Navigating the Trajectory of Palliative Care Pedagogy Through the Relationship of Patient, Family Members, and Healthcare Professionals

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Abstract

This study explored the challenges experienced by bereaved family members and healthcare professionals (HCPs) at the end-of-life in a hospital palliative care setting. The research focused on elderly persons suffering with a life-limiting illness. The study sought to identify common conflicts as well as strategies and helpful tools to negate these challenges from occurring in the future. Strategies and practical tools were introduced in a 2-part workshop (mirroring a flipped classroom approach) designed to assist HCPs in their professional development by providing more clarity through the trajectory of palliative care. A thematic analysis of the literature revealed 4 overarching themes: (a) lack of and ineffective communication (particularly between the bereaved family members and HCPs); (b) delivering effective symptom management for persons with a life-limiting illness; (c) lack of emotional support both for families and HCPs; and (d) feeling unequipped for the care involved during palliative care. The workshop highlighted the importance of effective conversation, establishing a safe and trusting environment, and encouraging consistent discussions that ultimately dictate the care provided in palliative care. The workshop adopted Kolcaba’s theory of comfort as its theoretical framework, which comprised three forms: relief, ease, and transcendence. In addition, the workshop introduced the acronym ADD—advanced care planning, having the discussion, resulting in the delivery of appropriate care unique to the individual with the life-limiting illness—for use as a guideline in HCPs’ practice. Findings of the study can make a positive impact by improving the quality of care during the end-of-life process in palliative care.
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CHAPTER ONE: INTRODUCTION

Placing a loved one in palliative care is a very emotional and difficult decision to come to terms with when an individual has been diagnosed with a life-limiting illness. When caring for a patient in palliative care there is a possibility of dealing with the end-of-life (EOL) process. Keeping this in mind, it must be asked if most individuals are ready to have the conversation about the care during EOL, closer to the end: Do individuals understand the difference between palliative care and hospice care? Where did palliative care originate from? I believe in order to discuss these types of questions, increasing awareness and establishing a comfortable and safe environment are essential in promoting palliative care pedagogy. According to Health Canada’s (2018) Framework on Palliative Care in Canada,

The term palliative care emerged in Canada in the mid-1970’s, initially as a medical specialty serving primarily cancer patients in hospitals. However, since then, the scope of palliative care has expanded to include all people living with life-limiting illnesses. With an aging population, demand for palliative care, delivered by a range of providers, has grown. (p. 4)

As a practising palliative care nurse, I have come to realize that many people have different views and beliefs about EOL and the use of comfort measures in palliative care. When meeting the needs of a patient, it is important to consider that “family and peers, religion culture, language, literature and the arts, and the media influence our attitudes towards death” (Southwestern Ontario Hospice Palliative Care Education Program [SOHPCEP], 2013, p. 14). The strong perception of death and dying may cause challenges with providing specific comfort measures in palliative care. Comfort measures
consist of treating the symptoms associated with a chronic condition or terminal illness. These treatments include but are not limited to pain management, sedation, repositioning, and fluid administration. Parola, Coelho, Sandgren, Fernandes, and Apostolo (2018) estimate “that each year more than 40 million people need palliative care, including 20 million who are at the end of life. Therefore, more healthcare professionals ... than before are needed to provide this care at the end of life” (p. 180).

The main goal as a healthcare provider (HCP) is to improve the quality of life during palliative care by focusing on the patient. Patient-centered care according to Health Canada’s (2018) Framework on Palliative Care in Canada is a major aspect of progressive palliative care:

Palliative care should be person- and family centered. This refers to an approach to care that places the person receiving care, and their family, at the center of decision making. It places their values and wishes at the forefront of treatment considerations. In person- and family-centered care, the voices of people living with life-limiting illness and their families are solicited and respected. (p. 4)

This is a professional standard of practice that is followed by HCPs; however, the process may become difficult when emotions are involved and rash decisions are made by family members. As a result, decisions made may contradict the best interest of the patient.

In my own personal experience as a palliative care nurse, a common dispute with the treatment provided during care was the administration of pain medication. A narcotic’s potency accompanied with multiple side effects and adverse effects can put the family members in a panic, questioning the overall intention of the HCP. Questions such as “how do I know that my relative will be pain free at the end of life, will he/she be
properly cared for by professional people” (Baillie et al., 2018, p. 5) are frequently asked and the challenge exists with the unpredictability of each condition and the prior knowledge of family members about pain management. Once the patient is no longer able to make their own decisions due to the severity of the condition, the Substitute Decision Maker (SDM) or Power of Attorney (POA) steps in to make the important medical decisions for the patient. This could become problematic if the SDM or POA makes a decision based on their own misconceptions about the comfort measures provided in palliative care. An example of this in my experience was a family member refusing pain medication for their loved one due to their own fears of the medication’s severe side effects. In this case, the family believed the nursing staff were speeding up the dying process through the administration of pain medication (hydromorphone). The patient continued to suffer, and consistent health teaching was required to inform the family members and patient of the specific care provided. However, was the conversation clear and concise between the patient, family, and HCP regarding the plan of care? Therefore, the need for ongoing health teaching by HCPs in a hospital setting is paramount to explain and further clarify the treatments that are performed during palliative care.

When addressing one of the questions above regarding the difference between hospice care and palliative care, I have witnessed the confusion between family members and patients when expecting a hospice care environment and instead receiving a palliative care environment in a hospital setting. Can HCPs distinguish the difference between both settings? I believed that defining the philosophy of hospice and palliative care was needed to highlight the difference of the two types of environments. In return, giving the HCPs a stronger understanding of the differences and similarities of both types of care to
feel confident in communicating with family members when there was an indication from families and patients that there was confusion between hospice and palliative care.

**The Difference Between the Philosophy of Hospice Care and Palliative Care**

When a patient is admitted to the hospital for palliative care, the process involves an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening 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. (World Health Organization, 2012, para. 1)

In preventing and relieving prolonged suffering, an interdisciplinary team of HCPs work together in providing dignity and appropriate comfort measures according to the need of the patient. For the purpose of this research, the hospital setting was the focus of the research. When an individual is admitted into hospice care, the patient is given a prognosis of 6 months or less to live by the attending physician and the patient is no longer receiving any further treatment. Hospice care is described as a type of palliative care. Hospice care “focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible” (American Cancer Society, 2019, para. 1). When this occurs, both types of care provided could be confusing to the public, when both are similar with the priority of care to the patient. While in hospice care, the patient is given less than 6 months to live; the multifaceted trajectory of palliative care is depicted through the unexpected train of events that occur. For instance, when an individual suffering with a
life-limiting illness begins to decline in a hospital setting, the patient is deemed end-of-life. Moreover, at this point, the decisions become more challenging and difficult to make with a lack of guidance. Due to the unpredictable life expectancy in palliative care, I felt it was paramount to have the main focus on the entirety of palliative care. In contemporary organizations, both hospice and palliative care are combined and referred to as hospice palliative care. Hospice care becomes a part of palliative care, however there are different settings for the type of care depending on the individual’s preference. For the purpose of this paper, I focused on challenges that may occur in providing palliative care in a hospital setting.

The following section expands on the origin of palliative care. Cicely Sanders was an instrumental influencer with the development of palliative care. St. Christopher’s Hospice was one of the first modern hospices, founded by Cicely Saunders in southwest London in 1967. Cicely Saunders had a monumental impact on revolutionizing the concept of hospice care by introducing the culture of palliative care.

**The Influence of Dame Cicely Saunders in Palliative Care**

Total pain was not considered an important factor of patient care before Cicely Saunders changed the perception of pain. Two myths were common in pain management between doctors and patients: One myth challenged by Saunders (2000) regarded the use of analgesics and how patients on pain medication would become dependent on them instead of treating the actual pain—a myth believed by many individuals today. Another myth was stating that the effectiveness of the analgesic was only based on the frequency of the doses. Thus, the medication was only short-acting and used for emergency situations (Saunders, 2000).
These myths were quickly refuted through the data collected in Saunders’s research. Her studies “introduced the idea of total pain, which included the physical, emotional, social and spiritual dimensions of distress” (Richmond, 2005, p. 1). Saunders’s findings lead to effective pain management as she “insisted that dying people needed dignity, compassion, and respect, as well as rigorous scientific methodology in testing treatments” (Richmond, 2005, p. 1). The holistic approach was identified as an essential component to follow in providing optimal care for a patient. Saunders became a medical director, studying pain management with the incurably ill and devoted her life to increasing the need for hospice palliative beds. In addition, Saunders made a difference by improving the quality of care to all patients in need of these services. Without Saunders’ consistent dedication and research in this specialized field and emphasis of the importance of palliative care in modern medicine, our society today would be less comfortable with the culture of palliative care.

The research conducted reflects the nature of Thanatology: the study of death and dying that looks at the human emotions, experiences, expectations, and the realities that occur during the dying process. Within this research, the gap was apparent in the general practice of health teaching that occurred between HCPs and family members/patients regarding the actual care that was provided. According to the literature (Bélanger et al., 2014; Caswell, Pollock, Harwood, & Porock, 2015; François, Lobb, Barclay, & Forbat, 2017), effective communication to determine the wishes of an individual, the ongoing care provided, and constant support was lacking within the general practice of palliative care in a hospital setting. The lack of knowledge that’s apparent during palliative care should be rectified through receiving pertinent conversations (health teaching). However,
the lack of knowledge and possible disagreement during these conversations, may pose a conflict and create challenges that occur when providing comfort measures at EOL in palliative care. The workshop developed in this paper helps to identify more practical strategies and tools to assist with effective communication in order to improve the overall quality of palliative care. The following section elaborates on the different facets involved with improving the quality of palliative care.

**Improving the Quality of Palliative Care**

Creating a safe space is crucial when starting the difficult conversation surrounding death. Losing someone is a challenging process and with the lack of discussion about the individuals plans of death and care provided during the EOL process, the experience becomes more daunting and stressful. According to the SOHPCEP (2013), the journey towards EOL can be overwhelming, however, “if the needs of a person who is dying are met, the journey can be a profound experience” (p. 21). Through advanced care planning (which is discussed further in Chapter 2) and effective communication with continuous discussion, this in turn helps to deliver the required care for the patient according to their wishes. This is a true reflection of the acronym “ADD” that I created for the purpose of the workshop as a guideline for palliative care practice.

As a HCP, this is ultimately the driving force that guides one’s practice while caring for an EOL patient in palliative care. In this new age of technology and advanced medical care, people are now living longer (Health Canada, 2018). Thus, the goal is to ensure that the journey of living concludes in a profound way for the patient and bereaved family members by alleviating any challenges that may occur. Due to the aging population and the increasing number of individuals dying from life-limiting illnesses,
palliative care has become an essential healthcare need within the society. The complexity of palliative care has resulted in the patient and family members encountering needs that are placing new demands on the healthcare system in different settings. In turn, the need for advanced care planning education in this specialized field is paramount (Ontario Palliative Care Network, 2019). Building a strong therapeutic relationship between the patient/family and HCP is vital to support the patient and family through this process and ensure that clear requests and decisions are made and performed when caring for a terminally ill patient.

The main purpose of this literature review was to explore the challenges experienced by bereaved family members, registered nurses, and attending physicians caring for an EOL elderly patient during palliative care in a hospital setting. I utilized a thematic analysis to identify the need for important discussions about palliative care. In the final portion of the paper, I presented a workshop that highlighted an educational session about palliative care specifically focusing on the EOL conversation between family and HCPs. In addition, the workshop included helpful methods to overcome the common challenges experienced in palliative care. The rigorous research focused on the lived experiences through the lens of the individuals involved in palliative care, which allowed for their voices to be heard. These experiences assisted in discovering effective strategies for palliative care pedagogy that could be implemented prior to and during hospitalization. Francois et al. (2017) stated that “conflict in palliative care is a recognized phenomenon, [however], there has been little primary research, and the few papers reporting conflict are based on anecdotal clinical reports” (p. 1459). This gap sparked an interest for my research and has influenced the direction of the paper by
shedding more light on the challenges and conflicts that occur, which in turn, determined the gap in research that exists about the complex process in adult palliative care.

What causes challenges to occur during palliative care between family members and HCPs? How can HCPs create a safe and comfortable environment to discuss the difficult questions with the patient and family members regarding death to improve the overall quality of palliative care? Are HCPs and patients/family members fully equipped with the knowledge to cope with the process of dying? The last question truly gives the rational for the development of the pedagogical workshop. How can incorporating palliative care pedagogy improve the overall care of a patient during the EOL process? These questions fueled the need for the research and workshop presented here. The common themes/challenges indicated throughout the literature review and my own empirical research in palliative care were the following: (a) lack of and ineffective communication, (b) delivering effective symptom management for a person with a life-limiting illness, (c) the lack of emotional support for both bereaved families and HCPs, and (d) feeling unequipped for the care involved during palliative care.

In this body of work, a meta-ethnographic synthesis approach was used to further explore the central phenomenon of interest. According to Noblit and Hare (1998), “a meta-ethnography is driven by some substantive interest derived from comparison of any given set of studies” (p. 3). The literature chosen was specific to the point of interest and a thematic analysis was used to discover the common metaphors/themes throughout the literature regarding the challenges experienced during palliative care. The common themes have identified the gaps in palliative care pedagogy, which are imperative to close in order to improve the overall quality of care. The rationale of the literature review was
to formulate an effective workshop that focused on improving the overall practice of caring for a patient receiving EOL care in palliative hospital setting. The research accomplished this by uncovering the common challenges that were experienced between bereaved family members and HCPs. The goal of the workshop was to negate these challenges from reoccurring in the future by educating HCPs about palliative care. In return, ideally making the EOL process a more tolerable and stress-free experience for all the stakeholders involved. In addition, these findings could help HCPs become more aware of the common challenges that may occur during palliative care to prepare and strengthen their knowledge and become better resources for the family members and patients.

The limitations in this research were the exclusion of other demographics with the EOL patients involved. I purposefully focused on the elderly demographic who are placed in palliative care due to their increase dependence and co-morbidities that accompany old age. According to Health Canada’s (2018) Framework on Palliative Care, “adults aged 45-74 are more likely to receive palliative care than other age groups. While about 89% of people with life-limiting illness, such as a progressive neurological illness, organ failure, or frailty could benefit from palliative care” (p. 5). Also, I am aware of the different palliative care settings; however, I focused on the hospital setting due to the higher percentage of deaths (60%) that occur in the hospital according to Health Canada and my own knowledge and expertise in this type of setting.

The Importance of Using Kolcaba’s Theory of Comfort

The theoretical framework that was employed in this study was Kolcaba’s theory of comfort. Kolcaba’s theory of comfort “is a middle-range theory for health practice,
education, and research. This theory has the potential to place comfort in the forefront of healthcare. According to this model, comfort is an immediate desirable outcome of nursing care” (Petiprin, 2016, para. 1). The following concepts described in this theoretical framework help outline this paper. The three forms of comfort are: relief, ease, and transcendence. Relief ensures the specific needs of the patient and family members are met (e.g., holistic approach including spiritual, physical, and emotional). This form of comfort could be achieved by informing the individuals involved with the care of the options that are available prior to hospitalization into palliative care. These options can consist of discussing the benefits of advanced care planning, advanced directives/living will, and familiarizing oneself with the decision-making process, which are discussed in further detail in Chapter 2. This ongoing process helps to relieve the anxiety one may have when suffering with a life-limiting illness.

The next form of comfort is ease, a feeling of contentment, which is experienced when the anxiety and stress is reduced during the EOL process in palliative care. The form of ease is achieved by increasing awareness of the challenges that may occur during this difficult process; reducing confusion about the care provided; increasing the need for conversation that includes continuous changes in the plan of care; and forming a trusting and safe environment to discuss the critical issues when receiving palliative care. This in turn would emphasize the importance of palliative care pedagogy in the hospital setting to ensure that the ease of contentment is achieved.

The last form of comfort is transcendence, which involves HCPs, patients, and family members who are able to rise above challenges and overcome them while developing coping skills. In this form of transcendence, HCPs will need to become better
resources for patients and family members to provide consistent support for bereaved family members through this difficult time. In addition, HCPs would use this workshop as a tool to identify and assess certain aspects of caring for a dying patient to seek help when needed. Furthermore, in order to achieve transcendence, the HCPs and bereaved family members need continued support and training to provide compassionate care for the patient preventing emotional burden of care/compassion fatigue from occurring. In Chapter 4, Kolcaba’s theory of comfort is discussed in further detail, followed by Chapter 5 that presents the workshop titled “The Journey to Finish Living: Practical Tools to Overcome Challenges Experienced in End-of-Life Care.” The development of the workshop, the purpose of the material, the content, the effectiveness of the workshop, how frequent the workshop would be held, and the evaluation tool are discussed in further detail below. This literature review and the development of the palliative care pedagogy workshop will in turn cause a cultural shift to occur.

A cultural shift in how we talk about death and dying is required to facilitate acceptance and understanding of what palliative care is and how it can positively impact people's lives. The integration of palliative care at the early stages of life-limiting illness facilitates this culture shift by supporting meaningful discussions among those affected, their families and caregivers regarding care that is consistent with their values and preferences. (Health Canada, 2019, p. 15)

The next chapters discuss the following: (a) advanced care planning process involved prior and during palliative care, (b) the EOL challenges experienced by bereaved family members and HCPs, (c) Kolcaba’s comfort theory and how this theory relates to reducing
the anxiety and stress of fear of the unknown with palliative care, and (d) the development of the workshop.
CHAPTER TWO: EXPECTATION VERSUS ACTUALITY DURING PALLIATIVE CARE

One must first reflect on their own values and perspectives regarding death and dying before embarking in the care of a person with a life-limiting illness. The real-life experiences in palliative care may ultimately shape an individual’s own perception about their expectations and views about the care provided. During this emotional journey, understanding the grieving process is essential with the challenges that occur during EOL in a palliative care setting. In her book *On Death and Dying*, Elisabeth Kübler-Ross (2004) introduced a model that highlighted five stages of grieving after her own research was conducted on the emotional experiences of persons who were diagnosed with a terminal condition. The stages of grief were denial, anger, bargaining, depression, and acceptance. This model has been used as a guideline to further understand the emotional experiences that occur during death and dying.

In addition, it’s important to understand that all individuals grieve differently as there may be a misconception that “everyone must move through all of the stages in a specific order”; rather, it is important to understand that “reactions can happen at different times all together, and in no particular order” (SOHPCEP, 2013, p. 157). As HCPs, providing care using a holistic approach and focusing on the wishes of the person directly dealing with the poor prognosis, may help the family and person cope better with the dying process near the end. How does one create a safe space to have the difficult discussions about the plan of care during palliative care? Fortunately, there is a general support for advanced care planning in Canada (Canadian Hospice Palliative Care Association, 2012); however, there is a continued need for more awareness surrounding the importance of advanced care planning and the documents such as advanced directives.
also considered a living will that are available to the public to plan the care prior to and during hospitalization. The process of advanced care planning and advanced directives will be explained further in this chapter.

In discussing this sensitive topic, the interdisciplinary team must be cognizant of the comfort level of the person and the environment. Approaching the conversation with empathy, compassion, and sensitivity is crucial in creating a safe space where communication is effective. According to Pfeifer and Head (2018), an interdisciplinary team includes physicians, nurses, social workers, and chaplain who are responsible for meeting the medical, psychological, and spiritual needs of the person. If the person is capable, then the person is able to partake in advanced care planning. The process may involve multiple disciplines within the interdisciplinary team when discussing the person’s future plans in palliative care. Thus, training is also imperative to ensure that the team for example, nurses, social workers, or even chaplains have obtained the necessary knowledge and skill set to approach this conversation successfully. Pfeifer and Head (2018) stress the importance of working together as a team to promote a holistic approach for the person to address all their needs in order to increase the quality of care. The goals of advanced care planning are “to help ensure that people receive medical care that is consistent with their values, goals, and preferences” (Detering & Silveira, 2019, para. 1) by allowing the person to express their personal wishes (spiritual, physical, emotional, and social); preparing the person and family members for the EOL process by “clarifying the patient’s understanding of their illness; elucidating the situation and treatment options” (Registered Nurses’ Association of Ontario, 2011, p. 34).

In addition, advance care planning also aims to discuss the “appointment of a substitute decision maker through a Power of Attorney for Personal Care (POAPC) and
advance directives” (Ontario Medical Association, 2014, p. 1). For the purpose of this chapter, I will focus on the importance of integrating this practice of advanced care planning in hospital settings and emphasize the need for engaging in this form of conversation and completing an advanced directive. The workshop highlighted the importance of advanced care planning through the use of realistic examples to illustrate the benefits of the process. An advanced directive is a written document used within the hospital setting to dictate what course of action would be taken if the person’s condition were to critically decline. End-of-Life Law and Policy of Canada distinguishes two types of advanced directives: *instructional advanced directive* and *proxy advanced directive*. 

An *instructional advanced directive* is a written document that states the medical decisions that the person would prefer once they are incapable of independently making their own decisions on interventions during care. Instructional advanced directives are also referred to as living wills. A *proxy advanced directive* is considered the individual whom the person appoints responsible for making the final decisions once the person is unable to competently make decisions regarding their care.

In my experience, the advanced directives that are used at my facility consist of four levels. Level 1 involves the decision to follow Do Not Resuscitate (DNR) and only comfort measures such as oxygen administration, repositioning, and pain management. Level 2 involves DNR, comfort measures, and antibiotic treatment. Level 3 consists of following a DNR status and if the person becomes critically ill the next mode of action would be to send the person to the nearest emergency site. Level 4 is the final level that involves a Full code status where the healthcare team would use cardiopulmonary resuscitation (CPR) to revive the person in a case where their heart stopped functioning.
Moreover, an advanced directive briefly reflects the person’s wishes if their condition were to change. This document is fully illustrated in Appendix A.

In other settings most policies give the person two options if a person was having a cardiac arrest. The two options are either Full Code or DNR. Discussing a person’s plans with family members and HCPs about their end-of life care can be very difficult and frightening. The tools in guiding a person and family member through the advanced care process is vital and in Chapter 3 this is further illustrated where the content for the workshop is highlighted. These conversations within the clinical setting are paramount. The need for continuous dialogue regarding advanced care planning in conjunction with completing an advanced directive is essential in a hospital setting to acquire more comfort in the care required during EOL. Advanced directives help to prevent any unclear care that could be carried out throughout the EOL process; for instance, “life sustaining interventions (e.g., cardiopulmonary resuscitation, intubation, or mechanical ventilation support)” (Yen et al., 2018, p. 266). Moreover, when this step is overlooked, the decisions regarding the person receiving palliative care is left to the family (SDM or POA) and healthcare team when planning the care of the person, once the person is no longer capable of making his/her own decisions. Detering and Silveira (2019) state that the benefits of advanced care planning are having a guideline to follow for the person, to ensure that their wishes align with the care provided. The instructions also help to reduce any additional decisional burden and anxiety for families and moral distress for HCPs. Furthermore, this will give the SDM comfort in knowing that they are making an informed medical decision based on the wishes made by the person suffering with a life-limiting illness.
Advanced Care Planning and Making the Tough Decisions During Palliative Care

Advanced care planning and advanced directives are considered living will instructions. In *The Encyclopedia of Elder Care: The Comprehensive Resource on Geriatric Health and Social Care*, Katz, Mezey, Capezuti, and Malone (2014) indicated that in 1991 the United States Congress passed the Person Self-Determination Act (PSDA), ensuring that the person was given the right to independently discuss their goals/wishes of the treatments provided in a variety of settings. Under the PSDA, the facilities must ask if advanced care planning has taken place with the completion of an advanced directive. PSDA gives the person and family the right and opportunity to plan their medical treatment goals and complete the necessary documents during advanced care planning. HCPs by law must comply and respect the decisions made by the person in their advanced directive (Katz et al., 2014, p. 18).

The decisions made by the person and family members during EOL care is sensitive and challenging to discuss during this already difficult time; advanced care planning or completing an advanced directive are then postponed due to this delicate topic. According to Bélanger et al. (2014),

Conversations about end-of-life decisions and the transition toward palliative care remain among the most challenging communication tasks for health care professionals, as initiating palliative care decisions often entails addressing a person’s impending death. The tendency to delay decisions about advance directives and to focus on curative treatments are major barriers to involving persons in making decisions about palliative care options. (p. 2)

The person ultimately should have the opportunity to participate in their care provided in
order to ensure that the person’s needs are met during EOL care. This ensures that the person preserves their autonomy during the decision-making process. In addition, the timing of the referral to palliative care is also a key element by assuring the person has full involvement with making the important decisions regarding their advanced directives prior to admission. This would result in the person with the life-limiting illness having full control and feeling satisfied with the care provided and improved quality of living which reduces unwanted suffering. HCPs, family members, and the person with the life-limiting illness are the primary stakeholders in any conversation/discussion when planning the care to understand the options available in providing holistic palliative care. Establishing a trusting environment between the person and HCP is paramount in order for the person and family to feel secure and confident with making the final decisions.

The literature consistently stresses the need for advanced care planning conversation to take place early, prior to hospitalization and before the disease progresses and interfered with the person’s cognitive state, thus causing the person to lose their capacity in making decisions regarding care. How do palliative care providers approach the discussion about the person’s options and EOL goals, beliefs, and values? Bélanger et al. (2014) illustrated a helpful approach that HCPs may use to begin the discussion about the person’s options regarding the EOL plan, including their belief and values. The first step in the approach involves the HCP introducing decisions and options while listening to the person to understand their wishes for the care provided. The ability to discuss these difficult decisions about EOL at an appropriate time is “considered a fundamental skill for palliative care providers” (Bélanger et al., 2014, p. 2). The medical expertise of the family physician will guide which decisions can be made weighing the risk and benefits; the person and family’s full involvement can make the decision during the discussion and
give consent for the interventions they would prefer, asking the necessary questions to clarify any misconceptions they may have about the specific treatment. In advanced care planning and discussing the advanced directive, the person dealing with a terminal illness is essentially confronting their future plans in dying. The stages of grief introduced earlier in this chapter describe the emotional rollercoaster most individuals may experience during the EOL process. Identifying the readiness of a person to discuss these difficult questions about death correlates with the questions that are asked during a consultation. According to the Ontario Medical Association (2014), advanced care planning is an ongoing process instead of a static plan including decisions that are made throughout the EOL process in palliative care.

The holistic approach in palliative care focuses on the entirety of an individual dealing with a terminal illness and families involved with the care of their dying loved one. The spiritual, cultural, physical, emotional, and social aspects of the person’s life are assessed by HCPs to understand the person’s expectations and EOL goals, which is essentially the sole purpose of advanced care planning. In order to understand the whole person and provide holistic care, discussing the care and wishes of the person prior to hospitalization are important to provide the appropriate care. For instance, if the person wishes to refuse cardiopulmonary resuscitation or any life-sustaining interventions at EOL and documents this by completing the advanced directive during advanced care planning, HCPs must respect the person’s living will. Furthermore, the workshop will incorporate the importance of holistic care and advanced care planning by providing models and tools that will be used by HCPs to facilitate an ongoing discussion that will allow individuals to express their wishes entirely in a safe space.
The literature indicates conflicting evidence regarding the influence on EOL care with completing an advanced directive. Some studies found that the advanced directives (ADs) did not have much effect with the EOL care (Booth & Lehna, 2016; Towsley, Hirschman, & Madden, 2015). For instance, Towsley et al. (2015) stated that “ADs have limited scope: they have not been shown to reduce unmet needs, to facilitate conversations, or to enhance planning for EOL” (p. 13). Other studies stated that ADs influenced the care provided (Detering & Silveira, 2019; Yen et al., 2018). The conflicting results were due to the ongoing decisions that are made throughout the EOL care and how instantly a decision about care can be changed verbally or written nullifying the original document. Initial decisions may be changed at any time in the goals of care with the person, SDM/POA and HCP involved. For instance, I have witnessed the patient and family members request a Level 3 (transfer upon order of a physician to acute care site or service without CPR) in their advanced directive, but closer to the end, change the advanced directive to a Level 1 (comfort care/support with no CPR).

Comfort measures within EOL care consider symptom management including but are not limited to pain control, oral fluids, positioning, treatment of fever, oxygen administration, mouth care, and suctioning. Yen et al. (2018) found that 79% of older individuals that completed their ADs during their advanced care planning, “were less likely to receive life sustaining treatments during the last month of life compared with those without AD completion” (p. 269). There are many decisions that are made with the management of symptoms throughout the care of a person with a terminal illness. Preserving individuals’ dignity and respecting their wishes through the trajectory of their illness is an expectation from HCPs and family. However, when these difficult decisions
are not addressed prior to palliative care treatment, challenges and conflicts may occur that interfere with the overall care of the patient.
CHAPTER THREE: CHALLENGES AND BARRIERS EXPERIENCED WITH THE CARE PROVIDED AT END-OF-LIFE

The common challenges that were expressed through the detailed experiences from family members and HCPs were (a) lack of and ineffective communication, (b) delivering effective symptom management for a person with a life-limiting illness, (c) the lack of emotional support for both families and HCPs, and (d) feeling unequipped for the care involved during palliative care. In the next portion of this chapter, I begin by discussing what constitutes a good death, which I believe was important to highlight due to the expectations that are present during the care of a dying individual. Then, I move onto describing the experiences of family members and HCPs during the care of a patient in palliative care in a hospital setting.

While there is no uniform understanding or definition of what constitutes a “good death,” persons and families across the developed world have identified maintaining control, good symptom management, an opportunity for closure, affirmation of the dying person, recognition of preparation for impending death and being a burden as being crucial. (Virdun, Luckett, Davidson, & Phillips, 2015, p. 775)

I believed this quote was essential to highlight from the literature due to the ambiguity of the ideology surrounding a good death; this then led to discovering the perception of how persons and families conceptualize the idea of a “good death” in a hospital setting.

Are the expectations of care from the family members the actuality of what occurs in their own experiences? One of the goals of a HCP is attempting to engage in advanced care planning in order to discuss the goals of care. However, the clarity of an individual’s
decisions may not always be communicated, resulting in challenges and barriers that occur during the care of an EOL person. The workshop addresses the need for advanced care planning by incorporating how the process is utilized in a hospital setting and the purpose of this process including the benefits for this form of practice during care. Most of the studies used in this literature review were European studies, a couple from Canada and the United States, and one from South Africa. This kept the literature very diverse and allowed me to view how other parts of the world deliver care for a dying person. Throughout my research, the question remaining was how can the workshop alleviate challenges and barriers and bring more clarity to the provision of palliative care during the EOL care in the hospital setting? Effective communication was the key factor for any clarity and providing a safe environment to discuss these concerns and challenges. In the majority of the studies, communication was the main challenge expressed by bereaved family members and HCPs.

**Challenges With Communication Between Family and Healthcare Professionals**

Lack of and ineffective communication between families and HCPs was an overarching theme. Hudson et al. (2015) found “the quality of communication can vary considerably and communication failures are the most common reason for complaints in health care, with end of life being no exception” (p. 2). The quality of the communication that occurs is imperative to explain the process of EOL care and the role of the stakeholders involved. Some family members voiced their concern of feeling “like they were in the dark.” Another challenge expressed by HCPs were due to language barriers when attempting to understand the information. In addition, feeling uncomfortable with approaching the HCP intensified the issues, causing more conflicts within the care of a person experiencing EOL care in the hospital setting.
Kisorio and Langley (2016b) reported conflicting data from families regarding the communication and information shared by nurses. Some families reported that communication was effective and the nursing staff was capable of addressing the concerns and discussing the EOL process along with the expectations of care. However, most of the families reported feeling confused and unsatisfied with care due to lack of communication from staff. For instance, one participant expressed their frustration by stating “we need to understand what is happening in the process. Nurses must explain things so that we can understand because surely, most of the time is like we are in the darkness because we don’t know what is happening” (Kisorio & Langley, 2016b, p. 61). Another family member voiced their concern stating “I didn’t understand the situation as a whole I found myself not knowing the seriousness, I was quite confused and a little bit lost and the [rest of the] family as well” (Kisorio & Langley, 2016b, p. 61).

Ong, Ting, and Chow (2017) reported that “Doctor–family communication was perceived to be mostly superficial” (p. 261). I found “superficial” was an interesting choice of word to describe the most important discussion that takes place within the plan of care for palliative care. The majority of articles used in my literature review highlighted the importance in understanding the valuable concept of effective communication, which was illustrated through the responses of participants in some studies. Kisorio and Langley (2016b) report a family member stating “the more we got answers to what we wanted to know, the more relieved we got” (p. 61). Divulging of information and discussion is an ongoing process during palliative care. The challenge lies in the time allocated in providing the information and ensuring that the nurses are within their scope of practice in providing important medical details specific to the
person’s progress. François et al. (2017) emphasized that most issues occurred due to a lack of communication:

Communication issues varied, the majority centered on difficulties in reaching a shared understanding of palliative care or goals of care. Communication difficulties often plague clinical practice, and dominate person experience feedback, despite a considerable body of work in communication training and education. (p. 1464)

When interviewing patients, family/caregivers, and HCPs, one participant in their study “described [a] lack of information and poor communication with health care providers: ... but nobody tells me anything ... even the doctors” (Duggleby et al., 2010, p. 3). In a hospital setting, there are some patients and family members that feel the effect with the lack of communication during their palliative care experience. With the uncertainty of palliative care, these patients and family members are entering into the unknown, an unfamiliar and frightening situation, where effective communication would contribute to the clarity of the care provided. In my professional experience, lack of communication was apparent due to the existing knowledge and information a person and family member obtained from their clinician regarding the specific care prior to hospitalization. Health teaching was provided in these cases, but in the end, the information may have appeared insufficient or unclear due to the type of questions that were repeatedly asked regarding the same care provided.

In a study by Caswell et al. (2015) conducted in the U.K., participants responded “that they had either not been told explicitly that their relative was dying or they had been told in a way that enabled them to understand or accept the news” (p. 8). The participants
stated that due to the lack of information, the death of their family member felt sudden and unexpected. Family members were unaware of the imminent death of their loved one. In Caswell et al.’s study, a wife described her experience with her dying husband in a hospital setting. A staff participant stated that the person’s conscious state had changed overtime and that the patient (husband) was more alert in the morning. The staff suggested that the morning was a better timeframe for the wife to visit her husband in order to communicate with the patient. The wife’s belief was her husband still had a couple of years of living. Thus, there was a lack of clarity in the person’s condition. The authors further clarify that

> When there was a lack of clarity in communication, whether through the use of euphemistic or vague language, this could lead carers [family members] to develop or perpetuate expectations which healthcare professionals would realize were unrealistic in the event of that carers’ understanding was successfully explored. (p. 9)

Furthermore, I believe palliative care education and the tools regarding what to expect with a dying person and the pertinent conversations are essential with improving palliative care in the hospital setting.

> Compassion and empathy are personality traits that are essential when dealing with a dying person. The transition from good health and a sudden change in events where the person was referred to palliative care by a general practitioner is difficult to process. According to Bélanger et al. (2014), “palliative care consists of a ‘holistic’ and interdisciplinary approach to care that seeks to improve the quality of life of persons and their families when confronted with a life-threatening illness” (p. 2). Bélanger et al.
(2014) definition brought more emphasis to the holistic approach in palliative care. This approach strives to ensure that the spiritual, emotional, social and physical needs are met for family and person. The holistic approach includes delivering effective symptom management. However, delivering effective symptom management was not always achieved in the literature and posed a challenge when there were misunderstandings or unmet expectations with respect to the provision of care for a dying person.

**Challenges With Delivering Effective Symptom Management/Comfort Measures for a Dying Person (Unmet Expectations)**

The challenges with delivering effective symptom management stem from the decision making that occurs during care of a dying person. For the purpose of the literature review, I focused on the geriatric person in a hospital setting who experienced EOL care and the challenges bereaved family members and HCPs faced with the overall care delivered. Different conditions can amplify the challenges that are experienced during palliative care. The person who is approaching the end of their journey of living typically has family members step in as the primary care givers (carers’) when patients are no longer capable of cognitively making their own decision. These family members are appointed substitute decision makers (SDMs) by the person, giving them permission to speak on their behalf.

François et al. (2017) used purposive sampling to specifically identify staff and bereaved family members who experienced serious conflicts during the palliative care in a hospital setting. The researchers stated that family members may experience misunderstanding about care due to cultural/language differences and miscommunication from general practitioners and other healthcare professionals causing friction and
conflict. For instance, the provision of fluid nutrition and pain management was one area identified as a concern. A staff member responded that different cultural groups believed the HCPs were giving up on their loved one by “starving” the person during the end-of-life process (François et al., 2017). Other literature highlighted the challenges experienced from HCPs feeling unprepared and unknowledgeable of the different cultures and their expectation with EOL care. For instance, a registered nurse voiced a concern regarding training stating

there is no training in cultures. You know, you’ve got different cultures, and different cultures do different things with, you know when someone’s dying. They might want a priest to come, or they might want someone to come and do something before they die or they, there’s so many different things [that may] come into play.” (Bloomer et al., 2019, p. 168)

Thus, more training and having early conversations to address the person’s needs may overcome the challenges experienced during EOL care.

Conflict regarding pain relief was another area of conflict noted by Francois et al. (2017), “family members felt their loved one were not receiving enough pain medication to control the pain” (François et al., 2017, p. 1461). Distressed was an emotional state that was expressed by the family members in an interview by a staff member. The staff stated “[the family member] agreed to the commencement of a syringe driver for management of symptoms. The next day the daughter came back to visit and her father remained alive but was no longer conscious. Her understanding of the situation was that he was starving to death … she was very distressed” (François et al., 2017, p. 1461). This
study emphasized the unknown in the dying process and expected goals were common determinants of conflicts.

In a study by De Witt Jansen et al. (2017) pain management was described as a “trial and error” process for EOL care. Physicians were faced with attempting to prescribe the appropriate analgesic for the condition based on their prior experience. One physician explained the process of prescribing analgesics:

There’s a catch twenty-two, there’s a potential for a lot of interactions with other medications that they are on, then you face the difficulty with the side effects of medications. So, it’s really about hitting a balance of making sure that you’re doing the person no harm and treating their pain. It’s finding a fine line. (p. 738)

Within this study, physicians felt the need to collaborate with other specialists to ensure the person was receiving the right dose and medication to relieve the pain. However, family members expressed their frustration with the physicians’ uncertainty and hesitation with prescribing medications.

In a study by Baillie et al. (2018), a bereaved carer expressed her interpretation of palliative care that her mother experienced. The bereaved carer described how her mother was restless and uncomfortable, and the staff eventually called the on-call general practitioner. The general practitioner assessed the person and decided to refuse to give her a “killing injection” as it might kill her; the person ended up dying a few hours later (Baillie et al., 2018, p. 5). This is common in my personal work experience, where physicians on call refuse to order an analgesic or sedative due to their own discomfort with prescribing a potent medication. One participant from Baillie et al.’s study inquired about the issue to further understand the problem: “Why do junior doctors find it difficult
to prescribe the analgesia in the doses prescribed by the hospice? Do they need more support?” (p. 5). In this case, ongoing education is needed for physicians to emphasize the need to promote dying with dignity and a review of palliative medications that are needed at the EOL care.

Baillie et al. (2018) stated that “the need for effective pain assessment was highlighted as an important issue by bereaved carers and healthcare professionals” (p. 4). In this particular study, participants identified pain as a priority. The participants included HCP, bereaved family members (carers), volunteers, members of the public, current carers, persons, and other. In one example, a bereaved family member, who was also a HCP was asking for more clarity regarding assessment of pain. The question was regarding the assessment of pain and the need to develop better tools to assess pain with a patient who is semiconscious or patients who are unable to verbally express their pain (Baillie et al., 2018). While the bereaved family member had a background in the healthcare practice, the participant still needed more guidance. Another question related to symptom management explored by a bereaved carer/family member was: “How do I know that my relative will be pain free at the end of life, will he/she be properly cared for by professional people?” (p. 5). Another caregiver/carer asked, “we say that people who do not want to drink at the end-of-life do not experience thirst, just dry mouth. How do we know?” (p. 8). These were all valid questions that essentially needed adequate time to be addressed. This article also discussed agitation symptoms experienced during EOL. Sedation is a common comfort measure that is practiced in palliative care. The concern expressed from the bereaved family carer was the lack of information provided about sedatives and the reduced time that they had to spend with their loved one due to the
person’s sedated state. How can a HCP allocate time to address these questions in a hospital environment?

Evidence through my literature review has indicated the negative correlation between the time allocated for effective communication and the satisfaction of care received from family members and patient. If there was insufficient time for communicating/addressing concerns with a person in palliative care, there was increased confusion and frustration from family members regarding the care provided. One family member stressed “the need for timely communication about essential information [which] was illustrated by this comment: ... if we would have known more of what to expect, what the symptoms are ... if we had known before, it would have been a lot easier” (Duggleby et al., p. 4). This is apparent even in my own practice when there is misunderstanding about the comfort measures provided. For instance, there was an incident where the son was appointed the Power of Attorney by the patient, which resulted in the son making medical decisions for his father. The patient had an unstageable bed sore and was incapable of making his own decisions due to his deteriorating state. However, the family member refused to allow the nursing staff to provide analgesic treatment for pain control. The son was very upset and believed the strong opioid would kill his father. The purpose of the analgesic was to keep the person comfortable and pain free, to relieve the father’s suffering.

Another common expectation or request for symptom management from families involved the provision of nutrition and fluids. Families would request fluids due to their loved one’s condition and their poor appetite experienced in the person’s last weeks of living. Families would feel that their loved one was suffering, which becomes another area of concern. The basic physical requirement consistent to Maslow’s hierarchy of
needs such as food or water was neglected according to family members (Schmutte, 2013). However, at this state when the person’s death is imminent, the body is unable to tolerate these types of treatments. Some HCPs would call these treatments futile treatments (Grech, Depares, & Sceri, 2018). In this case, HCPs are placed in an ethical dilemma where they are caught between listening to family who are concerned and anxious or using their nursing judgment, allowing the person to peacefully end their journey of life with dignity and free of suffering. Such dilemmas could become emotionally draining for all stakeholders involved. As a result, the need for emotional support would become critical during the care of an EOL patient in palliative care. Unfortunately, consistent emotional support was another challenge that was commonly expressed by patients, bereaved family members, and HCPs.

**Challenges With the Lack of Emotional Support for Families and Healthcare Professionals**

The complexity of a person in palliative care is important to understand from both HCPs’ and families’ perspectives when dealing with the emotional aspect of palliative care. Pask et al. (2018) referred to Bronfenbrenner’s Ecological System Theory, which conceptualized the complexity of palliative care by “categorizing [their] findings into the microsystem (person, needs and characteristics), chronosystem (dynamic influences of time ), meosystem (interactions with family/health professionals), egosystem (palliative care services/systems) and macrosystems (societal influences)” (p. 1078). In the literature, emotional support was lacking in all categories and was vocalized through the patients, families, and HCPs. In a palliative care setting, sometimes a patient’s length of stay is prolonged and closer to the end, individuals involved in their care such as caregivers (family members) and HCPs can experience emotional distress including
compassion fatigue and the emotional burden of care (Grech et al., 2018), or what is also called caregiver burden (Choi & Seo, 2019).

In their analysis of the concept of caregiver burden, Choi and Seo (2019) defined the term as “a multidimensional concept, [which] is attributed to the perception of physical symptoms, psychological distress, impaired social relationships, spiritual distress, and financial crisis that arise from caregiving tasks or care demands” (p. 287). Salmond, Ames, Kamienski, Watkins, and Holly (2017) defined compassion fatigue as an emotional state that occurs when “nurses continually connect with persons who are suffering and absorbing the persons' trauma or pain or when nurses care for traumatized persons and re-experience traumatic events” (p. 1805). This definition is in relation to nursing; however, compassion fatigue can also occur to anyone caring for a person with an illness, including families and friends. The symptoms displayed in some cases are having low energy; feeling empty or numb to situations; having nothing left to give; slowly depleting or withering away; being approached with constant questions and having no answers (SOHPCEP, 2013, p. 178). Compassion fatigue for some staff may be inevitable for nurses who are within the palliative care environment witnessing patients dying on a regular basis and having little support, or others might exhibit a better coping mechanism and seek help when needed. Salmond et al. (2017) stated that the lack of definition and awareness of CF resulted in HCPs’ “inability to identify and combat its effect on nursing practice” (p. 1806). The need for balance between work and personal life is important; having someone to talk to as an outlet and more education about CF/burden of care can yield a positive outcome and prevent more episodes of CF from occurring. In the workshop, I have defined the term- compassion fatigue/burden of care to increase awareness and to help HCPs identify the symptoms. Also, I have provided
useful strategies and resources to help cope with this emotional state when caring for a person who is at the end of life.

HCPs, particularly nurses, who are the frontline care for patients in a hospital setting are sometimes placed in challenging emotional situations where families expect the nurses to clarify what was said by attending physicians. For instance, in Caswell et al. (2015), a staff nurse expressed a concern:

there’s a lot of people that will just sit and nod at a doctor and when they’ve gone, will ask the nurse. We had a relative last week that literally said, the doctor’s just been and told them what’s going off, I didn’t understand a word he said, can you tell me what’s happening? (p. 6)

This can become emotionally burdening when the information is consistently unpleasant. In other situations, nurses feel the need to “emotionally distance themselves,” which was considered a protection strategy according to Parola et al.’s (2018) study in which a nurse explained that during the person’s hospitalization in palliative care, a connection was built between the family and person. The difficulty occurs with the age of the person and the connection that was formed, a professional relationship. At some point the family and person become family. When the person eventually passes away, the direct family, along with HCPs, are grieving.

Some nurses also expressed feeling of powerlessness in meeting all the needs of the person and family member (Parola et al., 2018). In my own experience as palliative care nurse, I can relate to the feeling of powerlessness. I can provide everything to ensure that the person is receiving the best quality of care according to the palliative care competencies; however, if the person continues to appear uncomfortable and restless, I suddenly feel powerless and helpless, which then begun to cause compassion exhaustion
and emotional burden of care. Grech et al. (2018) conducted a study using nurses’ personal experiences working in the ICU setting and caring for an EOL adult. The findings of this study emphasized the challenges experienced with nurses caring for patients at the end-of-life with a blood disorder and the support needed for the staff during the care provided. Peden-McAlpine, Liaschenko, Traudt, and Gilmore-Szott (2015) also conducted a study with nurses in a critical care setting and stated challenges with conversations that took place about EOL care when the trajectory of the illness was unclear. In Grech et al. (2018), one nurse described her experience as losing a battle in saving someone’s life. In this case it was difficult for the nurse to compartmentalize the dying person in palliative care, thus dealing with the disappointment of not living out the common assumption that all nurses save lives. Another nurse expressed her disagreement with the advanced directives with the continuing of life sustaining treatments for a person who was 94 years old. The nurse believed this was prolonging the person’s suffering and that was difficult to witness.

Emotionally disconnecting from the situations was sometimes how some HCPs refrained from taking most incidents/conflicts personally, ultimately affecting the performance of the HCPs. François et al. (2017), documented how nursing staff reacted to hurtful situations during care for a person in palliative care; a nurse said

I stepped back to be calm inside, but I’m actually angry. It depends what it is … what I try to do is I think, well it’s not that personal to me. They’re just questioning something because there might be ten things that are causing the, worry and this is just a small part. (p. 1463)
This nurse was able to reflect on the care in this scenario and refrained from taking the incident personally. However, when a conflict was raised where the family and patient was unsatisfied with the care provided, the nurse responded in this manner: “nobody really talked to me about it or nobody ever said how did that make you feel? And I was embarrassed because you know it’s not an everyday occurrence that your patients don’t feel grateful for any of your input” (François et al., 2017, p. 1463). Again, this situation portrays the lack of support from management and the organization when staff are coping with a dying person and the emotional burden in unsuccessfully meeting all family members expectations.

In palliative care when family members are involved, they help in assisting with the care of their loved one. The lack of emotional support experienced with bereaved family members were commonly perceived in the literature as a misalignment with the families’ expectations of care and feeling at times that staff were insensitive, which left staff appearing less compassionate and lacking empathy. For instance, a family member in François et al. (2017) stated “this lady who I don’t have any doubt that she is a top nurse. … She decided the best thing was to joke to break the ice and she said, ‘you know what, not everybody who comes here [a palliative setting] leaves in a coffin.’ That joke has stayed in my mind forever” (p. 1461).

Another family member in Kisorio and Langley (2016a) study conducted in South Africa stated, “nurses must be a little more compassionate, they must speak to the families nicely. … I mean little things matter, in such situations you must put yourself in somebody else’s shoes and say wait a minute, if this is me how do I want to be treated” (p. 62). Poor judgement from staff caused friction and in turn, the staff member displayed a lack of emotional support, which the family needed at this time. The family and person
must be able to form a healthy therapeutic relationship with the staff to trust and have confidence in the medical team. In the end, the care needs to reflect the patient’s wishes and the patient would need a supportive team advocating for them (Pfeifer & Head, 2018). Thus, the emotional state of the family and staff member can truly have a strong impact on the overall care of the person, and every party should be supported respectfully.

A few studies conducted in the U.K. incorporated the use of Liverpool Care Pathway (LCP). LCP was a practice introduced in the 1990s as a tool to help transfer persons from hospice to other settings (Caswell et al., 2015). LCP was used to plan and deliver the best quality of palliative care specific to the person. However, Caswell et al. stated

*The More Care, Less Pathway* report recommended the withdrawal of the LCP on a number of grounds. One of these was a lack of communication with staff reported by carers as their relatives were dying, as well as a lack of consideration shown by healthcare professionals to both persons and carers towards the end-of-life. (p. 3)

Moreover, the implementation of some practices may seem focused on person-centered but as a result may miss other factors that would improve the overall quality of care for the person and family.

Some family members in other studies used the feeling of “abandonment” during the care for their loved one. Others families also felt uncomfortable with approaching staff and inquiring about certain concerns due to the stress of the hospital environment and not wanting to become a burden by asking questions. Caswell et al. (2015) reported, “three families carers reported very poor relationships with staff, to the extent that they
felt abandoned and unsupported. In two cases carers struggled to find a member of ward staff to inform when their relative died” (p. 7). The family during this time are also experiencing emotional distress with the dying of a loved one. A family member who participated in the study by Caswell et al. (2015) described her experience as being dreadful due to the lack of emotional support. The daughter stated there was no staff present to discuss the current condition of her mother. She was puzzled and upset with the lack of support from staff. The daughter and family felt that since no one was able to communicate the status and condition of the patient, everything was left for them to figure out. She felt abandoned at the time of need and within the next hour, her mother passed away.

These real-life narratives of the participants’ experiences illustrated the detailed events of their loved one’s EOL journey by giving the participants a voice, and portraying their perceptions of care of a dying person. As a HCP, I suddenly felt the need to address these issues and wanted to do something to assist the families through this extremely emotionally packed experience. I am hoping that the practical strategies demonstrated in the workshop will provide emotional support for both HCPs and staff, which will be discussed in further detail in the workshop.

**Feeling Unequipped for the Care Involved During Palliative Care**

**Resulting in Conflict**

Within the existing literature, inconsistent education/training about effective communication, collaboration and the fear of making a mistake result in staff and family members feeling unprepared to care for a person at the EOL in palliative care (Ong et al., 2017). Unaligned expectations of palliative care between family members and staff cause challenges. Due to the unfamiliarity of the dying process, some family members
would be appalled if certain care wasn’t performed by nursing staff. A bereaved carer suggested that families of dying persons would benefit from research on ways to support them in coming to terms with the withdrawal of IV drips and hydration in the last days of life. I’m convinced this is the source of much dissatisfaction with the end-of-life care. (p. 8)

Consistent education/training for the ongoing decision-making that occurs in the EOL process is important. Questions, such as “why are fluids no longer needed during the last week of death?” are addressed in further detail within the workshop. Baillie et al. (2018) had a respondent express their concern with HCPs feeling reluctant to prescribe or administer analgesics. One respondent “described nurses refusing to give morphine to their dying loved one, another queried why healthcare professionals were seemingly wary of administering analgesia” (p. 5). This was the participant’s personal interpretation of their experience. In this case, I would seek more information from the attending nurse through their documentation and inquire about the pain assessment that was performed prior to the refusal of morphine.

Moir, Roberts, Martz, Perry, and Travis (2015) asked 60 nurses from one hospital in Idaho to complete a survey titled End-of-Life Professional Caregiver Survey (EPCS) which examined three domains: person and family-centered communication, cultural and ethical values, and effective care delivery. EPCS was used as a tool to determine the educational needs among nurses “with regard to communicating about palliative and EOL care and their current degree of comfort in caring for this patient population” (Moir et al., 2015, p. 109). The findings reported that nurses with more years of experience felt more competent in communicating about EOL. However, the “effective delivery of care”
domain scored low across person population area. Moreover, HCPs would benefit from “EOL care education in order to increase their own skill and comfort in caring for these persons” (Moir et al., 2015, p. 109).

Pask et al. (2018) stated that ineffective multiprofessional collaboration may cause more “complexity through problems with planning and disjointed [palliative] care” (p. 1084). Everyone within the interdisciplinary team including the patient and family need to be neutral when planning for a person in EOL care. If all stakeholders involved are well informed with the care provided, this would result in less conflict involving misunderstanding with the delivery of care and reduce the gap of knowledge during the care of a dying person.

Some family members are fully immersed in the care of a dying person. Kisorio and Langley’s (2016b) highlighted a challenge identified by a staff participant. The challenge was the fear of families making a mistake while attempting to help care for their loved one in the absence of the nurse and surrounded by unfamiliar machines, lines, and tubing that were attached to the person. The care then becomes overwhelming. One family member stated, “you will come and she has all these things attached to her, the machines, and you are scared to touch because you think, what if I mess [something up], what if I switch the machine off accidentally? But if I can do whatever under supervision, then it would be great” (Kisorio & Langley, 2016b, p. 62). This feeling was expected with the complexity of the machines and not having designated time from staff to explain the care plan in detail. Having the continued support and guidance from staff is a common request from the family members. Education in palliative care for families and persons was found beneficial with focusing on symptom management and improving the
quality of life during the duration of an illness (Price, Strodtman, Montagnini, Smith, & Gosh, 2018).

In research-based context where staff experience fewer deaths, they felt unprepared with the dying process. For instance, in the study by Ong et al. (2017), critical care nurses stated feeling less prepared to care for an EOL person. The participants could comprehend the complexity of the care, however due to the lack of “education initiatives” that was available for critical care patients who needed EOL care, some staff did not feel comfortable caring for these types of patients. According to Health Canada (2018), gaps in professional training exist due to fewer specialized HCPs in the field of palliative care. Canadian HCPs have reported the sporadic levels of training offered in palliative care. This places more strain on the “curriculum, development and education and training methods” (Ong et al., 2017, p. 6), putting more focus on the HCPs who practice outside of palliative care.

Bloomer et al. (2019) authoritatively concluded that more should be done to increase clinician awareness and understanding of EOL care. They believed that all organizations should have a mandatory recertification of palliative care, like recertification of CPR and vital assessments. A registered nurse in the study stated “I think it’s absolutely imperative that we have some sort of education that is mandatory every 12 months for end-of-life as well” (Bloomer et al., 2019, p. 168). Mandatory training, in turn will open up more conversation and allow people to think of alternative ways to improve palliative care. The process of implementing change will not occur over night and the buy-in must have the majority of followers to move this positive notion forward in an organization. This is essentially the main purpose of the workshop
presented here- to bring more awareness, creating the space to have these difficult
conversations pertaining to death and dying to make the experience more tolerable;
empowering families and patients to have an active role in the direct care, while making
informed decisions during advanced care planning that are in the best interest for the
patient. The family becomes the voice of the patient once the person loses their ability to
cognitively make their own decisions. Also, HCPs will feel more equipped with
knowledge about how to become better resources for the families and patients involved in
palliative care. Furthermore, at the end of this workshop, I am hoping that families will
feel more informed and have a better understanding of the care during end-of-life care.
Collectively, the workshop is intended to improve the overall quality of life for a patient
suffering with a life-limiting illness.
CHAPTER FOUR: EFFECTIVE STRATEGIES TO NEGATE CHALLENGES EXPERIENCED IN PALLIATIVE CARE

Palliative Care is respectful of, and responsive to, the needs, preferences and values of the person receiving care, their family and other caregivers. It is facilitated by good communication. Individuals and families have personal preferences and varying levels of comfort in discussing, and planning for the dying process. (Health Canada, 2018, p. 15)

The literature review highlighted common challenges that occur during the care of a patient with a life-limiting illness during palliative care using personal experiences from family members and HCPs. The care of a dying patient involves all stakeholders: the patient, family, and HCP. Good communication is a valuable tool to learn how to navigate the trajectory of an illness in palliative care. Kolcaba’s theory of comfort was introduced in Chapter 1 to focus on the premises of this developmental study. The theory of comfort was a nursing theoretical framework developed by Katherine Kolcaba in 1990. This framework incorporated practice in healthcare, education, and research. The theory of comfort’s main priority was attaining holistic comfort as a desirable outcome in healthcare. I believed this theory best described the main purpose of providing and improving the quality of palliative care. At the EOL, maintaining the comfort of a patient in palliative care is paramount for HCPs and families. Kolcaba’s theory of comfort used three forms to further understand the theoretical framework. The three forms are: relief, ease, and transcendence (Petiprin, 2016). In this chapter, I discussed how all three forms coincide with the research and in addition, included some methods that are used in creating the workshop.
During the care of a patient with a life-limiting illness, there are numerous factors that contribute to the overall care of the patient. When palliative care is provided for the patient, the care should adopt a holistic approach. Krinsky, Murillo, and Johnson (2014) introduce the contexts of the theory of comfort which focuses on the entirety of the patient: “The four contexts in which comfort is experienced are physical, psychospiritual, environmental, and sociocultural” (Krinsky et al., 2014, p. 148). The physical context addresses the body internally and homeostatic mechanisms; the psychospiritual context pertains to true awareness of self; the environmental context pertains to the outside surroundings and pertinent condition; the sociocultural refers to the interprofessional and social relationships. The breakdown of these contexts will hopefully broaden the understanding of the concepts that make up Kolcaba’s theory of comfort.

The understanding of the complexity of palliative care can be challenging. Palliative care can essentially be viewed as an umbrella that consists of life-limiting illness, symptom management, advanced care planning, EOL care, hospice care, bereavement care, active treatment, and improved quality of care. Although the topic of palliative care is broad, the rest of the paper will emphasize the importance of advanced care planning for a patient with a life-limiting illness; improving the delivery of symptom management through education; provide strategies of introducing a conversation about an EOL patient in palliative care; ultimately focusing on the main factors that can improve the overall quality of care with effective communication between staff and family and creating competent staff through the use of education.

At this moment, I would like to clearly identify the difference between palliative care and EOL care. I feel palliative care has been defined throughout the literature, but
EOL was simply considered as a part of this specific care, which in hindsight there is some truth to the assumption. It is important to understand that EOL does not necessarily occur in the moment before the last breath or when the heart’s beating has ceased. According to the National Institute of Aging (2017), “end-of-life care is the term used to describe the support and medical care given during the time surrounding death” (para. 6). Older adults in palliative care at the EOL was the focus of my literature review. This general population tends to live with more comorbidities and may need a lot more complex care for days, weeks, or even months before patients’ final hours of death. This experience is generally unique for all families and patients involved in this care. Thus, EOL experience is different for all patients. This is one of the reasons why even with all the expertise exhibited by HCPs, attending physicians sometimes will have the expected date of death incorrect due to the uniqueness of the illness. This is what I have found in my experience as a palliative care nurse. The care might be prolonged and the needs of the patient may drastically change during the palliative care journey. Throughout the palliative care journey, referring back to the theory of comfort and the forms and context that coexist within the theory, it is crucial to fully understand the paradigms of palliative care as it relates to the education initiatives that will be covered in the workshop.

**The Comfort Theory Applied to the Palliative Care Journey**

Attaining relief in the comfort theory is the beginning of the journey. Placing a loved one in palliative care once the individual has received a poor prognosis is never an easy decision to make. Inclusion of family members is crucial in the care of a patient with a life-limiting illness. This would include the values, goals and preferences of the family and patient during the decision-making process. The family members essentially become the voice of the patient when they lose the capacity to make their own decisions.
independently. Hudson et al. (2015) stated that the WHO advocated for the importance of improving quality of care for patients and also included families as well. The principle of family centered may seem foreign to some HCPs, however, patient-centered care should involve the family. Thus, “the principle of family centered care and the inclusion of family carer satisfaction with end-of-life health care is advocated as a key indicator of hospital performance” (Hudson et al., 2015, p. 7). During the decision-making process, the physician discusses the options available with the patient and families directly involved. However, once the conscious decision has been made to place the patient in palliative care, the challenging decisions have just begun.

Since everyone’s journey is different, assumptions of care should not be made; the patient and family should be completely involved and have the right to refuse any treatment according to the law in Canada. The relief form of comfort theory entails meeting the needs of the patient. If the patient is no longer able to have full control of their treatment, how can an individual ensure that their goals/wishes are respected and followed, feeling a sense of relief in the time of need? The importance of creating discourse about advanced care planning is key to ensuring one’s own wishes, views, and preferences are respected at the EOL care, hoping to give a sense of relief. This conversation can occur in a family meeting with all the important stakeholders involved. This conversation is encouraged to be completed as early as possible to ensure that the patient can participate in the decisions made for their care.

**The Relief in Knowing the Patient’s Voice Is Heard With ACP**

Decisions about the care at EOL are not an everyday discussion that individuals become accustomed to. For instance, making a decision about what to have for dinner, or what will be your next job endeavour, or what destination will you travel to next. All of
these examples have an intriguing answer and most individuals are looking forward to discovering the answers through the use of brainstorming. However, when the decision is planning the treatments and care required for the last weeks of living, this can become daunting and overwhelming. If a patient has been diagnosed with a life-limiting disease, advanced care planning (ACP) is definitely recommended. The ACP is completed by a capable individual, allowing them to have full control over their plan of care. The key word is capable; in advanced care planning, “capable adults have the right to express wishes through oral or written advance directives that provide instructions about their healthcare choices during a time of future incapacity” (Canadian Hospice Palliative Care Association, 2012, p. 7). ACP was discussed earlier in Chapter 2, but I will elaborate and clarify to draw more emphasis to the purpose of this process.

ACP is a conversation about a person’s values and beliefs; decisions surrounding one’s own wishes; goals of care at EOL; having the freedom to refuse or consent to any treatment of care; and appointing a substitute decision maker (SDM). The person can then begin to think about who will be included in this conversation such as family members, friends, HCPs, or even lawyers to draw up the papers about the will and finalize the power of attorney documents. In addition, the completion of an advanced directive and appointing one as the SDM may also be completed in the ACP process (Canadian Hospice Palliative Care Association, 2012). Why is ACP important? Life in general is very unpredictable and without any warning; an individual may find themselves in an unimaginable situation, where the person is no longer functioning in the normal capacity and have to rely on others to perform basic activities. At this point does anyone know the individual’s wishes? Who will make the decisions for that individual suffering with a life limiting illness (SDM)?
The benefits of ACP and consents are the following: Improves patient and family satisfaction with EOL care keeping the care inclusive—patient/family centered care; this conversation reduces the caregiver burden of care- the families will have confidence in speaking for the person once they are deemed incapable of communicating their wishes; decreases the opportunities for unwanted life-sustaining treatments- dealing with futile medical treatments; and the person has a higher quality of life and death (Hospice Palliative Care [HPCO], 2019). Advanced care planning allows the individual to reflect and communicate their wishes for their medical care in the future. In addition, the individual is planning on who will become their Substitute decision maker/Power of Attorney to speak on their behalf when they are no longer able to communicate their own wishes. According to Speak Up, (2016) “this plan would only be used if you are not capable of speaking for yourself. You can also change it at any time” (p. 4).

This is an ongoing process and one’s wishes can change at any point of time. Engaging in this conversation will ideally provide individuals with a sense of satisfaction and relief in knowing their voice has been heard in communicating their wishes for certain treatments at the EOL. Educating the community about the different players who are involved in the process and how to begin the conversation are important elements that were incorporated in my workshop in order for individuals to understand the value of ensuring that wishes are expressed through having the conversation during the ACP process. This in turn empowers the person and family, which will improve the overall quality of care for the dying person.

I hope this information helps give a better understanding of the importance of planning prior to admission or referral into palliative care. However, this cannot be completed if the HCP involved in the planning lacks the skills in initiating the
conversation within the hospital setting. In the hospital setting, the HCPs would generally be involved. Pfeifer and Head (2018) developed strategies in order to initiate the conversation about EOL care between patient, family, and HCPs. Before the conversation begins, Pfeifer and Head stated that one goal clinicians must achieve before engaging in discourse is completing their own homework, preparing themselves for the difficult content that needs to be discussed. Clinicians must arrive prepared in knowing the background of the patient (e.g., diagnosis, medical history, present condition). Also, it may be necessary to collaborate with other experts in the field to gain more knowledge of the palliative care and specific treatment options prior to the conversation. In addition, establishing a trusting relationship is crucial between all parties involved including patients, families, and HCPs. Furthermore, ensuring a safe and comfortable environment is key in order for individuals to openly share their wishes and ask questions, without the fear of feeling judged. “When planning a conversation related to the EOL, using a who, what, when, where, and how structure can be helpful” (Pfeifer & Head, 2018, p. 726). This concept of the five Ws is a very common abbreviation applied in many scenarios of life; however, the authors’ use of the five Ws in this context was very enlightening.

The Five Ws Strategy for the Conversation in End-of-Life

The concept of the Five Ws strategy for the conversation at the end-of-life encompasses the needs of the patient. Beginning with the question who, ensuring that the person has the required support system in their corner, it is always important to be aware of who will be a part of this conversation including the names and the relation to the patient. Different understandings and perspectives of death and the expectations of care from family members involved may cause conflicts derailing the discussion. Entering into this conversation may cause old wounds or trauma to resurface, making the
conversation more emotionally charged. Using a professional mediator, social worker or chaplain to assist in certain situations, may be beneficial and allow for everyone’s voice to be heard and validated (Pfeifer & Head, 2018). Working together as a team and concluding with final decisions with care helps ensure that everyone is on the same page and the patient is satisfied with their goals of care; knowing that they can be changed throughout the process. The question \textit{what} is pertaining specifically to the topic that will be discussed according to the clinician. Two questions are crucial to engage the patient and family. The first question is asking what the patient knows about his/her own diagnosis and the second question is regarding how much information the person would like from the clinician (Pfeifer & Head, 2018). This in turn will gage the conversation, exploring what the person knows about their illness and how comfortable they are with receiving more information.

Utilizing more open-ended questions will allow the patient and family to feel heard as they engage in the conversation, inquiring more about specific information. Bélanger et al. (2014) found that “conversations regarding death involved indirect questions that prompted patients to express their understanding of their condition. This discursive practice has been suggested in previous palliative care communication guidelines” (p. 14). Always being sensitive to the condition and showing compassion and empathy are important elements of a conversation about a patient’s future plans. The question \textit{when} is regarding the right time to engage in EOL discussion with the patient and family members with the full workload of HCPs. These types of conversations should never be rushed, patients and family members need time to process the information, inquire, make suggestions and think of a plan that works for them. The
question *where* pertains to the type of environment. For instance, family meetings are an effective environment to have a productive discussion. Although family meetings are not practiced in every organization, this should be implemented as an initial conversation for all stakeholders involved in advanced care planning. Francois et al. (2017) and Hudson et al. (2015) encouraged the practice of family meetings, which promoted engaging in conversation to resolve any misunderstandings about the care and allowing for the clarification of the goal of care to take place. The last question to address is *how*. Pfeifer and Hand (2018) stated the *how* focuses on “semistructured discussion plans [which] usually work best. … It is important to remember that the patient is the most important team member and that his or her preferences and informational needs guide the meeting” (p. 727). The goal is to take the time to listen to the patient and family to ensure that their wishes are clearly communicated and understood. When there is a misunderstanding of the required care the person and family would like performed, challenges/conflicts about the care could surface accompanied with increased stress, anxiety, and fear. The next section focuses on strategies for individuals involved in the EOL, providing valuable tools to feel at ease with the care.

**Reducing the Stress and Anxiety to Feel at Ease**

What causes challenges to occur during palliative care between family members and HCPs? Some challenges occur due to the unsatisfied expectations of the care from the families. Communication difficulties was a common barrier between families and HCPs. The expectation from families did not match the care that was provided or there was no appropriate conversation to discuss what was occurring. Francois et al., (2017) found that conflict was also identified as “mismatched expectations” (p. 1464).
According to Kubler’s stages of grief, anyone can begin the grieving process at any time. The stages of grief are denial, anger, bargaining, depression, and acceptance, and this concept should be considered when a conversation is taking place regarding care for a person with a terminal illness. Taking into account the different stages of the grieving process, would allow HCPs to become more empathetic with their approach in communicating about the plan of care during EOL.

Within the care of a person in a palliative setting at the EOL, the “management of pain and other symptoms is an important part of high-quality palliative care and an integral component of the individualized care plan” (Health Quality Ontario, 2018, p. 28). Throughout the trajectory of a person with a life limiting illness, many changes can occur with the person’s condition. As the change occurs this may also change the person’s original wishes. Furthermore, the assessment of pain management and other symptoms should be an ongoing process to ensure that the interdisciplinary team is aware of the updated goals of care through consistent conversation between HCPs and individual (with life-limiting illness) and family.

In Francois et al. (2017), the conflict model was used in the workshop to further understand the reason for conflicts between staff and relatives in palliative care. Appendix B illustrates this model, which was derived from the data collected in Francois et al. (2017). I feel this conflict model gives an accurate description of the concept of conflict by stating “that the data point to conflict as [an] emotional expression, which is managed by validating but not internalising emotions and responding systemically, such as through use of family meetings” (Francois et al., 2017, p. 1460). How do others perceive conflict while caring for a person in palliative care? The perceptions of others
involved in the care is explored in the workshop prior to introducing this model. Identifying and understanding the different challenges/conflicts that occur with delivering symptom management is important in order to think of effective strategies to overcome these challenges in the future. Majority of the literature emphasized the need for increased education for both HCPs and family members while caring for a patient in the hospital setting at EOL in order to have a deeper understanding of the care provided and engage in important conversations about the goals of care to ensure all needs are met for patient and family.

In this workshop, I discussed comfort measures provided in the hospital setting and the physiological changes that occur in the last hours of living; the consistent support needed for families and HCPs; provided a better understanding that this setting is a place to finish living and not a place to die and incorporated more resources for bereaved family members such as legacy work. According to the SOHPCEP (2013),

The Model to guide Hospice Palliative Care based on National principles and Norms of Practice has two very important concepts underpinning many education programs developed in Canada. Those concepts are the Domains of issues and the Process of Providing Care. Those two concepts together are the basis for the Square of Care. (p. 30).

Within the process of providing care, there are different levels of service models unique to meeting an individual’s needs. The four levels consist of primary care service providers who are responsible for managing the disease and ensuring the patient and family’s needs are met throughout the illness trajectory and at EOL. At the secondary level, consultants support primary care providers with facilitating educational programs
for the providers. At the tertiary level, consultants support the secondary level and primary providers. The fourth level comprises the care of the person and family. For the purpose of the workshop, I will be focusing on the tertiary level and the care of the person and family (fourth level).

The domains of issues associated with illness and bereavement are the following: disease mismanagement, physical, physiological, social, loss and grief, spiritual, practical, EOL care and death management, and family and person characteristics. For the purpose of the workshop, I focused on the literature review as it corresponded with the domains of issues associated with illness and bereavement. Both models are illustrated in Appendices C and D, respectively. I used this model as another framework to facilitate the content regarding the palliative care pedagogy in my workshop.

Identifying the issues that cause the conflicts and challenges coincides with the causes in the model of conflict (Francois et al., 2017), which is discussed below.

**The Domains of Issues Associated With Illness and Bereavement**

Referring back to the model discussed in Francois et al. (2017), conflict was considered an emotion and the first point highlighted the mismatch expectations and sub-optimal communication with care. The disease management will be specific to the individual’s prognosis. The trajectory is different for each individual dying with a life-limiting illness.

**Disease management domain.** These are issues derived from a lack of information; this information can be disclosed privately in a safe space where advanced care planning can take place, and the appropriate questions and concerns are addressed regarding the disease process and required treatment, in turn addressing the warning signs
from the model of conflict (Francois et al., 2017). Lack of communication was another conflict that was expressed in the research. Strategies with improving communication are the use of effective assessment tools to further explain the condition of the person. The two tools I highlighted were Palliative Performance Scale (PPS) and the Edmonton Symptom Assessment System (ESAS), which are used throughout the palliative care trajectory. The PPS looks at the illness trajectory in stages by measuring the person’s performance status. Within the PPS “there are three stages, Stable stage: when the score ranges from 100%-70%, Transitional Stage when the score ranges from 60%-40% and then End-of-life Stage when the score ranges from 30%-0%” (SOHPCEP, 2013, p. 40). It is important to note that the PPS assessment tool can only be completed by a regulated HCP. The ESAS “is one best way to get an overall sense of how the person is experiencing his or her illness” (SOHPCEP, 2013, p. 55). This tool is essentially used to help assess symptoms such as pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. Furthermore, anyone is able to use this assessment tool. The patient will generally be describing the severity of the symptom, but if a patient is unable to respond, the family will step in as the voice for the patient through an objective point of view.

Building a strong therapeutic relationship between the person, family, and HCPs is crucial to establish trust in knowing that the care provided is aligned with the goals of care of the person. Common language is another effective strategy, using simpler terms and refraining from using jargon when explaining important information. Collecting valuable information about the patient and family’s issues, making the family feel more at ease, acknowledging family members and addressing their concerns is also very
important. Promoting consistent engagement of family members and patients are ideal for the overall quality of care.

Concordant consultation was introduced in Caswell et al. (2015) as a communication model. Concordance involved encouraging empowerment and autonomy in the person’s own care and moving away from the compliance to physician’s advice (Caswell et al., 2015). “A concordant model of communication views the consultation between the clinician and patient as one in which a negotiated exchange takes place, in which the patient is able to participate fully and share her or his perspectives on offered diagnosis and treatments” (Caswell et al., 2015, p. 12). Health teaching as a form of education is important. I included the common physiological changes in the body at the EOL within the workshop. Moreover, the last strategy includes listening. “The most vital role of the communicator is to be a good listener. We effectively communicate with others and build solid relationships when we take the time and energy to listen to what is being said (SOHPCEP, 2013, p. 26).

**Physical domain.** The physical domain contributed to the challenges experienced, which consisted of delivering symptom management within the hospital setting. According to Health Quality Ontario (2018), under the Quality standard, the common symptoms that are experienced by a person suffering with a life-limiting illness are the following: “agitation, anxiety, changes in respiratory patterns and increased secretions, constipation, dehydration, delirium, depression, diarrhea, fatigue, nausea, pain, poor appetite, and vomiting” (p. 29). Communication is a key factor between family and HCPs before initiating any intervention (e.g., pharmacological or nonpharmacological). In cases regarding pain, some families felt their loved one was not
receiving enough or some were afraid of the severe side-effects or adverse effects of the strong medications (e.g., opioids). Again, the use of open-ended questions to explore the overall concern was paramount. Why do you feel your loved one is not receiving enough pain medication? What are the signs? Why do you feel your loved one does not need this pain medication? Coming from a place of empathy can have a positive impact when caring for a person with a life limiting illness and family. In the workshop, the common palliative medications delivered for comfort measures was identified.

Another common fear and concern which caused conflict when providing care is the reduced need for fluids and nutrition for a dying patient due to low appetite, resulting in the person refusing to or being unable to eat. It is important to note that “as death approaches, people often experience a decrease in appetite with little or no interest in food and drink. They may be unable to digest food or to take fluids by mouth” (Victoria Island Hospice, 2011, p. 2). At this point, comfort is required with mouth care and repositioning. Thus, discussion about nutrition is valuable near the end in the goals of care to address what the family and team working together would feel is best for the patient at this time. How to use this tool is discussed in the workshop. Finding more tools in order for staff to effectively communicate to the family and also including effective assessment tools into the care are beneficial for the care of the patient. Other symptom management identified within the literature included sedation and agitation. In the workshop, I reviewed the common medical interventions that are needed to manage these symptoms during palliative care.

**Psychological, social, practical, and spiritual domains.** This domain reflects the holistic approach of the patient. What is their own perception of death? Is emotional
support provided during this difficult time? Are cultural values, beliefs, and spirituality taken into consideration when caring for a patient? One common fear of patients with life-limiting illness is becoming a burden to their family members. Family members may need to be reminded that caring for their dying loved one is not their sole responsibility. They are family first before the caregivers (Healthy Quality Ontario, 2016). Based on my research, I believe that taking care of a dying person is a combined effort from both families and HCPs. In the hospital setting, encouraging as much family involvement is important to promote inclusiveness of care. However, it is important to minimize the emotional burden of care or caregiver burden. Another main conflict was the lack of emotional support received from medical staff. At times families felt a sense of abandoned, which was frightening and caused increased anxiety and fear (Baillie et al., 2018). In healthcare, there is a need to revisit the core values of kindness, humanity, and respect. The feeling of abandonment is an example of revisiting “feeling hurt and internalising” (Francois et al, 2017, p.1462) an emotion, which was outlined in the conflict model as a consequence from the lack of emotional support. “Something as simple as “engaging in therapeutic conversation with the person and family can reduce anxiety and isolation, enhance a person’s sense of dignity, clarify understanding, inform decision-making, build a relationship of trust, improve pain and symptom management and prevent conflict” (SOHPCEP, 2013, p.92). A nursing staff suggested in their response that support from other disciplines such as social workers, psychologists, counsellors, and church leaders are also welcomed to come and assess, reassure, pray and calm the situation putting the family at ease (Kisorio & Langley, 2016). Ensuring that the care is holistic and every domain was addressed was essentially for the care of the person
with a life-limiting illness. In regards to the support of nurses, another participant stated
the need for nurses to have debriefing or counselling (having someone to talk to) post
death of a patient. Nurses report the need for more support in dealing with dying patients
on a daily basis (Kisorio & Langley, 2016). The last two domains are discussed in the last
form of comfort transcendence.

The Feeling of Transcendence and Overcoming the Challenges With Support

This final form represents resilience in overcoming the challenges experienced in
palliative care. The bereaved family are grieving and dealing with loss.

End-of-life care/death management and loss and grief. This is a part of the
care trajectory that needs the most support. How are the families coping with
the dying process? In the workshop, I discussed the stages of grief using Kubler’s model
and further describe the differences between acute, chronic and anticipatory grief. Also, I
introduced legacy creation/legacy work/legacy activities. According to Allen et al.
(2008), “legacy activities [are] projects that may: (1) assist individuals and families in
initiating the process of life review and (2) result in a product that can be enjoyed by
family and friends prior to and after the individual’s death” (p. 1030). This concept
enables people with the life-limiting illness to tell their own personal story that can live
on (leaving a legacy). In the workshop, I gave examples of legacy activities and the
benefits with these activities (e.g., increasing positive dialogue for the person with the
life-limiting illness). The SOHPCEP (2013) stated that “supporting the person and family
in looking back, reviewing life events and milestones can help the person to identify
meaning. Education about the dying process for the person, family and caregiver is very
important” (p. 144); this would help individuals feel more prepared for the dying process.
The SOHPCEP promoted the idea of meaningful-focused coping. In addition, I provided some easily accessible resources to help support the bereaved family members at the end of the workshop.

Improving the overall quality of care for the person and family is possible with consistent integration of different strategies to ensure the person and family are comfortable and satisfied with the care provided; feeling more prepared for death and having a better understanding of the importance of continued conversation about the decisions made during end of life care in the hospital setting is the main goal. In the following chapter, I discussed the design of the program; incorporating certain methods regarding pedagogy theories; the length of the workshop; the accessibility; the preferred type of program; and the consideration of different types of learning as it pertains to palliative care pedagogy.
CHAPTER FIVE: DESIGNING A WORKSHOP ABOUT PALLIATIVE CARE PEDAGOGY TAILORED TO ADULT LEARNERS

Due to the different types of learners that exist in a classroom setting, teachers are becoming more open-minded to constructive approaches including *flipped classrooms* where students practice their agency and take more control over their learning experiences (Smith, 2017). This, in a way, takes the burden off the teachers and allows the students to explore and discover new knowledge and learn from each other. The teacher becomes a facilitator and coaches the students through the learning process. Constructive approaches promote meaningful learning that moves away from rote learning. I believe rote learning hinders the full learning experience, where the student uses techniques such as memorizing to learn the content but is unable to retain the information to transfer the knowledge in other settings. In regards to Blooms Taxonomy, rote learning is considered a lower level of thinking (Ganapathy, 2014).

Different aspects of learning affect the overall experience for a specific adult learner. This chapter highlights the importance of identifying different types of adult learners and learning theories to understand which theories would be most applicable for this specific workshop. In addition, I discussed the reason for choosing a workshop format to facilitate the information pertaining to palliative care pedagogy. The chapter continues on to integrate the concepts utilized within designing the program, including the finalized workshop Part 1 (online) and Part 2 (face to face), and describes the duration of the workshop and the accessibility.

In this workshop, recognizing the diversity in learners will promote inclusivity in a learning environment. As an educator developing this workshop, the question that
remained was: How do I discover when learning is taking place? Later in this chapter, I discussed how the transfer of learning occurred within the workshop and the use of a specific post questionnaire which would become the measurable tool in evaluating the degree of learning. Within this workshop, my goal was to achieve significant learning which involved meaningful learning. Merriam and Caffarella (1999) referred to Freedom to Learn in the 80s by Carl Rogers, who described his own theory of significant learning, which resulted in personal growth and development. Significant learning according to Rogers had the following characteristics: personal involvement—ensuring there is consistent participation from students; self-initiated—inately discovering the unknown; pervasive—changing one’s own way of thinking through the learning experience; evaluated by the learner—is this information beneficial and lastly essence in meaning—meaningful learning.

According to Mayer (2002), meaningful learning is viewed as an important educational goal, where students “build the knowledge and cognitive processes needed for successful problem solving” (p. 227). In the cognitive process, Blooms Taxonomy is utilized to expand on one’s critical thinking and gain a deeper understanding of the content. The use of these characteristics of significant learning and Blooms Taxonomy framework in learning helped develop the content and questions, which would foster a classroom of active learning and enhanced critical thinking. In addition, as mentioned earlier, the workshop integrated a flipped classroom approach. According to Smith (2017),

In a flipped classroom, students experience enhanced learning of course content through small group activities, class discussions, and student presentations. In
addition to lecturing, instructors spend more time assisting students with the
learning process, opening up their classrooms to new possibilities and ideas.
Students can then build on their knowledge of the information through in-class
activities created by the instructor. (p. 20)
The flipped learning concept also involves the students receiving content prior to the
learning session, preparing them with the prior knowledge that assists in completing the
innovative activities. The workshop follows this format with two parts. The first part of
the workshop consists of the course content which involves independent learning. Then
the second part consists of class discussion and small group activities allowing the
participants to collaborate and critically think of new ideas and solutions to participate in
the activities.

Building a community of learners was imperative to create a space where transfer
of knowledge was occurring in the workshop. In a learning environment, the transfer of
knowledge can either result in passive learning or active learning. Passive learning
generally occurs when students are being lectured at (receive information) or there is a
lack of engagement (no application) and as a result, fails to foster a positive learning
experience. However, the style of teaching continues to move from a traditional style of
teaching to a more progressive style of teaching where active learning can take place and
student centered is encouraged. Moreover, this workshop mirrors an interactive session
where the individuals are capable of exploring their own previous knowledge of the topic
and expand on their capacity of knowledge with the content promoting active learning.
The use of case scenarios, class activities, and incorporating class discussion in a
presentation format was utilized to facilitate Part 2 of the workshop. Srirachroen, Yuksen,
Sittichanbuncha’s (2015) looked at the advantages and disadvantages of different methods of teaching including workshops with medical students. The results indicated that workshops improved the academic performance of medical students based on their increased satisfaction in their learning experience during emergency medicine education. Sricharoen et al. (2015) stated that “a workshop is a teaching method that emphasizes student-teacher interaction in real situations. Students have time to think, analyze, and apply their knowledge to the problems they encounter” (p. 77). Although some teaching methods seem very mundane in educational institutions, determining which method was most suitable to facilitate the content was important during the process of developing this workshop.

Throughout this workshop, I focused on the participants previous personal experience and active learning (e.g., interaction, engagement) to ensure that overall satisfaction was accomplished. After completing part 2 of the workshop, I would welcome anonymous opinions on how the workshop could improve the learning outcome in the post questionnaire. As an educator, it is important to consider the space where the workshop would be held. In considering this crucial factor, I was hoping to build a safe environment to discuss the difficult questions about EOL in palliative care. As an educator, the hierarchy of power is important to understand when facilitating the workshop. Most individuals may feel that the teacher is equipped with evidence-based knowledge and the individuals are the students receiving information to learn and gain new insightful knowledge. Moreover, opening up the discussion with questions related to the content will give more autonomy to individuals’ learning experience. Essentially, this would encourage a learning environment that is tailored for adult education.
What constitutes adult education? Many theorists have offered their own definitions of adult education. Darkenwald and Merriam (1982) defined adult education as a “process whereby persons whose major social roles and characteristics of adult status undertake systematic and sustained learning activities for the purpose of bringing about changes in knowledge, attitudes, values, or skills” (Myers, Conte, & Rubenson, 2014, p.28). I believe adult education is a given choice to pursue in learning the unknown and inquire about previous knowledge for clarification. The following section provides an overview of the different types of learning and the theoretical framework of adult pedagogy that will shape the development of the workshop.

Different Types of Learning and Learning Theories

Since the 20th century, education has been viewed by many theorists as a complex concept, where learning is an integral part of the educational process. Education was viewed as a movement. What must education involve? This is a very broad question, but I felt this needed to be addressed. Jarvis (2010) formulated “three sets of criteria for consideration as a basis for education” (p. 40) and conceptualized education to involve the following:

- a learning process which is institutionalized but should not be a single event;
- a planned rather than a haphazard process;
- an essentially humanistic process because knowledge is humanistic and because the process involves human beings as learners and also maybe as teachers. (p. 40)

In my own interpretation of these criteria, I believe they had a strong correlation with the different types of learning and learning situations, which were identified in this literature. The two types of learning identified within the literature were intended and incidental
learning outcomes and the types of learning situations were *formal, non-formal, and informal*. I found Jarvis’s (2010) figure titled Possible Learning Situations to be fascinating. It described how the different types of learning are depicted in different types of situations (see Appendix E). For the purpose of this workshop, I focused on figure’s Box B—a non-formal education also known as non-formal learning situations where learning is intended. Also, Box B referred to the learning that is continuous and takes place in a general community, organization, conference, et cetera. In these types of environments, the learner is occasionally mentored. A common example would be facilitating a concept from the workshop (e.g., the need for advanced care planning in palliative care) in the community and incorporating the use of case scenarios in order for individuals to participate by brainstorming and thinking of solutions to apply what they have learned throughout the workshop (intended learning).

Community education includes non-formal learning, which was one of the main purposes in developing this resource. According to Jarvis (2010), Fletcher suggested that there are three premises in community education: 1) The community has its needs and common causes and is the maker of its own culture. 2) Educational resources are to be dedicated to the articulation of needs and common causes. 3) Education is an activity in which there is an interplay between the roles of student, teacher and person. (p. 56)

The workshop was developed using these guidelines to ensure learning was occurring. I wanted learners not only to learn from the educator but also from themselves in discovering new novel ideas and from each other within the classroom setting. Improving the practice in the healthcare field is key. How would I, as the educator, implement this
practice of incorporating valuable tools and strategies to navigate the trajectory of palliative care (EOL) in one’s practice? The uniqueness of each individual dealing with a life-limiting illness makes it difficult to assume everyone’s experience will be similar. Thus, the care is individually specific and constantly changing with the decisions being made during the EOL process in palliative care. Effective communication and providing the safe space to discuss the plan of care for EOL between the HCPs and family members/patients was important to convey in the content displayed in the workshop. With ongoing discussions within one’s care, this would ultimately help the families and patients’ voices to be heard and address any concerns regarding the care. Moreover, taking the time to have a formal family meeting is also helpful and families are encouraged to discuss the care plan once the patient begins to decline and the condition has changed. Family meetings are pertinent in the care of an individual with a life-limiting illness to address any mismatched expectations and confusion in order to help prevent any challenges that may arise during care in a hospital setting.

Learning in of itself is an “existential phenomenon—it is intrinsic to our being and to a great extent it is experiential, although in pre-conscious learning we have to recognize that some of our experiences may actually be precognitive and pre-conscious” (Jarvis, 2010, p. 38). With this in mind for the development of the workshop, how can this workshop integrate individuals’ past experiences to build on their previous knowledge? Dewey’s view of knowledge was enlightening. “Dewey claimed that knowledge is essentially humanistic in quality not because it is human products in the past, but because of what it does in liberating human intelligence a human sympathy” (Jarvis, 2010, p. 41). Essentially, in this workshop, empowering one’s way of thinking
and giving the individuals a sense of autonomy through their own intrinsic learning was a desired goal to achieve. The learner becomes responsible for meeting their own needs of learning by seeking and acquiring new knowledge. This humanistic concept of learning would be encouraged in an adult classroom environment.

In directing my focus on adult learners, I have to keep in mind the differences between the culture in an adults’ classroom setting as oppose to a children’s classroom setting. The difference of the two classrooms would be due to the level of maturity and other factors that may affect the culture of the classroom. As Merriam (2001) stated, In an “adult” classroom, adults feel accepted, respected, and supported; further, there exists a spirit of mutuality between teachers and students as joint inquirers. And because adults manage other aspects of their lives, they are capable of directing, or at least assisting in panning, their own learning. (p. 5)

However, what type of learning will assist in providing a humanist theoretical way of learning accompanied by a constructivist way of learning? There is the strong need for empowerment with the knowledge that one is interested in obtaining. Individuals’ past experience has an influence on their ability to learn new information. As adult learners, taking the initiative and embarking in a new learning journey to expand one’s own previous knowledge is admirable.

Maslow (1970) highlighted the correlation between the theory of human motivation and hierarchy of needs (Merriam & Caffarella, 1999, p. 257). Learners must be motivated to continue searching for the unknown and acquiring new valuable information needed within their daily lives. According to Merriam and Caffarella (1999), from a learning theory perspective, humanism emphasizes that perceptions are
centered in experience, as well as the freedom and responsibility to become what one is capable of becoming. These tenets underlie much of adult learning theory that stresses the self-directedness of adults and value of experience in the learning process. (pp. 256-257)

The freedom of choice as an adult learner in taking control of what they learn was important to consider. “Self-directedness” in learning within this workshop was incorporated through the use of questions and exploring what the learner’s previous understanding of palliative care pedagogy consisted of and what challenges HCPs have experienced during EOL care. The main focus would consist of effective communication through the ongoing discussions in the decision-making process with the care provided. The following section discusses the constructivist theory, which was another learning theory that helped in developing this workshop.

Krahenbuhl (2016) stated that constructivism illustrates knowledge as “a meaning-making process through which learners construct individual interpretations of their experiences and thus construct meaning in their minds” (p. 100). Students feel liberated in becoming emancipated from the traditional culture of teaching and feel the need to master their own learning ability. The process of engagement and finding meaning in one’s learning yields active inquiry within the learning process. Creating a sense of autonomy and uniqueness in one’s learning is important with the development of the workshop. As the educator, I am more of a facilitator or guide, coaching the students through the learning experience, allowing them to have full responsibility of meeting their own learning needs. Essentially the attainable goal is to encourage self-directed learning. Is this a practical goal in ensuring that all individual learning needs are met
within the workshop? Finding the common interest in one’s learning will assist in ensuring that learning is taking place. Life experiences motivates one to learn more within the world of knowledge.

Within this workshop, I am hoping the outcome will improve the general palliative care practice and increase awareness about continuously fostering a safe environment and incorporate this acronym ‘ADD’ as a guideline prior to palliative care. ADD was an acronym I created, which was formulated to act as a helpful guide to reduce the challenges expressed throughout the literature review in Chapter 2. The acronym represents: Advanced care planning (creating a safe space to plan); having the difficult Discussion (promoting continuous effective communication throughout the care between staff and families and patients); resulting in Delivering the required care to ensure that the patient’s wishes are respected and followed throughout the plan of care when the individual is deemed EOL. The following section discusses the need for the product; process of development; implementation and evaluation.

**The Need for the Workshop**

The need for this workshop was apparent through the literature review. A shift in the culture regarding death and dying was essential. There was a gap in knowledge about pertinent conversations regarding the EOL experience (i.e., what to expect) and how to approach these discussions effectively. This gap was evident through the various challenges witnessed in palliative care. Effective communication was a consistent challenge observed in palliative care, which was voiced from family members and HCPs. Due to the lack of conversation, there was potential for confusion and disappointment in the quality of care provided. Throughout the EOL process, more patients and family
members are faced with difficult decisions to make about the plan of care for a patient suffering with a life-limiting illness. Increasing awareness for the importance of ADD will be one of the focal points in the workshop. As mentioned in Chapter 1,

A cultural shift in how we talk about death and dying is required to facilitate acceptance and understanding of what palliative care is and how it can positively impact people's lives. The integration of palliative care at the early stages of life-limiting illness facilitates this culture shift by supporting meaningful discussions among those affected, their families and caregivers regarding care that is consistent with their values and preferences. (Health Canada, 2019, p. 15)

The cultural shift and having the discussion is needed. Within the workshop, different perspectives about palliative care and EOL would be explored and the content may enlighten and evoke a new way of thinking about this specific care.

What does EOL entail during palliative care? Due to the uniqueness of care for individuals with a life-limiting illness, the workshop will be targeted for the HCPs in this specialized field to feel comfortable and better equipped with the knowledge in having the important discussions to address EOL in palliative care with the families and patients. Towsley et al. (2015) stated that “conversations did not commonly include discussion of a living will/AD, preferences for code status or hospitalization, use of hospice, or other care practices such as patients’ wishes and values” (p. 8). Thus, it’s not just having the conversation, as a HCP; it’s understanding what to discuss to obtain the pertinent information from the patient and family in order to provide the necessary care to meet the overall needs of an individual suffering with a life-limiting illness. Also, continuous support throughout the process with both family members and HCPs is crucial to cope
with the anticipated outcome of the patient’s hospitalization. Towsley et al. also stated that “education and training for all staff is critical for developing skills to facilitate EOL conversations” (p. 13), hence the need for my educational workshop.

My first main focus was establishing the audience directed for the content. The most efficient way to improve the overall practice of caring for the EOL patient in a hospital setting was to direct my focus on HCPs in order for them to understand the value of family involvement. I am more knowledgeable about this sector due to my background in the field. My fellow colleagues have also expressed how beneficial this workshop would be for their practice. In collaborating with the family while caring for a patient with a life-limiting illness, treating the entire patient holistically is the ultimate goal. Providing this workshop will enable the HCPs to: become aware of the conflicts and misunderstanding that may occur with providing EOL care for the elderly in a hospital setting; create a safe space to discuss the individual’s wishes when capable regarding the plan of care; allow the patient and family to have full control over the care provided; become better resources for the family members; and feel more equipped to support the family through this time.

Through the literature review, communication difficulties were the main barriers between families and HCPs when delivering care for a dying person. In my experience in a hospital setting, trying to allocate time to discuss the EOL care with the family sometimes appeared impossible. The only time I had was approximately 10 minutes in the patient’s room or out in the hallway with the family between the care of five other patients. New practice should integrate family meetings throughout the care especially once the patient begins to decline and is moving from a palliative state to an EOL state.
This will help the family address any major concerns and iron out any confusion with the patient’s current condition. These meetings would last for approximately an hour with the concern previously documented, in order for the HCPs to enter into the meeting prepared with some solutions. Continuous effective communication about the EOL process and the required care is vital to ensure that all stakeholders involved are cohesive with the decisions made about the care provided.

**The Process in Designing the Workshop**

The process in designing the workshop took some special consideration in deciding which information was important and relevant to the research and palliative care to create the practical tools to navigate through this process. How would I achieve my goal of meaningful learning? The use of Bloom’s Taxonomy framework was useful in developing the overall questions within my workshop to ensure that learning has effectively taken place. Bloom’s Taxonomy consists of six categories ranging from simple to more complex level of leaning. The six categories are the following: knowledge, understanding, application, analysis, synthesis, and evaluation. The workshop would use a flipped classroom approach, which was discussed earlier in this chapter. Integrating this innovative concept would allow the students in the class to independently prepare for the workshop ahead of time to become familiarized with the course content. Classrooms then become more interactive and students are challenging their level of thinking in order to remember and retain the knowledge learned and apply the information in a different context. This in turn would re-emphasize the importance of active learning within the learning environment. I believe meaningful learning takes place once students have achieved the highest level of learning within the Blooms Taxonomy
framework, where the individuals have mastered the new skill/knowledge obtained trusting their own judgement and feeling competent in using this skill in different settings.

The content needed to review prior to the workshop is presented later in this chapter. Part 1 of the workshop, which is online, has modules to separate each topic and part 2 contains the interactive segment, which is face to face. The content provided to the participants would help them navigate and understand the practical tools being used within the workshop, increasing the participation during the session. The use of scenarios, critical thinking questions, role playing, and discussion would help encourage a higher level of thinking to ensure that the transfer of knowledge has taken place and the experience was more meaningful to the learner. At the end of the workshop, I have developed an evaluation section to assess how well this workshop has effectively improved HCPs understanding about palliative care.

**Detailed Step-by-Step Description of Workshop Part 1 and Part 2**

I begin the workshop by indicating the objectives of the workshop. This reflects what the participants will learn and take away from the content and activities. I have divided the workshop into two sections: Part 1 was the content formulated to review independently prior to the second section (Part 2) which involved activities promoting more interaction and collaboration—engaging the audience. The content in the document was outlined by using important definitions, models, figures, and assessment tools that are utilized within EOL and palliative care. As discussed earlier, Part 1 was separated into modules. I organized and prioritized my ideas; the first module needed to begin with defining the two types of care (palliative care and hospice care) in order to differentiate
the two forms of care that tend to be misunderstood. In the interactive portion of the workshop, exploring participants’ definition of palliative care and hospice care was important in order for the material to help expand their knowledge or clarify questions about the care provided.

The second module discusses the challenges experienced in palliative care, utilizing the constructivist theory of learning by allowing participants to use their own prior experience to collaborate and learn from each other. In this module, I briefly introduce an acronym that I created as a guideline to follow in order to improve one’s own practice in palliative care. The phrase including the acronym was “ADD this to your daily practice in palliative care,” which would be discussed in further detail in module 4.

Module 3 in the content further describes Kolcaba’s theory of comfort and how this theory relates to palliative care. The conversation is a difficult discussion to start in palliative care and the content elaborates on “How to start the conversation” including the “Five Ws strategy” to assist HCPs with the conversation at the EOL to obtain important information regarding the plan of care. Also, I included different models, assessment tools, and coping skills that could be implemented into practice. Amongst the content, the three assessment tools that would be used and supplied to the audience as handouts are the PPS, ESAS-R, and PACSLAC assessment tools which are also found in Appendix F.

Module 4 was an interesting module to create because it emphasized the new acronym that I wanted individuals to remember when caring for an individual at the EOL in palliative care. The acronym was ADD, which stood for Advanced care planning, ongoing Discussion, which hopefully would result in appropriate Delivery of care. These
strategies would be useful and the additional content would hopefully build on individuals’ prior knowledge.

Module 5 was a basic review of what to expect with a patient at the EOL, which covered the common physiological changes that occur at the EOL in palliative care. I believed this was important to include, in order to have a general understanding of the process and assist HCPs in becoming better equipped with discussing the dying process with family members. In the final module (module 6), I was able to incorporate a list of resources for the bereaved and HCPs working with patients in palliative care. Constant support is needed to help all individuals develop coping skills when dealing with the loss to become more resilient. I am hoping that individuals have the humanistic need to learn more about the journey of palliative care, and after attending the palliative care pedagogical workshop, individuals would feel more empowered and expand on their previous knowledge about EOL care in a palliative setting. As HCPs and caregivers, promoting dignity, quality, and comfort for individuals finishing their journey of living is a priority.

According to Cafarrella (2002), “adults, for the most part, are pragmatic in their learning. They want to apply what their learning to present situations” (p. 39).

Furthermore, the use of activities in Part 2 of the workshop was to enhance one’s own knowledge, understanding, application, analysis, synthesis, and evaluation to reflect Bloom’s Taxonomy framework. Part 2 consists of the interactive section of the workshop, which would encourage continuous engagement with the audience, exploring their own previous knowledge while building on their own personal meaning from the content learned in Part 1. My instructional segment would be through the use of
scenarios, role playing, and general critical thinking questions, which would allow the audience to actively participate within the workshop. The activities are broken into the same modules discussed in Part 1 and reflect the content accordingly. The use of scenarios and questions was purposeful because “participants are more motivated to learn when a variety of instructional methods are used” (Caffarella, 2002, p. 39). The following section contains the document, which is PART 1 of the workshop.
The Journey to Finish Living: Practical Tools to Overcome Challenges Experienced During End-of-Life in Palliative Care (Part 1)

By: Chiedu Nwaesei

Date: December, 21, 2019
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OBJECTIVES

- Define the difference between Hospice and Palliative Care.
- Identify challenges within palliative care
- Learn about Kolcaba's Theory of Comfort and how to incorporate the theory into the practice of palliative care.
- Learn helpful strategies to negate these challenges, understand why these conflicts occur (e.g., ADD)
- Understand the value of Advanced Care Planning
- Improve the overall practice of end-of-life care of a senior in a hospital setting through effective communication and the appropriate use of assessment tools and
- Review what physiological changes occur at the end-of-life
- Identify different resources for Bereaved family members and Healthcare professionals
MODULE 1
THE DIFFERENCE BETWEEN HOSPICE AND PALLIATIVE CARE

Hospice Care

- “Focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible” (American Cancer Society, 2019, para. 1).
  - This form of care is generally suggested when treatments have failed and the prognosis is 6 months or less to live.

Palliative Care

- “An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening 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” (World Health Organization, 2019, para. 1).

- The duration of Palliation is unpredictable, as healthcare providers and caregivers, promoting dignity, quality and comfort for an individual finishing their journey of living is the priority.

- End-of-Life care is a part of Palliative Care when patient’s condition deteriorates, but not all palliative patients result in death.

- Hudson et al. (2015) stated “the WHO advocates that palliative care should not only improve the quality of life for patients but also for their families” (p. 7).

- “Family centered care and the inclusion of family carer satisfaction with end-of-life health care is advocated as a key indicator of hospital performance” (Hudson et al., 2015, p. 7).
End of Life

- According to the National Institute of Aging (2017), “end-of-life care is the term used to describe the support and medical care given during the time surrounding death” (para. 6).
  - End-of-life does not necessarily occur in the moment before the last breath or the heart beating has ceased, this period can last for days, weeks, or even months before death.

  **How would you define Hospice and Palliative care?**
MODULE 2
WHAT ARE SOME CHALLENGES YOU MAY HAVE EXPERIENCED WHEN PROVIDING PALLIATIVE CARE IN A HOSPITAL SETTING?

Common Challenges Identified in the Literature:

- Communication between family and healthcare professionals (overarching theme)
- Delivering effective Symptom management / Comfort measures for a Dying person (Unmet expectations)
- The lack of emotional support for families and healthcare professionals
- Feeling unequipped for the care involved during palliative care resulting in conflict

Note: ADD (Advanced care planning, Discussion, and Delivery of care) is a guideline that has been created in addition to help in addressing these challenges, which will be discussed later in detail in Module 4.

As a healthcare professional can you relate to any of these challenges? If so, how did you solve the conflict?
KOLCABA'S THEORY OF COMFORT AND HOW THIS THEORY RELATES TO PALLIATIVE CARE

Kolcaba’s Comfort Theory

- Nursing theoretical framework that was created by Katherine Kolcaba in 1990.
- This framework incorporated practice in healthcare, education, and research.
- Prioritizes attaining holistic comfort as a desirable outcome in healthcare. This theory best describes the main purpose of providing and improving the quality of palliative care.
- At the end-of-life, maintaining the comfort of a patient in palliative care is paramount for healthcare professionals and families.
- Kolcaba’s theory of comfort used three forms to further understand the theoretical framework. The three forms are: relief, ease, and transcendence (Petiprin, 2016).
- Relief is ensuring the specific needs of the patient and family members are met (e.g., holistic approach including spiritual, physical, and emotional).
- Ease is a feeling of contentment, is experienced when the anxiety and stress is reduced during the end-of-life process in palliative care.
- The last form of transcendence, where healthcare professionals, patient, and family members are able to rise above any challenges and overcome them while developing coping skills.

The Context of Comfort Theory

The Holistic Approach

- Krinsky, Murillo, and Johnson (2014) introduced contexts of the theory of comfort which focuses on the entirety of the patient.
- “The four contexts in which comfort is experienced are physical, psychospiritual, environmental, and sociocultural” (Krinsky et al., 2014).
  - Physical context addresses the body internally and homeostatic mechanisms;
  - Psychospiritual context pertains to true awareness of self
  - Environmental context is pertaining to the outside surroundings and pertinent condition
  - Sociocultural refers to the inter-professional and social relationships.
The Value of Advanced Care Planning

The Relief in knowing that the Patient’s Voice is heard with ACP

What is Advanced Care Planning (ACP)?

• ACP is a conversation/process that allows “capable adults [to] have the right to express wishes [including one's own values and beliefs] through oral or written advance directives that provide instructions about their healthcare choices during a time of future incapacity” (Advanced Care Planning in Canada, 2012, p. 7).

• A Substitute Decision Maker is appointed by the individual, giving them permission to make medical decisions on their behalf.

• The key word is CAPABLE, this document is only used when the individual loses the capacity to make their own decisions, changes can be made at any time by individual or SDM, nothing is set in stone.

• Empowering the patient and family in taking control of the care of the individual suffering with a life-limiting illness.

• Having this care planned prior to hospitalization, gives the HCP and family a clearer idea of the individuals wishes in order to be more prepared, and provide/meet the necessary needs before it’s too late (e.g., request for the last rights performed by chaplain).

Start the Conversation

Who is involved in the conversation?

• The individual diagnosed with the life-limiting illness

• Family or friends who are deemed important to the individual to be present in the conversation

• Healthcare professionals

• ALL THE STAKEHOLDERS INVOLVED IN THE CARE
How is the conversation recorded?

- Written or verbal documentation of the individuals wishes.
- The advanced care plan can be changed at anytime throughout the end-of-life process (decisions are constantly being made).
- The individual should continue to reflect on the ACP to ensure the wishes are still aligned with the expected care.
- Creating a safe and trusting environment is key.

Note: It’s not just having the conversation, as a healthcare professional, it’s understanding what to discuss to obtain the pertinent information from the patient and family in order to provide the necessary care to meet the overall needs of an individual suffering with a life-limiting illness.

The Five W’s Strategy for the conversation in End-of-Life

- **WHO** is involved in the care according to the individual?
- **WHAT** is the topic of discussion according to the clinician? (Two questions are crucial to engage the patient and family. The first question is asking what the patient knows about his/her owns diagnosis and the second question is regarding how much information the person would like from the clinician (Pfeifer & Head, 2018). The use of OPEN-ended questions will help explore what the individual understands about their illness.
- **WHEN** is it the right time to have these discussions? (Are the individuals and family members ready or prepared to have the conversation? Before patient is placed in Palliative care?).
- **WHERE** can this conversation take place? Family meetings are encouraged throughout care and effective to ensure that the wishes of the individual and family is carried through based on the condition of the patient.
- **HOW** focuses on semi-structured discussion plans. The goal is to take the time to listen to the patient and family to ensure that their wishes are clearly communicated and understood.
Questions to guide the thinking process for Advanced Care Planning

1. What do I value most in terms of my mental and physical health? (For example, being able to live independently, being able to recognize others, being able to communicate with others.)

2. What would make prolonging life unacceptable for me? (For example, not being able to communicate with those around me, being kept alive with machines but with no chance of survival, not having control of my bodily functions.)

3. When I think about death, I worry about certain things happening (For example, struggling to breathe, being in pain, being alone, losing my dignity, etc.)

4. If I were nearing death, what would I want to make the end more peaceful for me? (For example, family and friends nearby, dying at home, having spiritual rituals performed, etc.)

5. Do I have any spiritual or religious beliefs that would affect my care at the end of life? (For example, certain beliefs about the use of certain medical procedures) (Speak Up, 2016).

Note: Understanding the purpose of Advanced care planning, utilizing the 5Ws to help start the conversation of end-of-life planning and the questions that will help guide the EOL process, will result in reducing the stress and anxiety experienced by the HCP and family members involved in the care.

Reducing the Stress and Anxiety to Feel at Ease

How do we address conflict with a person in palliative care? Why do conflicts tend to cause stress and anxiety when providing palliative care?

Here are some solutions, models and tools to reduce stress and anxiety to feel at ease:

- Communication difficulties were the main barriers between families and healthcare professionals when delivering care for a dying patient.

- Conflict occurred when expectation from families did not match the care that was provided or there was no appropriate conversation to discuss what was occurring.

- As a healthcare professional, it’s important to consider the Kübler’s stages of Grief when a conversation is initiated.

At any point of time individuals and family members may experience these stages of grief: denial, anger, bargaining, depression and acceptance including anticipatory grief. –
• Common language is another effective strategy, using simpler terms and refraining from using jargon when explaining important information.

• It's important to collect valuable information from the patient and family regarding the issue to make the patient and family feel at ease and satisfied that the concern has been acknowledged and addressed.

• Take advantage of the people that make up the care, and collaborate with team members, family members, chaplain, etc.

• Building a strong therapeutic relationship between the person, family and HCPs are crucial to establishing trust in knowing that the care provided is aligned with the goals of care for the person.

• Once the trust has been established discussing certain treatments such as comfort measures and common palliative medications are critical within end-of-life care. These comfort measures include but are not limited to: pain management, oral fluids, mouth care, treatment of fever, oxygen administration, and suctioning. The common palliative medications include but are not limited to: midazolam, scopolamine, hydromorphone, haldol, dexamethasone, and sandostatin.
The Models and Assessment Tools

Conflict Model

- In Francois et al. (2017), a model was used to further understand the reason for conflicts between staff and relatives in palliative care.

- This model gives a description of conflict by stating “that the data point to conflict as [an] emotional expression, which is managed by validating but not internalising emotions and responding systemically, such as through use of family meetings” (p. 1460).

- “Managed by validating but not internalising the emotions.” This is easier said than done when dealing with an already emotional situation with a loved one who is dying. However, consistent effective communication through family meetings can help families express their feelings and concerns by addressing the plan of care with healthcare professionals. Hudson et al. (2015) stated “open discussions between health professionals and family carers are an effective way of providing psychological support” (p. 2).

The Conflict Model
Communication Model

- Concordant consultation was introduced in Caswell et al. (2015) as a communication model.

- Concordance involved encouraging empowerment and autonomy in the person's own care and moving away from the compliance to physician’s advice (Caswell et al., 2015).

- “A concordant model of communication views the consultation between the clinician and patient as one in which a negotiated exchange takes place [an understanding], in which the patient is able to participate fully and share her or his perspectives on offered diagnosis and treatments” (Caswell et al., 2015, p. 12).

Note: These models will be helpful to effectively communicate and understand the conflict in order to address the conflict.
Assessment Tools

- The Palliative Performance scale (PPS) looks at the illness trajectory in stages by measuring the person’s performance status in 10% increments (only Registered staff can use this tool).
  - Within the PPS “there are three stages, Stable stage: when the score ranges from 100%-70%, Transitional Stage: when the score ranges from 60%-40% and then End-of-life Stage when the score ranges from 30%-0%” (Southwestern Ontario Hospice Palliative Care Education Program, 2013, p. 40).

- The Edmonton Symptom Assessment System (ESAS-R) “is one best way to get an overall sense of how the person is experiencing his or her illness” (Southern Ontario Hospice Palliative Care Education Program, 2013, p. 55).
  - Repeated use of this tool may help to track changes in symptom severity over time.
  - This tool is essentially used to help assess symptoms such as pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well being, and shortness of breath.

- Furthermore, anyone capable can use this assessment tool or family members involved in care.

More Assessment Tools

Pain is perceived differently from each individual

- OPQRSTU Symptom Assessment tool is used to guide a systematic assessment of identified symptoms. This tool can help ensure consistent and comprehensive symptom assessment in palliative care.

- Nurses must thoroughly assess each symptom

  - Onset - When did the Pain begin?
  - Palliation (provokes) - What brings the pain on? What makes the pain better?
  - Quality - Can you describe the pain?
  - Radiates - Where is the pain located? Where does it spread?
• **Severity** - What is the intensity of this symptom? E.g., Use Pain scale 0-10 to rate the severity of pain

• **Treatment** - What medications are you currently using? Was the treatment effective?

• **Understanding** - What do you believe is causing this symptom?

• **Value** - What is your comfort goal?

For a patient who is unable to communicate their pain.

• PACSLAC is used which stands for Pain Assessment Checklist for seniors with Limited ability to communicate according to the Hotel Dieu Shaver policy

**The Feeling of Transcendence and Overcoming the Challenges With Support**

• This final form represents resilience in overcoming the challenges experienced in palliative care. The bereaved family are grieving and dealing with loss.

• This is a part of the palliative care trajectory that needs the most support.

• Again, the Kübler stages of grief should be considered through the support process. There are different types of grief acute, chronic and anticipatory.

• **Acute grief**: that occurs shortly after loss.

• **Chronic grief**: prolonged and more intense.

• **Anticipatory grief**: begins at the initial stage when the terminal illness is diagnosed.

How are the family and staff being supported through this difficult time?

*In order to answer this question, I believe it’s important to understand that compassion fatigue does exist, and there are different types of coping mechanisms used, but for the purpose of this workshop, I have focused on the use of legacy work and meaningful-focused coping, which have helped individuals cope during this difficult time.*
Compassion Fatigue Exists/Caregiver Burden

- In their analysis of the concept of caregiver burden, Choi and Seo (2019) defined the term as “a multidimensional concept, [which] is attributed to the perception of physical symptoms, psychological distress, impaired social relationships, spiritual distress, and financial crisis that arise from caregiving tasks or care demands” (p. 287).

- Salmond et al. (2017) defined compassion fatigue as an emotional state that occurs when “nurses continually connect with persons who are suffering and absorbing the person's trauma or pain or when nurses care for traumatized persons and re-experience traumatic events” (p. 1805).

- CF is labeled as a state of exhaustion—physically, spiritually and emotionally; feeling less empathetic and more irritable with people.

- The symptoms displayed in some cases are having low energy; feeling empty or numb to situations which are common responses; having nothing left to give; slowly depleting or withering away; being approached with constant questions and having no answers (Southern Ontario Hospice Palliative Care Education Program, 2013, p. 178).

- Salmond et al. (2017) stated the lack in understanding the magnitude of CF caused HCPs to have difficulties in identifying the symptoms, which resulted in finding less solutions with developing coping skills in their nursing practice.

- The need for balance between work and personal life is important; having someone to talk to as an outlet and more education about CF/Burden of care can yield a positive outcome and prevent more episodes of CF from occurring.

Legacy Work

- According to Allen et al. (2008), “legacy activities [are] projects that may: (1) assist individuals and families in initiating the process of life review and (2) result in a product that can be enjoyed by family and friends prior to and after the individual’s death (p. 1030).

- This concept enabled people with the life limiting illness to tell their own personal story that can live on (leaving a legacy behind) essentially these activities are created to keep the memories alive for example: legacy recording, scrapbook, photo album, compilation of recipes of traditional meals into a book, plant a tree.

- http://www.hospicewaterloo.ca/legacy-activities/
Meaningful-Focused Coping

- “Meaning-focused coping does not attempt to change a problematic situation, nor does it directly decrease the pressure caused by negative emotions or distress. Instead, MFC aims to change the evaluation of a situation and to make beliefs, goals, and stressful situations more consistent so that individuals are more open to dealing with stressful situations” (Guo, Gan, & Tong, 2011).

- It makes the individual reflect on the situation and re-evaluate the experience - Ask questions such as “what part of that event was meaningful to me?”

- This results in a more positive experience and the individual becomes resilient, building on their coping skills, which is the goal.
MODULE 4

REMEMBER TO ADD THIS AS A GUIDELINE TO YOUR DAILY PRACTICE WITH PALLIATIVE CARE!

ADD stands for - Advanced care planning, ongoing Discussion, and lastly hopefully this would result in appropriate Delivery of care. This was more of a guideline to help navigate through the trajectory of palliative care.

Advanced Care Planning

The benefits of advanced care planning and consents, listed in The Hospice Palliative Care Ontario (2019), summarized the main points.

- First point highlighted the WHO approach mentioned earlier in Hudson et al. (2015) with family centered and person-centered care, by improving patient and family satisfaction with EOL care by keeping the care inclusive.
- Secondly, this conversation reduces the caregiver burden of care- the families will have confidence in making the decisions for the person once incapable.
- Third point refers to decreasing the opportunities for unwanted life-sustaining treatments- dealing with futile medical treatments.
- Fourth, increase the chances of dying in a preferred setting.
- Lastly, reducing the cost of supplies and resources for the healthcare system (e.g., transfusing blood to a patient at end-of-life). I will stress the fact that “this plan would only be used if you are not capable of speaking for yourself. You can also change it at any time” (Speak Up, 2016, p. 4). This is an ongoing process and one’s wishes can change at any point of time.
- As mentioned earlier, the 5W’s in starting the conversation about end-of-life and incorporating the questions which will guide the discussion about advanced care planning will be beneficial within the plan of care of a patient suffering with a life limiting illness.

Discussion

- Promoting continuous effective communication throughout the care between staff and families and patients are important for the ongoing decision-making to occur.
- FAMILY MEETINGS are encouraged in practice to discuss family and patients concerns with healthcare professionals.
• Attempt to have the discussion as early as possible in order to give the person (patient) an opportunity to participate in their own care, which may, in turn, help to reduce conflicts from arising.

• Compassion and empathy are personality traits that are essential when dealing with a dying person.

• With more discussion about death the culture will change and the conversation will become less stigmatized.

• Discussion about wishes (values and beliefs) with the stakeholders that the patient would like included in their care is key.

• End-of-life care is unique to the individual.

• The voice of the individual with the life-limiting illness will be heard by communicating one's own wishes and reduce the stress and anxiety experienced during care.

**Delivering the Required Care**

• To ensure patient wishes are respected and followed through the plan of care at the end of life.

• REMINDER: That the individual’s wishes can be changed at any time throughout the process.

• When the patient is incapable of making their own decisions, their Substitute Decision maker steps in as their voice. At this point, the Advanced Care plan would be implemented into the care.

• Pain and other Symptom management are important and when the wishes of the individual are communicated effectively this helps to guide the care according to the individual.

• In delivering the required care aligned with the individual’s wishes, stakeholders achieve transcendence in overcoming challenges with caring for a patient in palliative care.

• Within the delivery of care, as healthcare professionals, understanding the common physiological changes that occur at the end-of-life is important to include with health teaching. Also, including available support services for bereaved family members once the journey to finish living has occurred is beneficial.
MODULE 5
WHAT ARE THE COMMON PHYSIOLOGICAL CHANGES THAT OCCUR AT THE END-OF-LIFE DURING PALLIATIVE CARE?

Mental/Emotional Changes
The patient may exhibit the following:

• Withdraw, become quieter, less interested in what they may have enjoyed
• Sleeping more (may not wake up if you talk to them)
• Becomes confused at times
• Decline in all their senses, but their hearing is the last to go
• Restless, attempting to climb out of bed or hallucinating
• Begin making funeral plans and giving away their possessions (some individuals just know when their journey of living is coming to an end)

Haliburton Highland Health Services, 2018

Physical Changes

• Skin is cool to touch & appears pale
• A low-grade fever
• Increased changes in breathing pauses may be longer & more frequent (periods of apnea), breathing may be noisier (shallow breathing or laboured)
• Pulse may be rapid, irregular or weak.
• Discolouration that may look like bruising (“mottling”) begins usually on the feet and lower legs; this is because of slowing circulation—it does not hurt
• Noisy breathing is caused by a weakened cough reflex. The Patient may have difficulty in clearing his or her throat. This little bit of mucous can sound very loud! It usually does not cause the dying person distress or discomfort (death rattle).
• Pupils may dilate (get bigger)

Haliburton Highland Health Services, 2018
These are some resources to refer to but they are not limited to the list below; more resources can be found in the Framework on Palliative care in Canada:

- **Canadian Virtual Hospice** - Free online support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators.

- **Caregiver Compass** - Is a free and easy to access online resource that provides tips and tools to help caregivers manage their care-giving responsibilities, navigate the health care system, and deal with financial and legal matters.

- **Death Duola/End of Life Duola** - provides emotional, educational and practical support.

- **MyGrief.ca** - Free online grief and bereavement resources for Canadians

- **Victoria Hospice (Victoria, BC)** - offers a psychological and bereavement program including telephone support; in person counseling; a variety of bereavement support groups and more.

(Framework on Palliative Care in Canada, 2018, pp. 42-43)

In conclusion, by incorporating the Kolcaba’s comfort theory and remembering to ADD these guidelines to one’s practice in palliative care, this will in turn help to improve the overall quality of care with a patient suffering with a life-limiting illness.

Now we will move on to Part 2 of *The Journey to Finish Living: Practical Tools to Overcome Challenges Experienced During End-of-Life in Palliative Care*, an interactive Prezi presentation. Let’s begin!

You will access Part 2 of the workshop in the link below:

- 19 -
Implementation of the Workshop

The workshop will be introduced as a professional development tool for HCPs and available to the public on an online portal as well for an additional resource. This would then cater to all different types of learners. The length of the workshop will be 2 hours. The format of the workshop as discussed earlier will be in two parts to mirror a flipped classroom approach, where students are introduced to the material prior to class and use the classroom time for interactive activities to apply their knowledge. Part 1 will consist of learning content and Part 2 will consist of activities that would roughly take about 10-15 minutes per activity. The most appropriate learning activity would be a combination of face to face in the community and distance learning (online) in order for the workshop to be easily accessible. To incorporate a class discussion online, a forum would be created to ensure there is interaction between the participants at a given time.

At this given time, I would like to introduce three questions to prompt the HCPs in thinking further into the content displayed in Part 1 of the workshop. These questions will be taken up in Part 2 of the workshop, face to face. The questions are as follows: 1) In your own professional experience, was there ever a time you needed to discuss EOL with a family member? Please describe the experience; 2) What type of support do you feel is necessary when compassion fatigue is observed amongst staff or family member? 3) As a HCP, when challenges occur in caring for an EOL patient, how do you deal with the situation at hand?

As an educator, the technique I would use to facilitate the transfer of knowledge would be through the use of combining both coaching and mentoring techniques to encourage the humanistic and constructivist style of learning. My idea is to take the
initiative and pitch my research project to the annual Hospice Palliative Care Conference in Toronto. Then, I would hope to have the opportunity to work in the community and offer my educational workshop to hospice and palliative care facilities.

**Evaluation**

For the evaluation section, I had the opportunity to get some constructive feedback from a family member who is also a registered nurse. The feedback helped me understand which questions would be valuable to receive a strong and useful evaluation of the content learned. One main feedback that was consistent from my family member was the need for a connection from one topic to the next to ensure fluidity within the content of Part 1. Another feedback was ensuring that the objectives followed the order of the content within Part 1. Lastly, she enjoyed the use of the creative acronym (ADD) and felt that this can be used in her own practice. With the revision of material from Part 1 prior to the in-class section (Part 2), my family member felt prepared and comfortable to participate in the interactive portion of the workshop. Also, she gave feedback on the questions and activities in Part 2. Some questions and activities were not completely clear on the expectation that was required from each activity. Thus, clarity and clear wording were consistent with her feedback regarding the interactive portion. Overall, she learned a lot from the material and felt that the questions challenged her to use a higher level of thinking (critical thinking). Although this was only feedback from one HCP, I would hope in the future to seek out further feedback from a broader range of professionals once the workshop is successfully utilized in the community.

I was then able to utilize a questionnaire from Cafarella (2002) and added more questions to discover if the workshop was useful and effective. In creating my evaluation,
Reflective practice allows educators to receive important data to possibly use for future research or improve on the delivery of their workshop. The post questionnaire is presented in Appendix G.
CHAPTER SIX: CONCLUSION—SHIFTING THE CULTURE OF DEATH AND DYING THROUGH THE USE OF EFFECTIVE CONVERSATION

How would this workshop benefit the participant’s own practice in palliative care? The main goal as a HCP is to improve the quality of life during palliative care by focusing on the patient as a whole. Death is a unique experience for every individual and prior to this experience, care may be provided in the form of palliative care in a hospital setting. In the beginning of the paper, I introduced the question, do individuals understand the difference between hospice care and palliative care?

In my own experience as a registered nurse in palliative care and with the evidence portrayed in the literature, most individuals who are admitted with a life-limiting illness into palliative care may not have a clear understanding of the difference between palliative care and hospice care. In addition, their expectations may be misconstrued due to their personal view of death and dying. Thus, if the appropriate planning was not completed prior to admission, family members and HCPs may carry the burden of making the difficult decisions during palliative care. Is there a difference between hospice care and palliative care? In a hospital setting, hospice care is more predictable and the prognosis is 6 months or less to finish living with a terminal illness. On the other hand, palliative care is more unpredictable. Palliative care may last for days, weeks, months, or years with a life-limiting illness. In my research, I have come to realize that hospice care can become a part of palliative care once the illness becomes poor and the elderly patient is declining. EOL care is then introduced. The difficult conversations begin once the patient’s condition becomes more imminent. At this point of care, are families and HCPs prepared for the critical discussions that must take place
throughout the care? Is the care plan aligning with the patient’s wishes? Is there support available for individuals to cope with this emotional period in their lives? If challenges or conflicts occur during care, how can they be addressed or avoided in the future with palliative care pedagogy?

The workshop will help to navigate the trajectory of EOL in palliative care to have a clearer picture of what to expect and how to start the necessary conversation to discuss the plans for an individual with a life-limiting illness when hospitalized. The purpose of the paper was to explore the common challenges that occur with providing EOL care during palliation in a hospital setting for an elderly patient by exploring the lived experiences from families and HCPs. The review of the literature highlighted the gap of knowledge in palliative care, which in turn, presented the need to formulate a workshop regarding palliative care pedagogy.

In the literature review, a meta-ethnographic synthesis approach was used to further explore the central phenomenon of interest. The challenges expressed during palliative care from the participants were candid and detailed. In regards to advanced directives, most of the research argued the importance of incorporating this document into one’s care, while other research stated that this document had minimal impact on the type of care provided. The literature suggests that there is a gap in providing patients with information about advanced care panning and that ongoing conversation was absent from the care provided for an individual suffering with a life-limiting illness. Due to the lack of conversation between patient, family, and HCPs, conflicts occurred which caused challenges in the provision of care. Critical conversation would involve formal discussions among the individual, appointed substitute decision maker (SDM), and
HCPs. Timing is crucial when introducing advanced care planning. Having such conversations early provides the individual diagnosed with the life-limiting illness an opportunity to participate in their own care and express their own beliefs, values, and wishes with any treatments expected throughout care. At any time during care these wishes can be altered or changed by the individual if they are deemed cognitively capable. However, if the patient is no longer capable of making their own medical decisions, the responsibility is left to the SDM or Power of Attorney. This is the sole reason for having these discussions prior to care, to inform family and friends of their wishes in order for their voice to be heard and respected during the care.

The overarching theme within the existing literature was the challenge regarding the communication between families and staff while caring for an individual at EOL. There seemed to be an unintentional disconnect between the care given to patients and family members. The other common challenges expressed in the literature though detailed experiences from family members and HCPs included the delivery of effective symptom management, lack of emotional support for both families and HCPs, and feeling unequipped with providing palliative care. Palliative care is a complex concept that needs further education to close the gap and inform HCPs of the importance of creating a safe environment where individuals can converse about their wishes regarding palliative care.

Individuals endure a rollercoaster of emotions and experience different stages of grief according to the Kübler’s model. The stages of grief (different emotional states) are critical aspects to consider while providing care for the whole person in EOL. The conflict model by Francois et al. (2015) referred to conflict as an emotion which is affected by the “mismatched expectations and sub-optimal communication” (p. 1462). As
HCPs, using a holistic approach with providing care is paramount, which involves caring for the individual as a whole (patient- and family-centered care).

**Implications for Practice**

The workshop helped to highlight the theoretical framework, the important models, assessment tools, strategies, guidelines, and additional content to assist HCPs improve their own practice in palliative care. The theoretical framework used within this paper was Kolcaba’s theory of comfort, which consisted of three forms. Kolcaba’s theory of comfort “is a middle-range theory for health practice, education, and research. This theory has the potential to place comfort in the forefront of healthcare. According to this model, comfort is an immediate desirable outcome of nursing care” (Petiprin, 2016, para. 1). The three forms of comfort are: relief, ease, and transcendence. The first form of relief is ensuring the specific needs of the patient and family members are met (e.g., holistic approach including spiritual, physical, and emotional). The next form of comfort is ease, a feeling of contentment experienced when the anxiety and stress is reduced during the EOL process in palliative care. The last form of transcendence involves HCPs, patient, and family members who are able to rise above any challenges and overcome them while developing coping skills.

These three forms heavily influenced the structure of the paper, which prioritized the strategies that were advanced for palliative care pedagogy. The theory also helped to further understand the purpose of effective communication within the care of an individual at EOL. Another main focal point in the workshop was learning to ADD this guideline to one’s own practice. Effective communication was key in understanding how to start the conversation. The acronym ADD stands for Advanced care planning, ongoing
Discussion, and appropriate Delivery of care. ADD is a guideline to help navigate through the trajectory of palliative care. This workshop conveyed the importance of this guideline. The workshop has mirrored a flipped classroom approach where the participants involved in this session review the required content (in Part 1) prior to attending the interactive portion (class time) of the workshop presented in a Prezi presentation. This approach of facilitating the workshop will help students develop their own autonomy with their learning and expand on their own knowledge by applying what they have learned in the interactive section of the workshop (Part 2). The workshop was tailored to adult learners and the goal was to achieve meaningful learning through the use of both constructivist and humanistic learning approaches. Moreover, individuals must feel motivated and empowered to explore the unknown and take control over their own leaning. This in turn, will foster a positive learning environment.

**Recommendations for Further Research**

There is room for further research, where more studies incorporate unique strategies and research the effectiveness of the strategies based on the feedback from the bereaved family members and HCPs. I would like to see more longitudinal studies document how the family members’, patients’, and HCPs’ experiences vary with the decision-making process as they progress with the EOL journey. Preferably, this research could consist of the same family members, patient, and HCP (continuity of care). That would be interesting to read and elaborate on the existing research. The limitations of the study involved institutional settings and patient demographic. The focus of the setting was the hospital environment and seniors were the patient population of
interest. I would like to reach other patient demographic groups in further research corresponding to death and dying.

In conclusion, the purpose of this paper was to bring more awareness to the importance of having the conversation, and ensuring that there is relief in knowing that the voice of the individual suffering with the life-limiting illness is heard through advanced care planning. Also, within the ongoing discussion, the individual’s values, beliefs, preferences and wishes are being expressed, reducing the overall stress and anxiety for the stakeholders involved. Feeling at ease would be the end goal, with the individual knowing that their wishes are being respected during the provision of care. Finally, with transcendence the individual and family members are coping and becoming resilient with the required support during the palliative care experience. Another kind reminder is to ADD this guideline to one’s own practice prior to the EOL care process in palliative care. Utilize advanced care planning, ongoing effective communication throughout the care, and as a result the delivery of care will reflect the important discussion. In turn, this will help to ultimately change the culture of death and dying, eliminating the stigma, and allowing individuals to feel free with having the conversation to discuss wishes in regards to EOL in palliative care.
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Appendix A

Advanced Directives

Advance Directives
Complex Continuing Care

☐ Advance Directives Declined

☐ Level One (Support/Comfort Care). No CPR. This may include, but not be limited to: • pain management • oral fluids • positioning • mouth care • treatment of fever • oxygen administration • suctioning

Diagnostic interventions and transfer to an acute site/service will not normally be utilized for a patient who requests this level of Advance Directives. Any acute illness or accident not able to be treated on your unit will be addressed on an individual basis according to patient wishes.

☐ Level Two (Support/Comfort Care) and Antibiotics. No CPR. Care measures will include all procedures utilized in Support/Comfort Care as well as the administration of antibiotics if indicated. No CPR.

☐ Level Three – Transfer Upon Order of a Physician to Acute Care Site or Service. No CPR. Assessment would be made in the acute care hospital emergency department/or by most responsible physician and a decision made whether to admit the patient or return him/her to the sending unit or site. If symptoms indicate, the patient would be transferred to an acute care site/service for treatment.

☐ Level Four – Transfer Upon Order by Physician to Acute Care with ACLS, including mechanical ventilation. Transfer to an acute care site or service will be arranged immediately. Cardiopulmonary resuscitation (CPR) will be provided according to ACLS guidelines, and by ambulance personnel.

☐ Specific Instructions

———

** NOTE: Capable patients have the right to change their DNR status at any time. Be aware that if a patient asks for CPR, this overrides any DNR status that has previously been discussed and documented.

Signature of Patient or Substitute Decision Maker __________________________ Date (dmy) ____________

Signature of Witness ________________ Date (dmy) __________________

Signature of Physician ________________ Date (dmy) __________________

Chart Copy – Do Not Destroy

sc/forms/hds/advance.directives.ccc
Appendix B

The Conflict Model

*K. François et al. / Patient Education and Counseling 100 (2017) 1459–1465*

**Fig. 1.** A model of conflict between staff and relatives in palliative care.
Appendix C

Service Delivery Models

Each dying person and family will have unique issues and needs. Primary health care providers have always cared for the dying as part of their role and in many instances are capable of meeting the needs of the person and family. There are, however, situations when more specialized knowledge and skill would be of benefit to the person and family.

Diagram 2.6

Primary Care Service Providers
Responsible for managing the disease, identifying issues and providing for the basic needs of the person and his or her family throughout the illness trajectory and at end-of-life.

Secondary Level Consultants
Experts in hospice palliative care that support primary providers in every setting where persons/families receive care and develop training programs to educate primary providers.

Tertiary Level Consultants
Support secondary experts and primary providers on difficult to manage cases, educate and train secondary and tertiary experts, conduct research and develop advocacy strategies.

The Person and Family
Appendix D

Domains of Issues Associated With Illness and Bereavement

![Diagram of Domains of Issues Associated with Illness and Bereavement]

- **Disease Management**: Primary diagnosis, prognosis, evidence, secondary diagnoses, co-morbidities, adverse events, allergies.
- **Physical**: Pain, level of consciousness, function, safety, aids, senses, physiologic, sexual, fluids, nutrition, wounds, habits.
- **Psychological**: Personality, strengths, behavior, motivation, depression, anxiety, emotions, fears, control, independence.
- **Social**: Cultural values, relationships, isolation, safety, privacy, routines, financial resources, legal, family caregiver protection.
- **End of Life Care/Death Management**: Life closure, gift giving, legacy, preparation, anticipations, personal values, culture.
- **Loss, Grief**: Loss, grief, bereavement planning, mourning.
- **Patient and Family Characteristics**: Demographics, culture, personal values, developmental state.
- **Practical**: Activities of daily living, dependents, telephone access.
- **Spiritual**: Meaning, existential, symbols, icons.

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*Note: This includes a detailed listing on page 91.*
Appendix E

Possible Learning Situations

<table>
<thead>
<tr>
<th>Type of situation</th>
<th>Intended</th>
<th>Incidental</th>
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<tbody>
<tr>
<td>Formal</td>
<td>A</td>
<td>D</td>
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<tr>
<td>Non-formal</td>
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<td>F</td>
</tr>
</tbody>
</table>

*Figure 3.1 Possible learning situations.*

intention was to distinguish it from other forms of lifelong education occurring throughout the world, as the model shown in Figure 3.1 illustrates.

We can now illustrate the type of learning that might occur in each of the six different learning situations shown in Figure 3.1:

1. Box A is *formal education and training* that occurs in an educational institution and any other bureaucratic organization.
2. Box B can refer to the ongoing nature of learning that occurs in places such as the workplace, the community, and so on. Sometimes the learner is actually mentored in these situations.
3. Box C is both *learning in everyday life* and *self-directed learning*. It is the type of learning that we undertake when we decide to teach ourselves to use a computer program, and so on. It can be individual learning or part of a group project.
4. Box D refers to that *incidental learning* that occurs in formal situations, learning that is not always educational, but which the planners of the learning experience did not intend— for example, the realization that the instructor is not really as knowledgeable as we thought, or that the room is badly designed, or that the carer does not really treat me as an autonomous individual, and so on.
5. Box E also refers to *incidental learning* situations in non-formal and informal learning episodes.
6. Box F refers to *learning in everyday life*— to *pre-conscious and pre-cognitive learning*. It often results in tacit knowledge. This box is probably the most common learning situation of all, especially in rapidly changing
### Appendix F

**Assessment Tools**

#### Palliative Performance Scale (PPSv2)

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work, No evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>Normal activity &amp; work, Some evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity with Effort, Some evidence of disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Unable Normal Job/Work, Significant disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable hobby/house work, Significant disease</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50%</td>
<td>Mainly Sit/Lie</td>
<td>Unable to do any work, Extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40%</td>
<td>Mainly in Bed</td>
<td>Unable to do most activity, Extensive disease</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>30%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity, Extensive disease</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>20%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity, Extensive disease</td>
<td>Total Care</td>
<td>Minimal to no care</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity, Extensive disease</td>
<td>Total Care</td>
<td>Mouth care only</td>
<td>Drowsy or Coma +/- Confusion</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### TOOL: EDMONTON SYMPTOM ASSESSMENT SYSTEM (ESAS-R) INSTRUCTIONS FOR USE (MODIFIED AND REVISED)

Please circle the number that best describes how you feel NOW:

<table>
<thead>
<tr>
<th>No pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst possible pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>No tiredness (Tiredness = lack of energy)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst possible tiredness</td>
</tr>
<tr>
<td>Not drowsiness (Drowsiness = feeling sleepy)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst possible drowsiness</td>
</tr>
<tr>
<td>No nausea possible</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst possible nausea</td>
</tr>
<tr>
<td>No lack of appetite</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst possible lack of appetite</td>
</tr>
<tr>
<td>No shortness of breath</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst possible shortness of breath</td>
</tr>
<tr>
<td>No depression (Depression = feeling sad)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst possible depression</td>
</tr>
<tr>
<td>No anxiety (Anxiety = feeling nervous)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst possible anxiety</td>
</tr>
<tr>
<td>Best welling (Well-being = how you feel overall)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst well-being</td>
</tr>
<tr>
<td>Normal bowel function</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Worst possible bowel function</td>
</tr>
</tbody>
</table>

Person’s Name: __________ Date: __________ Time: __________

Used and modified with permission, Regional Palliative Care Program, Edmonton Zone, Alberta Health Services, 2011.
Body Diagram

Please mark on these pictures where it is you hurt.
Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

Use for Patients with cognitive impairment or limited ability to speak. Indicate with a checkmark, which of the items on the PACSLAC list occur during the period of interest. Each checkmark is worth 1 point. The sum of all columns equals the pain score.

**Reason for Assessment:**
- ☐ New Admission
- ☐ Change in condition/Behaviour

**Assessment Date:**

<table>
<thead>
<tr>
<th>Facial Expression</th>
<th>Present</th>
<th>Social/ Personality/Mood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grimacing</td>
<td></td>
<td>Hitting, striking out, pushing people,</td>
</tr>
<tr>
<td>Sad Look</td>
<td></td>
<td>kicking, scratching</td>
</tr>
<tr>
<td>Tightening of facial muscles</td>
<td></td>
<td>Not wanting to be touched</td>
</tr>
<tr>
<td>Change in eye (squinting, increased eye movement, dullness)</td>
<td></td>
<td>Not allowing people near</td>
</tr>
<tr>
<td>Frowning</td>
<td></td>
<td>Throwing objects</td>
</tr>
<tr>
<td>Painful Expression</td>
<td></td>
<td>Angry/Mad</td>
</tr>
<tr>
<td>Grim Face</td>
<td></td>
<td>Increased Confusion</td>
</tr>
<tr>
<td>Grinching Teeth</td>
<td></td>
<td>Anxious</td>
</tr>
<tr>
<td>Wincing</td>
<td></td>
<td>Agitated/upset</td>
</tr>
<tr>
<td>Open mouth</td>
<td></td>
<td>Cranky/Irritable</td>
</tr>
<tr>
<td>Creased Forehead</td>
<td></td>
<td>Frustrated</td>
</tr>
<tr>
<td>Screwing up nose</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity/Body Movement</th>
<th>Present</th>
<th>Other (Physiological Changes/ Eating/ Sleeping Changes/Vocal Behaviours)</th>
<th>Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fidgeting</td>
<td></td>
<td>Pale face</td>
<td></td>
</tr>
<tr>
<td>Pulling away</td>
<td></td>
<td>Flushed, Red face</td>
<td></td>
</tr>
<tr>
<td>Pinching</td>
<td></td>
<td>Teary Eyed</td>
<td></td>
</tr>
<tr>
<td>Restlessness</td>
<td></td>
<td>Sweating</td>
<td></td>
</tr>
<tr>
<td>Pacing</td>
<td></td>
<td>Shaking/Trembling</td>
<td></td>
</tr>
<tr>
<td>Wandering</td>
<td></td>
<td>Cold Clammy</td>
<td></td>
</tr>
<tr>
<td>Trying to leave</td>
<td></td>
<td>Changes in sleep patterns (decreased sleep, increased sleep during the day)</td>
<td></td>
</tr>
<tr>
<td>Refusing to move</td>
<td></td>
<td>Changes in appetite (decrease or increase in appetite)</td>
<td></td>
</tr>
<tr>
<td>Thrashing</td>
<td></td>
<td>Screaming/Yelling</td>
<td></td>
</tr>
<tr>
<td>Decreased activity</td>
<td></td>
<td>Calling out (i.e. for help)</td>
<td></td>
</tr>
<tr>
<td>Refusing medications</td>
<td></td>
<td>Crying</td>
<td></td>
</tr>
<tr>
<td>Moving Slow</td>
<td></td>
<td>A specific sound of vocalization (i.e. &quot;ow&quot; for &quot;ouch&quot;)</td>
<td></td>
</tr>
<tr>
<td>Impulsive Behaviours (repeated movement)</td>
<td></td>
<td>Moaning/ groaning</td>
<td></td>
</tr>
<tr>
<td>Uncooperative / Resistant to care</td>
<td></td>
<td>Mumbling</td>
<td></td>
</tr>
<tr>
<td>Guarding sore area</td>
<td></td>
<td>Grunting</td>
<td></td>
</tr>
<tr>
<td>Holding/rubbing sore area</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clenched Fist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going into fetal position</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strit/Gritted</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Score Interpretation:**
- 0 - 4 = Calm situation, no pain or very mild pain
- 5 - 8 = Moderate amount of pain
- 9 - 11 = Severe Pain
- Greater than 11 = Severe pain and distress

**Care Plan Updated:**

**Signature:**

(Fuchs-Lacelle, S. & Hadjistavropoulos, T., 2004)

**TOTAL OF ALL BOXES**

October 2013

sciforms hs/pain assessment checklist seniors PAC SLAC

CHART COPY – DO NOT DESTROY
## Appendix G

### Participant Post Questionnaire

**The Journey to Finish Living: Practical tools to overcome challenges experienced during End-of-life in Palliative care**

**Date - Tentative**

Please circle the rating that best describe your experience to this session.

1 = Strongly Agree  2 = Agree  3 = Somewhat Agree  4 = Disagree  5 = Strongly Disagree

1. The session objectives were clear and reflected what was learned in the content.

   1  2  3  4  5

2. The instructional techniques (case scenarios, role play, class discussion etc.) were helpful in creating meaning to your learning experience.

   1  2  3  4  5

3. The instructor focused the presentation on the session objectives and used the instructional technique and materials well.

   1  2  3  4  5

4. The overall workshop contributed to my knowledge and or skill base and I feel confident using this in my future practice.

   1  2  3  4  5

5. My learning needs were met with attending this workshop.

   1  2  3  4  5

6. What are some ideas that could have been incorporated into this workshop to improve the overall success of the workshop?