failure (Laryionava et al., 2018; Papadatou et al., 2002).

Emotional fluctuations, detachment, and regulation were described as being important when supporting this population. Healthcare workers are sometimes detached from their patients, as feelings of exhaustion, being overworked, and mental depression were quite prevalent (Citak et al., 2013). An emotional detachment was also felt as an avoidance strategy to help healthcare workers avoid burnout (Papadatou et al., 2002). Such phrases as 'closing pain in a little drawer' or 'switching off' were used to describe emotional detachment (Papadatou et al., 2002). On the contrary, it was explained that emotional detachment, defined by personal boundaries, meant not caring, and if a nurse could no longer feel emotion or was not impacted by the death of their patient, they needed to re-evaluate their profession (Cook et al., 2012). Balance was required with developing emotional detachment to help protect healthcare workers but also ensure that they were still able to express emotions and not be disconnected from their patients and families in a way that made them unable to feel (Cook et al., 2012; Fanos, 2007; Papadatou et al., 2002).

2.5 Processing grief and accepting death

This analytic theme consists of two descriptive themes: the impact of illness deterioration and the diverse faces of grief. When supporting children with life-limiting illnesses, healthcare workers found it difficult to manage imminent death, changes in treatment options, and to prognosticate (Hendricks-Ferguson. et al., 2015; Laryionava et al., 2018; Rashotte et al., 1997). Grief was experienced in many ways, including cumulative grief, disenfranchised grief, private grief, and public grief (Hendricks-Ferguson et al., 2015; Papadatou et al., 2002; Papadatou et al., 2001; Rashotte et al., 1997).

2.5.1 Impact of illness deterioration

It was felt that healthcare workers had difficulty supporting adolescents and young adults who were dying, mainly because of the view that it was unjust for someone at this age to die in relation to adults (Laryionava et al., 2018). This perception influenced oncologists' decision-making regarding treatment, which was described as the most stressful aspect of their clinical practice (Laryionava et al., 2018). Chemotherapy was sometimes used, even when it was known that it would not be beneficial, as oncologists had difficulty coming to terms with a young person dying (Laryionava et al., 2018). The impact of illness and the overall death was described as a vacuum that resulted in feelings of emptiness (Furingsten et al., 2015). This emptiness caused issues with adjusting and overall letting go as healthcare workers did not have a chance to say goodbye (Furingsten et al., 2015). Healthcare workers were tasked with being the key decision makers, which resulted in stress and feelings of wanting to do their best as quickly as possible (Laryionava et al., 2018; McCloskey & Taggart, 2010). Supporting dying children was described as distressing and unfair and evoked feelings of powerlessness, helplessness, sadness, and sorrow (Furingsten et al., 2015; Papadatou et al., 2001; Rashotte et al., 1997). It was felt that the depth of the emotions towards the death of a patient was often dependent on the family's response at the time of their child's death (Rashotte et al., 1997). Novice nurses were found to experience painful emotions and had a more challenging time coping with the death of a patient, as it took experience to develop healthy coping strategies (Hendricks-Ferguson et al., 2015; Rashotte et al., 1997). It was important for healthcare workers not to take the death of a patient personally and understand that their patients might die (Fanos, 2007).

Coming to terms with and discussing prognosis was expressed as causing emotional difficulty (Côté et al., 2019; Hendricks-Ferguson et al., 2015; Papadatou et al., 2002; Pearson, 2013). It was felt that being able to answer questions about their prognosis was difficult and left healthcare workers at a loss for words and feelings of helplessness (Papadatou et al., 2002). There was sometimes tension between nurses and physicians when it came to end-of-life conversations, as nurses felt that physicians struggled with facilitating the end-of-life conversations and that they were able to better share this information as they were more aware of what the families needed to hear (Hendricks-Ferguson et al., 2015). This role tension was caused by nurses accepting their patients' death and physicians focusing more on finding a cure (Hendricks-Ferguson et al., 2015). Shifting to a palliative approach to care was sometimes viewed as impacting the therapeutic relationship between the patient and family (Côté et al., 2019). Regardless of acceptance, there was never a good time in a child's life to discuss goals of care about end-of-life care (Côté et al., 2019).

2.5.2 The diverse faces of grief

The grief experienced by healthcare workers was described in a multitude of ways – from cumulative grief to disenfranchised grief to private grief and public grief (Hendricks-Ferguson et al., 2015; Papadatou et al., 2002; Papadatou et al., 2001; Rashotte et al., 1997). Healthcare workers caring for this population experienced multiple deaths, sometimes within a short period (Papadatou et al., 2002; Rashotte et al., 1997). The grief experienced was different for each death, as the relationship and attachment built were different for each patient (Hendricks-Ferguson et al., 2015; Rashotte et al., 1997). Cumulative grief resulted in emotional pain, which was addressed through self-reflection and viewing grief as a learning process (Rashotte et al., 1997). When multiple deaths occurred, avoiding grief was a way healthcare workers protected themselves from feeling overwhelmed (Papadatou et al., 2002). Grief was described as a fluid process, which fluctuated between finding ways of coping with the grief or avoiding and repressing it (Papadatou et al., 2001). Disenfranchised grief was also experienced by healthcare workers who did not believe they had the right to grieve as they were not family (MacDermott & Keenan, 2014). Healthcare workers dealt with this disenfranchised grief by finding ways of controlling their feelings of distress and displacing their attention to their clinical work (Papadatou et al., 2002). It was suggested that grieving a patient was an ongoing process, and there was a need to continuously relocate the loss (Papadatou et al., 2002).

Grief was described as a private experience as the need to be professional and be viewed as being strong and in control was described (Fanos, 2007; Papadatou et al., 2002; Rashotte et al., 1997). Healthcare workers' ability to be alone, cry alone, and grieve alone was described as being professional and allowed healthcare workers to keep up the façade of being strong and able to cope (Fanos, 2007; Papadatou et al., 2002). For physicians, grief was sometimes described as a lonely, individualised process, which they faced alone as physicians were viewed as needing to be in control and to hold things together (Papadatou et al., 2002). There was a reluctance among paediatric oncologists to let their colleagues know that they were having a hard time coping (Fanos, 2007). If grieving in private was necessary, journaling or physical expressions of grief, such as releasing a balloon, were viewed as essential outlets of grieving because not expressing emotions and taking grief home was viewed as unhealthy (Pearson, 2013; Rashotte et al., 1997).

Healthcare workers were incredibly proud of their colleagues and the support that they provided to each other, which was described as being pivotal in being able to care for this population (Beaune et al., 2018; McCloskey & Taggart, 2010; Pearson, 2013). Team support was described at four levels: information, clinically and practically, emotionally, and through meaning-making (Papadatou et al., 2001). Due to the shared experience of the incredibly emotional situations, strong relationships were built among the team, which was valuable support in caring for this population (Pritchard et al., 2011). Sharing with their colleagues was more helpful, as there was an understanding of the lived experience as opposed to sharing with family members (Cook et al., 2012). Strong teams made healthcare workers feel as if they could face the unbearable as they were in it together, and if someone needed to step in, they had the comfort of asking for assistance (Furingsten et al., 2015). Grieving was felt to be a collective experience, and having this support was described as supportive, rewarding, energising, satisfying, and imperative to care (Beaune et al., 2018).

2.6 Discussion

This systematic qualitative review of the literature and thematic synthesis described the emotional experiences of healthcare workers who care for children, adolescents, and young adults living with a life-limiting illness. The synthesis of the 17 studies resulted in three overarching analytic themes: a rollercoaster of emotions, maintaining an equilibrium, processing grief, and accepting death. All 17 studies related to caring for this population in various settings throughout the trajectory of illness up until death. The findings suggest that there are many emotions experienced when caring for this population: Helplessness, powerlessness, guilt, stress, worry, anxiety, and anger were the most common (Citak et al., 2013; Cook et al., 2012; Côté et al., 2019; Donohue et al., 2018; Furingsten et al., 2015; Hendricks-Ferguson et al., 2015; Laryionava et al., 2018; Papadatou et al., 2002; Papadatou et al., 2001; Rashotte et al., 1997; Reid, 2013).

Plutchik developed a wheel of emotion to categorise and better understand emotions which can be seen in Figure 2.6.1. The wheel begins as a cone of eight primary emotions – joy, trust, fear, surprise, sadness, anticipation, anger, and disgust – which unfolds into a wheel (Plutchik, 2001). According to Plutchik’s wheel of emotions, emotions are caused by a combination of multiple primary emotions (Plutchik, 2001, 2020). This wheel will be used to explore further and understand the emotions which resulted from this systematic review.

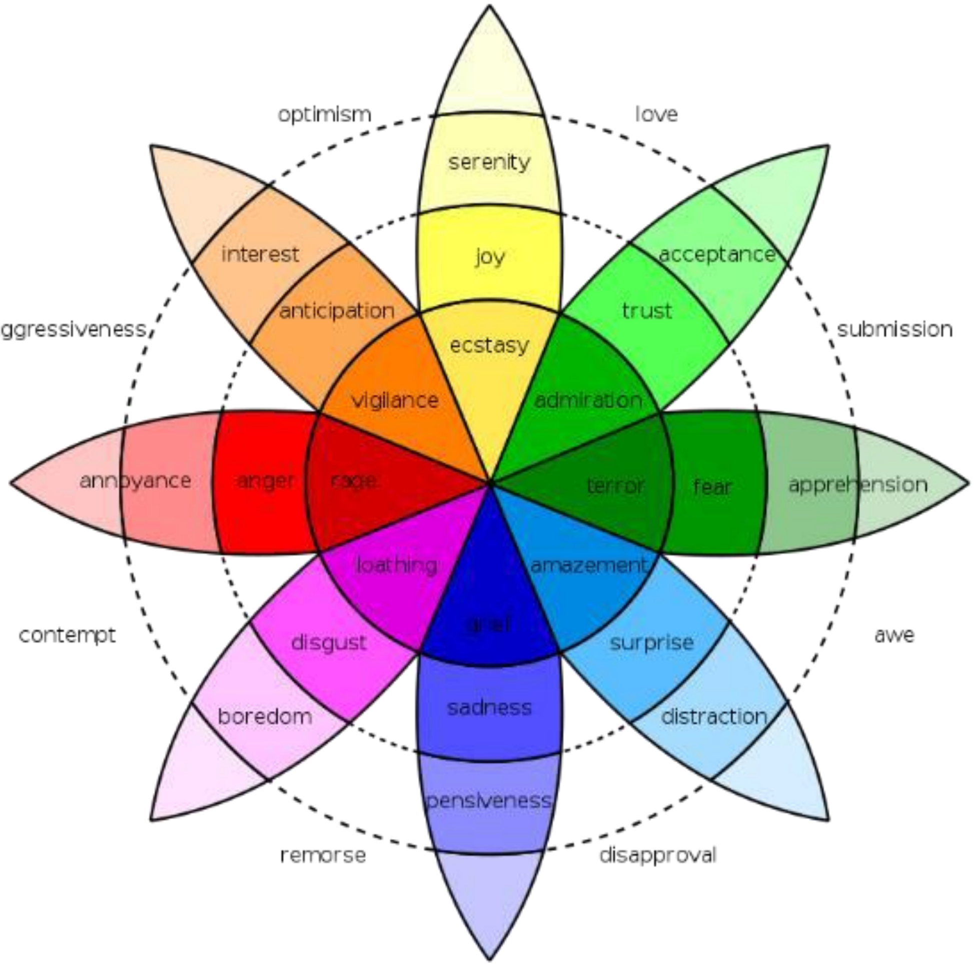

Figure 2.6.1 Plutchik's wheel of emotions from "Summarizing emotions from text using Plutchik's wheel of emotions" by Abbasi & Beltiukov, 2019, Technologies for intelligent decision making support, 166, p.291. Permission granted to reproduce this image.

When critically examining this wheel of emotion and the emotions experienced by healthcare workers who care for this population, there was an uneven weight of emotions centred around three primary emotions: fear, sadness, and anger (Citak et al., 2013; Donohue et al., 2018; Furingsten et al., 2015; McCloskey & Taggart, 2010; Papadatou et al., 2001). Within the synthesis, sadness was not as common among the 17 studies; however, the emotion of grief was much more common across the synthesis. Grief was found to be an intense emotion experienced both individually and as a team. Anger and stress were also common emotions experienced, and these emotions were rooted in a sense of control and helplessness, powerlessness, and guilt experienced when this control was lost (Citak et al., 2013; Cook et al., 2012; Laryionava et al., 2018; Papadatou et al., 2001). The emotion of guilt was prevalent throughout the studies, and according to the wheel of emotion, remorse is felt through a combination of emotions. When critically reflecting on the findings of the synthesis, guilt was experienced as a result of multiple factors which other emotions experienced simultaneously. Of all the emotions identified through the synthesis, there was an uneven weight towards the more negative emotions. This could be attributed to the population being served and the belief that children, adolescents, and young adults should not die.

Although the wheel of emotions was more negative than positive, when working with this population, positive emotions, such as love, hope, empathy, trust, gratitude and personal rewards, were experienced (Beaune et al., 2018; Donohue et al., 2018; Papadatou et al., 2001). The emotion of love is a result of multiple emotions experienced at once, emotions such as joy and acceptance (Plutchik, 2020). This aligned with how participants described developing a love for their patients through multiple emotions developing into a strong connection. Working with this population also resulted in gratitude, and appreciation for life, health, and their children's health.

Throughout the synthesis, there was a difference in how novice nurses coped with working with this population versus more experienced healthcare workers. It was believed that as novice nurses gained more experience, they found better coping methods (Cook et al., 2012; Hendricks-Ferguson et al., 2015). Additional training and education would support novice nurses when reflecting on this finding through a critical lens. There was not a time would pass when working in this field that would make supporting this population any easier. The emotions experienced by novice nurses were also experienced by healthcare workers who had worked in the field for many years. Finding ways of coping was imperative, however, when the focus of most healthcare workers was on building relationships; through these connections, the most prevalent emotions were experienced despite years of service, as years of service did lessen emotions. It just allowed for findings ways of better coping with emotions.

Throughout the systematic review, there was a focus on children and only three studies differentiated between children, adolescents, and young adults. Cancer was viewed as the largest interruption in an adolescent or young adult's life, given the stage of life there are in and the life ahead of them (Laryionava et al., 2018). There was unfairness and injustice experienced by healthcare workers when supporting adolescents and young adults at the end of life (Laryionava et al., 2018). Given where this population is in the life cycle, knowing that illness was stealing their future from them was difficult and made acceptance by healthcare workers difficult. The needs of adolescents and young adults differ from those of children; however, within this review, there was a lack of emphasis on this, as most of the studies did not separate the findings based on age groups.

2.7 Limitations

Emotions are quite subjective and often impacted by such things as culture, environment, and support systems. The majority of the studies were located in high-income countries, which therefore led to a lack of representation from countries in which resources were limited. Given that all of the studies were in high-income countries in which they had more resources than low-income countries understanding the experiences in these countries would have provided an equitable approach to the emotions experienced. The study settings were a limitation, as most of the studies were conducted in hospitals. There was very little focus on community care, and there were no in-patient hospices involved. The ethnicity of the participants was rarely reported, and therefore minority ethnic groups may not have been well represented. Given that emotions are sometimes related to culture (Velayutham & Perera, 2004), understanding the cultural implications would have been beneficial. Other demographic data, such as educational level of training, gender, age, and languages spoken, were not well reported, which limited the understanding of emotional experiences between different cultural and socio-economic backgrounds. Nurses and physicians were well represented within the synthesis; however, this review lacked heterogeneity, as many other healthcare disciplines were not represented. There were a number of studies that focused on children who required palliative care as a result of advanced illness, which resulted in less of a focus on life-limiting illness. Also, the studies involved were mostly focused on children, with less of a focus on adolescents and young adults.

2.8 Strengths

This systematic review spanned 11 different countries. This allowed for an understanding which was not specific to one part of the world. The review question supported a wide range of childhood illnesses, and therefore there was not a focus on one particular disease. This review also involved an in-depth analytic process, which allowed the experiences of the healthcare workers to be visible. The decision to broaden the review focus to include children was a strength as there was an understanding of the emotional experiences from a larger context. Only two of the studies focused particularly on adolescents and young adults. For most of the studies, it was not possible to disaggregate data on this population;

therefore, expanding to include children was a strength. This highlighted how adolescents and young adults are often grouped into the experiences of caring for children and the need to further understand the experiences of caring for this population given the challenges that were expressed through the review. This decision was also beneficial because the studies included in this review spanned multiple settings and illnesses, which allowed for an in-depth understanding of emotional experiences of caring regardless of demographics.

2.9 Further research

This systematic review demonstrated the emotions experienced by healthcare workers caring for children and young adults. With any review, gaps emerged, in which further research is needed. Further research is needed to explore this phenomenon in low-income countries. There is also a need for research conducted outside of hospitals. Additional research is needed on the experiences of novice nurses versus experienced nurses and the role that time and experience in the field makes when supporting this population. There was mention of adolescents and young adults being difficult to support; yet the majority of the studies did not have specific experiences based on the age of the patient. Given the difficulty associated with supporting adolescents and young adults, further research is needed to understand what supporting this population is like for healthcare workers. It would also be helpful to understand these experiences outside of the hospital setting, given the hospital focus in the majority of the studies reviewed. Focusing specifically on the adolescent and young adult population would allow for an in-depth understanding of this experience.

Chapter Three: Methodology and Methods

3 Introduction

The aim of this chapter is to present the philosophical underpinnings, methodology, and methods of this study to understand the lived experience of healthcare workers who provide palliative care to adolescents and young adults with cancer. Details are discussed regarding the sampling, data collection, and data analysis process used. Reflexivity and the steps that were taken to address research quality and ethical considerations are also discussed.

3.1 Research question and study objectives

What are the lived experiences of hospice healthcare workers who care for adolescents and young adults with a diagnosis of advanced cancer who are receiving palliative care? The study objective of this study is to gain an in-depth understanding of the experiences of healthcare workers who provide palliative care to adolescents and young adults living with advanced cancer.

3.2 Research paradigm

The ontological and epistemological stances clarify the underpinnings of a study, which influence the choice of methodology and provide a justification for the methods used to collect and analyse data (Carter & Little, 2007). Ontology is related to the form of the nature of reality and what is known about it (Guba & Lincoln, 1994). Constructivism is based on the premise that experiences are developed based on an individual’s perceptions, constructing multiple meanings to a phenomenon (Creswell, 2013). Constructivists view the world through a subjective lens, in contrast to the positivist lens, which is based on objectivity, testing hypotheses, and using experimental designs to measure variables (Marczyk, DeMatteo, & Festinger., 2005; Sarantakos, 2005; Tuli, 2010). This study explored the individualist experiences of healthcare workers caring for adolescents and young adults. This was congruent with a constructivist approach as it enabled an in-depth understanding of the multiple meanings of the phenomenon.

Epistemology is based on the nature of knowledge and focuses on the relationship between the knower and what is known (Guba & Lincoln, 1994). Interpretivism focuses on subjectivity as opposed to objectivity and believes that there is not one path to understanding knowledge (Willis, 2007). A realist argues that the perception of the world is a single objective reality; however, interpretative researchers do not support this notion (Tuli, 2010; Willis, 2007). They believe that humans view reality through a lens that is socially constructed, and as the aim of this study was to explore the lived experience of the participants, a constructivist-interpretative lens provided the ontological and epistemological foundation (Mutch, 2005).

3.3 Methodology

The constructivist-interpretative foundation underpins various methodologies (Table 3.3.1). Three different methodologies were explored to determine which had a utility to answer the research question. Grounded theory, narrative analysis, and phenomenology were considered in selecting a methodology for this study.

Table 3.3.1 Methodologies and philosophical underpinnings

Methodology	Constructivist/interpretative underpinning	Relation to research question
Grounded theory	Classical grounded theory has been deeply rooted in critical realism. However, when it is subjective, dialectical, and relativist, it fits into a constructivist understanding of the world (Annells, 1996). Knowledge is seen as socially and actively constructed through an experiential world (Goulding, 1998).	A constructivist approach to grounded theory understands the role that the researcher plays in shaping and analysing the data (Williamson, 2006). However, the grounded theory focuses on generating theories through the data. This approach did not fit with answering the research question as the intent of this study was not to generate theory (Glaser & Strauss, 1967).
Narrative analysis	Individuals make sense of their world by sharing stories (Bailey, 2002; Burck, 2005; Reissman, 1993).	As the aim of narrative therapy is to generate stories as a way of describing, reflecting, and sharing an experience, the notion of storytelling did not fit with the research question for this study (Bingley, Thomas, Brown, Reeve, & Payne, 2008; Fins, Guest, & Acres., 2000). Individuals sharing their stories is important and allows for interpretation through the eyes of how individuals reconstruct events to explain their world. However, given that this study was focused on an in-depth understanding of lived experience, storytelling was not the main focus (Reissman, 1993).

Phenomenology	The interpretivist/ constructivist paradigm grew out of Husserl's phenomenology (Mackenzie & Knipe, 2006). The inductive study of conscious phenomena was created through objection of the positivist paradigm (Sanders, 1982). Phenomenology has multiple branches, which were developed by various individuals including Husserl, Heidegger, Merleau-Ponty, and Smith (Langdridge, 2008).	Describes the meaning of lived experience based on a specific phenomenon (Dowling & Cooney, 2012). It is based on the premise that all experience must be understood from the way in which people see the world (Langdridge, 2008). The different forms of phenomenology are underpinned by similar philosophical underpinnings. However, the focus of each differs in the type of meaning being sought through each experience (Langdridge, 2008; Smith & Osborn, 2007). Given the focus on experiences through the eyes of the individual, this methodology was congruent with the research question.

As previously stated, the aim of this study was to understand through the voices of the healthcare workers the experience of supporting adolescents and young adults, phenomenology was selected as the methodology that showed utility to meeting the aims of the study.

3.4 Phenomenology

There are various types of phenomenological approaches: descriptive phenomenology, interpretative phenomenology, the phenomenology of perspective, and interpretative phenomenological analysis (Larkin, Eatough, & Osborn, 2011; Mackey, 2005; Pietkiewicz & Smith, 2014; Smith & Osborn, 2007). Each type will be described to justify the type of phenomenology used for this study.

Table 3.4.1 illustrates the philosophical underpinnings, approach to research, and the concept of phenomenological reduction from the lens of Husserl, Heidegger, Merleau-Ponty, and Smith, who are all phenomenological researchers.

Table 3.4.1 Types of phenomenology

	Descriptive phenomenology	**Interpretative phenomenology**	**Phenomenology of perception**	**Interpretative phenomenological analysis**
Philosophical underpinnings	Positivist framework with a focus on a Cartesian duality of mind, body, and spirit. Focused on epistemology.	Focused on ontology and the meaning rather than what is known (Mackey, 2005).	Rejects the notion of realism and idealism and believes that meaning is ambiguous (Thomas, 2005).	Based on the constructivist/ interpretivist view through wanting to understand the individual's experiences (Larkin, Eatough, & Osborn, 2011). IPA takes a phenomenological, hermeneutic, idiographic stance (Spiers, Smith, Simpson, & Nicholls, 2016; Kirkham, Smith, Havsteen-Franklin, 2015; Smith, Flowers, & Larkin, 2009).
Approach to Research	Focused on the essence of the true meaning and associated reality to the life world or lived experience (Dowling & Cooney, 2012).	Moved beyond description to interpretation while focusing on being in the world, the world, the understanding of dasein, and uncovering hidden meaning (McConnell-Henry,	Placed an emphasis on the concept of embodiment by focusing on the body and the world (Thomas, 2005).	IPA researchers bring forth the personal experiences of people who are embedded in their world (Larkin & Thompson, 2012).

		Chapman, & Francis, 2009).		
Phenomenological reduction	Bracketing is imperative when understanding experience (Finlay, 2008).	Rejected the notion of bracketing (McConnell-Henry et al., 2009).	Rejected the notion of bracketing (Thomas, 2005).	Acknowledges the role of the researcher making sense of the lived experiences of the participants (Shinebourne, 2011).
Relation to research question	Given the focus on an in-depth understanding of experiencing, bracketing was not viewed as being beneficial in answering the research question.	This approach fits with the research question, given the focus on interpretation. However, the main focus on the exploration of dasein was not the main objective of answering the research question.	The research question was not specific to understanding the concept of embodiment. This approach was not viewed as being able to best answer the research question.	This approach is congruent with the study objectives of this study. This approach shows utility in answering the research question based on the in-depth focus of the perceptions and views of the participants.

3.4.2 Descriptive phenomenology

Husserl's development of descriptive phenomenology was built on the premise of attending to the way individuals perceived their experiences by recognising the subjective meanings of the phenomenon (Pietkiewicz & Smith, 2014). Phenomenologists are able to understand what makes a phenomenon unique through the use of eidetic reduction (Pietkiewicz & Smith, 2014). The eidetic reduction was described by Husserl as a philosophical way of making concepts clear, detailed, and comprehensive (Paley, 1997). Husserl created a concept called 'intentionality', which is described as an individual's awareness of an event or an object (Reiners, 2012). Descriptive phenomenology takes on an approach that involves a concept called phenomenological reduction (bracketing), in which the researcher separates all preconceived notions from the research (Erichsen, Danielsson, & Friedrichsen, 2010). Bracketing allows for all prior supposition and assumptions to be separated from the phenomenon being explored (Larkin et al., 2011) Husserl, believed that bracketing is necessary to ensure that the researcher has separated all existing knowledge in order to fully understand the lived experiences of the participants (Reiners, 2012; Giorgi, 1997). When examining the utility of this form of phenomenology for this research study, the concept of bracketing did not fit with the aim of interpreting the experiences of the healthcare workers. My involvement in the research was viewed as playing a role in how this lived experience was understood.

3.4.3 Interpretative phenomenology

Heidegger critiqued Husserl’s work, seeking to move beyond description and focusing on being in the world rather than knowing the world (Reiners, 2012). Unlike Husserl’s focus on epistemology, Heidegger’s interpretative phenomenology focused on ontology and the meaning of being (Mackey, 2005). Heidegger focused on the concept of hermeneutics, which is the process of bringing out things that are not usually visible in human experience (Lopez & Willis, 2004). Hermeneutics denotes that our understanding of the world is created by our interpretation of it (Reiners, 2012). Interpretative phenomenology includes the hermeneutical circle, which is a circular form of interpretation that is shared among individuals (Conroy, 2003). The term 'dasein', also referred to as 'there-being', was coined by Heidegger, in which individuals are always involved in meaningful context based on where they are located (Larkin, Eatough, & Osborn, 2011).

Interpretative phenomenology preconceptions should come second in relation to the new object and viewed the concept of fore-conceptions as an obstacle to interpretation (Smith, 2007). However, it is not possible to know which preconceptions may be significant to a certain phenomenon, and therefore the process of interpretation is iterative and part of the hermeneutic circle (Shinebourne, 2011). It is difficult to identify preconceptions; however, a strong reflexivity process can assist with this, which overall supports a robust interpretation of experiences (Horrigan-Kelly, Millar, & Dowling, 2016). This approach showed utility to support the research question as it moves away from the descriptive and focuses on interpreting (Larkin et al., 2011).

3.4.4 Phenomenology of perception

This approach to phenomenology focused on embodiment and intersubjectivity (Larkin, Eatough, & Osborn, 2011). The main focus of this phenomenological approach looked further than just the subject-object divide (Carman, 1999). Embodiment shifted phenomenology away from the inner subject and overlapped with Heidegger's concept of intersubjectivity (Larkin, Eatough, & Osborn, 2011). When examining the research question and this approach to phenomenology, the focus on embodiment and intersubjectivity did not fit with the aims of what this study seeks to better understand.

3.4.5 Interpretative phenomenological analysis (IPA)

Interpretative phenomenological analysis does not support the notion of one generalisable truth; it supports an ontological understanding of reality as a subjective construct that values the voice of each individual's experience and perception (Aldridge, Fisher, & Laidlaw, 2017; Larkin, Watts, & Clifton, 2006; Snelgrove, 2014). Both the participant and researcher are engaged in the co-construction of meaning, and the researcher also has to produce a detailed interpretative analysis (Smith, 2007). IPA offers an in-depth analysis of the healthcare workers' experiences of caring for this population. This methodology has become a recognised approach to qualitative research in clinical and health psychology, as its aim is to understand individuals making meaning of experiences while integrating interpretation and the researcher (Macleod, Shepherd, & Thompson, 2016).

When looking at the philosophical tenets of descriptive and interpretative phenomenology, interpretative phenomenology best suited this research study (Reiners, 2012). Given that my involvement with the research was viewed as adding depth and breadth to the analysis, the concept of bracketing was not congruent with the research question (Reiners, 2012). Due to the emphasis on gaining an in-depth understanding of lived experienced, underpinned by hermeneutics, IPA’s strong methodological approach was viewed as answering the research question while holding true to the meaning-making of the phenomenon being explored and my involvement with the research.

3.4.6 Theoretical framework for interpretative phenomenological analysis

IPA takes a phenomenological, hermeneutic, idiographic stance, and this provided the theoretical framework for this study (Spiers, Smith, Simpson, & Nicholls, 2016; Kirkham, Smith, Havsteen-Franklin, 2015; Smith, Flowers, & Larkin, 2009). As the healthcare workers in this study make sense of their personal and social world, reflexivity played a role in making sense of their interpretation process (Vachon et al., 2012; Smith, 2004). The idiographic commitment of IPA ensured that the healthcare workers played an integral role throughout the research process, which may contribute to existing nomothetic research

(Kirkham, Smith, & Havsteen, 2015; Shinebourne, 2011). The interpretative epistemological and IPA methodology are informed by each of these theoretical underpinnings (Shinebourne, 2011). It is phenomenological, as IPA is a qualitative methodology that seeks to explore the participant's personal experience (Kirkham, Smith, & Havsteen-Franklin, 2015; Larkin & Thompson, 2012; Snelgrove, 2014; Smith, 2004). However, IPA goes deeper than describing participants' perceptions of a phenomenon and involves a double hermeneutic process (Smith, 2004). As the participant tries to make sense of their world, the researcher is also trying to make sense of the participant making sense of their interpretation process influenced by their own contextual position in the world (Vachon et al., 2012; Shinebourne & Smith, 2009; Smith, 2004). The challenge is for the researcher to be critical and practise reflexivity to assess how their prior experiences influence the research (Finlay, 2008). IPA overlaps with the concept of the hermeneutic circle through interpretation being a dynamic and iterative process between the object of interpretation and the interpreter (Shinebourne, 2011).

As the focus of this study was on the lived experience of healthcare workers, an interpretative phenomenological epistemology provided an appropriate foundation for the understanding of the creation of knowledge. In comparison to the other phenomenological approaches, IPA lent itself to an in-depth understanding of lived experience. This approach answered the research question and was congruent with the underpinning paradigm. It would have been difficult to gain an in-depth understanding of lived experience through an objective lens, as their individual life experiences shaped the reality of the participants. The experiences were not based on one singular truth. A subjective lens allowed for congruence with the research question.

3.5 Research reflexivity

My educational training and clinical practice have been built upon the process of critical consciousness. Critical consciousness considers how our own biases, assumptions, and cultural worldviews influence the ways we understand differences and power dynamics (Sakamoto & Ronald, 2005). During this study, I had an ethical responsibility to ensure that I operated in a way that promoted social justice and understood the implications of oppression (Suarez, Newman, & Glover Reed, 2008). By allowing critical consciousness to play a role in my reflexivity, I was able to continuously reflect on my biases, power, and privilege and the role that this played in how I understood the research being conducted in this study.

It was important that I continuously reflected on myself and my relationship to the research (Ritchie, Lewis, Nicholls, & Ormston, 2013). Reflexivity was maintained through a self-reflective journal, which was kept throughout the research process. When interviewing the participants and analysing the data, the journal was very beneficial in helping to critically think through my thoughts and assumptions. I also joined an IPA group online, which allowed for critical thinking and further exploration. Biweekly supervision with my supervisors provided me with an environment in which reflexivity was also maintained through academic discussions.

3.6 Study design

3.6.1 Setting

The results of the systematic review illustrated the lack of research in settings other than hospital settings when supporting adolescents and young adults. Paediatric hospices were selected for this study due to the limited research in in-patient hospices and because adolescents and young adults living with advanced cancer are sometimes supported within this setting. Also, given that there was a focus on all healthcare workers, hospices work with interdisciplinary teams, which would allow for the recruitment of multiple healthcare disciplines. A scan was done, and there are six paediatric hospices in Canada.

3.6.2 Study population

According to IPA principles, finding a closely defined group of participants plays an integral role in answering the research question (Smith & Osborn, 2007). It is important that IPA researchers ensure the study population is homogeneous to understand the shared insights into the phenomenon of study (Smith & Osborn, 2007). The definition of homogeneity used for this study is described below. In order to gain an in-depth understanding of the experiences of hospice healthcare workers, multiple healthcare disciplines were included in this study. They included physicians, nurses, personal support workers, and therapists. Given that within palliative care an interdisciplinary approach to care is important, gaining insights from each discipline was viewed as supporting a robust understanding of the lived experience (Crawford & Price, 2003).

3.6.3 Homogeneity

As a way of better understanding the lived experiences and perceptions of the participants within an IPA approach, a homogeneous sample should be reflected (Alase, 2017). It is imperative that all participants share similar lived experiences of the phenomenon being explored (Creswell, 2012). To better understand how homogeneity is viewed, multiple IPA research studies were examined (Antoine et al., 2018; Lamb & Cogan, 2016; Merriel, Hussein, Coomarasamy, & Larkin, 2018; Nyashanu, Pfende, & Ekpenyong, 2020; Volpato, Banfi, Valota, & Pagnini, 2018; Y. Wang et al., 2017). Homogeneity can be viewed in a multitude of ways including such things as geographic homogeneity, life experiences homogeneity, physical homogeneity, psychological homogeneity and demographic homogeneity (Robinson, 2014). Homogeneity does not have to be specific to one characteristic, and this concept is subjective. For the purpose of this study, homogeneity was achieved through the collective experience of participants working at a paediatric in-patient hospice and the shared experience of supporting cancer, similar to another study which sought homogeneity through the experience of disease (Clabburn, Knighting, Jack, & O'Brian, 2019). Therefore, although the sample of this study may be viewed as having variations making it less homogenous, the inclusion criteria ensured that the sample was homogenous (Tatterton & Walshe, 2016).

3.6.4 Sampling

Rigour in IPA refers to the appropriateness of the sample and the thoroughness of the study (Smith, Flowers & Larkin, 2009). IPA researchers recruit a homogeneous sample with a smaller sample size; however, there is no exact number of what this sample should be (Chapman & Smith, 2002; Pietkiewicz & Smith, 2014; Wagstaff & Williams, 2014). This study utilised purposive sampling, which is congruent with an IPA (Smith & Osborn, 2007). The aim was to find a homogeneous sample with the shared experience of providing palliative care to adolescents and young adults living with cancer. It is important that the participants selected for this study share the criteria defined below.

Table 3.6.5 Inclusion criteria and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Over 18.	Those who are not paid by the hospice.
English Speaking.	Senior management
Healthcare workers who work in palliative care providing care to adolescents and young adults in an in-patient hospice in Canada.	
Experience with supporting adolescents and young adults with a diagnosis of cancer.	
Provide care for patients at the hospice and are employed by the hospice.	

3.6.6 Recruitment method

All six Canadian paediatric hospices were invited to participate, and four chose to take part in this study. Each hospice was contacted by telephone, and a connection was made to a staff member who supported research studies at the hospice. Each hospice identified one staff member who acted as the liaison between the researcher and the participants. This staff member provided information about the study to all frontline staff through the use of the research recruitment flyer (Appendix 7). The inclusion and exclusion criteria were shared with the hospice to ensure that the participants who were selected possessed specific knowledge in regard to the research question (Curtis, 2000). Hospice healthcare workers who were interested in participating in the study were provided with a participant information sheet, the expression of interest form, and the informed consent form (Appendices 8, 9, and 10). Once the hospice had completed the recruitment process, a schedule was created, which included the date and time the interviews would take place. Contact between myself and the participant was made on the day of the interview.

3.6.7 Sample size

Once the recruitment process was completed, each hospice shared the number of participants that came forward to take part in the study. Although saturation is not sought within IPA, there have been benefits discussed to recruiting fewer participants as a focus is on depth as opposed to breadth (Brocki & Wearden, 2006; Pietkiewicz and Smith, 2014; Bowlby, 1997). It has been recommended that researchers refrain from collecting an extensive amount of data from a large number of participants, as they may be unable to capture all of the meaning of each participant's experience (Collins & Nicolson, 2002; Pietkiewicz & Smith, 2014). Determining the sample size within an IPA study is based on an assessment of the experience being explored. There are examples of studies where the final sample varies from one to 81 participants, with these quite different sample sizes being justified on the basis of diagnosis, setting and experience (Clare, Rowlands, Bruce, Surr, & Downs, 2008; Robson, 2002). The sample for this study was based on the rarity of adolescents and young adults dying of cancer in an in-patient hospice and was influenced by the experience of healthcare providers working in an in-patient hospice supporting adolescents and young adults. There were also pragmatic considerations, given that I was travelling in person to each hospice across Canada and needed to capture interviews whilst I was there on a single visit, which influenced the decision to collect additional data with each visit. An active decision and active choice was made to be more inclusive as I was focused on breadth within the definition of homogeneity. Given that I was interested in multiple disciplines, if I had had a smaller sample size, I would not have only been able to include as many diverse disciplines as I did.

3.6.8 Data collection

One of the goals of this study was to produce rich, meaningful, and detailed experiences of this phenomenon (Pietkiewicz & Smith, 2014). I flew across Canada to each hospice, and face-to-face interviews were conducted, which has been the technique that has been used in other published IPA research studies (Kelly & O’Brien, 2015; Schweitzer, Griffiths, & Yates, 2012; Vachon, Fillion, & Achille, 2012). The interviews allowed for a connection with the participants through dialogue and also allowed for flexibility and richer data (Smith, 2015). Open-ended and non-directive questions provided the foundation for the interviews (Kelly & O’Brien, 2015). Each interview began with the question, 'Can you please tell me about the experience of providing palliative care to adolescents and young adults living with cancer?'. Probing and non-leading questions were asked to further explore the participants’ experiences. See Appendix 11 for the research interview guide. Through the dialogue with participants, an in-depth exploration of the participants’ experiences was conducted, which arose through the modification of initial questions and prompts based on the responses of the participants (Smith, 2015; Pietkiewicz & Smith, 2014).

Building trust and having robust participant information forms and consent forms helped participants understand that anonymity, confidentiality, and privacy were upheld. Written consent was obtained prior to each interview beginning. The participants shared their experiences and due to sensitive issues being discussed, participants were aware that pseudonyms would be used to help maintain anonymity. Participants were also aware that two supervisors were overseeing the research study through Lancaster University.

Given that the healthcare workers were the experiential experts on the phenomenon being studied, they were given maximum opportunity to express their experiences (Smith, 2015). All of the interviews lasted approximately an hour, and all of the interviews were digitally recorded and encrypted on an IPAD.

Field notes were taken immediately after the interviews to ensure that nonverbal communication and emotions were captured and for reflexivity. Personal reflection in IPA is integral and allows for an importance to be placed on reflections through the analysis process (Kelly & O'Brien, 2015). As personal reflections could be viewed as bias, a reflexive journal was kept throughout the data collection process (Kelly & O'Brien, 2015; Evans, 2007).

3.6.9 Distress during and after data collection

As a result of existential issues being related to IPA studies and the phenomenon being discussed, it was important that attention was paid to how the interview process was impacting the participant as we went through the interview (Pietkiewicz & Smith, 2014). I ensured that all participants were provided resources for additional support if emotional distress was experienced. A distress protocol by Haigh & Witham (2013) for qualitative data was also utilised as well as my own skills as a social worker to help further identify if a participant was experiencing distress.

3.6.10 Data management

All of the interviews were recorded on a password-protected iPad and kept locked in my suitcase when not in use as I travelled to and from the hospice. Upon completion of each interview, each transcript was copied onto an encrypted file on a personal laptop, which was also password protected. The laptop, field notes, and reflexive journal, along with all of the consent forms, were kept in my locked suitcase.

All of the devices used were password protected, and passwords were changed every month. All paper files, including field notes and the reflexive journal, were stored in a locked cabinet once I arrived back home in Canada. All transcripts were stored on an encrypted file and will be kept for ten years, and all data were backed up to an external hard drive, which is stored in a locked cabinet. All paper files, text data, and the reflexive journal will be stored in a locked cabinet as a permanent archive for further reference if needed. Once the final report has been submitted, all personal details and audio recordings will be destroyed.

3.6.11 Safety

For the data collection process, the Lancaster Guidance for Lone Working document was adhered to; however, this does not have to be used (Appendix 12).

3.6.12 Transcribing

Each interview was transcribed verbatim through a third-party company. A confidentiality agreement was signed by this company, and an encrypted process was used to deliver all data. The company destroyed all data once the researcher received the transcripts. Before the company agreed to transcribe the interviews, I made the company aware of the nature of this research study and the risk of emotional distress. The company understood, and there was no issue with them transcribing the data.

3.6.13 Data analysis

The data analysis process followed IPA guidelines and had a robust data analysis process, which was pertinent and congruent with IPA's aim of gaining an inside perspective of the experience under investigation (Smith & Osborn, 2007; Tebbet & Kennedy, 2012). This section of the study consisted of the researcher engaging in an interpretative relationship with each transcript (Smith, 2015; Smith & Osborn, 2007). The IPA method is an iterative and cyclical process that involves a 4-stage process: a first encounter with the text, preliminary themes being identified, grouping themes into clusters, and tabulating the themes into a summary table (Biggerstaff & Thompson, 2008). This 4-stage process was used for the analysis for this study and will be described**.**

3.6.14 Stage one

Each transcript was read twice to ensure accuracy and to capture the essence and meaning of each interview (Smith, 2015). Each reading also allowed for new insights to emerge (Smith & Osborn, 2007). The first time the transcript was read, the audio was listened to, and the second read did not include the audio. The software NVivo 12 was used to help organise the data. An example of how the data were organised in NVivo is found in Appendix 13. Throughout the first reading, all key terms, phrases, words, and insights were highlighted on the right-hand margin (Smith, 2015). There were sections of the transcripts that were richer and therefore required more comments (Smith & Osborn, 2007). Nonverbal expressions, such as laughing, crying, and silence, were included in the transcript to ensure that all nonverbal actions were accounted for (Adolfsson, 2010). This process continued for the complete transcript.

3.6.15 Stage two

The second reading began where initial notes were turned into codes and then emergent theme titles (Smith & Osborn, 2007). An example of a coded transcript can be found in Appendix 14. I then compared all of the emergent themes back to the transcript (Leung, 2015; Smith, 2015; Tebbet & Kennedy, 2011). During this phase of the analysis process, connections between the theoretical framework of IPA and the voice of the participant were developed (Smith & Osborn, 2007). This process was repeated for all the transcripts individually.

3.6.16 Stage three

The 18 interviews resulted in 1699 codes across the data set. The codes for each transcript were reviewed to determine duplication of codes or codes, which meant the same thing but were coded in different ways. All of the duplications of codes across the data set were eliminated. Once refined, there were 248 codes across the dataset. These 248 codes were analysed by going back to the data and understanding what the participant was saying. The codes were then put into themes that reflected the participants' experiences. All the emergent themes were then categorised into clusters, and I began looking for connections between each theme by going back to the transcript. All the clusters identified were checked back to the transcript to ensure that the participant's voice was interpreted accurately. Mind mapping was done with each emergent theme and the clusters to understand each theme better. A copy of a Mind Map can be found in Appendix 15. Multiple supervision meetings were held with my supervisors in which I presented the themes, and when we discussed each emergent theme, I was recommended to go deeper into what the participants were saying. The mind mapping exercise helped me to go deeper as I could view each theme from a higher level and then drill down to what the participants were saying. During one of the last supervision meetings I had about my analysis, I created a PowerPoint presentation for my supervisors to explain the subordinate and superordinate themes developed through this study. This phase of the study was an iterative process, as it involved a close relationship between myself, my supervisors and the voices of the participant (Smith & Osborn, 2007). This phase also illustrated the double hermeneutics of IPA, as I was trying to make sense of what the participant was saying while at the same time trying to make sense of their interpretation (Smith, 2015; Smith & Osborn, 2007).

3.6.17 Stage four

The clusters were then given an overarching name, and these represented the subordinate themes (Smith & Osborn, 2007). A final table consisting of the superordinate themes across the data set consisting of subordinate themes of each interview was constructed (Smith & Osborn, 2007). The challenging part of this process was prioritising the data to determine which themes to focus on and reducing them (Smith & Osborn, 2007). The superordinate themes were not selected mainly by prevalence but also by the richness of the themes and how the participants' voices were reflected (Smith & Osborn, 2007). This stage of the study was iterative and involved going back to each transcript as a way of capturing any earlier insights that may have been missed. During the analysis, I interacted with the data at a high level of interpretation to identify similarities and how this fit with the overarching theoretical framework paired with the characteristics of each participant (Smith & Osborn, 2007). Verbatim extracts were used to provide context to the superordinate themes (Kelly

& O’Brien, 2015). The use of verbatim extracts in an IPA study illustrates sensitivity to the raw data (Shinebourne, 2011).

3.7 Ethical considerations

The four basic principles of ethics – beneficence, non-maleficence, autonomy, and justice – will be upheld throughout this study (Reyna, Bennett, & Bruera, 2007). As this was a very sensitive subject, there were many ethical considerations, which are discussed in the ethics application (Appendix 4). One of the critical ethical challenges related to this study was around the potential for emotional distress when sharing experiences of caring for adolescents and young adults. Resources for emotional distress were provided to each participant before each interview beginning. During the interview, when participants became emotional, it was important that I asked if a break was needed and, at times sat in silence until the participant was ready to continue with the interview. The termination of the interview was possible if the participant chose not to continue, however this did not occur. Anonymity was an important ethical consideration given that many stories were shared and personal opinions on organisational deficits. It was important that all identifying information was removed, which was done by excluding the name of the hospice when stated and changing the names of the participants.

3.7.1 Research ethics committee approvals

Research ethics were sought and submitted to Lancaster University, the Faculty of Health and Medicine Research Ethics Committee (FHMREC), and the Health Research Ethics Board through the University of Alberta. The approvals can be found in Appendix 5 and Appendix 6.

Chapter Four: Findings

4 Introduction

In the previous chapter, the methodological underpinnings of this study – constructivism, interpretivism, and phenomenology were discussed. The methods used to recruit healthcare workers from 4 hospices across Canada located in four different provinces, was also discussed. The white circles in Figure 4.1 provides an illustrative view of the province each hospice was located in for this study. Each of the hospices provides care based on physical, emotional, mental, and spiritual needs. The hospices all have interdisciplinary healthcare providers who deliver care based on the needs of the patients. Respite care is quite common in all the hospices, whereas the experience of an adolescent and young adult dying was rare. The services provided at each hospice can be found in Appendix 16. The 4-stage data analysis process was explained, which resulted in the creation of superordinate and subordinate themes. In this chapter, the findings of the research, which illustrate the lived experiences of the healthcare workers who care for adolescents and young adults living with cancer, will be described. The two superordinate themes will be discussed – balancing on a tightrope and acting as a proxy.

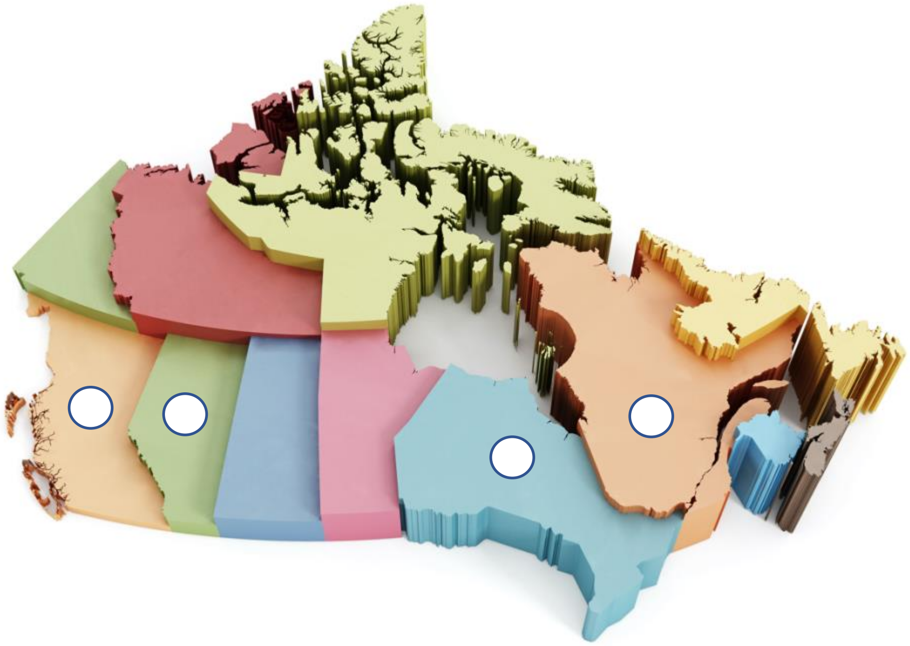

Figure 4.1 Location of hospices across Canada (from left to right, British Columbia, Alberta, Ontario and Quebec). A license was purchased from iStockphoto.com to use this image.

4.2 Interview characteristics

During the period of July to November 2018, interviews lasted between 43:24 and 59:55 minutes, with a mean of 51.58 minutes. The interviews took place at each hospice over one or two days depending on the number of interviews that needed to be conducted. Eighteen individuals participated in the study, and all participants were pseudonymised. All participants were interviewed once. Within this study, there were nine different healthcare disciplines represented, and the years of experience working with adolescents and young adults in paediatric palliative care ranged from 4 to 34 years ,with a mean of 13 years. The sample included eight nurses, two palliative care physicians, two personal support workers, one child-life specialist, one music therapist, one spiritual care coordinator, one recreation therapist, one recreation and legacy coordinator, and one family coordinator. There were

14 female participants and four males, and the age range was 32 to 62 years, with a median age of 46. Table 4.2.1 provides the detailed participant demographics:

Table 4.2.1 Participant demographics (n=18)

Participant characteristic	**Measure**
Sex	
Female	14
Male	4
Age	
Range	32-62
Mean	46
Healthcare specialisation	
Nurses	8
Palliative care physicians	2
Personal support workers	2
Child-life therapist	1
Music therapist	1
Recreation therapist	1
Spiritual care coordinator	1
Recreation and legacy coordinator	1
Family coordinator	1
Years of experience working in palliative care	
0-5	3
6-10	4
11-15	6
16-20	3
21-25	1
26-30	0
31-35	1

4.3 Research themes

Using the data analysis method outlined in Chapter Three, from the 18 interviews, 1,699 preliminary codes were generated. These codes were refined and were assumed into 248 codes, which were then interpreted to form themes. The list of codes can be found in Appendix 17. A total of 10 subordinate themes were identified, which were clustered into two superordinate themes. Following the IPA guidelines, verbatim quotes are used to ensure that the voices of the participants are heard through the interpretation of their lived experiences (Brocki & Wearden, 2006). The first superordinate theme – balancing on a tightrope – is underpinned by experiences of uncertainty. The six subordinate themes illustrate the balance healthcare workers try to maintain when providing care, making decisions, and supporting families.

The second theme – acting as a proxy – illustrates what it is like being an outsider to the family, a paid professional, and support to the parental role. The four subordinate themes demonstrate the experiences of observing adolescents and young adults and their families and the experiences of caring from this perspective. Table 4.3.1 illustrates the superordinate themes and subordinate themes.

Table 4.3.1 Superordinate themes and subordinate themes

Superordinate themes	**Subordinate themes**
Balancing on a tightrope.	• Seeking ways to relate despite the inevitability of experiencing failure and loss • Transitioning care: heroes, uncertainty, and failure • Early referrals and crisis situations: the role that time plays in making connections • Small decisions and big decisions: focusing on the path of least regret • The bridge between adolescents and young adults and their families • Being comfortable with being uncomfortable
Acting as a proxy.	• Deflating the elephant in the room: complex conversations require honesty and transparency • An uncertain future • Hope: its transitions and forms. • Adolescents and young adults being cared for in a hospice versus a hospital

4.3.2 Superordinate theme one: Balancing on a tightrope

This superordinate theme, consisting of six subordinate pieces, reflects the common experience of a sense of failure when dealing with the fear of not being able to make every experience perfect and maintaining the hero narrative often associated with healthcare workers in this field. Supporting adolescents and young adults are described as complex and multidimensional, as it involves the healthcare providers sitting in a place of uncertainty and discomfort. Healthcare providers experience uncertainty and discomfort as being rooted in supporting decision making and being the middle person between the adolescent and young adult and their families, while ensuring that healthcare workers can live with the decisions that are made. Accomplishing the wishes and dreams of the adolescent and young adult is one way that uncertainty was countered, as healthcare workers felt it is their job to tie up loose ends. That sense of ownership over the adolescent and young adult played into the notion of doing their best all of the time.

4.3.3 Seeking ways to relate despite the inevitability of experiencing failure and loss

Finding ways of relating to adolescents and young adults played an important role in the delivery of care. Healthcare workers worked hard at building connections that would support the hopes and wishes of adolescents and young adults:

> *'The critical role that we play really is through relationships. If we can develop a relationship with a family or a patient, we can understand and translate for them the medical tools that will serve their hopes and wishes better.'* ***Palliative Care Physician Kurt***

Concerns were raised that the relative lack of shared interests with the adolescents and young adults for whom they cared could lead to challenges in finding a basis upon which to develop a relationship. Exploring different music interests were described as one way of relating to this population.

> *'A typical doctor thing is to say, "How are you? How is your pain today?" And I'll come in and say," Wow. What music are you listening to?" Like they'll have their headphones on. "Oh. I don't know that band tells me about it." I've gotten into some really interesting conversations with kids about bands ... when a kid tells me, "Oh I listen to this band." I'll go home and I'll YouTube it and I'll listen to it and...then I'll be able to have a conversation with them.'* ***Palliative Care Physician Howard***

There had to be a process when building relationships, as when healthcare workers don't have a connection, it makes working together difficult. When that connection is made, the relationship is mutually beneficial.

> *'If I go straight up ahead and ask questions about his disease without having that process in between ... there might be some resistance. I think that we mutually help each other maintain that relationship even though things get hard ... we can always work towards the same goal.'* ***Personal Support Worker Brittney***

The age of the healthcare workers played a role in the ability to connect with adolescents and young adults. Healthcare workers who were younger had an easier time building relationships than healthcare workers who were older, as the younger workers tried to connect with them by acting like a friend. As adolescents and young adults are on the cusp of adulthood, they have more abilities to make the decision about who is involved in their circle of care, as opposed to younger children whose parents make the decision. It was felt that adolescents and young adults sometimes viewed older healthcare workers as a parent and therefore at times found it harder to relate.

> *'I find that the older nurses here have a hard time connecting with the adolescents and then the younger nurses here connect ... more easily with the adolescents here.'* **Nurse Dexter**

Supporting adolescents and young adults was challenging. There was a sense of failure when a healthcare provider could not connect with the adolescent and young adult. Insecurities were attributed to a large age gap between the healthcare workers and the adolescent or young adult, which made building connections difficult. Healthcare workers try and stay informed about the most up-to-date technology and trending music as one way of being relatable.

> *'I'll do my best to, you know, find ways to bring that kind of music to ... them ... but, you know, I think ... sometimes maybe the age ... difference ... might make a ... bit of difference to the fact that I am an older adult as opposed to, you know, someone closer to their age. And I found, for instance ... I've had music therapy interns working here with me ... and, generally speaking, they've been like in their ... early 20s. And that I, I found that somehow that has helped too, you know, to kind of ease that relationship building.'* **Music Therapist Kelsey**

Sharing the same gender and being closer in age were attributes that made connecting easier:

> *'I definitely relate more to other males ... and it's harder to connect with the females, but I would say that they do relate pretty well to me…. I would say it's an age thing, too. I think that ... they relate more to those who are closer to their age who have similar interests than to those that are farther their age.'* **Nurse Dexter**

Adolescents and young adults were difficult to connect with, as healthcare workers sometimes have to show what they have to offer in order to be invited into the adolescents' and young adults' circle of care.

> *'Teens I find ... you have to kind of find that place ... where they can relate with you or that they are going to trust you or that they see a reason to invite you into their experience ... it seems that there's more processes happening on their end .... I think teenagers need to know that there's a good reason why they should do that....”* ***Spiritual Care Counsellor Liza***

There is an intersect between identifying commonalities based on interests and relatable things such as age and gender. There is value in maintaining autonomy and independence with adolescents and young adults, as healthcare workers caring for this population can sometimes be viewed as a parent from the adolescent and young adult's perspective, and therefore building that connection was challenging.

There is a pressure felt by healthcare workers to make connections with adolescents and young adults, as there is this need of wanting to be accepted and liked. When healthcare workers were unable to build that connection, a sense of failure was felt on their end. The awkwardness of trying to find connections and build that relationship sometimes made the healthcare workers feel like an inconvenience to the adolescent or young adult. Adolescents and young adults were often perceived as being interested in spending their time doing other things.

> *'I think you want so you want so badly to make connection in this work that if you don't, then it feels like, it feels like a failure, but you just need to realise that it was never necessarily the intention for the patient.... I don't think he really did. I think I was, um, I was always from the beginning I felt like just another person. And so, for somebody who wants to really focus on something, I was more like another interruption, and so I think I tried to change it so that I would catch him between activities, and he was always, he was always very polite ... but there was just never anything more than that.'* ***Child Life Specialist Kayla***

Healthcare workers spend a lot of time and effort finding ways of relating, and when they do so, relationships are formed. Attachment plays a role in creating intimate and personal bonds with each adolescent and young adult. As adolescents and young adults move through their illness, healthcare workers experience difficulty once the death occurs, due to the intimate attachments that were built. Once the death of the adolescent or young adult occurs, feelings of loss are experienced. Feelings of attachment and loss differed for each healthcare worker depending on the role they played with the adolescent and young adult and their family.

> *'I feel like I care about every one of our kids deeply, but there are some who maybe have had a bit more of a difficult family situation and I was a steady person to them. So, they leaned into me a little bit more.”* ***Recreation and Legacy Coordinator Helen***

As the attachment grew, the relationship also grew stronger, and the death of the adolescent or young adult was described as painful. It was difficult when a healthcare worker was not on shift and would come to work and find out that the adolescent or young adult had died. Upon reflection of an adolescent or young adult’s death, this was said.

> *'We had one little guy. He was 15, and I come in and the girls at the counter said ... did you hear ___ passed away? And honestly all I could do was stand there and cry. I walked up and down and all I could do is cry ... 'cause he's one that we worked with a lot ... and I tell him, I whisper in his ear that he was driving me crazy, and he just laughed.... He lights up my heart and he broke it at the same moment.”* ***Personal Support Worker Brittney***

As finding ways of relating was important, the failure to connect was what healthcare workers tried their hardest to avoid. Grief occurred when the adolescent or young adult had died, and attachment played a role in this grief. Whether there was a failed connection between the adolescent or young adult or grief due to the death of the adolescent or young adult, the loss was felt in either situation.

4.3.4 Transitioning care: heroes, uncertainty, and failure

When supporting adolescents and young adults living with cancer, healthcare providers who worked in oncology explained that curing cancer was often the main goal of treatment, as their job was to be the hero, fight cancer, and help people survive. The need to fight a battle or win a war was explained as the way that some healthcare workers in oncology approached illness when caring for adolescents and young adults. This approach of battling advanced cancer caused a divide between cancer teams and hospice teams as palliative care is often viewed as a failure and as a last resort in treatment options. There were times when adolescents and young adults with advanced cancer were sent to the hospice while receiving active treatment, and a divide was felt, as the goal of the hospice is not curative treatments. It was felt that there needs to be a shift in caring when transitioning care from curative treatments to hospice care, as this may help to break the narrative of heroes versus failures. If cancer was approached differently prior to adolescents and young adults being referred to hospice care, healthcare workers would be able to better support them and families through this transition of care.

> *'That sense of we're going from cure to palliation and comfort care ... is often a shift that I think feels more difficult professionally within the cancer population ... because of cancer, because of language, because of everything we know in media..and life, it's all about surviving and fighting.... I find here is ... such a shift that there really needs to be almost a philosophical shift for families to be able to go from..active treatment here is ensuring you're comfortable, is ensuring you're not in pain....'* ***Child Life Specialist Kayla***

Supporting adolescent and young adult healthcare teams and families who were focused on curative measures was a hard place to sit and caused challenges in delivering care at the hospice. Within the hospice teams, physicians try not to mislead their adolescents and young adults about the illness, as they understand when curative measures are no longer an option. Part of the role of the team is trying to help other healthcare workers embed palliative care into what they do. At times their abilities as a team have been questioned, when the outcomes of what teams want are different from what the hospice provides. It was felt that they support transitions of curative care to hospice care as well as they can.

> *'Trying to help healthcare practitioners think of palliative care as something that they do, just not so intentionally or not so upfront ... when we are getting to the point of deliberately thinking palliative care ... because we are recognising there is uncertainty about our ability to achieve certain desired for outcomes ... life-threatening or life-limiting, the terminology keeps waxing in and out ... so we're very good about supporting that transition as well as it can be.'* ***Palliative Care Physician Kurt***

When supporting adolescents and young adults, uncertainty was often experienced due to the limitations of what could be provided. The experience of supporting adolescents and young adults as they transitioned from curative treatments to moving into the hospice was difficult. There were experiences of being faced with an uphill battle with families and adolescents and young adults when honest conversations did not take place prior to referrals being made. It was felt that if the hospice team was involved earlier, acceptance of hospice care from adolescents and young adults and their families would be less challenging and would better align with what the hospice provides.

4.3.5 Early referrals and crisis situations: the role that time plays in building relationships

Healthcare workers often wanted more time to build relationships, but a poor prognosis often meant that this was not possible. Time gave the healthcare provider an opportunity to learn more about adolescents and young adults and their families. Healthcare workers felt that the early integration of palliative care was the foundation of relationship building. Early referrals gave healthcare workers the time they needed to support families throughout the illness.

> *'The more and more they come and get consulted, and familiar faces, and get used to working with the team and seeing what they can offer ... it's just time.'* **Nurse Joy**

When time was not possible due to a crisis situation, trust and support were built differently, driven by imminent needs. Crisis referrals at the end of life for adolescents and young adults were described as occurring often. Healthcare workers described themselves as firefighters, who are parachuted in when there is a crisis and cure was no longer an option. As time was described as not always available, through the highly emotional intensity, connections were built but in a different way.

> *'The relationship they built with the person who was there for that last 3 days was phenomenal. So, because of the emotional intensity, if you can still serve a need and be seen to serve that need, that relationship will evolve, as opposed to often*

> *what we're aiming for is trying to develop the relationship so that our medical role can be trusted thereafter.'* **Palliative Care Physician Kurt**

This quote illustrated how time does is not always needed to build connections; however, time was experienced as being important in being able to get to know the patient, what is important to them, and to provide care less in a crisis and more proactively.

4.3.6 Small decisions and big decisions: focusing on the path of least regret

Healthcare workers play an important role in decision-making with adolescents and young adults and their families. They place a lot of pressure on themselves to do the best that they can be based on decisions made. These decisions impacted the way healthcare workers are able to come to terms with the role that they played in the adolescents and young adults' and families' lives. Healthcare workers are always trying to do their best and live with decisions that would cause them the least regret in the future.

> *'It's a negotiation, it's a process every time, and ... there are times when you are left saying, "I wish it hadn't had to have been that way ... and we're trying to find the path of least regret ... so when it comes down to hospice, I think what I'm finding is we are all of us trying to do what we think is best for this young adult.'* ***Palliative Care Physician Kurt***

Self-reflection played a role in the need of healthcare workers to do their best. Thoughts of healthcare workers second-guessing their choices was common. Healthcare workers have to live with the decisions that they make, as they take on the accountability for framing the experiences of adolescents and young adults and their families. When death is ultimately the inevitable outcome, there can still be negative and positive experiences for the adolescent or young adult, their family, and the healthcare worker. Regardless of the outcome, these experiences shape the professional practice of healthcare workers and negative outcomes often caused feelings of failure.

> *'I think as a caregiver, you look back, and did I miss signs, could I have anticipated this, could I have called Mom earlier ... you are stuck with the guilt and grief of a caregiver and trying to create this experience for a family to be as peaceful and supportive as ... you can. And when that doesn't happen, I think you, you carry that and ... for your practice and for that family that you have somehow shaped their experience. And sometimes, it's negatively and not positively.'* ***Nurse Kim***

Nurse Kim shared a story of an adolescent whom she supported who died suddenly and the impact that this had on her. The adolescent's mom had placed glow-in-the-dark stars on the ceiling in his room. That evening they had planned to stargaze and raised the hospital bed as high as it could go so that he could feel as if he was touching the stars. The adolescent's mother stepped out of the room, and the adolescent asked Nurse Kim for some tea. Nurse Kim returned within 5 minutes, and the adolescent was unresponsive and had died. She struggled with calling the doctor, and when the mom came back inside had shared the news with her.

> *'I was by myself ... and then Mom was honestly like grief stricken and angry and.it didn't go the way that I would have ever wanted it to go, and he died ... and so.... I*

> *don't even think looking back like anything would have necessarily changed or gone any different but ... then you go through all the emotions ... like they didn't get to say goodbye and I didn't get to hold him, and I didn't get to say, "I love you." and all that stuff.'* **Nurse Kim**

This story describes painful and unavoidable uncertainty with this population and how suddenly things can change. Healthcare workers often strive to ensure that adolescents and young adults experience memorable moments, and regret over the loss of control is experienced when things do not go as planned. When reflecting on situations that did not go as expected, healthcare workers often reflect back on their actions, trying to think of ways they could have done things differently. There was a sense of failure that was expressed, and when special moments change, the tragedy is often the focus of the experience and not the fact that the adolescent or young adult was living with an incurable illness. When a tragedy is experienced, healthcare workers often reflected on all of the things the adolescent or young adult did not get to experience, and regret is often experienced.

Wanting everything to be perfect and avoiding feelings of failure and regret were described as a reason for making decisions driven by emotions. The difficulty of knowing when emotions were entangled with trying to best support the adolescent or young adult was described as challenging.

> *'This girl was 17, and she was coming for a doctor's appointment, and she had more lung nodules in her lungs. And the doctor was talking to her parents, and she was kind of begging me to tell her what the scan showed and ... my gut told*

> *me that I should feign ignorance and let that discussion be held with her mom, and dad, and the doctor, but I didn't listen to that and I ... got swept away by emotion and her asking me, begging me to tell her, and I told her and it absolutely, it was the terrible thing to do. She was devastated and then her parents came and then they, you know, she knows, and we weren't here. It was terrible and I will never do that again…I always have to be very careful with my boundaries.'* ***Nurse Joy***

Healthcare workers bear suffering while rationalising decisions that were made. Healthcare workers often fixate on what they perceive as a mistake and experience feelings of regret when the experience was not perfect. Having situations take an unexpected turn result in regret and overall, a sense of failure.

Prognostication should cautiously be discussed, as giving adolescents and young adults and their families an exact time was described as often being incorrect. When discussing prognosis, analogies are sometimes used as a way of supporting families to better conceptualise prognosis. However, having the ability to observe the way adolescents and young adults and their families digest the information is important when sharing these analogies. Analogies had to be shared with sensitivity, or they could come across in an unsympathetic way that was not deliberate and end up being hurtful.

> *'And that hit the family that I was talking to a bit too hard at that point ... but to be able to say that I've pushed you over the edge, I've recognised[d] that, I've broken through an emotional shield.... I felt that I had used a poor analogy for that*

> *particular moment.... I hadn't been aware of how close to not being able to handle what we were talking about the family was.”* **Palliative Care Physician Kurt**

There is a need for healthcare workers to feel as if they have all of the answers and have the ability to make each situation perfect. When situations don’t go as planned, there was a need for healthcare workers to forgive themselves as a way of working through their sense of failure and suffering. Having the ability to forgive themselves and understand that they are human was a way of coping when things didn’t go as planned. Reflecting on personal vulnerabilities played a role in forgiveness.

> *'I think I've become a lot more ... forgiving of my humaneness ... I can't get it right all the time ... having compassion, not just for the vulnerabilities I see but also for my own ... humaneness and vulnerabilities.'* ***Music Therapist Kelsey***

When walking on a tightrope, being in a dilemma was viewed as being one of the hardest places to sit when the parents wanted to go in a direction that was not medically advised. Balancing the hope of the family and the well-being of the adolescent or young adult was challenging when faced with these dilemmas. Palliative Care Physician Kurt described a dilemma where the family wanted the use of extensive treatment options that were not beneficial to the adolescent or young adult. The adolescent or young adult decided to do the treatment as a way of appeasing his parents. Situations like this are difficult to work through, and healthcare workers feel it is their job to protect the adolescent or young adult, but they also understand the difficult situation families are in as they try to maintain hope in all possible ways. Healthcare workers felt it was important for them to open up space for the adolescent or young adult to say what they wanted and know that they had the support of the team.

> *'He was probably fifteenish.... I said that, you know, "I don't see this medically serving you in any way. I see it potentially making you very uncomfortable without gaining you anything. But I see you trying to appease what every party is asking for. Is this the best way you can see going about it, or would you be comfortable saying, 'I just can't face this anymore,' and we can support you in that?" and I let him direct us.'* ***Palliative Care Physician Kurt***

Having these meaningful conversations with the adolescent or young adult often strengthens the relationship between the healthcare provider and the adolescent or young adult. This also helped the healthcare provider cope when things did not go as planned. Taking time to balance their roles in a premeditated way was important when supporting adolescents and young adults and their families. It is often the role of healthcare workers to balance the see-saw between the adolescent or young adult and the family and ultimately know when they needed to spend more time with the patient. Acknowledging that the parents may have received more attention than the adolescent or young adult was important. Spending more time at the bedside was one way of ensuring that the adolescent and young adult were being well supported and supporting adolescents and young adults to make decisions based on what they wanted and not what their parents wanted.

Conversations around advance-care planning were uncertain and complex conversations to have with families and adolescents and young adults, as there is not always an agreement between the adolescents and young adults and their parents. Adolescents are unable to make care decisions of their own until the age of 16, and therefore their parents still have the final say. Healthcare workers are sometimes blamed when things don’t go as planned. Multiple family meetings are often held as a way for healthcare workers to communicate with families about their decision options. When families make decisions that are not in the best interest of the adolescent or young adult, healthcare workers experience feelings of guilt.

> *'We recently had a family, and it was a mother and her son ... and ... there was a lot of issues with the DNR form ... and her signing it and not signing it .... But it just felt like nothing we were doing was good enough because she kinda portrayed that on us ... DNR was signed, and then Mom found out ... and said she never signed it ... so there's ... a meeting with one of our physicians, and Mom and ... he died at hospital.”* **Nurse Dexter**

Uncertainty played an important role in advance-care planning discussions. There is a need to make it clear to families that decisions made were never set in stone and could change as the disease progressed. Knowing that decisions were not final helped participants cope:

> *'I always tell families when I'm having advance-care planning discussions, this is a conversation that has no end until the end has declared itself, because we don't know what's going to unfold, when and next.'* ***Palliative Care Physician Kurt***

It was the role of healthcare workers to discuss many possibilities when it came to advance-care planning as a way of not having to bear the suffering of decisions made, discussing multiple options helped them cope with uncertainty and fear. Being able to share multiple scenarios also helped adolescents and young adults and the families better conceptualise their choices and plan for the unknown. Being transparent and using expressions that were not cliché was imperative.

> *'We often say to families, "Live day to day", and I don't say that to families because I don't think it means anything. I always say it's a fridge magnet. What I tell ... people are you live, and you literally plan multiple possibilities at the same time.... I cannot place the mom who said to me that, I wish I remember which mom said it to me. She said, "Only at ______ a parent meets her kid's kindergarten principal and funeral director in the same week.'* ***Palliative Care Physician Howard***

4.3.7 The bridge between adolescents and young adults and their families

Healthcare workers felt it was their job to try and make things as good as it could be. Part of that included helping to facilitate healthy relationships between adolescents and young adults and their families. It was felt that it is their job to build and maintain a bridge between adolescents, young adults, and their families while understanding that everyone has their own beliefs. It was the goal of healthcare workers to ensure that the family's relationship is maintained.

> *'I will be very honest and authentic and recognise that each has their own set of truce, and to try to help them come to a ... bridge so their relationship isn't destroyed.'* ***Nurse Joy***

Healthcare workers felt that adolescents and young adults are often more comfortable with speaking with them than their parents, due to complex relationships and the need to protect their families. Being this bridge helps healthcare workers maintain relationships with adolescents and young adults and their families, which overall improves how they are able to meet the needs of the adolescent or young adult.

> *'We ... had ... a kid that actually came a while back. I think he was ...15. He lived most of his life outside of Canada. He came to Canada once he got sick. He met his mom for the first time in years ... he was working his relationship with her ... and it wasn't easy because the communication wasn't ideal ... so we were that bridge between them, where he would feel more comfortable telling us ... that he was uncomfortable, that he was feeling pain ... he was uneasy saying that to his mom because he didn't wanna make her nervous, he didn't wanna stress her out ... so we were that bridge where we were able to try to bring the two closer during that period of time....'* ***Personal Support Worker Steven***

Healthcare workers experienced multiple ways in which death was explained to adolescents and young adults by their families. These conversations were often driven by faith and beliefs, which at times caused discomfort. The notion of reincarnation was described as difficult when adolescents and young adults believed that once death had occurred, they eventually came back to life. Not acknowledging death for what it is was viewed as having an impact on how adolescents and young adults died and the way families grieved after the death. Religious beliefs that framed death in a non-permanent way were distressing for healthcare workers. However, they expressed the importance of understanding that every family views death differently, and it is not up to them to tell families how to view or cope with death.

One of the biggest challenges faced by healthcare workers when balancing their role with adolescents and young adults and their family was pain management. It is difficult for healthcare workers to manage pain and symptoms, as parents sometimes express the belief that the medicines used caused their child to die faster. There were times when the adolescent or young adult would be in pain, and the parents would want either more medicines or fewer medicines without acknowledging what the adolescent and young adult were feeling. Healthcare workers experience a sense of failure when adolescents and young adults are in pain. Healthcare workers would provide comfort based on their clinical expertise, and there were experiences when the parents blamed the healthcare workers when their child had died.

> *'So, in the end, it was hard to manage the child's pain and get them comfortable with the parents suggesting that their kids were fine ... and ... then at the end, us ... giving the medications to help with comfort and then almost turning around and saying that we killed their child.'* ***Nurse Dexter***

Given the emotional environments of the hospice, adolescents and young adults and their families sometimes take their frustrations out on healthcare workers. This was difficult to cope with, as healthcare workers try to do their best, and when families or adolescents and young adults are upset, a sense of failure is experienced. Reflection played an important role in dealing with their experiences of failure. Healthcare workers must remember that adolescents and young adults and their families are managing difficult situations, which they are not often familiar with, and the feelings of the adolescent or young adult and the families are sometimes projected onto them. Having the ability to remember not to take things personally was important in finding ways of managing this projection.

When working with adolescents and young adults, at times, you work more directly with their parents. When working with families, difficult social and family circumstances play a role between the adolescent or young adult and the healthcare provider. Relationship status between parents, whether they were divorced or separated, were factors which impacted care delivery. Healthcare workers must create a strong middle ground to support the whole family unit.

> *'I think we managed to negotiate a really good middle ground where everybody was having their needs met ... it did involve an awful lot of...planful conversations ... and structuring time and trying to support this girl ... facing her death, dealing with symptoms, having two sides of the family that couldn't get together.'* ***Nurse Sally***

Understanding the experiences of adolescents and young adults was important, and recognising that some families have experienced trauma and grief in their lives, however, they were able to get through it and, in some ways, control the outcome. Healthcare workers expressed that as a parent, there was a loss of control, and this made dealing with their child’s illness that much harder.

> *'We've had families who've been here who have been refugees. Who've ... witnessed horrors in the world and they've actually said this is the worst. This is like watching their child die and not being able to change that outcome. And ... that to me was just rough like shocking ... because of hearing their stories and*

> *knowing where they just came from and what they live through....'* ***Recreation Legacy Coordinator Helen***

Being able to take a step back and observe the family is an important way to support families. Being able to bracket one's personal feelings gives space for various ways of supporting families and their individualistic needs while also understanding the role of trauma and how this supports families' approach to death.

4.3.8 Being comfortable with being uncomfortable

Healthcare workers exert a sense of ownership over adolescents and young adults and make it their responsibility to ensure that they do their best. It fits into this hero narrative of healthcare workers wanting to make all dreams and wishes come true. While trying to do their best and meet these wishes, feelings of worry, concern, and discomfort were sometimes felt as healthcare workers did not want to fail. There were times when granting certain wishes felt risky; however, the healthcare workers wanted so badly to make the adolescents and young adult's experience perfect that they went ahead anyway. There was an importance of letting go of control and supporting the adolescent or young adult to do what they wanted, even if it did not fit with what the healthcare team thought was the right thing.

> *'There was a young man ... he was 17. And he was a Haitian ... he came from Haiti ... and ... his mother was over there ... and he needed to see his mother. So, it wasn't easy because he had a lot of ... medication and he had to go alone to Haiti and ... we weren't sure if he would ... he could make it ... we arranged everything and then he was over there with his mother and ... it was very poor.*

> *And he had a phone, a satellite phone and he had to go where it was very hot in high mountains to talk to us and when I talked to him, he was like, "This is the best day of my life. I'm with my mom ... she's with me. I'm in ... her arms" ... and so for me, that was great, you know ... it wasn't the best conditions over there, but he was with his mother ... and he came back, he died a few days after that....'*
> ***Nurse Alissa***

One of the difficulties of supporting adolescents and young adults was when there were complex family dynamics, such as divorced parents. Having to witness the adolescent or young adult wanting to have both parents come together was described as difficult. Healthcare workers often felt it was their role to help navigate the complex family dynamics and would take it upon themselves to make everything as peaceful as possible.

> *'A child who died here of cancer ... and his parents were splitting up and it was close to Halloween ... he just wanted his parents to be together, and they didn't really get along but ... they came here together ... and he liked costumes and ... he liked music and air guitar ... and his parents so that they didn't have to really face each other decided to dress up ... they were totally in ... costume so they couldn't see each other and they started playing ... when he saw his parents like that, he just got up on his bed and he starting playing [laughs] ... and he died the day after."* ***Family Coordinator Alexandra***

Being comfortable with being uncomfortable involves the ability to accept uncertainty and accepting the choices of an adolescent or young adult which valued their own personal values and beliefs. This sense of ownership enabled healthcare workers to believe that they had the right to question decisions that were made when it didn’t fit with what they believed. Palliative Care Physician Howard described an experience in which they supported a young woman who was dying of a brain tumour and declined treatment as it was not going to prolong her life. After making this decision, she found out that she was pregnant. She decided that she wanted to keep the baby and have her family raise this child. This caused many emotions during a meeting, and the team's ethics and moral compass interfered in recognising that it was this young woman’s right to make her own choice. There was a divide within the team, as some believed that going through the treatment would harm the baby, and making this decision made the adolescent and young adult selfish. A discussion was held where the goal was to realign the team and understand the adolescent or young adult’s wishes while not thinking of themselves.

> *'I really went in and said ... I need to help people see that there's really a couple a clear choices to be made, and they're ultimately this young woman's choice. None of them violate ethical principles, none of them violate the law ... some of them were very distasteful to people in the room.... And people were having all these kinda conversations that really weren't about the clear thing in front of them, which is this isn't your choice....'* **Palliative Care Physician Howard**

When healthcare workers are managing difficult situations that do not fit with their personal ethics, values, and beliefs, finding individual ways of healing and coping plays an integral role when supporting adolescents and young adults.

> *'Your heart ... is going to be broken in this work. The difference is some people repair it with steel and some people prepare it with gold. Some people have hearts*

> *of steel, and some people have hearts of gold, and it's the way in which we allow ourselves to heal from that ... because we're going to break. These are kids who are dying.'* ***Recreation and Legacy Coordinator Helen***

4.4 Superordinate theme two: Acting as a proxy

This superordinate theme consists of four subordinate themes revealing the healthcare workers observations and perceptions of caring for this population. Engaging in complex conversations was discussed in-depth with the participants. These conversations were difficult and required being transparent, honest, and direct. These conversations were often impacted by the role that families played and the need for adolescents and young adults and families to protect each other from what was viewed as hurtful information. As the future for adolescents and young adults is quite uncertain, an emphasis was placed on living in the moment and finding meaning and purpose each day. Hope was viewed as playing a fundamental role in this population and as something that continuously changed. Working and caring for this population at a hospice was different from that at a hospital and more appropriate for care. The challenges of adolescents and young adults fitting into the adult palliative care system was described.

4.4.1 Deflating the elephant in the room: Complex conversations require honesty and transparency

Adolescents were felt to intuitively understand if they were being lied to. Being honest and sharing accurate information enabled the establishment of trust. The one way that adolescents and young adults felt control was through knowledge, even if this knowledge was not what they wanted to hear. At times, the adolescent or young adult already knew the answers and tested the healthcare worker to see if they could trust them. Being authentic and genuine is pivotal in supporting complex conversations. Using euphemisms was not a good way of communicating. Being direct and straight-forward while also being empathetic and caring was viewed as important when having complex conversations.

> *'I don't use euphemisms. I don't dodge around things.... So if I want to know about a kids sex life I say, "Are you having sex? Do you have a partner? What's that all about?"... Then they can decide what language they want to use with me.'*
> ***Palliative Care Physician Howard***

One of the most direct and challenging questions that is often asked is 'Am I dying?' and after hearing that they are going to die, expressing that they do not want to die. It is important for healthcare workers to understand that they cannot change the inevitable even though they wish that they could.

> *'Asking adolescents what is it that they're afraid of? I think one of the things I find hard is, sometimes, they're saying, "But I don't want to die" and us having to say, "We wish you didn't face dying at this point too, but I can't stop it from happening." And ... I haven't really delved too much into what is it that makes them they say that, because that's very common."* ***Palliative Care Physician Kurt***

Adolescents and young adults tend to open up when their parents are not around, and this is something that usually occurred in the middle of the night.

> *'Sometimes they just wait till the middle of the night when their parents aren't around and that's when the questions come. Or it might be that the parent's gone*

> *out for a shower, and they're on their own in the room, and there might be something that's scaring them or a question that's been bothering them, and they will ask it then.'* ***Nurse Jasmine***

Adolescents and young adults would ask direct questions and would want frank and direct conversations. By addressing these direct questions, the elephant in the room began to deflate. Death was something that everyone knew was imminent; however, the need to protect on both ends did not allow death to be acknowledged. Once direct questions were answered, although emotional, there was often a sigh of relief, and healthcare workers were able to better support the adolescent and young adult in different ways.

> *'And in the middle of the night 'cause it was a very common thing this teen said to our nurse ... "I'm gonna die aren't I?" The nurse said, "Yes, that's what's gonna to happen here." And the girl cried for a little bit and the nurse just stayed with her and then the nurse said, "What does that mean to you? What would you like?" And the girl said, "I want to have a big party before I die with all my friends." And the nurse says, "That's a great idea. Let's plan the party.... And she also said, "Don't tell my parents that we had this conversation because that will upset them.'*
> ***Palliative Care Physician Howard***

Adolescents and young adults were described as at an age where they were thinking about the future and such things as university, marriage, and planning their goals and having dreams. When the conversations about death were had, adolescents and young adults often thought about how this would impact their future and all that they dreamt of it to be.

> *'Adolescents are very quick to ask. How is this going to affect my life? How's this going to affect my self-esteem? How is this gonna affect my English class? How is this going to affect that ... degree I wanted to pursue at this university?"* **Nurse Sabrina**

Although healthcare workers viewed some adolescents and young adults as being quite mature, it was important that healthcare workers remembered that discussing death and dying was not something that many had done. Having these existential conversations slowly at a level they could understand was important, while also having the humility to understand that trust may be with someone else on the team and supporting the team member in which there was trust to facilitate these conversations was important.

Families who were open to having these direct and frank conversations were able to spend more quality time with their child, building memories and making the best of the time that they had left. The journey of their child's illness was described as one of peace. This cohesiveness supported the family and team in being able to make wishes come true and refocused the family to live in the moment.

When asked complex questions, taking time to dig deep and open up reflective space was important. Healthcare workers taking the time to let the adolescents and young adults know that they didn't have to rush out of the room and could be there and be present was helpful in being able to address these questions. Explaining to the adolescent or young adult that although death was imminent, the team would continue to provide the best care until the end was important. Spiritual care was described as being beneficial in helping to support adolescents and young adults to discuss complex questions. Nurses or physicians did not always have the scope of practice to address existential questions; however, being able to open the door to this conversation and allow someone from spiritual care to take the lead was beneficial.

> *'Spiritual care is available to us, but some of the questions that we're asked are profoundly meaningful, as opposed to medical ... and it's been a blessing to be able to work with people in those areas sufficiently to be able to say, "At least I can get that conversation rolling, if not to its fulfilment, to a point where they know it's permissible and I can find someone who can take it even further later on."* ***Palliative Care Physician Kurt***

Adolescents and young adults at times were aware of their imminent death and did not want to talk about it or acknowledge it. They were described as being comfortable with not knowing all of the details. Healthcare workers found ways of communicating with adolescents and young adults who would give one-word answers or would not speak at all while also meeting the family's needs in other ways.

> *'I can think of 2 kids who kind of stopped talking to people, but because I went in with ... what do you want? I want to make sure you have what you need ... so one child who stopped talking to anybody, but his mom was like, "I want a piñata so I can, you know, so I can hit it [laughs] and I can get out my you know." And I was like, "Okay," so we made sure that there was a piñata here almost every day."*
> ***Recreation Legacy Coordinator Helen***

This population is often unheard as they have their parents speaking on their behalf as well as their healthcare team, and their voice is sometimes lost. Being present and listening is beneficial when supporting adolescents and young adults. Adolescents and young adults are able to express their feelings and needs and felt heard when just their healthcare team was present.

> *'So sometimes you just don't say anything. You just listen ... you have to have big ears and a ... small mouth ... you have to listen to them. And then as long as they ... start talking to you ... you can talk to them ... but you have to listen a lot."*
>
> ***Family Coordinator Alissa***

As healthcare workers often felt as if they had to have all of the answers, it took bravery to be present and not speak. Having a silent presence is important when there was not much that could be done to change the situation. Being present and listening also supported healthcare workers to reflect on their own personal practice and identify their personal needs to be able to support adolescents and young adults and their families, as well as whether they needed to take a step back. Being a compassionate presence was important. This involved listening with empathy, observation, and opening space for multiple emotions. While being present and by showing love and compassion, words were not needed, and silence made a difference in the lives of adolescents and young adults.

4.4.2 The cycle of protection

When supporting adolescents and young adults, there is a need for parents to protect their children from information regarding their diagnosis and prognosis, which parents viewed as harmful. This need to protect in some cases was based on cultural beliefs, and in other cases, death was not accepted by families, as this population dying was not a normal part of the life cycle and therefore should not be accepted without a fight.

> *'I don't want to use the word acceptance because it.. comes down to the family's experience and whether ... within that culture and within that fight because we, we've met some families that said like, "We are doing curative care until they stopped breathing." That is the only way I can feel comfortable and confident with going forward."* **Child Life Specialist Kayla**

Beliefs and values based on culture and religion played a role with adolescents and young adults wanting to protect their parents. At times, home remedies were used to stop cancer, and it was evident that the adolescent or young adult was in distress; however, they chose to do the treatment as a way of appeasing their parents. Culture also played a role in how death was discussed and what could and could not be shared with adolescents and young adults. Healthcare workers often try to find a balance between an ethical dilemma and respect for the family when information was being withheld from an adolescent or young adult.

> *'For cultural and religious reasons ... we just couldn't, just say to the child.. he was 13, that he was dying. And that caused much angst.... Especially with nursing, feeling that he had a right to know ... I would try and say to nursing, "Yes, it is distressing but he knows, but he respects ... his parents and so he's ... following their culture and he's ... experiencing his palliation this way, where everybody knows he's not going to survive. But he doesn't need it pushed into his space ... he knew."* **Nurse Joy**

Balancing autonomy and independence was a struggle when paired with grief and denial. Healthcare workers are often in the middle of this need for adolescents and young adults and families to protect each other, and in the end,
are sometimes blamed when things don’t go as planned.

> *'Young man was 19 ... and he came into the hospice very, very reluctantly ... I think he's not willing to be here was just like complete reluctance to engage in the fact that he was dying … he was one of these one syllable young guy so ... he wanted to go home early, and I said to his parents, "We haven't tuned up his symptoms enough." And they said, "Look he's 19 years old we can't control him.... I think it went very badly and at the very end when he died ... we were told that we had treated their son very poorly or there's one parent that said ... a veterinarian wouldn't done this with a dog with what we had done with their son....”* ***Palliative Care Physician Howard***

4.4.3 Hope: it’s transitions and forms

Hope is fundamental for healthcare workers, adolescents and young adults, and their families. Hope is something to look forward to or something to help people through the situation they are facing. As adolescents and young adults moved through the trajectory of illness, hope changes. Although some families' hope involved planning for the future, being hopeful for the future did not mean that a family was in denial.

> *'But the other thing I noticed in families is sometimes they'll be talking about hopes for the future, which they know at the same time are impossibilities. And*

> *we've learned from families before us that those are not synonymous with I don't get it ... but they're a way of being able to stay present in the moment and be there when they're needed."* ***Palliative Care Physician Kurt***

Having a boyfriend or girlfriend was important to adolescents and young adults as well as building a future and a family together. There were times when the adolescent or young adult wanted to spend all of their time with their partner looking towards the future. Having the ability to escape reality provided hope and supported them to find ways of always being connected despite the impending death.

> *'We ... also had a 17 year old, and he had ... a ... long-term girlfriend, and it was like incredible to see them being so young and still like so in love... and I guess having that hope with their love ... and like his girlfriend even talked about like wanting to have a baby with him ... so ... she had the child. It's like ... forever. It was incredible to see actually.'* ***Nurse Lindsay***

When working with adolescents and young adults, one of the biggest goals of the healthcare team was to ensure that the adolescent or young adult's hopes were achieved. Experiences were described around special milestones with this population, such as holidays, prom, graduating from school, being sexually active, and getting married. Healthcare workers did everything that they could to complete those wishes and help them reach those milestones. Whether it was turning the hospice living room into a prom or, for one family who did not believe in sexual intercourse before marriage, hosting a wedding so that this wish could be met. Supporting those hope transitions was a way of supporting the grief of the families and having them build memories to hold onto during their bereavement. It also helped the healthcare workers cope with their own grief and experience feelings of satisfaction when hopes were met.

4.4.4 Adolescents and young adults being cared for in a hospice versus a hospital

Among the hospices, care was provided to anyone under the age of 18. Once the adolescent turned 18, there was usually a transition of care from paediatric palliative care to adult palliative care. Given the unique needs of adolescents and young adults, they do not do well in the adult system. Adolescents and young adults are a small population among the adult population, and healthcare workers felt that adolescents and young adults experienced feelings of not belonging and not fitting in. This had nothing to do with the maturity of the adolescent or young adult but rather not wanting to be around other patients who were double their age. There were not a lot of experienced healthcare workers in the adult system who supported adolescents and young adults. As a result of this, some of the hospices made exceptions and supported adolescents and young adults who were over 18, as the care was viewed as better serving not only their physical needs but also their emotional and mental needs.

> *'It's just a kid who's not ready to be doing what adults expect them to do who isn't comfortable being around a lot of older people. Some of them are really ... and I'm going to put this in quotes "acting out" but some of them are really just emotionally having a hard time ... so we've had 22, 23 year olds on the programme who really were just bad fits, and I would say so much that it's not the cancer agency although it does happen there but certainly they end up in the*

> *major hospitals. Those hospitals are really not friendly to teens and young adults at all.'* ***Palliative Care Physician Howard***

The hospice environment was also compared to the hospital environment. In the hospice there is much more flexibility around the delivery of care. Given that in a hospice, setting the focus is not on such things as giving needles and taking vital signs; the focus is really on what the adolescent or young adult wants and following their direction. The hospice was described as a home-like atmosphere in which their day revolved around the choice of the adolescent or young adult and what was important to them.

4.5 Chapter conclusion

Within this chapter, the findings of the 18 interviews conducted with hospice healthcare workers who care for adolescents and young adults with cancer was presented. A total of 10 subordinate themes were identified, which were arranged into two superordinate themes: balancing on a tightrope and acting as a proxy.

The experience of balancing on a tightrope demonstrated the need for hospice healthcare workers to do as much as they could for adolescents and young adults by carrying out grand gestures and fulfilling wishes. The hero narrative was described, as well as the need to try and do as much as possible to ensure that these special moments were carried out. Feelings of pride were expressed when these wishes were granted, and on the contrary, feelings of guilt and remorse were shared when these wishes were not fulfilled. There was a need to take the path of least regret as a way of coping with the death of an adolescent and young adult by ensuring that the hospice healthcare workers did as much as they could when supporting this population.

Hospice healthcare workers expressed the need to build connections and forge relationships. Adolescents and young adults were described as a distinct population given the stage of life they are in, and because of this, finding ways of connecting was viewed as imperative to being able to provide care. Hospice healthcare workers described wanting so badly to make a connection and described ways in which they would try to relate, all of which were viewed as fostering trust, transparency and honesty.

Hospice healthcare workers expressed the tightrope that they are often balancing on when supporting adolescents and young adults and their families. There was a need to find ways of being comfortable with being uncomfortable and understanding that they often had to balance the needs of the adolescent and young adult with the needs of the parents. This often caused distress as hospice healthcare workers wanted to ensure that the needs of the parents were not overtaking what the adolescent and young adult wanted. When supporting families and adolescents, and young adult, having complex conversations about advance care planning was important and needed to be rooted in honesty and transparency. There was a need for hospice healthcare workers to protect and protection was viewed in three ways, protecting themselves, protecting the adolescent and young adult and protecting the family. This need to protect was difficult to manage; however, the hospice healthcare workers tried their best to avoid failure and feelings of remorse. Healthcare workers hoped that when decisions were made, they could look back and not experience feelings of guilt and remorse. In the next chapter, the findings in this chapter will be interpreted in relation to theory and broader literature.

Chapter Five: Discussion

5 Introduction

Within this chapter, the key research findings about the *lived experiences of hospice healthcare workers who care for adolescents and young adults with a diagnosis of advanced cancer and receiving palliative care* are contextualised with reference to relevant international literature, theory and policy. Through an interpretation of the hospice healthcare workers' sense-meaning, two superordinate themes, *balancing on a tightrope* and *acting as a proxy,* were identified. *Balancing on a tightrope* encapsulates the aim to act in a manner which maintains the hero narrative associated with hospice healthcare workers, whilst managing the fear that it might not be possible to make every experience perfect. The *acting as a proxy* theme is centred around how hospice healthcare workers hold space for complex conversations, whilst dealing with the reciprocal cycles of protection which exist between adolescents and young adults, their families, and hospice healthcare workers.

Inherent within both superordinate themes is a need for, or call to, action. The steps taken and gestures made by hospice healthcare workers reflect this action-focused orientation: the need to do, with little evidence of their emotions, such as helplessness, powerlessness, guilt, love, gratitude, all of which were previously identified through the literature review and synthesis described in chapter two. Crying was found as part of the lived experience within this research, but only as an emotional outlet or protective method of coping. Indeed, whilst hospice healthcare workers were able to hold space for adolescents and young adults and their families, there was little evidence of them holding space for themselves (i.e., being with), which the earlier systematic review identified as important. Protection of self, however, was identified as important, forming a key part of the cycles of protection (whereby hospice healthcare workers want to protect themselves, adolescents and young adults and their families; adolescents and young adults seek to protect their families; and their families want to protect adolescents and young adults). These interlinked aspects of doing for rather than being with and the cycles of protection are explored in this chapter, drawing on international literature and focusing first on the notion of a good death, an exploration of decision making and building relationships. Second, the cycles of protection between all parties will be discussed, followed by an exploration of the transitional hero narrative, advance care planning and crying.

5.1 Doing for rather than being with

The research findings centred around being the hero, being comfortable with being uncomfortable, the need to build relationships and supporting the transitions of hope appear to be related to notions of ‘doing’. Within this study, it was found that healthcare workers strive to do their best while taking the path of least regret. There was a need to build relationships as a way of making connections, and through these connections came an understanding of what was important to the adolescent and young adult. When these connections were made, healthcare workers understood the wishes of the adolescent and young adult and tried their best to do what they could to make these wishes come true. This may be rooted in the notion of doing as the ways of being the hero and taking the path of least regret were through ‘doing’ actions, Whether it was through doing things to provide meaningful moments based on wishes or facilitating decision-making which was viewed as causing less distress. Wish fulfilment in this study is embedded in the need to do. However, wish fulfilment by health and social care workers is also suggested as a way of being with by meeting needs and listening to how families are adapting and coping (Ewing, 2009, Wolfe, 2004). The findings of this study go beyond meeting needs and understanding families; the findings of this study further support the notion of wish fulfilment underpinned by daily interactions (West & Zimmerman, 1987) conducted by hospice healthcare workers.

The notion of doing resonates with Swanson's middle-range theory of caring (Swanson, 1991). Swanson describes five caring processes: knowing, being with, doing for, enabling, and maintaining belief (Swanson, 1991). Doing is defined as being rooted in nursing practice and the ability for the nurse to do for their patients what they cannot do for themselves with the overall goal of taking care of the patient's welfare through providing comfort, dignity, predicting needs, protecting from harm, and conducting procedures (Lillykutty & Samson, 2018; Swanson, 1993). Doing for also includes psychosocial approaches to care with therapeutic communication interventions to assist with patients' healing (Swanson, 1993). When looking at similarities with Swanson's middle-range theory of caring within palliative care, studies focusing on volunteer involvement in palliative care utilised this theory and viewed "doing for" as meeting the practical needs of patients with the goal of maintaining well-being (Bloomer & Walshe, 2020; Dodd et al. 2018). The findings of this study illustrated that hospice healthcare workers provide practical assistance to adolescents and young adults through everyday tasks of caring to ensure that the needs of adolescents and young adults are met. However, the notion of doing was not just focused on the well-being of the adolescent and young adult but also on the well-being of the hospice healthcare workers. The divergence of the findings with this theory illustrates what is beneath the notion of doing, an understanding that "doing for" may also be related to how hospice healthcare workers maintain their personal well-being.

Doing for may also be a way of coping with the difficulty of supporting adolescents and young adults.

Related to the subordinate themes, being comfortable with being uncomfortable and the multiple ways in which hope is viewed, hospice healthcare providers felt that when they were able to do for adolescents and young adults, there were feelings of hope and pride as they were able to recognise meaningful moments under challenging situations. However, when these actions of doing were not successful, there were feelings of guilt and remorse and thoughts of wanting to do more for the adolescent and young adult. This is congruent with the literature, which explains that when healthcare providers could not meet the wishes of adolescents and young adults, burnout and compassion fatigue were experienced (Thompson, Shura, & Utz, 2021). Stories that the hospice healthcare workers shared were expressed in two ways, either positively or negatively. There was this sense of accomplishment when wish fulfilment occurred. However, when wishes were not fulfilled, failure and regret were shared, focusing on what hospice healthcare workers could have done to impact the outcome.

It is important to note that the notion of "doing" is not necessarily a "bad" or "wrong" thing. It can have a positive impact not only on the adolescent and young adults but also on their families and hospice healthcare workers. Wish fulfilment is viewed as enriching life, maintaining hope, easing suffering, and adding joy (Shoshani, Mifano & Czamanski-Cohen, 2016; Ewing, 2009). Wishes are viewed as being different from a goal; wishes are meant to be magical experiences which go above and beyond day-to-day experiences, a way of making dreams a reality (Shoshani, Mifano & Czamanski-Cohen, 2016). Fulfilling wishes also helped hospice healthcare workers build relationships with adolescents and young adults. As demonstrated with the subordinate theme centred around the importance of making connections, wish fulfilment was often one of the ways in which these connections were made. Fulfilling wishes supported hospice healthcare workers to discover what was important to the adolescent and young adult and, in turn, created a space for trust to be built.

5.1.2 Doing more to achieve a "good death."

As hospice healthcare workers often felt like the bridge between adolescents and young adults and their families, they found it challenging to support the needs of adolescents and young adults when adolescents and young adults conflicted with their parents around care decisions. Challenges arose when parents wanted treatment options that the healthcare workers viewed as harmful, and the adolescent and young adult went along with it to make the parents happy. Such things as when the healthcare team did not view alternative medicines as benefitting the adolescent and young adult. Acknowledging the adolescent and young adult’s voice is an attribute that constitutes a good death (Chong, Walshe, & Hughes, 2021). Regardless of their age or communication abilities, adolescents and young adults should feel supported and given the opportunity to make decisions (Chong et al., 2021). This is similar to the findings of this study in that there was an incident when a young adult was taking treatment which was perceived by the healthcare team as making him suffer, but it appeased his parents. The hospice healthcare workers met with the young adult and explained that they would be supportive if he wanted this treatment to end. Witnessing parents force their viewpoints on the adolescent and young adult when they are able to make their own decisions is difficult (Avery et al., 2020). Hospice healthcare workers felt it was their job to support the adolescent and young adult in all decisions, even if those decisions meant going against the needs of their parents. Hospice healthcare workers felt that being that bridge between the adolescent and young adult often meant reminding the adolescent and young adult that they are there for them and did not want them to make decisions they were not comfortable with. This finding supported the notion of a good death in which adolescents and young adults were involved in how their care was delivered.

As the adolescent and young adult's disease progresses, although they can legally make decisions physically, there are times they are unable to do so (Avery et al., 2020). This demonstrates the oscillation between the desire for adolescents and young adults to make decisions and their ability to do so based on their illness progression. Hospice healthcare workers often feel like they are walking on a tightrope, balancing their needs with the needs of the adolescent and young adult and their family's needs. Similar to the literature, parents are viewed as the unit of care who are the experts in their child's illness (Spiers & Beresford, 2017), hospice healthcare workers in this study found value in working alongside families. Through this study, it was important that multiple possibilities were shared with families to ensure that the adolescent and young adult's needs and wishes were met. Hospice healthcare workers described their need to take the path of least regret. This path often involved hospice healthcare workers hoping that families made decisions that ensured that adolescents and young adults had a good death.

Consistent with the findings of this study, the literature explains that given the complex decisions families are often making, it is the ethical duty of the healthcare provider, in particular, the physician, to give as much information as possible to families to support shared decision-making (Jones, Contro, & Koch, 2014). Given the intense family involvement in the adolescent and young adult population, it is important for healthcare workers to find ways of supporting complex family dynamics (Avery et al., 2020; Bergstraesser, 2013; Mellor, Heckford, & Frost, 2012). Supporting these complex dynamics was described as imperative by the hospice healthcare workers in this study, who felt that when supporting adolescents and young adults, a big part of it is supporting families. This was demonstrated in the ways the hospice healthcare workers described how they supported parents who were divorced. The integration of the family systems theory has been described as beneficial in providing palliative care for patients and families (Mehta, Cohen, & Chan, 2009). Family system theory is grounded in understanding family dynamics, which includes power, boundaries, and communication, and discusses open family systems and closed family systems (Bavelas & Segal, 1982; Rothbaum, Rosen, Ujiie, & Uchida, 2002). Hospice healthcare providers explained that they spend much time understanding and supporting families, more so than adult patients, given the age of adolescents and young adults. Hospice healthcare workers found that when they understood how families functioned and the complex dynamics between families, death was improved.

When supporting adolescents and young adults, it was found that there is a connection between grand gestures and how a good death is defined. When supporting adolescents and young adults, the transition to death is eased when there is a fulfilment of wishes (Ewing, 2009). The notion of a "good death" is commonly discussed and has also been criticised as there is no way of knowing if the concept of a good death among adolescents and young adults is even reasonable (Walters, 2004; Welch, 2008). Hospice healthcare workers explained that watching this population die was difficult as adolescents and young adults were viewed as too young to die. However, experiences leading up to death can result in adolescents and young adults having meaningful moments contributing to what some would consider a good death (Gazelle, 2001). This study found that the grand gestures from hospice healthcare workers were more than altruism. Within this study, it was suggested that these actions might be rooted in finding ways of coping with the unfair death of adolescents and young adults. Healthcare workers going beyond their call of duty by carrying out gestures have been described as being rooted in compassion (Sinclair et al., 2018). However, these grand gestures were described as an indicator to understand better if these actions are from a place of altruism or an internal motivator for external recognition (Sinclair et al., 2018). It was suggested that the experiences of these grand gestures helped frame the definition of a good death. Caring for adolescents and young adults has been described as the most challenging population to support (Stein et al., 2019; Tutelman, Drake, & Urquhart, 2019), however, being able to carry out grand gestures supported hospice healthcare workers. Similar to this study of hospice healthcare workers wanting to do their best, there are comparisons in the literature that explain that "getting it right" was viewed as a strong reason and reward for working in paediatric palliative care (Taylor & Aldridge, 2017). The ability to get it right played a role in determining what the hospice healthcare workers in this study perceived as a good death.

5.1.3 Doing for while supporting decision-making for adolescents and young adults

The findings of this study indicate that healthcare workers shared their dual experiences of understanding the relationship between age and decisions making while also understanding the need for families to be involved not just because of a legal aspect but also because of the paternalism associated with supporting adolescents and young adults. The literature states that during advance care planning conversations, silence is not helpful and given the age of adolescents and young adults, honest conversations with adolescents are usually delayed by families due to the question of legal competence of this population as well as a reluctance to refer to palliative care (Burgers et al., 2021; Wiener, Zadeh, Wexler, & Pao, 2013). The results of this study suggest that hospice healthcare workers experience many adolescents and young adults who are quite mature for their age and have good insight into their illness and treatment options. These findings are in agreement with previous literature in which professional caregivers recognise that adolescents and young adults often illustrate great insights into their illness and have valuable insights into making decisions based on how they choose to live their lives (Schrijvers & Meijnders, 2007; Wolfe, 2004). This is consistent with the literature, which describes some adolescents and young adults as having premature wisdom when living with illness (Weiner et al., 2015; Zebrack, 2011). Living with advanced cancer has proven to be problematic in achieving milestones and making decisions (Nolan et al., 2014); however, hospice healthcare workers have this unwavering belief in adolescents and young adults and often do whatever they can to support their needs.

The conceptualisation of doing for through the decision-making process underpinned the subordinate themes in which the experiences of hospice healthcare workers were related to having honest and transparent conversations, listening, and holding space for silence. Hospice healthcare workers valued the ability to listen more and speak less. Hospice healthcare providers felt that decision-making was one of the most challenging aspects of the job for healthcare workers when families were closed off to discussion. This study found that when families are closed off to discussions, hospice healthcare workers spend more time doing things that would build trust. This is in contrast to the systematic review findings in which the healthcare workers at times felt exhausted and incompetent when decision-making was difficult and at times circumvented communication with patients and families (Citak, Toruner, & Gunes, 2013). The hospice healthcare workers in this study were relentless in finding ways of ensuring that communication with families was open and transparent.

Hospice healthcare workers felt, at times, they needed to accept doing less, which was described as difficult when families went against the hospice healthcare workers' recommendations and the families ultimately blamed them for the death of their child. Although healthcare workers provide honest and confident communication, families coming to terms with end-of-life treatment options may never happen, given the burden families face (Bergstraesser, 2013). As this is hard to accept, healthcare providers may be disappointed with how things unfold given decisions made and healthcare workers finding ways of coping with these decisions (Bergstraesser, 2013). It has been found that even when death is imminent, parents continue to hope for their child’s survival as making end-of-life decisions is felt to be the hardest treatment decision during their child’s cancer journey (Hinds et al., 2005; Wiener, Weaver, Bell, & Sansom-Daly, 2015). Doing less is often involved with being comfortable with being uncomfortable and understanding that hospice healthcare workers must find ways of coping with the decisions that families make by understanding that families ultimately know their child best.

Crisis decision-making was found to be common when supporting adolescents and young adults living with advanced cancer. Within the literature, it is explained that adolescents and young adults often received active treatment weeks before death, and do-not-resuscitate orders were only completed when death was imminent (Keim-Malpass, Erickson, & Malpass, 2014). This study found that crisis decision-making was difficult for a multitude of reasons, including often not having a relationship built with the adolescent and young adult and their family and potentially saying something which may be viewed as harmful. This finding is comparable to the findings in the systematic review in which healthcare workers felt nervous about saying the wrong thing or not having the correct answer when supporting adolescents (Hendricks-Ferguson et al., 2015). The findings of this study suggest that when dealing with crisis decision-making, the healthcare workers protected themselves by giving multiple options to adolescents and young adults and their families as a way of avoiding regret when reflecting on the situation in the future. There was a reassurance that was felt by hospice healthcare workers by giving multiple options to ensure that they did everything possible when supporting crisis decision-making. This ensured that hospice healthcare workers were able to cope, knowing that they did their best.

The findings of this study found that the age of the adolescent and young adult should not be the determining factor in expressing wishes around advance care planning. Given that adolescents and young adults living with advanced cancer are forced to confront their mortality earlier than expected, it was felt that they often have valuable insights into their illness, which should always be heard. Families deciding not to have adolescents and young adults involved in decision-making was found to be distressing to the hospice healthcare workers. The literature explains that when adolescents and young adults are involved with advance care planning, healthcare workers experience less decisional regret and lower levels of distress as they can make a more informed decision (Barfield et al., 2010; Wiener et al., 2013; Wolfe, Hinds, & Sourkes, 2011). It is essential, however that healthcare workers understand that although adolescents and young adults are often competent to make complex decisions (Hinds et al., 2005; Lyon, McCabe, Patel, & D’angelo, 2004; Wiener et al., 2008; Wiener et al., 2012), there are times when adolescents and young adults are more comfortable having their parents make their medical decisions (Wiener et al., 2015). Through this study, it was found that providing adequate information, and then doing less at times and just being present was what was needed as decisions were being made.

5.1.4 Healthcare workers doing everything they can to build relationships

The hospice healthcare workers in this study created strong attachments in which they developed intimate and personal bonds with adolescents and young adults. When attachments are formed, individuals feel deserving of care and have trust in knowing that care will be provided (Bartholomew, 1990). This study found that feelings of gratitude and self-fulfilment were experienced when attachments were made. It was felt that how healthcare workers experienced grief was based on the attachments they had made with adolescents and young adults. Attachments resulted in more intimate relationships with increased positive effects for both the provider and the patient (Ciechanowski, Walker, Katon, & Russo, 2002). Hospice healthcare workers explained that they sometimes had stronger attachments with particular adolescents and young adults, and these attachments remained in their memories as experiences which had impacts on their lives. These strong attachments were related to the ability to do more, as when this connection was made, conversations about end-of-life wishes were shared, and these wishes were often accomplished.

When supporting adolescents and young adults, hospice healthcare workers experience the need to make attachments as they want to build that connection. Hospice healthcare workers described being unable at times to relate to adolescents and young adults because they viewed themselves as older. This inability to connect results in low self-esteem among hospice healthcare workers which is also described as being related to preoccupied attachments (Tan, Zimmermann, & Rodin, 2005). Preoccupied insecure attachments involved an insatiable need for approval from others (Bartholomew & Horowitz, 1991). Hospice healthcare workers were in constant need of wanting to be accepted and wanting support from adolescents and young adults to build that attachment. Building that attachment may be related to the need for grand gestures and understanding the wishes of adolescents and young adults as a way of being able to cope with this work. The healthcare workers believed that if they were able to connect, they would be able to provide better care.

Healthcare workers expressed that they experienced adolescents and young adults sometimes demonstrating a dismissing attachment style. This attachment style involves individuals who want to receive care, however, have issues with trust (Tan et al., 2005). This study found that healthcare workers value building trust with adolescents and young adults. Adolescents and young adults were described as not having many experiences with the healthcare system, and because of the many changes in their lives, trusting the healthcare workers was sometimes difficult. It was expressed that it was important that healthcare workers understood this and tried not to take things personally; however, for some this was difficult as making connections was viewed as imperative to providing care. When a healthcare provider focuses on trust and makes efforts to demonstrate an interest and show through their actions that they are there for the needs of the adolescent and young adult, the dismissing attachment style may change (Tan et al., 2005). This study found that healthcare workers find ways of coping with a dismissive attachment, sometimes involving stepping back and having another team member with a stronger connection provide support.

5.2 The cycles of protection.

Hospice healthcare workers supporting adolescents and young adults protect themselves by doing rather than showing their emotions. As demonstrated through the systematic review findings in Chapter Two, healthcare workers at times, placed emphasis on controlling emotions and not displaying emotion when supporting children with life-limiting illnesses (Pearson, 2013; Rashotte, Fothergill-Bourbonnais, & Chamberlain, 1997). However, healthcare workers at times found value in the experience of sharing emotions with the adolescent and young adult and the family as they believed this demonstrated that they are human (Rydé, Friedrichsen, & Strang, 2007; Scheer, 2012). This need for healthcare workers to protect themselves can be related to the notion of distancing, in which healthcare workers create boundaries to protect themselves from getting too involved and to prevent burnout (Cook et al., 2012; Fanos, 2007; Meadors & Lamson, 2008). This notion of healthcare workers protecting themselves through actions of doing was found to be necessary to this study; however, the literature spoke to such things as meditation, spiritual practices and specialised training in emotional management as protective factors related to working in palliative care (Kobler, 2014; Novack et al., 1997; Woolley, Stein, Forrest, & Baum, 1991). Healthcare workers develop personal approaches to managing the demands of doing this work instead of relying on the resources and practices organisations should have in place to support their workers (Kobler, 2014; Novack et al., 1997; Woolley, Stein, Forrest, & Baum, 1991). This illustrates the need for a shift in policies to better protect healthcare workers' wellness.

5.2.1 The transitioning of the hero narrative and the need for personal protection

The hospice healthcare workers' experiences of having to support the transition of the hero narrative are often created within oncology settings as the hospice setting is viewed as a place of failure and no hope. The hospice healthcare workers worked hard to overcome the cancer metaphors, similar to the literature that explains the negative connotations associated with cancer metaphors (Grant & Hundley, 2008; Penson et al., 2004; Reisfield & Wilson, 2004). These metaphors and the need to avoid failure is consistent with the literature, which states that adolescent and young adults well as healthcare workers avoid referrals to palliative care due to the stigma as this care is often viewed as a failure with no hope (Abdelaal et al., 2021; Mack et al., 2016). Hospice healthcare workers experienced this often caused conflicts between the oncology and hospice teams. This need to help patients fight cancer was more common among the adolescent and young adult population hence the reasoning for late referrals to the hospice (Pritchard, Cuvelier, Harlos, & Barr, 2011; Wiener et al., 2015).

Generally, the hero discourse in cancer is used to decrease the negativity associated with cancer (Epton et al., 2020; Reisfield & Wilson, 2004; Slobod & Fuks, 2012). This discourse has been described as military, violence, and journey metaphors, which have negative and positive ways of conceptualising the cancer experience (Semino et al., 2017; Slobod & Fuks, 2012). It was found that hospice healthcare workers had to work hard at helping adolescents and young adults view hospice as a place where they could be well supported and not just come to die. Palliative care teams have begun changing the name of their teams to include “supportive care” as this was viewed as more accepted by adolescents and young adults and oncologists (Burgers et al., 2021; Dalal et al., 2011). This was congruent with the findings of this study as two of the hospices renamed their teams not to include “palliative care”, resulting in an increase in referrals and more acceptance of their role. In addition, it was found that hospice healthcare workers from other disciplines were more likely to refer when the name of their program did not include palliative care, as it was easier to digest. The findings of this study are consistent with the literature, which explains that steps are needed to bring awareness to hospice care as a way of receiving referrals earlier on in the trajectory of illness to improve trust with families, which is believed to be the foundation of care (McConnell, Scott, & Porter, 2016).

The irony, however, was that the work of hospice healthcare workers is also very much rooted in being the hero, just in a different way. The subordinate theme of being comfortable with being uncomfortable illustrated the need for hospice healthcare workers to be the hero even when being the hero meant feeling not as confident at times. The heroic actions of healthcare workers are grand gestures, acts that are morally excellent and go above and beyond (Cox, 2020; Heyd & David, 1982). This need to be the hero was interpreted as a protective factor that hospice healthcare workers used to cope with the inevitable death of the adolescents and young adults they cared for. Coping is defined as behavioural and cognitive ways of dealing with the demands of difficult situations both internally and externally (Montero-Marin et al., 2014; Scherck, 1999). The hospice healthcare workers in this study explained that doing their best was important to them as they wanted to ensure that although the adolescent and young adult was dying, they did everything to ensure their wishes could be met. Accomplishing these wishes often involved adolescents and young adults and their families viewing hospice healthcare workers are heroes.

Through the findings of this study and the need for hospice healthcare workers to carry out grand gestures, a connection was made between the transactional stress process model and the concept of coping. The transactional stress process model provides a framework in which stress is a unique phenomenon where emotions and behaviours are based on how stressors are appraised and the coping skills for dealing with these stressors (Gellis, 2002). The transactional stress process model has delineated coping with stress into two styles, problem-focused coping, which alters the environmental source of stress and emotion-focused coping methods, which lessen personal emotional stress (Aldridge & Roesch, 2007; Lazarus & Folkman, 1984). The findings of this study fits with emotion-focused coping in which mechanisms are used to deal with regulating emotions without directly facing the source (Gellis, 2002). Thus, the actions of hospice healthcare workers and their need to be the hero enables avoidance of confronting the impending death of adolescents and young adults and helps healthcare workers to cope and protect themselves from the stressors of supporting adolescents and young adults.

Poor psychological outcomes have been associated with emotion-focused coping when there was avoidance of dealing with the stressors of caring (Folkman, 1997; Folkman & Moskowitz, 2000). Ineffective coping strategies have resulted in burnout and negative emotional impacts among healthcare workers (Uren & Graham, 2013; Lazarus, 1993). The findings of this study found that emotion-focused coping through actions of wish fulfilment which were seen to be important to adolescents and young adults and their families, were important; however, there were implications for hospice healthcare workers when things did not go as they hoped for. The findings of this study found that the expectation of wish fulfilment is often a personal expectation the healthcare workers placed on themselves and could be a coping mechanism. Hospice healthcare workers gain satisfaction from fulfilling these wishes. This coping mechanism acts as emotional protection when positive emotions are experienced (Uren & Graham, 2013). This is consistent with the stories shared in this study where wishes were fulfilled as these stories were shared, there was a sense of pride and accomplishment.

The story of the stars in which the adolescent died in the middle of this wish being fulfilled illustrates the negative impacts of things not going as planned. The coping mechanism was setting up this wish without acknowledging that death may occur at any time and when the end did occur, a sense of failure and disappointment was experienced. Coping is a way of dealing with internal demands with the hope of achieving a positive reappraisal of the stressful emotions of supporting this adolescent (Aldridge & Roesch, 2007). The guilt and sadness experienced when this child died resulted in poor outcomes for the healthcare workers, which is consistent with the burnout experienced as a result of inadequate coping mechanisms (Ogoma, 2020; Rodríguez-Rey et al., 2019). This study has illustrated that coping through actions of grand gestures is common when supporting adolescents and young adults, and the perception of failure when the grand gestures do not work. This is consistent with healthcare workers having to balance being the hero with being human and having to deal with these multiple identities and the impact of when these identities conflict (Thompson et al., 2021). The findings of this study suggest that hospice healthcare workers may deploy these coping styles to be able to do this work and avoid vulnerability.

To avoid the vulnerability of this work and face the difficulty of supporting adolescents and young adults, it was found that hospice healthcare workers place a protective shell around themselves. This interpretation emerged from the subordinate theme centred around the cycle of protection. Paediatric palliative care healthcare workers address the multiple needs of their patients while trying to protect their own well-being (Forster & Hafiz, 2015). If the protective shell breaks, there are risks of compassion fatigue and burnout. Burnout among palliative care healthcare workers is common, given the suffering they witness through supporting patients and families (Perez et al., 2015). Through the findings of this study, this protective shell is also manifested as doing and demonstrates coping mechanisms created by hospice healthcare. Vulnerability is often viewed as a weakness, and if healthcare workers are vulnerable, they are at risk of exposing their need for support, perfection and control (Plante & Cyr, 2011). It was found that hospice healthcare fulfilling wishes prevents the need to focus on being vulnerable, and facing stressors and overall supports the concept of coping. Coping mechanisms in the literature focus on spiritual beliefs, sharing experiences with a partner, peer support, compartmentalising and finding ways of identifying the good within each experience (Forster & Hafiz, 2015). There is a need for better resources to support healthcare workers with coping with this work consistently rather than having them experience the negative emotions of insufficient coping mechanisms (Kavalieratos et al., 2017; Maffoni et al., 2019; Uren & Graham, 2013).

Self-care mechanisms are described as ways of preventing burnout and compassion fatigue among paediatric palliative care providers (Kase, Waldman, & Weintraub, 2019; Levine et al., 2013; Rourke, 2007). The self-care mechanisms of team support, social engagement, mindfulness, resilience, and education about adolescents with advanced cancer have been described as anticipatory prevention of experiencing compassion fatigue to bolster the well-being of healthcare providers and overall improve care (Back, Steinhauser, Kamal, & Jackson, 2016; Kase et al., 2019; Levine et al., 2013; Rourke, 2007; Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2013). Although team support, self-reflection, and debriefing were described as important in this study when supporting adolescents and young adults when you critically examine the actions of hospice healthcare workers supporting this population, the grand gestures and wish fulfilment were viewed as actions of self-care and a way of coping that overall prevented compassion fatigue and burnout. This, in turn, was interpreted as a protective shell that healthcare workers created to cope with the challenges of doing their job.

5.2.2 The cycle of protection between hospice healthcare workers, adolescents and young adults and families

Hospice healthcare workers often experience adolescents and young adults hiding their pain and suffering from their parents as a way of protecting them and their families by hiding their sadness and grief as a way of protecting the adolescent and young adult. According to the literature, when caring for adolescents and young adults, there is a sense of mutual protection where the parents withhold information to protect their children, and children withhold sharing their pain, fears and anxieties as they want to protect their parents (Atout, Hemingway, & Seymour, 2019). This is consistent with the findings of this study in which the healthcare workers described the protective shell they often witness. Hospice healthcare workers described this as the 2 am conversations when adolescents and young adults often want to speak with the hospice healthcare workers without their parents being present. Given the connections built with hospice healthcare workers, adolescents and young adults felt safe opening up to them. Adolescents and young adults do not feel the need to protect hospice healthcare workers, and this reflective space often results in meaningful conversations.

5.2.3 Advance care planning: balancing protection and trust

Healthcare workers have described an emotional block to supporting adolescents and young adults living when discussing prognosis when death is imminent(Kenten et al., 2019; Lotz, Jox, Borasio, & Führer, 2015). This emotional block is consistent with the findings of this study in which hospice healthcare workers explained discussing prognosis as one of the most difficult parts of their job, given how complex and uncertain these conversations are. There are times when healthcare workers avoid sharing this information as a way of protecting themselves from taking away hope from the adolescent and young adult (Kenten et al., 2019). The findings of this study found that reluctance to share this information had less to do with protecting the adolescent and young adult and more to do with protecting the relationship they have with the adolescent and young adult and their families. This plays into the cycle of protection and is consistent with the literature, which explains that healthcare workers tend to close their eyes to these conversations as they do not want to break trust and face the inevitable (Lotz et al., 2015). Maintaining trust and honesty was pivotal when having these conversations. There were times when the hospice healthcare workers had let their emotions take over when over-sharing information about prognosis and the guilt experienced afterwards was challenging to cope with. Therefore, having this protective shield when discussing prognosis was found to be important.

There has been no determined time as to when it is appropriate to begin advance care planning conversations within paediatric palliative care, however much of the literature does explain that earlier conversations are more beneficial as trust and connections can be made when sharing sensitive information (Basu & Swil, 2018; Durall, Zurakowski, & Wolfe, 2012; Sanderson, Zurakowski, & Wolfe, 2013). Although early integration of palliative care was expressed as being important within the findings of this study, it was also found that trust and connections are often made in crisis situations. This study suggests that because referrals to the hospice are often late, attachments and trust are built through crisis situations through very intimate moments in very little time. Serious medical illnesses are often described as situations where attachment behaviours are activated through stress and uncertainty (Goldberg, 2000). Families tend to connect to healthcare workers who genuinely care for their children and value their input (Madrigal & Kelly, 2018). Hospice healthcare workers felt that if they can prove to serve a need, time is not always needed to build trust. Hospice healthcare workers found that uncertainty and stress helped drive the attachments made as there was less of a focus on time and more on being present. These findings are consistent with the notion that familiarity with patients sometimes acts as a barrier to providing care, as the long-standing connections resulted in healthcare workers doing things for patients without asking as they figured that they knew them so well (Hill, 2014). Familiarity was found to take away autonomy and independence at times as healthcare workers became comfortable with the patient and made assumptions about their needs (Hill, 2014). Through the use of interpersonal skills, availability and transparent communication about a patient’s needs, the relationship-building phase of taking time to get familiar with a patient can at times be bypassed (Csikai, 2004; Luker, Austin, Caress, & Hallett, 2000; Nolan, 2011). Consistent with the findings of this study, although earlier conversations are important when making decisions around advance care planning, additional time is not always needed as trust and familiarity can be built through crisis situations.

Although hospice healthcare workers in this study reflected on crisis situations and at times felt pride in what was accomplished often with very little time, they struggled with crisis situations as they were not able to do as much as they were unable to get to know the adolescent and young adult and fulfil their wishes. This relates to emotion-focused coping and grand gestures. When there was less time to make connections, healthcare workers in this study struggled with coming to terms with the death of an adolescent and young adult. This study found that the lack of doing often result in poorer outcomes. When looking at the transactional stress model, crisis situations often resulted in problem-focused coping methods in which the goal is to manage situations that are the source of stress (Gellis, 2002). In the crisis circumstances identified in this study, imminent death and managing pain and symptoms were paramount to ensuring comfort at the end of life. Although problem-focused coping is said to have higher rates of psychological well-being than emotion-focused coping (Folkman, 1997), this study found that healthcare workers experienced guilt in a crisis situation because they could not do more.

5.2.4 Crying as a protective way of coping

In Chapter two, crying was described as common when supporting children with life-limiting illnesses (Furingsten, Sjögren, & Forsner, 2015; Henao-Castaño & Quiñonez-Mora, 2019; Papadatou, Bellali, Papazoglou, & Petraki, 2002; Papadatou, Martinson, & Chung, 2001; Rashotte et al., 1997). This is consistent with this study's findings in that crying was viewed as a normal response to working with adolescents and young adults. Given the emotional intensity of the work in palliative care, it was understood that crying occurred often. For hospice healthcare workers, being able to sit at the bedside of an adolescent and young adult who was dying and cry appropriately was seen as important. Hospice healthcare workers described themselves as being human. Although they cried often, they needed never to take away from the experience of the family in which the family would be comforting them. This was consistent with the empirical work of the systematic review in that there was a relationship between crying and having control (Pearson, 2013; Rashotte et al., 1997). Hospice healthcare workers felt it was important to control their emotions, and controlling crying in public was viewed as necessary to some as they always wanted to maintain professionalism. On the other hand, crying behind closed doors in private was common, and having this alone time after a difficult experience was viewed as important to taking proper self-care (Pearson, 2013; Rashotte et al., 1997).

This study found that it is likely that crying is a way of coping, which is consistent with the literature, which states that crying is a protective factor in releasing emotions and maintaining a healthy emotional equilibrium (Rydé et al., 2007) and that healthcare workers have to permit themselves to cry (Jones, 2005). In this study, crying was often a coping action in response to moments of meaning, whether it was because of the results of a grand gesture, experiences of grief, guilt or sadness, reactions to loss after strong attachments were made, or the death of an adolescent and young adult. Whether done privately or publicly, crying occurred often and was either an individual experience of coping or a shared experience of coping among team members.

5.3 Chapter Conclusion

The aim of the discussion chapter was to understand the experiences of hospice healthcare workers who provide palliative care to adolescents and young adults living with advanced cancer in relation to the findings in Chapter Four, theoretical frameworks and existing literature. There is a need for hospice healthcare workers to do, which may be a way of coping with the complexities of supporting adolescents and young adults. This notion of doing allows hospice healthcare workers to find ways of managing the difficulty of witnessing adolescents and young adults die by focusing on meaningful moments and doing the best they can to avoid being with and experiencing feelings of guilt, regret, and remorse. These meaningful moments created through the hospice environment create a sense of purpose for the hospice healthcare worker, adolescents and young adults, and their families.

The cycles of protection demonstrate how hospice healthcare workers create ways to continue this work despite the challenges. The association between carrying out grand gestures and a good death demonstrated how protection is often created as a way of not facing the reality of impending death. Building trusting relationships based on honesty and transparency was essential and helped protect hospice healthcare workers and adolescents and young adults, and their families. Crying was found to be a way of coping and also a way for hospice healthcare workers to protect themselves.

Chapter Six: Conclusion

6 Chapter Introduction

Through this research study, I sought to answer the following research question, "What are the experiences of healthcare workers who provide palliative care to adolescents and young adults living with advanced cancer?". This research question was answered through a robust process following all of the steps of IPA (Smith, 2011). The experiences of healthcare workers in this study focused on the need to do rather than to be, the cycle of protection, and understand how adolescents and young adults receive care by acting as a proxy.

6.1 Research strengths and limitations

Given IPA's strong philosophical and theoretical underpinnings, along with the precise data collection and analysis procedures, there was great strength in this methodological approach (Wagstaff et al., 2014). The focus on the embodiment of the lived experience allowed me to dig deep beneath the surface to interpret this phenomenon through the hermeneutic circle (Smith, 2011). The in-depth interviews with the participants allowed for an intimate deliberation of the lived experiences of hospice healthcare workers who care for adolescents and young adults with advanced cancer (Alase, 2017). There is not an exact number of participants recommended for an IPA study; however, smaller sample sizes have been said to be better for this method, given the in-depth analytic process (Smith, 2011). Challenging decisions needed to be made when conducting this research study, and normally in IPA, there are smaller sample sizes. I decided, which sat outside of the norm, to have a larger sample size to gain a more in-depth understanding of the phenomenon. I do not believe this impacted my ability to gain an in-depth understanding of this phenomenon, as I allocated additional time to the analytic process to ensure I stayed true to the idiographic nature of IPA. Being a novice researcher, I went into this process with an open mind. I was nervous about not getting enough participants and wanted a broader sample rather than a distinct role and aimed to collect data from different healthcare disciplines. I did not discard any data, although pragmatic conversations of just focusing on nursing staff were discussed during my supervision meetings; however, given the in-depth understanding that was being sought, it was felt that focusing on one discipline would limit the experience being investigated. By including data from all 18 participants, I gained an in-depth understanding of this phenomenon, given the idiographic nature of IPA. There was intentionality in the sample of various disciples, given the philosophy of palliative care, and I believe this allowed me to answer my research question.

The direct quotes allowed the participants' voices to be heard and authentically demonstrated their experiences. Each process of this research study was congruent with the processes of IPA (Smith, 2011). The interview process supported an environment that the participants called therapeutic, as it was led by the participants and focused on their lived experiences. It helped me to enter the world of healthcare workers while being curious and open-minded (Eatough & Smith, 2008).

Within IPA, it is suggested that the participant sample be fairly homogeneous (Smith & Osborn, 2007). The definition of homogeneity is subjective and based on the interpretation of the researcher. The participants in this study were homogeneous in terms of field of work and place of work. This sample is congruent with the inclusion criteria. Given that hospice palliative care is based on a holistic, interdisciplinary team approach, the sample was appropriate for this study. Other IPA studies have taken this approach in which homogeneity was determined based on the population worked with (Antoine et al., 2018; Lamb & Cogan, 2016; Tutelman, Drake, & Urquhart, 2019; Volpato et al., 2018; Wang et al., 2017). Within the systematic review, most of the experiences shared were those of nurses; although my study was predominately nursing, given the reality of care with this population, I could stay true to my focus which was more than just the nursing perspective. How homogeneity is defined in this study is a strength, as the varied disciplines with the shared work experience based on both population and setting allowed for an in-depth understanding of care congruent with the philosophy of palliative care.

The limitations of this study are defined by limitations to one setting – the in-patient hospice. There needs to be an understanding of the experiences of healthcare workers who care for adolescents and young adults who are dying in other settings, in particular hospitals, which is where the majority of adolescents and young adults are dying.

There are limitations in this study based on gender, healthcare disciplines, and ethnicity. In this study, there were only four males; this study could have benefitted from having more male participants. There were also many nurses who participated in this study. Having more psychosocial disciplines, like social workers, care workers, or physicians, may have resulted in additional findings.

6.2 Reflections on quality

Qualitative research plays a vital role in the study of quality and safety (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). The quality of the research for the thematic synthesis was examined through the use of the Quality Assessment of Research for Thematic

Synthesis: Critical Appraisal Skills Programme (CASP), as it was congruent with the approach taken within a thematic synthesis (Jaarsma et al., 2014; Thomas & Harden, 2008).

Following Smith's (2011) criteria for a good IPA study, the following must be met: There must be a clear focus, strong data, rigour demonstrated using direct quotes, ability to discuss each theme in-depth, move away from descriptive and move towards interpretative, convergence and divergence within the analysis, and a thoughtfully written piece of work. This study followed each of these steps. Each process taken throughout the study was congruent with the principles of IPA.

6.3 Clinical and policy implications

The notion of doing may be a way of coping. Support from hospice management is needed to implement coping mechanisms and supports for healthcare workers who care for adolescents and young adults.

This study highlighted that healthcare workers need to be doing rather than being. There was a focus on grand gestures and tying up loose ends to ensure that adolescents and young adults had meaning and purpose at the end of life, while meeting the personal needs of the healthcare workers. This study suggests that healthcare workers avoid facing the emotional labour of this job through actions of doing. It is suggested that these doing actions act as a protective shell for the healthcare workers to avoid what is happening. The value of making sense of a child’s death and finding meaning was widely cited within the literature (Furingsten et al., 2015; Macpherson, 2008; Papadatou et al., 2002; Papadatou et al., 2001;

Plante & Cyr, 2011). Through my interpretations, I found these actions of doing and finding meaning were ways the healthcare workers coped and ultimately supported the ability to do this work. However, the grand gestures resulted in many different experiences. When the grand gesture was successful, it was viewed as a small victory; however, when the grand gesture did not work, it was viewed as a failure. There is a need to better understand the success and failure of grand gestures and how these grand gestures are potentially used as a coping mechanism and protective shell to care for adolescents and young adults who are dying.

There is a need to understand if a better death can occur due to grand gestures, as there is a point where the focus shifts from grand gestures and death must be faced, or grand gestures may not be possible. We must better understand if we are attributing a good death to grand gestures.

This study suggests that in order to understand the experiences of hospice healthcare workers, we must also acknowledge the duality in which healthcare workers view their experiences through their eyes and the eyes of adolescents and young adults. When developing policies regarding the care for adolescents and young adults, the lived experience of healthcare workers can help provide insights as to what these policies should be.

The findings of this study highlight the need for non-paediatric palliative care healthcare workers to better understand the role of paediatric palliative care and the support it provides to adolescents and young adults living with advanced cancer. The renaming of paediatric palliative care programmes demonstrates the lengths organisations have gone through to ensure that they receive referrals. Policies should be implemented to ensure that all healthcare workers understand the role of paediatric palliative care in supporting adolescents and young adults.

Nurses feeling that they had to be present 24/7 illustrates a gap in resources. Funding for paediatric hospices should be assessed to ensure that there are proper staffing ratios and multiple disciplines to provide the care needed within the hospice setting. There is also funding needed for additional staff who are trained in psychosocial care to support nurses who often are responsible for providing all aspects of care.

6.4 Contributions to knowledge

This study contributes to advancing the existing research literature and theory in adolescent and young adult research with a focus on hospice healthcare workers. This study adds to general knowledge about best practices in this phenomenon in the following ways:

A.) It is the first interpretative phenomenological analysis to focus on the experiences of hospice healthcare workers caring for adolescents and young adults with advanced cancer, specifically living in a hospice in Canada. The use of IPA illustrates the personal experiences of the participants and their experiences when acting as a proxy. Although this study was focused on hospice healthcare workers, it also resulted in knowledge about the adolescent and young adult population through the eyes of the participants.

B.) This study illustrates the challenges faced by healthcare workers when caring for adolescents and young adults and demonstrates the need for additional training and education for healthcare workers to care for this population.

C.) This brings to light the hero narrative as a coping mechanism and the need for hospice healthcare workers to be that hero by ensuring they are always doing their best. It highlights the pressure that this places on hospice healthcare workers and the need for more resources to help healthcare workers cope.

D.) This study highlights the high risks that completing grand gestures has on healthcare workers. If the grand gestures were not possible, what would burnout and compassion fatigue look like for this population.

E.) This study illuminates the need for an early integration of palliative care for this population and a need for the education and healthcare system to change. The education system trains healthcare workers to save lives, and this training plays a role in adolescents and young adults receiving unnecessary aggressive treatments at the end of life. The personalisation of failure is highlighted as well as the impact that this has on referrals to in-patient hospice care.

F.) This study highlights the difficult position that hospice healthcare workers are in when caring for adolescents and young adults and their families. There is a constant push and pull, and the hospice healthcare workers are often in the middle, trying to maintain a healthy balance. Hospice healthcare workers emphasise the importance of treating adolescents and young adults like adults and not children and findings ways of ensuring that their voices are heard.

G.) The study demonstrates the need to protect, from different perspectives, the adolescents and young adults, the parents, and the healthcare workers. Given the age of adolescents and young adults, there is a very paternalist approach to care by the parents and the hospice healthcare workers. The parents and adolescents, and young adults are in a cycle of not wanting to harm each other from additional pain and suffering. The healthcare workers protect adolescents and young adults, go above and beyond and often must find ways of having private conversations to ensure that adolescents and young adults are being heard and cared for. The healthcare workers also do much of these actions of protection to protect themselves, with a focus on taking the path they least regret.

H.) This study focuses on hospice healthcare workers being comfortable with being uncomfortable and the meaning that comes from letting go of control, building trust while maintaining hope. This was demonstrated through several stories, illustrating the hospice healthcare workers remaining in the passenger seat while the adolescent or young adult controlled the destination.

6.5 Recommendations for future research

To further explore the findings of this study, these recommendations would help build on the understanding of healthcare workers' care for this population.

A.) Further research is needed to better understand what doing rather than being means when supporting adolescents and young adults, focusing on coping and protection.

B.) Further research is needed to understand if grand gestures can occur in other settings, focusing on time and resources and how much this is encouraged within the hospice setting versus other settings.

C.) Further research is needed to understand the need for healthcare workers to have no regrets and how healthcare workers cope with loss through grand gestures.

D.) Further research is needed to better understand the occupational health of healthcare workers who care for adolescents and young adults who are dying and how they are supported through the grief and loss they experience.

E.) Further research is needed to understand how adolescents and young adults dying of advanced cancer are cared for in countries where resources are limited, and grand gestures may not be an option to better understand how this work is carried out and how this impacts the notion of doing and a good death.

F.) Further research is needed to explore the needs of healthcare workers who care for this population, with a focus on attrition, compassion fatigue, and burnout.

6.6 Reflections on being a novice researcher

Completing this PhD has been one of my life's most rewarding yet challenging experiences. It has been an honour sitting with each of the participants and understanding their lived experiences. Hearing each experience and each story made my research feel so real, and watching it come to life through my findings was meaningful. Learning about the experiences of caring for adolescents and young adults was unique, and I gained knowledge and insights that I did not have before. Having the privilege of travelling across Canada and visiting the four hospices was a life-changing experience. Feeling their compassion while also holding space for the grief and suffering, not just from the participants but from each hospice, was something that will stay with me forever.

Continuous reflexivity played an essential role throughout my research process. I had to remember my role as a researcher and not as a clinician working in hospice palliative care. I had to do constant checks to ensure that my interpretations were based on the experiences of my participants and not those of my own. Going through the interview process and the findings process was emotional. Reliving the experiences of each story told and of each child who died was challenging; however, taking breaks between interviews and time between analysing each interview was very important. When I was emotional during the interview process, it was vital for me to take time and reflect on where the emotion was coming from. After each interview, I reflected on this to better understand my own emotions and ensured that I could work through those emotions by writing down my feelings and moving on to the next interview. My positionality of having a social work background assisted in the interview process as I was able to gauge when participants needed a break and understood the importance of holding space for silence when needed.

I did receive feedback from one hospice on the interview process and how it felt therapeutic to share experiences, as the participants were not often given this opportunity.

Reflexivity and my positionality strengthened my thesis and contributed to my preparation for the thesis, my choice of an IPA research method and my analysis process. Given my experience in the field, I did not think bracketing would be possible and viewed my experiences as vital to the analysis process. This was congruent with the theoretical underpinnings of IPA and hermeneutics. As I was going through each finding, it was important that I stayed true to what the participant was saying and not allow my own experiences to overshadow this process. Each time a theme was developed, part of my reflexivity was checking the transcript and ensuring that the verbatim extracts matched the participant's experiences. Reflexivity is an ongoing process that will continue even when my research process has been completed.

My monthly and then bi-monthly supervision was what supported me throughout this process. The guidance and support I received from my supervisors were invaluable. These sessions not only helped me grow as a researcher but also helped to build my confidence, knowledge, and skills and address my impostor syndrome.

6.7 Finals remarks

This study began with a limited understanding of caring for adolescents and young adults. Using the robust process of IPA, built upon constructivism, interpretivism, phenomenology, hermeneutics, and idiography, this study concludes with an in-depth understanding of what it is like caring for adolescents and young adults receiving palliative care while living with advanced cancer in a hospice. Through the contributions to knowledge, this study can help inform the clinical ways healthcare workers care for this population, improve the provision of care for adolescents and young adults, and help develop policies to better meet the needs of all involved.

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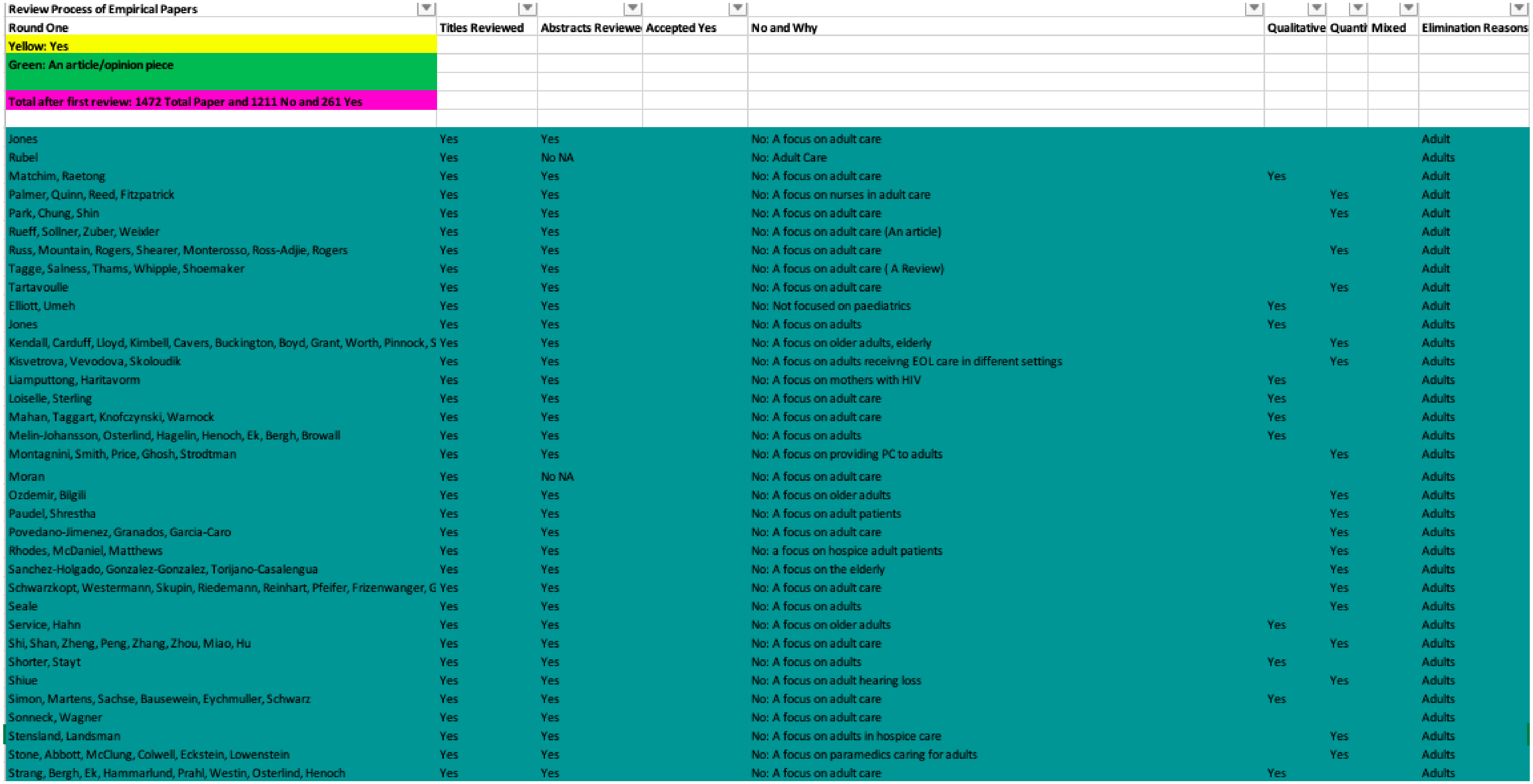
Appendix 1: SPIDER Strategy literature search terms

			MEDLINE Term	PsycINFO Terms	CINAHL Terms	Age Limiters
S	Sample	Healthcare workers (may include students)	Healthcare Workers ((MH "Social Workers") OR (MH "Health Personnel") OR (MH "Nurses") OR (MH "Medical Staff") OR (MH "Allied Health Personnel") OR (MH "Counselors") OR (MH "Physicians") OR (MH "Pediatricians") OR (MH "Oncologists")) OR AB ("doctor*" OR physician* OR nurs*) OR TI ("doctor*" OR physician* OR nurs*)	Healthcare Workers (DE "Clinicians" OR DE "Counselors" OR DE "Psychologists" OR DE "Social Workers" OR DE "Therapists" OR DE "Health Personnel" OR DE "Home Care" OR DE "Community Services" OR DE "Caregiver Burden" OR DE "Hospice" OR DE "Caregivers") OR TI ("doctor* OR physician* OR Nurs* OR "Care Worker*" OR "healthcare worker*" OR "healthcare provider*") OR AB ("doctor* OR physician* OR Nurs* OR "Care Worker*" OR "healthcare worker*" OR "healthcare provider*")	Healthcare Workers ((MH "Social Workers") OR (MH "Counselors") OR (MH "Case Managers") OR (MH "Allied Health Personnel") OR (MH "Nurses") OR (MH "Physicians")) OR TI (nurs* OR physician* OR doctor* OR "social worker *") OR AB (nurs* OR physician* OR doctor* OR "social worker*")	MEDLINE Age Groups: Infant: 1-23 months, Child, Preschool: 2-5 years, Child: 6-12 years, Adolescent: 13-18 years PsycINFO Age Groups: Infancy (2-23 mo), Preschool Age (2-5 yrs), School Age (6-12 yrs), Adolescence (13-17 yrs), Adulthood (18 yrs & older), Young Adulthood (18-29 yrs) CINAHL Age Related: All Infant: birth-23 months, Child, Preschool: 2-5 years, Child: 6-12 years, Adolescent: 13-18 years, All Child: 0-18 years, Young Adult: 19-24 years
PI	Phenomenon of Interest	Emotional experiences of healthcare workers who care for children and young adults living with a life-limiting illness	Emotions ((MH "Hope") OR (MH "Hate") OR (MH "Hostility") OR (MH "Happiness") OR (MH "Guilt") OR (MH "Frustration") OR (MH "Forgiveness") OR (MH "Fear") OR (MH	Emotions (DE "Emotional Processing" OR DE "Emotional States" OR DE "Forgiveness" OR DE "Negative Emotions" OR DE "Positive Emotions" OR DE "Emotions" OR DE "Emotion Recognition" OR DE "Emotional Development" OR DE "Emotional Health" OR DE	Emotions ((MH "Emotions") OR (MH "Affect") OR (MH "Anger") OR (MH "Anxiety") OR (MH "Fear") OR (MH "Compassion") OR (MH "Guilt") OR (MH "Frustration") OR (MH "Happiness") OR (MH "Hope") OR (MH	

"Psychological Distress") OR (MH "Sadness") OR (MH "Pleasure") OR (MH "Love") OR (MH "Loneliness") OR (MH "Courage") OR (MH "Emotions") OR (MH "Anxiety") OR (MH "Anger") OR (MH "Boredom") OR (MH "Attitude") OR (MH "Behavior")) OR AB ("emotion*" OR "experience*") OR TI ("emotion*" OR "experience*") Life-limiting Illness ((MH "Terminal Care") OR (MH "CRITICAL CARE") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Nursing Care")) OR TI (“life-limiting” OR “lifelimiting” OR "end of life" OR "end-of-life" OR "serious illness") OR AB (“life-limiting” OR “lifelimiting” OR "end of life" OR "end-of-life" OR "serious illness") Children and Young Adults ((MH "Child") OR (MH "Adolescent") OR (MH "Child, Preschool")) OR TI ("Child*" OR ADOLESCEN* OR TEENAGER* OR "YOUNG ADULT*" OR KID*) AND AB ("Child*" OR adolescen* OR teenager*	"Emotional Intelligence") OR TI "emotion* experience*" OR AB "emotion* experience*") Life-limiting Illness (DE "Death and Dying" OR DE "Chronic Illness" OR DE "Disease Progression" OR DE "Hospice" OR DE "Palliative Care" OR DE "Terminal Cancer" OR DE "Terminally Ill Patients") OR TI ("life-limiting" OR "life limiting" OR "life-threatening" OR "life threatening" OR "end of life" OR "end-of-life") OR AB ("life-limiting" OR "life limiting" OR "life-threatening" OR "life threatening" OR "end of life" OR "end-of-life") Children and Young Adults (DE "Pediatrics") OR TI ("child* OR "adolescent*" OR "teenager*" OR "young adult*") OR AB ("child* OR "adolescent*" OR "teenager*" OR "young adult*")	"Hopelessness") OR (MH "Jealousy") OR (MH "Laughter") OR (MH "Disgust") OR (MH "Pleasure") OR (MH "Love") OR (MH "Psychological Distress") OR (MH "Sadness") OR (MH "Suffering") OR (MH "Worry") OR (MH "Motivation") OR (MH "Personality")) OR TI “emotion* experience*” OR AU “emotion* experience*” Life-Limiting Illness (MH "Cancer Patients") OR ((MH "Critically Ill Patients")) OR TI ("life-limiting illness* OR "life limiting illness*" OR "serious illness*" OR "hospice care" OR "Palliative care" OR "life threatening illness*" OR "life-threatening illness*") OR AU ("life-limiting illness* OR "life limiting illness*" OR "serious illness*" OR "hospice care" OR "Palliative care" OR "life threatening illness*" OR "life-threatening illness*") Children and Young Adults ((MH "Pediatric Oncology Nursing") OR (MH "Cancer Care Facilities") OR (MH "Hospices") OR (MH "Oncology Care Units")) OR TI ("child*" OR "adolescen*" OR "teenager*" OR "young adult*") OR AB ("child*" OR "adolescen*" OR

			OR "young adult*")	"teenager*" OR "young adult*")
D	Design	Interviews, questionnaires, focus groups, case study, observational studies		
E	Evaluation	Their experiences		
R	Research Type	Qualitative or mixed method		

Appendix 2: Literature review screening process



Review Process of Empirical Papers								
Round One	**Titles Reviewed**	**Abstracts Reviewe**	**Accepted Yes**	**No and Why**	**Qualitative**	**Quanti**	**Mixed**	**Elimination Reasons**
Yellow: Yes								
Green: An article/opinion piece								
Total after first review: 1472 Total Paper and 1211 No and 261 Yes								
Jones	Yes	Yes		No: A focus on adult care				Adult
Rubel	Yes	No NA		No: Adult Care				Adults
Matchim, Raetong	Yes	Yes		No: A focus on adult care	Yes			Adult
Palmer, Quinn, Reed, Fitzpatrick	Yes	Yes		No: A focus on nurses in adult care		Yes		Adult
Park, Chung, Shin	Yes	Yes		No: A focus on adult care		Yes		Adult
Rueff, Sollner, Zuber, Weixler	Yes	Yes		No: A focus on adult care (An article)				Adult
Russ, Mountain, Rogers, Shearer, Monterosso, Ross-Adjie, Rogers	Yes	Yes		No: A focus on adult care		Yes		Adult
Tagge, Salness, Thams, Whipple, Shoemaker	Yes	Yes		No: A focus on adult care (A Review)				Adult
Tartavoulle	Yes	Yes		No: A focus on adult care		Yes		Adult
Elliott, Umeh	Yes	Yes		No: Not focused on paediatrics	Yes			Adult
Jones	Yes	Yes		No: A focus on adults	Yes			Adults
Kendall, Carduff, Lloyd, Kimbell, Cavers, Buckington, Boyd, Grant, Worth, Pinnock, S	Yes	Yes		No: A focus on older adults, elderly		Yes		Adults
Kisvetrova, Vevodova, Skoloudik	Yes	Yes		No: A focus on adults receivng EOL care in different settings		Yes		Adults
Liamputtong, Haritavorn	Yes	Yes		No: A focus on mothers with HIV	Yes			Adults
Loiselle, Sterling	Yes	Yes		No: A focus on adult care	Yes			Adults
Mahan, Taggart, Knofczynski, Warnock	Yes	Yes		No: A focus on adult care	Yes			Adults
Melin-Johansson, Osterlind, Hagelin, Henoch, Ek, Bergh, Browall	Yes	Yes		No: A focus on adults	Yes			Adults
Montagnini, Smith, Price, Ghosh, Strodtman	Yes	Yes		No: A focus on providing PC to adults		Yes		Adults
Moran	Yes	No NA		No: A focus on adult care				Adults
Ozdemir, Bilgili	Yes	Yes		No: A focus on older adults		Yes		Adults
Paudel, Shrestha	Yes	Yes		No: A focus on adult patients		Yes		Adults
Povedano-Jimenez, Granados, Garcia-Caro	Yes	Yes		No: A focus on adult care		Yes		Adults
Rhodes, McDaniel, Matthews	Yes	Yes		No: a focus on hospice adult patients		Yes		Adults
Sanchez-Holgado, Gonzalez-Gonzalez, Torijano-Casalengua	Yes	Yes		No: A focus on the elderly		Yes		Adults
Schwarzkopt, Westermann, Skupin, Riedemann, Reinhart, Pfeifer, Frizenwanger, G	Yes	Yes		No: A focus on adult care		Yes		Adults
Seale	Yes	Yes		No: A focus on adults		Yes		Adults
Service, Hahn	Yes	Yes		No: A focus on older adults	Yes			Adults
Shi, Shan, Zheng, Peng, Zhang, Zhou, Miao, Hu	Yes	Yes		No: A focus on adult care		Yes		Adults
Shorter, Stayt	Yes	Yes		No: A focus on adults	Yes			Adults
Shiue	Yes	Yes		No: A focus on adult hearing loss		Yes		Adults
Simon, Martens, Sachse, Bausewein, Eychmuller, Schwarz	Yes	Yes		No: A focus on adult care	Yes			Adults
Sonneck, Wagner	Yes	Yes		No: A focus on adult care				Adults
Stensland, Landsman	Yes	Yes		No: A focus on adults in hospice care		Yes		Adults
Stone, Abbott, McClung, Colwell, Eckstein, Lowenstein	Yes	Yes		No: A focus on paramedics caring for adults		Yes		Adults
Strang, Bergh, Ek, Hammarlund, Prahl, Westin, Osterlind, Henoch	Yes	Yes		No: A focus on adult care	Yes			Adults

Appendix 3: Example of a CASP quality assessment

Critical Appraisal Skills Programme (2022). CASP (Thematic Synthesis) Checklist [online] Available at: *https://casp-uk.net/images/checklist/documents/CASP-Qualitative-Studies-Checklist/CASP-Qualitative-Checklist-2018_fillable_form.pdf*

A focus on three main quality issues, quality of the reporting, sufficiency of the strategies, assessment of the appropriateness of the study methods (Thomas & Harden, 2008).

Study Name: Ethical Challenges When Caring for Dying Children	
Questions	**Appraisal**
Was there a clear statement of the aims of the research?	To describe caring as represented in healthcare workers' experiences of caring for dying children.
Is the qualitative methodology appropriate?	Yes.
Was the research design appropriate to address the aims of the research?	Yes, phenomenology is appropriate as this focus is on lived experiences.
Was the recruitment strategy appropriate to the aims of the research?	Yes. Involved nurses that had recent experience of caring for a dying child.
Were the data collected in a way that addresses the research issue?	Yes, semi-structured interviews
Has the relationship between researcher and participants been adequately considered?	Not stated
Have the ethical issues been taken into consideration?	Yes and well stated.
Was the data analysis sufficiently rigorous?	Yes, data was analyzed in four steps focusing on open reading, meaning units, constituents, and essence.
Is there a clear statement of findings?	Yes. Five major findings.

High-Rating

Appendix 4: Lancaster University ethics application

Research Design and Practical Research Ethics

1. Title of Project:
An Interpretative Phenomenological Analysis: Exploring the Experiences of Healthcare Workers Caring for Adolescents and Young Adults at the End-of-Life

2. Name of applicant: Nadine Persaud

3. Type of study

✓ Involves direct involvement by human subjects

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self-Assessment part B. This is available on the Research Support Office website LU Ethics Submit this, along with all project documentation

4. If this is a student project, please indicate what type of project by ticking the relevant box:

☐ PG Diploma ☐Masters dissertation ☐MRes ☐MSc ☐ DClinPsy SRP

☐ PhD Thesis ✓☐PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being/Mental Hlth

☐MD ☐DClinPsy Thesis ☐ Special Study Module (3rd year medical student)

3. Type of study

✓ Involves direct involvement by human subjects

☐ Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

Applicant information

5. Appointment/position held by applicant and Division within FHM:

PhD Candidate, Division of Health Research, Faculty of Health and Medicine

6. Contact information for applicant:

E-mail: nadinepersaud5@me.com Telephone: 011-1-647-887-3401

Address: 13 Manitoba Place, Brampton, Ontario, Canada, L6R-2H9

7. Project supervisor(s), if different from applicant:

Name(s): Dr. Sarah Brearley, Dr. Catherine Walshe

E-mail(s): sarah.brearley@lancaster.ac.uk cwalshe@lancaster.ac.uk

8. Appointment held by supervisor(s) and institution(s) where based (if applicable):

Dr. Sarah Brearley, Senior Lecturer in Health Research at Lancaster University.

Dr. Catherine Walshe, Professor of Palliative Care at Lancaster University and Editor in Chief, Palliative Medicine.

9. Names and appointments of all members of the research team (including degree where applicable)

Nadine Persaud, BSW, MSW, RSW, PhD Candidate

Dr. Sarah Brearley, PhD

Dr. Catherine Walshe, PhD

NOTE: **In addition to completing this form you must submit a detailed research protocol and all supporting materials.**

10. Summary of research protocol in lay terms (maximum length 150 words).

Aim

To understand the lived experience of healthcare workers who provide palliative care to adolescents and young adults who have a diagnosis of cancer.

Background

The physical, psychosocial, and informational needs of adolescents and young adults who require palliative care and have a diagnosis of cancer is different from children and adults (Gupta et al., 2016). This also changes as they are moving through key stages in their life that is interrupted from the moment of diagnosis (Gupta et al., 2016). There seems to be a lack of research on the experiences of healthcare workers who support this population. Therefore, understanding the experiences of healthcare workers will allow for an in-depth perspective of the lived experiences of these workers with this specific population. The researcher hopes to better understand what it is like caring for this population and what can be done to better support healthcare workers and the patients.

Study Design

This study will utilize an interpretative phenomenological analysis.

Research Methods

Data will be collected in six paediatric hospices across Canada. Semi-structured, face-to-face interviews will be conducted with healthcare workers who provide palliative care to adolescents and young adults living with advanced cancer. Interviews will last approximately one hour and will either be conducted at the hospice or through video conferencing. Data analysis will follow the IPA guidelines and will include line-by-line coding and thematic analysis.

Discussion

This study seeks to understand the experiences of healthcare workers working in palliative care with adolescents and young adults living with cancer. The results of this study will provide an in-depth understanding of the experiences of healthcare workers across Canada in paediatric hospices working with this specific population. This information would be valuable as cancer is the third leading cause of death for this population.

11. Anticipated project dates

Start date: May 2018 **End date: September 2019**

12. Please describe the sample of participants to be studied (including minimum/maximum number, age, gender):

Healthcare workers who care for adolescents and young adults at the end-of-life.

13. How will participants be recruited and from where? Be as specific as possible.

Setting

Data will be collected from paediatric hospices across Canada. Having more than one hospice setting will allow for an in-depth understanding of the lived experience of the healthcare workers across potentially different contexts. This will also strengthen the overall study.

Sampling

Rigour in IPA refers to the appropriateness of the sample and thoroughness of the study (Smith, Flowers & Larkin, 2009). The literature indicates that IPA researchers recruit a homogenous sample due to a smaller sample size (Chapman & Smith, 2002; Pietkiewicz & Smith, 2014; Wagstaff & Williams, 2014). This IPA study will utilize purposive sampling, which is congruent to an IPA design and will ensure that the participants who have been selected possess specific knowledge in regard to the research question (Curtis, Gesler, Smith, & Washburn, 2000). The objective is to gain diverse perspectives from various healthcare discipline. Snowball sampling will also be used if needed as a way of recruiting additional participants (Kelly & O'Brien, 2015). Additional participants acquired through snowball sampling will come from the participants that are recruited through purposive sampling (Kelly & O'Brien, 2015). There will be an ongoing programme of information regarding the study, which will be beneficial if further recruitment if needed. If this occurs, snowball sampling may be used, and participants will invite other colleagues to be involved if interested. Depending on the number of participants that are recruited and the diversity of the sample set, it may not be possible for all who are interested to take part. Therefore, there will be a clear message in the email to the participants about the need for a range of disciplines needed for the study. If too much of one discipline is recruited, the researcher will purposively select participants.

Sample Size

There is no rule regarding the ideal number of participants needed for an IPA design, however, there have been studies that range from 1-30 participants (Brocki & Wearden, 2006; Pietkiewicz & Smith, 2014). Within IPA, there have been benefits discussed to recruiting fewer participants as a focus is on depth as opposed to breath (Brocki & Wearden, 2006; Pietkiewicz and Smith, 2014). It has been recommended that researchers refrain from collecting an extensive amount of data from a large number of participants as they may be unable to capture all of the meaning of each participant's experience. (Collins & Nicolson, 2002; Pietkiewicz & Smith, 2014). The sample size will be based on the richness needed to study this phenomenon, the similarities and differences that the researcher would like to compare and contrast, time restraints and the access to participants (Pietkiewicz & Smith, 2014). It is anticipated that approximately 15-30 participants will be required for this study. This range will allow for flexibility with the sample size, while also ensuring that time can be taken to fully understand the full experience of each participant.

Non-participation

A log will be kept of people who decline to participate or drop out of the study. The reasons for the non-participation if given will also be documented.

Recruitment

It is essential that the recruitment phase does not come across as coercive and therefore the researcher will ensure that all of the hospices are aware of the process and assist in recruiting participants in an ethical manner. There are six paediatric hospices in Canada, and all have expressed an interest in enabling those who work at the hospice to participate in the study, pending ethical approval. Each hospice has identified one key person that will work act as an internal support to the researcher. This key person will provide information about the study at staff meetings and through their communication tools with a flyer that will be provided (Appendix one). The flyer will also be displayed in staff and public areas. People who are interested in participating in the research can either request more information from the key support person at the hospice (who will be supplied with a stock of participant information sheets and response forms, appendices 2 and 3) or contact the researcher directly for more information.

The researcher will then email or telephone potential participants to further discuss the study (appendices 5). Consent forms will be signed prior to each interview beginning. Interviews will not be conducted unless the informed consent form has been signed. The participants will be sharing their experiences and if there are such things as system challenges, they may be reluctant to share if they are identifiable, therefore participants will be aware that pseudonyms will be used to help maintain anonymity. Participants will be made aware of the fact that the researcher has two supervisors who will be involved in the research study.

14. What procedure is proposed for obtaining consent?

Consent forms will be signed prior to each interview beginning. Interviews will not be conducted unless the informed consent form has been signed.

15. What discomfort (including psychological e.g. distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

As a result of existential issues being related to IPA studies, it is important that close attention is paid to how the process is impacting the participants (Pietkiewicz & Smith, 2014). Pietkiewicz & Smith (2014) explain the importance of the researcher developing their interviewing skills when conducting an IPA study and using counselling techniques when situations may become awkward or emotional. Given that the researcher is a registered Social Worker, the researcher has extensive training in counselling and therefore will utilize these skills if needed. The researcher will ensure that resources are provided should the participants require additional support. The researcher will also utilize a distress protocol by Haigh & Witham (2013) for qualitative data to help further identify if a participant is experiencing distress. This protocol has a section that supports the researcher, which is useful given the IPA design of this study.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of a lone worker plan you will follow and the steps you will take).

For the data collection process, the Lancaster Guidance for Lone Working document will be adhered to for the purposes of this study. I will create a schedule that indicates the date, time and location of the interview that I am conducing. This schedule will include an emergency procedure including an individual that can be contacted for emergency purposes. I will ensure that I have a system of checking in and out when working in the field. Seeing that I live in Toronto and there is a time difference in the UK, I will check in and out with the reception at my place of employment. We have current policies in place for individuals that work alone in the community. These practices will be followed and shared with my supervisors. My schedule will also be shared with my supervisors.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

As this is an IPA study, reflecting back on experiences can be a therapeutic in some ways. The benefits may be that the healthcare workers had time to reflect on their practice.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

N/A

19. Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

2.8 Data Collection

The moral justification for this study is to better understand the experiences of healthcare workers and make a valuable contribution to the palliative care field that in future can hopefully inform the practice of others. Prior to collecting data, the first step will be submitting the proposals to the different REB’s for each hospice as required. The proposal will then be submitted for review by the Lancaster University Research

Ethics Committee through FMHREC. Once approvals have been received, the data collection process will begin.

It imperative that informed consent is obtained from all of the participants. Informed consent ensures that the participants are aware of all that the study entails and that they have the right to withdraw. Consent forms will be obtained on the day of the interview. If the interview is occurring via video conference, the consent will be scanned on that day and sent to the researcher (appendices four). One of the goals of this study is to produce rich, meaningful and detailed experiences of this phenomenon (Pietkiewicz & Smith, 2014).Where possible, Face-to-face interviews will be conducted, which has been the technique that has been used in other published IPA's research studies (Kelly & O'Brien, 2015; Schweitzer, Griffiths, & Yates, 2012; Vachon, Fillion, & Achille, 2012). If a face-to-face interview is not possible, the interview will take place via video conference. The interviews will be semi-structured, which will allow the researcher to connect with the participants through a dialogue, which allows flexibility and richer data (Smith, 2015). This technique is congruent with an IPA design. Open-ended and non-directive questions will provide the foundation for the interviews (Kelly & O'Brien, 2015). The questions will be derived from existing literature (Pietkiewicz & Smith, 2014). Please see Appendix 6 for the research interview guide. Smith (2011) has explained that the participant's ability to discuss their experiences is not very straightforward at times and will require a process of interpretation and engagement. Through this dialogue, the researcher will conduct an in-depth exploration of the participants' experiences, which arise through the modification of initial questions and through prompts based on the responses of the participants (Smith, 2015; Pietkiewicz & Smith, 2014).

Given that the participants are the experiential experts on the phenomenon being studied, they should be given maximum opportunity to express their story (Smith, 2015). Interviews are anticipated to last approximately an hour and more time will be given if needed. All of the interviews will be digitally recorded on an iPad and will be encrypted with a password-protected code and the iPad will be stored in a locked cabinet. Upon completion of each interview, each transcript will be copied onto an encrypted file on a personal laptop that is password protected. The laptop will be stored in a locked cabinet when not in use.

Field notes will be taken right after the interviews to ensure that all nonverbal communication and emotions are captured. Personal reflection in IPA is integral and allows for an importance to be placed on reflections through the analysis process (Kelly & O'Brien, 2015). This may also be viewed as a bias and therefore it is important that a reflexive journal is kept throughout the data collection process (Kelly & O'Brien, 2015). This is useful as in qualitative research subjectivity is not as clear as in quantitative research (Drapeau, 2002). A reflexive journal will allow the researcher to capture all personal experiences and reflections regarding the study (Evans & Hallett, 2007). All of the field notes and the reflexive journal will be kept in a locked cabinet.

All of the devices used will be password protected and passwords will be changed every month. All paper files, including field notes and the reflexive journal, will be stored in a locked cabinet. All transcripts will be stored in an encrypted file on the researcher's computer for ten years and will be backed up to an external hard drive that will be stored in a locked cabinet. All paper files, text data, and the reflexive journal will be stored in a locked cabinet as a permanent archive for further reference if needed. Once the final report has been submitted and the dissemination of the final report, all personal details, and audio recordings will be destroyed.

Seeing that the researcher will be the only person reading and analysing the data, the participants will be made aware of this (Oliver, 2010). For the data collection process, the Lancaster Guidance for Lone Working document will be adhered to. Please see Appendix 10. The researcher will create a schedule that indicates the date, time and location of the interviews being conducting. This schedule will include an individual that can be contacted for emergency purposes. The researcher will ensure that there is a system of checking in and out when working in the field. Given that the researcher lives in Toronto and there is a time difference in the UK, the researcher will check in and out with the reception at the place of employment, in which there are current policies in place for individuals that work alone in the community. These practices will be followed and shared with my supervisors. My schedule will also be shared with my supervisors.

2.9 Data Analysis

Ensuring that the study has a robust data analysis process is pertinent within IPA to fully understand an inside perspective of the experience under investigation (Tebbet & Kennedy, 2012). The data analysis process will follow the IPA guidelines (Smith & Osborn, 2003). This section of the study consists of the researcher creating an interpretative relationship with the data (Smith, 2015). Each transcript will be read twice to ensure accuracy and to capture the essence and meaning of each interview

(Smith, 2015). Throughout each of the readings, line-by-line coding will be done, and all key terms, phrases, words, and insights will be highlighted and put into a table (Smith, 2015). Thematic analysis will occur and then a comparison of the similarities and differences between the transcripts and all emerging themes and sub-themes will be identified. All of the emerging themes and sub-themes will then be categorized into another table. The researcher will compare all of the themes back to the transcript to ensure accuracy, reliability, and validity of each theme (Leung, 2015; Smith, 2015; Tebbet & Kennedy, 2011). It is estimated that transcription will take seven hours per interview. Each interview will be transcribed verbatim with the assistance of a software called Transcribe. Nonverbal expressions such as laughing, crying, silence and other emotions will also be included in the transcript to ensure that all nonverbal actions are accounted for (Adolfsson, 2010). Once all of the themes have been identified, verbatim extracts will be used to provide context to the themes (Kelly & O'Brien, 2015). The use of verbatim extracts in an IPA study illustrates sensitivity to the raw data (Shinebourne, 2011). Sensitivity to content is one way of ensuring validity. Given that direct quotes will be used, it is important that the participants understand anonymity will be upheld through the use of pseudonyms. The reflexive journal will be analysed and used to provide clarity on the IPA process (Kelly & O'Brien, 2015). The journal will support the findings of the themes and may generate themes (Kelly & O'Brien, 2015).

The four basic principles of ethics, beneficence, non-maleficence, autonomy, and justice will be upheld throughout this study (Reyna, Bennett, & Bruera, 2007). It is important that participants trust the research process as they do not have control over the data collection and the way in which the study will be written (Oliver, 2010). Building trust and having robust participant information forms and consent forms should help participants understand that anonymity will be upheld. Confidentiality ensures that the privacy of all participants is respected. Participants will be aware that direct quotes will be used and therefore the data will not be completely confidential, however, all personal details will be confidential. All personal information will be stored in another file that is separate from interview transcripts. The participants will be made aware that confidentiality will not be upheld if data arises that reflects the significant risk of harm to themselves or someone else (Oliver, 2010).

20. If relevant, describe the involvement of your target participant in the *design and conduct* of your research.

The goal of IPA is to gain an in-depth understanding of how participants view their social and personal worlds (Erichsen, Danielsson, & Friedrichsen, 2010; Smith, 2015). It also aims to expand and understand the deepness of the range of experiences of the participants (Goulding, 2005). It supports a hermeneutic phenomenology in which the researcher and the participants are viewed as sense making agents (Smith, Spiers, Simpson, & Nicholls, 2017). IPA values the experiences of the research and takes into account their experiences and knowledge of the phenomenon (Goulding, 2005). IPA is based on the entirety of one’s lived experience (Giorgi, 1997). This methods also focuses on the personal perception of an object or event in a subjective manner (Smith, 2015). IPA has been described as a dynamic research method as it acknowledges the influence that the researcher has throughout the research study, in particular the data analysis phase (Tebbet & Kennedy, 2012). IPA is a two-fold process also known as a double hermeneutic in which the researcher tries to understand the participants’ world as the participants try to make sense of their own world (Smith, 2015). IPA fits well with this study as an exploration of healthcare workers experiences supporting adolescents and young adults who are dying of cancer is the primary aim. This method will allow me to better understand the meaning that the participants attribute to their experiences.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

All of the interviews will be digitally recorded on an iPad and will be encrypted with a password-protected code and the iPad will be stored in a locked cabinet. Upon completion of each interview, each transcript will be copied onto an encrypted file on a personal laptop that is password protected. The laptop will be stored in a locked cabinet when not in use.

Field notes will be taken right after the interviews to ensure that all nonverbal communication and emotions are captured. Personal reflection in IPA is integral and allows for an importance to be placed on reflections through the analysis process (Kelly & O’Brien, 2015). This may also be viewed as a bias and therefore it is important that a reflexive journal is kept throughout the data collection process (Kelly & O’Brien, 2015). This is useful as in qualitative research subjectivity is not as clear as in quantitative research (Drapeau, 2002). A reflexive journal will allow the researcher to capture all personal experiences and reflections regarding the study (Evans & Hallett, 2007). All of the field notes and the reflexive journal will be kept in a locked cabinet.

22. Will audio or video recording take place? ☐ no audio ☐video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.

- Transcripts will be kept for 10 years on an encrypted file on a password protected computer after the study has been completed. After this period of time, all transcripts will be destroyed.
- Paper files, text data and the reflexivity journal will be kept in a locked cabinet as a permanent archive for further reference and research is needed.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected. The password on the computer will be changed monthly as a measure of extra security.
- The typed version of your interview will be made anonymous by removing any identifying information including names. Anonymized direct quotations from the interviews may be used in the reports or publications from the study, however no names will not be attached to them. The study will utilize pseudonyms to ensure anonymity. The participants will select their own pseudonyms.
- All personal data will be confidential and will be kept separately from the interview responses and will be destroyed once the research study has been submitted for publication/examined.

23. What are the plans for dissemination of findings from the research? If you are a student include here your thesis.

- Summarized and reported in a thesis.
- Submitted for publication in an academic or professional journal
- Conference and seminar presentations pertaining to palliative care.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

The first step before beginning a research study is ensuring that ethics approval has been obtained. Following the proper ethical procedures will ensure that all potential ethical issues will be addressed at each stage of this study. Due to the fact that the study requires human participants, it is imperative that ethical guidelines are followed and upheld throughout the whole research process Oliver (2010) has explained the importance of a moral justification for research studies. The moral justification for this study is to better understand the experiences of healthcare workers and make a valuable contribution to the palliative care field that in future can hopefully inform the practice of others. The first approach will be obtaining approval from one local IRB in Canada and this study will be conducted in Toronto. It will then be submitted for reviewed by the Faculty of Health and Medicine Research Ethics Committee (FHMREC at Lancaster University). The self-assessment form and the project information and ethics questionnaire will be completed followed by the completion of the FHMREC form. Within this application all advertising material, invitations, consent forms, information sheets, interview schedules, interview guides and debriefing sheets will be included. All of these forms can be found in the appendices of the research proposal. It is important to note that the researcher will operate from an anti-oppressive framework in which each participant is viewed as an individual despite gender, class, education, socio economic status, culture, religion, and sexual orientation. It is imperative that I am non-judgmental and approach each participant with uncertainty, respect and dignity.

There are no matters that I wish to seek guidance

Signatures: Applicant: ……………………......................................

Date:

……………………………………………………...............................
.....

Project Supervisor* (if applicable):……………………………………..

Project Supervisor* (if

applicable):……………………………………..

Date:

…………………………………………………….................................

......

*I have reviewed this application and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Appendix 5: Lancaster University Faculty of Health and Medicine Ethics Committee

Applicant: Nadine Persaud
Supervisors: Catherine Walshe and Sarah Brearley
Department: Health Research
FHMREC Reference: FHMREC18014

08 October 2018

Dear Nadine

Re: An Interpretive Phenomenological Analysis: Exploring the Experiences of Healthcare Providers

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

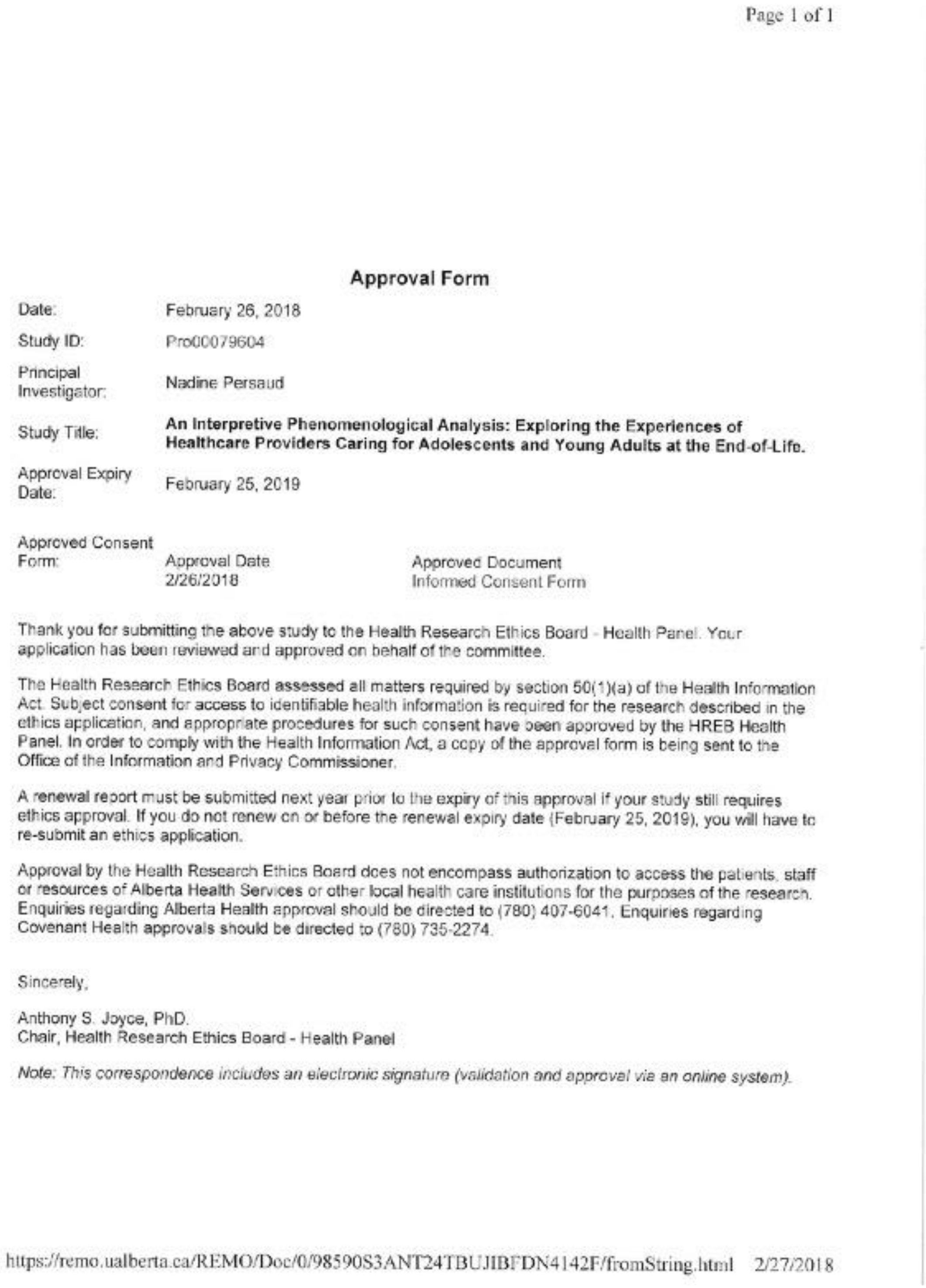
Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E. Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.

Appendix 6: University of Alberta Health Research Ethics Board



Page 1 of 1

Approval Form

Date:	February 26, 2018	
Study ID:	Pro00079604	
Principal Investigator:	Nadine Persaud	
Study Title:	**An Interpretive Phenomenological Analysis: Exploring the Experiences of Healthcare Providers Caring for Adolescents and Young Adults at the End-of-Life.**	
Approval Expiry Date:	February 25, 2019	
Approved Consent Form:	Approval Date 2/26/2018	Approved Document Informed Consent Form

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel. Your application has been reviewed and approved on behalf of the committee.

The Health Research Ethics Board assessed all matters required by section 50(1)(a) of the Health Information Act. Subject consent for access to identifiable health information is required for the research described in the ethics application, and appropriate procedures for such consent have been approved by the HREB Health Panel. In order to comply with the Health Information Act, a copy of the approval form is being sent to the Office of the Information and Privacy Commissioner.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date (February 25, 2019), you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health approval should be directed to (780) 407-6041. Enquiries regarding Covenant Health approvals should be directed to (780) 735-2274.

Sincerely,

Anthony S. Joyce, PhD.
Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

https://remo.ualberta.ca/REMO/Doc/0/98590S3ANT24TBUJIBFDN4142F/fromString.html 2/27/2018

Appendix 7: Research recruitment flyer

You are needed to participant in a research study through Lancaster University!

Are you a healthcare provider who has 3+ years' experience providing palliative care to adolescents and young adults who have a diagnosis of cancer? If yes..I would like to hear from you!

What is involved?

- Participation in one semi-structured face-face interview where you will be able to share your lived experiences of this phenomenon.

When and Where will the interview take place?

- Interviews will begin between XX and XX. The date, time and location will be based on your availability and convenience.

Next Steps

If you are interested in participating in this study, please visit XX located at XX in (Insert name of institution here) where you will find the Participant Information Sheet and the Expression of Interest Form (EOI). Please mail or email me the EOI form within two weeks, and I will contact you!

If you require more details, please do contact me!

Researcher's Name: Nadine Persaud, BSW, MSW, RSW, PhD Candidate
Telephone: 1-647-887-3401 **Address:** 25 Brunswick Ave, Toronto, Ontario, M5S-2L9
Email: n.persaud@lancaster.ac.uk.

If you would like additional information about the research evaluation process, please contact Dr. Sarah Brearley at Tel: +44 (0) 1524 592574 or Email: sarah.brearley@lancaster.ac.uk

Appendix 8: Participant information sheet

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Participant Information Sheet

An Interpretative Phenomenological Analysis: Exploring the Experiences of Healthcare Workers Caring for Adolescents and Young Adults at the End-of-Life

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

What is the study about?

The purpose of this study is to explore the lived experiences of healthcare workers who work with adolescents and young adults requiring palliative care and have a diagnosis of cancer.

Why have I been approached?

You have been approached because the study requires information from people who are healthcare workers who have 3+ years' experience working with adolescents and young adults who require palliative care and have a diagnosis of cancer.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part in this research study.

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

If you decide that you would like to take part in this research study, you would be asked to participate in a one-on-one semi-structured interview. The interview will last from 1-1.5 hours. The date, time and location will be based on your availability and convenience.

Will my data be Identifiable?

This study does intend to utilize direct quotes to better illustrate the participants experiences. Therefore, the data will not be completely confidential. However, to ensure anonymity and confidentiality of identification, pseudonyms will be used, and all personal details will be confidential.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- Transcripts will be kept for 10 years on an encrypted file on a password protected computer after the study has been completed. After this period of time, all transcripts will be destroyed.
- Paper files, text data and the reflexivity journal will be kept in a locked cabinet as a permanent archive for further reference and research is needed.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected. The password on the computer will be changed monthly as a measure of extra security.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymized direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. The study will utilize pseudonyms to ensure anonymity.
- All your personal data will be confidential and will be kept separately from your interview responses and will be destroyed once the research study has been submitted for publication/examined.

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

What will happen to the results?

The results will be summarised and reported in a thesis and will be submitted for publication in an academic or professional journal. The intent is that the findings of this study will also be presented at conferences related to the phenomenon.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

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

Who has reviewed the project?

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

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

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

Nadine Persaud BSW, MSW, RSW, PhD Candidate
Division of Health Research
Faculty of Health and Medicine
25 Brunswick Avenue
Toronto, Ontario, Canada
M5S2L9
Email: n.persaud@lancaster.ac.uk
Tel: 1-647-887-3401

Supervisors:

Dr. Sarah Brearley
Division of Health Research
Faculty of Health and Medicine
Furness College
Lancaster University
Lancaster, LSALLY 4YG
United Kingdom
Email: sarah.brearley@lancaster.ac.uk
Tel: +44 (0) 1524 592574

Dr. Catherine Walshe
Division of Health Research
Faculty of Health and Medicine
Furness College
Lancaster University
Lancaster, LSALLY 4YG
United Kingdom
Email: c.walshe@lancaster.ac.uk
Tel: +44 (0) 1524 510124

Complaints

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

Name of Research Director for your Division: Dr. Elizabeth McDermott
Title: Director of Studies, Palliative Care
Tel : +44 (0) 1524 510847
Email : e.mcdermott@lancaster.ac.uk
Faculty of Health and Medicine
Lancaster University
Lancaster
LSALLY 4YG

If you wish to speak to someone outside of the PhD Palliative Care Doctorate Programme, you may also contact:

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

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

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

Distress Centre Help Line
408-HELP
24/7 Distress and Crisis Line
Open 24 Hours a day, 365 days a year
Provides life-sustaining emotional support to those in need.
https://torontodistresscentre.com/408-help-line

Gerstein Crisis Centre
416-929- 5200
24-hour Community based mental health support
http://gersteincentre.org/

Appendix 9: Expression of interest form

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Expression of Interest Form

Research Study: An Interpretative Phenomenological Analysis: Exploring the Experiences of Healthcare Workers Caring for Adolescents and Young Adults at the End-of-Life

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

I am interested in taking part in this evaluation because I currently am involved in working with adolescents and young adults who are dying from cancer. I also have more than three years supporting this population at the end-of-life. Please return this form either by post or by email to the researcher at the address below, who will contact you to discuss the project and answer any questions you may have about the research and whether you would like to participate.

Please complete the following but only provide contact details that you are happy to
Share:

Name: ____
Health Discipline:
Contact: Mobile phone:
Email:
Home phone:
Work phone:
Postal address:

Researcher contact details:

Nadine Persaud BSW, MSW, RSW, PhD Candidate
Division of Health Research
Faculty of Health and Medicine
25 Brunswick Avenue
Toronto, Ontario, Canada, M5S2L9
Email: n.persaud@lancaster.ac.uk
Tel: 1-647-887-3401

Appendix 10: Informed consent form

Consent Form

Study Title: An Interpretative Phenomenological Analysis: Exploring the Experiences of Healthcare Workers Caring for Adolescents and Young Adults at the End-of-Life

We are asking if you would like to take part in a research project. The aim of this study is to understand the lived experience of healthcare workers who support adolescents and young adults who have a diagnosis of cancer and are at the end-of-life.

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

Please initial each statement

Name of Participant___________________________________
Signature____________________ Date ___________

Name of Researcher __________________________________
Signature ____________________Date ___________

Appendix 11: Research interview guide

Research Interview Guide

1.) Please tell me about the experience of providing palliative care for adolescents and young adults living with cancer.

Prompts:

- Can you please tell me more about X?

Appendix 12: Lancaster University Guide for Lone Working

Revision	**Date**	**Nature of Revision**	**Prepared by**	**Approved by the University Safety, Health and Wellbeing Committee**
Manual of Safety Guidance first published May 2007		• Build closer link to the University's Arrangements for Risk Assessment	Angie Park	**June 2016**

A lone worker is someone who carries out their work activities by themselves without close or direct supervision.

In practical terms, persons are considered to be lone workers if they have neither visual nor audible communication with someone who can summon assistance in the event of an accident or illness.

This guidance should be read in conjunction with the University's **Guidance on Safety in Fieldwork** which offers detailed practical guidance.

PROHIBITION

Lone working must be prohibited in the following activities:

- working in a confined space.
- electrical work involving manipulation of live, uninsulated power conductors using insulated tools.
- other electrical work where at least 2 people are sometimes required

ACTIVITIES FOR SPECIAL CONSIDERATION

High risk activities that require specific attention when planning safe lone working arrangements include working with:

- Chemicals, particularly corrosive, toxic, explosive, flammable, asphyxiant, or narcotic substances, products or reactions
- Cryogenic substances
- Class 3B/4 lasers where the beam is not fully enclosed
- Power tools and machinery

- Working on or near water
- Working at height

RISK ASSESSMENT

- There is no specific regulation that directly relates to Lone Working. The arrangements for safe working in any situation fall within the Management of Health and Safety at Work Regulations 1999. This regulation requires that a suitable and sufficient **Risk Assessment** is carried out and adequate controls are in place. The manager/supervisor [principal investigator] is responsible for ensuring that this happens.

- The University's Risk Assessment process requires the assessor to apply the hierarchy of controls. The first of these is to eliminate the risk completely which must be the first consideration for Lone Working if at all possible.

- It is expected that the risk assessment process is undertaken as a collaborative exercise by both the lone worker and their manager/supervisor [principal investigator] and that the agreed safe working procedures are recorded and communicated to all persons who may be required to work alone and any other employees who have a role to play in ensuring their safety.

DOES LONE WORKING ENHANCE THE RISK?

If lone working is being considered then a review of the current risk assessment is the starting point.
It is important to stress that only significant risks must be controlled. Where normal working practices do not pose significant risks, the assessor should consider whether by undertaking the task as a lone worker it will increase the risk to the individual. To do this the assessor should consider the following categories.

- **Workplace:** does the area where the lone working will take place introduce any significant hazards? For example will it be properly lit throughout the period of the work, is there other equipment in the area that could pose a hazard, will emergency exits be available, could the lone worker be vulnerable to violence during the work or when travelling to or from the workplace?
- **Task:** is there anything about the task that means carrying it out as a lone worker is not appropriate. For example are there any accident scenarios that would require others to respond – if so how will you arrange this?

- **Individual:** consider the individual carrying out the lone working. For example do they have the necessary experience, are they medically vulnerable?

ARE INCREASED CONTROLS REQUIRED?

If you identify additional risks you will need to determine appropriate controls. Lone workers should not be put at a greater risk than others. You need to record any additional controls that you think are appropriate in your risk assessment.
When deciding on the controls you should consider the following;

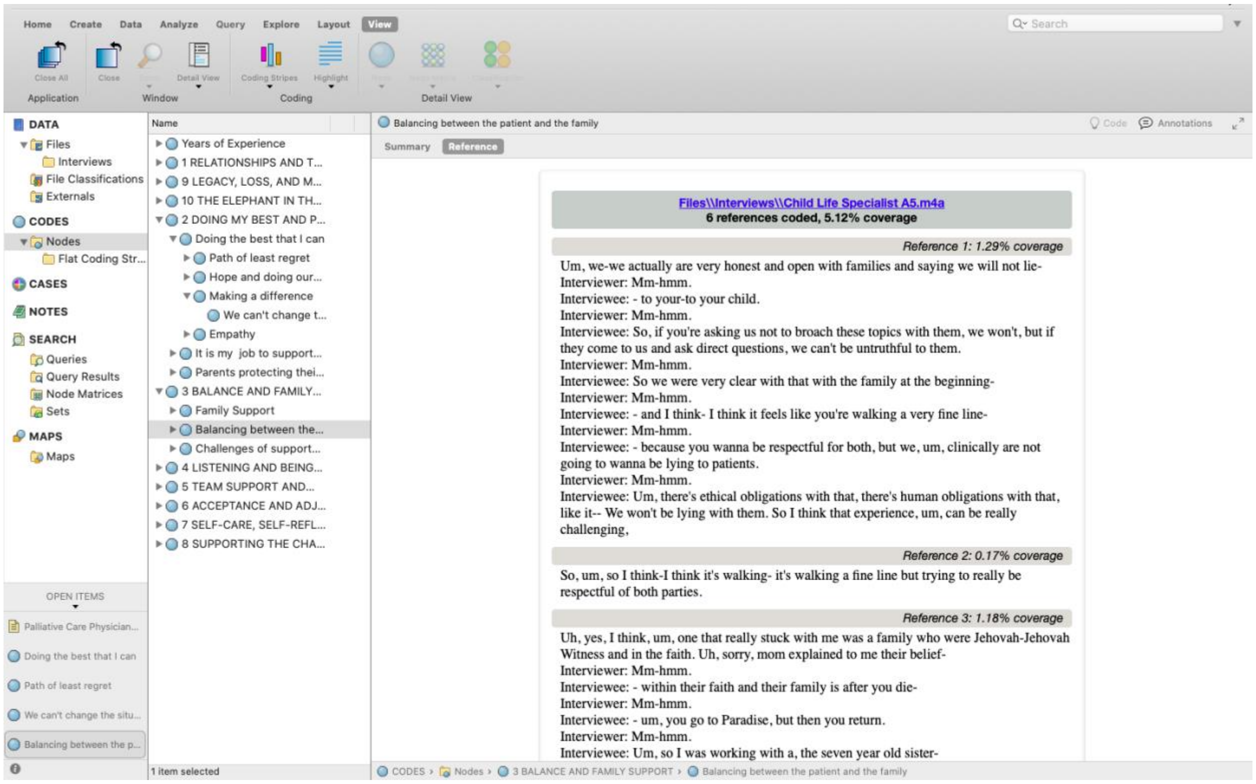
- a system of checking in and out
- the development of an enhanced emergency procedure and response
- additional training for the individuals and those expected to support them
- the use of technology to monitor
- additional levels of first aid equipment and protocols

APPROVAL TO CARRY OUT LONE WORKING

Departments must develop their own approval route for permitting lone working for staff and students.

The approval route must include a suitable and sufficient risk assessment and sign off procedure. It would be appropriate to include the Head of Department and/or their competent nominee in such a process.
Where enhanced emergency procedures and response form part of the additional controls, University Security must be included in their development.

Appendix 13: NVivo example of the organisation of data



Files\\Interviews\\Child Life Specialist A5.m4a
6 references coded, 5.12% coverage

Reference 1: 1.29% coverage

Um, we-we actually are very honest and open with families and saying we will not lie-
Interviewer: Mm-hmm.
Interviewee: - to your-to your child.
Interviewer: Mm-hmm.
Interviewee: So, if you're asking us not to broach these topics with them, we won't, but if they come to us and ask direct questions, we can't be untruthful to them.
Interviewer: Mm-hmm.
Interviewee: So we were very clear with that with the family at the beginning-
Interviewer: Mm-hmm.
Interviewee: - and I think- I think it feels like you're walking a very fine line-
Interviewer: Mm-hmm.
Interviewee: - because you wanna be respectful for both, but we, um, clinically are not going to wanna be lying to patients.
Interviewer: Mm-hmm.
Interviewee: Um, there's ethical obligations with that, there's human obligations with that, like it-- We won't be lying with them. So I think that experience, um, can be really challenging,

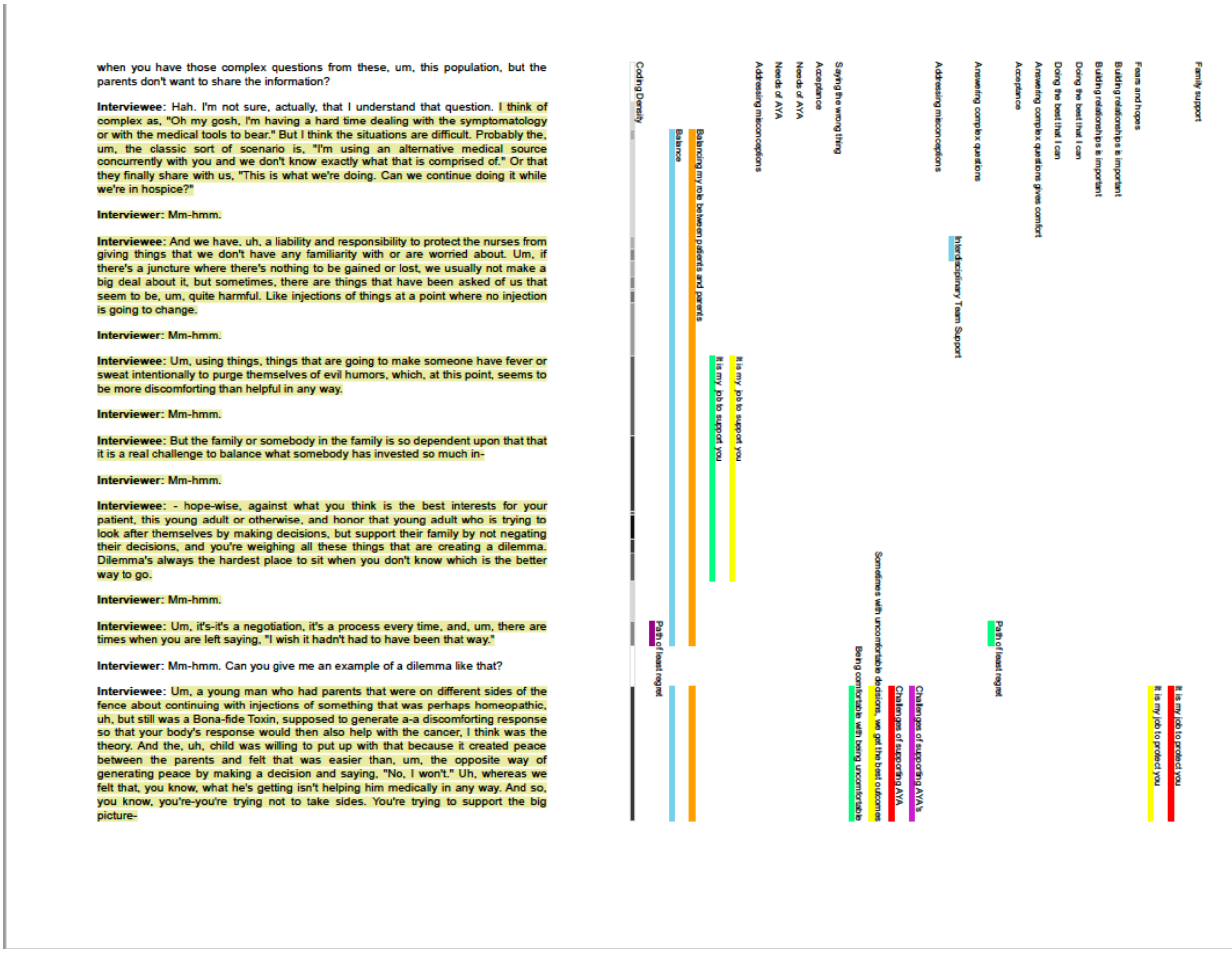
Reference 2: 0.17% coverage

So, um, so I think-I think it's walking- it's walking a fine line but trying to really be respectful of both parties.

Reference 3: 1.18% coverage

Uh, yes, I think, um, one that really stuck with me was a family who were Jehovah-Jehovah Witness and in the faith. Uh, sorry, mom explained to me their belief-
Interviewer: Mm-hmm.
Interviewee: - within their faith and their family is after you die-
Interviewer: Mm-hmm.
Interviewee: - um, you go to Paradise, but then you return.
Interviewer: Mm-hmm.
Interviewee: Um, so I was working with a, the seven year old sister-

Appendix 14: Example of a coded transcript



when you have those complex questions from these, um, this population, but the parents don't want to share the information?

Interviewee: Hah. I'm not sure, actually, that I understand that question. I think of complex as, "Oh my gosh, I'm having a hard time dealing with the symptomatology or with the medical tools to bear." But I think the situations are difficult. Probably the, um, the classic sort of scenario is, "I'm using an alternative medical source concurrently with you and we don't know exactly what that is comprised of." Or that they finally share with us, "This is what we're doing. Can we continue doing it while we're in hospice?"

Interviewer: Mm-hmm.

Interviewee: And we have, uh, a liability and responsibility to protect the nurses from giving things that we don't have any familiarity with or are worried about. Um, if there's a juncture where there's nothing to be gained or lost, we usually not make a big deal about it, but sometimes, there are things that have been asked of us that seem to be, um, quite harmful. Like injections of things at a point where no injection is going to change.

Interviewer: Mm-hmm.

Interviewee: Um, using things, things that are going to make someone have fever or sweat intentionally to purge themselves of evil humors, which, at this point, seems to be more discomforting than helpful in any way.

Interviewer: Mm-hmm.

Interviewee: But the family or somebody in the family is so dependent upon that that it is a real challenge to balance what somebody has invested so much in-

Interviewer: Mm-hmm.

Interviewee: - hope-wise, against what you think is the best interests for your patient, this young adult or otherwise, and honor that young adult who is trying to look after themselves by making decisions, but support their family by not negating their decisions, and you're weighing all these things that are creating a dilemma. Dilemma's always the hardest place to sit when you don't know which is the better way to go.

Interviewer: Mm-hmm.

Interviewee: Um, it's-it's a negotiation, it's a process every time, and, um, there are times when you are left saying, "I wish it hadn't had to have been that way."

Interviewer: Mm-hmm. Can you give me an example of a dilemma like that?

Interviewee: Um, a young man who had parents that were on different sides of the fence about continuing with injections of something that was perhaps homeopathic, uh, but still was a Bona-fide Toxin, supposed to generate a-a discomforting response so that your body's response would then also help with the cancer, I think was the theory. And the, uh, child was willing to put up with that because it created peace between the parents and felt that was easier than, um, the opposite way of generating peace by making a decision and saying, "No, I won't." Uh, whereas we felt that, you know, what he's getting isn't helping him medically in any way. And so, you know, you're-you're trying not to take sides. You're trying to support the big picture-

Interviewer: Mm-hmm.

Interviewee: - of the family circle so that the child can get the most support from everybody possible.

Interviewer: Hmm.

Interviewee: But what he had to go through physically to accomplish that was really discomforting to be a part into.

Interviewer: And how did you deal with that?

Interviewee: I spoke with him and-

Interviewer: How old is he? Sorry.

Interviewee: He was probably fifteenish. And, um, I said that, you know, "I don't see this medically serving you in any way. I see it potentially making you very uncomfortable without gaining you anything. But I see you trying to appease what every party is asking for. Is this the best way you can see going about it, or would you be comfortable saying, "I just can't face this anymore." and we can support you in that?" and I let him direct us.

Interviewer: And what did he want?

Interviewee: He said, "The only way that I can see it possible for the one parent to be able to still come and so forth is to do this, and I know the other parent will be there no matter what. And I just have to get them to the point of recognizing that I want them more than anything else, and so this is the way I see forward."

Interviewer: And that's what he continued to do?

Interviewee: He did.

Interviewer: Wow.

Interviewee: He did. Um, the cost to him was a-a lesser discomfort than he was worried about facing, I think.

Interviewer: Hmm. And if you think back to that situation, would you have done things differently?

Interviewee: I don't see how I could have.

Interviewer: Mm-hmm.

Interviewee: We all approached him as a team-

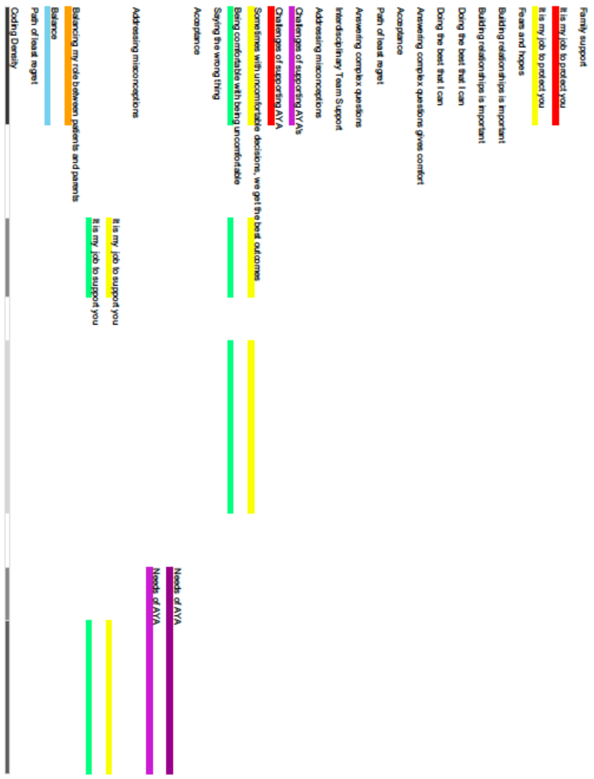
Interviewer: Mm-hmm.

Interviewee: - at various points. We all tried to make sure the decisions that he was making-

Interviewer: Mm-hmm.

Interviewee: - were decisions that still fit-

Interviewer: Mm-hmm.



Interviewee: - because everything changes over time, and so your decisions are allowed to change, and we let him know that.

Interviewer: Mm-hmm.

Interviewee: But in the end, we were there to say that, "And we will support you with whatever you feel you need to do, and you can't change that really. If there's something that we can do, if it serves a purpose that is in your best interests, we will. If there's something that we can do, but it doesn't serve any purpose," that's what we were trying to help him understand. But it did serve a purpose for him to just not a medical one.

Interviewer: Exactly, yeah. That-that's really, really interesting. I think it, um, I think it kind of brings me to the point where, you know, um, when someone is 15 and they're underage and their parents are still there at-- the responsible one, but you're 15 and you still want to make decisions. What is that, like? What has been your experience with that with someone who's at the receiving palliative care?

Interviewee: Um, very rare when you get to the point-- because you can't really provide palliative care to a family that doesn't want you-

Interviewer: Mm-hmm.

Interviewee: - that you end up with two great a divide to find common enough ground. Um, I think in the hospice setting, I've never actually encountered it where we failed to say at least we'll figure a way to go forward even if nobody's gonna be happy,-

Interviewer: Mm-hmm.

Interviewee: - and we're trying to find the path of least regret. But the ones where we have found that the families don't like what we are willing to or not willing to do, um, those are the families who often say, "I don't need your services anymore." That hasn't been the hospice family. Those have been the families whose children typically are younger.

Interviewer: Mm-hmm.

Interviewee: They are the voice for their children because their children can't voice such things, and, um, their philosophy or their, um, demands are ones that they would rather serve independently rather than trust their child to be in the hands of someone who said we'll do what's standard or acceptable from our policy, et cetera.

Interviewer: Mm-hmm.

Interviewee: Um, so when it comes down to hospice, I think what I'm finding is we are all of us trying to do what we think is best for this young adult.

Interviewer: Mm-hmm.

Interviewee: And we will do all of us our best to respect what that young adult asks. Legally, it's informed assent, I suppose, I suppose to consent.

Interviewer: Mm-hmm.

Appendix 15: Mind Map Two: Doing My Best and Protection

Doing the best that I can

The path of least regret

- *Path of least regret*
- *I am confident but sometimes I need reassurance*
- *Never giving up*
- *Saying the wrong thing*
- *We are all human*

The role of hope in doing my best

- *Hope and doing our best*
- *Hoping for a good outcome*
- *Hope and Pain*
- *Hope does not have to be a cure*
- Making a difference
- We can’t change the situation, but we can make it better

Empathy is important

- *Empathy*
- *Empathy and pain are related*

It is my job to protect you

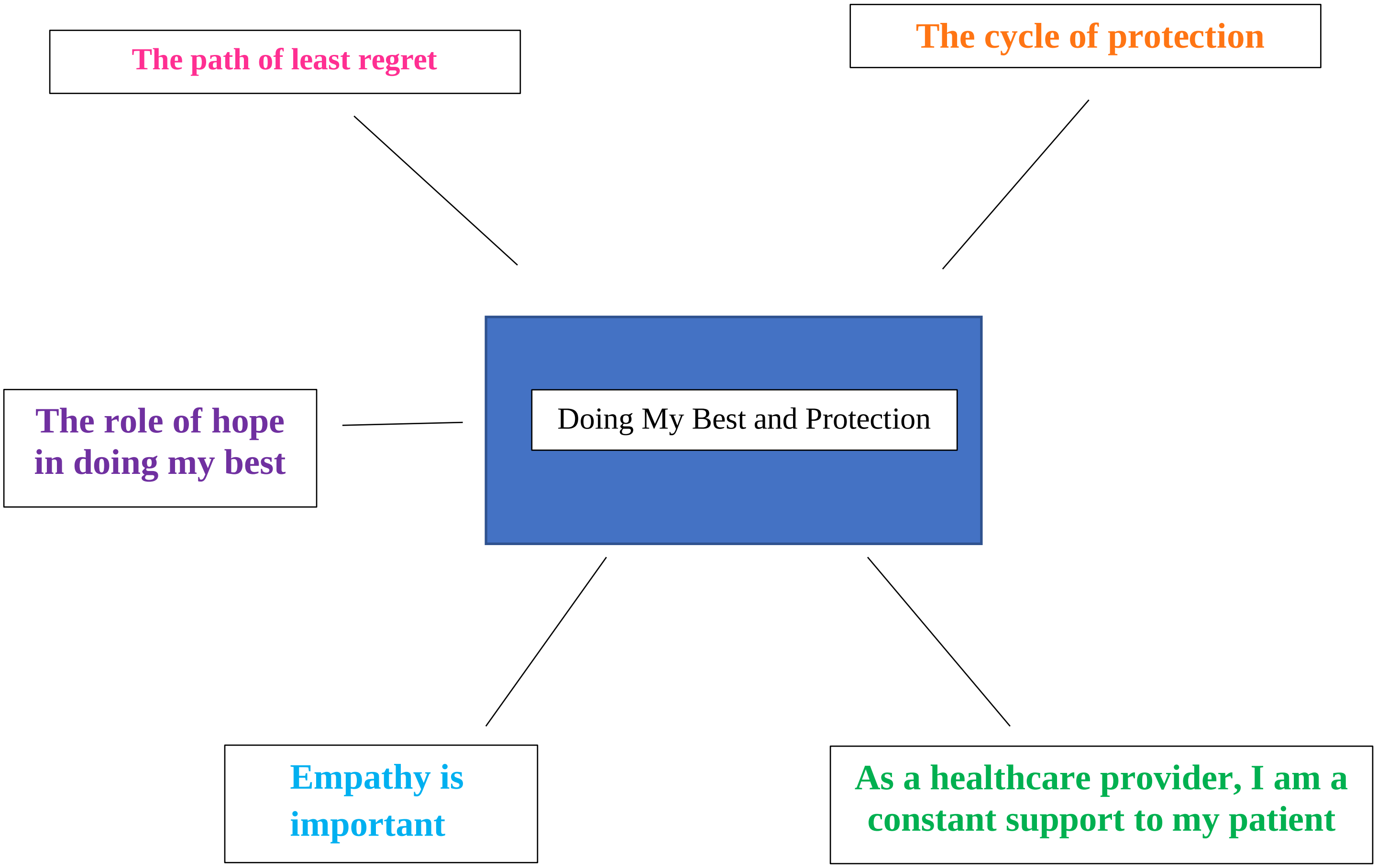
As a healthcare provider, I am a constant support to my patient

- *It is my job to support you*
- *Supporting the patient is important*
- *Being a constant support to the patient*

The cycle of protection

- *Parents protecting their child*
- *Patients protecting their parents*

Mind Map Two: Doing My Best and Protection



Appendix 17: List of codes

List of 248 Codes

So: Source Ref: Reference

Code (Node)	So	Ref
Years of Experience	6	6
My past experiences impact my future	7	15
Ages supported	5	7
My practice is underpinned by my education	5	8
Legacy, loss and making every moment count	1	1
Grief and Loss	17	34
Loss of a future	13	29
Loss as disease progresses	7	13
Grief	6	9
As an AYA there are many losses	5	6
Loss of hobbies	3	7
Sharing meaningful moments	7	9
Living in the moment is important	12	33
Making every moment count	11	56
Sharing memories help me cope	6	11
Laughter is important	4	7
Hospice is about living	4	10
Framing legacy experiences differently at the EOL	4	5
The importance of legacy support	6	24

Fun moments	4	10
Special moments at the EOL	6	8
Wishes at the end of life	6	15
Wishes and desires of the patients	5	12
Relationships and trust	1	1
Building relationships is important	17	87
Creative ways of starting conversations	12	39
Finding ways of building relationships	6	10
Building relationships take time	7	14
Connecting through music	2	6
Trust is essential	12	70
Building a culture of trust is important	6	9
Building relationships creates comfort	4	6
As a nurse I create a safe space for my patients	4	5
Special bonds with special patients	6	14
Building relationship with AYA can be difficult	6	8
Building relationships is difficult when there is no acceptance from the patient and the family	5	12

I connect more with adolescents	3	11
Accepting that I am not always going to connect with a patient	1	1
You can still support the patient through the trust of someone else	8	18
Early referrals help to build relationships	5	8
Earlier referrals allow for stronger relationships	3	4
Fears and hopes	17	71
Hope and acceptance	6	11
Hope and being cured are connected	4	5
Hope comes in different forms	13	25
Hope Changes	8	13
Hope and strength	4	5
Hope of living every moment	4	8
Hope can be small	3	3
Hope and being present	5	7
Hope changes when treatment path changes	6	10
Hope is fundamental	4	4
Dealing with my personal fears is important	4	5
Challenges of supporting AYA's	16	91
Late referrals	9	20
Misconceptions of palliative care	6	17
Addressing misconceptions	8	21

Overcoming misconceptions	5	9
Changing the word Palliative to help with the misconceptions	2	7
Perception of palliative care	4	5
Lack of resources	6	9
Paediatric palliative care and adult palliative care	5	12
Palliative care falls within a grey area	4	6
Black and white	3	6
Crisis	3	8
This work is emotionally difficult	7	20
Sometimes I cry a lot	6	9
my job is hard, but it is what I do	5	6
Witnessing tragedy	5	8
Not taking things personally	9	13
Humility and uncertainty	5	6
Experiencing pain and suffering	4	9
AYA's are the most challenging population	4	5
AYA's search for identity	2	5
Adolescents are all unique	15	46
Adolescents are very aware of themselves and the world	1	2
Exceptional and special patients	8	13

Adolescents have a greater awareness regarding illness	3	4
Adolescents understand life and death differently	2	2
Adolescents have a liveable past	2	2
Patients have different masks that they wear	1	3
Adolescents are at a stage where they are growing and developing	1	3
AYA's are wise beyond their years	15	61
AYA's are dealing with many things at once	1	1
Some AYA's are aware of what is going on	6	8
The internet allows for children to be more aware	3	7
AYA recognize the impact of their illness on others	2	2
Maturity Levels of the AYA population	1	2
Needs of AYA	15	73
Choice and Control	14	40
Autonomy and independence	12	38
Independence among AYA	3	15
Finding creative ways of maintaining autonomy and independence is important	9	15
Choice at the end of life	5	7
Respecting choice	4	5

Choice and trust	4	5
Advance Care Planning stops when death declares itself	3	4
Advance care planning	5	13
Control and MAID	2	6
Being non-judgemental is important	12	19
Emotions are important	13	39
Meeting teens where they are at	7	11
Relationships are important to AYA's	7	10
Hospice is home	5	5
Maintaining Normalcy with AYA's	3	11
Do not make assumptions	2	5
Advance symptom management	5	7
Understanding pain management	7	11
Focusing on symptom management and not palliative care	5	7
Being pain free is important	2	6
It is important to know when something is outside of my scope of practice	13	34
Knowing when to step back	13	32
Knowing when to back off	7	8
Who's needs are we serving	4	7

Knowing your limitations is important	2	8
My team just gets it	11	25
Interdisciplinary Team Support	18	97
Holistic Care	8	20
Debriefing with the team	7	9
Supporting my team is important	6	12
My team provides me with courage and trust	6	10
Working as a team is important	4	8
Teamwork is hard	7	17
Elephant in the room	16	49
Deflating the elephant in the room	17	58
The importance of honest conversations	14	59
Answering complex questions	13	55
It is important to dig deep when faced with complex questions	11	23
Meaningful conversations with AYA's	5	6
Finding ways of having open conversations with the patient	5	5
Being direct and honest	5	8
Being asked complex questions requires reflection and truthfulness	5	6

Transparency with AYA is imperative	5	9
Communication is key	4	4
Communication and teamwork	4	4
Being mindful while sharing information is important	2	5
Closed families	10	28
My patients open up when they are alone	12	30
Opening up reflective space as a healthcare provider is important	10	28
Personal faith beliefs	9	24
Rituals at the end of life	6	7
Religion and values at the end of life	4	8
Supporting faith needs	4	5
Every faith has certain beliefs	3	5
Challenges with faith beliefs and death	3	6
The role of spirituality on professional practice	3	10
There are good moments and there are bad moments	4	10
The relationship between suffering and spirituality	2	12
Culture in palliative care	4	5
Sometimes teens don't want to talk about things	7	14

AYA's are sometimes closed off	5	7
Acceptance	15	59
Acceptance of Disease	6	8
Acceptance versus denial	5	8
Sometimes with uncomfortable decisions, we get the best outcomes	16	34
Being comfortable with being open	10	16
This is not about me; it is about the patient	10	21
Things change quickly	6	12
The future is uncertain	10	19
Shifting from curative treatment to palliative care	6	21
A shift to focus on quality of life	8	16
Death is inevitable	4	5
Acceptance of care is needed	1	1
Self-care is important	14	21
Self-reflection	18	41
My loss is different from the family's loss	4	6
Crying as a way of Coping	4	6
Remembering my patient	3	7
Personal closure	1	7
This work has changed me	12	41
Personal Meaning and purpose	8	28

This jobs puts life into perspective for me	9	12
This job gives me what I need	5	6
Grateful	4	6
This work is a privilege	4	9
This is where I am meant to be	3	3
Inspiration from others	3	6
This job is my utopia	3	4
I get more than I give	2	4
This work is rewarding	2	6
This work has given me more confidence	2	3
This work is a calling of God	1	1
This work has taught me the value of the people in my life	6	13
My patients teach me	7	17
I am a different parent because of my work	4	9
As a parent, this job impacts me differently	3	6
Impacts on how I parent	1	1
This work changed my life	4	8
This work has changed me	5	5
This work has made be appreciate living in the moment	3	3
Impact on personal life	3	7

This work changed my perception on life	2	2
This work has made me appreciate the simple things in life	3	3
This work has impacted my personal relationships	3	3
This work has changed the way I view the world	3	3
This work changed me	2	3
The impact of this work on personal relationship	2	2
Impact of work on my life	1	1
Separating personal and professional life is difficult	11	26
My self-care impacts my ability to be present at work	5	6
Recognizing the signs of burnout is important	3	9
Doing the best that I can	15	119
Path of least regret	11	39
I am confident but I sometimes need reassurance	8	18
We are all human	7	18
Saying the wrong thing	7	20
Never giving up	7	8
Hope and doing our best	10	20
Hoping for a good outcome	6	8
Hope and Pain	1	1

Hope does not have to be a cure	1	1
Making a difference	9	17
We can't change the situation, but we can make it better	8	13
Empathy	6	7
Empathy and pain are related	1	4
It is my job to support you	12	45
Supporting the patients is important	3	6
Being a constant support to the patient	2	18
Parents protecting their child	7	12
It is my job to protect you	16	56
Patients protecting their parents	10	32
Silent and listen have the same letters	9	29
Importance of listening and opening up reflective space	9	20
Listening is imperative when supporting AYA's	4	4
Being present and taking my time is important	7	17
Listening and being presence is important	9	15
Making observations are important	4	7
As I listen to my patients, I am also reflecting	4	7

The importance of being a compassionate presence	2	9
Family Support	16	61
Every family dynamic is different	12	33
Accepting family dynamics	3	4
Every family is different	2	7
Dynamics within families	2	5
Understanding the needs of the family	7	7
Meeting the family where they are at	7	9
Family support comes in different ways	6	10
Sibling’s support	4	13
Being in the moment with families	5	5
Balancing between the patient and the family	14	46
Balance	15	44
Supporting family’s needs and the child’s needs	5	7
I am in the middle when working with patients and their families	3	7
Challenges of support the patient and the parents	4	5
Being in the middle of the patient and parent is difficult	5	10
Respecting the decisions that parents make	5	6

Having sensitivity towards parents	2	4

Appendix 16 : Hospice Services

Hospice Location	**British Columbia**	**Alberta**	**Ontario**	**Montreal**
Services Provided				
Clinical Care	X	X	X	X
Medical Respite Care	X	X	X	X
Recreation Therapy	X		X	
Counselling	X	X		
End-of-life Care	X	X	X	X
Full-time Education School Program	X			
Art Therapy	X	X	X	
Music Therapy	X	X	X	
Community Care	X	X	X	
Community Outreach	X	X	X	
Grief Support	X	X	X	X
Social Work		X	X	X
Child-Life Specialists		X		
Bereavement Support			X	X
Spiritual Care	X	X	X	X
Perinatal Care			X	
Day Program		X		
Family Support	X	X	X	X