EXPERIENCING DEATH AND DYING DURING A GLOBAL PANDEMIC AT THE ROTARY HOSPICE HOUSE IN PRINCE GEORGE

by

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Abstract

This practicum report is a summary of my experience at the Prince George Rotary Hospice House and a reflection upon the death and dying process during a global pandemic. Aspects of my practicum report are explored via a literature review, time spent at Hospice House and self-reflection on my personal and professional framework. My experience at Hospice House provided me the opportunity to witness death and dying in a home-like environment with full supportive care where the focus was always the guest and family. During this practicum I had the opportunity to wholeheartedly connect with people as they transition into another phase of life while I also supporting families during this difficult time. A common theme that provided comfort to the hospice care team was that perhaps the dying person was transitioning into a beautiful world where their family and friends await their arrival.

The knowledge I gained from this practicum will continue to support my professional practice in acute care, where death and dying are predominate. As I continue my social work journey I am reminded of being open-hearted, being present in the moment with people as they are in pain, and acknowledged that being a part of someone's dying journey is an honour.

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Chapter 1: Introduction

The purpose of this report is to demonstrate what I have learned during my practicum at the Rotary Hospice House. Hereafter, Rotary Hospice House will be referred to as Hospice House. Chapter 1 introduces my focus on death and dying during a global pandemic and identifies major learning objectives. Chapter 2 outlines the practicum setting and discusses the history and philosophy behind Hospice House while describing the population the Program aims to serve. Chapter 3 showcases the theoretical orientations I chose and their implementation during my practicum placement. Chapter 4 provides a literature review to address several aspects of palliative care and their relation to Hospice House. Chapter 5 outlines the major learnings I experienced during the practicum placement and explores implications for personal and professional practice in future. Lastly, Chapter 6 will conclude with my implications for personal and professional practice along with my conclusion.

Introduction to Palliative Care

Palliative care is a specialty service that includes an interdisciplinary team focused on improving the quality of life for those suffering from a serious illness at any stage in its development. It shifts the focus of care from providing aggressive medical interventions to focusing on symptom management and allowing for a natural and dignified death. This type of care gives the health care team the opportunity to manage physical symptoms of pain and distress, while also providing emotional relief to the patient and their family and, ideally, encouraging a spiritual connection within the family. This type of care can be initiated in response to a poor prognosis and can remain the focus of care until the end of life. Palliative care can be delivered in various locations;

however, it is vital to recognize that providing end of life care should be offered within someone's home community near their family and friends. It is also important to acknowledge that Hospice House in Prince George is the only hospice house that serves palliative patients in the Northern Health region. For the focus of this practicum placement and report, I will explore end of-life-care at Hospice House in Prince George. More specifically, this report will demonstrate how I had the opportunity to observe death and dying during this global pandemic and how I will implement these learnings in my future social work practice.

On March 11, 2020, the World Health Organization announced a global pandemic due to the coronavirus disease, also known as COVID-19. This illness is an acute respiratory virus that appears to have originated in Wuhan, China in 2019 (World Health Organization, 2021). There continues to be ongoing research to sort out the details and long-term effects of the disease. Consequently, this report will not focus on the virus itself but will discuss how it has impacted people's emotional, physical, mental, and spiritual well-being during end-of-life care at Hospice House.

COVID-19 rapidly changed the way health care was delivered globally and, specific to this practicum, during the end of a person's life. Before COVID-19, palliative care always strived to provide holistic care by including family members as the main caregivers. Families were known to provide love and affection while also nurturing their loved ones; this was seen as the foundation of healing for many palliative-care patients. Currently, the pandemic has necessitated isolation of families from their dying loved ones to decrease transmission of the virus; predictably, this development has negatively impacted palliative patients. Patients and families now rely more on the health care team as the main caregivers because families have become limited in the level of care they can provide due to public health restrictions, resulting in families providing more virtual support to their loved ones.

The changes in how health care is delivered during the COVID-19 pandemic was initiated by necessity from the tsunami of sick patients who were being admitted to hospitals for intensive care and symptom management arising from the pandemic. Unfortunately, this created a higher risk that palliative patients and their families might catch COVID-19 while in hospital and therefore a transfer to Hospice House was often suggested.

The influx of patients who were infected with COVID-19 resulted in burnout and shifts in staffing levels for many health care professionals. Furthermore, the shift in the delivery of health care resulted in focusing on acute illness while protecting the safety of the health care staff. During this time, the health care system often failed to meet the emotional, mental, and spiritual needs of patients and their families during end-of-life cases (Haut, Leeds & Livingston, 2020). This deficit negatively impacted the way palliative patients died because they were not receiving the level of care they deserved during their final days. The COVID-19 pandemic has also restricted travel, visitor access to facilities, and reduced visiting hours in the hospitals. As a result, palliative care has been forced to incorporate virtual means.

Learning Outcomes

My practicum placement was at the Hospice House, in Prince George, BC. Hospice House was designed to provide pain and symptom management for palliative care patients and provide care for people at the end of their lives when they cannot remain at home. My learning objective for this practicum placement was to understand the core philosophies and value system at Hospice House to develop my clinical social work skills for the time when I would return to hospital social work. In addition, I hoped to understand loss and grief in depth while also being able to provide emotional and practical support to patients, families, and staff members. It was important for me to understand the resources at Hospice House and how these resources could benefit most families when involving community services. Finally, it is important to note that all my learnings were experienced through a global pandemic in which health care was delivered in dramatically altered ways.

I also recognized being at Hospice house for my practicum placement I would encounter some ethical considerations that I would need to be mindful of. During my time at hospice I was mindful that I had been a registered social worker for 10 years working at the hospital and I was now shifting my role to a MSW student. I realized I would need to remind the team I would be working with of the difference in my roles, along with colleagues who phoned Hospice House to send over new referrals.

Here are the main learning goals and the activities that I initially chose as I entered my practicum to help me grow:

1. Understand the Values and Vision of Hospice House

a) I will read any literature published by Hospice House where it describes and elaborates on their core value system. I will discuss this value system with the leadership team and front-line staff in different disciplines at Hospice House to understand their perspectives and how they apply and experience these values.

b) I will review the British Columbia College of Social Workers code of ethics and reflect how these values are similar and congruent with the values at Hospice House.

2. ***Practice Remote and Online Support***

a) As needed, I will provide emotional support to patients' families over the phone or by way of video calls. I acknowledge some patients have been transferred to Hospice House from remote communities and therefore may be feeling isolated from their families. Being isolated can cause unnecessary stress for patients at the end of life. These virtual discussions will help me identify and understand the advantages and disadvantages of virtual support. It is important to be aware that not everyone has access to a phone or other technology for communication. I will do my best to work with families who have limited access to technology, and this may require incorporating other family members who have phone and internet access. This will give me the opportunity to learn more about the ethics involved in remote treatment.

3. ***Understand How the Staff Copes With End-of-Life Situations***

a) I will meet with various staff at Hospice House and seek input from them about their self-care strategies.

b) I will read literature on self-care strategies that staff use in other hospice programs.

c) I will implement self-care strategies that I have learned from staff members.

d) I will keep a journal of my practicum journey including my self-care strategies and reflect on it and discuss it with my placement supervisor at the end of my placement.

4. ***Develop and Implement Healthy Self-Care Strategies***

   a) I will set aside time each week to practice self-care. I will add this into my journal and reflect upon it once my practicum is complete and reflect to see how effective it was.

   b) I will ensure I maintain healthy working boundaries, I will be mindful of dual relationships and boundary violations based on my BCCSW code of ethics.

5. ***Provide Emotional Support to Patients and Families***

   a) I will start by shadowing staff when they provide emotional support to patients and families. Afterward, in private, I will talk with staff members about their interactions with clients to better understand the techniques they used and why.

   b) Once I feel comfortable, and within my scope of practice, I will seek to provide emotional bedside support to patients and families.

   c) I will encourage emotional support for families outside of the patient's room if they require it. Hospice House has ample space indoors and outside to meet with people.

6. ***Become Familiar With Resources Provided at Hospice House***

   a) I will read the website created by Hospice House to explore the range of services they provide.

b) I will discuss with the team what resources are available to them and how the pandemic has impacted staff.

c) Once I am familiar with the existing resources, I will discuss service options with families that they may require while they have a loved one admitted to Hospice House or that they may require later.

7. Understand How Community Services and Hospice House Interact

a) I will seek to understand the types of services contracted out by Hospice House.

b) I will take opportunities to provide community referrals as needed.

8. Understand the Hospice Intake Process for New Patients

a) I will shadow and observe the charge nursing during the intake process.

b) I will ask my questions of the charge nurse after the intake is completed.

9. Understand the Triage System: New Patients and Hospice House

a) I will ask to be a part of the triage system and observe the way staff process referrals.

10. Learn and Apply Terms and Language Used at Hospice House

a) In the first week of my practicum placement, I will ask my direct supervisor at Hospice House about key terms and language they use and those that they avoid using.

b) I will continue to shadow staff and observe the language they use. Identifying appropriate language right away will help me build a strong rapport with the staff, patients, and families. I will make a list of key terms used at Hospice House and explore them on an as-needed basis.

I aimed to develop the skills necessary to provide good palliative care services as a social worker within Hospice House by working through these learning objectives. I wanted to learn to contribute as a part of a multidisciplinary team that focuses solely on the comfort of dying guests and their families. I expected that I would witness the staff overcome and confront difficult situations. I anticipated that I would engage in difficult conversations with guests and family members while providing the necessary support, all while focusing on my self-care. This would be done under supervision from a senior staff member working directly with the guests and their families. Also, including supervision from Erin Anderlini the Hospice House manager and Brenda Drazdoff my MSW consultant who provided feedback to my practice.

Chapter 2: Practicum Setting

This section of my report describes Hospice House. In addition, it outlines how Hospice House was developed and the ongoing efforts to keep the program active. Finally, this section of the report explores the services Hospice House provides and the internal resources it offers. All of these factors played integral roles in my practicum placement at Hospice House.

Why Prince George Rotary Hospice House?

My desire to complete a practicum placement at Hospice House in Prince George, British Columbia (BC), was motivated by my ongoing need to understand and spend quality time with guests, families, and staff who are involved in end-of-life care. The idea was that I gain more knowledge about palliative care and the issues that surfaced or become doubly important during the COVID-19 pandemic, with particular focus on practice in a northern community. Overall, the idea was that the experience I gained at Hospice House would better enable me to work with guests and their families from a grounded, person-centred perspective while continuing to focus on individual needs and recognize that each guest inhabits a unique story and requires an individualized care plan. As we continue to work and study through a global pandemic—one that has affected the way people die by separating families, in my opinion it should never diminish from the dying experience. It was in learning about Hospice House that I recognized that a practicum placement there would provide the most benefit learning experience and help me meet my goals.

Northern Resource

Hospice House is the only palliative care facility in Northern BC. It is located in

Prince George, BC, and situated on the Lheidli T'enneh First Nations territory. Hospice House is a 10-bed home that serves guests from Haida Gwaii to Quesnel, and from the northeast, toward Fort. St. John. Because this is the only hospice facility in the Northern Health region, people come from remote communities to access this specialty service. In the process of relocating for the purpose of accessing hospice care, these guests and family members are being separated from their extended families and informal supports and are likely to spend their last days in an unfamiliar environment. However, they do gain access to formal grief supports within Hospice House.

History of Hospice House

In 1987, Dr. Staniland and nurse Esther DeWitt agreed that the Prince George community would benefit from the provision of a specialized palliative care approach to dying individuals (Prince George Hospice Palliative Care Society, 2019). Shortly after, the National Hospice Palliative Care Association was formed (Prince George Hospice Palliative Care Society, 2019). Esther DeWitt is currently active in the hospice community and was known to train volunteers and family members so they would be better able to provide bedside palliative care in individual patient's homes (Prince George Hospice Palliative Care Society, 2019) The community saw a real need for a hospice where dying individuals could receive appropriate care and die with dignity when they were unable to die at home (Prince George Hospice Palliative Care Society, 2019). Soon after, the Prince George Rotary Club supported the initiation of this project and helped raise $255,000 to purchase the house (Prince George Hospice Palliative Care Society, 2019). The community took pride in this project and built the first freestanding Hospice House in British Columbia, rather than adding additions to other facilities for singular hospice rooms (Prince George Hospice Palliative Care Society, 2019). The development of Hospice House responded to the need for grief support, education, and training, the elements of which were foundational to the services in the program's development (Prince George Hospice Palliative Care Society, 2019).

Over the years, Hospice House expanded its services by increasing its capacity to serve people with a life limiting illness. Simultaneously, community members took on greater responsibility and contributed time, practical support, and financial aid to ensure the expansion of Hospice House was completed (Prince George Hospice Palliative Care Society, 2019). After experiencing the sometimes-devastating impacts of its limited capacity, in 2009 Hospice House had the opportunity to expand its space from 5 beds to 10 with financial support provided by capital campaigns and BC housing (Prince George Hospice Palliative Care Society, 2019). In addition, in 2019 Hospice House launched a campaign called 'caring for our home' that raised funds to enable updating the bedrooms (Prince George Hospice Palliative Care Society, 2019).

Current Philosophies and Value System

Hospice House strives to engage "compassionate staff and volunteers who provide specialized hospice care to meet the needs of the person, families, and community, through bedside care, outreach, grief support, and education" (Prince George Hospice Palliative Care Society, 2019). The work of Hospice House is grounded on the following values: courage, diversity, dignity, integrity, and collaboration (Prince George Hospice Palliative Care Society, 2019). While "fostering personal relationships through patience and understanding," Hospice House "strives to ease pain and provide symptom management to ensure an individual is living as actively as they can with their life-limiting illness" (Prince George Hospice Palliative Care Society, 2019, np). In practical terms, this means providing symptom relief by using medications and non-pharmaceutical techniques to ensure a person can achieve the best quality of life for the remainder of their life. The mission statement of Hospice House is as follows: "To enhance the quality of life and death of individuals experiencing progressive life-threatening illness and help people work through grief and loss by providing supportive programs and services" (Prince George Hospice Palliative Care Society, 2019, np). This statement provided me with a critical guidepost as I completed my practicum placement; it helped me in understanding the fundamental value system undergirding the services performed at Hospice House. Moreover, it is congruent with my belief system with respect to providing holistic care.

Client Population

Hospice House provides direct patient care to individuals who are living with a life limiting illness. Staff take pride in providing emotional and practical support to families who may be struggling with the loss of their loved ones.

The client population services provided at Hospice House range from symptom management care, respite care, and end-of-life care for anyone with a life-limiting illness (Prince George Hospice Palliative Care Society, 2019). Symptom management care involves assessing a guest who appears in physical distress and providing relief with the help of specialized nurses. This approach may require an interdisciplinary team that involves the guest's family physician, nurse, counsellor, grief support worker, and family (Prince George Hospice Palliative Care Society, 2019). Admittance of such guests to Hospice House is considered short-term; the goal of treatment is to alleviate symptoms so the guest can return home.

Hospice House is run with the understanding that caring for someone full-time can be stressful. Therefore, respite care is also provided through Hospice House and it is recognized as an integral part of palliative care (Prince George Hospice Palliative Care Society, 2019). Respite care provides relief to families and enables them to maintain healthy coping strategies in their daily lives and thus bolsters stability. When guests are admitted for respite care, families are welcome to be present at Hospice House while allowing the care team to provide needed support; alternatively, families have the option to stay home while the care team provides emotional and practical support to the guest (Prince George Hospice Palliative Care Society, 2019).

Lastly, end-of-life care is provided to guests in their final weeks, days, and hours of life. Care offered at this time seeks to provide symptom management to ensure someone experiences the best quality of life possible. During this final stage, families are welcome to partake in end-of-life support but are given the opportunity to not partake if they cannot be present and there is no judgment if families cannot be involved. During this phase, families are provided with grief support and efforts are made to ensure they do not feel they are alone (Prince George Hospice Palliative Care Society, 2019).

Challenges Identified in Northern Communities

When focusing on small locations, there are numerous debates about what it means to be “rural.” For example, Zapf (2009) asserts that a population of 1,500 to 50,000 people defines “rural”; however, others assess the rural nature of a location based on population density, population size, distance from an urban area, or distance to essential services. Rural social work practice was first recognized in the 1930s by

Josephine Brown but faded from meaningful attention for the next 30 years because Brown’s work was undervalued (Martinez-Brawley, 2015). Northern remote communities have distinctive characteristics and qualities and unique social work practices. Within this unique social work practice, social workers abide by a code of ethics and work to remain culturally sensitive and flexible in their professional roles. It should be noted that northern remote communities can present significant challenges to social workers seeking to provide palliative care; these obstacles include dual relationships, possible relocation of patients for specialty services, lack of family support, minimal grief support, transportation, and finances.

Hospice House Services

Hospice House provides a variety of programming in its attempt to meet people’s emotional needs. The following is a list of programs: teatime for the soul, grief and grub for guys, broken circle, one-on-one caregiver support, coffee for the caregiver, helping children with loss, children’s grief program, remote and online support through community match, remote hospice, and Zoom grief support.

Palliative Performance Scale

Health care professionals measure a person’s illness trajectory using the palliative performance scale (PPS). This scale guides health care professionals to better understand where the person is in their illness. The PPS is a pertinent measuring tool used by the Hospice House staff and hospitals. The tool identifies five categories to determine the progressive decline in a palliative person. Based on that information, it is determined if the individual is ready for admission to Hospice House. According to Victoria Hospice House (2011), a “PPS serves as a way for the interprofessional team to communicate with each other or with residents and families as it can be used as a guide to help in initiating and facilitating conversations about a palliative care or end-of-life care transition" (p. 3).

Lee et al. (2021) conducted a study to examine the PPS. Over a 2-year period, physicians and nurses evaluated 315 patients using a weekly PPS evaluation. The authors used the data to analyze the significance of PPS scores in- group A (PPS ≥50%) and the changes in the PPS scores after the first and second weeks affected survival in patients who survived for ≥2 weeks. The PPS scale is used to guide health care workers when identifying a decline in a patient's health because it serves as an effective predictor of likely survival (Lau et al., 2009). Understanding likely survival is important because it can be used to guide a patient in a transition from receipt of active medical interventions to palliative-orientated care (Lau et al., 2009).

Funding

Hospice House is a not-for-profit society that provides high-quality care to guests with a life-limiting illness. It relies heavily on its finance committee, which works closely with the board and the management team to ensure Hospice House has the appropriate funds needed to run effectively while providing quality services and ensuring safe staffing levels (Prince George Hospice Society Annual Report 2020–2021). Due to the COVID-19 pandemic, several fundraisers had to be cancelled to adhere to public health restrictions and keep the public safe (Prince George Hospice Society Annual Report 2020–20211). A portion of the fundraising activities were shifted to virtual events. This impacted the overall revenue brought into Hospice House and it fell short by $855,355 when compared with funding raised the previous year (Prince George Hospice Society Annual Report 2020–20211). Major sources of revenue for Hospice House derive from the following sources (Prince George Hospice Society Annual Report 2020–2021):

- Dream Home Lottery & 50/50 Tickets
- Northern Health
- Donations and fundraisers
- Amortizations of deferred contributions
- Hospice per diem
- City of Prince George tax exemption
- Government subsidies
- Other sources. (np)

Fund raising is an important resource for Hospice House. If they did not have this level of funding, the program's services would be limited and the program itself may not exist. This would mean guests within the region who require high-quality end-of-life care would need to seek alternative places for care and a place to die.

In conclusion, Hospice House is a ten-bed home with trained staff in palliative care who are compassionate and ready to walk alongside the dying person and their families. My desire when starting my practicum placement at Hospice House was to better improve my palliative care skills while slowing down and being present in the moment while people die. In the following chapters, I will discuss that journey.

Chapter 3: Personal Positioning and Theoretical Orientation

This chapter outlines my personal positioning and a description of the strengths-based and person-centred approaches relative to my theoretical orientation. The theoretical orientation discussed in this chapter includes common factors that are central to my professional practice and that align with my values. I will also note that my social work practice is constantly evolving as I grow as an individual and social worker.

Personal Positioning

This section of my report outlines my personal background, which is bound to my personal experience with death and dying as an acute care social worker. Death and dying is near and dear to my heart and I will elaborate on its importance in this section. I started my career by working with high-risk youth in group homes in Prince George. This job helped me develop the ability to quickly build strong relationships. I soon realized that working with vulnerable people is what I wanted to do. Soon after this experience, I got a job as a registered social worker at the University Hospital of Northern BC (UHNBC). I spent 10 years serving patients in acute crisis and providing emotional and practical support to their families. Grounded in this experience, I continued my journey in acute care where I started my shift one morning by reading the notes of my colleague from the night before. The note stated, “sat with the patient, as he took his last breath.” There was nothing more written on the note. In this exact moment I knew I wanted to sit with people as they were dying as my colleague did; it felt similar to a powerful awareness into where I could see my social work journey taking me. At that moment, I knew I wanted to be that person—one who held the hands of a person as they were dying alone, someone who provides dignity and grace as that person crosses over. I realized at that moment I was on the right path. Furthermore, I embedded myself in learning more about palliative care and found ways to be creative during end-of-life moments. During all my experiences in palliative care, I knew I wanted to broaden my knowledge base to facilitate dignity in dying for palliative care patients.

In 2009, I graduated with a Bachelor's Degree in First Nations Studies from the University of Northern British Columbia (UNBC). In light of all the teachings and knowledge it comprised, obtaining this degree was an honour and it reined me to be more culturally sensitive, while appreciating culture and being more mindful of the Indigenous histories including past trauma. I learned to have thoughtful and articulate conversations with vulnerable Indigenous peoples as I practice hospital social work. My degree provided me with a developing framework within which I can meaningfully acknowledge and honour Indigenous peoples and their trauma, trauma that sometimes results in their resiliency today. While seeking to understand colonization more fully and how its various forms have impacted Indigenous peoples, their culture, and future generations, I learned to work to provide a culturally safe work environment while empowering my colleagues to have similar or congruent values that effectively serve Indigenous peoples in the north.

I continued my education and in 2011 obtained my bachelor's degree in social work from UNBC. This process positioned me to become a registered social worker at the UHNBC, where I work with patients and families who were encountering traumatic situations. As a registered social worker, I have the honour and opportunity to help patients and families navigate the complex health care system while supporting them during a critical time in their lives. My experience there has included informing patients they may be dying due to their illness and supporting them and families during that time, while also witnessing a mother watch her infant take their last breath. The experience that comes from the acute care setting is overwhelming; however, I have the privilege of working with a diverse, multidisciplinary team that is supportive and mindful of each delicate situation. During my experience at the hospital as a registered social worker, I am certain I positively impacted people during critical times in their lives and helped to optimize their quality of life. I was taught to be a strong advocate and to always be creative in my practice; these elements remain the core of my practice. When working with patients at the end of their lives, their needs and requests infrequently fit in a simple box; therefore required critical, creative thinking is required to best provide person-centred, individualized care to avoid lumping people into categories and assuming two or more individuals require the same level of care and the same approach.

I had the opportunity to attend a one-week intensive course on palliative care that was facilitated by the main palliative care physician and palliative care social worker from Victoria Hospice House. During the course I saw the benefits of unique palliative care practice during end-of-life care. This course taught me that it is okay to allow dying patients to drink as many fluids as they desire at the end of their life and not worry about fluid retention. I learned to provide practical pain and symptom management using a non-pharmaceutical approach. I was also taught how to have difficult conversations with patients and families when informing them of a poor outcome. My interest in this path evolved and as I grew in my career I always sought to practice in a culturally safe way with a person-centred approach.

My most recent experience is grounded in working as a registered social worker in the intensive care unit at UHNBC during the COVID-19 pandemic. I have continued to watch patients who experience dyspnea due to infection with the COVID-19 virus while supporting families virtually to accommodate the extreme limits imposed on visitation in the unit. This experience of watching patients extremely breathless, without families at their bedside, has induced significant secondary trauma within the health care teams. During my time in the intensive care unit, I had the solemn honour several times of holding an individual's hands as they took their last breath in isolation, separated from their family. I have had to tell families their loved one had passed away while the families were at home under strict isolation orders; I have also had to be creative in my practice to ensure families could see their loved ones, something which has been achieved virtually. Virtual support has added an extra layer of stress within my current job; nevertheless, I have been curious to understand how families manage and cope with being separated from their sick loved ones and how they are actively coping while they cannot be present when their loved one passes away. Additionally, I have wanted to better understand what programs and approaches the resource community is offering to address and support loss and grief support during this time.

In summary, in my personal, academic, and work experience, I have witnessed patients dying alone, families feeling helpless, and the health care team crumbling. With more time spent in the field, I believe social workers can develop a more unified approach to provide better end-of-life care during the COVID-19 pandemic and reduce the burden on families when their loved ones are dying. I am aware of my own experiences, personal biases, and beliefs about providing a dignified death; I hope to remain person-centred throughout my career.

Theoretical Orientation: Strengths-Based Care and Person-Centred Care

Strengths-Based Care

The American Psychological Association defines theoretical orientation as “an organized set of assumptions or preferences for given theories that provide a counsellor or clinician with a conceptual framework for understanding a client’s needs and for formulating a rationale for specific interventions” (Kasa-solutions, 2021, p. 1). Below I will describe two theoretical orientations I believe are imperative to palliative social work. Many existing social work models meet the needs of palliative patients living in Northern communities. This report, though, will discuss the strengths-based and person-centred approaches to care that I used during my practicum placement at Hospice House.

Recent developments in social work practice have led practitioners to analyze the importance of specialty services (Collier, 2018). A generalist practitioner, for example, assesses each concern by exploring possible solutions from different vantage points and considers quick problem-solving. Such an approach, however, is not a specific line of inquiry with a clear pathway (Collier, 2018). A generalist approach may work for remote communities where specialty services may not exist or may be limited. The Prince George Hospice House is geographically located in a Northern community where one may think generalist practice would be used. However, the Prince George Hospice House has the privilege of having access to practitioners who have specialized in palliative care and therefore generalist practice is not used. Specialty services draw on individual’s strengths for problem solving.

The strengths-based model dictates that social workers look for positive elements in complex issues and utilize resources rather than focus on limitations (Brocious et al., 2013).

According to Oliver and Charles (2015), the term “strength-based” was first used in social work in the 1980s by a team at the University of Kansas. The team focused on the philosophy behind the strengths-based case management theory used in association with people with serious and chronic mental illness. The framework promoted assertive outreach, such that the patient’s case manager accompanied the patient - mentally and physically -to navigate the challenges of community living. This concept was “underpinned by the belief that social work’s emphasis on problems merely gave them a new vitality, the approach focused on client strengths and goals and framed clients as directors of their case plans” (Oliver & Charles, 2015, p. 3). Case managers thoroughly assessed their patients’ strengths and utilized a personal planning tool to encourage achievable client goals (Oliver & Charles, 2015). The relationship between the case manager and patient was viewed as therapeutic and are seen as a key factor in reducing hospital admissions (Oliver & Charles, 2015). Emphasis remains on discovering, affirming, and enhancing individual’s capabilities, interests, knowledge, resources, and goals (Cederbaum & Klusaritz, 2009; Oliver & Charles, 2015). At the same time, an important principle of this approach is that people have the capacity for continued growth as well. This framework operates with the belief that the addition of strengths increases the likelihood that individuals will realize the goals they have set for themselves (Cederbaum & Klusaritz, 2009). People are more likely to make changes when they are a part of the solution. The strengths-based approach focuses on empowerment, identification of resources, and promotes creativity in recognizing a client’s skills and assets (Cederbaum & Klusaritz., 2009).

Social workers have adapted the strengths-based model as a framework to care for a patient while acknowledging and recognizing a patient’s internal resources and viewing the patient as resourceful. The strengths-based approach assumes all people have a set of strengths; even if they are experiencing problems, these strengths and challenges will help guide them during difficult times in their lives. Strengths-based practice requires a belief in a person’s ability and commitment to self-identify and build on their own strengths while navigating a difficult situation (Oliver and Charles, 2015). During these challenging circumstances, “the ultimate goal of social work is to bring about a balance between the realities of a person’s capabilities and a person’s social situation” (Zapf, 2010, p. 1).

A strengths-based approach is used in remote communities where individuals have a strong sense of resiliency that develops in the absence of supports and services; this approach works well with a strong partnership among providers and families (Oliver & Charles, 2015). In such circumstances, individuals and their families are active participants in identifying problems and concerns, decision-making, and planning to promote and restore their wellbeing (Oliver & Charles, 2015). The National Association of Social Workers (NASW) (2022) notes that building on people’s strengths is central to the profession. This perspective is used most often to look for strengths in clients who might otherwise be viewed as only having deficits (Swartz, 2017). Viewing clients as resourceful beings is the key factor in the strengths-based approach.

Empowerment is another component of the strengths-based approach because the framework focuses on identifying someone’s strengths and internal resources to problem solve and implement change in their own lives (Cederbaum & Klusaritz, 2009). Social workers promote a client's characteristics and capabilities and acknowledge that people's behaviours are unique and should be well-respected. As quoted from the BCCSW code of ethics "a social worker shall respect the intrinsic worth of the person served in professional relationship with them" (BCCSW, 2009, p. 3). Thus, becoming aware of an individual's strengths may require careful observation, listening, and understanding from the practitioner (Cederbaum & Klusaritz, 2009).

Person-Centred Approach

A person-centred approach focuses on what the person can do, rather than focusing on what the person cannot do: it "takes a radical look at the human being as a person" (Thorne & Lambers, 1998, p. 39). Thorne and Lambers (2013) state, "the human being is not observed and treated as an object, instead individuals are encountered as persons" (p. 49). Carl Rogers had congruent thoughts on this framework. He viewed people as having been born healthy and creative individuals. He believed, therefore, that their behaviour would naturally tend toward the social and constructive and would not require regulation, direction, or punishment from the outside world (Tudor et al., 2004). In keeping with this idea, palliative care should position the patient as the core decision-maker in their medical journey. This approach to practice enables patients to feel empowered while navigating a difficult medical system and making decisions in their lives when they have limited choices.

The person-centred approach is based on the concept that "social forces are the root of people's difficulties, and it is through the empowerment of people as self-determining actors in their own lives that social and personal change can be brought about" (Murphy et al., 2013, p. 706). Each person is seen to have immense strength and is viewed as irreplaceable while their practitioner also recognizes their value and is viewed as unique (Cooper & McLeod, 2011). In these situations, patients are made to feel safe and free from judgment, which allows them to develop a healthier view of the world and a less distorted view of themselves than they would otherwise have (Cherry, 2021).

Carl Rogers emphasized that person-centred theory is a very basic philosophy and, in essence, a way of being. It is not about learning a value system to guide your life and practice. Rogers emphasized that people are not manipulated into adhering to a specific belief system but “are offered the climate in which to take risks of experiencing reality as it is for them” (Thorne & Lambers, 2013, p. 13). This environment allows patients to feel empowered as they explore what is important to them and to rely on what works best. For example, during end-of-life care, pain and other distressing symptoms can be managed through medications; however, not all patients want to experience the side-effects associated with high doses of narcotics and may choose alternatives that may positively reduce their pain. Using a person-centred approach, the patient would be allowed to voice their wishes and the health care team provide pain relief based on information provided by the patient. No assumption would be made that the only way to manage the patient’s pain is medication. Anyone who subscribes to a person-centred approach and practice holds an awareness that “every human being possesses the capacity to shape his or her own life and that the main objective of every form of aid should be to support the capacity, that is to promote human freedom and autonomy” (Thorne & Lambers, 2013, p. 38–39).

Overall, person-centred theory is not merely a theory, but rather a way of living; it ensures the individual you are working with is able to have “an experimental open-ended approach to life in which the personal experience of the individual is considered the highest authority" (Thorne & Lambers, 2013, p. 16). In saying this, there seems to be a shift in practice from one where experts considered themselves to be the most responsible advocate in a patient's care plan, to one where patients have self-responsibility (Thorne & Lambers, 2013). It is also important to note that, "in theory and in practice the person-centred approach has formed a shift of paradigms from the object to the person, from observation to encounter, and from interpretation to empathy" (Thorne & Lambers, 2013, p. 50). While practicing a person-centred approach in palliative care, there are many uplifting factors to consider, even while adhering to the BC College of Social Workers code of ethics. Effective use of the strengths-based approach helps the social worker fulfill their professional responsibilities and provide autonomy to patients, enabling them to share and address their needs during end-of-life care.

Tudor et al. (2004) argue that the person-centred approach is informed by philosophical values found among phenomenological thinkers and note that effective practitioners show a high level of congruence and consistency between what they experience, what they symbolize in awareness, and what they communicate. They also assert that, to practice effectively, the personal values and beliefs of practitioners need to be congruent with the philosophical values of the person-centred approach. In other words, the higher the level of congruence between the practitioner's values and the values that underpin the approach, the more effective practitioner will be.

In conclusion, my goal was to be mindful of my personal positioning during my practicum placement. I recognized that I had been working at the hospital for 10 years and my philosophy in acute care would be different than the approach at Hospice House.

I also wanted to focus my learning through the person-centered approach and the strengths based framework; I felt that these two orientations would fit best with my personal and professional work style.

Chapter 4: Literature Review

In this chapter, I review the current literature and describe how it connects with my practicum experience plans at Hospice House. Additionally, this section provides a general definition of palliative care; a history of palliative care's origins; and a description of when the need to implement palliative care is greatest, who should receive palliative care, why people choose palliative care, and where people can do so. This literature review also explains what Hospice House is, who can access hospice care, when people need to be admitted to hospice care, and why individuals—and their families—have chosen hospice care as a place to go for the guest to die. In closing, I discuss the importance of the interdisciplinary teams at Hospice House and how social workers play a role in palliative care.

What Is Palliative Care?

Palliative care is defined by the Canadian Hospice Palliative Care Association (2021) as follows:

> a specialized form of healthcare for individuals and families who are living with a life-limiting illness that is usually at an advanced stage… (its goal is) to provide comfort and dignity for the person living with the illness, as well as the best quality of life for both this person and their family. (p. 1)

This definition compliments the World Health Organization's (WHO) definition, which is, "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification" (Blackmore & Parker, 2020, p. 1). Blackmore & Parker (2020) suggest that palliative care "affirms life and regards dying as a normal process and intends neither to hasten nor postpone death while integrating psychological and spiritual aspects of patient care" (p. 1). Further, they note that palliative care offers a practical and emotional support system to help people live as actively as possible while it simultaneously helps families cope.

Palliative care is a holistic approach in health care that provides pain and symptom management at the end of life while providing emotional support to families. It falls within the medical model; however, it tends to be a less intrusive approach in health care than much of health care that occurs within the medical model. For example, patients no longer require regular blood work and they receive less diagnostic testing and more symptom control while focusing on quality of life through a multidisciplinary team approach.

Wallerstedt et al. (2018) researched health care professionals' perceptions of what palliative care represents. They found that despite all the attention in the literature received on this subject, there was still confusion and concern surrounding the term "palliative care," what services it offers, and how to implement palliative care in practice. The authors collected data by conducting 12 interprofessional focus group interviews within the hospital and outside the hospital setting. During the study, Wallerstedt et al. (2018) revealed three domains:

> first, a blurred conceptual understanding [took shape] as participants described palliative care using synonyms, diagnoses, phases, natural care and holism; second, a challenge to communicate transitions concerned the importance of how and when the transition to palliative care was communicated and documented; finally, a need for interprofessional collaboration was described as well as the

> consequences for severely ill persons, relatives and healthcare professionals when it [i.e., the need] was not [clearly] established. (p. 1)

The authors reported that most participants felt the term “palliative care” was a confusing concept. It was broadly understood to be equivalent to end-of-life care, terminal care, and the final phase of life. While some participants understood palliative care to be a “downward process [continuing] for days, months or years”, a common perception among participants was that palliative care provided a holistic type of care that including physical, psychological, social, and existential aspects of care (Wallerstedt et al., 2018, p. 79). Despite all the positive work that is being done in palliative care and the knowledge available in current literature, Wallerstedt et al. (2018) urgently encourage health care providers to seek more education and training in this field.

There are many reasons patients would require palliative care services. One example would be, those with end-stage kidney disease who require renal replacement therapy. Axelsson et al. (2019) note that patients with end-stage kidney disease have a high symptom burden such as feeling fluid overloaded, breathless, pain and fatigue; therefore palliative care can offer symptom management through a palliative care lens. The goal would be to decrease hospital admissions, including intensive care units and keep patients at home for as long as possible. The authors conducted a study aimed at exploring healthcare professionals’ views on the provision of care. Specifically, the study’s main objective was to describe nurses’ and physicians’ perspectives on palliative care for patients who are on maintenance hemodialysis. The data collection involved four focus-group interviews with 17 renal nurses and 5 renal physicians in Sweden. Participants described palliative care as end of-life care associated with hemodialysis withdrawal or palliative dialysis for symptom management. The same participants also identified a need for the improved early and late palliative care approaches. A change in treatment focus would mean that the health care team needs to have difficult conversations with clients, and perhaps hemodialysis may not be offered in the event the patient may not live a good quality of life; in contrast, good palliative care measures could be implemented. It is important to note the authors did not interview allied health team members in the renal department; these professionals bring many different perspectives to health care, providing holistic care, and I feel they would have been a good addition to the study. Overall, there appeared to be awareness among participants that further development in understanding palliative care is greatly required to meet the needs of these patients and their family members.

In my experience working with patients who have end-stage kidney disease, they are commonly relocated from their home communities for the sole purpose of receiving hemodialysis. Hemodialysis is considered to be a life sustaining therapy, without this therapy a patient would die. This means patients are removed from their social network, culture, and the safety of their community. The result is that they live their final days, weeks, months, or years alone. If the multidisciplinary team continues to complete advance care plans with patients who are at risk of significantly reduced kidney function, then patients would be better informed about their choices and might perhaps choose to stay home and enjoy quality the of life over quantity of life.

History of Palliative Care

In the past, palliative care was thought of as a disease-specific approach to illness. The World Health Organization, however, has asserted that the principles of palliative care should be applied as early as possible to any chronic and fatal illness and should be paired with providing emotional and spiritual support to families and caregivers (Blackmore & Parker, 2020).

Dame Cicely Saunders is believed to be the founder of the palliative care movement. Saunders was a nurse who had had a religious conversion during her professional journey and had become a devoted Anglican (Duffin, 2014). While working at St Luke’s Home and serving less fortunate people dying in London, she decided to enter medical school (Duffin, 2014). Later in her life, as 20-year-old nurse, she came to have a strong friendship with David Tasma, a Polish patient who was dying of cancer (African Palliative Care Association [APCA], 2018). This patient left Saunders £500 to start a home or hospital to alleviate the physical and emotional suffering of dying people. This step began the modern hospice movement and gave rise to palliative care (APCA, 2018).

Saunders sought to understand and solve pain issues among dying people. She continued her education and became a physician, despite a tremendous backlash of different perspectives on end-of-life care in Britain and America (APCA, 2018). In 1967, Saunders opened a hospice house named St. Christopher’s Hospice, which was situated in Sydenham, South-East London. She genuinely believed that dying people who received the right type of care in the last days of life could experience a more dignified death (APCA, 2018). Reflecting on a time early in her career when she was working with a dying man, she remarked: “I once asked a man who knew he was dying what he needed above all in those who were caring for him. He said, ‘for someone to look as if they are trying to understand me” (APCA, 2018, p. 1). With this, Saunders implied it is nearly impossible to fully understand another person; however, she recognized the patient did not ask for any one thing in particular but simply for someone to care enough to try.

Saunders spent her career building a philosophy that affirmed dying is as natural as birth and should be painless, with no suffering (APCA, 2018). After spending time with dying patients and hearing their stories, She reported that she understood the concept of "total pain," which included physical, social, emotional, and spiritual pain (APCA, 2018). Although Saunders noted that her approach to pain was very straight-forward, she asserted that constant pain required constant pain control (APCA, 2018). She advocated for analgesics to be given regularly to prevent a pain crisis rather than to work to control pain only after it had flared up (APCA, 2018). Additionally, Saunders argued that pain medication should be used progressively - as needed - from mild to aggressive to ensure patients did not get into a pain crisis. She believed that each person's case should be addressed in a very individualized manner and no two cases are the same. In making this assertion, Saunders recommended that each dying person have a care plan and—because dying was seen through a holistic lens- support ought to extend to their families (APCA, 2018).

Saunders was a firm believer that through the administration of constant pain medications, there was a less likely chance for patients to having a pain crisis. This value appears congruent with that of Joseph Bullar, an author who documented his journey and cautiously recommended that other physicians use opium and chloroform to comfort their dying patients. He argued that doctors wrongly withhold treatment, in the form of medications, based on the fear that they were hastening death (Duffin, 2014). Today, because of advancements in palliative care, specialists are much more likely to be confident that administering aggressive medications they are not hastening death but, instead, are minimizing suffering or enabling an experience free from suffering (Duffin, 2014).

Who Should Receive Palliative Care?

Palliative care is an approach in health care that aims to care for people who have the following illnesses (though the list is not limited to these) and according to Rosenwax & McNamara (2006) it should be considered at the end stage of the disease, illness or serious event:

- cardiac diseases (congestive heart failure);
- lung disease (chronic obstructive pulmonary disease, asthma);
- cancer (any type, especially when there is a diagnosis of metastasis);
- renal disease;
- advanced neurocognitive disorder (i.e., Alzheimer's, Parkinson's);
- end-stage liver disease;
- end-stage amyotrophic lateral sclerosis;
- end-stage multiple sclerosis;
- any catastrophic brain injury;
- strokes with poor outcome and no quality of life; and
- HIV/AIDS.

Palliative care is designed for people at any stage of an illness that cannot be cured. It is suitable for children, adults, and the elderly. This type of care is used with many people with a life-limiting illness. Even though someone with a life-limiting illness can access palliative care, they can also continue to pursue full medical interventions with the hope that a cure or a productive treatment can change their particular condition. Palliative care is pursued with the intention that once a cure has been achieved the patient will no longer need palliative care services. It is also an option for people who have had several admissions to hospital, including visits to the emergency room due to a pain crisis, distress resulting from other causes, and, or failure to cope well with illness at home within the year.

Research shows a patient’s likelihood of their health care team having a conversation with them about palliative care depends on their diagnosis and the practitioners comfort level with the conversation. Patients with a non-cancer diagnosis tend to have less palliative discussion with their health care team. Rosenwax & McNamara (2006) claim that the needs of people with complex life-limiting non-cancer conditions warrant the attention of palliative care practitioners. Rosenwax & McNamara (2006) conducted a research study in Western Australia between July 2000 and December 2002 that focused on people who died from cancer and non-cancer deaths. There were 27,971 deaths during this period and the author determined that 68% of those who died of cancer received palliative care but only 8% of people who died of a non-cancer diagnosis received palliative care.

Example of Individuals Who Should Be Considered for Palliative Patient

Palliative care should be considered anytime a person is diagnosed with a life limiting illness, for example an elderly patient with stage 5-kidney disease. These patients are thought to have few treatment options. Such patients should be considered for dialysis only after a full bio-psycho-social assessment is completed including their full medical history to determine if this patient is a good candidate for life sustaining therapy in the form of hemodialysis (Williams, 2012). If dialysis is not a viable or life-sustaining option that can provide a good quality of life, the patient should be managed medically with dietary changes to prolong life (Williams, 2012). In my experience, healthcare providers rarely have difficult conversations with patients with stage 5-kidney failure, or with their families. I have observed that more patients are started on dialysis, than are having discussions about palliative care options. I have witnessed these patients struggle with activities of daily living and undergo repeat hospital admissions. Williams (2012) noted that the advantage of dialysis is lost on patients with high levels of comorbidity and suggested:

> Establishing patient preference is an imperfect process, and many patients appear to regret their decision to undergo dialysis. With active medical management, efforts shift from prolonging life to emphasis on symptom control, dietary and medical treatment, and quality of life. Patient survival time can be remarkably long (p. 1).

When to Implement Palliative Care

Palliative care is a multidisciplinary specialty that promotes optimizing a person's quality of life while reducing suffering and focusing on symptom control for the patient and supporting the families who have been affected by a serious illness, regardless of the patient's prognosis (Gelfman et al., 2017). This level of care includes pain and symptom management; spiritual, and emotional support; guidance with decision-making and a care plan that can be followed while at home and brought with them, if they require admission to the hospital or Hospice House (Gelfman et al., 2017).

Palliative care should be strongly considered when a person has been diagnosed with a life-limiting illness and the prognosis indicates they have 6–12 months to live (Gwyther, 2011). At this time, end-of-life care can be adapted while someone is still at home and has decided to stop treating their illness and focus on controlling their symptoms from the illness. Heart failure can be used as an example of a life threatening illness suitable for palliative care. It is a chronic and progressive illness affecting six million Americans: in the United States, 870,000 people are diagnosed with heart failure each year and despite advanced medical therapies, 40% of patients diagnosed with heart failure die within a year of first hospitalization (Gelfman et al., 2017). Patients diagnosed with heart failure suffer from physical and psychological symptoms and face functional limitations and an unpredictable medical trajectory (Gelfman et al., 2017). Gelfman et al., specify physical symptoms of heart failure can, for example, include pain, fatigue, breathlessness, and depression; psychological symptoms can include fear, anxiety, sadness, and frustration. As indicated by the authors it is important to recognize that not everyone will experience the same symptoms, and some medications used to treat heart failure may cause depression. The authors assert depression can impair a patient's quality of life and put burden on the patient's family to do more for the patient than they are able and willing to. It is imperative that the health care team have difficult conversations if about whether it is the right time to implement palliative care (Gelfman et al., 2017). It is important to know that palliative care can be implemented even while someone is seeking full medical interventions and hoping for a cure or effective medical treatment. When a cure or efficacious treatment is established, palliative care services will stop.

Palliative care should be considered when patients transition into a long-term care home as the focus of care is on comfort, dignity and honouring the individual where they are currently at in their life. Relevant research has been conducted on this topic by Persson et al. (2021). Their qualitative research study in a long-term care home engaged staff as participants to assess whether they thought there was a readiness from the patients to implement palliative care for adults entering the facility. The report outlines how "professionals indicated that palliative care starts well before the older person's last days and can, in fact, be a long process that begins the day the older person moves into a nursing home" (Persson et al., 2021, p. 5). Staff participants emphasized how important it was that they have increased knowledge about palliative care and it was not identified in the article how much knowledge the staff already had in palliative care. Participants noted it was important to begin palliative care as soon as an adult is informed of their incurable health condition. Staff participants believed that providing palliative care—during the dying process—should be the goal and not just during patient's last days. Unfortunately, the latter practice appears to be most common these days (Persson et al., 2021).

Health care professionals measure a person's illness trajectory using the palliative performance scale (PPS). This scale guides health care professionals to better understand where the person is, in their illness. Lee et al. (2021) conducted a study to examine the PPS. Over a 2-year period, physicians and nurses evaluated 315 patients using a weekly PPS evaluation. The authors used the data to analyze the significance of PPS scores in-group A (PPS ≥50%) and the changes in the PPS scores after the first and second weeks affected survival in patients who survived for ≥2 weeks. The PPS scale is used to guide health care workers when identifying a decline in a patient's health because it serves as an effective predictor of likely survival (Lau et al., 2009). Understanding likely survival is important because it can be used to guide a patient in a transition from receipt of active medical interventions to palliative-orientated care (Lau et al., 2009).

Why Do People Choose Palliative Care?

The World Health Organization endorses palliative care as an approach in health care that focuses on improving the quality of life for patients who have a life-limiting illness while also supporting the client's family's needs (Wajid et al., 2021). This approach in health care relieves suffering when it makes use of early identification, proper assessment, and follows a care plan (Wajid et al., 2021). People choose palliative care because it can treat pain and other distressing symptoms such as breathlessness, anxiety, and nausea, but it also considers a person's psychological and spiritual needs (Wajid et al., 2021). People appreciate palliative care because it strives to involve the patient's family and support network in the caretaking process but also recognizes that caregivers need emotional and practical support during this difficult time (Wajid et al., 2021). Additionally, patients choose palliative care because there is bereavement support which can be beneficial after a family loses a loved one. Patients who choose palliative care receive services through a team-based approach which seeks to keep patients living as actively as possible until the end of life (Wajid et al., 2021). In my experience, when patients choose to shift their focus of care to palliative care, those patients experience relief. There are no more tests or blood work, no imaging, and, in the event the patient is admitted to hospital, the nurses exercise a more hands-off approach to checking vital signs, blood sugar, and blood pressure. During this time, patient plays a more imputative role in directing their care needs with the support of their families.

The Role of Social Work in Palliative Care

Social workers play an integral role in the health care system and specifically in palliative care. Roles within a multidisciplinary team may become blurred at times as the goal of each discipline’s are similar. However, social workers have clear guidelines within its profession. The following are social work competencies: “advocacy, assessment, care delivery, care planning, community capacity building, evaluation, decision making, education and research, information sharing, interdisciplinary teamwork, and self-reflective practice” (Bosma et al., 2009, p. 2). These competencies guide social work practice and promote high quality care.

Taylor et al. (2018) define the role of palliative social workers as being “responsible for supporting the psychological needs of patients and their families during and after traumatic experiences, including the diagnosis of a chronic illness, or during final stages of life in palliative care” (p. 1). Social workers see beyond the physical needs of a sick patient. While social workers agree their needs to be a strong emphasis on addressing a patients’ physical needs, it is also strongly recognized that other aspects of a patients needs cannot go unmet. Therefore, social workers play an integral role during palliative care for patients and their families by providing emotional, mental, spiritual and psychological support. Many times these needs are met through completion of a bio-psychosocial assessment to determine ones needs and how they can be met.

Furthermore, during palliative times, a patient’s mental health needs may go unrecognized due to, a higher need to meet their physical needs of pain. Taylor et al. (2018) report that “cancer patients felt psychologically stressed and their mental health needs were not met, such as when they lack enjoyment of life, fear future pain, or feel like a burden to their family" (p. 1). Social workers can provide emotional and practical support in these situations through bedside conversations and implementing community services as seen fit. Social workers will collaborate with other community members to ensure the patient's needs are being fully met. For example, social workers can implement home supports to ensure physical needs are being address, counselling services for grief support and creating care plans to ensure future needs are met. When these aspects of someone's life are not being considered, unfortunately it can add a lot of extra burden to sick patients and their families.

Taylor et al., (2018) remark: "unfortunately, those who experienced negative psychosocial feelings sought out a hasten death" (p. 1). There was no remark in the article if social workers were involved during these situations. However, it is vital to include social workers in all aspects of a palliative patient's care plan. It is important to understand that not all communities have access to social workers, however, during these times there needs to be an attempt to locate social workers virtually, someone with more experience in palliative care or reach out to families and utilize the skills they bring.

Furthermore, terminal diagnoses do not affect only the dying patient; they also affect the patient's family members. As Taylor et al. (2018) observe, "family members consistently report feelings of distress, anxiety, and worry about financial, physical, and social issues during the course of diagnosis, treatment, and life after [the] death of their loved one" (p. 1). Social workers are trained to provide grief support while having difficult conversations with—and provide advance-care planning for—family members to ensure all needs are being met to create better quality of life for everyone involved. This requires early intervention and meeting frequently throughout a patient's palliative progress to improve the family's overall wellbeing. This also may require legal documentation to be drawn up and signed by the patient to ensure the family does not have to make difficult decisions regarding finances and assets once the patient has died.

It is helpful to recognize that social workers' knowledge about anticipated grief and bereavement can help patients and families navigate systems before and after death; other disciplines within palliative care may defer to social workers for direction and support. Furthermore, social workers organize and facilitate family meetings for the patient and their family that include the health care team to discuss goals of care and clarify the patient's wishes. Social Workers also assisting with complex discharge planning to help a patient who wishes to die at home. They promote patient self-determination "while acting as a liaison between the family and health care providers" (Arnold et al., 2007, p. 65).

In addition to providing psychological and spiritual health for patients, Taylor et al. (2018) promote the importance of social workers developing pain management skills for use during end-of-life care. The authors assert that "pain management competence is indisputably important for end-of-life care when patients are unable to advocate for themselves" (p. 1) and pharmaceuticals are no longer effective. Low pharmaceutical efficacy occurs more commonly in patients who have a higher tolerance to opioids resulting from substance use. Social workers play a vital role in advocating for pain management and in reducing the stigma associated with patients who use substances. They also work to ensure equity in care. Pain management is known to be managed primarily through pharmaceutical management; however, for patients who suffer from pain, underlying anxiety or limited physical ability to move may be factors.

Social workers consider all aspects of a persons life, this includes emotional and practical needs of those receiving palliative care while strongly advocating for pain management. This has shown to improve psychological health and improve quality of life for patients and their families in the dying stage.

Where Can One Receive Palliative Care?

Historically, palliative care was only delivered in hospitals and people normally died at home, sometimes without adequate support. Nowadays, palliative care is increasingly found in a variety of settings (Meiere, 2011). It is a healthcare approach for patients who decide they want to focus on comfort care rather than curative medical interventions. According to Meire (2011) a person can palliate in the following places, though this list is not comprehensive:

At home (with family supports),

- A hospital—acute care,
- An in-patient palliative care unit,
- A Long-term care home (if the individual already resides there),
- A hotel (if the individual is homeless and has supports),
- A friend’s home,
- A Hospice House.

In the next section of my literature review I am going to discuss hospice care, which may appear somewhat redundant with what I have written about palliative care; however, the section below will describe in further detail what palliative care looks like through a hospice care lens. It is also noteworthy that palliative care and hospice care may appear similar, however hospice care is one environment in which you can receive palliative care and palliative care does not need to be delivered in hospice house.

What is Hospice House?

In this section I will provide a brief overview on Hospice House. It is important to note that Hospice House appears to provide the same level of care throughout all programs, however some programs may offer specific services that others do not. The primary purpose of hospice houses is to improve physical and psychosocial symptoms of the guests while influencing family caregiver wellbeing, healthy bereavement outcomes, and promote guest, family, staff, and physician satisfaction (Meiere, 2011). These objectives are accomplished through an interdisciplinary team of physicians, nurses, social workers, spiritual counsellors, pharmacists, care aides, physical therapists, occupational therapists, registered dieticians, psychologists, and others (Meiere, 2011). One major goal for staff who work at a hospice house is to quickly identify and effectively treat distressing symptoms; some symptoms have been independently shown to increase medical complications and increase hospitalization. In addition, hospice teams will often meet with guests and their families to establish appropriate and realistic goals while working to support families.

Who Can Access Hospice Care?

Seow et al. (2018) report that palliative care is often initiated very late in the dying process. These authors indicate there are three main trajectories of dying that are seen in conjunction with terminal illness: a cancer diagnosis; organ failure; which is generally manifests as heart and, or, lung failure; and frailty, commonly resulting from a neurocognitive disorder following low physical functioning (Seow et al., 2018). Evidence suggests, however, that all types of individuals with a life-limiting illness can access hospice care and do so at every stage of illness (Seow et al., 2018).

Hospice care has three main levels of care. First, the house team provides pain and symptom management. For example, when a person in the community is struggling with symptoms that cannot be managed at home with the support of their general practitioner, they can be admitted to Hospice House per practitioner instructions for symptom management. If a guest is suffering an acute pain crisis (or extreme nausea and vomiting) and home medications are ineffective, Hospice House will provide hospital-grade medications to relieve those symptoms. Second, hospice care provides respite services for guests with a palliative diagnosis when they are struggling at home to manage their activities of daily living. Respite provides caregivers time to rebound and focus on their self-care before their loved one returns home. Lastly, Hospice care provides end-of-life care and bereavement support to their families.

When Are People Admitted to Hospice House?

Hospice care was established to improve the quality of life for people dying at home. People with a life limiting illness and their families made it clear that the process of dying at home resulted in poor quality of life for the ill person experiencing substantial pain for approximately three days before death (Foley, 2005). Dying at home also required costly services that represented a substantial financial burden for families (Foley, 2005). Hospice care was designed to remove the burden of dying at home and provide a holistic environment in which guests and families felt naturally safe and burden-free (Foley, 2005).

Guests are admitted to hospice house when their PPS score is below 30%, require assistance with their activities of daily living, and or, are nearing the end of their life.

Hospice guests and their families are choosing for the ill individual to die in hospice, rather than staying at their current location. There are a variety of reasons for this decision; it may be due to a lack of friends or family to care for them at home as they die. Some people wish not to die in a hospital where the environment is busy and the focus remains on acute patients. Other people require admission to hospice for pain and symptom management; generally, these guests arrive from their homes where their practitioner can no longer effectively manage their symptoms with home medications. Additionally, in some cases, nursing assistance is required to apply intravenous medications for immediate relief. These admissions requiring symptom control can be as short as a few days and as long as weeks. Last, some guests come to hospice for respite when their caregiver cannot continue to care for them. Ideally, these guests will return home once the caregiver is feeling well rested and supported. At times when leaving Hospice House from respite, the health care team implements home supports for the guest to prevent caregiver burnout in future.

Why Do Patients and Families Choose Hospice House?

The goal of hospice care is to "give thorough, interdisciplinary, and team-based palliative care to patients entering the last months of their life. Studies have proven that patients experience feelings of being cared for, reduced pain, and positivity in hospices," (Wajid et al., 2021, p. 5). Which results in a better quality of life. Hospice care is an important aspect of the dying process.

Wajid et al. (2021) conducted research with participants in Bengaluru, India regarding why hospice care is important and reviewed four themes, however I will discuss two of the main themes researched. The first was that it helps with pain management; this was identified as a primary factor for entering hospice care. They explain, "pain affected the participants psychologically due to the feeling of loss of control which led to negative behaviours such as suicide attempts" (p. 4). One participant stated that due to intolerable pain, they attempted suicide ten different times. This participant remarked there was nobody to help with pain management until they were admitted to the hospice. Second, the authors observed that participants experienced the benefits of altruism; they report this feeling was due to the help participants received from others while in hospice. There feelings derived from feeling altruism include receiving kindness from others and the willingness to discuss organ donation (Wajid et al., 2021). The authors indicate that because "most patients were treated with love and respect at the hospice, their physical, emotional, and social needs were taken care of" (p. 4). These participants indicated a feeling of gratification. As Wajid et al. (2021) note:

> participants had expressed their desire to donate their organs after their death as an expression of gratitude. Participants felt that they have a duty toward their fellow human beings by helping them any way they can because of all the help they have been receiving at the hospice. They felt that by doing so, they might save lives and simultaneously improve many lives related to the recipient (p. 4).

In conclusion, Wajid et al. (2021) assert that most participants expressed a deep desire to have a good death, that is, they wished to die quickly, without pain, and in a safe environment such as a hospice. One participant remarked, "I want to die with absolutely no pain" (p. 5). The authors interpreted this last motivation as the result of participants feeling that they had already endured a great deal of pain and suffering during their illness and, as a result, wished for a painless death.

The location of death may be symbolic for the individual and create a dignified death. Therefore, having a good place to die was found to be important (Wajid et al., 2021). In my experience working as a hospital social worker, when shifting focus from life sustaining therapy to palliative care, families have expressed the desire for their loved ones to remain in a chosen location that appeared symbolic to them. Furthermore, certain feelings associated with the environment bring about a sense of comfort at the time of death. The authors speculate the participants may have lived in a place where they had peace, but as they began to suffer from their illness at home before entering hospice, they came to associate discomfort and pain with their home (Wajid et al., 2021). Consequently, they wished to die in hospice instead of at home because of the feeling of security and comfort they experienced in hospice (Wajid et al., 2021).

Overall, this study shows that patients choose to move to a hospice because it provides comprehensive care for patients nearing their end of life and bereavement support for families (Wajid et al., 2021). Thus, hospice staff focus their care efforts on reducing pain and managing symptom to improve quality of life and establishing the dignity and safety necessary to enable a peaceful death.

Barriers to Accessing Hospice Care

End-of-life care is considered a human right, according to the World Health Organization (2020). However, Stajduhar et al. (2019) assert that end-of-life care remains inaccessible to many people. Individuals with a life-limiting illness continue to encounter significant barriers when accessing a hospice centre. The authors conducted a research study to identify what barriers people faced when seeking access to hospice care. They also explored structural vulnerability and informal and formal supports. They report five major themes that surfaced in their research: “(1) survival imperative; (2) normalization of dying; (3) the problem of identification; (4) professional risk and safety management; and (5) cracks of a ‘silo-ed’ care system” (p. 1). Although the five themes were presented separately, the barriers were interconnected. For example, participants indicated that gaining access to hospice when dying was a lower priority survival; that is, the need for food and shelter superseded that of compassionate end-of-life care (Stajduhar et al., 2019).

Stajduhar et al. (2019) indicate most people who require palliative care services from hospices tend to share similar socioeconomic profiles and are diagnosed with illnesses, with fairly predictable trajectories such as cancer. The authors report that these people come from dominant social groups with strong family and community connections and commonly have stable housing. But this is not always the case: “many dying people fall outside this demographic, such as those who are experiencing homelessness or unstable housing, poverty, mental illness and substance use, and stigmatized diseases such as HIV/AIDS and Hepatitis C”, these people may not have the same privilege to access Hospice House due to their circumstances (Stajduhar et al., 2019, p. 1). Research on access to hospice care for vulnerable populations suggests those who are homeless are unable to access palliative care until very late in their illness, if at all, due to social determinants of health; vulnerable populations have fewer social supports and “often die alone in acute care, shelters, and transitional housing or less than ideal places such as alleys, streets, and vehicles” (p. 1).

Regardless of socio-economic status, people who have low social determinates of health, which are known to be non-medical reasons that may affect a person’s health outcomes, may not be able to access hospice care due to geography. Individuals who reside in rural and remote communities may be in an area where hospice care is not offered and must relocate to access it. The effort may not be worth it for some. Such individuals may choose increased suffering at the end of their life to remain at home.

Hospice House in Prince George charges a per diem rate of $39. This may not appear to be a significant expense for some; however, many who live below the poverty line, or individuals who already have other large expenses, may be unable or unwilling to take on the extra expense, especially when the family will need to pay for the person's funeral.

Interdisciplinary Team in a Hospice House Context

Health care is starting to shift from a physician-centred care team to an interdisciplinary team. According to Schofield and Amodeo (1999):

> This approach in health care allows for improved access to care for patients and patient efficacy in self-care behaviours and improved role satisfaction for practitioners, reduction in both length of hospitalization and premature admissions, and an increase in the use of different team members to meet a client's varied needs. (p. 1)

The interdisciplinary team model is valued for its ability to "[relieve] the burden of treatment for the staff, facilitating work with difficult patients, offering greater objectivity than a staff member working alone would have, and enabling workers to empathize with the patient and each other" (Schofield & Amodeo, 1999, p. 1). However, the authors note there are challenges in working in an interdisciplinary team. Each discipline reflects different levels of academic credentials, this sometime results in differences of opinion. Because each discipline comes from a different background, each tends to operate in a manner that follows their particular ethics and values, which can impede their ability to work together. As Schofield and Amodeo (1999) observe, this discrepancy results in:

> tensions related to team participation, different levels of personal by various team members, disparate jargon and technologies, physician dominance, role confusion and blurring, heavier time commitment required by participants for the interdisciplinary approach, team member's sense of insecurity about the worth of the team approach, a shift in professional status for some disciplines, and lack of administrative support. (p. 1)

Currently, at the Rotary Hospice House, the interdisciplinary team consists of (but is not limited to) the following staff: physicians, nurse practitioners, nurses, care aids, grief support workers, volunteers, community social workers, and pastoral support (Prince George Hospice Palliative Care Society, 2019).

Various health care teams are rooted in the philosophy that collaboration between different professionals increases critical thinking in developing patient-centred care plans (Parker-Oliver et al., 2005). In other words, these professionals are working within an interconnected approach to achieve the same goal. Teams that are grounded on an interdisciplinary focus and choose to work together discover that cooperation requires great effort and investment (Parker-Oliver et al., 2005). Interdisciplinary collaboration is grounded on the belief that reciprocal process of a singular goal is not accomplished by an individual alone and rather team contribution. Parker-Oliver and colleagues (2005) assert "this definition focuses on the synergy, which emerges from collaboration, identifying it as an active, ongoing, productive process" (p. 1). When working as a team, patients receive holistic care. For example, one area of interdisciplinary focus is the management of pain for the dying person. Pain management requires attention to the "physical, spiritual, financial, and psychosocial needs of the patient and his or her family, none of which can be accomplished by only one 'kind' of professional" (Parker-Oliver et al., 2005, p. 1).

Hospice care was conceptualized as an interdisciplinary team model focusing on providing holistic care. For example, "Cicely Saunders, founder of the modern hospice movement, serves as a role model for interdisciplinary work because she was trained as a social worker, nurse, and physician" (Parker-Oliver et al., 2005, p. 1). As such, Saunders wore many hats and brought a wealth of knowledge to each patient she cared for. In the hospice setting, "teamwork is critical to the service and management of the entire person and his or her environment and is essential in providing a 'good death' for the hospice patient" (Parker-Oliver et al., 2005, p. 1). Using an array of interventions through different professionals, the interdisciplinary team "can stimulate positive change within their teams" and thereby enhance patient care (Parker-Oliver et al., 2005, p. 1).

In conclusion, the above literature outlines the important connections between palliative care and hospice care and their similarities. Furthermore, Chapter 6 will summarize my learning experiences from being at Hospice House.

Chapter 5: Learning Experiences From my Practicum

In this section I outline my learning goals and describe tasks I completed, with examples, to promote my learning. I am grateful the Prince George Rotary Hospice House took me on as a practicum student: my learning was rich and I more deeply learned effective palliative care skills. I felt supported by each staff member at Hospice House and by my academic supervisor and MSW student colleagues. As I progressed through the practicum, I felt respected as a member of the hospice team. Taking on a student role after being a registered social worker for 10 years, I felt a sense of fear, anxiety and uncertainty; over a short while, I felt at ease and it seemed that the universe had brought me to the right place at the right time.

Below I describe how I met my learning goals, outlined in Chapter one. In addition to my original ten learning goals, I added four new goals to my learning contract as learning opportunities arose during my time at Hospice House. Below, I have my original goals listed (1 – 10) and I have also listed my new goals (11 – 14) and described how I addressed them.

1. Understand the Values and Vision of Hospice House

Prince George Rotary Hospice House operates with the vision that they are "leading excellence in Hospice care" (Prince George Hospice Society Annual Report 2020–2021, p. 1). Their mission asserts that "compassionate staff and volunteers provide specialized Hospice Care to meet the needs of the person, families, and community through bedside care, outreach, grief support and education" (Prince George Hospice Society Annual Report 2020–2021, p. 1). Overall, in my observation it was noted that the staff at Hospice House shared the same aim: to provide excellent palliative care. This is the organizations goals and is evident in the workers' professional practice. For one example, I observed that hospice staff shared a similar value regarding substance use with the guests at the end of life. I saw staff acknowledge the importance of working with a harm-reduction model and allowing guests who requested alcohol to have alcohol in moderation to help them to enjoy their last days of life - if alcohol would not impact the administration of pain management. One staff member suggested dipping an oral swab into alcohol to allow the guest to experience the taste; this amount of alcohol would not interfere with activities of daily living or medications. I appreciated the idea because it reflected thinking outside the box. In addition, I noted that hospice staff's caring for a guest extended to caring for their family unit. This was evident as staff ensured that families were fed, hydrated, rested, and supported through their grief. Many times I witnessed staff sitting with families in the living room or standing with them in the hallways while having lengthy conversations about the death and dying experience. There was never a time when a staff member rushed through these conversations despite their workload.

2. Practice Remote and Online Support

When I began my practicum at Prince George Rotary Hospice House, I anticipated that most of the grief support would be conducted virtually. As public health orders shifted in response to the COVID-19 pandemic, most of the grief support was provided face to face. Consequently, I did not develop much skill in providing online support. I did, however, have the opportunity to discuss online support with the grief support staff and they acknowledged that when groups were conducted over Zoom, the format enabled clients to join from remote communities; this was also true for individuals who were too sick or too weak, or who otherwise were unable to attend in person. The obstacles to providing effective online support included trying to engage simultaneously with clients over Zoom and in person; additionally, group facilitators were unable to identify or interpret clients' non-verbalized emotions, which made supporting them more difficult. Although I had limited experience with online Zoom support groups, in my narrow experience it appeared to be a positive experience for clients. I understood the use of Zoom as an opportunity for clients who were not able to join in person to participate in a way that was beneficial. I noted that out-of-town participants who joined the group had been recommended to do so by their practitioners because other communities were not offering this type of online support.

3. Understand How the Staff Copes With End-of-Life Situations

I had the opportunity during my practicum to meet with various staff at Hospice House to discuss their coping strategies. It is understood that anyone who comes to Hospice House either comes to receive end-of-life care; pain and symptom management; or respite care, because their family is unable to provide the level of care they need for a short time during the client's illness. All admissions into hospice are related to death and dying and I was curious about how staff members find and replenish the inner strength to keep coming back to work and how they cope outside the work environment. A common theme echoed by the team was that of "being able to talk about their work stories they experienced was enough to feel lighter." One staff member remarked, "it's like having a jar full of balls and each time you talk, and share your story, you're giving one ball away and eventually you can make room for the few balls left" (personal communication). Another theme common among the staff was the feeling of gratitude for working with dying guests and supporting their families and recognizing that it is an honour to walk the journey with them.

4. Develop and Implement Healthy Self-Care Strategies

Entering my practicum placement at Hospice House, I was well aware that the work there would sit heavy on my heart. Much of the grief support that is done at Hospice House is guided in the idea of co-regulation, which helps clients regulate their emotions based on your emotions. Co-regulating takes a lot of energy, which promoted me to acknowledge that self-care would play an important role in my practicum journey. In discussion with one of the grief support staff I was reminded that radical self-care was critical to enduring and thriving in hospice work, meaning putting ourselves first holistically. One hospice team member used the phrase "we are selfing," which meant to frame our self-care not as selfish, but as a form of prioritizing our own needs. On day one I started journaling about my workday, my learnings, my observations, and about how I had felt throughout the day. At the end of each week, I reflected on my journaling and it helped me synthesize and appreciate my learning.

Journaling also helped me move my thoughts out of my head and onto paper so that I didn't ruminate on them throughout my days and weeks. I was able to reflect on the many beautiful moments that impacted me. This helped me bring a deep appreciation for the practicum work I was doing, and I was humbled to walk in companionship with so many individuals at the end of life. I was reminded that prior to coming to Hospice House, I struggled to address the loss, grief, and the dying journeys of children.

During my time at Hospice House, I was reminded that children are very much a part of the dying journey for their family members as they witness death at Hospice

House and I therefore needed to find a level of comfort when working with children. I slowed myself down and reminded myself that my children were safe and healthy and that I was a part of someone else's journey and this journey—at the hospice—was not mine. I would come home, look at my beautiful children, talk to them about their day, make dinner with them, lie with them in bed and even tiptoe back into their rooms as often as I needed to reassure myself that my children were right there. I spent many weekends bike riding, going for walks, and spending time in nature with my children to ground myself. Also, when I felt the need to ground myself at hospice, I walked the labyrinth at the back of the facility; this feature of the hospice is self-soothing and provides a safe space for self-reflection These self-care techniques will continue to be an important part of my self-care as I continue doing social work.

5. Provide Emotional Support to Patients and Families

At Hospice House I became a part of the grief support staff and, in this role, we met with guests and their families at bedside and throughout the building. I made sure to introduce myself as a social work student and explain my role. I had the opportunity to sit with guests and, or, their families to hear about their dying journey hear the individual's story. I enjoyed listening to families share intimate stories that elaborated on who the person was before they became sick. Guests also took time to share their personal history, which might include their childhood, family members, things they enjoyed, and—in the transition to dying—how these elements had shifted and changed. I learned quickly that when a patient is unconscious due to sedations, or because it is part of the dying process, it's always best to inform the dying patient that you are in the room and about to speak with their family. Denise (a member of the grief-support staff) encouraged me to ask permission from the family to sit down and, once seated, inform the guest I would be talking with their family and that they might hear my voice. I found this step made a profound difference in honouring the dying patient and respecting the family. This addition to my practice helped me feel that I was acknowledging and honouring the guest even though they were unable to engage in discussion.

6. Become Familiar With Resources Provided at Hospice House

Families experiencing loss from the death of a loved one may benefit from the resources provided at Hospice House. Hospice House offers grief supports through attending groups and one on one support for families. Hospice offers trained grief support workers to help families while they have a loved one dying at the facility; additionally, trained volunteers can provide support to families throughout an individual’s stay at hospice and after the family member has died. Hospice House has the following programs:

Children’s grief support groups and family grief support groups

Grief support: Broken Circle, Grief and Grub for Guys, Tea Time for the Soul; and Zoom grief support and immediate onsite grief support

Caregiver support: Coffee for the Caregiver; and one on-one caregiver support, community volunteer visits, and caregiver support videos

Remote and online support: virtual grief support and remote hospice

Families have the option to attend one or more groups when they feel ready. There is no cost to attend groups. Also, if you cannot attend a given session, this is met with understanding. The groups are very informal, and people can attend the group when they need. Hospice recognizes that people’s lives can be very busy, especially during circumstances that make hospice necessary and during the grieving process. Due to the COVID-19 pandemic, Hospice House has had to change the way it offers groups. For example, some groups are online, via Zoom, while other groups have reverted to face-to-face meetings. During in-person groups, participants are separated by 6 feet and there is no physical touching, which can be problematic because touch can be an important part of the support process.

7. Understand How Community Services and Hospice House Interact

Hospice House operates with a multidisciplinary team. There is a strong focus on nursing, care aids and grief support workers. However, there are also circumstances in which social workers are required to assist guests and families. During such occurrences, if a guest is already connected to a community social worker, the guest is encouraged to contact the social worker or they can ask the hospice staff to do it. However, if the guest is not connected to a primary care social worker, hospice will make a new referral to the interprofessional team through Northern Health. During my time at Hospice House, there was no standard amount of time within which a social worker would pick up the new referral: they might call back in five minutes or, sometimes, it took days or a week. It is important to note that most guests at Hospice House have limited time, due to their life limiting illness. In discussion with the team, I learned that a guest would often die before a social worker from the community would come to see them.

In other experiences, I learned that funeral homes play a significant role at Hospice House. Families must call a funeral home when their loved one dies, and the funeral home will contact hospice right away to make arrangements to care for the body. There never appeared to be any hesitation on the part of a funeral home when there was an urgency around picking up a body.

External spiritual care services are welcomed at Hospice House if a guest or family requests it. Again, there appeared to be no hesitation with spiritual services coming into hospice quickly, they appear to understand that a guest's time is limited time and spiritual care providers prioritize them. It is important to recognize that Hospice House is rebuilding community cohesion as they work to become more engaged with the community by providing grief support with volunteers and by providing education. This community work is offered in people's homes, long-term care facilities, and private organizations (big and small).

8. Understand the Hospice Intake Process for New Patients

New referrals come from the hospital or community and are always referred by the physician. If a guest comes from a hospital, the care team may be very much involved in the referral process to hospice. Each referral comes with multiple layers of paperwork, which includes the following: consent to care facility admission, palliative registration forms; hospice referral that includes the palliative performance scale (PPS), medical orders for scope of treatment (e.g., do not resuscitate, nurse's notes from the previous few days (if available)); additionally, a physician may order medications for a guest once they are admitted to hospice. When all the necessary documentation has been collected, the nurse lead or the registered nurse for the shift will assess the referral based on the information received. When this assessment is complete, the nurse will contact the referring individual or the person most involved with this guest to gather any crucial information. The nurse may ask questions regarding diagnosis, prognosis, previous treatment, current medications, current symptoms, family involvement, who the temporary decision maker is and if they have had COVID, have COVID, or have COVID-like symptoms. When all relevant information has been collected the nurse will determine bed availability and whether any other referrals are pending for individuals who may soon need hospice care. At this time, if the nurse accepts the guest for admission to hospice, the nurse then contacts the referring person and informs them of the acceptance into hospice; if the family is unable to bring their loved one into hospice, the nurse will ask the referring individual to contact BC ambulance to arrange transportation. Once the guest arrives at hospice, the nurse and care aids ensure the guest is comfortable in their room, begin their assessment, ensure the individual's symptoms are managed, and create a care plan to implement sound palliative care measures.

9. Understand the Triage System: New Patients and Hospice House

Triaging new referrals that may arrive from the hospital or community, including people in their own homes or from long-term care homes can be quite challenging. One nurse explained this process as akin to "being a detective" and "needing to ask the right questions," which can seem like a game of Jenga. Confusion can arise because Hospice House can receive referrals at any given time and in no particular order; occasionally, several referred guests may come all at once. Hospice House has 10 beds and while they may have two available beds at a given time, three new referrals who require admission may be made at roughly the same time. The nurse in charge must contact all referring parties and discuss the respective client's diagnosis, understand their PPS score, the difficulties they are having, and what each individual's family supports look like. Once all the required information is gathered, the nurse must make an executive decision and provide beds to the most suitable guests. Once the beds are filled, the unplaced guest will be waitlisted for the next available hospice space. It should be acknowledged that hospice staff take referrals very seriously and consider all relevant aspects of each potential guest.

10. Learn and Apply Terms and Language Used at Hospice House

Shortly after spending time with the staff at Hospice House, I learned that most of the language I use is congruent with the team's use of language. However, I was informed the staff use the word "guest," not "patient." It was explained to me that a person entering Hospice House is coming into our home; consequently, the term "guest" is considered to be most appropriate. When Hospice House staff members support community members in the community, they use the term "client" because they are entering the client's home. At the beginning of my practicum, I struggled to use the terms "guest" and "client" appropriately because I am used to using the term "patient"; over time, however, I was able to adapt to the preferred terminology at Hospice House and it came to feel natural.

Additionally, I'll note that I often heard hospice staff say the following to dying guests: "your family is here with you; I am also here with you: you are not alone; everything is all right, there is nothing to fear; I'ts okay to die if you're ready" (observation). "[Because we, who are alive, can offer assistance and be of service […[t]he awareness that no one dies alone is comforting" (Leary, 2012, p. 70).

11. Increase Knowledge of Group Work, Including Co-facilitation

Hospice House facilitates several groups each week. At the beginning of my practicum placement, I asked to join groups with the goal of understanding the healing journey that derives from attending such groups. Naturally, I was able to join the discussion, and found myself co-facilitating. Of all the activities and responsibilities I undertook, groups had the largest impact on me during my practicum placement. During groups, family members shared their stories about their loved one who had died, the dying journey, and about how the death had significantly impacted their identities. A common theme that surfaced in groups that was significant to me was that secondary grief often seemed to have a larger impact on the family then the death itself. For example, when a loved one died, some families noticed how their friends stopped inviting them to social gatherings because they were now single and coming alone, and they noted that friends would avoid them in public because the friends were uncomfortable and didn't know what to say to the family in these circumstances. Additionally, I noted many family members who attended groups recognized they would fall into roles they had never imagined or would have chosen; for example, a man who had lost his wife would now have to learn how to braid his daughter's hair and learn about her changing body and hormonal shifts. Similarly, a woman who had lost her husband would have to learn to take on tasks her husband had completed in the house and maybe become an income earlier if she were not so already.

I participated in groups for adults, and groups for children, and I found that I was more comfortable working within the adults group. In my experience in the children's groups, I found that children express their grief in a way that differs greatly from that of adults. For example, children use body language and are likely to act out to how their loved one has died, whereas adults will express their losses verbally. I also noted that children find it easier to express their grief through play. The children's groups included crafts, puzzles, paint, blocks, and books, and the children would engage their grief work while participating in toy time; this means of expressing themselves appeared to come very naturally to them.

12. Provide an In-service to the Hospice Care Team

I was asked by a Hospice staff if I would be willing to conduct in-service training on the Mental Health Act. Hospice House had recently had a guest with a mental health disorder who had been transferred from the hospital; the individual also had an end-stage non-curable illness. I was informed the staff did not feel comfortable with this complex situation because they are not familiar with the Mental Health Act and he was coming as a certified mental health guest. I took the opportunity to learn about the situation, gather information on mental health, and, using my existing knowledge on mental health, put together a PowerPoint and a handout to present to the team. We discussed the case, the Mental Health Act, and how we could provide dignity to someone who is dying and who suffers from a mental health disorder. There was great discussion during this presentation, and I was provided with lots of positive feedback. Shortly after this presentation, I was asked to conduct a presentation on medical assistance in dying (MAID). I gathered the appropriate information, created a PowerPoint, and asked a colleague who prescribes MAID to join. The presentation provided remarkable learning; prompted a fruitful, useful discussion; and resulted in a significant amount of gratitude for the information. Both presentations were informative for the hospice care team and for me.

13. Increase Knowledge of Grief

I went into my practicum thinking that I understood the concept of grief and it turns out I mostly understood it in the abstract. Working at Hospice House helped me develop a more concrete understanding of grief. I spent some time watching videos about grief and one that stood out to me was *Speaking Grief*. The video communicates that the one thing that we are promised when we are born is that we will die. We do not know when, but we know it will happen. The video explains that even if we are not actively grieving, we nonetheless carry the idea that eventually we will have to make space for grief because everyone encounters loss. One message contained in *Speaking Grief* is that experiencing grief is made unsafe when one is told how they should grieve; for example, telling someone not to cry or that there's a period of time after which they feel less sad. During my observation at hospice, I was taught that grief has many stages and guilt is one of them. However, it can be helpful to remind people who are grieving and who feel guilt that guilt only applied in circumstances when a person does something wrong intentionally. At hospice we also discussed the four stages of grief: (1) accepting the reality of the loss, (2) experiencing the pain of loss, (3) adjusting to a new life, and (4) directing emotional energy away from loss and into reinvestment. I was taught that when people are grieving, they may circle through these different stages several times and that there is no linear way to process grief.

14. Understand the Non-verbal Communication of Dying Individuals

Maggie Callanan and Patricia Kelley, in their book *Final Gifts* (1992), acknowledge that dying people have their own way of communicating in ways other then using words. Dying people communicate through their behaviour and actions to show us what they are experiencing. The authors note that it is common to see dying people reaching for someone, or perhaps something unseen; smiling, waving, and nodding, and that they may make weak attempts to talk to someone that is invisible to those in the room. To most people, these behaviours may appear odd or inappropriate and are often categorized as confused and many times guests are sedated to keep them safe. Callanan and Kelley (1992) believe that the dying person is, in fact, experiencing something and this something is often seen as a stage that occurs near death: “Contrary to popular belief, or perhaps from wishful thinking - because of our own discomfort with death - dying people know they are dying, even if no one else knows or has told them” (p. 73). The authors assert that dying people attempt to share their experience by using symbolic language and thus indicate their preparation for death. Callanan and Kelley (1992) state that “this behaviour is a nonverbal way of communicating experiences of dying, showing that dying people aren’t alone, that others who have died are meeting them” (p. 173). During my time at Hospice House, I would often witness guests trying to get out of bed, as if they needed to go somewhere. I would sit with them, use my voice to keep them calm, and create a safe environment for them. I had the opportunity to reflect on this idea and engage with the staff who echoed these beliefs. A common theme noted by staff members was that these behaviours game the team hope that there is something beyond life as what we know it; the idea provides some comfort.

Ethical Considerations

In preparation for my practicum placement at Hospice House, I had to consider ethical considerations and conflicts that might arise. The section that follows outlines ethical dilemmas I encountered and how I dealt with them.

Guard Against Participating in Dual relationships

I am a registered social worker and currently an employee of Northern Health at the University Hospital of Northern British Columbia (UHNBC). I have referred several individuals to Hospice House and spoken with the nursing staff to provide collateral information about families. In light of these responsibilities and actions, it was important for me to explore possible conflicts. I was mindful of my position upon coming to Hospice House. First, I thought it was important to introduce myself as a MSW student, not as a social worker. I often reminded hospice staff that I was there as a student to learn and observe and that I was not there in an official capacity as a registered social worker. I frequently encountered new referrals who came from the hospital from my colleagues who had requested my involvement for ongoing social work support. Again, I had to remind my colleagues that my role was that of a MSW student at hospice and that if there was a need for a social worker we would have to complete a referral to a community social worker. I also reminded hospital colleagues that if there was a need for grief support there are hospice staff trained in grief support and that trained volunteers were also able to address this need. Each time I had to have this clarifying discussion with Hospice House and hospital staff it was well respected and there were no difficulties in moving forward. Last, because I have been working in the health care field for 10 years, I have built many relationships with people who have chronic illnesses and with their family members who had been in and out of the hospital. I had some fear about the likelihood of encountering these patients and families in Hospice House for end-of-life care. I was worried my presence would cause role confusion for the guest and families; fortunately, this issue did not arise.

In conclusion, my practicum experience far exceeded what I could have asked of it. I felt all my learning goals were achieved and much more. I learned—again—how to provide good palliative care services, through this time during a global pandemic. I felt very much accepted as a part of the hospice care team. The team has my utmost respect and admiration in light of the level of care they provide their guests and each other. The practicum placement opened my eyes to deeper levels of loss and grief. I had become conditioned to dealing only with death; during the practicum experience, though, I had the opportunity to meet with families who had encountered loss and I came to better understand how such losses has impacted their lives in the present and the nature and complexities of the recovery journeys these families were on. I found that my time at hospice impacted me in ways that required much more self-care, particularly as I became more aware of my own heartache, losses, and grief.

One important lesson I learned during the placement was that rather than providing information right away, it was better to ask an individual or families what their understanding of the current circumstances was. For example, if a family member presented with doubt, worry, guilt, and anger about their loved one being admitted to hospice, I would ask them "What is your understanding of your mother’s illness” and, or, “What is your understanding of what hospice offers?” These questions give some power back to individuals who are vulnerable and grieving, and it encourages them to speak about what they know. For the most part, individuals and families have the right information; they just need help articulating their knowledge and validation of their awareness and feelings.

It is worth noting that it is important that we acknowledge our own suffering when we walk alongside a dying guest at the same time we support their family. Naturally, our hearts open up to the presence of suffering and pain. “In providing a soulful response to another person’s pain, we must discover and nurture two qualities that are within us: humility and unknowing” (Wolfelt, 2009, p. 19). We must open our hearts, be focused and attentive in the moment; being a part of a person's dying journey is about intimacy, immediacy and being present. I have a strong belief that individuals know when they are about to die. I have heard many times from hospice guests that they were going to die this day, or this week, or this month; often, the prediction—or premonition or intuition—came true. In one occurrence, a guest told me that in a dream she was flipping through a calendar and the calendar did not go beyond April. She said that this was when she knew and accepted that she was going to die at the end of April, which she did.

Chapter 6: Implications for Personal Professional Practice

In this chapter I discuss the main themes in my learning experiences at the Prince George Rotary Hospice House and how they shifted me wholeheartedly, not only as a student and a social worker, but also as a woman. I will describe how this new knowledge will pertain to my development in my social work practice as I continue my career as a hospital social worker. Though this experience did not come without challenges, during the beginning of my academic studies UNBC went on strike, then we lived through a global pandemic that demanded a shift in the way we learned. Yet, after all the challenges and beautiful learning experiences through this academic journey, I have found that my greatest accomplishments and learning came from each individual who crossed my path.

First, I am humbled by the guests and families at Hospice House who allowed me to be part of their dying and grieving journeys, respectively. I also want to acknowledge that my deepest learning was enhanced and made possible by the knowledge and wisdom shared by the Hospice House staff: I am forever changed and forever grateful. It is important to acknowledge that my learning experience also came with struggles; as I began my Masters in Social Work (MSW) journey in September 2019, UNBC went on strike and, shortly after, we began to live and work as a global pandemic took hold and evolved. Inevitably, these events and forces altered the way I learned and worked. However, despite the challenges encountered on my MSW journey, I became a better social worker and am grateful to all the people involved and I look forward to bringing all this new knowledge into my hospital career.

I want to acknowledge that I had to spend a portion of my practicum relearning the skills and attitudes constitutive of good palliative care. In short, I had to sit down and be present in the moment with individuals as they were dying and forget about all the other tasks that required my attention, and, often in the company of the person's family. I had to accept that my own pain was going to surface and to learn how to make space for it and be kind to myself. I also learned from families who had lost loved ones months to years earlier and who continued to grieve. The main learning from this was that our relationship does not end with the person who died; our relationship just changes and we build the capacity to manage this pain. However, for the purpose of this section, I will outline my personal self-growth and provide recommendations for my future social work practice.

Self-care

I was keenly aware at the beginning of my placement that I was going to be surrounded by loss, grief, and death. Knowing this, I was very mindful that self-care needed to be an important aspect of this practicum journey for my family and myself. As such, I made self-care a significant part of my practicum process by including it into my learning contract. One of my most effective forms of self-care for me was journaling. I allotted 30–60 minutes each day to journal, this enabled me to acknowledge the sadness that came from working with death and dying and put these thoughts on paper and leave them there; somewhere safe and it created space for further learning.

Furthermore, because self-care was a learning goal of mine I gave myself permission to schedule self-care beyond journaling into my days as often as I needed them. For the most part, I used these times to ground myself, connect with nature, and give myself space and permission to let go of the sadness inherent in hospice work. For example, Hospice House has a labyrinth in their backyard and I was able to utilize this space anytime I required some time to myself. It really grounded me by walking outside, through the path and clear my head.

The Need to Slow Down

When I started my practicum at Hospice House, I was very aware that my usual pace of work was quick. I remember telling the grief support staff that I was very much used to working in a hospital where work was fast paced and everything felt rushed. There were always traumas, critical events, and people who needed to go home—like, yesterday. The moment I walked into Hospice House, I was reminded in discussion and through observation that there was no need to rush there. This was particularly true when I would meet with a guest and, or, their family; in these encounters, it was vital to leave my busyness behind and be present in the moment. You need to be able to show that you have the capacity to give all of yourself to all of them. This was a crucial skill I learned when at Hospice House. This practice has also benefited my personal life: it has helped me feel more peace in all my activities. This built my capacity to carry on and prevent potential burnout.

Be Present in the Moment

There is nothing more humbling then being invited by a family to join the dying journey of their loved one, especially when the guest is asking for you specifically. The dying journey is very intimate and personal, and we should hold gratitude when we participate in such a process. In the moment, it is important to stop your tasks and join the family by giving them your fullest attention, your time and energy. This may mean sitting at the edge of the bed and holding the hand of a dying guest, sitting on a chair, or getting cozy next to the family on the couch. Sometimes, families wanted you to sit in silence and other times, they wanted you to cry with them, or laugh while they shared stories. Being invested in those precious moments created a healthy bond. Furthermore, there would be times where families brought their dogs into the room to be with the dying guest; it was very evident that the animals could sense something was changing. When I showed affection to the dogs, the families appeared to grow a deeper bond with me.

I learned quickly that it is okay to feel sad. It is okay to feel your own pain, and it's important to be kind to yourself. One can make space for the pain, but ensure the family knows your attention is focused on their loved one. The ultimate goal in participation is to create safety.

Practice Heart Work

Brené Brown says it best: "wholehearted living is about engaging with our lives from a place of worthiness. It means cultivating the courage, compassion and connection to wake up in the morning and think 'no matter what gets done and how much is left undone, I am enough" (Brown, 2010, p. 1). Brown's (2010) assertion inspires me to believe that I knew that when I came to Hospice House and worked with an open heart, from a place of love, compassion, and kindness, that I did the best I could each day: this is equivalent of practicing heart work. This was my biggest self-growth journey. At the beginning of my practicum, I always felt that I could offer more—that I should have more capacity to talk longer with guests and families; however, Brown's affirmation reminded me I was doing the best I could. After that, I internalized the knowledge that I was working from a wholehearted place.

Suggestion for Policy Changes at Hospice House

During my time at Hospice House, I had the opportunity to review the current policies and practice standards and engage in discussion from each member of the multidisciplinary team. Moving forward my suggestions to Hospice House for policy change would be to improve the communication between Hospice and the hospital when the hospital is sending a new referral. During my time, I witnessed many hospital referrals come through and each time there was a different amount of information provided and there was no consistency in the information. Many times the hospice staff received the bare minimum information and had to contact the person who sent the referral and ask for further details. Also, sometimes the guest would arrive from the hospital and the information provided about their PPS was inaccurate or they had extensive wounds or required more than two people to provide their personal care. I would highly suggest moving forward that Hospice create a policy to ensure more in-depth conversations are happening before a guest arrives at hospice from the hospital and the information being provided is accurate; this will only allow for better patient care. Overall, I believe having more effective communication will strengthen the relationships between colleagues working at the hospice and in hospice.

Furthermore, I had the opportunity to take part in and facilitate a few educational in-service training opportunities during my time at hospice. These education sessions were greatly beneficial to my learning. However, it was noticeable that not all the staff attended these educational sessions but would have really benefited from them. It would be my suggestion that hospice creates a policy that any educational session is mandatory and paid for all staff. This can be offered once a month so that hospice staff are not fully relying on outside agencies for this type of knowledge and the hospice staff can be more self-reliant. Overall, this opportunity would allow for better palliative care for this regional facility that serves everyone in the north. I suspect this suggestion may be accepted from the staff, however I worry that funding may be a barrier, as hospice is a not for profit organization and funds are allocated very specifically.

Suggestions for Research in Hospice Care

Through my literature review, my time spent at hospice and all my conversations with guests and families I inquired why this regional hospice facility does not have a full multidisciplinary team including a dietician, occupational therapist, physiotherapist, pharmacist and social worker. I am curious to know the impact other hospice facilities have when they work with a full multidisciplinary team. To be more specific, palliative care social workers bring particular knowledge to the team and while hospice does have knowledgeable staff, they do not practice through a social work lens. Hospice staff heavily rely on community social workers for all their social work needs. However, it is important to note these community social workers are generalists and do not have a speciality focus in palliative care. They also carry a caseload in the community, which means they prioritize their caseload based on everyone's needs and hospice guests may not be seen within an appropriate timeline. Furthermore, if these community social workers have never met the guest or families before, they are forced to build a quick rapport, whereas if there was a hospice social worker, rapport would come naturally as that social worker would have seen those guests and families on a regular basis whether that was through bedside support, or discussions passing by in the hallway. As research continues, I would suggest further research into the benefits of having a full multidisciplinary team and more specifically hospice social worker and how it would impact hospice care.

Lastly, because I just studied and completed my practicum during a global pandemic, I would suggest further research into how the Covid-19 pandemic impacted the way people died at hospice house. I would like to see future research on if the death and dying experience was significantly different, how so, and if the experiences were all negative. I would like to hear about the trauma inflicted onto families who were unable to be with their loved ones as they were dying due to the pandemic. I would also like to understand how this trauma would be treated and resolved or if we have left a footprint of trauma on people's hearts.

Conclusion

In conclusion, my practicum placement at Hospice House has thoroughly shifted my personal and professional framework. As a result of spending time with guests, families, staff, volunteers, and the administration staff, I am forever changed—and forever grateful. I believe I now have better palliative care skills to care for guests at the end of their lives. I hope this report contributes to the field of social work by highlighting the ongoing need for education in palliative care, the importance of slowing down, and the value of being present and opening your heart to guests and families even as one recognizes their own pain and holds space for it.

Reflecting back on my practicum journey, I consider everything I have learned and look forward to implementing them into my future practice in my hospital career. I understand and recognize that Hospice Care is significantly different than acute care, however small changes that I can embed will be:

- Slowing my pace down. I was told once at Hospice House that, “nothing is ever an emergency”. This statement stuck with me.
- Sitting down while speaking with patients and their families. It looks very intimidating when your standing in a room while everyone else is sitting or laying. It also feels like the person standing holds power. I will choose to sit.
- When entering a patient room, I will leave my pain outside the room and give all of my energy to the patient and family members.
- I want to remember all the little things. When I was at Hospice House, I remember the staff members always asking the families if they had anything to eat, or drink, or wanted a short break outside. I will remember to ask families all these questions.
- Mostly importantly, I want to make time for myself at work. I want to take time out of the busy day to complete a self-check. This may require me closing my office door, going outside, or journaling my thoughts onto paper to ensure they do not pile up inside where I cannot manage my work stress. I want to remain in a healthy place so I can continue my social work journey and continue being a healthy mom.

I also hope this report encourages readers to be kind to themselves and each other: as part of this, those working in the healthcare and social work fields need to practice authentic self-care as we continue to support people as they die and live through the global pandemic.

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