EXPLORING NURSES PERCEPTIONS OF THEIR LIVED EXPERIENCES OF PROVIDING PALLIATIVE CARE

by

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Abstract

As the demand for palliative care services increases in Canada, nurses continue to play a vitally important role on the interprofessional team. However, many nurses feel ill prepared and desire opportunities to enhance learning in this specialized field of care. The purpose of this study was to explore the lived experiences of nurses caring for those living with terminal illness and approaching end-of-life. Using narrative inquiry, participants included both novice and expert nurses practicing palliative care. Research methods included semi-structured interviews and a researcher journal. Twelve participants described their experiences with care delivery, including their perceptions of qualities and characteristics needed to care in this specialized field, and the preparation needed to provide palliative care today. A key finding was that not only patients journey through this critical time, but nurses also experience a journey of practice. In this presentation, I present a visual of the palliative care nurse's journey as outlined by participants. Their journey identified moments that impact the ability to provide optimum care, including: (1) the need for specialized learning, (2) the nurse-physician relationship, (3) early palliative care intervention, (4) the stigma of death and dying, (5) management of grief, and (6) dealing with the unexpected (such as a global pandemic). I will discuss implications for palliative care going forward. Throughout, I include insights learned as a palliative care nurse, nursing educator, and researcher.

Keywords: palliative care, end-of-life, early career, expert nurse, lived experience, journey, education, narrative inquiry.

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Finally, I would like to acknowledge a very special appreciation for my participants in this study. They are extraordinary nurses who are dedicating their lives to one of service in nursing and more specifically in palliative care nursing. In sharing their life experiences with me I have grown in depth and breadth of knowledge and am inspired by the work they do. I will be forever grateful for their insights, their words of caring, and their dedication to working with those journeying towards their end-of-life.

Dedication

I dedicate my work to my greatest champion of all, my mom Gabriella Ofelia Papaiz. As my number one supporter she has modeled the way and shown me what it means to work hard, to be resilient and most of all to be kind. Thank you for always believing in me and encouraging me to be the best that I can be.

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Chapter One: Looking Back/Looking Ahead - The Journey Begins

Challenges to healthcare have become increasingly concerning. The need for palliative care in Canada, in particular, is increasing as the population is aging and living with illness much longer. Statistics Canada (2015, 2018) reported the proportion of seniors aged >65 years will be approximately 25% of the population by 2036, an increase from 15.6 % in 2014. It is predicted that the number of seniors in Canada will more than double to more than ten million persons. The very elderly, aged 80 and over, have also steadily grown, constituting 4.1% (1,426,900) of the population as of 2012, and projected to be 2.6 times higher in 2036 compared to 2009, and estimated to reach 3.3 million persons by 2036 and 5.1 million by 2061. People living with chronic and life-limiting illness are also increasing with 74% of all seniors having reported living with one or more chronic conditions (Canadian Institute for Health Information, 2011). The increased prevalence of chronic illness leads to more deaths, and while our elderly population is living longer, the number dying is increasing, with more than 307,132 Canadians dying in 2021 (Statistics Canada, 2022). These important statistics, the accessibility of palliative care services, and having health care professionals trained in palliative care are all prominent factors for consideration for future health care delivery.

The journey towards death is most often a difficult one for individuals and their families. Yet, despite the many fears and preoccupations about death that occur throughout life, people continue to live until their final moments. The words “we live until we die" reflect this common belief for those working in palliative care (Canadian Hospice Palliative Care Association [CHPCA], 2019).

In this dissertation, I look at the phenomenon of palliative care through the lens of personal story. I was first introduced to palliative care as a community nurse. My experiences in caring for patients at end-of-life became a significant part of my practice and a source of ongoing questions over time as I moved into new roles and responsibilities. I found myself returning to the question of what more could be learned about how we care for people when cure is no longer an option, and they are facing end-of-life.

As a nurse and nursing educator, it was the role of nurses that was central to my questions. I sought to study the experiences of nurses as they journeyed their practice in palliative care to learn from their stories. Using narrative inquiry, I recount stories of palliative care nurses, including my own, with the goal to bring greater meaning and new knowledge to nursing practice. Before I share these stories, it is important to delve into the field of palliative care, to understand how it came to be and why it is important to study.

What is Palliative Care?

Palliative care is a type of care that aims to improve the quality of life of patients and their families who are living with life-threatening illness, through the relief of suffering and treatment of pain and symptom management (World Health Organization, 2018). The Canadian Hospice Palliative Care Association (CHPCA) (2019) stipulated that having access to palliative care allows patients to gain more control over their lives, helps patients manage their care needs more effectively, and allows family members to be more supported during this important time.

Palliative care nursing is a new specialty area and has been in Canada only since the early 1970s when it was first recognized in formal practice (CHPCA, 2019; Health Canada, 2019). Father of palliative care in Canada, Dr. Belfour Mount advocated for palliative care as a way of giving life a better ending and having founded the earliest hospice movement, he challenged all of us to think about how we approach end–life care and its meaning for the people we care for (Mount, 1993). He spoke of healthcare providers needing to have an understanding of the whole person, which included being able to listen attentively to both what is said and unsaid and recognizing that palliative care demands attention to detail. Often patients are not only battling with physical pain symptoms, but also a much deeper pain of impending loss and of leaving life's journey with unfinished business. This metaphor of battle of both physical and existential pain speaks to the complicated meanings we make as relational humans and of how we will experience end-of-life, including the preparations we make for this final stage. Nurses encounter many patients with various illnesses and disease trajectories during their careers and are present with most patients at end-of-life (Dunn et al., 2005). As such, nursing in palliative care begs the question of how nurses prepare to provide for patients and their families during this final stage of their life journey.

Another leading Canadian physician, Harvey Chochinov, used the metaphor of air travel to describe a perspective for life and death. He compared birth as a time when our lives take flight and that we remain airborne throughout our lives. We experience some turbulence from time to time but are so engaged in our journey that we forget that landings are inevitable. Chochinov (2012) reminds us of the importance of a good and gentle landing, recognizing that while dying is inescapable, dying poorly ought not to be. Providing quality palliative care is dependent on a deep understanding of patients' experiences and causes of suffering (Chochinov et al, 2008). The above metaphor speaks to the preparations needed for this final stage of life and even more importantly, how nurses need to be prepared to provide for patients and their families during this time.

Understanding Palliative Care Through Story

Today, palliative care is studied widely and continues to be a field of paramount inquiry within the research community. Palliative care nursing has many stories to tell, steeped in meaning and knowledge and important to understand, including teaching about living with terminal illness and the experiences of giving and receiving care. Stories have been described as an extraordinarily rich medium, acting to interpret and make sense of events, infused with multi-layered meanings, arising from personal and socio-cultural experience (Bingley et al., 2008). Storytelling offers a lens through which we may gain a more nuanced understanding of end-of-life experiences (Bingley et al, 2008). As humans, and more specifically as nurses together with our patients, my participants and I (as well as many other nurses) have lived storied lives and these stories have become teaching tools for others to learn by. Dame Cicely Saunders and Elizabeth Kubler-Ross were pioneers in this field and paved the way for learning what is important at end-of-life and were instrumental in moving the palliative care movement forward. It was more than 50 years ago that Dame Cicely Saunders (Oransky, 2005), who founded the earliest hospice movement, recorded, and used over 1000 narratives to better understand care at end-of-life. Elizabeth Kubler-Ross, whose foundational work on death and dying, privileged the voice of the dying and was inspired by thousands of patient and caregiver narratives that ultimately lead to a better understanding of the concepts of death, grief, and bereavement (Kellehear, 2019). As we tell our stories, we are giving an account of our lives and as such, this helps to make sense of our experiences and brings meaning to our lives (Stanley & Hurst, 2011).

Within this dissertation, I embed storied experiences from my journey as a palliative care nurse. These storied experiences are formatted in italics to separate them from participant stories, discussion, and researcher reflections. The first is included below to introduce a moment when I first began to wonder how best to support a dying patient.

Storied Experience: My Earliest Palliative Care Experience

> *"Come on in dear," she says as I enter the house. Greeted by whom I assumed was my new patient's wife, she directed me towards the back of the house. "He's in there," she says. I slowly approach the bedroom. My patient is lying in bed and turns as I enter. "I am your nurse," I say and walk over to his side. "I don't need a nurse," he says. "I am not dying today!" I take a step back.*

The memory above highlights one of my earliest experiences caring for someone nearing the end-of-life. I recalled thinking, what do I say now? Where do I begin? What if they refuse my care? How can I help? I also remember feeling that I had so much to learn as I swallowed deeply and stepped forward to say hello once again.

This next storied moment similarly highlights the questions that continued to arise for me as I experienced my first patient choosing to die at his home.

Storied Experience: Understanding Patient Choice

> *My patient was adamant he wanted to die at home with his wife by his side and his children close by. He strongly conveyed that he wanted to die in his own bed. I had never experienced anyone die at home before and was concerned about what that might look like for him, his family, and even for myself. Having had little experience with caring for someone who is dying I wondered if I had the skill to make this happen. What if something went terribly wrong and his pain and symptoms got out of control? How will the family react? How can I support them through this stressful time? And how can I make this passage for my patient as comfortable as possible? I had so many more questions than answers and so little experience to go on.*

Over the many years of my practice, these questions, and many more, led me to want to learn more about the experiences of other nurses also journeying in palliative care. This research study has created a space for in-depth reflection through a researcher lens and has enhanced my own learning. Before I continue, it is important to introduce myself to situate my role as researcher.

Situating My Research: Who Am I?

I often tell others that death is an inevitable part of the human experience, yet I also see how it is an experience that is poorly understood. As a nurse clinician, having worked in palliative care for more than 20 years, I have both witnessed and been empathetic to knowing that many people fear illness, the time when end-of-life approaches, and death itself. Yet, as a new nurse, I did not plan to work in palliative care.

Storied Experience: My Foray into Palliative Care

> *I came into palliative care quite by mistake. After graduation I worked on a number of different units from mental health to a stroke unit, to a small stint with pediatrics, then on to surgical urology, a medicine floor, and a plastics unit, just to name a few. Here, mostly, patients were treated for their illness and while some patients did die, care was mostly about following doctors' orders and care of the body following death. At that time, little was known about palliative and end-of-life care, and it was when I became a community visiting nurse that I came to learn about what caring for people with life limiting illness really meant.*

After almost two decades of clinical, administrative, and teaching experience, my passion for palliative care continues to be fueled from my philosophy of caring. Through my own personal experience working with nurses in general practice, I began to notice gaps of knowledge and understanding in this field, and I grew to become a strong advocate for palliative care nursing education. As my role expanded to provincial consultant for our regional health authority, I supported nurses with care management issues in palliative care and provided provincially funded education programs for nurses and other allied health professionals (VON Canada, 2017). Colleagues spoke of the many challenges of palliative care nursing and reported feeling ill-prepared with inadequate knowledge for practice in palliative care.

Today, my role in nursing administration permits a bird's eye view of the full scope of nursing education and training and has been a catalyst to wanting to explore more fully nurses' experiences with palliative care and caring for those at end-of-life. I work closely with faculty and curriculum development, participating in regular reviews to ensure competency standards are met (Canadian Association of the Schools of Nursing [CASN], 2014). Not surprisingly, previous accreditation reviews identified palliative care content as being limited in nursing programs where I have worked and became an impetus for me to research the lived experiences of palliative care nurses to offer further insights into what teaching and learning gaps exist in palliative care education.

The profession of nursing assumes a significant role in palliative care and has been ideally suited for me as my worldview is founded in a humanistic philosophy of caring, where the values and needs of the people I care for are at the forefront in my approach.

Overview of Study

My doctoral coursework and residencies contributed to a re-examination of my interests in palliative care research and informed my thinking to consider the significance of nurses' perspectives and their experiences when providing palliative care. Nurses, through their therapeutic proximity and trusted relationship with patients bring opportunities for learning about how we care for others at the end-of-life and what is needed in the development of practice knowledge and skills to ensure the highest quality of life care (Murray et al., 2009). I explored nurses' perceptions of their experiences in providing palliative care, including the qualities, characteristics, challenges experienced, and perhaps most importantly, the knowledge needed to provide this specialized care.

To take a deeper look into the lived experiences of nurses working in palliative care, I conducted a narrative inquiry with twelve nurses. My intent was to highlight the voices of their experiences in relation to professional learning. Nurses, through their therapeutic proximity and trusted relationship with patients bring opportunities for learning about how we care for others at the end-of-life and what is needed in the development of practice knowledge and skills to ensure the highest quality of life care (Murray et al., 2009).

I believe this study has relevance for health care providers, including nurses and nurse educators, as it contributes to a better understanding of what is needed in preparation and practice in palliative care, along with challenges experienced, and areas for improvement.

Definitions

Throughout my dissertation there are a number of definitions and acronyms such as those used to describe classifications of nurses. I have listed these definitions to aid in understanding of terminology used.

Palliative Care. The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of persons and their families facing the problem associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (Government of Canada, 2023; WHO, 2018). This global definition has been adopted in Canada as the standard definition for palliative care. The province of Ontario expanding on this global definition, refers to palliative care as patient-centered coordinated care that aims to relieve suffering and improve quality of life for patients and their families at all stages of illness. Palliative care focuses on a holistic approach to treat the impact that an illness has on patients and their families and is often provided in addition to clinical care that focuses on treating the illness itself (Ministry of Health Ontario, 2021).

Hospice Care. The term hospice care is often used interchangeably with palliative and shares the palliative care definition. Whereas palliative care is ideally initiated at the time of diagnosis of the illness and when curative measures are not expected, the term hospice care is usually reserved for patients at the very end of their life with only days and hours to live.

Nurse. A nurse is someone who is registered to practice with their regulatory body in a province or territory in Canada. They can be a Registered Practical Nurse (RPN in Ontario) who has graduated from an accredited college program, a Registered Nurse (RN) who has graduated from a college diploma program prior to 1999 or a degree program after 2001, or a Nurse Practitioner (NP), who has additional training including a master's degree and has the designation of RN-extended class. For the purposes of this study the term nurses is used throughout, and the profiles will identify the individual levels of practice.

Diploma RN. An individual who graduated from a college diploma program prior to 1999. They are licensed to practice with their provincial regulatory body as a registered nurse. In 2001, the entry to practice requirement changed in Canada to a Bachelor of Science in Nursing (BScN) degree for RNs, in all provinces with the exception of Quebec.

Diploma RPN. An individual who graduates from a college diploma program. They are licensed to practice as a registered practical nurse (RPN) in Ontario. In other provinces, they carry the title of Licensed Practical Nurse (LPN).

Preceptor. A nurse who works with a nursing student while they are in their clinical practicum.

PSW. Personal Support Workers provide tasks of daily living, personal care and hygiene, restorative/activation activities, and home management activities (Home Care Ontario, 2014).

Looking Ahead

The next chapter begins with an overview of the theoretical paradigms that informed my work. I then delve into the significant research literature specific to palliative care in nursing education, including access to this specialized education, competencies required of this care and of palliative care as an approach to care. I discuss the representative literature found in each of these areas.

Chapter Two: Journeying Through the Literature

In this chapter, I discuss the theoretical underpinnings that have influenced my research and then describe the literature specific to palliative care nursing, includes access to specialized education, nursing competencies required for professional practice, and how palliative care is considered more than a specialty and extends to an approach to care.

Educational Theories Related to Nursing

Educational theories are central to my research and include humanistic theories of caring and human compassion, similar in context to those found in nursing theory. Learning in nursing education takes on many forms and as both a cognitive and practiced based profession, it requires nurses to learn through several processes. It is through a complex and complementary approach to learning that nurses can conceptualize their practice. The expectation is that through a continuous, ongoing acquisition of nursing knowledge they learn the cognitive and technical aspects of care that will ensure quality professional practice (College of Nurses of Ontario [CNO], 2019). Several learning theories in the application of nursing education are found in the literature each trying to explain how nurses acquire, organize, and deploy their skills and knowledge. In the following sections, I describe some of the theoretical underpinnings of learning theory used in undergraduate nursing education and important to my research in palliative care education.

Learning Theories of Inquiry Through Reflection

Dewey (1916/2009) described learning as a process that consists of delving into the meaning of experiences as we seek to understand and expand our knowledge of learning from life events. In his theory of action and reflection, Dewey (1916/2009) proposes reflective thinking and its relationship with learning arises only in problematic situations. For an experience to be educational, a connection is first made, and a subsequent value is placed on that experience. Nurses, for example, move their level of thinking beyond critical thinking to integrate meaningful phenomenological perceptions of patient experience (Johnson & Webber, 2015). A perception of patient experience includes consideration of patient diversity, and patients' unique situations as part of their reflections.

This perspective is in keeping with Dewey's (1938) suggestion that education and experience are in a progressive relationship whereby learning is grounded in real experiences. Speaking to constructivism, he described this reconstruction of education and experience as a complex intellectual operation that involves observation of an event, knowledge of similar past experience, and a judgment of what is observed and recalled that establishes a "richer and more organized form of knowledge" (Dewey, 1938, p. 74). He determined that through this active process, new information is linked to prior knowledge and new knowledge is constructed. This purposeful process of recalling experiences and considering their meaning under a new focus can translate into an expanded understanding of previous knowledge.

In my experience, reflective practice is a key component of the nursing curriculum. Nurses are taught early in their education program that reflective thinking is the ability to examine their actions and experiences with the outcome of developing their practice and enhancing clinical knowledge (Caldwell & Grobbel, 2013). Educational theory describes reflection as a method of using experiential knowledge to enable professional and personal growth and to reinforce continuous learning (Gustafsson & Fagerberg, 2004). The ability to reflect is especially true in palliative care, as nurses must consider many factors within the reasoning process to maximize quality of life care. Nurses learn through practice and reflective learning is a required standard towards continuing competence, maintaining licensure, and quality improvement in nursing practice (CNO, 2019).

Reflecting in learning is consistent with Schon's (1987) educational theory of reflection, which speaks to the initial learning from an event and the subsequent rethinking of the situation as an opportunity for the learner to consider the myriad of emotions and thoughts and thus contributes to ensuing further learning from the event. His theory describes a process of evaluation, followed by a categorization of valuable pieces of information that can be used for the future. Reflecting on emotions and thoughts related to events is evident throughout nursing education and practice, and is especially seen in palliative care nursing, where situations and interventions are often highly charged with emotions and feelings, each presenting in their own unique way. It is through a reflection process that the situation can be reviewed and reconstructed to allow for new learning to take place.

Dewey's (1916/2009) theory of continuity also speaks to the influence of past experience and of reflection on future experience. He proposed that the present experience is a function of accumulated experiences and interactions and frame situational dynamics of the present event. Schon (1987) further identifies the significance of learning through practice where "practitioners are exposed to the traditions of a community" (p, 36). Here is where they learn about their environments, what is expected in their practice, and where knowing in action occurs. Learning through practice is a principal element of knowledge acquisition and aligns with how nursing knowledge is constructed through lived experiences and experiential learning in their clinical placements and using simulation experiences. Knowledge is applied to practical situations and evolves into even more complex knowledge.

These two theorists and their perspectives on learning have far-reaching implications in narrative inquiry, the methodology I selected for this research, and the stories of experiences told in my study. Further details will be discussed in the methodology section.

Nursing Theories

In this section, I discuss how nurses learn. Watson's (1987) theory of human caring has been a strong influence in my work as a palliative care nurse through her prescribed "ten caritas" or core concepts of human caring (Watson's Caring Science Institute, 2010). These include having humanistic and altruistic values that practice a loving kindness towards self and others. Human caring involves being authentically present, honouring the hope and faith of others, and the work needed to develop trusting and caring relationships. Paterson and Zderad (1988) described this philosophical stance as one where nursing is an experience lived between human beings and that each nursing situation reciprocally evokes and affects the other's existence. As such, it places emphasis on life's meaningfulness and existential awareness in the nurse-patient relationship. For me, caring for individuals near end-of-life was a natural and complementary extension of my nursing journey and one where I am able to view the patient holistically, as a whole person rather than simply an illness or injury.

Nursing knowledge has concepts unique in perspective and specific to its discipline. The ontological assumptions in nursing include two types of knowledge acquisition, one being objective and logically constructed, while the second is more subjective and inductively constructed through reason (Bonis, 2009). Using a variety of methods of knowing, nurses perceive and gain knowledge of themselves and their environment. Carper's (1978) seminal work in understanding nursing epistemology identified four fundamental patterns of knowing that form the conceptual and syntactical structure of nursing knowledge. The first includes empirical knowledge that originates from a positivist paradigm and is derived from facts and research intended to predict and explain relationships (Fawcett et al., 2001; Mantzorou & Mastrogiannis, 2011).

The second is ethical knowing that houses the moral component of nursing knowledge, and is defined by values, beliefs, and obligations to guide practice. However, nursing knowledge also recognizes that ethical practice extends to personal reflection of one's own values and beliefs, where choices are individualized and based on what is good, desired, or right for the patient and family (Peters et al., 2013). Noddings (1995) discussed the ethics of caring and advocated for teaching caring themes as a way to connect students to greater existential questions. She believed that the development of ethical caring contributed to their competency development, helping them to explore their own values and principles and enabling new knowledge construction. She also believed that ethics in caring is grounded in the development of an individual's morality and how it directs behaviour through a set of rules and expectations. Moral development in nursing education is consistent with nurses' national code of ethics that espouses a predetermined set of nursing values and ethical responsibilities (Canadian Nurses Association (CNA), 2017b). The Registered Nurses Association of Ontario (RNAO) (2017) provides guidelines for teaching activities and resources regarding ethical practice. These are intended to promote the development of ethical practice through reflection and the integration of theory, principles, and best practices, in order to meet the standards as set out by the regulator (CNO, 2018).

Aesthetic knowing is the third, and it is described as the art of nursing, bringing with it a direct feeling of experience acquired through a subjective interpretation (Carper, 1978). Caring is a human experience that is unique and personal, and based on aesthetic qualities in the nurse–

client relationship (Mantzorou & Mastrogiannis, 2011). Kostovich and Clementi (2014) concurred that the art of nursing is about being able to respond to the social, mental and spiritual health of patients and their families, and includes having nursing presence. Aesthetics provides a unique way in which nurses work with patients to explore perceptions of their lived experiences and their self-awareness of their healthcare needs.

Watson's (1987) theory of human caring further describes how caring progresses towards greater health, wellness, and illness prevention. Patients, even nearing end-of-life, receive much needed health promotion as nursing practice seeks to improve their quality of daily life. The ability for nurses to respond empathically is individual, intuitive in nature, and allows for a person's unique lived experience. In their clinical placements, students work with patients and their families and view their healthcare through the client's lived experience, broadening their own understanding of their patients' challenges and issues.

Personal knowing is the fourth way of knowing and considered one of the most difficult to learn. It involves the inner experience of becoming self-aware, whole, and genuine (Watson, 1987; White, 2012). It requires the learner to reflect on personal passions, commitments, and integrity, and involves knowing oneself before being able to know others. Personal knowing takes time to develop, and it is through self-reflection of one's own values, beliefs, biases, and motivations that nurses can authentically interact with and form meaningful relationships with others.

Chinn and Kramer (2008) introduced a fifth and final pattern of knowing from a sociopolitical perspective and called it emancipatory knowing because it engages the learner in issues of equity, justice, and transformation in nursing practice. As nurses learn about the determinants of health, they are exposed to issues such as poverty, unemployment, culture, age, race, sexual orientation, and marginalization and "lifts the gaze of the nurse to extend to a broader context of health and nursing practice" (White, 2012, p. 214). Emancipatory knowing aligns with critical social theory and how nurses are involved with social justice issues every day. It emphasizes how it is important for them to create a space where patients feel safe to be vulnerable and to share in their journeys. Lapum et al., (2012) found that stories have the capacity to transform oppression into liberation as a means of self-discovery. In nursing theory, knowledge acquisition involves the simultaneous interaction of the five different ways of acquiring knowledge and aligns with humanistic theory. They are constructed through experience, shaped by reflection, and expressed by meaning, not unlike theoretical perspectives of learning in education.

Another influential nursing theorist was Patricia Benner. Benner (1982) described nursing practice as having stages of expertise and requiring ongoing and long-term career development**.** This work was adapted from the Dreyfus model of skill acquisition to nursing practice (Dreyfus & Dreyfus, 2005). Benner (1982) noted that skill acquisition is attained over time with increased experiences. In their careers, nurses pass through five levels of proficiency beginning with novice practitioner, moving to advanced beginner, competent, proficient, and finally, to expert. The transition is dependent on the "reliance on abstract principles and the use of past, concrete experience as paradigms" (Benner, 1982, p. 402).

The theoretical perspectives discussed above hold a prominent place in my study, setting the underpinnings of conceptual learning patterns that are embraced in nursing palliative care education and training.

Nursing in Palliative Care

In this section, I turn to the literature that considers the nursing role in palliative care. Nurses care for patients across the lifespan and are advocates for health and wellness at every stage of life. In providing end-of-life care, they often have a constant, highly visible, and fundamental role at this stage of life (Canadian Nurses Association [CNA], 2019). It has been recognized with increasing concern that nurses are not adequately prepared to navigate complex health care decisions when providing care at end-of-life (Fabro et al., 2014; Kirkpatrick et al., 2017). Nurses have reported feeling anxious, have difficulty with communication, and view end-of-life care as stressful and unpleasant (Peters et al., 2013). Concerns of inadequate preparation have been a much-deliberated topic and continue to interest researchers as they look for new ways to include palliative care education within undergraduate nursing curriculum (Bond et al., 2016; Henderson et al., 2017). My own early experience with nursing education mirrored many of these concerns. Nursing research has confirmed that undergraduate programs often fail to adequately prepare nursing students to care for dying patients and their families (Dunn et al., 2005; Mallory, 2003). Students described having low confidence levels and feeling a lack of competence in caring for terminal patients and would like more experience as part of their education (Kwekkeboom et al., 2005). Low confidence levels led to questions of preparation for practice in palliative care, and the expectations of nurses to have skill and expertise to care for those living with life-limiting illness.

In 2003, palliative care nursing became a specialty in Canada and now has a national certification available for registered nurses, post-graduation (CNA, 2017a). Palliative care is performed in all primary care settings and at all stages of illness, not just nearing the end-of-life. The palliative approach to care is highly individualized, placing patients and their families at the center of all decisions and considerations of care. It is also holistic and accounts for all the domains of care including one's physical, psychological, social, spiritual, and practical needs (CHPCA, 2017). Further, palliative care continues after the patient has died, and provides bereavement support to family and friends. For some nurses and health care practitioners, administering palliative care is more than just a knowledge specialty, it is their approach to practice.

Palliative care education assumes a key role in preparing nurses and formal caregivers for the issues encountered by persons living with life-limiting illness. Research regarding the extent to which palliative care education exists in undergraduate programs found there is limited emphasis on teaching end-of-life care (Dunn et al., 2005; Henoch et al, 2017; Schlairet, 2009). Dickinson (2007) compared professional programs' curricula from 122 medical schools and 580 nursing baccalaureate programs and found that while 87% of both reported offering "something" in palliative care, the average number of hours for both was found to be less than 15. This research is consistent with what I have seen in nursing programs and the messaging received from nurses working in palliative care.

Increasing demand for online palliative care course delivery in both undergraduate programs and for continuing education programs has created much debate with many proponents valuing face-to-face instruction and interaction rather than online delivery methods (Spice et al., 2011). These researchers and others found that students preferred direct contact with their classmates and professors, were more engaged, and that it enhanced their ability to be supported and mentored, as well as being most effective and valuable in knowledge transfer (Connell et al., 2011). Connell et al. (2011) found learner engagement was found to be a critical factor for success in knowledge acquisition. While the delivery format was considered most convenient for connecting distance learners and more recently the pivoted focus of delivery during the pandemic, online discussions were challenging, and effective online tutoring strategies were needed for promoting connectedness and meaningful online discussions. In a recent study, Williams et al., (2020) found that participants reported greater benefits from in-person learning than from web-based training. Results of the study revealed four complementary social processes shaped education and training preferences for palliative care education. The following processes impacted learners' perceptions of training effectiveness and included "being actively engaged and focused, interacting and networking, finding meaning and relevance, and exercising reciprocity" (p. 801).

Knowledge transfer and skill acquisition and how it relates to students' developing self-confidence in palliative care practice, was the focus of other studies. Gerlach et al. (2015) found that following completion of a palliative care course, the majority of students' scores increased in confidence levels and self-efficacy, and knowledge of core palliative care issues improved significantly. Again, this is consistent with my own experience and feedback received from both practicing nurses and students following the delivery of a palliative care course. Access to a dedicated palliative care course enables students to discuss issues fully and openly and improves knowledge acquisition and retention. This position is supported by much research that speaks to the need for better palliative care nursing preparation in education (Bush & Shahwan-Akl, 2013).

Access to Palliative Care Education

Research regarding the accessibility of palliative care education was also found to be limited. Kortes-Miller et al. (2007) looked at workers offering palliative care in long-term care homes and found that staff lacked education in palliative care and that access in rural areas for education and lack of relevant curricula were barriers to learning. Health Canada's (2019) most recent report and implementation of a national framework for palliative care identified gaps in professional training and stated few health care providers specialize in or practice in palliative care. Further, greater capacity building is needed for curriculum development and educational training, in order to meet the increasing expectations to deliver basic palliative care services.

Research has affirmed the value of palliative care education and identified factors important for nurse learners (Anderson et al., 2015; Glover et al., 2018; Shaw & Abbott, 2017). The exploration of nurses' experiences with palliative care practice and education in my study adds to the discussions and identified other important considerations needed to enhance nursing practice.

Stanley and Hurst (2011) identified that through sharing stories or narratives of illness experiences we can make meaning of suffering and death**.** The narratives of nurses, as caregivers, help to make sense of this critical time and of end-of-life issues for care receivers. Stories shape people's sense of self and offer glimpses into how meaning and knowledge is constructed in the process of becoming a nurse and developing practice (Jacobsen et al., 2017). Choosing narrative inquiry as my methodology allowed for important concepts and themes to be gleaned during my exploration of nurses' perspectives and stories. This research added to current palliative care discussions, informed curriculum strengths and gaps for nursing education, and supports improvement towards standards of excellence in palliative care.

Competencies Needed

In 2002, a national model to guide hospice palliative care was created and continues to provide important direction to government, health care professionals, and educational programs to develop services and improve care throughout the illness trajectory (Ferris et al., 2002). The model is based on concepts of effective communication, group function, and the ability to facilitate change, all central to nursing palliative care education. This section speaks more in-depth about the role of these competencies to help support learning and practice in palliative care.

In nursing practice, a number of studies have reported challenges for nurses in their development of necessary communication skills in palliative care. Nurses reported feeling unprepared and lacking competency in having end-of-life discussions and providing decision support (Murray et al., 2009; Price et al., 2018). Further, education continues to have systemic deficits in knowledge of palliative care and contributes to pervasive confusion between palliative care and hospice care (McDarby & Carpenter, 2019). Learning and utilizing communication strategies when caring for patients living with terminal illness is a foundational competency in building an effective therapeutic relationship, and "depends on formal caregivers being skilled at effective communication" (Ferris et al., 2002, p. 57).

Used with informed and skilled decision-making, effective communication can lead to better care delivery decisions, less conflict, and a more effective plan of care for the patient and family. Ballesteros et al. (2014) reported that palliative care education helped students to know how to interact, communicate, and better understand patients. Even more interesting was that the students felt the palliative care course provided them with a more comprehensive view of the nursing discipline. Gaining more knowledge may be related to the fact that palliative care addresses many domains of care and sees the patient from a holistic perspective. In administering palliative care, the nurse is able to value each person as an autonomous and unique individual where care is guided by the person and is based on dignity and integrity of the care provided to them. Further, Ballesteros et al. (2014) reported that students felt that the palliative care course contributed to their personal growth, prompted them to reflect on their own death, and promoted more self-awareness**.** They also found that the integration of palliative care content was of immense importance in the nursing curriculum. Other comparable studies also found palliative care education to have a positive impact on student attitudes toward the care of the dying (Mallory, 2003), and had a positive influence in future practice (Bush & Shahwan-Akl, 2013).

Palliative Care as an Approach to Care

Palliative care is an approach to care that rests on a holistic philosophy and provides an approach to care that "recognizes the needs of the whole person in the care plan," not simply the manifestations of the illness (CHPCA, 2014, p. 7). It enables nurses to develop important therapeutic relationships to facilitate a change in the illness experience. Nurses play a vitally important role as a member of the interprofessional team (Dunn et al., 2005; Moreland et al., 2012), and spend more time with patients at the end-of-life than any other health discipline (Wallace et al., 2009). They have a role in leading and enabling effective communication and collaboration among various disciplines, across numerous settings, and to identify issues to minimize inadequate or fragmented care (Peden-McAlpine et al., 2015). To become effective change agents, the Ferris et al. (2002) model arms nurses with knowledge, skills, and tools that help them to identify issues, gain an understanding of the effects of those issues, determine goals, and identify possible solutions (Biedrzycki, 2003; CHPCA, 2013).

Palliative care, over the last two decades, has become a widely researched topic and continues to gain interest and momentum as governments increasingly support the development of comprehensive strategies for palliative and end-of-life care in their provinces (Alberta Health, 2021; Province of British Columbia, 2017; Province of Nova Scotia, 2016; Province of Ontario, 2016). The strategy in Ontario has mobilized many organizations to come together to learn more about the current state of palliative care and to help identify gaps in our system. In 2011, the Declaration of Partnership and Commitment to Action document was created and has been the impetus for much needed research and development of a shared vision for palliative care (Province of Ontario, 2011).

Looking Ahead

In the following chapter, I introduce the methodological research design of my study. I include how I came to decide on the value narrative inquiry brought to my exploration of the lived experiences of my participants as palliative care nurses and the researchers that influenced my decision. I present my research questions, describe the methods used, and discuss ethical considerations important to this work.

Chapter Three: Methodological Research Design

Qualitative Research is described as a form of research that places emphasis on the socially constructed nature of reality, the intimate relationship between the researcher and what is being studied, and the situational constraints that shape inquiry (Denzin & Lincoln, 1994/2011). Qualitative researchers look for answers to their questions on how our experiences are created and give us meaning. Unlike quantitative research that looks for causal relationships between variables, qualitative research is best suited to address a research problem where the variables are unknown and need to be explored (Creswell, 2012). According to Creswell (1998),

> Qualitative researchers commit to extensive time in the field; engage in a complex and time-consuming process of data analysis to find themes; write long passages to substantiate claims; participate in a form of social and human science research that is evolving and changing. (p. 17)

These attributes appealed to me because I wanted to explore the nature of the experience of nurses, to hear their stories to better understand their experiences and to potentially learn more about palliative care.

Van Manen (1990) described lived experience as both the starting point and endpoint of phenomenological research with the intent of transforming lived experience into a "textual expression of its essence" (p. 36). He believed that through our lived experiences, we gather interpretive significance by giving memory to them. While Van Manen is writing about phenomenology, which is a methodology in its own right, the concept of lived experience is pertinent to a number of other qualitative methodologies such as ethnography, case study and biography, as well as narrative inquiry. In all these methodologies, through recollections and upon reflective examination, new information may be gained. It is for this reason that I chose my methodology to be qualitative in nature, specifically using the methodology of narrative inquiry. My previous experiences, and review of the literature, led me to believe nurses working in palliative care have much to tell about their experiences and I had much to learn.

Why Narrative Inquiry?

Narrative inquiry seeks to understand an individual's experiences (Chase, 2011; Clandinin & Connelly, 1990). It is defined further as "a way of inquiring into experience that attends to individuals' lives but remains attentive to the larger contexts and relationships within which lives are nested" (Clandinin et al., 2017, p. 91). It seeks to understand "influences of continuity and wholeness on an individual's life experience" (p. 17). Narrative melds the boundaries between various aspects of experience together, so that in a professional life, curriculum is considered to be composed of all of the experience we have lived, both personally and professionally (Connelly & Clandinin, 1990).

Narrative inquiry is interpretive in nature and draws on storytelling to understand human experience (Chase, 2011; Clandinin & Connelly, 1991). It encourages reflection and the telling of stories on the part of participants (Clandinin & Connelly, 1991) through the "construction and reconstruction of personal social stories" (Connelly & Clandinin, 1990, p. 2). How knowledge is constructed is based on the telling of stories in present time from what we have reconstructed of a past experience (Chase, 2011). Shields (2005) described the importance of hearing another's story as a way to engage and connect with others "across time and place and involves the reconstructing of stories from the past that enlightens our present knowledge" (p. 180).

Narrative inquiry is seen as both a phenomenon and a research methodology. It is a "phenomenon in that it is always shifting, moving and complex and yet, also a method in that it is about negotiating relationships, purposes, and ways to be useful" (Kim, 2016, p. 206). As stories are collected and narratives are written, they help to characterize the human experience from an interpretive paradigm (Kim, 2016). In this way, narrative inquiry is a philosophical perspective of being and reality and, like other qualitative methodologies, is “guided by our beliefs and feelings about the world and how it should be understood and studied” (Denzin & Lincoln, 1994/2011, p. 13). This naturalistic approach brings meaning to research questions and is framed within a humanistic philosophical perspective (DePoy & Gitlin, 2011).

Within the field of medicine, narrative inquiry has similarly been described as both an important theoretical perspective and an established methodological framework that is “useful in studying medical learners’ identity making in medical education” (Clandinin, et al, 2017, p. 92). Jacobsen et al. (2017) used narrative pedagogy in nursing research to explore vulnerability and concern in nurses’ stories, along with “expressions of strong emotions and markers of uncertainty” (p. 11). They analyzed written stories of nursing students with a focus on challenging situations from clinical practice, finding narrative inquiry helped to put stories within a larger context. Within palliative medicine research specifically, narrative inquiry is described as “one of the most significant mediums through which we define and shape our cultural and personal interactions and is integral to human communication as a means to describe, reflect, share, and perform” (Bingley et al, 2008, p. 654).

Four Directions of Narrative Inquiry

Clandinin and Connelly (2000) outlined four directions of inquiry described as inward, outward, and backward and forward. The first direction involves looking inward to ourself, towards our internal conditions of feelings, hopes, morals, and values. Looking outward focuses on the existential conditions and what is happening in our environment, including what is impacting us, and our realities (Clandinin & Connelly, 1994, 2000). The third and fourth directions simultaneously look forward and backward across time including the past, present, and future, as life experiences occur in various places and in relationships with others. This multi-directional perspective aligns with Dewey's (1938) foundational concepts of situation, interaction, and continuity.

These four directions align closely with how nursing theory describes the construction and reconstruction of nursing knowledge. For example, looking inward is described as considering important internal conditions such as feelings, hopes, aesthetic reactions, and moral dispositions. This view of looking inward supports Carper's (1978) aesthetic and ethical ways of knowing in nursing theory where experience is unique and personal and comes from within. Looking outward supports both the concepts of how empirical knowledge is acquired and that of Chinn and Kramer's (2008) emancipatory nursing knowledge gained by considering social interactions and issues that arise through experience. Finally, backward and forward refers to our relationship with time, as the acquisition of nursing knowledge is never ending. Through their lived experiences of providing care, nurses' reflections are an important part of their nursing role that considers past events and how these lived experiences impart knowledge in the present and in the future. How events are recalled and retold is integral to future learning and nursing practice. I kept Clandinin and Connelly's (2000) four directions in mind throughout this research.

The Researcher's Experiences

Researchers further described that the sharing of stories through narrative inquiry can inform and guide us towards a better understanding of our own journey as we construct and reconstruct the meaning held in our stories of lived experience (Clandinin & Connelly, 1991; Shields et al., 2011; Shields, 2019). This was my aim in my research study and a reason for selecting narrative inquiry. It was a way for me, in listening to my participants' experiences and the sharing of our stories, to further understand and bring meaning to my own personal experiences, specifically that of working in palliative care. At the same time, my experiences served as a point of connection with my participants that aided in building trust as they recalled their own stories.

My Research Design

Using the methodology of narrative inquiry, I drew upon interviews as a method of inquiring into nurses' experiences as a way of understanding how their experiences have shaped their social, cultural, and professional knowledge in this field of work. I focused on the experiences of nurses who have worked with patients and their families as they are journeying towards end-of-life. The question asked was, "What are the lived experiences of palliative care nurses that inform their practice at differing points of their career from early career to expert?" I sought to learn what events and situations led them to work in palliative care and the impact those experiences have had on their lives as a whole, including the meanings and beliefs they have constructed in light of their experiences.

Participant Recruitment

In this study, I invited participation from two participation groups: a) early career nurses and b) expert nurses. The reason I sought two participant groups was to ensure differing amounts of experience and varying practice settings (acute care, long term care, and community). No practice setting was specifically excluded for this reason. Seeking a varying range of nursing practice allowed for a rich tapestry of experiences to extend understandings of palliative care practice.

Early Career Nurses

Early career nurses were recruited from two sources. The first source was nursing students nearing completion of a 4-year BScN university program, and I sought to meet with them during their final preceptorship experience. The Canadian Association of Schools of Nursing (CASN) (2011) requires all undergraduate curricula in Canada to integrate palliative and end-of-life competencies and indicators to support learning outcomes in palliative care. While nursing students may not yet have significant practical experience with palliative care, their early understanding of palliative care as a practice set an important first step for the range of stories and experiences I collected.

A second source for early career nurses were nurses just beginning their careers following graduation (1-3 years' experience) from the local hospital with interest or experience in palliative care. While there are additional stages of clinical competency in nursing development (Benner, 1982) from novice to expert, I selected early career nurses (novice practitioner and advanced beginner) as one of my target participant groups for several reasons. Early career professionals are in the beginning stages of their career development and report feeling vulnerable and ill-prepared in the workplace resulting in stress and anxiety when caring for dying patients and their families (Shaw & Abbott, 2017). I have noticed that early career nurses are increasingly asked to take greater leadership roles. Within acute care settings, early career nurses also experience palliative care for the first time. First experiences with patient death can have a significant influence on practice and working with individuals who are dying (Anderson et al., 2015). As a participant group, early career professionals would bring their initial early experiences to the discussion.

Expert Nurses

The second group was composed of expert nurses (5+ years' experience) from the Provincial Palliative Care Consultation Network. Members of this group are nationally certified in Hospice Palliative Care and are required to have a minimum of five years' experience in this specialty. Benner (1982) defines expert nurses as operating from a deep understanding of the total situation where their performance is flexible and highly proficient. As nurses develop their clinical practice their analytic ability develops over time and results in highly skilled professionals in care. This target participant group would bring the perspectives of nurses with considerably longer years of practice, along with greater expertise in palliative care from working with dying patients and numerous death experiences.

Sampling and Recruitment Procedures

I planned to interview 12 participants. Kim (2016) suggested that if the goal is to collect the life stories of the participants, the sample of interviews will usually be smaller as the interviewing process is often lengthy. Purposeful sampling was used for this study. Purposeful sampling is widely used in qualitative research to identify and select rich information related to a phenomenon of interest (Suri, 2011; Fossey et al., 2022). Also known as purposive or selective sampling, this technique is used to recruit participants who can provide in-depth and detailed information about the phenomenon under investigation (Fossey et al. 2002; Suri, 2011).

Participants were sought by invitation via a Letter of Information (Appendix B). Letters of introduction were distributed by a third party in order that I did not have contact with the participants until they responded directly to me with their interest in participating. The specific recruitment details are noted below for each participant group:

- Early Career Nurses: For 4th year nursing students, an invitation was sent out by the program secretary via a distribution list. For novice nurses, an invitation was sent by the administrator at the local hospital.
- Expert Nurses: Invitations to participate were sent by email through a distribution list by the chairperson of the Provincial Palliative Care Consultation Network.

The selection of participants was based on a first come, first-serve process with the goal of equal distribution across groups. As participant responses were received, six nurses expressed interest and met the inclusion criteria for the early career nurse category. I received eight expressions of interest in the expert category and accepted the first six. The remaining two potential participants were notified to thank them for their interest and advised I would reach out should additional interviews be required.

Deciding on the number of informants has been questioned in qualitative data research. Beitin (2012), in the field of narrative inquiry, suggested that six-twelve participants is a reasonable range when redundancy becomes evident after six interviews. Kvale (1996) suggested approximately 15 participants +/- 10 based on time and resources available. Adequacy of sample size is also determined by the idea of saturation. Data saturation refers to the point in the research process when no new information is discovered in data analysis, and this redundancy signals to researchers that data collection may cease (Kim, 2016; Saunders et al., 2018). I return to this concept in the analysis section below.

Research Methods

I drew upon three research methods to collect data within this narrative research design: a) semi-structured interviews, b) research journal, and c) storied experiences.

Semi-structured Interviews

I utilized semi-structured interviews with nurses of varying years of practical experience as noted above. An interview is defined as an information gathering action process conducted through verbal communication and occurring face-to-face or by telephone (DePoy & Gitlin, 2011). It is also a way of understanding the meaning of phenomena (Kuzmanic, 2009). Interviews are often conducted one-on-one and “provide unique insights into the complex lives of individuals” (Kim, 2016, p.157). Carter et al. (2014) further explained that studying human phenomena through in-depth interviews (IDI) with individuals or groups is a powerful tool for gaining an understanding of human beings and exploring topics in depth, including rich information about personal experiences and perspectives. My selection for interviews aligned with my study’s goal to seek individual experiences and stories. Interviews are widely used in Narrative inquiry as a common method of narrative schema that reflects personal knowledge and experiences and provide unique insights of individuals in a society (Clandinin & Connelly, 2000; Kim, 2016).

Each interview was approximately one and a half hours via Zoom between May 2020 and December 2020. The shortest interview was 56 minutes and the longest was 1 hour and 41 minutes and all came to a natural conclusion. As my research began at the beginning of the pandemic, meeting with participants in face-to-face interviews formats was discouraged by provincial public health regulations requiring travel to be restricted due to the lockdown measures (Nielsen, 2020/2021; Province of Ontario, 2021).

The guiding interview questions were inspired by my review of the literature as well as my work in the field of palliative care as a clinician. I asked broad, open-ended questions that invited the sharing of stories and not just the answering of questions. Guiding questions were intended to open the conversation with participants about their work as a palliative care nurse. For example, questions like, “What does palliative care mean to you? What has been your experience with hospice and palliative care in your career? What are some of the challenges of being a hospice palliative care nurse?” These types of questions were intended to initiate a recall of experiences they would choose to share with me. These guiding questions sought to position the dialogue within the context of palliative care to better understand how and why participants had come to work in this specialty field. Please see Appendix A for an overview of the guiding questions for each participant group. Questions were similar but adapted to reflect differing levels of experience. The guiding questions were not pilot tested but were reviewed with my supervisor and committee.

I use the term conversation above to describe the informal nature of our dialogue, which took place in a relaxed and unhurried manner. At the beginning of the interview, I reassured each participant that my physical space during the time of the interview in my home office was protected and private, and that there were no opportunities for a confidentiality breach. All participants joined the Zoom platform from a computer device (desktop or laptop) from their home environments. I asked all participants to re-confirm their interest in participation, and that they were in an environment where they could speak freely. Some participants needed to turn off their video from time to time during the interview due to connection strength but maintained audio. Interviews were audio-recorded using a remote hand-held recorder capturing the audio through the Zoom meeting call. This choice was made to avoid recording video as a safeguard to support confidentiality.

At the end of the interview, I explained that the data would be transcribed within two weeks and should any follow-up interviews be needed to clarify information, it would be scheduled at their convenience. Following the completion of the transcription, each participant was sent a copy via a personal email they provided. Prior to sending the transcript, all identifying features were removed, and their name was replaced with their self-selected pseudonym. Participants were invited to edit, add, and remove any portions in keeping with their consent to participate. All participants responded to my email, indicating they had read their transcript. All but one had no changes. This participant included some clarification where the transcription was unable to determine the words used due to poor connection. There were no errors in the transcriptions noted by the participants and follow-up interviews were not required. Once all transcripts were returned, I printed them to begin closer analysis.

Reflective Journaling

I maintained a reflective journal throughout the interview data collection process as a method of recording my thoughts and experiences. Barnard et al. (2000) suggested that maintaining a personal journal of insights, preliminary understandings, ideas, thoughts, dilemmas, and decisions made during research aided in capturing the moment and avoided future recall issues. I wrote in the journal immediately following each interview, taking time to reflect on what I heard from participants, and to consider shared and differing experiences of my own. The journal documented the date and time of interview and was identified by only the participant's chosen pseudonym. I noted reactions, including verbal and non-verbal responses and reflected on the palliative care experiences that I heard myself sharing with participants, or that came to mind as I wrote in my journal.

The four directions of inquiry as described by Clandinin and Connelly (2000) were at the forefront of my journaling. I looked *inwards* at my thinking (the internal conditions of feelings, hopes, morals, values) as I interpreted participants’ experiences. As they shared their stories, I journaled my perceptions about what I was hearing. Looking *outward*, I aimed to capture their insights about the realities of palliative care nursing as related to the larger context of palliative care and its role in society. I remember noting the fear of one of the participants when she described her first experience with death and writing that in my journal. Another was noting the excitement that one of the expert nurses emoted when working with students and seeing "the light bulb turn on." Their evocative stories prompted me to *look back*, recalling my own memories and what I had learned from their past and present experiences. At the same time, I looked *forward,* and circled ideas that spoke to future improvements. As I cross referenced these entries with the transcriptions, they were instrumental in helping me to confirm and reinforce what participants were saying.

Shields (2005) described reflection as a way to reflect on our own personal experiences, which allows the opportunity to reinterpret and reconnect our understanding of those experiences and reflect on how our interpretations may have changed over time and place. Schwind et al., (2011) described the narrative reflective process as a way to fine tune ourselves as "instruments of care" (p. 4). It is through our reflective conversations that we can increase our self-knowing, inform our personal and professional relationships, and thus "enhances a nurse's ability to sense the unfolding patterns in patients, families and communities" (p.4).

Storying Experiences

Inviting stories of what it was like to be a palliative care nurse allowed the door of memories to open for my participants and in listening to their stories, many of my own came flooding back. In conjunction with my researcher journal, I took time to story significant personal experiences that arose within my journal reflections. Storying or storytelling is a way to communicate important information and gives the researcher an opportunity to learn from another’s experience (Jacobsen, et al., 2017). When we hear a story it catches our attention, and we often remember the meaning behind it more so that when facts are provided without a story. When we story our own experiences we not only relay a message but also feel the emotion too. Jacobsen et al.’s (2017) found a strong presence of emotion characterized most of the stories in their study, recognizing a “need for narrative pedagogy in healthcare . . . to understand the suffering of others as seen through their lifeworld and through an understanding of their life stories” (p. 13).

When storying my personal experiences, I took care to remove any identifying factors. I did this by decontextualizing time and space and eliminating any descriptors that might be identifying to others (Kim, 2016). This process ensured confidentiality of my previous patient and family experiences in palliative and end-of-life care. Storying was a significant choice of method as it provided me with the space to dig more deeply into the impact left on me as a nurse by my patients’ end-of-life journeys.

Data Sources and Analysis

According to Miriam & Tisdell (2016), data analysis is “a complex procedure that involves moving back and forth between concrete bits of data and abstract concepts, between inductive and deductive reasoning, between description and interpretation. These meanings and understandings or insights constitute the findings of the study” (p. 202). In my study, data sources included the transcripts from 12 interviews as well as my researcher journal, and drafts of my storied experiences. Carter et al (2014) suggested it is important to collect different kinds of data sources on the same phenomenon to improve research inquiries (Carter et al., 2014). I sought Richardson and St. Pierre’s (2008) concept of crystallization, referring to a coming together of sources that allows for a multidimensional reflection of patterns, ideas, and directions.

My data analysis was iterative and ongoing. As each interview took place (May to December), I scanned the expanding data to determine if new ideas or perspectives were being presented or if saturation had been reached within the depth and breadth of information received. I determined that a subsequent round of optional follow-up interviews was not required as emergent themes across interviews began to appear and the intricacies of individualized experiences across 12 participants offered rich data for analysis.

My analysis process unfolded as follows:

- Transcriptions were organized into the two groups, one for the nurses in the expert category and the other for the early career nurses.
- I read and re-read the transcripts, writing notes in the margins. I noted similarities and differences between the shared experiences of participants and areas to return for more in-depth review.
- I then sectioned out the responses according to individual questions to assist with organizing the information. The only electronic software used for data treatment, management and coding was Microsoft Word.
- I created a chart to synthesize the information further with key points of response across questions. I colour coded recurring words and descriptions where themes began to emerge. I also returned to my researcher journal to reread my notes from the interview to look for commonalities and differences.

- One column in the chart included key terms used to describe the characteristics of a palliative care nurse. With these words, I created a Word Cloud using the free digital tool, *WordItOut*. I explain this process further in Chapter Four.

This process is much like the *Data Analysis Spiral* that Creswell (1998) shares where researchers move back and forth through a spiral of "describing, classifying, and interpreting data…[as they] describe in detail, develop themes…and provide an interpretation in light of their own views or views of perspectives in the literature" (p. 144).

In addition to these specific task-oriented steps, I identified key moments within my researcher journal to story my relevant lived experiences. I also developed written introductions for each participant to introduce them and their foray into nursing and palliative care. I further clarified emerging themes and identified key quotes and relevant stories to help me craft my writing.

Dissemination

The letter of information I shared with participants explained that initial dissemination would be in the form of my doctoral dissertation with the intention to publish in appropriate journals (e.g., the Canadian Journal of Nursing Research, Journal of Clinical Nursing, and those more specifically related to palliative care such as the International Journal of Palliative Nursing or the American Journal of Nursing), sharing findings at conferences, and engaging in further research studies to continue my ongoing interest in PC nursing practices. The Letter of Information also communicated to participants that they could contact me directly for future publications.

Ethical Considerations

The methods of my study were consistent with all requirements outlined in the research ethics approval I received from the university and related agencies. Confidentiality, ethical reflexivity, awareness, and sensitivity to the needs of the participants were forefront for me to preserve the integrity of the research and to honour the lives and shared experiences of the participants. In this section, I share a closer look at the ethical considerations I considered and prepared for at the onset of this work.

Confidentiality

I sought informed consent prior to beginning this study. Consent forms were included with the information letter and were received prior to the interview date (Appendix B). Safeguards included the use of pseudonyms to uphold the confidentiality of the participants and the removal of identifying information within stories shared. A pseudonym list was kept in a password protected electronic file on my personal computer. The audio files were also kept on a password protected electronic file and deleted at the time of writing to allow for cross-checking if needed and to coincide with the steps outlined in the ethics protocol. The recruitment process allowed interested participants to make the choice to participate.

Insider/Outsider

As a nurse, administrator, and now researcher, my research interest has been shaped from my lived experiences. Clandinin and Connelly (2000) suggested it is critical to articulate a relationship between one’s personal interests and sense of significance in the work and lives of others. It is my nursing background and interest to learn more about the experiences of other palliative care nurses that has led me to this point. It is this very same background that leads me to hold a deep understanding of the context of this study through an insider/outsider role. Dwyer and Buckle (2009) described being an insider researcher as an opportunity to enhance the depth and breadth of understanding a population that may not be accessible to a non-native scientist, while being an outsider provides an opportunity for a more objective view. A benefit to being a member of the group one is studying is acceptance. Dwyer and Buckle (2009) explained: “One’s membership automatically provides a level of trust and openness in your participants that would likely not have been present otherwise” (p. 58). Another is that it is a starting point of commonality that affords access into groups that might otherwise be closed to outsiders. I began this research study with the understanding that participants might be more willing to share their experiences with me as a researcher as I am also a nurse because there is an assumption of understanding and shared distinctiveness.

Participant Welfare

The welfare of participants is of primary concern in qualitative research (Polkinghorne, 2005). Palliative care subject matter can become emotionally overwhelming. I was cognizant that questioning is of utmost importance in the interview process (Clandinin & Connelly, 2000; Kim, 2016). Kim (2016) described how successful interviews happen when critical advance preparation is made with consideration of responses that will include the “why, how, where and when contexts” (p.170). In providing examples, Kim stressed that avoiding jargon, pursuing detail, and deferring sensitive questions until rapport has been established are important strategies to ensure meaningful answers.

When discussing a topic such as palliative care, often many of the dialogs can elicit emotional memories and experiences. As mentioned in my outline of the interview method, I ensured questions were open-ended to allow choice of what participants felt comfortable sharing with me. I was careful not to rush the participants in their descriptions of their experiences and took time to ask for clarification or ask if they could expand on their comment. I advised each participant at the start of the interview that they had the right to pause at any time, decline any question, postpone their participation, or withdraw from the interview, if our conversation became difficult to continue.

I was also cognizant of my own past experiences and the feelings that were returned to me, and as such I wanted to ensure that participants were provided resources in the event they experienced any personal discomfort or difficulty as a result of the experiences/perceptions shared during the interview. I had ready at hand resources that I could share including contact information for the Mental Health Helpline (1-866-531-2600) and the Distress and Crisis Ontario Centre (416-408-HELP). Both were accessible 24 hours a day, 7 days a week. For those participants who were working as nurses, they were also advised that they may have employee assistance programs within their institution that they could access. These measures were put in place to attenuate the psychological risk of telling stories about palliative care nursing. This safeguard was also placed within the Letter of Information and Consent for the participant.

The Canadian Nurses Association (CNA) outlines a code of ethics that all nurses must follow that includes non-maleficence or doing no harm (CNA, 2017b). In nursing research, ensuring participants have control over their participation demonstrates a measure of maintaining this code. As a nursing researcher, it was imperative that I upheld this ethical consideration for my participants.

Reflexivity

The participants' stories shared within this doctoral study highlight the lived experiences of palliative care nurses as retold through their own interpretation of the event or situation, and further narrated through my researcher lens. As the teller of their stories, I recognized that my lens was influenced by my own experiences in palliative care. Reflexivity was needed in my interpretation of participants' stories. Through the practice of reflexivity, researchers can reveal their personal understanding and inclinations towards theoretical orientation and how a reconceptualization is made through a process of construction, deconstruction, and reconstruction (Iannacci, 2007). Shields (2005) described the practice of reflexivity as the revisiting of important life events that involves the reconstructing of stories from where they occurred in the past to present day understanding, and as our journey continues, we "learn from our past and reinterpret as we go" (p. 180). The revisiting and reconstruction of such stories is important because when retold, they bring knowledge from the intervening years and provide the resources from which new knowledge is made.

Trustworthiness

Quality in narrative research is often determined by its trustworthiness in providing the research community with assertions that the findings are a strong basis for understanding human action (Peden-McAlpine et al., 2015). Further, trustworthiness of data depends on the integrity and honesty of the research (Moss, 2004; Polkinghorne, 2005), and as such, qualitative research criteria exists to define its trustworthiness.

For example, Lincoln and Guba's (1985) influential work outlined four criteria for building trustworthiness. They proposed that rather than use traditional research criteria often found in rationalistic paradigms (internal validity, external validity, reliability, and objectivity), that naturalistic research focuses instead on credibility, transferability, dependability, and confirmability. Credibility is often characterized through prolonged engagement, persistent observation, and can include member checks and reference materials (Lincoln & Guba, 1985). Transferability encompasses purposeful sampling of palliative care nurses capable of speaking to the phenomenon of study along with the goal for thick description. Dependability looks towards a clearly outlined process of inquiry that can be repeated in another time and place (not replicated). Confirmability is supported through reflexivity and triangulation, or in this case, crystallization of sources leading to reasonable and meaningful interpretation. I expand on this concept in the next section.

I kept these criteria for trustworthiness in mind at the onset of my study. Key pieces I put in place to support trustworthiness included prolonged interview time (an hour to an hour and a half), member checking of transcripts, the goal of thick description (Geertz, 1973), and use of quotes to forefront participants' words. Stories were not collected with the intent to replicate understanding that each story shared was situated within time and space. These stories are recollections and reflections of events, not necessarily the actual events as they unfolded.

In another point related to trustworthiness, Kim (2016) discussed the importance of trust and rapport between the interviewer and the interviewee as a way to create knowledge through the human interaction within the interview process. As participants shared their experiences with me, I felt a collective closeness (familiarity) with them. I sought to build trust by sharing my own personal experiences. Some participants noted this common ground in our interviews. They noted feeling a common connection in our practice and that they were sharing with someone who understood their work and shared their experiences. Participants spoke of feeling grateful for this research and its goal to bring their journeys to light.

The Question of Validity

Validity was mentioned above in relation to trustworthiness but merits further discussion. In their search for truths, dissenters of qualitative research have challenged its validity, rigor and quality, and reliability and generalizability (Loh, 2013), and claimed it is vulnerable to interpretation and bias by virtue of its nature. Narrative theorists argue that narrative is less about accessing factual accounts and more about understanding the meanings individuals create and live by, and further that “validity” of narrative is only in question when the truths are considered irrelevant (Bingley et al., 2008). Richardson and St. Pierre (2008) described triangulation as a form of analysis occurring in traditional research whereby the researcher assumes there is a fixed “point” or “object” that can be triangulated to validate findings (p. 478). As Richardson (2000) noted: “the central imaginary for "validity"…is not the triangle - a rigid, fixed, two-dimensional object. Rather, the central imaginary is the crystal, which combines symmetry and substance with an infinite variety of shapes, substances, transmutations, multidimensionalities, and angles of approach” (p. 934). “Crystallization… deconstructs the traditional idea of "validity" we feel how there is no single truth…and crystallization provides us with a deepened, complex, thoroughly partial, understanding of the topic... we know there is always more to know” (p. 934).

In the present creative types of analysis in narrative propose that research has moved beyond scientific validity measures to include literary and artistic forms of data, where the boundaries of observation, witnessing and retelling of stories, and memorializing, deconstructs the traditional idea of validity in that there is no single truth but rather what evolves is a deepened, complex, and only a partial understanding of the topic. As noted above, there is always more to know.

Iannacci (2007) cautions that with all research, it is important for researchers to ensure that they maintain a critical assessment of where the criteria may fall short. He stated that in order to further the internal validity of narrative research, it is important to continually locate, name, examine and reflect upon biases and beliefs throughout the research to remind the reader that the researcher is very much present within the narratives they are constructing and theory choices they are making. This is what he describes as a critical assessment of criteria. Iannacci (2007) says "no single set of criteria can be used to cultivate or assess validity in narrative inquiry" (p. 73), but rather it is a matter of looking at these criteria critically as well as explicitly describing where they fail or come short.

In this study, I do not aim to present the single truth of what it means to be a palliative care nurse. My experiences were my own. I also believe that there were many nursing experiences that could contribute to a better understanding of palliative care yet to be heard. I collected multiple stories of experiences that encompassed a collection of encounters of palliative care practices that spanned cultural, social, and professional understandings across the period of time I was engaged in this research. With crystallization in mind, my research methods of interviews, researcher journal and storied personal experiences sought to offer a multidimensional consideration of palliative care nursing to illuminate important meanings and content beyond my own experiences.

Reciprocity

A final consideration for my study was that of reciprocity. Given (2008) described reciprocity as balanced patterns of giving and taking between people, and while research relationships are not necessarily reciprocal, ethical research practice requires researchers to consider what they take from research participants as well as what they give to them. As mentioned, individual transcripts were provided to participants for member checking following the interview and transcription process. Cho and Trent (2006) described this as a technique that enables confirmation of accuracy of information and provides opportunities for reciprocal learning resulting from emerging themes.

Yet, reciprocity is more than member-checking. Engaging in a relational experience with my participants through the sharing of stories, offered a mutual benefit through story. As thoughts, feelings, and practices were shared with me, this new knowledge brought new meaning to my existing knowledge. As I shared similar stories in response, I believe I offered validation for participants of their experiences and also potentially added to their existing knowledge. It is possible the sharing of my experience influenced responses, and I acknowledge my influence and engaged in reflexivity as shared above. Yet, it is also possible my knowledge and experience with palliative care practice permitted yet another focus in which they could critically reflect and view their experiences. Lindsay and Schwind (2016) discussed this approach as an opportunity to co-create what was learned through our combined views, enhancing learning for each of us that can reveal new patterns of understanding and resonances across our experiences through the stories told.

Summary and Looking Ahead

Placing participants' voices in the forefront along with researcher reflexivity was important in my commitment to include all points of view, protect participants' well-being, and contribute to authentic participation in educational research. In the ensuing chapters, I narrate the experiences of my nurse participants and their journeys working in palliative care. I begin with an introduction to each of my participants and what brought them to this specialty area.

Chapter Four: An Introduction to Palliative Care Nurses

In this chapter, I introduce the expert and early career nurses who so graciously and eloquently recounted their heartfelt experiences of what it means to be a palliative care (PC) nurse. Their narrative experiences are presented in this and subsequent (two) chapters to expand perspectives into the lives of nurses who care for individuals and their families during their final period of end-of-life. I begin with an introduction of each participant, including what guided them towards becoming a palliative care nurse, their experiences with providing palliative care since they began their career, and what palliative care means to them. I offer these portraits as a beginning foray into getting to know my research participants. While they each entered nursing from different paths, they have come to share a common experience in palliative care. Some knew not long into their career journey that palliative care was a practice area that would become a lifelong dedication, while others are just starting their nursing careers and have yet to determine where their passion lies. Regardless of their path of entry into the realm of caring for end-of-life individuals, these portraits highlight the ways they will be forever connected in their knowledge gained from these experiences.

These portraits are not intended to be full professional profiles of a palliative care nurse but to contextualize the individuals who contributed to the findings presented in this dissertation. Following the portraits, I turn to the qualities and characteristics identified as important by participants in palliative care nursing.

Let's Meet the Participants

An overview of participants is presented in Table 4.1, including pseudonyms, areas of current employment and years of experience. The 12 introductory portraits that follow are presented in corresponding order beginning with expert nurse participants.

Table 4.1

Participant's Current Employment and Years' Experience

Name	Area of Employment	Nursing experience
	Expert Nurses	
Barbara	PC Consultant (Homecare & Hospice)	30 + years
Rose	PC Consultant (Long Term Care & Hospice)	5 years
Alexander	PC Consultant (Community & Long Term Care)	10 years
Gladys	PC Consultant (Community & Hospice)	16 years
Shirley	PC Consultant (Community & Long Term Care)	36 years
Diana	PC Consultant (Community & Long Term Care)	24 years
	Novice Early Career Nurses	
Charlotte	Medicine and PC unit	1 year, 3 months
Alice	Medicine and PC unit	1 year, 6 months
Kristin	Emergency	2 years, 8 months
Margo	Homecare	Completing preceptorship
Sparrow	Medicine	1 month
Nicole	Cardiac Care Unit (CCU)	Completing preceptorship

Expert Palliative Care Nurses

Barbara - A Nursing Experience Spanning Three Decades

First graduating with her nursing diploma**,** Barbara spent her early years working in acute care in a variety of settings from emergency to medicine and then surgery. She then returned to school to complete her undergraduate degree. She received no training in hospice or palliative care and early in her career, she recalled observing people actively dying on the same floors as all other patients. Over time, she began to notice she was often the nurse assigned to dying patients. This observation led her to feel that expertise in caring for those dying was not seen as a requirement and that all nurses "could do palliative care."

Barbara sensed that something was different about herself. As she gained more and more experience with patients at the end of their lives, she found the experience to be very fulfilling. Following the completion of her degree program, she was offered an opportunity to become a visiting nurse. "They saw something in me," she recalled. She transitioned to visiting nursing in what felt like a leap of faith. In this role, she provided palliative and end-of-life care more frequently. She began learning more about palliative care and ways to support other health team members to also learn more about caring for patients at the end-of-life. In her current role, she is a PC consultant who supports health care providers to deliver palliative care through out-reach programs administered by a local hospice. She teaches and provides guidance to nursing colleagues. Her motto has always been and continues to be "one person at a time."

Rose - Always Wanted to Be a Palliative Nurse

Before becoming a nurse, Rose was a personal support worker (PSW) working with an elderly population. She entered nursing school with the intent of continuing this work. In her first year of nursing school, Rose came across an article about June Callwood, a long-time advocate of hospice and volunteerism in the hospice movement. This article resonated with her feeling that hospice palliative care was the "quintessential essence of what nursing is supposed to be." This moment led her to request hospice for her final year's practicum.

While her first career experiences included working in a community setting in group homes, Rose transitioned to residential hospices and caring for those at end-of-life. The care provided in hospice is the type of care that Rose believes is the culmination of everything nurses learn. It provides glimpses into a person's humanity with the opportunity to see people in all their beauty throughout their final days and even in their death. For Rose, each death is unique and provides an intimate perspective of the patient and family unit as they journey together in these final moments. Rose believes that this care informs the "art of nursing," the advocacy needed for palliative caring in nursing education, and that palliative care education should be integrated throughout nursing education as a benefit for all future nursing care.

Alex - Early Personal Life Experiences Led to Palliative Care

Alex lost both his mom and his grandmother within a span of three months early in his nursing career. Not yet working with palliative patients, Alex found his experience as caregiver for his mother and grandmother to be fundamental to his understanding of palliative care. In his words, this experience was "one that shaped me into who I am today." Upon graduation, Alex started his career in acute care on a medicine floor but soon noticed that he wanted to spend most of his time in the palliative care unit. "I really felt this was the right fit for me," he explained. Unfamiliar with providing palliative care, he began asking questions of colleagues about how best to manage this type of care. He found there were no expert palliative care nurses he could turn to for support, which led him to feel "left to figure it out on [his] own." He realized that his nursing training did not provide him with the knowledge needed to provide appropriate palliative care. Thinking back to his undergraduate nursing program, Alex recalled only a 30-minute lecture in palliative care that was focused primarily on care of the body. Finding himself in difficult situations and with limited understanding of palliative care fueled a desire to learn more.

He enrolled in palliative care courses to supplement his knowledge and began to advocate for more palliative care education for new nurses.

As time progressed, Alex accepted a full-time position in community nursing with more patients in need of palliative care but also where he was paired with an expert nurse to support his growth. For Alex, this mentoring significantly contributed to his learning. Now working as a palliative care consultant, mentoring is one of the most important tasks he has today as he seeks to build capacity in the nursing profession.

Gladys - An Unexpected Nursing Career Path

Like many beginning nursing students, labour and delivery was where Gladys wanted to be with goals of becoming a midwife. Gladys' mom was a pediatric oncology nurse and Gladys remembered "hating [her] mom's job growing up." She remembered so much sadness in her mom's work that Gladys swore she would never follow in those steps. As life would have it, Gladys had a unique opportunity to be placed at a children's hospital working in oncology during her third-year externship placement. Her fear of having a similar career as her mom led her to turn this opportunity down at first. However, she decided to speak with a former mentor for advice (a nurse from an earlier placement in a fertility clinic) who encouraged her to explore this unique chance for a placement in pediatrics, one not generally offered to third year students. Janice recalled, "I'm a spiritual person and I prayed about this decision and felt that both God and my preceptor were pushing me to take this chance." Interpreting this reflection as a spiritual nudge, Gladys decided to give it a try. Though terrified of working in an environment that gave her mom so much pain, her preceptor showed her kindness and gentility, allowing her to grow and flourish. For Gladys, this experience felt like a chance to walk together with someone who showed her the meaningfulness of the work she was doing.

Despite her initial fears, Gladys’ work with children at Sick Kids Hospital helped her manage her fear of dying. This experience became the “hook” that led her to choose a career in palliative care. She found children to be some of the world’s greatest teachers and that their approach to death was “something we can all learn from.” Similar to other participant stories, Gladys did not have any direct training in palliative care in her nursing education.

Shirley - The Medical/Surgical Unit as First Stop to Palliative Care

Early in her career, while working on the medical/surgical unit, Shirley was impacted by the death of a woman in her early forties with two young daughters. She recalled:

> I started crying and crying . . . I opened the closet and slid in behind the door in that patient’s room because I didn’t know what to do. Then the husband who had just lost his wife came in and comforted me.

For Shirley, this was one of the most embarrassing things to have ever happened to her. Looking back on this experience, she felt unprepared for caring for this woman and her family. There had been no mention that this woman was dying, and this was the first time Shirley had ever witnessed someone dying. She recalled thinking to herself. “I do not know what I do not know,” recognizing a significant gap in her knowledge.

Shirley returned to school to complete her graduate studies in nursing with a strong desire to teach. Upon graduation, she began a university teaching position. She then took a step back from her position to raise her children. She returned to teaching (with nursing and personal support worker students), also spending time with her students in long term care clinical placements. It was here that she experienced caring for individuals who were journeying to their end-of-life. Shirley found herself drawn to working with the elderly in nursing homes often watching them dying alone and without family. Palliative care gradually became a strong focus for her. When a hospice opened in her region, she decided she could make a difference by helping people to live as fully as possible before death. Her journey with palliative care continues today in her role as a palliative pain and symptom management consultant. Despite starting her nursing career with no exposure to palliative care, she is now a strong advocate for quality end-of-life care.

Diana - Stumbling into Palliative Care

Diana had been an oncology nurse for over 10 years when the cancer center where she worked wanted to develop a palliative care program. At the time, palliative care was not a well-known term with few officially recognized programs. She was selected for having “had her feet on both sides,” an acknowledgement that she worked with people at end-of-life in the cancer clinic. This was Diana’s first foray in this specialized field of care. It was an “eye opening experience” with much to learn. Oncology had not prepared her for caring for individuals with life limiting illness where treatment was no longer an option. Developing the palliative care program, she learned from patients about what it was like to be dying, what their needs really were, and what was needed to provide exceptional care. During this same time, Diana’s mother was dying. The nurses looking after her mother would ask Diana what care she wished her to have each day. Diana recalled, “I remember thinking I don’t want to be that decision maker. I just wanted to be her daughter. They didn’t understand and I thought I had to step in because otherwise I was letting my mom down.” This personal experience helped Diana to see the value of simply being a daughter for her mother. She came to understand that palliative care requires space for family members to contribute in their own way while experiencing their loved one’s end-of-life journey with them.

After several years of working in the cancer center, Diana moved to Kenya and became the Director of Nursing for an acute care hospital. Her responsibilities included enhancing their oncology services and preparing for a comprehensive hospital accreditation. At the completion of the work, Diana was asked to remain in Kenya to develop a palliative care curriculum to educate nurses. This was an exceptional time in her work. She observed an unprecedented commitment and appreciation to learning from Kenyan students and felt valued by her learners. Diana, herself, had come to Canada as a refugee and appreciated the value of being able to give back something to this world. During her time in Africa, she witnessed the incredible courage of people, their suffering with little access to analgesics, and their bravery as they faced death. She saw this experience as yet another opportunity to provide service in other ways, from the setting up of programs, to mentoring of compassionate care teams, to training volunteers and reducing the stigma associated with cancer and dying. Each of these experiences contributed to Diana's development as a palliative care nurse seeking to forward the palliative care movement in this part of the world. Her international experience fulfilled a dream of hers to be able to give back some of the knowledge that she had been grateful to receive.

Early Career Nurses

Charlotte - Palliative Care as Mentally Exhausting Work

Originally a law clerk with a human resources background, Charlotte returned to school for nursing as a mature student with the goal to care for people. Her foray into nursing education was somewhat "chaotic" due to an unfortunate timing where her program experienced two labour disruptions. During her training, Charlotte completed her preceptorship in a medical/palliative care unit and interviewed for a position upon receiving her registration. While she was preparing to write her licensure exam, she worked part time in a long-term care home for a brief period as a personal support worker. Upon successfully passing her registration exam, she soon after secured her full-time employment in nursing on the medical and palliative care unit and has been practicing for a little over a year. As she started her career in this area of the hospital, she noticed a routinely high number of medical patients in her daily assignment and found the work to be very physically exhausting. Both a medical and palliative care unit, oftentimes her assignments would also include caring for patients on the palliative unit. She explained, “We have the opportunity to work on both sides of our floor and when you are on the palliative side for a number of days, it is mentally exhausting, more than you know.” Wanting to provide optimum care to her patients, the focus of care was primarily about helping family members to understand what was happening for the patient and to help them to accept that end-of-life was approaching for their loved one.

For Charlotte, her time working in the PC rooms was like being on an oasis, where time seems to slow down. With one-on-one care needed, she explained, “it is that next level of care which is more personable.” She found this to be more fulfilling than the fast-paced care found in other units. However, Charlotte noticed challenges within the “oasis” of these rooms as well. On these busy units, she noticed that patients and families received mixed messages about their prognosis and that providing continuous support for families requires much energy and resilience.

Alice - Palliative Care as Emotional Experience

Like Charlotte, Alice is also a relatively novice nurse working on an acute care surgical unit. She recently completed her nursing education and soon after passing her registration exam, was hired on an inpatient surgical floor after completing her consolidation. Alice’s first experience with palliative care was as a third-year nursing student with a community-based project that involved the development of a brochure for family members to educate them about medical assistance in dying. She recalled, “This was my first introduction to a patient passing away. It was a surreal moment because they had chosen to die.” This experience provided a different perspective of an individual passing away.

For Alice, palliative care is a place where nurses can spend time with their patients and ensure that they receive the care they deserve. In her words, “It is a chance where we get to sit with the patient and give them time they need.” This is part of the role where dignity for the patient can be preserved. She finds caring for a patient is often accompanied with a lot of emotions from both the patient and family as they journey through this period of time together. Alice finds that working on a fast-paced unit does not allow time for this kind of individualized care and nurses often feel guilty that they cannot be with their patients more, especially for those that do not have any family. The team’s focus is often on curative measures and saving people rather than caring for them to enhance their quality of life before death. Alice sees palliative care as comfort care, an important and normal process of life that is not well recognized in an acute care setting. Alice does not feel that she was well prepared in her training for what to expect when a patient is dying. She believes more emphasis is needed on communication with patients and families and also how best to manage the emotional components of this specialized work.

Kristin - All Nursing Can Involve Palliative Care Nursing

Kristin began her nursing career in a complex continuing care unit with dementia patients in an acute care hospital. Over the next couple of years, she continued to work on various units gaining experience with in-patient medicine and emergency nursing. Kristen then decided to return to school and enrolled in her master’s in nursing education where she is working towards her nurse practitioner designation.

Kristin believes PC can happen anywhere and does not necessarily need to be in a palliative care unit. In her experience, Kristin noticed there would occasionally be patients in her units who were nearing end-of-life and where palliative care was required. Working in a non-palliative care designated unit highlighted for her that nurses need to be prepared for everything. All nurses need to be able to have access to resources to help them to deliver the care these individuals require at end-of-life. During her nursing training, Kristen found there was little focus on providing care at end-of-life. Like Alice, she felt unprepared when the time came to manage and advocate for her patients. To compensate, she turned to more experienced nurses to ask for guidance. She described these seasoned nurses as having mentored her through some very difficult cases and where she feels she learned the most about palliative care.

Margo - A Focus on Community Nursing

Margo's early venture into caring for others was working as a PSW for three summers. It was during this time that she first saw patients at the end of their lives. During her nursing training, Margo's teacher suggested that based on her interests, she might like to try community nursing for her final placement experience. She recalled being criticized by her classmates for even considering not being in acute care. Magot's PSW experience was the incentive needed to take a chance, one for which she was grateful.

Margo also recalled receiving little information about PC in her curriculum during her nursing training. She explained: "There wasn't enough information to prepare us for the type of conversations we would be having with the family and all of the emotions that would be involved." Margo recalled one time when she noticed there was lots of activity within a patient's home, including, "a lot of emotions and a lot of family and a lot of conversations going on." Her preceptor's calming and reassuring way was instrumental in not only helping the patient and family but also in providing her a supportive learning environment. Margo described compassion as flowing from her preceptor and allowing her to experience the significance of the nursing visit for not just the patient but for the family members too. The moment was made more significant in that Margo's grandmother had the same diagnosis as the patient. At the time of our interview, Margo was just completing her preceptorship and had plans to be writing her registration exam within the following two-three months post program completion.

Sparrow - Personal Experiences Led to Becoming a Palliative Care Nurse

Sparrow began her caring journey with her mom at a very early age. Her mother, due to very early trauma, had developed mental health issues compounded with physical health problems and was regularly seen in the emergency room or hospitalized for a developing psychosis. This prolonged exposure to the health care system and seeing all that her mother went through in her illness, stirred a need in Sparrow to care for people.

Sparrow's nursing career started as a registered practical nurse with a return to school through a bridging program to obtain her degree in nursing. During this time, one of her neighbours was receiving palliative care and being cared for at home. Sparrow observed how he was vulnerable and could no longer speak or move due to his illness. Communication became difficult, yet she saw nurses working closely with him and building a trusting relationship. Sparrow found observing this experience to be humbling. For her, it felt like the essence of humanity to be able to help someone in a time of crisis. Both this experience, and caring for her mother, led her to request a final preceptorship practicum in a hospice. Sparrow knew that she wanted to work with patients at the end-of-life.

Sparrow's hospice care practicum experience demonstrated to her the ways hospice care offered a safe place to die with dignity. Though the experience was short, she described it as being very impactful. Just one month into her nursing career at the time of our interview, Sparrow recalled thinking that it is important when providing care that we do not take life and these experiences for granted. Providing this type of care provided Sparrow with a sense of purpose: "It is humbling and leads me to feel that the people we care for also help us to grow and be part of who we become."

Nicole - Inspired to Become a Nurse Through Medical Experiences

Between the ages of 12-16, Nicole experienced not one but six pneumothoraxes, where her lungs kept collapsing. She developed a strong rapport with one of her nurses during treatment, a nurse from North Bay who made a lasting impression on her. This early experience with the health care system set the wheels in motion for Nicole 's journey into nursing. In her first year of nursing school, Nicole's grandmother passed away. Her grandmother had been in kidney failure receiving dialysis for years. While dialysis is considered the end stage and requires palliative care, looking back, this moment was the first opportunity for Nicole to think about a life coming to an end. For her final placement, Nicole wanted to be placed in a maternal child unit, but she was instead offered a placement in the Cardiac Care Unit (CCU). Other than her grandmother, Nicole had little experience caring for someone at the end-of-life up to this point. During her CCU placement, Nicole found patient care to be generally very rushed at the end-of-life. Patients often arrive very ill, where they and their families are unprepared for the overwhelming medical event that finds them needing this critical care. She observed how the CCU was an area where many patients died and the environment was noisy and fast-paced, which appeared to take away from important patient and family time and their ability to connect during those last days.

For Nicole, palliative care is about being able to provide a quality of life in those last days. It requires acknowledging that end-of-life is approaching for patients while not dismissing the fact that they are still a person, with likes and dislikes and that they must be seen as a person and do their best to enrich their patients' lives to the extent they can at this critical time. As an example, Nicole offered, "Even when my patients are heavily sedated or non-responsive or on a ventilator, I still talk to them and tell them what I am doing while I am washing their face." Nicole felt that this was an important step in being able to provide palliative care in a fast paced, medicalized atmosphere where time is of the essence and making a connection is paramount for critically ill patients and their families. Overall, Nicole described her experience with preceptorship as very good. She is considering continuing work after graduation in the intensive care unit or working in oncology. In either specialty area, Nicole sees herself as wanting to contribute to patients' quality of life. Nicole elaborated this goal as follows: "I want to look at them as a person still and acknowledging what they like, what they dislike and not ignoring any of those things …. It's enriching, that part."

Taking a Closer Look

Now that I have introduced all twelve participants and how they came to be interested in palliative care, I turn next to the first level of analysis from the transcripts that considered the words used by these palliative care nurses to describe their work.

Qualities and Characteristics of Palliative Care Nurses

At the beginning of this study, as a fellow nurse, I imagined I would hear commonly cited qualities of nurses, such as having empathy, compassion, and a desire to care for others. While these qualities were identified as important for nurses working in palliative care, a number of other qualities and characteristics were also cited. In order to demonstrate the frequency of the words across participants, I first identified descriptive terms within the transcripts. I then counted the number of participants who used each term. I did not count the frequency of the word itself across transcripts to avoid an imbalance if one person used the word many times while another said it once. Using a word cloud application called WordItOut, I entered the frequency of participants who cited each word to create the visual (Figure 4.1). The more participants that used the same word, the larger the text size. Interestingly, the descriptive term most frequently cited by both expert nurses and early career nurse participants equally was the need for nurses to be knowledgeable in palliative care. In the discussion below, I make connections to the literature where relevant.

Figure 4.1

Qualities and Characteristics of Palliative Care Nurses

Taking a closer look, eight of the 12 participants spoke of the importance of having preparation in the specialty of caring for patients at end-of-life as one of the most important assets required to be able to care for someone in their journey towards death. For example, early career nurse Alice stated:

> I would say it's not necessarily always a senior nurse who would be the most appropriate nurse to care for someone at end-of-life. Rather I think those nurses that actually specialize in palliative care would be the best go-to person.

The Canadian Hospice Palliative Care Association (2013) speaks to the complexity of palliative care mentioned by Alice as not only including disease management but also the management of a number of issues including physical, psychological, social, spiritual, practical, end-of-life management and also helping patients and family cope with grief and loss. This complexity also stands out in the variety of terms presented in Figure 4.1.

The next most commonly cited quality (seven times) was the need for a palliative care nurse to be resilient. Expert nurse Diana placed resilience at the top of her list, explaining:

> There is a need to have a healthy philosophy about death and dying and a commitment to really leave no stone unturned to care for your patient. It is about having that inner strength, that inner confidence which takes time to develop, and that means sometimes putting your fears aside.

Expert nurse Gladys described having resiliency as "being able to continue to do this work when it can feel so hard." Similarly, early career nurse Kristin described the need for resilience:

> You have to be both physically and emotionally resilient . . . The hours are long, and nurses can easily burn out if they are not able to compartmentalize themselves to be able to support the patient and family through this process and the difficult decisions they will have to make. It is a very emotional time.

Other early career nurses appeared to speak to resilience though did not name it as such. Sparrow recalled having to be “emotionally, mentally and physically sacrificial” and “having to have fortitude” to care for someone at the end-of-life. Charlotte suggested “caring and time is needed to work with these patients and a nurse has to go the extra mile and be able to be emotional and also uphold barriers as needed.” It has been my experience that resilience is often used to describe the work of nursing as the shifts are generally long, with a number of patients to care for. Reyes et al. (2015), for example, conducted an integrative review of resilience in nursing education and found that resilience was viewed as a trait or personal capacity that allowed students to be able to adapt, withstand challenges, and remain in the nursing programs. They described resilience as a characteristic that enables coping with stressors, the modification of thinking and results in successful adaptation. Interestingly, four of the six early career nurses made a point of identifying that there are strong emotional components to providing care at end-of-life, and it is important to set boundaries in order to protect their well-being in a highly emotional caring time.

An additional quality emphasized by early career nurses was having to work hard. Charlotte described palliative care nursing as having to “go the extra mile” and as “exhausting work.” Alice spoke about how, “There are a lot of emotions and when you have several patients per day to care for, it is hard to find the time needed for PC patients and their families.” Expert nurses leaned more often to a willingness to learn as an important quality to care for patients at end-of-life. Barbara visualized a journey with patients where nurses are “responsive to their needs, which includes being open minded, a willingness to listen and to seek out new information as needed to supplement care.” Rose reflected on the beginning of her nursing journey, sharing “I did not know what I did not know.” This self-awareness helped her to seek new information and learn from patients and other healthcare providers. Gladys acknowledged that nurses must have "perseverance to increase their knowledge, along with ongoing reflectivity for a better understanding of their patient's needs."

For expert nurses, the need for ongoing learning remained important despite the years of experience they had. Barbara, who was approaching retirement, continues to dedicate three-four hours per week to researching information in palliative care and that keeping on top of emerging information has continued to help her to support and provide guidance to new and emerging nurses entering this specialty area.

Other qualities and characteristics were also cited by the nurse participants as important and cannot be understated even if only mentioned by one or two participants. A number of familiar nursing qualities included having compassion and empathy for patients and family members, along with a genuine disposition for caring. Other terms that made their list were the importance of being a good listener and a good communicator, while also needing to remain professional, open-minded, and flexible in their approach to care. Overall, 15 unique qualities and characteristics were identified as required for nurses to be able to deliver this specialized care. These terms offered an initial understanding of what it means to be a palliative care nurse as I then deepened my analysis to explore stories of participants' lived experiences.

Looking Ahead

As I developed the introductions shared in this chapter, I was reminded of my own early beginnings in nursing and first palliative care patient assignments. The notes I took in my reflective journal contributed to expanding my introduction in Chapter One and the storied experiences of my first memories within this field. As discussed in Chapter Three, my insider/outsider role (Dwyer and Buckle, 2009) meant I understood the context of the transitions into palliative care nursing that were described by participants. My experiences were similar but different, but our shared experiences set the foundation for the stories that unfolded. While the descriptive terms highlighted in Figure 4.1 were not new to me or to what I have experienced as a nurse, I learned which terms were most significant to my participants and why. I pondered these terms in my reflective journal and they remained in the forefront as I dug more deeply into the phenomenon of palliative care nursing.

Chapter Five: The Palliative Care Nurse Journey

As I dove more deeply into participants' and my own lived experiences three key views of palliative care became central to describing the work of palliative care nurses: (a) sacred, (b) exhausting and emotional, and (c) challenging. My personal, storied experiences continue to be shared throughout in italics to indicate the ways in which I am looking inwards, outwards, forward, and backward at my journey across time and place and in relationship to others (Clandinin & Connelly, 2000). At the conclusion of the chapter, I present a graphic that embeds the key points shared about what it is like to be a palliative care nurse.

Sacred Work

Throughout our conversations, expert nurses often spoke about palliative care as sacred work. Barbara reflected: "we are not in charge, our patients are, and I feel privileged to be on this journey with them, and I feel it is a sacred role that I have almost every day." She described every moment as being able to make a small difference for her patients: "It is those moments that you leave them with and those that you create the environment for them to be able to make decisions that make a difference." Alex also spoke about nursing in palliative care as sacred work: "While I find doing direct care rewarding, it doesn't fulfill me the same way as being able to help mentor others and teaching them about the art and science of this care." It is here where Alex felt that he could truly give back by sharing his knowledge with others: "This is where I feel I am able to give in a different way. You can do so much more by training more people to do this sacred work than trying to do it all by yourself." Rose related palliative care nursing to walking alongside families. She explained:

> It is the quintessential essence of what nursing is supposed to be, it's all the focus, the culmination of everything that we work towards as nurses. It's person-centered care that's

> dictated by the person and whoever they identify as family and we are to walk, I don't even say alongside of them, I say we walk behind them as we offer support when and where it's appropriate.

Rose viewed those moments where palliative care nurses see patients' vulnerabilities as a chance to practice the "art of nursing." She continued: "They are little glimpses into a person's humanity where they open the door for us to look inside and be present, to be able to hold that space with them and just be there." Rose further described that what she feels contributes to this work:

> Nurses need to be aware of their feelings around death first and foremost, in a very personal sense before they begin to address it in a professional sense. And I think they need to be kind, I don't think you need to be nice in this role, I think you need to have genuine kindness where you have the intent of caring for others. I think they need to have humility and be willing to make mistakes. I think they need to be strong in their resolve. . . . I tell [nursing students] 'If you don't like people then I don't think this is the right career path for you'. I don't mean to be crass in saying so but if you don't like people then this is not where you should be . . . . . . our job is always to serve.

Similarly, Shirley also spoke of this notion of sacredness when describing her role to serve as what she saw as important in palliative care nursing: "I've always thought it is a privilege to be a nurse, a palliative care nurse, taking care of people, patients, and their families at end-of-life. It really is a sacred place and it's a privilege."

Even early career nurse Sparrow described her limited work in palliative care as humbling for all those around the patient. I remember noting how her tone was somber when she described her experience of caring for a neighbour who was nearing their end-of-life:

> He could no longer verbalize, he couldn’t move, he couldn’t do any of that anymore, but he could communicate with his eyes. He showed so much love for the people who helped him. It was humbling for each PSW and nurse, to have his trust as you were coming into his home and caring for him. For me that was so humbling.

Sparrow was the only early career nurse to describe a sacredness to her work. As I listened to Sparrow recount her experience, it reminded me of a time where I had a similar humbling experience. It was with one of the first patients I cared for who was diagnosed as needing palliative care. I looked backward and inwards as I storied this moment.

Storied Experience: Nursing as Sacred

> *I had been providing care in his tiny home for several weeks. One day, when his time was nearing, I sat quietly in his room with him, holding his hand. Hoping to provide some comfort, I reassured him that I would be with him and his family when it was time. As my visit ended, I said my goodbye, reiterating I would return tomorrow before leaving quietly. He did not speak but looked up with gratefulness in his eyes. It was very moving for me. As I left the room and closed his door, there sat his elderly wife on a chair. She looked up at me with tears in her eyes but spoke no words. I did not know what to do or say in that hushed moment but realized that words were not needed at this time. I remember putting down my bag and going to hold her in my arms. We stayed that way for a minute or two. I could feel her sadness knowing what was to come.*

When I think of what sacred work means to me, I think of work that requires respect and reverence. Sacred work is my perception of what embodies being human and an interconnectedness I experienced when working with my patients and their families, and most especially in palliative care and when working with people at the end of their lives. Patterson and

Zderad (1988) described humanistic nursing as not a matter solely of doing but also of being where the nurse opens to the reality of the situation and provides their "total being" in the nurse-patient relationship (p. 21).

Remembering these experiences and listening to participants describing their lived experiences with their patients as sacred, led me to think about my philosophical stance around the meaning of human caring. I remembered a poem I had previously saved by Davidson (2006) that described nursing as being a sacred place:

> *Deliver meds. Titrate drips. Synthesize data. Conduct every possible act to bodily substances that under normal circumstances would remain unseen. Analyze rhythms. Take orders and execute flawlessly. Drive care. Push harder. Get it now. Get it done.*
>
> ***But this is not why you are here.***
>
> *Answer alarms, bells, and buzzers.*
>
> *Turn, tug. Pull, lift.*
>
> *Straighten, clean.*
>
> *Wash and wash again.*
>
> ***Physical, rewarding work, though not the reason for your calling.***
>
> *The most memorable days of many lives are spent in a hospital.*
>
> *Crisis days. Cataclysms.*
>
> *Life-altering events.*
>
> *Families drawn—no, thrown together.*
>
> *Shaken badly, living through a nightmare.*
>
> ***And, then there is you.***
>
> *Fielding their stress, emotions, and reactions.*
>
> *Translator, interpreter, and advocate.*
>
> *The human that makes this inhumane experience bearable.*
>
> *The touch of your hand, the warm soft caress of your voice.*

> *Your honesty that cuts through the jargon, gentle, but true.*
> ***You provide them shelter.***
> *You. There.*
> *For them. Caring.*
> *Seeking the special connection*
> *that allows you inside their most private moments.*
> ***That is why you do it.***
> *Shift after shift.*
> *Despite the endless challenges imposed by a larger cause.*
> *Through the knowledge and compassionate acts.*
> *You are a Nurse because you nurse*
> *the mind, the body, and the spirit.*
> *In the Sacred Place of Nursing.*

Today as I reflect on this poem and these memories that have returned while listening to my participants' recollections, I am reminded why I always describe my work as a palliative care nurse as a privilege to be with my patients. It is an intimate moment in time where patients and families allow you into their lives and place their trust in you. Barbara, Rose, Alex, Shirley, and Sparrow felt this too.

Exhausting and Emotional Work

A number of the early career nurses described palliative care nursing as emotional and often exhausting work. Relationships with both patients and families were offered as examples. Charlotte described one particularly difficult time:

> There was this one patient whose only son was having a really hard time. He was constantly trying to feed [his father] vitamins while he was “out,” almost non-responsive,

> and asking why we aren't giving his dad intravenous fluids, and why are we not taking his blood pressure anymore. I was constantly having to find ways to explain to him . . . that his father was at end-of-life.

Charlotte recalled feeling like the physician had given up. To her, it seemed the physician "was giving mixed messages to the patient and family and making it harder for the nurses to provide care." Describing the intensity of the caring that happens with palliative care, Alice used similar words:

> It's emotionally exhausting after the death happens, after you deal with it. …you're so exhausted from the day and it could have happened in the morning of your shift, and you still have eight hours of your shift left. You just keep going. That can be tough on you.

Alice concurred and drew attention to how nurses working on busy units do not have a chance to grieve and how that can contribute to the emotionality of the work. While she felt that with every experience there was an aspect of personal and professional growth, she continued,

> We take that [death] sometimes personally too. I think a lot of it touches us and we bring it home with us. We grieve it as well in a way and so I think having a chance to debrief … would be good.

Margo recalled a similar early palliative nursing experience that left her feeling and observing a range of emotions:

> I just remember my preceptor was trying to explain it to me, but it was just a lot to take in, because going into the home, there are a lot of emotions, and a lot of family, and a lot of conversations.

She looked back to how her preceptor prepared her for the visit:

> She said that this was going to be a longer visit. We are not rushing out of here. It doesn't matter what we have after … this is where we are right now. And definitely giving the family the time that they need to talk."

Initially, when Margo and her preceptor arrived, the family was eager to share how the patient had rallied after thinking he was going to die through the night. As the family asked questions, Margo observed that her preceptor's conversations with the patient and family were different from other visits. She noticed her preceptor was trying to prepare them for what was to come. The patient also appeared to be doing the same. Margo recalled how the patient was "thanking my preceptor for everything she had done for him, almost like he was saying his goodbyes, like he [knew] he was ready to go now." Despite her limited experience in palliative care, Margo had begun to get a sense of the intensity of the work. She returned to the many emotions she experienced:

> Working with the family, in such a sensitive time, it's hard to not become personally invested and very emotionally invested in it. …It's definitely hard to have separation of personal life and I guess in some ways you can't fully separate that ever, but just trying to have that barrier where you can manage your own emotions and protect yourself as well, because you need to be able to function and not be completely wrecked after a palliative visit or end-of-life visit, whatever stage they're at.

Early career nurse Nicole shared the following insight in her recollection of what it is like to be a palliative care nurse:

> Being a person. Being a human. Essentially, all of our patients pass away and that's your job. And being good at that, I think, is being in tune with your own emotions and

> checking in with yourself . . . being okay with saying, “That wasn't fun. I built this connection with this person and now they're gone.” I think it takes an emotional toll.

Nicole connected being human with what makes a good palliative care nurse, identifying this emotional work as “one of the biggest challenges for palliative care nurses.” She expanded: “You learn all of these things that make a person special or unique and their interests and you talk about those things and then the patient passes away.”

When analyzing the interview transcripts, I noticed it was only early career nurses that noted the emotional, exhausting work of palliative care. I, too, was reminded of my early experiences with caring for patients who were nearing end-of-life. Those first experiences were very emotional for me as families tried to find ways to cope with the thought of losing their loved one. I remember times when there were noticeable battles between siblings and family members as to the care and treatment expectations. As the healthcare provider in the home, they would often turn to me for help to solve their conflicts. These moments were when I first began to realize that I did not yet have all of the tools to support them during this highly charged time. I storied one particular moment that arose in my researcher journal after speaking with Margo. As Margo recounted her experience, I relived a similar memory that brought me back to a time early in my career when I had been caring for an elderly patient and her husband.

Storied Experience: Nursing as Emotional

> *One night I received the call that she was not doing well. When I arrived, her breathing was laboured, and I sensed her time was approaching. With her husband by her side, we quietly kept vigil together. Watching him see her draw her last breaths was very emotional for me. Over the months I had visited, they had shared their many years together and their love story with me. You could feel the grief he was experiencing, and I*

> *felt a deep sadness for him and all he had lost. As I got into my car after the visit, I cried for a moment. I wished I had a chance to speak with a colleague, someone, about the relationship I had with my patient and the moving experience I had the privilege to witness. In those years as a home care nurse, we did not have opportunities to talk with colleagues about the experience, to debrief the event, but I remember thinking then that it would have helped me to acknowledge my own grief. After taking those few moments, I started the car and continued with my schedule for the day, because that was what you did.*

Storying this experience, I also resonated with Kristin's description of moments like this one as "walking the emotional line." In these moments, she explained, palliative care nursing "requires not only physical resilience as related to the physical demands of the work, but also requires emotional resilience to provide care and prevent burnout."

I noticed that expert nurses spoke about palliative care as sacred while early career nurses focused on the ways in which palliative care is emotional and exhausting work. I pondered further why this might be. Early career nurses, in the beginning stages of their evolving practice and with limited experience, are learning so much. They are having to contend with the myriad of emotions that surround patients and their families at this critical stage of life and spoke of finding it to be very stressful and seen as exhausting work. I was reminded of the work from Cross (2019) that offers a possible reason. Cross's review found that end-of-life nursing interventions included ongoing symptom management where nurses witnessed their patients struggling with pain, the trauma of illness and the suffering of disease. Cross further highlighted how observing these struggles on a daily basis, while trying to focus on maximizing the quality of their patient's care, could create significant stress for nurses.

Alternatively, it was interesting that the expert nurses did not describe palliative care in the same way. Rather, as shared earlier in this section, they spoke to the sacredness of caring, seeing it as a privilege when providing this type of care. Perhaps the greater years of experience of expert nurses has allowed them time to acquire tools for their practice and associate these critical experiences with a more seasoned view; one of honour to accompany their patients during their journey and a sacredness for this work, which reflects the very essence of humanity.

For me, as I learned more about palliative care and the approach it took in providing care at this stage of life, I began to fill my toolbox with knowledge and experiences, which provided me with more comfort working in those difficult situations. I, like my participants, recognized it could be very fulfilling and privileged work and one where we could begin to make a difference in the care and journey of our patients.

Challenging Work

Despite where nurses stood on their trajectory of these first two views of palliative care nursing, sacred or exhausting and emotional, they all spoke to ways in which palliative care nursing is challenging work. Six specific areas of challenge included: (a) the training required to work in hospice and palliative care, (b) challenges of nurse-physician relationships, (c) the need for earlier palliative care diagnosis and interventions, (d) stigma surrounding death and dying, (e) the need to grieve, and (f) the unexpected (*COViD-19*). I elaborate on each challenge with examples.

Specialized Training

Expert nurse Barbara found one of the biggest challenges faced by nurses is not having enough education in palliative care. She noticed how:

> Nurses are often taking things into their own hands and are trying to carry the ball too long and do not recognize that none of us have that skill to be able to be the whole team and some are not able to recognize their weaknesses.

It was not just a matter of a single course to prepare for this specialized field. Barbara expanded:

> What they need is education, and more education, in their program. Then, when they go through their training, whatever training it is, they need more education at that level, in order to transfer the skills [in palliative care].

Another expert nurse, Shirley, concurred with Barbara's need for more education and training across degrees of experience. She knew "maybe one person who had taken some advanced palliative care education" and how "the comfort with palliative care was not there." She expressed disillusionment with some of the work she was seeing in the field and attributed it to the lack of knowledge within the nursing staff:

> When I had students in placement and a unit where there were end-of-life patients, the staff didn't know enough about pain control or symptom control and were fearful. I remember one RPN saying, and he had a student with them that day, and said "I'm not going in there. I'm not giving that person their last injection." So, then that's what the student hears and what kind of education is that? That's not very beneficial.

Shirley also felt nursing programs needed more palliative care education and learning:

> I always ask the students about their palliative care education and knowledge, and once in a while, I'll come across the student who seems to know about palliative care, but I think maybe it's because they're interested, and lot of the other ones seem to say that it was just touched upon here and there and they didn't have a specific lecture that incorporated some palliative care education. I have been teaching in clinical settings with 4th year

> nursing students for several years as a clinical educator and student knowledge generally of palliative care was minimal.

As an expert nurse consultant, Alex meets with many nurses on a regular basis providing education and support in palliative care in the community and in long term care homes. This has afforded him a broad view of the limited knowledge many nurses have as a result of inadequate education available to nurses in their nursing programs. He felt palliative care education was the starting place for nurses working in this specialty area:

> I wanted to get across how important I think it is to have that foundational palliative care education as part of our undergrad. I think it's so key, as death touches every area of nursing - why not prepare the nurses for that?

The need for more education and training to care for patients at end-of-life was supported by early career nurses. Nicole described her education in palliative care as “mostly textbook” and not being enough:

> In one first-year course, we learned about post-mortem care. I remember emailing one of my professors at the beginning of this placement to ask if she had any resources or things that she could share with me about end-of-life care and how to handle patients passing away because I felt like I didn't know enough. I felt like I wasn't prepared. I mean, there's no real way to prepare someone. The first time you see death as a nurse or as a person, it's the first time. You can do all the talking in the world but until you see it and you experience that, there's no way to make an equivalent of that experience or feeling through textbooks or through teaching ….

Charlotte also described being unprepared to provide palliative care, noting the tension she felt between learning to save people and experiencing death for the first time:

> All along in our four years we are learning how to save people …. and the mentality is save, save, save. So, the first time you come across somebody that's passing you think ‘oh my God, what do I do when they stop breathing?’ And chest compressions on what am I supposed to be doing and you go to that “save” mentality that's been a long-structured mentality in all care, in nursing, in doctors. So, you need to be able to shift your mind and help them go peacefully, help them go without pain, and help the family.

Similarly, Margo pointed to the challenge of education. She recalled not having “a great understanding of palliative care.” It was not until her final placement that she had “an opportunity to be with patients at their end-of-life.” At the same time, Margo, recognized she did not seek out learning in this area as a student:

> I didn't take any opportunities to take extra courses or extra time during clinical and now that I'm in the field I feel like . . . I should have learned more, taken more opportunities but maybe it should be part of the base course structure, the education. …It [palliative care] is something that we touched on briefly and then we moved on because you have to squeeze everything into your 6-weeks . . .

This idea of palliative care as just being “touched upon” was noted by both expert and palliative care nurses, indicating the need for more.

Kristin similarly noted “a gap in the education part . . . with our training” in relation to palliative care. She observed this was more a case of avoidance rather than absence:

> It’s funny though because when you look at the description of inpatient medicine or inpatient surgery, it does describe palliative care and it should be there. …[educators] really don’t emphasize that . . . I didn’t think that I would see it [palliative care] and so I didn’t pursue further education for palliative care upon graduation.

Describing her final preceptorship, early career nurse Margo also mentioned avoidance on the part of practicing nurses:

> . . . it seems like a lot of nurses shy away from palliative care but maybe that's because they don't feel like they're well equipped for it. If you're working in certain hospital units or just certain areas, you just don't see palliative care so maybe a lot of people still feel it's not relevant to them based on where they want to work.

Kristin identified specialized knowledge as a challenge for physicians too. She explained: “Physicians' lack of knowledge is a barrier because it creates barriers for us to have to go through to get our patient the appropriate care, which in this case would be palliative care.” I return to this aspect of knowledge in relation to physicians in the next two sections.

Researcher Reflection

It stood out to me how Nicole, Sparrow, Kristin, Charlotte and Margo, all recent graduates, were quite vocal about their experience with training in palliative care and expressed discomfort with their first forays into caring for patients at end-of-life. Their lack of preparedness seemed paramount for them, and the void of palliative care education was glaring. This need for training resonated in the experiences of the expert nurses working in palliative care. Barbara, Shirley and Alex all recalled that too often working with nurses who do not have enough knowledge about palliative care, are not able to recognize their deficiencies in knowledge and generally are not comfortable in its delivery. This is supported in nursing literature, which I will expand upon in Chapter Eight.

Nurse Physician Relationships

Both expert nurses with their significant experiences, and early career nurses new to the profession, spoke to the challenge of working with physicians. Expert nurse Rose has felt and “observed the struggle that a lot of nurses have in addressing inequities in care to physicians. At times, she has felt “almost muzzled [by physicians] from asking questions.” She explained:

> . . . because the doctor knows best and there's this mentality, even in hospice palliative care. I find sometimes physicians are like “nope, I know.” And I'm like “but can you help me understand why you would choose that? Just help me to understand what your rationale is. Maybe you know about research that I don't have access to, so please help me understand’. . .

Rose found she sometimes needed to “pander to” physicians for help to understand. Rose has learned to seek out alternative ways to communicate with physicians, taking caution to not tell physicians what to do:

> . . . my response is always “the patient may benefit from” or “the resident may benefit from,” can we try it, assess it, evaluate it, and then see if it's working. If it's effective, perfect, then we can continue. If it's not effective then we need to reassess, and we need to come up with a different plan.

Expert nurse Diana spoke to a similar power imbalance when working with some physicians. She shared the example of prescriptions as “a piece of the power that doesn’t allow you to do your job.” She recalled a physician asking her to see a patient but:

> . . . wouldn't believe the patient was in as much pain as the patient said he was. I feel totally helpless because I'm not a nurse practitioner, I'm a palliative care consultant. I can't write prescriptions . . ..

Diana wondered if it was “respect or credibility” that led to this power imbalance. Regardless, she found “the patient suffers.” For her, this is what makes the nurse-physician relationship “the biggest piece that can be a challenge.”

Early career nurse Charlotte, who works on both a medical floor and a palliative care unit, offered another possible reason. She noticed that some physicians see the diagnosis of needing palliative care as giving up on them. She explained:

> I enjoy working on the medical side but there are times when the patient just needs palliative care. They need that extra touch, that extra one-on-one time. When they move over to the palliative side, they're able to have more visitors which is especially important. The visiting hours don't apply to them. …[it's] more of a peaceful environment, it's a nicer way to go . . .

Charlotte expanded on sometimes needing to justify these benefits to physicians:

> I find that some doctors, we sort of have to push against so that [patients] can have that. Because it's a benefit to them and I think that some doctors still feel like they're giving up when they declare a patient to be palliative. But really, it's just the next phase of care. It's not a defeat.

This idea of pushing against physicians' viewing palliative care as a defeat suggests that palliative care nursing requires a strong advocacy voice, even with physicians, to ensure patients and families receive the care needed at end-of-life. Like expert nurse Rose, Charlotte found strategies, such as "sending messages and writing communication notes" helpful to try and champion for patients to be diagnosed as needing palliative care. Expert nurse Gladys has heard many professional staff rely on years of experience to equate to knowing their job well. …She has observed "physicians who call themselves the palliative care team and yet, they only take care of people when they have only weeks or days to live" and wishes they wouldn't call themselves in this way. She went as far as to say, "The physicians working in long-term care don't understand how to support people dying . . ..” Gladys connected the frustration shared by nurses to the ways that healthcare is still dominated by a medical model of care:

> Patients are often diagnosed as needing palliative care too late. I feel protective, I still feel very frustrated at the lack of education, the lack of consistency, the lack of skill, the lack of the holistic philosophy of palliative care. It's still not truly being person-centered, there’s still a highly medical model there.

Gladys added, “I think we've come a long way with advanced care planning and speaking up and starting conversations but it's still not where I would like to be.” Gladys’ concerns tie in the previous barrier of specialized training, showing how these barriers are not isolated from one another. When discussing the sacred work of palliative care nurses, Rose also aligned palliative care education with the essence of person-centered care, a model designed to improve individual outcomes and as a result of patients being more involved in their own care (Registered Nurses Association of Ontario [RNAO], 2015).

Researcher Reflection

As I listened to the participants’ stories of their challenges working with physicians, I recalled similar struggles in my researcher journal. Following Charlotte’s interview, I wrote:

> *I remember a time working with a physician during a home visit. He was very patient focused. I was surprised at first how he sat down with the family on the couch and took the time to be present with them. I remember him speaking quietly and in a reassuring voice, with words of comfort and support. This had not been my experience with physicians making home visits. They were often rushed and only dealing with symptom management issues. I remembered thinking at the time that this was a good example of*

> *real caring for not only the patient but also the family and what I thought palliative care should look like. [Researcher Journal]*

I have seen the integral role physicians play in palliative care. Participants' descriptions of their experiences included interactions with physicians whose focus appeared to be on managing care using the medical model approach and curative measures. Yet, my entry reminds me of the ways in which a palliative approach is more holistic, focusing on more than pain and symptom needs, to include the psychosocial needs of the patient and family. Without this approach, a delay in timely diagnosis may lead to care needs not being met. This concept of the need for early diagnosis and intervention is expanded upon in the next section.

Early Palliative Care Intervention

Participants recalled from their experiences that palliative care is not initiated soon enough in their patients' care journey. Rose suggested, "Long-term care facilities think they do palliative care well. Hospitals think they do it well, but the reality is that they don't." Expert nurse Gladys offered that, "Early intervention or early introduction of when somebody is diagnosed with a progressive life-limiting illness is when palliative care should be introduced." Part of this early intervention involves asking "What's important to you now?" in comparison to "These are the treatment options." For Gladys, this involved a change in philosophy that is fitting of the holistic model she mentioned when speaking to the barrier of the nurse-physician relationship.

Gladys described the delivery of palliative care as being inconsistent for many patients. She explained:

> I would like to see it early on. I would like to see it throughout their care. I would like to see it more resourced. Palliative care is not looked to as a specialty. I think we're still

> fighting to be seen . . . I would like to see it as a specialty but also incorporated throughout as it's everyone's business. The inconsistency really creates so many challenges, so it's not resourced, and the education isn't seen as valuable. You know if you're doing the work and you've seen people die. But it's more than that, there's more depth to it.

Gladys raised important points about palliative care being under-resourced and not recognized as a specialized area of care for those nearing end-of-life.

Early career nurse Charlotte noticed a similar concern about timing when diagnosing palliative care. While she speaks to the recurring message around the physician role mentioned in the previous section, here the emphasis is on the ways doctors can support the need for earlier intervention. Comparing two examples with different families, she recalled a clear distinction in the physicians' approaches. In the first example, the doctor did not like to promote palliative care, and this led to sending mixed messages to families - messages she felt were "confusing for the family and making it worse for them." The second physician, on the other hand, was "supportive and clear with family members about the diagnosis and how palliative care could support the patient's quality of life. This doctor was more knowledgeable in palliative care." Pondering these examples, Charlotte viewed palliative care as more than a simple equation:

> It's more personable care. It's more driven around what that patient needs. So, I guess you could say next level care or more personable care, something like that. Because it's not just "so if your hemoglobin is this, we're going to do this." It's not X plus Y equals this. It is more than that.

Early career nurse Nicole agreed that sometimes the human part of caring is overlooked, especially when nurses are busy. She finds "just about every shift now there is someone crossing the line." She described having limited time to spend with patients and some of the challenges this brings: "

> . . . I always try to focus on that [patients' end-of-life nearing] even though they're heavily sedated and unresponsive. …it's so easy to not tell them that you're washing their face and it's so easy to not tell them that well, "I'm going to move you up in the bed now." On the other hand, for the patients that are still awake, and the goal is to transfer them down to the palliative floor, it's an interesting feeling talking to them, because they know, and I know what is happening.

More than this, however, are the things that go unsaid with these patients who know death is approaching:

> It's like a big elephant in the room but you don't talk about it. I would never go, at this point, and ask them how they're feeling about dying even though I know that they probably do have a lot of thoughts. I think it'd be better for an expert or someone who's more versed in it to talk about it, but I haven't seen that. Someone asking and talking to the person themselves about their thoughts and feelings about it [dying].

Nicole felt that understanding patients' thoughts and feelings "would drastically change and improve the way we care for them at the end-of-life." She included that if earlier palliative care was provided, patients would have access to an expert to support these necessary conversations.

As I reflected on these narratives from nurses working in the trenches of palliative care, I was surprised to learn that based on their experiences, many patients are still not being diagnosed early enough in their life-limiting illness journey to truly receive the care and attention that they need. It was this way when I was nursing too and, I had hoped it had changed with time. I thought back to what was unspoken.

Storied Experience: The Unspoken

> *In my early days of providing palliative care, I remember being asked questions from my patients and their family members that I could not answer, partially because as nurses we were told that it was the doctor's job to discuss the seriousness of the illness and the patients' plans for advanced directives, and partially because I was not trained in how to have these conversations, how I could be supportive and what patients were needing to hear. I remember too many of my patients at this time still had not had an official diagnosis from their doctor about their condition being terminal. Many things were left unspoken, and patients would be left feeling unsure of the future with pain and symptom management the only focus.*

Within my own experiences of caring at end-of-life, I felt that discussions about palliative care were most often arriving late in my patients' illness trajectory, and a recurring message from participants in this study. It was not until I was working as a palliative care consultant in mid-career that I found some relief. It came in the form of a simple test developed by Dr. Joanne Lynn in 2005 that helped to identify those patients who might benefit from earlier access to hospice and palliative care. Downar et al. (2017) found that physicians who delay making a prognosis for end-of-life care were seen as being a barrier to patient access to palliative care services. The simple test asked physicians to reflect on the surprise question "Would I be surprised if this patient were to die within the next 12 months?" (Lynn, 2005). Since its inception, this test has gained support as a simple, practical way of identifying patients at high risk of dying and continues to be adopted into frameworks for assessing hospice and palliative care needs (Downar et al., 2017).

According to Murray et al. (2017), palliative care is associated with terminal cancer, and is often delayed until the last weeks or days of life when disease focused treatments are no longer effective. These researchers described the initiation of palliative care late in the treatment process as a missed opportunity for patients and families to receive this much needed service. Late initiation of palliative care services is in keeping with the ongoing use of the medical model of care where the focus is on curative treatments and for prolonged periods. Some physicians see end-of-life care, supportive care, and palliative care as what is prescribed when there is nothing further that can be done for their patients. Reed and Watson (1994) first looked at the impact the medical model had on nursing practice and found that it offered a narrow focus of health care. Their study found that while the medical model at times showed some compatibility with nursing values, it had little to offer practice and may have a negative effect on humanistic nursing approaches to care.

The test question remains a key tool used by physicians to determine the most appropriate time to initiate palliative care (Canadian Institute for Health Information, 2018). Yet, my participants' experiences suggest incorporating this test into the assessment process may not be utilized as significantly as was intended. Despite the question being developed and introduced by physicians for physicians, according to the experience of both the participants and my own experiences, the test does not appear to have resulted in earlier conversations with patients and families or earlier diagnosis and interventions. I have found that while answering the question provides the initiation of the conversation, the medical community continues to struggle with how and when to discuss care options. Unfortunately, this diminishes the time period for patients and families to access palliative care and participate in their end-of-life plans.

Stigma of Death and Dying

Another challenge that participants described was the stigma surrounding death and dying. Participants spoke about how death and dying is often a difficult subject to discuss openly with loved ones and even with some professional staff. Expert nurse Diana described the stigma of death for her patients and the need to navigate hard conversations to overcome this challenge. These hard conversations are like “the elephant in the room” that Nicole mentioned in the previous section in relation to the need for earlier palliative care intervention. Diana saw these conversations as ones “That takes time. It takes maturity, it takes insight, it takes personal security. If you’re insecure, you're not going to necessarily be able to say, ‘I don't know.’” Diana wanted to approach a patient’s fear by taking “baby steps” together. Diana’s solution was to reframe her attitude: “I think it's how you face the challenges and how you park your ego and use your knowledge and skills.” Rose concurred that reframing our attitudes around end-of-life and death was needed and stressed, “I do this every single day and death is not a failure, and we need to hear that voice.”

Revisiting her earlier comparison between doctors, early career nurse Charlotte observed how the doctor who was well trained in palliative care stood out. She hoped other doctors noticed in her work, “the acceptability of being able to let someone go” rather than being “concerned about prescribing opioids.” She added, “They really just don't have a handle on it unless you're experienced in palliative care.”

In community nursing, expert nurse Alex also described nurses he was working with as being fearful of death and how to manage end-of-life care. He explained: “I think there's still so much fear and stigma among a lot of nurses and that they are scared to be there at end-of-life…” As an expert nurse consultant Alex meets with many nurses on a regular basis providing education and support in palliative care in the community and in long term care homes. This has afforded him a broad view of the limited knowledge many nurses have as a result of inadequate education available to nurses in their nursing programs. Alex recalled a change in visiting nurses who had been providing active/aggressive treatments:

> The moment they turned to palliative care, the nurse didn't want to provide that care and would kind of trade them off to me who did the palliative care. It was such a disservice because that nurse got to know that client for maybe a year and they have that relationship and then because they didn't feel comfortable even wanting to go anywhere near it [palliative care], they literally just sacrificed that connection and the result the patient was having to make a new connection with a nurse.

Looking towards a solution, Alex proposed greater exposure to palliative care during undergraduate courses, a familiar message that has been shared across barriers. He expressed, "... I hope that someday it is more a part of the foundational education so people can feel more comfortable with it and erase some more of the stigma. Then we will be able to provide better hospice palliative care." As expert nurses, both Alex and Diana recognized the need to advocate for more educational experiences in their education programs in order to develop their knowledge and skills and better prepare them for these difficult conversations and challenges found in palliative care delivery.

The stigma around death and dying was noticeable in early career nurse Sparrow's limited experience with death as a nursing student. She recalled that the opportunity to experience death was minimal, and almost hidden, during her practicum. She did not understand why but pondered several possible reasons:

> I was thinking about my clinical placements, where death in the sense was pretty much hidden from us. Every time, it seemed, and it's just occurring to me now, but every time someone was dying or just about to die, we were pretty much ushered away from that area. It was like they were protecting us from it. I don't know if that's the hospital regulations or what they were asking for, privacy or something, but that's constantly what it was. We were not there when the person was dying. But my patient did die. In this case, we did her post-care, after she had died. But that was the first time I've ever seen a clinical instructor involve us in that area.

Nicole found it odd to be in healthcare and "not talk about death." She explained:

> I think that's a little odd. Because then you're purposely being, not ignorant, but to an extent thinking none of my patients are going to die, that everyone's going to live, it's going to be unicorns and rainbows when in reality that's not the case.

Nicole acknowledged that in practice, sometimes nurses "have our hands tied a bit in terms of what we are and aren't allowed to say to the families, where our jurisdiction overlaps with what the families should and shouldn't know." She expressed difficulty in having conversations with family about death and dying in these cases, wondering what she could and could not say. She saw physicians being the ones "that can open that conversation up around end-of-life . . .about final wishes and where we want to take the course of treatment." The challenge of the nurse-physician relationship appeared directly related to this challenge of stigma.

Early career nurse Alice raised similar concerns and thought it was important "we realize that death is a normal process." Alice continued:

> I think that's also an important part of nursing and every nurse should experience it [death], as tough as it can be. I think it opens our eyes to caring for these individuals and

> enhancing their quality of life before death. …it has opened my eyes. I try to think of it as, “This is the best for the patient, under the circumstances” and obviously it's going to be hard on the family. But the patient may have been suffering for a long period and now this care is giving them some relief and us taking care of them with certain medication protocols or even being there to reposition them, makes such a difference.

While it is expected that expert nurses with extended experience in caring for individuals at end-of-life would have this understanding of normalizing death, Alice’s early understanding of this concept set her apart from other early career nurses and was foundational to her understanding of a specialized care approach for her patients.

Nicole’s sharing of her experiences reminded me of a similar tension I experienced. The patient, a mom, had presented to the hospital a couple days earlier. The report indicated she had metastatic cancer with days to live but the family members did not want their mom to know that she was dying. I storied this moment, still recalling the unfolding of that day.

Storied Experience: The Stigma of Death and Dying

> *During morning care, I could see that she was in considerable discomfort and planned to see if pain medication had been prescribed. Before I left her room, I asked her if she had seen her doctor recently and if she had any questions about her illness. She shook her head and looked at me with fear in her eyes. She said that any information must first be given to her through her husband, who would then decide if there was something she should know. Respectfully, I left her room to inquire about analgesia for her pain and found her husband standing in the hallway with their two grown sons. I let him know how she was doing that morning and asked if his wife knew of her diagnosis. He said no and that I was not to tell her. He advised me that she did not need to know anything about her*

> *diagnosis or prognosis or anything about her illness and that he would answer any questions she had.*

I understood the husband viewed himself as the family leader but as an early advocate for patient-informed care and consent to treatment, I was shocked at his response and at first, did not know how to handle it:

> *I returned to the nursing station and must have looked pale because one of the other unit nurses asked what was wrong. I told her the conversation I had with the husband, and she reported that the doctor was advised by the husband that no communication was to go to the patient - only to him. I remember thinking that here was this patient who was being denied the opportunity to understand what was happening to her and to realize these last days of her journey in her own way. What if she had people she needed to reach out to? What if she had unfinished business to attend to? What kind of family would deny their loved one this opportunity to share her fears or experience with them? In those early days, I had so many questions and was still learning how to manage my own values and beliefs and how best to support my patients with theirs. It was an early realization for me of the power the words "death and dying" had in our ability to provide care.*

The experiences shared above, both past (my own) and present (those of my participants), speak to the taboo that still exists when caring for patients at end-of-life. Participants, both expert and early career, discovered that they had to navigate the conversations with knowledge and understanding of the situation and more importantly learned to read their patients and family members' needs based on time spent together. These nurses needed to decipher family values and expectations and appropriately respond to questions at a moment's notice.

Management of Grief

Another significant challenge described by the participants was the need for nurses to be able to grieve the loss of their patients. As a number of participants previously described, experiencing the death of a patient and the emotional charges that come during the finality of this life experience can leave nurses feeling overwhelmed with emotions while trying to remain professional and supportive to family and significant others. For expert nurse Rose, grief was intricately tied to supporting healthcare workers to provide excellent care:

> . . . part of really excellent palliative care is making sure that your staff are capable and supported in their own grief. And I think that's one of the big pieces that they missed was, “How do we support healthcare providers in providing palliative care?” They don't have the skill set already and now they have to deal with the ramifications of that complex compounded cumulative grief. And we're giving them no resources.

Rose acknowledged support was available through employee assistance programs (EAP) but emphasized this “is not sufficient. I think it's actually disrespectful to say to someone “Oh, just check on your EAP.”

Rose pondered further the importance of this psychosocial aspect:

> Anticipatory grief is so important, and we so often just miss it. And there's no grief support or grief groups for healthcare providers and I find that challenging. I've been working with a lot of my long-term care homes to try and get them to put together a grief group for providers so that way they can talk and say, “Joe Blow was a bit of a bastard, but we really miss him!”

Expert nurse Gladys also felt this same lack of support that Rose described. She shared an overwhelming experience with the loss of a child patient:

> We [Gladys and the nurse] went in after he had died and she [the nurse] was very methodical and task-oriented and that bothered me, and I remembered thinking this isn't the way it's supposed to be …. I remember standing and filling up the water and waiting to see if the water was warm and all of a sudden I felt this wave of grief, and I felt, thought, *no I can't do this. This isn't a safe place. She's not a safe preceptor. I can't be emotional*. And I just dropped the bowl and started to weep because I thought in my head, it doesn't matter if the water is warm or cold and he's a child. I remember being so taken aback by this. The water could be cold, and it doesn't matter because he's dead. And then there was this dialogue – *no, it does matter, it does matter that the water is warm.*

Unprepared for this grief, Gladys recalled how her preceptor's response did not offer space for her own grief: "You know, this isn't your grief. This isn't your journey. This isn't your grief. This belongs to this family, and we have a job to do." Gladys remembered thinking, "that's not true, but I'll figure that out later."

Despite the challenges of patient loss, early career nurse Alice expressed gratitude for her experiences:

> Well, I think palliative care is such a special type of nursing. I feel very grateful to have had the chance as such a young nurse to experience palliative patients. …sometimes, I don't have a chance to take it all in properly, but I do think I've had great experiences with the patients and family members, some harder than other.

At the same time, Alice similarly spoke to a need to debrief and grieve due to these relationships that formed with palliative patients. She explained:

> … I think a lot of it touches us in our personal lives because we do bring some of it home with us when we can't fully grieve it or debrief it, but I do think being able to work with

> palliative patients has really helped me with my career and I'm happy to be dealing with it as a new nurse.

Gratitude and grief had the potential to exist together for Alice when experiencing the death of a patient.

Listening to my participants describe their experiences with grief while caring for their patients reminded me of my early days working in palliative care. One moment stood out in my journal and I took time to story this experience.

Storied Experience: Unprepared for Grief

> *It was the third day of a three-day shift during my consolidation. One of the patients I was assigned to had been admitted for symptom management for cancer pain. I had started to get to know her a bit. This morning's report indicated her pain was starting to get under control unlike the previous days where she had been struggling with her breathing. However, her pain was increasing again today. I provided her early morning care and when I left, she was resting with her husband by her side. While helping another patient, I heard the call bell ringing. It was my morning patient's room. I arrived at her door and found my patient's husband leaning over her stating something was wrong. She was not responding to him and her colour was ashen. He was in distress. I called for my preceptor who came running to help and together we determined that the patient had passed away. Even though the doctor had written a Do Not Resuscitate order on her chart, I was not prepared for her imminent death, or the look of anguish I saw on her husband's face. I was also not prepared for the grief I would feel at her loss. Even though she had terminal cancer and was nearing end-of-life, I was just not prepared. I remember*

> *thinking I could not offer any comfort to her husband. I felt numb and started to cry. Was this what death was going to look like? Is this what I was to expect as a nurse?*

Working with a seasoned nurse I recalled a statement she made that stayed with me all these years. It goes like this:

> *During our lifetime, most people experience a loss on average about 6-7 times. Not everyone that many and some maybe more. But nurses, they experience loss about 6-7 times per year. For palliative care nurses, it can be as many as 6-7 times per month. And we grieve each one of those in some way. [Researcher Journal]*

At the time, I did not know how true this statement was or was not. However, I thought of it each time I experienced the loss of one of my patients, especially as a palliative care nurse, and she was not wrong.

Looking back to the recollections of my participants, it was evident that as nurses (myself included), we developed relationships with our patients and patients' families. Intimate moments were spent together with them, sometimes learning some of their most personal beliefs, values, memories, and ideals. These relationships can extend over time and often a natural desire to care for them occurs. When a patient dies and the relationship ends, the caring does not stop. It takes time to loosen its grip on the emotions and the memories of their time with us. Afterall, did we not get into this profession because we wanted to care? Taking some time to acknowledge the period spent together and the interactions shared in those intimate moments speaks to the grieving time needed in our profession. It helped me to see the value I could bring to palliative care nursing and the support I needed to be able to provide for my patients and their families at end-of-life.

The Unexpected (*COViD-19*)

As mentioned in Chapter Three, my study took place during the first year of the COVID-19 pandemic. For this reason, I spoke with participants about the influence of the pandemic on their work as palliative care nurses. The rapid spread of the COVID-19 virus left participants worried about their own safety while trying to care for their patients. Participants spoke to the impact of the pandemic on relationships with patients, the importance of communication, and the tremendous impact on families during the final days of their patient's lives. While these points have also been made in other sections of this chapter, they take on a different sense of need and urgency here.

What stood out first was how the pandemic hindered participants' goals to develop relationships with patients. Gladys described a moment during the early infectious period for health care workers where they had to learn to work closely with full personal protective equipment (PPE):

> Before the pandemic, I remember a time when nurses and doctors wouldn't even do up the back tie of their gowns. They were just hanging off and sloppy in their care. I remember thinking that it showed patients that you don't value your care for them and showed that your uniform and what is supposed to protect you *and me* isn't important enough to do up.

Instead, Gladys felt, "Those are important little things. Actually, [my] gowning and masking is showing you that I really care for you and I'm going to sit in it even if it is uncomfortable." She remembered staying in one patient's room for an extended period of time:

> . . . and she finally looked at me and said, "Aren't you really hot in that mask?" I answered, "I actually didn't even notice it anymore because I just love being here with

> you and this is secondary and no, I hadn't really thought about it." I didn't acknowledge that I've been wearing this mask for an hour and a half and that's a long time in a negative pressure room where you can't touch or move or anything.

Gladys recalled an experience shared with a social worker colleague who was also trained as a death doula:

> . . . it took her three hours to finally not be afraid of being with her dying patient who had COViD even with her gloves, gown, and facial mask. …with every touch she would think, "Oh my gosh. Is this enough, am I protected enough, are my gloves on, right?" . . .

As Gladys continued, she linked the earlier barrier of grief to this story:

> For me, this was an example of how we can still give so much behind the barriers we have. If we perceive them as barriers and treat them as barriers, they will be barriers. But if we work to overcome them, I think that can be seen and heard and felt from the patient and family.

Full protective equipment created additional barriers for nurses when providing palliative care during the pandemic as Gladys further explained:

> . . . like wearing gloves that can impact the human touch. It really does. Would you want a facial with someone who's wearing gloves on your face? But there are ways around that. For example, saying, "I wish that I could touch my hand to your face" or "I wish this were different," not "I need to hurry up and get out of here." Also being aware of the communication with our eyes and what they do and even our forehead and how much we're speaking with our nonverbal messaging.

The compassion and insight that Gladys shared reminded me of my own feelings about how human touch impacted my patients. Holding their hand is such a simple gesture and yet a powerful one of being present with our patients and communicating without words that we are there for them and value their journey. McPherson and White (2017) explored the use of touch by nurses in palliative care, offering reflective questions for nurses to explore personal and professional boundaries, and cultivate awareness within this practice.

Communication was another area that stood out in participants' responses around the pandemic. Expert nurse Barbara recalled how COViD-19 resulted in a progressive nursing shortage as nurses became ill and units became increasingly short-staffed. This shortage challenged not only the healthcare system's ability to deliver care, but also to care for one another as nurses. Barbara explained:

> I think it's changed how we communicate with each other. We focus on the importance now much more about relationship building with patients, and how to manage the shortage of staff. …The pandemic changed everybody. It's also changed our awareness of washing our hands. …I think it's changed us in terms of caring. We care now for each other in a different way too. When we have our staff meeting once a week, everybody gets so excited to see everybody, it's incredible.

Taking a different perspective, expert nurse Rose expressed disappointment that palliative care and individuals dying from terminal illness were not more highlighted by palliative care service providers during the pandemic period:

> . . . I really wondered where our voice was. And even still, when I look at the essential services that are outlined by Ontario, I think that it's dismissive of the fact that hospices are considered an essential service. And I think that actually speaks volumes to the fact that we have lots of work to do in palliative care. During the COViD-19 pandemic, we

> haven't been hearing from nurses because many felt muzzled and not allowed to speak the way physicians are. …

Diana agreed that nurses missed an opportunity to talk about the value palliative care brings to end-of-life during the pandemic. She shared how the pandemic has highlighted death for many, yet lacked the messaging about the work in palliative care that nurses do:

> There's a lot of fear of death and understandably. I'm afraid too. …I see the media showing nurses lamenting because they had to use an iPad to help the family say goodbye and the nurse has to hold the patient's hand and how sad for the family, how sad for the nurse, how sad for the patient. But I don't hear the other part of it that the patient died peacefully despite not having the family at the bedside. The person died with dignity. They died with peace.

Diana wanted to see "palliative care players uniting with a message to the media or to the government to say, "what we do is important and here's how we can give dignity to people even in their last moments, even when they're dying of something as awful as COViD."

We heard from Gladys how patient relationships were impacted in the care delivery and from Barbara, Rose, and Diana about how communication plays a key role in understanding palliative care, especially in times of extreme crisis. This time was very difficult for palliative care nurses to experience and will likely go down in history as one of the most traumatic times for healthcare workers and the Ontario (and global) healthcare system.

The impact on families was threaded through discussions around the pandemic. Several of the early career nurse participants, including Nicole, were front line workers during this period. Nicole described her acute care experience at this time:

> I think COViD has been awful. You see the hospital restrictions on visitors and right now, in the cardiac care unit (CCU), you can only visit one person and it's a two-hour window in the morning and a 2-hour window in the afternoon and there's many hospitals that don't even do that now. Where if you have a patient who is palliative, they're just not allowing visitors and that really, I think, diminishes the quality and the value in those last days.

She went on to describe how receiving palliative care at home was also impacted:

> Imagine if you are receiving palliative care at home during this pandemic and scared of letting the caregiver in the house because you know that person has gone from this house to that house. Perhaps they went grocery shopping, and you are trying to protect your loved one while trying to stay in your bubble and worried that they could bring something in. [It] is very unsettling.

Sparrow concurred more access to families was needed:

> Nobody wants to die alone. My biggest fear, it's probably the same as everyone else, is to be unloved and to be left behind or alone because we were not made to be creatures to live by yourself, not to interact with others. We are stronger together than we are apart, and covid-19 has separated us from our support systems.

Alice similarly described the pandemic as taking nursing time away from not just their patients but their families members too:

> Gowning up [fully using a gown], a mask and a face shield, that in itself is time-consuming to get dressed up in your gear to go into a room. I feel like for those palliative patients, their time alone can be very socially isolating, and they were passing away without family. Eventually we started letting in family members for palliative patients,

> but I think socially it makes you kind of upset because they're in there by themselves and you try to do the best you can to get into the room but it's more of a process to gear up and gown up and it's quite socially isolating.

Charlotte agreed that the experiences through COViD-19 were hard to watch:

> There were people that were dying alone and even when they weren't named palliative, you were only allowed one visitor and it was not one at a time but one consistent visitor so once [a patient's] wife was allowed in, he couldn't have his kids. Somebody that didn't have a spouse, they had to choose one of their children and they're not in a capacity to make that decision, so it was a huge impact, and it was painful.

Similar to the early career nurses, the expert nurses also saw the heartbreak and sadness that that pandemic brought to their work areas. Patients were unable to have their family members close. Family members could not be with and bring comfort to their loved ones, nor could the staff be working and watching all of these interactions in palliative care units.

However, some expert nurses also saw a renewed opportunity to learn from this global experience. Expert nurse Diana suggested the restrictions of the pandemic might challenge nurses to see how they can provide alternative support and care:

> COViD-19 has impacted the people who practice palliative care. First, it's forced us to think about how to manage the end stage of life. Another is it's forced us to look at virtual care because you can't really provide care if you're not allowed to go into a facility. It's forced us to be innovative in that I am now providing frameworks for people in long term care homes to assess people and then they're phoning me and we're talking about it. It's forcing the staff to learn more about palliative care and to actually go to the bedside and do the assessment where they wouldn't have had to do before because I did it.

What Diana did not see that worried her was “the impact on society . . .” It did not appear to her that the pandemic was leading to a greater “valuing or appreciating or understanding the importance of palliative care.” Expert nurse Shirley, who works as a palliative pain and symptom management consultant, was optimistic, however, that the pandemic could impact how palliative care is considered and delivered in the future:

> I think that palliative care and end-of-life care might become a little bit more normalized. There are some discussions happening now that wouldn't have happened otherwise like end-of-life decisions and thinking about end-of-life decisions. I think with social media outlets asking, 'are you talking to your loved ones about your wishes and advanced care planning’? … we've had interactions with community agencies who normally would have shipped their patients off to hospitals who are now taking care of people nearing end-of-life. So maybe an expanded role for caregivers in different settings and in retirement homes as well, is in the future. We know retirement homes are seeking more palliative care education because they have people who normally would have been transferred out to hospital or had the community nurses coming in to provide care.

As Shirley and others point out, the pandemic brought a heightened awareness of death that has been unprecedented in recent history (Public Health Ontario, 2022).

Researcher Reflections

Looking back to the height of the COViD-19 pandemic, I recall many news reports of how family members were restricted from seeing their loved ones, not only those who were in acute crisis but also patients who were nearing end-of-life. I learned from these reports that nurses experienced significant patient losses and that many were unprepared to deal with the magnitude of caring for those dying and death. Practicing palliative care during the time of

COViD-19 was stressful and chaotic. As participants shared, they had little time to provide anything that could closely resemble a palliative approach to care and quality of life until the patient's natural death. In the community setting, many family members were forced to be sole caregivers and received little support due to staffing shortages. In long term care homes, many end-of-life patients who did not contract COViD-19 suffered because of protocols and restrictions placed on care facilities and their workers.

While some participants felt that the voices of palliative care nurses were dimmed during this time, I reflected on how their participation in this research offered a space to have their voices heard. I learned from my participants that while the pandemic was a tragedy of epic proportions, and even a mass casualty event as suggested by Arya et al., (2020), there were some lessons learned and opportunities for enhanced palliative care delivery in nursing. These lessons included capacity building through virtual support and guidance for nurses at the bedside, as well as a heightened understanding of death and dying in our society. Both expert and early career nurses highlighted the importance of that critical time in the last weeks and days of life and how palliative care nursing can impact the quality and level of care received by patients and their families.

Visualizing the Journey of Palliative Care Nurses

The narrative experiences shared by my participants in this chapter offered the opportunity to further my understanding, and those of others in healthcare, of palliative care nursing experiences. In my research journal, I found myself returning to the visual of a journey, which I expand in this section. This journey encompasses the three key views presented in this chapter (sacred, emotional, challenging) that contributed to the overall journey of palliative care nurses. I began to sketch graphically what this journey looked like across participants to visually represent the phenomenon of palliative care nursing. I then worked with a graphic designer to bring this visual to life.

Figure 5.1 presents the visual depiction of the palliative care nursing journey as experienced by the nurses in this study. It is a road that is filled with moments that impact nurses' ability to provide optimum care in a time in individuals' lives when they are most vulnerable and count on our support. It also illustrates how over time and context, what it means to do palliative care work and how it moves along a continuum.

Explaining the Visual

The road a nurse travels with her patient (and the patient's family), as they journey towards end-of-life, has many winding turns and dips, some are gentler than others, while some have significant impacts on the care delivery. Earlier in this chapter, the trajectory of the nursing experience in palliative care is described by early career nurses as hard, and often emotional and exhausting work. In this specialty field, there is a lot for nurses to know, to feel, and to learn in order to become competent and confident to perform their duties.

All nurses who provide palliative care travel this road though the details of their journey may differ. Significant trials to provide optimum care are experienced along the way. As the journey for nurses begins, they learn early on that specialized training is required to be able to meet their patient and families' needs. At the same time nurses are also challenged in their relationships with physicians. With increased knowledge and training in this specialty, nurses advocate strongly for their patients for increased services and more specialized care. Often, they experience resistance to their advocacy as many physicians are not trained in hospice and palliative care and are reluctant to initiate early diagnosis and intervention strategies for palliative care measures. Conversations about end-of-life matters are often difficult for physicians to engage with patients and families. Our healthcare system's focus toward disease is primarily on curative measures and many see impending death as a failure. Advocacy for early

Figure 5.1 *The Journey of Palliative Care Nurses*

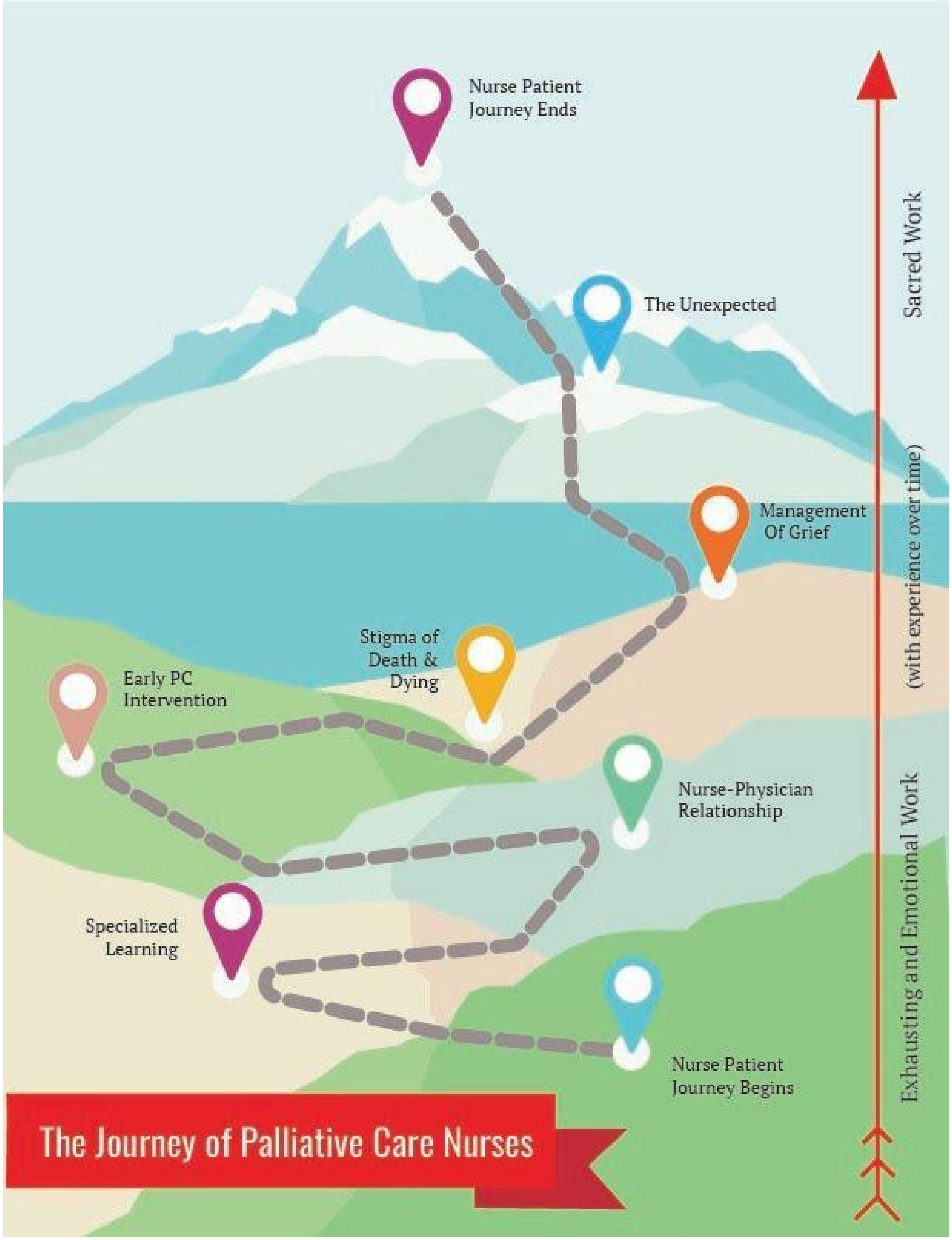

Image conceptualized by author and designed by Maddison Norman (2022) intervention for palliative care services brings much needed resources sooner to the care journey and enhances patients' quality of life for the duration of their journey.

Another challenge experienced by nurses in this study is the general stigma associated with death and dying. Not only physicians but nurses are also challenged to explore end-of-life discussions with their patients and family members. Sometimes patients and families are not ready to accept that curative measures are no longer working to restore health and require time and support to understand that palliative care can offer much needed assistance for their care needs and enhance and support more optimum care during this life period.

Another challenge in the journey is that of real or impending grief and bereavement experienced by both the patient and family members as well as the nurse. As diagnosis for supportive care presents, patients and their family members come to the realization that their life journey is ending. Patients and their family members often experience anticipatory grief of their impending loss. Nurses engage with patients in their grief experience and continue to help their patients find ways to bring meaning and legacy to their lives. Further, this is a delicate period of time for nurses as they also experience grief as the nurse-patient relationship ends. For nurses, this is a time of intense reflections of their practice, determining what mattered, what went well, what could have been improved, and find that they have a need for their own grief to be expressed and shared. For nurses, this can happen with each patient experience or over an accumulation of experiences with caring for individuals at end-of-life.

Sometimes the journey does not end here. There is also the possibility of the unexpected that may happen for patients and their families during their end-of-life period. These unexpected events could include other illnesses or family tragedies, natural disasters, global threats such as terrorism and war, just to name a few. During the period of my study, we experienced a massive viral pandemic that was global in nature and had a direct and sustained impact on the health care system and the delivery of all services in all health sectors. Having to witness this magnitude of death and the burden on resources as health care providers and for those receiving care left an indelible mark in the delivery of palliative care during this period and one that participants felt needed to be addressed.

As the caring journey ends, and with each successive experience, the idea that palliative care work is hard and exhausting at times, transitions to what expert nurses call sacred work and a privilege to care for their patients. Perhaps over time it is the realization that they are sharing the experience at a very vulnerable, final and important time in their patients' lives and that the privilege to journey this time with their patients brings meaningfulness and sacredness to the experience.

Looking Ahead

The following chapter narrates those participants' experiences that resonated most with them and left an indelible impression on them and in their practice. These narratives describe connections made with patients and families that go beyond the normal therapeutic relationship, as well as professional catalysts for ongoing learning and how nurses make meaning through their caring at end-of-life.

Chapter Six: Expanded Narratives of Palliative Care

Humans live storied lives and these stories become a way for us to make meaning. Stories provide opportunities for personal and professional growth, and by extension also become teaching tools for us to learn. Significant moments, in both our personal and professional lives, play a critical role in our learning. In keeping with Clandinin and Connelly's (2000) directional framework, as we recall these moments, we reconstruct our knowledge of those experiences and find new meaning in that new understanding. Shields (2005) described the recall of memories as an opportunity for the reinterpretation of educational experiences. The reconstruction of seminal life events, and learning from our past, can inform and guide the present. Schwind et al. (2011) also speak to the value reflective practice brings us as professionals. They described a narrative reflection process as a way to "fine-tune self-as-instrument-of-care" (p.2). Using reflective tools such as storytelling, writing, and conversations, relational knowledge deepens and becomes a way to increase self-knowing, which can lead to new discoveries of being, doing, and becoming.

As a nurse, educator, and now researcher, I am coming to understand the power of story in new ways. In this chapter, I narrate the moments my participants described as resonating most with them and having the greatest impact on their practice. I could feel the sensations they described as I learned what palliative care meant to them, while at the same time, recalling similar and different experiences of my own. I conclude this chapter with a momentous experience of my own, one that brought much meaning and learning to my practice and a moment that stays with me still today.

Significant Moments in Palliative Care

In my close analysis of the transcripts, the narrative of the participants revealed four overarching types of significant moments, important to them and included: (a) connections made with patients and families, (b) catalysts for professional learning, (c) meaning making of caring at end-of-life, and (d) the actions of advocacy. I elaborate each with examples in this section.

The Connections We Make

When describing those moments that stay with you, expert nurse Rose suggested the act of providing palliative care is the "quintessential essence of what nursing is supposed to be. It's all the focus, the culmination of everything that we work towards as nurses." This focus on connections was noticeable in many of the stories shared by participants. Rose went on to share an example of a particularly impactful moment with a patient with whom she had become close. Rose had been her primary nurse for some time and recalled a moment near end-of-life when she had become minimally responsive:

> I looked around her room. You could see all these handprints of her children from when they were growing up. She had a little stool with a handprint, and she had a painting with a handprint on it and she had a photo when they were really little. And so, I asked, 'Do you think that they would like to have her handprint?' . . . We gathered garbage bags, paints, and canvases and while she was no longer responsive, the children painted her hands and each made a painting with their hand and her hand, and it was really beautiful. She passed the next day. And I'll never forget the impact that [those moments] had on me.

As Rose described this particular experience, I could feel the emotion in her voice and see the caring in her face. She added:

> These are the moments that we are supposed to bring to them [families]. I truly believe that . . . because I knew her. I'd spent a lot of time with her to know what was meaningful and purposeful in her life.

I could see how important this legacy work was for Rose as she recalled the connection she had made with the patient and then the patient's family. She recalled other moments of washing a patient's face, moisturizing their hand, and even gentle touches. Similar moments were described by Gladys in the pandemic-related challenges. Rose continued to eloquently summarize such moments:

> I think those moments are really beautiful and we get to be privy to them and we're so fortunate because people open themselves up to us in their most intimate and vulnerable time. It is human interaction at its best. It is such a privilege and I'm so fearful that sometimes other nurses don't see it as a privilege...and that makes me sad.

As I listened to Rose recount her experience, I could hear the softness in her voice when she used the words of privilege when caring for her patients.

Connection for Margo was highlighted in relation to families of patients. Pondering what resonated most about caring at end-of-life, Margo shared: "Not only are you reassuring the patient but you're also reassuring the family members especially when they cannot be with their loved one. ...you are caring for the family almost to the same extent that you are caring for the patient, it is just more on an emotional and mental level". This sense of connection still included the patient but as a new nurse, Margo was learning to pay more attention to families.

> Like Rose, expert nurse Diana focused on the connections with patients that helped her to grow as a nurse.

Diana recalled navigating a particularly difficult moment: "What do you say to a patient when they say 'I have multiple sclerosis and now I have metastatic colorectal cancer, God must really hate me' …. What do you say?" It was the connection with patients that remained with her:

> Touching that patient somehow emotionally, building that bridge with them . . . sometimes that means you have to cross 3/4 of the way to do that. Yet, you have to be conscious of what you're doing, and you have to be committed to that and that's the challenge. If the nurse is of the belief that, “Well, I made this recommendation, if you want to take the medicine or you don’t want to,” that's a whole lot different than saying “Yeah, I understand you're afraid of this but how about we work together, how about we take a baby step, and I will be with you.” Those are the moments that stay with you.

Alex similarly described an impactful moment of a patient that helped him, like Rose, to “see the beauty in hospice palliative care.” It took place when he was caring for a patient who was receiving aggressive oncology treatments, sometimes being sent an hour and half away for treatment without family at her side. He shared how he journeyed through the experience with her:

> My patient really just wanted to be able to stay home, have good days with their family and be pain free. …I still remember it was a holiday weekend and we hadn't been able to manage her pain at all. She had severe ovarian cancer and horrible abdominal pain, and it kept escalating. We continued to increase her pain control, but it wasn't helping. It was then that I finally took the time to sit down and talk with her.

Alex’s connection with this patient led him to have a meaningful conversation with her, a skill he attributed to learning from an earlier experience. He explained:

> My mentor taught me that before you go into someone's home, you have to take all of your baggage and put it in the back seat of your car, lock it there and leave it there. …you need to be fully present with the person. So that's what I did with her, and she broke down and talked about all the stuff she hadn't planned for - she really wanted to get her

> will in order, she had to figure out how to divide her family business among her three sons so that they could continue it on when she died. Once we finally talked about everything, I realized she was given the space and time to release it. Until that point her pain was always 10 out of 10 but when I came the next day, her pain was a 0 out of 10.

Continuing to ponder the artistic nature of palliative care, Alex pinpointed a holistic approach that helped him to connect with what was important to the patient:

> It's not all about the medication or the science. That’s what’s so special about palliative care, is it's a holistic approach. It’s taking care of that whole person. I know that one still sticks with me, and I can look back on it and say we did some really good work there. For me, it's one of the most rewarding parts of the nursing profession - to do hospice palliative care. We’re able to give a gift to them and [in doing so] they give a gift back. It's quite beautiful.

These stories reminded me of similar feelings when caring for my own patients. The story below came to mind. Rose’s descriptions of care and connection especially reminded me of a specific moment ingrained in my memories, and now with a new light and focus. In sharing this storied experience, I also resonated with Alex’s above mention of the whole person. At this moment, care went beyond pain medication. In this storied experience, I revisit a time when a patient had not been able to share her illness with her daughter. She was feeling overwhelmed with her situation and lack of connection with her loved one.

Storied Experience: Knowing Your Patients

> *I remember her saying to me, “I want to tell her about my situation and that I am dying but don’t know how. When I think of her and that I have not seen her in so long, the pain seems to be stronger, and the medication does not help.” There were tears in her eyes*

> *and such sadness that it was hard to not look away. I reached for her hand and held it for a time, realizing there was little "nursing help" I could give her on this day, other than to be present with her and allow her to share her sorrow. She was describing for me a pain that could not be relieved by medication. It was an existential pain that exacerbated her physical pain.*

This was yet another time in my practice where I learned that caring for my patient went far beyond the obvious symptom management to a place where listening to her lived experience allowed for a better understanding of the meaning making that was her life experience.

The Connections We Make Continued

As a palliative pain and symptom management consultant, Barbara worked with students and nurses new to palliative care and making a connection with them was important for her. She had come to the conclusion that "palliative care is what I am supposed to be doing with my life. It is much deeper work, especially when I am with a student…when I see that spark in a student. It is a visceral thing." She felt a strong need to share knowledge as a tool that would help to build capacity in this specialty and recalled this moment:

> When I talk to healthcare providers or visit patients with them, I connect with their heart right away and I see things that they may have missed, just by their speech, just by what they say or what they don't say. …I look at them and I think, 'what are they trying to say.' I take a few moments sometimes because they're so frantic.

Barbara went on to describe how she feels when she is able to support her nursing colleagues, helping to build capacity in palliative care:

> So, it's baptism by fire . . . and they are scared. They call me crying, and say, "I don't know what to do." And that is where I can help. That is where it [being there for them]

> has the most meaning for me, to be able to help them, support them, and show them the way.

For Rose, Diana, Alex, Margo, Barbara, and myself, the connections made with their patients, students and colleagues were some of the moments that resonated most strongly for them. The art of being present and in the moment with patients made a difference in the care they provided. It is important to note, however, that with connection comes a sense of loss. Nicole pointed to this in Chapter Five as part of the emotional and exhausting work of palliative care nurses, especially for early career nurses.

Catalysts for Professional Learning

It is often said that we do not know what we do not know, until we know. Nursing practice is steeped in experiences that bring much reflection and culminates in ongoing opportunities for learning. While Alex, Rose, and Diana spoke to the role of connections within their most impactful moments, they also highlighted the ways these moments served as catalysts for professional learning. Alex shared how his early experiences helped to guide his career path:

> When I first graduated, there was a patient that was really suffering at end-of-life, and I didn’t know how to help them. I couldn't reach anyone for support. All I had was a symptom management kit, but I didn't really have any education on how to use it at that point. The symptom management kit had instructions on how to use it and so that’s what I did. The patient ended up dying about an hour later and for me that was a big catalyst of ‘I really need to figure out how to get more education.’ This was a very scary moment for me and when I knew I needed to seek mentorship.

Rose felt a similar need to build on discomfort towards new learning:

> I think that nurses in hospice palliative care really need to be comfortable in having discomfort. …we might be dealing with something that we might not completely know or understand but how do we show up for that person? How do we show up for that family? How do we show up for that community? And how do we show up for ourselves? That is what helps us to grow and learn and be better.

Diana recalled how significant moments, such as the one shared in the previous section, showed her she “had so much to learn.” She equated these challenging questions about death to moments where she “grew as a professional.” She recalled talking with a patient who asks, “What’s it like to die?”:

> While I have a sense of humor, I couldn't say to him, “Well, no one sent me a postcard, I don't know.” I had to learn a different set of skills. I had to learn how to, with honesty, answer that question with some sense of dignity and a sense of hope.

For early career nurse Kristin, despite her limited experience working with patients nearing end-of-life, there were two things that resonated for her and sparked growth in learning. The first was the realization that she needed to "jumpstart" her education to expand her "understanding" of what is palliative care and the second was that in each experience, she was building her knowledge about how to care, and advocate for patients who were dying. She explained: "I have been able to take a lot of the knowledge that I gained from those experiences and implement it with those patients... I have learned the value of standing up for those patients as a really great growing opportunity for me".

Listening to Alex, Rose, and Kristin describe these impactful moments of learning reminded me of my role as a nurse educator. I have worked with new nursing staff at the bedside in sometimes difficult end-of-life situations. I could often see the uncertainty in their eyes and fear, at times, of doing or saying the wrong things. I wanted to support them. Doing so brought with it great fulfillment. I recall attending palliative care conferences to learn more about communication techniques and how to best support not only my patients with difficult conversations, but also nursing students and colleagues struggling with aspects of palliative care nursing practice. The stories my participants shared with me helped me to remember these occasions where we worked through the difficult situations together and the importance of supporting them and offering guidance during those critical moments.

Making Meaning of Caring at End-of-Life

As Gladys, Alice, Nicole, Sparrow, and Shirley recalled acts of caring at end-of-life, they described care as consisting of a deeper understanding and appreciation of their patients' needs and wants from their loved ones. Their stories moved beyond making connections as they grappled with comprehending the meaningfulness of care during a time when their patients and their loved ones were most vulnerable. For example, expert nurse Gladys described how a patient's husband guided her in knowing what to do and how to deliver quality palliative care:

> I remember watching this nurse rub this woman's feet. I was thinking ‘oh boy this isn't okay’ as I was reading the distressed body language of the husband looking at the nurse rubbing his dying wife's foot. I just stopped and turned to the husband and said, “If she could speak to us right now, would she want us to be touching her?” . . . Her husband responded, “Actually, she wouldn't like that.” . . . she had a history of horrific abuse and did not like being touched. It is about being able to pick up on the little nuances and the skills of body language and to be able to read people and understand their wants and needs…. It is really just about being open to who they are, being open to learning the nuances and having a heightened sense of awareness.

In this next story, Gladys recalled another impactful time where she learned from her patients' parents:

> . . . there was a little boy who I got really close with. He was a single child, his parents had fertility issues, he was the only grandson, the only nephew, he was everybody's world, and he was dying, and I was so curious and so afraid. That curiosity and that fear sat so close together and [the family] kept inviting me into their space, this sacred space. … that intensity, that mystery, that intimacy. The family were reading him books and they were lying in bed with him, and I was just like "wow!." This family. . . really modeled meaningful care . . . how did they know how to help their child die so beautifully? . . . but then I noticed the nurses and the medical team were so far away from journeying with them and really cared for him at a distance. …I had a lot of wonder and curiosity about the model of palliative and end-of-life care . . . it wasn't part of my training . . .

For Gladys, learning about care came from her observations of the family's interactions with her young patient. She emphasized the need to put aside "biases, thoughts, feelings, worries, and wishes for somebody else" and "to actively listen, to be able to read someone's body language."

Still in her early career, Alice recalled moments of meaning-making with families that were steeped in expressions of gratefulness:

> In saying their 'thank yous,' families have told us the impact of the care they had received, and that really stays with you. I have experienced death within my family, so I was a little bit more prepared. … You have to put yourself in their shoes and it gives you a better understanding of how they could be feeling in that moment. It is really eye-

> opening, and it's helped me a lot in terms of realizing the dignity that people deserve before passing away.

Alice suggested that palliative care,

> . . . is a completely different kind of care. It’s about making them comfortable and enhancing their quality of life, and it’s a lot to wrap your head around. It's those moments though that you feel you've really helped them through their last stage of life.

Early career nurse Nicole shared a similar perception of the meaning of care for patients at end-of-life:

> You become more aware of what you're doing. …with the palliative care patient . . . you're very aware that when you bring them their meal trays, that everything is placed properly, it is accessible for them to pick up the fork, or to help someone eat. I am doing it in a way that honours the fact that it might be the last time that they have a meal. …for a palliative care patient, you're really ensuring are you doing the best job that you can … and in everything that you do, you are very aware of the skills that you're practicing knowing that it might be the last time or that there's only five more meals or ten more meals left for them.

This awareness of small but significant moments became part of looking inward to the essence of providing care at end-of-life.

Though she did not describe a specific moment, early career nurse Sparrow was coming to learn the value of living until our final breaths. She described how working with patients at end-of-life has impressed upon her a humility she did not have previously. She reflected:

> It [working in palliative care] impacted me as to how I treat life and myself and people around me. Like, not taking things for granted. You hear about it all the time but when

> you actually see how short life is, it makes me want to live life in the present, in the here and now, whereas when I was younger, I used to live in the past or somewhere in my mind and I couldn't face reality. But it [caring at end-of-life] also gives me a sense of purpose and it's humbling, very humbling, because even though it may seem to some extent that we are helping them, I also think that the people we help also help us.

For Sparrow, watching patients approach their end-of-life brought a stronger reflection to the meaningfulness of life.

This concept of the need to care for patients fully and in a special way at end-of-life, and the impact of every action, was also very present for expert nurse Shirley, particularly during the recent pandemic. She was on a palliative care unit where patients were not being admitted and limited family access had some patients discharging themselves home. Shirley described witnessing a particularly difficult time that will stay with her for a long time:

> Only those [patients] that had no other recourse were being admitted. Individuals needing palliative care were waiting ‘til the last minute ‘til they couldn’t be managed at home anymore, because their loved ones [family] couldn’t come in to be with them. How awful was that situation? It's heartbreaking for family members and patients and for the staff too seeing the angst of families upset. Staff were very sad, adding to the burden of their caregiving when you know that people are suffering without their loved ones nearby or are denying themselves palliative care services because of the restrictions.

For Gladys, Alice, Nicole, Sparrow, and Shirley, their intimate experiences with caring in these relationships went beyond the nurse-patient therapeutic relationship standards as set out by the regulator (College of Nurses of Ontario, 2006), and allowed for a deeper interpretation of the care required and enabled a stronger understanding of the heart with their palliative patients and their families.

The Action of Advocacy

Charlotte's significant moment focused on advocacy. Earlier in Chapter Five, Charlotte spoke to ways she navigated the nurse-physician relationship for the benefit of patients. Elaborating upon her significant moment, Charlotte recalled her persistence to have a patient moved to a palliative care suite where his wife could be by his side. She recalled:

> . . . It was painful to watch and the doctors . . . breezed through and had their 30 second visit. . . we're with him 12 hours a day and listening to him cry for his wife. So, I spoke with [name of doctor] and finally got this poor guy named palliative and we took him down to the suite… his wife came and spent the day with him where he finally passed peacefully that night.

I sensed this experience was a pivotal moment in her nursing journey and one that meant a lot for her practice. Her success in advocating for this patient stemmed from her unwavering desire to support her patient to have the best quality of life until he drew his last breath. She spoke to her heart beating in her chest when she was standing up for her patient and how this was one of the best feelings ever. She felt confident that she was right and able to verbalize to the physician what was needed for the patient. Charlotte went on to share:

> There [have] been a few times now that I have been the one championing for my patients to have palliative care ... and when it happens, I felt that it was nice to be part of that, I felt like we won against it.

As an early career nurse, Charlotte had very few experiences with palliative care, and this may explain why this moment of advocacy stood out most to her as she navigated the challenge of nurse-physician relationships. Speaking up to a physician for a patient’s care is one of the harder skills to develop and being successful likely impacted Charlotte as a beginning palliative care nurse.

While Charlotte was the only one to mention advocacy as her significant moment, the importance of advocacy has been shared by other participants. I also remember my experiences as a beginning nurse and the fears I had when approaching physicians. I worried about how I would be perceived as a novice nurse, not yet having established a confidence in my practice and knowledge. Charlotte’s narrative helped me to recall these experiences with advocacy and how I gained confidence over time, which resulted in better discussions with physicians about better quality of life for my patients and their families too.

Looking Across Significant Moments

Listening to my participants’ impactful moments brought a flood of memories of situations and experiences I had during my own clinical practice. I could feel each of their experiences as they recounted their stories. And their narratives became part of my own as I journeyed through their memories with them. Their descriptions of the beauty of the work that resonated for them in palliative care returned me to my experiences with my own patients as their journeys were ending. It provided me with another reflection of those times, now through their eyes, which touched me again in their beauty and meaningfulness for me.

While the perspectives of each of the participants were individual and distinct to them, the complexity of these significant moments meant that for some participants, the type of stories sometimes crossed more than one of the above themes. These interconnections highlight how as caregivers, we uniquely and differently experience providing palliative care, and the distinct characteristics, as represented in Figure 4.1, identified by the participants as needed to be a palliative care nurse. This next story is a recollection of an early experience that crosses several types of significant moments described above by my participants. It arose in my journal as a key moment to story. In this experience. I made connections with those in my care, was exposed to the need for professional learning, and recognized that caring for those who are at end-of-life is special. It is a moment that resonates with me still today.

Storied Experience: An Impactful Moment

> *After I became a new mom, I decided to explore community nursing rather than return to the hospital right away. I was hired in the home care program, and I had been working in my new role for about three months or so when I received a call from the community nursing office that a visit was needed for an 82-year-old male, new to the program and with a diagnosis of bowel cancer. I picked up the limited paperwork available and made my way to my new patient's home. He lived on the outskirts of town in a small trailer park. I pulled up to his home and was met at the door by the patient's wife. She welcomed me in and brought me around to see my patient. I first met him sitting in his recliner watching his favourite television show. He smiled as I entered, and we began the process of getting to know one another.*
>
> *I worked through the standard nursing history and physical assessment only to learn that he had decided that he did not want to receive any treatment for his illness and was only going to be followed by his family physician for pain and symptom control. "However long it took," he said. As his new nurse, I felt obligated to try to speak to him further to consider all of his options, but he was firm in his resolve. The first visit came to a close and I promised to return later that week to check in and see how he was doing.*

As I started to walk out, I met his wife quietly sobbing in the kitchen. She looked up at me. I motioned for her to come outside with me to ensure her privacy and asked how she was feeling. She told me that she was saddened by her husband's decision not to pursue treatment and that they had been together for over 60 years. She could not imagine her life without him and had many questions for me. It was on this day that I began to realize the formidable task in front of me and questioned if I was prepared to help this new patient and his family with what was to come, their decision making, and this final journey.

So began my introduction into the world of palliative care. I traveled to meet this patient 1-2 times per week as his condition allowed, more frequently when his pain became worse. Generally, he began to decline over the weeks but always seemed to have a smile for me when I visited. I found myself needing to support his wife as much as, and at times even more so, than my patient, as she watched her husband's life slowly change and seemingly slip away.

As the weeks passed, we slowly began the preparations for my patient's death. He was adamant he wanted to die at home with his wife by his side and his children close by. "Under no circumstances will I go to the hospital," he said. "I want to die in my own bed"! I had never experienced anyone die at home before and was concerned about what that might look like for him, his family, and even for myself. Having had little experience with caring for someone who is dying, I wondered if I had the skill to make this happen? What if something went terribly wrong and his pain and symptoms got out of control? How will the family react? How can I support them through this stressful time? And how *can I make this passage for my patient as comfortable as possible? I had so many more questions than answers and so little experience to go on.*

My patient became frailer as the days continued and he stopped taking food. His wife was cooking all of his favourite meals, but he would have none of it. His need for more morphine was making him increasingly nauseated and I found that adjusting his medications became an almost daily nursing task. As he became more somnolent and less responsive, his wife became tearier in anticipation of things to come.

Occasionally, one of their children would drop by for a visit and would ask me questions about prognosis and life expectancy. These questions were hard to field with limited knowledge, however, I did my best to support them and offer what information I could. I encouraged the family to speak with a funeral home and began making preparations for how, when the time came, we would manage. By this time, I was seeing my patient every day and had given his wife my home phone number with the instructions to call should she see a turn for the worse.

That call came 2 nights later. It was just after 11:00 pm when my patient's wife called to say it looked like he was taking a turn. His breathing sounded noisy, and she asked if I would come. I arrived a few minutes later and found the place filled to capacity with all six of the children and their spouses. They were all anxious for my arrival and wanted to know what was happening.

I went in to check on my patient and his condition had deteriorated. His breathing was laboured and there were loud wheezing sounds coming from his lungs. I knew they were filling up with fluid due to his increasing weakness and immobility. I ministered to him, giving him a little more morphine to help with his laboured breaths and he seemed *to settle a little. I sat quietly for a few moments with his wife and held her hand and told her what a great job she was doing in caring for her husband. She looked up at me and seemed grateful and shared that it was a labour of love for her.*

I walked out into the living area and shared with the children that their dad was comfortable for now and that I would stay for as long as he needed me. I encouraged them to go and sit with their dad and talk to him, to hold his hand and that even if he was sleeping, they would bring him much comfort and assurance knowing that they were there with him. After a while, a peacefulness descended with family talking quietly, some in the kitchen, and others in quiet corners. One time when I was listening to his breathing, he opened his eyes briefly and smiled at me. I stayed there for a time and as his wife held his hand, he took his final breaths. I had managed to control his pain and reduce his secretions to allow a more comfortable death.

I went out to tell his children that he had passed, and all came in two by two to say their goodbyes. I remember noticing that there was such a palpable sense of peace. I returned to my patient's bedside and completed my documentation, feeling like this event was almost surreal. I recorded vital signs on my patient chart and confirmed time of death and that the funeral home had been called.

I turned to my patient, said my goodbye, and felt thankful for these few moments where I could remember him and our time together. It was late summer and as dawn was approaching, I could see the beginning of rays of sunlight starting to creep in through the small window. It would be morning soon. My patient was no longer in pain or discomfort and had been able to remain at home with his wife and children at his side, just the way he wanted. Was that a successful death I wondered? I had heard the term spoken before

> *but had yet to understand if this is what success looked like. I felt gratitude for this experience, for what it taught me, and for being allowed to take this journey with him and his family.*
>
> *As I prepared to leave the trailer, I sensed so much love in this little place. I said my goodbyes and reassured them that the funeral home would be there soon. I received a heartfelt hug and there were many thanks passed along as I made my way to my car. As I put my nursing bag in the trunk, I looked up to see the sun starting to crest over the horizon and the sky lit up with an explosion of golden colour. It was a beautiful sight, one I will never forget, and it washed a feeling over me that I was truly fulfilled and perhaps experiencing my calling. I knew in that moment that palliative care and looking after patients and their families was a very important part of nursing and the right place for me.*

While I had yet to learn many things about palliative nursing, particularly about those skills, knowledge, and expertise needed, it was the caring that I felt could make all the difference for those at their end stage of life’s journey. After all, we live until we die, until we take our last breath. For me that is the true essence of palliative care. Perhaps this story also highlights what “sacred” is all about?

Looking Ahead

Participants’ sharing of those resonating moments was one of the highlights of the study for me. I heard the ways nursing in palliative care is about making connections with our patients and discovering what those connections mean for us as we make meaning in our journey with our patients. It can also be a time when we reflect on our experiences and see how those experiences have contributed to our learning and professional growth. When faced with difficulties and challenges, part of the nursing role is to look for solutions and to advocate for change. Passionate about their work, participants offered recommendations they felt would go a long way to improving palliative and end-of-life care. The following chapter chronicles their recommendations for palliative nursing practice.

Chapter Seven: What is Needed to Improve Palliative Care?

In this chapter, I share participants' voices about what will enhance quality of care at end-of-life, and influence change in the delivery of services. These recommendations are grounded in the transcript data and include my storied experiences. My personal standpoint is expanded in Chapter Eight as I look back across Chapters Four to Seven.

The first area of recommendations focused on a team approach and enhanced communication for care delivery. In the second area, participants spoke about how public awareness of palliative care is necessary for enhanced understanding of palliative care issues, as well as investment in palliative care through resources. The third area returned to the familiar topic of palliative care education and included mentorship for nurses and healthcare workers as the most important factors impacting quality of care at end-of-life.

A Team Approach and Enhanced Communication

While the need for early intervention was previously described as part of a nurse's journey in Chapter 5, expert nurse Gladys expanded on the need to improve the palliative care experience for individuals with a team approach to care:

> We need to acknowledge the value of hospice palliative care. I don't think a family doctor would ever hesitate to say, "You have heart issues but oh, I don't know about a cardiologist." Yet, they hesitate sending them to an oncologist [where palliative care assessment often begins after a referral from a general practitioner] when it's not their wheelhouse. …doctors need to practice saying, "These are the experts," or "this is what we really need to think about."

Gladys thought “we've missed the mark on not having combined or designated palliative care teams.” She went on to describe her experience with working with a team and the benefits for patients and their families:

> Journeying with a team, a small group of people who are caring for you during such an intimate and intense time, is what is needed. They’re the knowledge keepers and experts and there to walk alongside you and impart this knowledge as you go through this journey. And then they’re there afterwards for the family. It's not always about the nurse or doctor necessarily but about the expertise of that group of people that the patient and family benefit from.

Expert nurse Diana concurred with Gladys and felt that in order to enhance someone’s quality of life, regardless of where they were in their illness trajectory, a number of skill sets are required:

> I don't think it's anyone person's purview or any one profession’s purview, in my mind you can't do hospice palliative care without a team. Whether it's multidisciplinary or whether it's a team of professionals like nurses, you need that group to work together because everyone brings a different skill set and everyone brings a different level of expertise, and everyone supports each other. In this specialty you witness a lot of suffering and see a lot of pain. You need a team to support you.

Gladys found a team approach allowed for patients and colleagues to be her greatest teachers.

Other participants supported a team approach as well. When discussing who would be most appropriate to care for someone with a life-limiting illness, expert nurse Rose included family as part of a team approach:

> I don't think there is one person, I think it has to be a team approach. I think that the team needs people who are experts on the person who are the family

> members and whoever they identify as family members. … And then I think it needs to expand out to who they identify as family or loved ones.

Margo expressed feeling intimidated when having to speak with physicians. Though early in her career, she recognized the importance of the need to share information:

> It feels more like collaboration… It really is a conversation, you're talking with them [doctors and nurses], you're actually collaborating, and they recognize that you have things to tell them and ideas to contribute and then you can collectively figure out what would be a good solution or a good approach. It's definitely a team approach and not just somebody telling you what to do.

While expert nurses Gladys, Diana, and Rose had considerable experience and opportunities to witness the value of working within a team environment, Margo (who was still learning her role) had already begun to experience the value and need to share information and knowledge. She saw this as an integral form of collaboration that would further support her practice.

Like Margo, expert nurse Shirley, with extensive community experience, spoke to the team's role in communication with the patient:

> They also need early and open communication with the healthcare team at all times so everybody's on the same page and moving forward together. This is important for the patient to understand what treatments may or may not be beneficial. We are still caring for people who are clearly and have been clearly palliative . . . they're still getting active treatment because nobody's had a significant discussion with them, and they keep trying different treatments.

Shirley’s message about communication was not only for teams and patients but also family members:

> Nobody's talking to them [patients and family] about their terminal illness. It's still about treatment, treatment, treatment. And then “oh, you are actively dying now.” …This is still happening. The challenges are with the family members who are suffering. If those discussions don't occur early and ongoing, then members that are watching mother die … they're just suffering so much.

For Shirley, this type of communication was integral to providing support and resources for patients to die at home.

It became clear that enhanced communication was intertwined with recommendations for a team approach. Another example came from early career nurse Margo as she spoke to the need for orientations. Margo noticed that when first assigned to other specialty areas, there are orientations but that this was not the case with palliative care. Margo suggested:

> I think it would be important to have better orientation in palliative care for our unit. We do have the policy that we refer to. But I also think it would be important that if you have a palliative patient on the unit that everybody on the floor is aware so they can come and check on you when you are caring for them.

In keeping with Margo’s comments about the importance of orientation to palliative care, Alice also recalled that when working on the units, there was minimal training offered:

> On our floor we don't really have any training with palliative care. We do have a policy we follow for end-of-life care but no direct training. It's more skills based. And I get we aren’t a palliative floor, but it [death] can happen, it can happen anywhere. So, I think that should be something that is touched on in every unit.

In sum, participants shared passionate views about their experiences with caring at end-of-life and felt that using a team approach was very important to be able to capture a full complement of skills to meet the needs of their patients. They also felt that enhanced communication offered a more focused quality approach to care.

Investment in Palliative Care and Public Awareness

Another area where participants felt there was opportunity to improve palliative care services was that of public awareness. Expert nurse Gladys shared frustration in Chapter Five "with the inconsistency of knowledge, skill, and truly understanding what hospice palliative care is." She stressed, "I really want the public to understand what this care delivery is, what this philosophy means, and that early engagement is really key." Expert nurse Shirley expressed hope for improvement with ongoing investment in palliative care in the future: "Recently there has been a greater focus on palliative care and more hospices… more resources for people to learn about end-of-life. Hopefully, there will be a shift of more knowledge and greater education in the community going forward." Shirley was optimistic that increased resources would contribute to the presence of more hospice and palliative care in the community, to further improve the quality of end-of-life care.

Expert nurse Diana raised concerns around the need for public education in the previous chapter when sharing her Covid experience. Here, she expands on this need for greater "comfort around the use of the word death" and what this might mean:

> We don't necessarily have a societal understanding that death is a natural part of life. It's going to happen to all of us, and so I think public education and the public getting more comfortable around the idea of death would help enormously to bring about better understanding. If people weren't so afraid… I mean nobody wants to lose

> anybody … but bringing about those conversations and normalizing death for people and people supporting one another would be huge.

Normalizing death was also mentioned earlier by Alice in relation to overcoming the stigma of death in nursing. A greater public awareness of palliative care and understanding of death was suggested to improve the quality of the experience for patients and their loved ones. Both expert and early career nurses felt this would help to open lines of communication with patients and families further and allow for easier transitioning at this stage of life.

Education and Ongoing Professional Learning

While the concept of learning in nursing has been raised in previous chapters, I turn next to a closer look at participants' views on the significance of palliative care education and what is needed to support better quality delivery of nursing services in palliative care.

Undergraduate Programs

Expert nurse Diana, having been involved in curriculum development in another position, recognized "there's so much to learn in nursing training. …and for teachers, there is so much to teach." She recommended a move to concept-based teaching and offered an example:

> . . . we look at shortness of breath as a concept and say okay, could be lung cancer, it could be pulmonary emboli, it could be CHF, it could be TB, and teach in that way . . . move to end-of-life…?

While this move made sense to Diana, she recognized it would mean "re-jigging the whole entire curriculum" and would involve a changing mindset. Yet, she felt:

> You should be able to walk onto the floor if you've had that kind of education and say, "Well, here's a patient who is struggling to breathe. Why is this patient having this

> symptom at this time?” Then think okay, it's because they have mesothelioma because they’ve been exposed to asbestos. Now what's my approach going to be? Versus it's because of fluid overload because they got a blood transfusion, and they didn’t get Lasix afterwards and should have.

As noted in Chapter Five, early career nurses felt strongly that they were limited by their lack of exposure and training in end-of-life care. For some this caused distress and they had recommendations for better preparation for practice. Sparrow had this to say:

> I think getting some experience in hospice and palliative care would have been important for us to learn. Not everybody knows right off the bat how to handle it [someone dying] and to take care of people who are in that stage of life. When my patient died last semester, the two classmates who were with me were pretty much traumatized. I don't think they were mentally prepared, and I don't think I was either.

Sparrow recognized that “everybody knows that eventually you're going to die but to actually see it, it can shake people very much.” Offering two solutions, she suggested “…more opportunities to explore the conversations around dying or practicing with simulation would have been helpful to prepare us better.”

Sparrow suggested the use of case-based scenarios and added that simulation would be another opportunity for learning about palliative care within clinical courses:

> Like how we did simulation sometimes where we had people who are like actors. I think it would be useful to have someone who is in the acting position, so they [students] are watching whoever is teaching it, how they would act towards a person and give them a guideline. Because hearing about it, talking about it, is different than acting it.

Sparrow added that "…For those people who are willing to learn it would be a good opportunity for them because they can see it if they are visual learners, they can hear it if they're auditory, and they could get their hands on it afterwards." Kristin supported this need, suggesting: "…there's not a lot of hands-on palliative care education. . . When you have hands-on experience, you get just more out of the education." Kristin is speaking to hands-on experience as part of clinical practicum, rather than simulation and recognizes that working directly with patients is the optimal learning environment.

Margo thought "ideally every nursing student should look at some form of integration of their palliative care knowledge through experience before they graduate." Despite being a new graduate, Margo was insightful about her suggestions for nursing curriculum:

> . . . I do think it does need to better prepare new graduate nurses. I think a lot of the curriculum is skill-based because you do have to have that under your belt but not everyone wants to do certain skill-based nursing. …In palliative care you have to have a particular set of skills for a special type of nursing. There's a lot forgotten in the curriculum that I think they need to touch on more.

Early career nurse Nicole, also felt palliative care should be "more integrated, as opposed to like a separate unit." She offered an example:

> . . . in Maternal Child, the idea of the possibility of a mom or baby passing away wasn't really addressed. The same way in surgery we don't talk about things going wrong, we're talking about the dressing changes and how to prime an IV line. Surgery is major, it's a life-changing thing, and so being able to integrate it regularly in the program as opposed to it being its own course or its own unit would be better.

Early career nurse Alice shared another example of what was learned vs. what was needed:

> We didn't have any palliative patients in our clinicals. But I think they [nursing program] could put a bit more emphasis in the curriculum on palliative care because I do think it is lacking. We did do a lab where I know we assisted with wrapping up the body, but it was such a short lab. I think it does deserve a bit more emphasis, especially as a new grad going out it is kind of shocking your first one [death]. You're like "whoa!" It is hard to know how to react, and until it happens you do not know how you will truly deal with it.

An integrated curriculum would aim to look at these situations from multiple lenses. Alice reminds us of the way she, and participants, were greatly impacted by their first experiences with death. Evident here are the need for specialized knowledge, and discussions related to death and grief, several of the key challenges along a palliative care nurses journey from the previous chapter.

In the previous discussion around the stigma of death, Nicole mentioned the surprise that a field that deals with death does not talk about death. She emphasized:

> Addressing it [death] is needed. I think another interesting way or thing would be to have more of a conversation than a lecture about it. I know that might put a lot of people in uncomfortable situations. Some may not really want to talk about it, but I think that in itself, not wanting to talk about it, is almost an issue on its own.

She recommended students have the opportunity for discussion in a small-group, controlled environment::

> I think the word conversation is really the key word because then it also brings the ability for students to express discomfort. Whereas when you're in a lecture you're not going to raise your hand and say, "I don't like this." But if you are in a conversation in

> a smaller setting, it's easier for you to speak up in front of a small group then interrupt a professor and say, “can I leave?” if the conversation becomes uncomfortable.

The concept of integration of palliative care curriculum in all levels of nursing education was also addressed and strongly supported by expert nurse Rose. She explained:

> My dream would be to see it [palliative care education] integrated as a thread through all of nursing and through graduate school. I would like to see it in all areas not just tacked on to a subject because the thing is, a palliative care approach can benefit anybody in the continuum of care. I think that sometimes it's limiting in the sense that it's taught in like chronicity so automatically a new nurse would normally go to compartmentalizing where they learn that education. Whereas if it is threaded throughout every course, it helps them to bring context to the fact that it's an approach to care, and not just somebody is palliative.

In sum, participants suggested that palliative care should be fully integrated throughout the curriculum, while others offered that dedicated case-based or concept-based learning would provide a more relevant approach to learning palliative care concepts. Nurses still early in their careers felt the opportunity to practice in lab/ simulation settings was important during their training. These spaces would provide for small group conversations potentially allowing for greater comfort with palliative care concepts. Such learning opportunities could result in better preparation and greater confidence in providing palliative care.

Beyond Undergraduate Programs

Expert nurses also looked at the need for professional learning beyond undergraduate programs. Mixed in with their recommendation was a strong concern about limited desire to receive more education. Diana shared, “I don't see staff wanting to receive more education.”

During homecare visits with nurses, she would say, “Well, my role is mentorship, to support and coach you. Remember we talked on the phone; you have to come with me to see the patient.” Yet she found:

> I will get maybe two-thirds of the people coming and staying for five minutes and saying they have to go and leaving and not coming back. …I don't see that commitment to learning. I mean, some of them have bluntly said, “I am here because I have to be here but I'm not getting paid for this time. I have to go and work another 8 hours after you taught me so now today, I have a 12-hour day”.

Diana raised questions: “So how do you teach in that environment? How do you stoke that fire? How do you get people passionate about it? You can’t. I don't see people too terribly interested.” I remember noting Diana’s frustration in her voice as she recalled her experiences with supporting fellow nurses in her community role.

Gladys also expressed frustration, but more so with her own lack of knowledge when she was a novice nurse. She recounted this early experience after attending a palliative care workshop:

> … I was like “why don't we all have this”? I felt we should have known this, been better prepared to provide this care. I was like “I could have been doing it this way better for so long.” ... We [nurses] were thrown into these positions because this is just the care delivery we did, not because of foundational knowledge. …and I think I could have cared for people so much better, understanding the depth of pain and symptom management or delirium. …. I felt that I was neglected, you know, ripped off and I see that now.

Barbara points to the benefit of workshops to further develop palliative care knowledge.

Desire to learn, passion, and skill set are possible reasons highlighted by Barbara. Barbara, like other expert nurses, observed similar experiences with nurses working in community palliative care:

> I would say half of them are willing to learn and then there is the other half who are in that select category of. “I know it, I don't need that, I'm tired, I've been through school, I don't want to do any more, I'm busy enough.” That type. I think that if you don’t have the skill, I don't think you will last in palliative care…

Barbara went on to explain why: “You have to have a certain skill set and if you don't have that passion for working with families, and wanting more education, you're a danger to yourself and you're a danger to the patients that you're looking after.” Barbara characterized the lack of training to be systemic in our health care system:

> The novice nurse doesn't get the training in their school program. They don't get proper training. And while I understand that this can be the case with new workers, there is training lacking in our coordinators, like our nursing coordinators, our PSW coordinators. They don't get any training in palliative care. And educators don't get any training in palliative care either. Even at the hospital they don't. And the managers aren't trained, and don’t receive training on the job. That's where we should start is to train them and have them transfer the skill to the novice workers.

Barbara suggested a case-based learning approach, a similar suggestion offered by early career nurse Sparrow for undergraduate programs. She explained the benefits: “You remember situations even if we're kinesthetic or we learn visually or auditory, we absolutely learn by association. Everybody learns by association so case-based learning is the way to go and how you deliver it can be individualized." Barbara provided this example that she felt really engaged with nurses:

> As part of an advanced care planning module … I got six interested nurses to take it. Following we debriefed and we had study sessions afterward. I came up with all these case scenarios and put them into groups and they were beside themselves. They're so excited. They were learning and they're saying "what more can we learn from this? And how can we transfer this"?

In her comment, Barbara is referring to working with nurses who were taking the CAPCE course (Comprehensive Advanced Palliative Care Education) that is available for RPNs and RNs post-graduation. Case-based learning is used in both undergraduate and further educational certifications and is not a new concept but is recommended for greater use by Sparrow and Barbara.

Expert nurse Rose shared similar reflections about the quality of care being delivered in both acute and long-term care. She expressed her concerns observed when working alongside nurses as a palliative care consultant in both of these venues:

> Unfortunately, it breaks my heart to say this, but long-term care does not do palliative care well. I work very closely with them, but I don't think that staff have the time to care for people in these homes as well as they could. And the staff often doesn't have the education. And I definitely don't think hospitals do it well either. There are very few palliative care units where I'd say "Yes, I'd be willing to send a family member to a hospital setting."

As I listened to Rose make this comment, I felt the impact of her words. Rose is concerned that there are no places that do palliative care well, including hospitals, which are the default healthcare area for everyone.

As a future step in nursing education, Rose described how palliative care education should extend beyond the undergraduate program:

> Then in post-graduate I think if they wanted to specialize or sharpen their skills then there should be post-graduate courses available. I think that's necessary and important, and I think that needs to be continuously revisited if you want to stay on top of it because practices change. I think it's necessary to keep that acuity and the only way to do that is to continue taking education and continue sharpening those skill sets.

Reminiscent of the suggestions for undergraduate programs, Rose spoke to the need for integration:

> I am always taking courses… I take webinars, I take presentations, I have conversations, anything that even remotely links to palliative care, I'm willing to try and take and see how it can be integrated into palliative care. And I have yet to find something that I can't integrate into palliative care.

In her passion for palliative care learning, Rose recognized that to be a good palliative care nurse, ongoing education is necessary.

The above reflections by Diana, Barbara, Rose and Gladys, all palliative care consultants with expert knowledge of palliative care issues, bring real examples of the challenges they have experienced when supporting fellow nurses in palliative care. They provide recommendations for ongoing professional learning, including an integration of more palliative care education in post-graduate programs and a change in practice to a case-based approach of care. They described experiences where their exposure to limited knowledge in palliative care was brought to their attention, both in their own learning and those of others whom they supported in their consultation roles today. As a result of these experiences, palliative care has become and remains a considerable focus in their work today. Their experiences with palliative care practice reminded me of my worries over the years.

Storied Experience: Realizing I Had a Lot to Learn

> *Soon after I graduated, I remember thinking that I had so much training, but also, a deep fear that I would not be knowledgeable enough to truly care for people well. Looking back, I was right. I still had much to learn and experience as I began my career. In those early days, I did my best to observe and model more experienced nurses to learn more. I remember wanting to demonstrate goodwill and reliable practice to my colleagues and supervisors. I also recall one of those nurses telling me, "Keep your head down kid. Stay humble and learn from your experiences. Think about your work and think about how you can do better ... and then do better." I felt a strong sense of responsibility and wanted to do a good job for my patients. After all, I chose this profession that was about caring for others, and that is what I was going to do. In those early days of my nursing practice, when a person was approaching their end-of-life, I noticed there was not a strong focus on quality of life and care at life's end. The thought was, "after all, they are going to die anyway." It was not until I began to care for these individuals (experiencing the interactions involved and the connections made) that I realized there was additional important knowledge needed. Caring at end-of-life was becoming a specialty in nursing practice.*

Looking back, the nursing environment of today has changed greatly since I became a nurse.

When I first graduated, the Nursing Act (1991) had not yet been introduced. This act came into effect in conjunction with the Regulated Health Professions Act (1991) to determine how the nursing profession was to be regulated in Ontario (Government of Ontario, 2021). The Nursing Act (1991) contained a scope of practice statement and itemized a list of controlled acts authorized to nursing as well as provisions and regulations specific to the nursing profession (College of Nurses of Ontario (CNO), 2022). Through this government legislation, the CNO developed entry-to-practice competencies that are the foundation for nursing practice. They were used as a reference to understand practice expectations and became a standard of care for this regulated profession and upheld the need for ongoing education and training to remain competent (CNO, 2019).

It was not until a decade or more later, in the early 2000s, that palliative care was becoming more recognized by our healthcare system. This time coincided with the amalgamation of two important associations, the Hospice Association of Ontario (HAO) and the Ontario Palliative Care Association (OPCA) to become Hospice Palliative Care Ontario (HPCO). These two organizations were working independently at that time to improve palliative care education and hospice care in Ontario (HPCO, 2022). The amalgamation of these two organizations was a significant achievement for hospice palliative care unifying the sector's voice and creating an opportunity for greater advocacy to government for improved palliative care services. This was a turning point in my professional practice as a palliative care clinician, educator, and administrator.

I could see how much expert nurses had learned over their many experiences. Even the early career nurses who were still in the early days of their practice development and in the midst of a global pandemic, recognized the need for ongoing learning to support their work as palliative care nurses. In their recommendations for integration, many of the participants also spoke of mentorship as part of the education needed for ongoing professional learning. I expand this section next.

Mentoring and Being Mentored: Its Significance in Palliative Care

Perhaps not surprising, most expert nurses described being mentored as a significant experience in their nursing education. Their stories highlighted the ways mentorship provided the support and encouragement they needed to work in palliative care. For example, with over 30 years of nursing experience, expert nurse Barbara described mentoring as much needed when she began her career:

> When I graduated there was no palliative care offered anywhere. There was no one to learn from and as a new nurse I knew nothing about palliative care. Over the years, I learned that mentors are so important …. With no formal training in PC in nursing education, we need nurse mentors who have experience in hospice palliative care.

Similarly, expert nurse Rose recalled mentorship as central to her early nursing experiences: "Caring for someone at the moment of passing, sitting with them and being mentored by an experienced nurse was so important for me." This mentorship was influential in her decision to work in palliative care.

It took expert nurse Alex a little more time to find a mentor in his early nursing experiences. He explained:

> I was left on my own to figure it out and quickly learned what I did not know about palliative care. It was not until I found a mentor after my first year, and the moments that we shared that really resonated and became meaningful for me.

Alex called himself lucky to have access to a nurse who had dedicated knowledge in oncology and palliative care and who became a mentor for him as he navigated this field of nursing. As mentioned in Alex's portrait in Chapter Four, he now advocates for this specialized nursing to have both a mentorship component and additional formal education in the specialty for nurses to be change agents in the care of individuals at end-of-life.

It appeared that mentorship and mentoring came in several forms with both positive and negative influences impacting participants' learning experiences. Expert nurse Gladys, for example, reported:

> I was exposed to both good and bad mentors during my training and I learned from them both. Education and mentorship is key for service providers to help them to incorporate the value of hospice palliative care in their care.

Expert nurse Diana, with a number of years more experience than Gladys, emphasized a similar point:

> Nurses need to seek out mentors, including those you do not like, and this is not just who is teaching you or who you want to be like, but also who you don't want to be like. And being able to sort that out in your head and say, "I don't want to be like this person, I don't want to become the person I hate, and I need to be mindful and self-aware."

Diana described mentoring and the mentorship she received as one of the most important parts of her experience. Both Gladys and Diana reflected that it was not just the good mentors but also the ones who were not so good as having taught them important things and described those mentors as modeling behaviour that they did not want to adopt, and how they wanted to do things better.

Interestingly, despite their limited experience in practice, the majority of early career nurses also identified the importance of mentoring and the significance it had on their learning. Early career nurse Margo, still in her final consolidation of nursing education, described how her preceptor had prepared her for what she was to expect in each patient visit, and modeled behaviour while outlining expectations for their nursing visit. She recalled:

> She was really good at making sure she's doing what was right for her patients, like understanding what their concerns are, what they want, and what they expect from her. She lets them know she's there for them and I see that as so comforting for patients.

Margo recalled feeling fortunate to have been paired with a nurse whom she really "clicked" with and who has become a mentor for her. Her mentor described community nursing as requiring a generalist perspective. Entering patient homes was a very different environment than a hospital or long-term care facility, and for this reason, her mentor described wanting to do her best to prepare Margo for what she would see. Similarly, early career nurse Sparrow described her experience as having the good fortune to work alongside a practical nurse who she described as "being really there for her patients, in the way she cared for them, she was authentic and real and meant everything that she said and did for her patients."

After having worked a couple of years in various units now, early career nurse Kristin also felt strongly about the mentoring she received. She described the teachings of her mentors as supportive and enabling, which resulted in increasing confidence to provide the required nursing care. Kristin shared, "I learned all of the palliative care stuff from them, from the management of narcotics, to being able to support and advocate for the family with other members of the care team." Kristin felt that mentoring offered not only knowledge about palliative care, but also strategies on how best to manage complex issues while working with a healthcare team. She was emphatic that without this support, she would have felt lost in those early days and patients and their families would not have received the care they deserved.

Alice, an early career nurse in her second year of practice, felt that having a relationship with experienced palliative care colleagues would have been helpful in learning to care for patients at end-of-life. Her words harken back to the palliative care journey (see Figure 5.1) outlined in Chapter Five: “When a patient dies, I would have liked to have the opportunity to debrief with my colleagues so that we can learn from each other and support each other.” This need to debrief has been mentioned by Shirley, Rose, Charlotte, and Nicole in previous sections. Expert nurse Barbara offered a possible reason why in relation to mentorship: “New nurses starting out need to debrief their experiences with someone who can support and guide them through the process.” For Alice, a mentor to share this experience with would have strengthened her practice in palliative care.

The words of the early career nurses supported a point raised by expert nurse Gladys. Linking mentorship with professional learning, she offered this ensuing thought:

> I think nursing education and mentorship are key and go hand in hand. Mentorship is education, its knowledge transfer to practice, and it's the conversations that I've had with my mentors over the years to really drive this work home. It has been essential for me. I can have the knowledge but what does that look like in practice? Mentorship, I think, is beyond the fellowship that physicians do for years to have a specialty, I think it’s what we need in hospice palliative care nursing too.

In the previous section, Gladys shared frustration at the lack of education, consistency, skill, and holistic philosophy of palliative care. Here we see how mentorship can support these areas of necessary knowledge for palliative care nurses.

As I listened to my participants' experiences with mentorship, both seasoned and new to practice, I was reminded of the mentors who impacted my life and learning. While I had a number of them over the many years of my nursing career, one in particular stands out for me. Looking back, I see the way she inspired and motivated countless health care professionals to strive for excellence in the delivery of palliative and end-of-life care, and to commit themselves to ongoing professional growth and development. Her dedication was contagious and was respected by all who knew her. Like my participants, I felt fortunate to know and learn from her. To revisit my mentorship experience with Brenda, I wrote her a letter as part of storying my past experiences.

Storied Experience: A Letter to My Mentor

Dear Brenda,

Like many, I too, was blessed to have met and known you. You had come into my life a little later in my nursing career and are someone I will not soon forget. Your warmth and goodness of character was quick to draw me in and you always found a way to bring us together for a common good. One of the most important things that you bestowed on me was to always be patient-centered and in your words to "give a damn." Always one to speak your mind, it was one of your endearing qualities. I saw you as an angel of palliative care and was grateful to know and work with you before cancer came to your door. As I sat at your bedside, I realized this was likely to be my last time with you. You reminded me of all the things that were important in the work we were doing. "Think of how amazing our work is Vivian," you said. "We have the privilege of journeying with those we care for at the end of their life," you said. "We can't take that for granted and we have to be the best we can be. Don't ever stop learning, don't ever stop helping others to be the best they can be too. Our patients depend on *that," you added. The seriousness of your own situation that day punctuated those words for me, and I was often reminded of them as I grew to be a nursing educator and leader. I continue to model your vision and passion for palliative care.*

Rereading this letter, I found myself thinking about how mentoring and mentorship has long been considered important in nursing practice. The College of Nurses of Ontario (2002) developed professional practice standards that are well established and provide a framework for nursing practice that describe professional expectations for all nurses and in every practice area. The concept of mentorship exists in two of the seven practice standards. The first is in the practice standard of accountability where nurses have a duty to share nursing knowledge and expertise with others to meet client needs (CNO, 2002, p. 4); and the second is under the practice standard of professional relationships where they are required to share knowledge with others to promote the best possible outcomes for clients (CNO, 2002, p.12). Yet, it was clear that mentorship was a key part of the lived experiences of these palliative care nurses, both as a desire for and a key reason for why they currently worked in palliative care nursing. I return to this discussion of mentorship in the next chapter where I consider how we create spaces for mentorship.

Overall Recommendations for Palliative Care

Looking back across the recommendations in this chapter, I considered the action statements arising in the words and experiences of participants. Table 7.1 summarizes five overall recommended action statements with the specific next steps that were suggested. In the next chapter, I return to these action statements as I reflect on what I have learned across these data chapters and in relation to the literature.

Table 7.1

Recommended Action Statements

Recommended Action Statement	**Specific Next Steps**
A team approach is required	➢ Ensure a team approach is used when providing palliative care ➢ Include patients and families as part of the team. ➢ Establish a "palliative approach" to care.
Enhanced communication is essential	➢ Establish conversations about palliative care early in the patient's journey by experts in palliative care (knowledge keepers). ➢ Discuss resources available earlier in the illness trajectory. ➢ Mandate workplace preparation in palliative and end-of-life care in those areas where palliative care is provided.
Greater public awareness improves care	➢ Educate the public regarding palliative care. ➢ Establish opportunities for access to more resources. ➢ Promote greater public awareness around the "normalizing" of death (for both the public in general and for nurses and end-of-life care providers).
Palliative care education is paramount for foundational knowledge	➢ Integrate palliative care education throughout the nursing program. ➢ Develop enhanced problem-solving skills through a case-based and concept-based learning approach. ➢ Increase focus in labs and simulation in education. ➢ Provide training in palliative care at all levels of practice (clinician, management, administration). ➢ Encourage and support additional training in this specialty area.
Mentorship significantly contributes to greater learning	➢ Provide mentorship to all nurses entering palliative care practice. ➢ Ensure mentors are specifically trained in palliative care to allow for knowledge transfer. ➢ Encourage novice nurses wanting to work in palliative care to seek mentors to enhance their knowledge. ➢ Support expert nurses in palliative care to provide mentorship and knowledge translation. ➢ Allow time for debriefing with mentors to support new and novice nurses.

Looking Ahead

In the next chapter, I highlight and discuss overall findings of what I have learned through this research journey. I review the limitations of the study and the next steps where I feel further research would contribute to a better understanding of nursing in palliative care. It is my hope that the results of this research will contribute to supporting the needs of an aging population by ensuring that nurses are ready for the road ahead and what nursing in palliative care will demand in the future.

Chapter Eight: A Look Back

My doctoral journey provided a unique opportunity for a deep dive into the practice of caring at end-of-life. I sought to better understand the lived experience of palliative care nurses and wondered if their experiences were similar to my own as a clinician in my earlier years. My participants shared stories of actual practice that brought to life an otherwise very somber topic, that of caring for people living with terminal illness. I revisit what I have learned through this research, and consider limitations, next steps for research, and future directions to support palliative care nurses.

What I Learned

In my early days of working with patients who were dying, I did not yet fully comprehend palliative care. With each new experience, my understanding of the palliative approach to care changed. Today, learning from my participants (how they came to practice in palliative care, what was important to them, and how they saw the role of nursing care in the last stages of life) contributed to the recollection of my own experiences and brought forward the importance of practice in this specialty of nursing. This was also an emotional journey for me that included a glance back in time and an inwards reliving of my thoughts and feelings that arose from the recollections. In my researcher journal I wrote:

> *This journey of doing my PhD in palliative care has been a personal one for me and about the ultimate meaning of caring. The patient's journey towards the 'finalness' of life is a very intimate one for each of us and not always understood or accepted. While it can be said that nurses enter the profession because of a strong desire to care for others, nurses who provide palliative care are privileged to care at a stage in life when there is no chance for return. It is an opportunity to value a human life at its ultimate*

> *end, to provide comfort and ease of burden, and to share the journey together with their patients that is unique to them alone. [Researcher Journal]*

I also looked outward through the lens of my participants' experiences and towards a reinterpretation of my own knowledge. Being able to revisit and reinterpret my experiences through multiple lenses allowed me a better understanding of palliative nursing practice and the hope that this reconstructed knowledge can impact and support palliative nursing care in the future.

Revisiting the Palliative Care Nurse's Journey

As the narratives of fellow nurse colleagues unfolded, I relived my own recollections of palliative care nursing. I once believed that palliative care was about a patient's journey towards their final end-of-life. I came to learn that nurses journey this path alongside their patients as well. Palliative care nurses experience both trials and elations with their patients as they pave the road together, finding meaning in life and bringing quality to its end.

I have been privileged to care for people as they journeyed their final days and remember those moments as some of the most meaningful in my nursing career. The experiences in palliative care taught me humility and kindness, and what it is like to care for others in their most vulnerable of moments. As a nurse educator and researcher, my participants taught me the significance of the nursing journey in palliative care and likened it to a road. Together, the nurse walks alongside the patient and their loved ones, facing many turns and challenges in their delivery of care. As we journey together to ease suffering and provide the best quality of life, being well prepared is paramount to advocate for and deliver the best that medical science has to offer. We are companions for our patients with a specialized expertise in aspects of nursing that deals with all of the manifestations of illness including dying.

Within this journey, there are many intricacies. Figure 5.1 highlighted the challenges along the way. In this final chapter, I outline what nurses saw as necessary to navigate and lessen the challenges of their palliative care nurse journey. I return to the five areas of recommendation suggested by participants in the previous chapter and reframe them as key messages that emerged across the data.

Key Messages About Palliative Care Nursing

I present each of the key messages followed by my reinterpretation of what participants and I have come to understand as needed in nursing practice at end-of-life. I include a consideration of the relevant literature.

We Cannot Do This Alone

Overwhelmingly, participants reported that palliative care cannot be provided in isolation and requires a team approach to work with the person and family helping them to understand and define their needs and goals. They described that working alone is a challenge and that being able to have access to different team members brings different levels of expertise and provides a balanced approach of knowledge of care for the individual and their loved ones. Each team member works to develop a therapeutic relationship where the person and their family is at the center of care, and both individually and together advocate for ongoing appropriate care and treatment based on the person's expressed needs and goals.

This concept of cohesiveness in care delivery is strongly supported in research. Mistry et al. (2015) described the nature of palliative care delivery as requiring a healthcare team to function as a unit to ensure that providers were "on the same page about patient's wishes and care needs" (p. 4) in order to deliver comprehensive, timely, and accessible care. Also important for the participants' view of a team approach was the need for support through the grief and bereavement period. This point was raised by participants, not only for the family needs after the patient has deceased, but also to support each other as nurses journey through these intimate experiences with their patients, often accompanied with intense emotions, anxieties, and fears. This is a change in the philosophy of nursing practice. Early in my career, nurses were expected to be able to handle difficult situations and often worked alone with little support or opportunity to debrief their experience. I remembered those times and how I wished that I could connect with a fellow nurse to share my experience and the feelings I was having about my practice. This doctoral research has expanded on this view and the idea of being able to reach out to colleagues and share expertise can support nurses navigating through these often difficult and intimate encounters to deliver better quality end-of-life care.

Being Fully Present is Essential

The concept of care has been central to my work as a nurse. As a nurse clinician, I have worked in a number of specialty areas but caring for people in palliative care and at end-of-life has been uniquely rewarding in my career. I have found that palliative care and nursing share common goals and values in caring. I understood the goal of palliative care is to relieve suffering and to support the best possible quality of life for patients and their families when curative measures are no longer possible. In training, I learned that nursing is based in caring, respect for human dignity, and where each patient experience is unique and requires caring through the establishment of a therapeutic nurse-patient relationship. In palliative care nursing, I believed I was charged with care that encompasses compassion, empathy, and a whole person response that addresses all of the domains of care, including the physical, psychological, social, spiritual, and disease management needs through to the dying process and grief and loss periods. Simply, the palliative approach to care cares for the “whole” person rather than just caring for the “hole” in the person.

As we explored common beliefs and values, I learned from our collective knowledge of caring. As participants described the type of care needed for those at end-of-life, enhanced communication was expressed as essential in the delivery of care particularly for individuals diagnosed with life-threatening illness. Some participants described this enhanced communication as being fully present and purposeful while providing care and ensuring their establishment of a meaningful experience for their patient. Noddings’ (2012) research aligns with this concept of presence and expressed the act of caring as a “sequence of encounters” (p. 772) providing an opportunity to demonstrate empathy in the relationship through an attention approach that satisfies a need in the cared-for, which enriches our lives as carers and completes the caring relationship.

Similarly, Macpherson (2018) described the importance of nurses adopting a family-centered model of care where intimate encounters included being fully present and listening with depth and empathy to another’s suffering contributed to staff and patients finding meaning through their connection. Participants also recommended that therapeutic conversations need to be established early in the patient’s journey and nurses need to be mindful of the challenges of these discussions as patients come to terms with their prognoses and end-of-life matters. In their recollections, participants described the need for active listening and how their body language can reveal powerful messages about what they are feeling and what they communicate to patients and family members during these times of uncertainty. This is described as the “art” of nursing where the “doing for” and “being with” patients embodies the holistic work of the nurse (Kostovich & Clementi, 2014). Carper's

(1978) nursing theory of aesthetic knowing further discusses the art of nursing as the component that includes the personal side of knowledge, with an awareness of the immediate situation for the patient and how to respond to individual circumstances. Rose used this very same phrase, art of nursing, when describing nursing as sacred work. Other participants spoke of the relationship that develops with the patient as one of trust and understanding and how enhanced communication methods can be therapeutic and can assist in more positive outcomes during the patient's journey. This concept of mindfulness is further explored by Nilsson (2016) and described as a requirement for bringing empathy and compassion into health care practice.

Understanding Death and Dying Improves Care

Working in palliative care, participants described the dying process as an inevitable part of the human experience, and one where there needs to be a better understanding that death is something we will all face by virtue of being born. As a beginning palliative care nurse, I too, remember having difficulty initiating conversations about dying with patients and their family members. I remember thinking it was all so final and how talking about their death could possibly help them. At times, I would feel anxious about my own feelings about death and what the next visit might be like.

Participants shared that normalizing death was a first step in understanding this inescapable journey that we all face. They also identified how discussing the concept of death continues to cause anxiety for health-care providers when caring for patients at end-of-life is. These experiences are in keeping with Henoch et al. (2017) who explored the attitudes of nursing students in a longitudinal study and found that preparing students to care for dying patients significantly predicted positive changes in attitudes towards dying. Peters et al. (2013) had earlier described that nurses can be impacted with what they called "death anxiety" (p. 19) and necessitates nurses to have insight into their personal beliefs about death and dying. Their study found that having more positive attitudes contributed to less anxiety and better outcomes for the patient's experience.

Anxiety towards dying and death may be part of the stigma that participants also spoke of as a challenge in their practice journey. Shen and Wellman (2019) recently studied and found evidence of stigma in palliative care and described it as a barrier to its utilization because of increased negative stereotyping of the patient by practitioners where patients were diagnosed as palliative. Their findings concluded that this medical treatment [palliative care] that is deemed valuable and beneficial is "stigmatized and illuminates a major barrier to providing treatments that may alleviate pain and improve quality of life" (p. 378). Participants drew from their own experiences that a greater acceptance of the reality of death as a naturally occurring stage of life, aids in having conversations with patients and their families about their illness, helps to establish more opportunities for access to resources, and would ultimately help to support patients in overall care at this most vulnerable time. Several of the participants advocated for the need for greater public awareness of death.

Palliative Care Education is Paramount

Nursing education is steeped in a long history of caring. Florence Nightingale, born in 1820, was one of the first nurses in history to formalize nursing education; she is known internationally as the foundational philosopher of modern nursing and first nursing theorist (Glasper, 2020). Florence's career was rooted in her efforts to formalize nursing education which led her to establish the first scientifically based school of nursing in 1860. Nursing education has evolved considerably over the last century and a half and remains critical to a profession dedicated to caring in modern secular nursing training. Yet, participants had much to say about the need for more education. The importance of education in palliative care was a recurring theme for the participants throughout their sharing of their experiences.

In nearly every conversation, they discussed that greater preparation was needed in this specialty area. To begin, the participants recommended that more palliative care education is essential in nursing programs as death can occur in all specialty areas, from medical and surgical units, to labour and delivery, to pediatrics and mental health units. This is strongly supported in research where studies have found that learning about palliative care should form part of the basic training of all healthcare professions and nurses as part of their university courses (Ballesteros et al., 2014; Glover et al., 2018; Henoch et al., 2017; Price et al., 2018). In order to be adequately prepared, participants further believed that the delivery for palliative care needs to be enhanced to include case-based and concept-based learning approaches that focus on development of enhanced problem-solving skills. They felt strongly that this would allow a more holistic approach to care that includes the relief of suffering and the improving of patients' quality of life at end-of-life.

Participants also provided examples of how an increased focus of learning within the laboratory setting and in simulation experiences would provide students with the opportunity to practice scenarios in a safe environment. They felt that being able to work through simulated experiences would provide them the opportunity to explore their own values and beliefs about dying and death and would allow practice with difficult conversations and a better understanding of their role as primary caregivers for their patients. The use of high-fidelity simulation in end-of-life care was reported as a promising educational tool to empower nursing students with the appropriate knowledge and tools needed for end-of-life experiences (Shaw & Abbott, 2017). Participants also felt that learning about a palliative approach to care was not limited to only students but should also include additional training at all levels of practice to include individuals in management and administration of those supporting palliative care services.

In a related topic of education, participants also highlighted the importance of workplace preparation needed in care settings where palliative care is provided. Through their experiences, they recognized the importance of receiving an orientation to the policies and protocols of these units in order to better manage the disease process and pain and symptom issues.

Mentorship Contributes to Greater Learning

Nurses are often considered the frontline providers of services for patients and their families at end-of-life. Many studies have reported that more education in palliative care helped to manage increasingly complex individuals requiring high quality palliative care (Kaasalainen et al., 2012; Eriksson et al., 2015; Ingleton et al., 2013; Sawatzy et al., 2009). It is not surprising that participants spoke highly of the need for expert nurses to be mentors and for novice palliative care nurses to be mentored as an educational recommendation for this nursing specialty.

Mentorship played a significant and comprehensive role in knowledge acquisition for the participants, who felt it was an important contributor to palliative care learning. Participants felt that having a mentor would allow them to reach out with questions as difficult situations arose, to be able to discuss changes in the goals of care and to find ways to communicate effectively with patients and family members. Mentorship improved clinician knowledge in palliative care, including communication skills, team collaboration and symptom management and was a basic requirement for all providers who treat patients with advanced serious illness (Burgunder-Zdravkovsky, et al., 2020).

As my participants recalled their experiences of mentorship, I was reminded of my early days of community nursing and working alone. Having had a fellow nurse to reach out to would have benefited my practice and alleviated many moments of anxiousness and worry. Having a mentor has been described as a strategy to facilitate the transition to practice that includes increasing self-confidence, nursing satisfaction, and contributes to recruitment and skill mastery and workforce retention (Ford, 2015; Gunberg Ross et al., 2015; Myall et al, 2008; Pesut & Greig, 2018; Santucci, 2004; Weese et al., 2015). This strategy was described as an important first step in creating a place for nurses to explore their experience, to learn and grow through reflections and discussions, and build confidence for their next experience and furthering their practice knowledge.

Participants also described mentors as needing to be specifically trained in palliative care to allow for improved knowledge transfer and should be supported in palliative care units for nurses new to palliative care. Slimmer (2012) identified the hallmark of an effective mentoring program as having experienced mentors who have passion, confidence, and the expertise to guide others towards excellence. Coaching and mentoring in nursing education have been highly regarded as important tools for workforce development, enhanced motivation, resulting in quality practice at the point of care (RNAO, 2015). In recent years, there has been considerable research about mentorship in nursing practice that found the application and effectiveness of nursing mentorship programs to have an impact on job satisfaction, professional competencies, and staff turnover rates (Lyons, 2021; Pesut & Greig, 2018; Zhang et al., 2016)). Other researchers have found that the quality of professional practice improved through targeted education and mentorship (Burgunder-Zdravkovsky et al., 2020; Duffy, 2015; Mijares & Radovich, 2020).

Grief and bereavement was another area where participants felt that mentors would provide additional support. As nurses can develop complex and intense relationships with their patients and families, participants described caring during the last days and hours as bringing high emotions and an intensity to the work and can be an incredibly stressful time for early career palliative care nurses. Participants recommended mentorship as a strategy that can aid to reduce stress and help with dealing well with the dying person and family.

Earlier in chapter seven, I spoke of a special mentoring experience that became a turning point in my professional practice. It was one that highlighted leadership in palliative care nursing practice and without this experience, I am not sure I would be where I am today. I am grateful for the mentors I have had, and though few, they were significant for me, and my growth is a direct reflection of their influence. This research has strengthened my understanding of mentorship as a key responsibility in providing exceptional care for our patients at end-of-life.

Considerations

Narrative inquiry recommends maintaining a smaller sample size of 10-15 participants as important to be able to yield sufficient yet meaningful data and within a reasonable range before redundancy is seen (Kim, 2016; Lincoln & Guba, 1985). My participant numbers fell within this range. One of the twelve participants identified as male and while this may appear to be an unbalanced sample related to gender distribution, it is representative of the nursing population, where nurses identifying as male comprise approximately 10 percent. Within the scope of this study, I did not consider the unique impact of a male nurse's lived experiences.

I drew upon nurses with expert knowledge in palliative care as well as nurses early in their career with limited experience in this specialty area. This study grouped participants across two generalized levels of expertise. I acknowledge this grouping is not illustrative of the many distinct stages of practice a nurse transitions through in their career. As Benner (1982) indicated, nursing knowledge grows with experience. However, it was valuable for this study to include nurses from two different stages of practice as a way to draw upon various phases of development and experience in their nursing journeys. While it might be anticipated that expert nurses would have comprehensive knowledge of caring at end-of-life, the nurses beginning in their careers with limited experience brought important data of first impressions of caring at this critical time. Further, it allowed for more recent recollections of their nursing education and its role and impact in preparation for practice. Although the findings from participants' experiences cannot be considered universal to all nurses, they offer insight into the individualized journeys they navigate with their patients and family at the end-of-life. The stories of the participants represent their own unique, lived experiences from the time they were first graduating from their nursing programs to their professional practice working in palliative care and while unique and specific to the participants in this study, they may resonate with others exploring this topic.

As a narrative researcher, my values and beliefs about my own nursing journey influenced my understanding of this specialized nursing practice. However, in having this knowledge, it also helped me to connect with my participants with a shared understanding of palliative care practice. My contextual knowledge was instrumental in helping me to develop interview questions and engage in conversations with the participants. Narrative inquiry allowed me to be reflexive in my role as researcher engaging in meaningful moments with participants, learning of their inspirational experiences, along with their challenges in nursing practice at end-of-life. As part of my data management, I used member checking with my participants during the data collection process to confirm the accuracy of information. Reflexive thinking is embedded in the nursing process and considered essential for the development of autonomous, critical and advanced practice and useful to develop and mature professionally (Caldwell & Grobbel, 2013). Narrative inquiry as a methodology offered similar opportunities for reflective thinking during the interviews. Now as I reach the conclusion of this study, the lived experiences within can be used by both new and expert nurses (and all nurses at any point in their stages of practice) to further learn and grow as they read, reflect, and take up the process of looking back to look forward.

Next Steps

As a nurse, trained in the empirical model, I was taught to look to traditional science for concrete answers with data points to support my questions. When I started my doctoral journey, I learned from my professors and in my courses that there were alternative ways of inquiry and how I might answer my question. "What is needed to improve palliative care"? What could be better than to look to those who are at the bedside, those who spend the most time with patients at end-of-life? Nurses. Introduced to narrative inquiry research during my doctoral coursework, I was shown another method of how I could learn from those who are dedicating their time and journeying their lives alongside us traveling the final stage of our lives. Through this process of turning the story (Creswell, 1998) of my research to narrative inquiry, I learned so much.

Looking ahead to future research, narrative inquiry offers rich and unique opportunities to further explore how working in palliative care is experienced differently than at other levels of nursing practice. Through inquiry, questions are asked and opportunities to think critically about the information presented unfolds. Inquiry is a learning tool often used in problem solving and ultimately to communicate findings. As a next step, additional narrative inquiry studies could be expanded to include other levels of practitioners, including registered practical nurses and nurse practitioners, as well as personal support workers and other allied healthcare workers. All of these levels of health practitioners bring their own unique experiences in the caring journey. Working within a different scope of practice may bring forward further insights into their experiences and what is needed to support their practice providing end-of-life care.

It would also be important to expand research to include healthcare professionals in other provinces. In recent years, Ontario has seen an increased commitment in palliative care services but that has not been the case in other parts of the country. With an aging population, healthcare providers will care for increasingly complex patients who are dying not only in urban centers but in many rural parts of the country. Having a broader understanding of the palliative care journey of other health care practitioners will help to support an ongoing commitment to care for all Canadians at end-of-life.

Palliative care education and mentorship of new nurses to palliative care practice came out as a strong contributor to the experiences of nurses as they travel along with their patients' end-of-life journey. It was important for me as a clinician, educator, and researcher to explore nursing care at end-of-life and learn of both the inspirational moments as well as the challenges nurses faced in their journeys. Ongoing research is needed regarding the impact nursing education and mentorship has on nurses' lived experiences and the care journey the experience with patients and their families.

Thinking about next steps for me as a nursing administrator, I envision an opportunity to support and influence curriculum development in palliative care beginning with undergraduate degree programs as well as post-graduation certifications in palliative care. My current position and experience as a nursing educator has afforded me a broad view of palliative care education and through this doctoral journey I feel this learning experience can be shared with our education community to enhance learning for nurses and front line workers which will subsequently improve patient care. I know that we can do better. Further, I would like to personally engage in research to better understand how nursing students can be impacted in their learning journey using simulation and enhanced palliative care education as strategies to improve their lived experience of learning and caring for individuals living with life-threatening illness.

Through the process of authoring this dissertation, I have become aware of the sacred space I have created for my participants. I see that their participation in this research has provided them an opportunity to share in depth the situations, events, and experiences that matter to them and help form their perspectives for ways that palliative care might be improved. They have had a place for their voices to be heard in ways that are personal and storied.

Thinking about how I might create a similar space for nurses in my present role, such as the one experienced conducting this study, a number of options came to mind. There are different communities of practice in palliative care, from formal ones that have been established by our professional organizations to more informal groups such as “death cafes” where local community members can come to gather to inquire and learn about palliative care. During these cafés, overarching questions are explored and usually there is a primary topic of discussion. Perhaps it is time to explore a different kind of knowledge community that is less formalized. For example, Olson and Craig (2000), writing about what they term ‘knowledge communities’ describe more informal “small group conversations where individuals get together and can articulate how they are making sense of situations, explain their actions and examine their stories in concert with others” (p. 670). Such opportunities allow what they called the individual’s narrative authority to be confirmed, expanded or revised in light of others’ experiences, reflections and responses to experiences shared in the group.

Establishing a knowledge community creates an informal space where nurses can reach out, share their insights and their journeys. It is an opportunity to expand their knowledge in a safe place to debrief their experiences in the company of those that have/are traveling the same path. Such a space provides the potential to extend informal mentorship opportunities for nurses when time is a challenge and daily life gets in the way. It seems to me that we remain a death denying society with few places to talk informally about death and dying. Knowledge communities could support such talk, help change attitudes and help nurses and other professionals who take that journey with us, not only to ease our pain and distress, but to be better prepared to walk alongside us when our time comes.

Clandinin and Connelly (1995) use the term ‘personal practical knowledge’ to describe how the stories we live become the knowledge base we use going forward in our personal and professional lives in the present and the future. I return once again to Clandinin and Connelly’s four directional narrative approach of how looking back through my experiences and inwards to my thoughts and feelings about those experiences has brought me to a place of new knowledge in the present. As I look forward and outward to what the future can hold, my newfound knowledge will help to inform what steps I can take as I move towards a future where nurses feel they are better prepared and supported in their professional journeys.

Final Thoughts

As the number of elders and those living with chronic illnesses increases, palliative care nursing will continue to grow exponentially and will take an even greater role in the future. I believe that this research study has offered an important view of the knowledge and skills required and has made important recommendations for nursing in palliative care. It is another step forward that contributes to the understanding and articulation of what is needed for nursing preparation in this specialty practice area.

The stories and experiences of the participants in this study shine a light on the meaning of what it means to be a palliative care nurse, including what is required of nurses as they walk with patients who are dying. Working with patients at the end of their lives is fraught with emotion and finality. It takes courage to share the intimate moments and reflections of this work, of which I am forever grateful. I wish to express my sincerest appreciation to each of the participants (Barbara, Alex, Shirley, Gladys, Rose, Diana, Charlotte, Alice, Kristin, Sparrow, Nicole, and Margo) for coming forward and participating in my research study. You are truly angels. Thank you for the work that you do.

This study has expanded my understanding of what it means to be a palliative care nurse. My doctoral journey is not only about a professional topic but is also a personal one. As a daughter who is caring for a loved one with a life-limiting illness and on their palliative journey, I have both the perspectives of being a palliative care nurse and that of a family member journeying alongside them. I have an upfront and personal view and am inspired to want to continue to help nurses who dedicate their lives to caring during this meaningful stage of life.

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Appendix A: Guiding Interview Questions

Early Career Nurses

- Please tell me about yourself. (Stage of your career, your pronoun preference, types of nursing experiences to date, etc.).
- What does hospice palliative care mean to you?
- What has been your experience with HPC since graduation/while in nursing school? How has this experience impacted your understanding of what it means to be a nurse who cares for someone at end-of-life?
    - If a 4th year nursing student, replace with:
        - Have you had experience caring for a dying patient? If yes, how has this experience impacted your understanding of what it means to be a nurse who cares for someone at end-of-life? If no, what does it mean to care for a person who is nearing end-of-life?
- Who is the most appropriate nurse to care for someone with a life-limiting illness? Why?
- What words would you use to describe a palliative care nurse?
    - Follow-up prompt:" What kinds of qualities or characteristics are needed personally and in the nursing profession to be a HPC nurse?
- What are some of the challenges of being a good HPC nurse?
- What is needed to improve PC experiences for those living with terminal illness?
- Do you think that nurses are seeking HPC education following the completion of their training? Why or why not?
- Is HPC education in nursing important? Why and why not? What professional learning is needed to work with Palliative patients?

- What are the palliative care nursing moments that stay with you and influence how you care for your patients? Please elaborate.

Expert Nurses

- Please tell me about yourself. (Stage of your career, your pronoun preference, types of nursing experiences to date, etc.).
- What does HPC mean to you?
- What has been your experience with HPC across your career? How has this experience impacted you understanding of what it means to be a nurse who cares for someone at end-of-life?
- Looking back at your experiences, what is it like to be a palliative care nurse across career stages of expertise (novice to expert)?
- Who is the most appropriate nurse to care for someone with a life-limiting illness? Why?
- What words would you use to describe a palliative care nurse? What kinds of qualities or characteristics are needed personally and in the nursing profession to be a HPC nurse?
- What are some of the challenges of being a good HPC nurse?
- What is needed to improve PC experiences for those living with terminal illness?
- Do you think that nurses are seeking HPC education following the completion of their training? Why or why not?
- Is HPC education in nursing important? Why and why not? What professional learning is needed to work with Palliative patients?
- What are the PC nursing moments that stay with you and influence how you care for your patients?

Appendix B: Participant Information Letters

Participant Information Letter and Consent Form for Nursing Students

Study Title: Exploring Nurses Perceptions of their Lived Experiences of Providing Palliative Care

Principal Investigator: Vivian Papaiz, PhD Student, Schulich School of Education, Nipissing University

Dissertation Supervisor: Tara-Lynn Scheffel, PhD, Associate Professor, Language and Literacy, Schulich School of Education, Nipissing University

Dear Potential Participant,

I am conducting a research project aimed to enhance research in palliative care nursing practice. I am interested in hearing about palliative care nurses' lived experiences in order to explore the qualities, characteristics, challenges experienced, and perhaps most importantly, the knowledge needed to provide palliative care. This project is not mandated in any way by the Nursing Program for which you are enrolled. While I am the manager of the nursing program at Nipissing University, I am not involved in the assigning of grades. My role does not influence or negatively affect your program completion or requirements to complete the course. I am conducting this project for my doctoral research and because I am interested in learning more about your experience as a student in relation to the topic of palliative care.

As a participant in this study, you are invited to participate in an interview to discuss your experiences in providing palliative care and to share your understanding of those nursing moments that have influenced your work in palliative care nursing. The interview will occur on a mutually agreeable date, and in a quiet environment at a location of your choice.

Your participation will involve:

- *Individual Interview* – Taking part in a face-to-face individual interview with myself.

  Note: While face-to-face interviews are preferred, remote video conferencing can also be used for interviewing participants and this will be offered through online technologies (i.e., Zoom, WebEx), if needed (1-1.5 hours).
- *Transcript Review* – Reviewing the transcript of our interview for accuracy and completeness, including adding, editing, or removing any of the transcribed conversation as you choose (up to 30 minutes).
- *Follow Up Discussion* (optional): A follow up conversation if further discussion is needed or responding to any final questions/clarifications with me by phone or video conferencing (30-45 minutes).

As a participant, you understand that:

- Participation is voluntary and you can withdraw from the interview at any time without consequence by letting me know during the interview that you do not want to continue. In addition, you can choose to not answer any question asked during the interview. The final option to withdraw is following your confirmation of the transcript and can be communicated by email.
- Hard copies of data, and electronic data will be stored on a password protected external hard drive and locked in my work office in a locked cabinet in the School of Nursing at Nipissing University or my home office. Data will be stored securely for 5 years post publication. Only I will have access to information collected about your identity.
- Your name will be kept confidential throughout the project and onward, and any identifiable information will not appear on any documents. There is a chance that someone who knows you and your experiences may be able to identify you, but your name will be replaced by a pseudonym and every effort will be made to remove identifiable information including your input on the transcripts.
- While every effort will be made to maintain confidentiality, it cannot be guaranteed if you choose to speak outside the context of the research about your participation.
- Lastly, it is important to note that our interview conversation may elicit emotional memories or experiences because of the topic of palliative and end of life care. In the event that you experience any personal discomfort or difficulty because of the experiences/perceptions shared during the interview, please contact the Mental Health Helpline (1-866-531-2600) or the Distress and Crisis Ontario Centre (416-408-HELP). Both are accessible 24 hours a day, 7 days a week. Your employer may also have employee assistance programs available to you.

Once you have signed the consent form, please scan and return to (name)@nipissingu.ca or we can sign it in person at the beginning of the interview.

If you have any questions or concerns about the study or about being a participant, you may contact me or my supervisor Dr. Tara-Lynn Scheffel for further information:

Vivian Papaiz, RN, MN, PhD Student
Schulich School of Education
Nipissing University
705-xxx-xxxx ext. X or 705-xxx-xxxx

Tara-Lynn Scheffel PhD
Supervisor and Associate Professor, Language and Literacy
Schulich School of Education, Nipissing University
705-xxx-xxxx ext. X

This research study has been reviewed and approved by Nipissing University Research Ethics Board. For concerns or questions regarding the ethical conduct of the study, you may also contact the Nipissing University Research Ethics Department, at [redacted]

This study has been reviewed and received ethics clearance through Nipissing University's Research Ethics Board. If you have questions regarding your rights as a research participant, contact: Ethics Administrator, [redacted]

Study Title: Exploring Nurses Perceptions of their Lived Experiences of Providing Palliative Care

I have reviewed the Letter of information for this study and understand what is being asked of me. By signing below, I give my consent to participate in this study.

Name: ____
(Please Print)

Signature (Participant): ____________________Date: _________________________

Participant Information Letter and Consent Form for Early Career and Expert Nurses

Study Title: Exploring Nurses Perceptions of their Lived Experience of Providing Palliative Care

Principal Investigator: Vivian Papaiz, PhD Student, Schulich School of Education, Nipissing University

Dissertation Supervisor: Tara-Lynn Scheffel, PhD, Associate Professor, Language and Literacy, Schulich School of Education, Nipissing University

Dear Potential Participant,

I am conducting a research project aimed to enhance research in palliative care nursing practice. I am interested in hearing about palliative care nurses' lived experiences in order to explore the qualities, characteristics, challenges experienced, and perhaps most importantly, the knowledge needed to provide palliative care.

As a participant in this study, you are invited to participate in an interview to discuss your experiences in providing palliative care and to share your understanding of those nursing moments that have influenced your work in palliative care nursing. The interview will occur on a mutually agreeable date, and in a quiet environment at a location of your choice.

Your participation will involve:

- *Individual Interview* – Taking part in a face-to-face individual interview with myself.
  Note: While face-to-face interviews are preferred, remote video conferencing can also be used for interviewing participants and this will be offered through online technologies (i.e., Zoom, WebEx), if needed (1-1.5 hours).
- *Transcript Review* – Reviewing the transcript of our interview for accuracy and completeness, including adding, editing, or removing any of the transcribed conversation as you choose (up to 30 minutes).
- *Follow Up Discussion* (optional): A follow up conversation if further discussion is needed or responding to any final questions/clarifications with me by phone or video conferencing (30-45 minutes).

As a participant, you understand that:

- Participation is voluntary and you can withdraw from the interview at any time without consequence by letting me know during the interview that you do not want to continue. In addition, you can choose to not answer any question asked during the **interview. The** final option to withdraw is following your confirmation of the transcript and can be communicated by email.

- Hard copies of data, and electronic data will be stored on a password protected external hard drive and locked in my work office in a locked cabinet in the School of Nursing at Nipissing University or my home office. Data will be stored securely for 5 years post publication. Only I will have access to information collected about your identity.
- Your name will be kept confidential throughout the project and onward, and any identifiable information will not appear on any documents. There is a chance that someone who knows you and your experiences may be able to identify you, but your name will be replaced by a pseudonym and every effort will be made to remove identifiable information including your input on the transcripts.
- While every effort will be made to maintain confidentiality, it cannot be guaranteed if you choose to speak outside the context of the research about your participation.
- Lastly, it is important to note that our interview conversation may elicit emotional memories or experiences because of the topic of palliative and end of life care. In the event that you experience any personal discomfort or difficulty because of the experiences/perceptions shared during the interview, please contact the Mental Health Helpline (1-866-531-2600) or the Distress and Crisis Ontario Centre (416-408-HELP). Both are accessible 24 hours a day, 7 days a week. Your employer may also have employee assistance programs available to you.

Once you have signed the consent form, please scan and return to (name)@nipissingu.ca or we can sign it in person at the beginning of the interview.

If you have any questions or concerns about the study or about being a participant, you may contact me or my supervisor Dr. Tara-Lynn Scheffel for further information:

Vivian Papaiz, RN, MN, PhD Student
Schulich School of Education
Nipissing University
705-xxx-xxxx ext. X or 705-xxx-xxxx

Tara-Lynn Scheffel PhD
Supervisor and Associate Professor,
Language and Literacy
Schulich School of Education, Nipissing University
705-xxx-xxxx ext. X

This research study has been reviewed and approved by Nipissing University Research Ethics Board. For concerns or questions regarding the ethical conduct of the study, you may also contact the Nipissing University Research Ethics Department, at [redacted]

This study has been reviewed and received ethics clearance through Nipissing University's Research Ethics Board. If you have questions regarding your rights as a research participant, contact: Ethics Administrator, Nipissing University, 100 College Drive, North Bay, ON P 1 B 8L7 or [redacted]

Study Title: Exploring Nurses Perceptions of their Lived Experiences of Providing Palliative Care

I have reviewed the Letter of information for this study and understand what is being asked of me. By signing below, I give my consent to participate in this study.

Name: ____
(Please Print)

Signature (Participant): _________________________ Date: ___________________________