WISDOM IN QUIET OBSERVATION: HOSPICE PALLIATIVE SOCIAL WORK

by

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Abstract

This practicum report is a summary and reflection upon a Master of Social Work practicum completed at Victoria Hospice, supporting my desire to understand the role of a social worker within an interdisciplinary hospice palliative healthcare team. Several aspects of my practicum experience are explored through a literature review, embracing a biopsychosocial-spiritual model of practice. Included is a brief examination of Medical Assistance in Dying (MAiD) and its legislation in Canada. The knowledge gained from this practicum will guide my hospice palliative social work practice in northern BC, which in turn will provide a learning environment for future social work students wanting to specialize in this area of practice.

TABLE OF CONTENTS

Acknowledgment

First and foremost, I would like to acknowledge and honour the patients and families with whom I had contact at Victoria Hospice. Thank you for allowing me to be part of your journey. It was a privilege to support and serve all that I had contact with. These experiences were invaluable to my learning and helped me to understand the dying process within a biopsychosocial-spiritual model of practice. At times I struggled with witnessing the process, but I always strove to sit within a place of unconditional love and to be non-judgmental in understanding the decisions made by patients, families, and healthcare providers.

I would like to acknowledge the staff at Victoria Hospice for allowing me to fulfill my practicum requirements within their interdisciplinary hospice palliative healthcare team. Your caring and empathetic care for patients and families was exemplary in its human kindness and gentle presence for all those who faced death. Thank you for allowing me to observe and learn from your example. This practicum permitted me to grow professionally and personally, and the lessons learned will never be forgotten.

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Chapter One - Introduction

This report is a summary and reflection on my learning experiences during my practicum placement at Victoria Hospice Society's in-patient unit. In this, Chapter One, I introduce my reasons for pursuing a practicum placement in a hospice palliative care setting, and provide an outline of the structure of this report. Chapter Two, is an examination of the shift in aging demographics in Canada and British Columbia, the challenges northern citizens experience in the delivery of services, and hospice palliative services for rural and remote Aboriginal communities in BC. The knowledge of this shift in aging demographics influenced my choice to pursue a practicum experience in hospice palliative care. In Chapter Three, I provide a detailed description of the practicum site, and services provided by Victoria Hospice. In Chapter Four, a theoretical orientation of both the practicum site and my own position within this area of social work practice are outlined. Chapter Five provides a comprehensive literature review that encompasses the relevant hospice palliative issues I experienced during my practicum. Chapter Six discusses my learning goals and experiences and what I have gained from them. Chapter Seven suggests future implications and recommendations from these experiences for professional social work practice and social work curriculum. And finally, Chapter Eight provides my concluding thoughts.

Northern British Columbia (BC) has experienced an out-migration of older adults to rural areas in search of relaxed lifestyles and cheaper accommodations (Hanlon & Halseth, 2005; Shandro, Veiga, Shoveller, Scoble, & Koehoorn, 2011). These individuals are now aging and dying-in-place, some of whom have and/or will develop life-threatening illnesses, placing further pressure on an already stressed provincial healthcare system (Howell et al., 2011). My interest for pursing a practicum placement in a hospice palliative care setting evolved from my understanding of northern BC's unique challenges in the delivery of healthcare and supportive services for individuals aging and dying-in-place within rural and remote settings, and my desire to understand the role of a social worker within an interdisciplinary hospice palliative healthcare team. The experiences at the practicum site will allow me to support and mentor other aspiring social workers interested in specializing in hospice palliative social work.

Chapter Two – Background of Hospice Palliative Care in BC

This chapter provides an examination of the shift in the aging demographics in Canada, Aboriginal and non-Aboriginal populations in BC, and includes the challenges faced by service providers in the delivery of services for end-of-life (EOL) in rural and remote communities. The knowledge of this shift in population demographics, along with the lack of specialized services in hospice palliative social work, prompted me to consider a practicum placement in a hospice palliative care facility. The knowledge and experiences acquired in such a facility would then be transferrable to rural and remote settings in northern BC for both Aboriginal and non-Aboriginal populations.

Shift in Aging Demographics

As previously stated, Northern BC has experienced an out-migration of older adults to rural areas (Castleden, Crooks, Schuurman, & Hanlon, 2010; Hanlon & Halseth, 2005; Shandro et al., 2011). A greater number than ever before in Canadian history are now aging and dying-in-place, many of these individuals have and/or will develop life-threatening illnesses. As well, cost cutting measures have taken a toll on the health care structures in the north, and there is an apparent imbalance in the aging demographics of the citizenship in smaller communities. Ambulatory services and medical facilities in smaller communities are restructuring as older healthcare professionals are nearing retirement age, and creating gaps in service (Harrington & Heidkamp, 2013). Fewer healthcare professionals living and practicing in northern BC's rural and remote communities are available (Charles, Bainbridge, Copeman-Stewart, Art, & Kassam, 2006). Agencies such as the BC Emergency Health Services are implementing new programs to support this shift in delivery of emergency services. In January of 2016, Phase One of a newly created program, the *Community Paramedicine Program*, was initiated. Communities across the province are being invited to engage in decision-making and implementation of emergency services according to the needs of their community (BC Emergency Health Services, 2015). Yet rural and remote communities are in need of acquiring required resources to live healthier and safer lives while struggling to support and maintain the level of acceptable professional care deserving of the elders within their communities.

A shift in the aging demographics in BC continues to place a greater demand on its provincial healthcare system (Hanlon & Halseth, 2005). This is due in part to the Baby Boomers living, aging, and dying-in-place. Statistics Canada estimated “in 2014/2015, the growth rate of the population aged 65 years and older was 3.5%, approximately four times the growth rate of the total population” (Statistics Canada, 2015, para. 9). Statistics Canada states, “the annual growth rate of this age group has accelerated since 2011, when the first members of the baby boom generation (persons born between 1946 and 1965) turned 65. On July 1, 2015, 18.2% of baby boomers are aged 65 years and older” (Statistics Canada, 2015, para. 9). These estimates on population demographical shifts are reflected in northern BC. Advancement of medical procedures, new medications and prevention programming contribute to the baby boomers living longer and healthier lives (Christensen, Dobblhammer, Rau, & Vaupel, 2009).

Canada can expect larger numbers of the population dying and hospice palliative services will be in greater need. The Canadian Cancer Society states in its 2016 *Palliative Care Report*: “improvements to the palliative system in Canada is desperately needed. Without clear national standards and accountabilities, individual jurisdictions are left to develop their own policies, programs and guidelines, resulting in inconsistent or inadequate access across the country” (Canadian Cancer Society, 2016, p. ii).

Statistics Canada states "people of all ages require care at the end of life [EOL], and given the aging of the population, [in Canada] it is estimated that by the year 2020, there will be 40% more deaths annually than in 2003. Furthermore, approximately 90% of Canadians will eventually die as a result of a prolonged illness (Health Canada, 2007, p. 1). The federal Liberal government has recognized the financial burden associated with caring for a terminally ill family member. In January 2016, the Canadian federal government extended the time a caregiver can receive Compassionate Care Benefits through the Employment Insurance benefits program. The length of time to receive benefits have been revised from six weeks to 26 weeks, and further revisions to the Compassionate Care Benefits program are expected later in 2016 (Government of Canada, 2016a).

The BC provincial government also recognizes an aging population demographic and as such is re-evaluating service provision, while taking into consideration the elderly population who will be developing life-threatening, terminal illnesses, and experiencing end-of-life (EOL) processes. The British Columbia Ministry of Health (2006) also defined and regulates hospice palliative care, offering a proposed practice framework. The provincial vision of quality of hospice palliative care is that professionals and family members support dying individuals and care is ethically driven as well as patient and family-centered care. The afore-mentioned framework defines service delivery with accessibility for a cost effective and affordable hospice palliative care model. This proposed model must include easy access by those individuals and their families who are experiencing the dying process. Accordingly, the British Columbia Ministry of Health (2006) indicates that an interdisciplinary team approach is the most favorable and acceptable means of support within this delivery model. It emphasizes patients and their families, alongside supporting healthcare professionals, community members, and spiritual leaders, to comprise the health care support team during EOL. The overall objective of British Columbia Ministry of Health's (2006) initiative was to shift hospice palliative care from medical settings to those who are most intimately connected to the dying individual, and for "health authorities to plan for the particular characteristics of the communities and services for which they are responsible, provided the services are consistent with [British Columbia's Ministry of Health's] overall principals and objectives" (British Columbia's Ministry of Health, 2006, p. 6). In northern BC the Northern Health Authority oversees EOL care, and demands for EOL resources in this area of the province will continue to be strained due to the increase of aging individuals. Indeed, health authorities may not be able to "keep up with the demand" (Cinnamon, Schuurman, & Crooks, 2008, p. 140) for quality hospice palliative care in the region.

Challenges in the Delivery of Services to Northern Regions

Many northern BC residents feel disconnected from the lower mainland in ways other than geographical location due to the unique challenges in accessing healthcare and other services. Winter temperatures, weather conditions, geographical locations, terrain, transportation, and social isolation influence and hinder the nature of the work, delivery, and availability of services (Pugh & Cheers, 2010). Funding needed to sustain services and programming also influence the populations being served (Pugh & Cheers, 2010). Boom and bust industrial cycles in northern rural and remote communities have direct influence on the population growth and in turn availability of quality community health services (Shandro et al., 2011).

Recruitment and retention of professional healthcare workers in northern BC is also challenging due to lower wages, higher workload expectations, and small town lifestyles that may not be attractive to younger professionals starting their careers (Green, 2003; Halverson

& Brownlee, 2010; Pugh, 2007). Being socially visible contributes to the difficulties of maintaining confidentiality, thereby putting pressure on a professional to maintain a strict balance between one's professional and personal life (Green, 2003; Halverson & Brownlee, 2010; Pugh, 2007). With the exception of a few stoic and unique individuals, young professionals attracted to northern BC communities tend to be transient. They gain knowledge and expertise in a short period of time in order to move to larger populated centers. Larger community centers offer more opportunities in career advancement, accommodations, entertainment, and other pertinent services. Lack of professionally trained health care workers in rural and remote communities is directly influencing the standard of care required and received within rural communities in northern BC and throughout the world (Charles et al., 2006; Wilson, Truman, et al., 2009). New and innovative ways of delivering hospice palliative care are being examined in order to create viable and accessible healthcare services for those in rural and remote communities in BC (Cinnamon, Schuurman & Crooks, 2008; Crooks, Castleden, Schuurman, & Hanlon, 2009; Crooks, Castleden, Hanlon, & Shuurman, 2011; Gaudet, Kelley, & Williams, 2014; Howell et al., 2011; Hughes, Ingleton, Noble, & Clark, 2004; Kelley, 2007).

People within northern rural and remote communities are frequently required to leave their home communities in search of adequate and specialized health care, including hospice palliative care. The traumatic psychological process that accompanies an illness, injury, or death is overshadowed by the physical circumstances, and medical professionals are sometimes left feeling inadequate to support the bereaved (Castleden, Crooke, Schuurman, & Hanlon, 2010). The possibility of leaving one's home community for specialized treatment is daunting and for Aboriginal people leaving traditional territory may pose a significant stress on their personal health and well-being (Zapf, 2010). The connection to the land is incorporated into all aspects of life both for Aboriginal and non-Aboriginal individuals (Zapf, 2010). Having a family or community member die in an unfamiliar setting is both disturbing and detrimental to both the individual dying, and to their family and friends, particularly if the bereaved are not present for the final moments of death (Castleden, Crooke, Schuurman, & Hanlon, 2010; Howell et al., 2011; Lawson, 2007; Pesut, Robinson, & Bottorff, 2014; Wilson, Cohen, Deliens, Hewitt, & Huttekier, 2013; Wilson, Couper, et al., 2009; Wilson, Justice, Sheps, Thomas, Reid, & Leibovici, 2006). Physicians and healthcare professionals are now being encouraged to support home deaths to ease some of the pressures on healthcare facilities due to the direct and indirect costs of dying (Government of British Columbia, 2015; Wilson, Cohen, et al., 2013).

Hospice palliative care organizations across Canada are dependent on volunteers in the delivery of services to patients and their families, as well as to assist in non-direct patient care (Claxton-Oldfield, Jefferies, Fawcett, Wasylkiw, & Claxton-Oldfield, 2004; Jenkins & Cook, 1981). Syme and Bruce (2009) argue that hospice palliative care has strayed from “hospice societies [which were] community based, voluntary, grassroots organizations” (Syme & Bruce, 2009, p. 20), making way for institutionalized hospice palliative care settings. This may not be accurately reflected in rural and remote northern BC communities. Volunteer hospice movements in smaller rural communities may not have the funding required to support hospice palliative interdisciplinary teams, palliative care coordinators, or specialized settings in order to accommodate the dying therefore, the burden of care may rest on a few stoic individuals, not by choice but by necessity (Downing & Jack, 2012; Jenkins & Cook, 1981; Robinson, Pesut, & Bottorff, 2010). Health care professionals practicing in northern BC with specialized knowledge of hospice palliative care need to be supported by informal helping systems to adequately serve the needs of palliative patients (Jenkins & Cook, 1981).

EOL Care in Rural Indigenous Communities

The Aboriginal population in BC is much younger and continues to grow at a faster rate than the non-Aboriginal population (BCStats, 2006). The National Aboriginal Health Organization's (NAHO) discussion paper regarding EOL and palliative health states:

> Aboriginal Peoples live in non-isolated (64.7%), semi-isolated (9.1%), isolated (24.6%) and remote-isolated (1.6%) communities with varying proximities to service and urban centres. Access to health care services is directly correlated to the degree of isolation experienced by some communities…A significant number of communities are accessible only by air or seasonal road. Others are accessible by road, but are more than an hour away from a major service centre. (p. 7)

Remote Aboriginal communities in northern BC, accessible only by air, have limited "access to equipment, nursing, homemaking, education and expert medical advice" (Canadian Hospice Palliative Care Association, 2007, p. 15) which contributes to the isolation and fear of dying at home without adequate healthcare support. Furthermore, provincial healthcare often does not acknowledge or compensate for off-reserve care, citing it is the federal government's responsibility to pay for care received by Aboriginal, Inuit, and Metis peoples (Canadian Hospice Palliative Care Association, 2007).

Aboriginal peoples are stuck in the middle of a healthcare funding tug-a-war between provincial and federal governments, contributing to the lack of continuity of services and quality of life choices. Aboriginal patients attending out of community for medical appointments, or transferred to larger centers for specialized care, are frequently alone without family. Lack of funding and available transportation opportunities for family members to reach and return from the larger urban centers after their loved one has recovered or died contribute to the stress experienced by all involved (Castleden, Crooks, Morgan, Schuurman, & Hanlon, 2009). Upon further investigation, limited funding extends to training and programming for both formal and informal hospice palliative care providers, and many of the sentiments expressed by rural Aboriginal communities about the inability to access hospice palliative care are echoed by mainstream Canadian rural society. Despite these funding challenges "communities do have strong potential for capacity building around providing hospice palliative care, especially if there [are] opportunit[ies] for formal training in informal caregiving at end of life" (Castleden, Crooks, Morgan, Schuurman & Hanlon, 2009, p. 9). Jenkins and Cook (1981) suggest that rural communities hold a great deal of knowledge and support for those who are in the process of dying. In smaller communities where there is limited number of professionals, a core group of natural helpers may form an informal helping system and step forward in time of need.

The values and traditions maintained within smaller communities contribute to the support system and natural helpers provide "intuitive understanding and innate skills" (Jenkins & Cook, 1981, p. 415). Tight-knit communities consisting of extended families in Aboriginal communities also provide the support dying and bereaved individuals require while moving through their loss and grief (Castleden, Crooks, Hanlon, & Schuurman, 2010; Improving End-of-Life Care in First Nations Communities Research Team, Lakehead University, 2015; Pesut, Robinson, & Bottorff, 2014). A social worker in contact with northern communities, especially Aboriginal communities, will need to practice from a trauma-informed, sensitive-practice perspective due to Indian Residential School experiences of elders, and intergenerational traumas within Aboriginal communities (Kaspar, 2014; Sochting, Corrado, Cohen, Ley, & Brasfield, 2007).

Summary

In this chapter I identified the need for and the challenges facing the delivery of quality hospice palliative care services for rural and remote northern BC and Aboriginal communities. The shift in the aging demographics in rural and remote northern communities is expected to heavily influence the availability of hospice palliative services to smaller communities in rural and remote BC. Professionals, such as myself, experienced in hospice palliative care, will be required in the delivery of hospice palliative care services in rural and remote settings. In the next chapter I provide my reasons for pursing a practicum placement with the Victoria Hospice Society and a detailed description of its evolution, and the services provided by the society.

Chapter Three – Practicum Placement Site

Social Work fieldwork or practicums are an integral part of social work education (Tsui, 2005). Coupled with course work, mentorship and apprenticeships are considered the optimal environments for learning one's profession. Practicum placements offer an opportunity for students to observe professionals in their chosen field of practice and create learning opportunities for students to explore and examine delivery models and concepts, while integrating those experiences into their own practice. Finding a practicum site that allows for opportunities for personal and professional growth in the chosen specialization within social work can be daunting but yet rewarding. I found a suitable practicum site that would provide me an opportunity to observe the dying process and shadow professionals within a hospice palliative interdisciplinary healthcare team and learn practice skills and abilities in serving this population. This chapter provides my rationale for securing a practicum placement with the Victoria Hospice Society and outlines the services offered by this Society.

Why Victoria Hospice?

My practicum placement was motivated by a desire to gain an understanding of the role of a social worker within an interdisciplinary hospice palliative care team, and to become familiar with the structural influences on gaining access to adequate hospice palliative services within BC. This overall understanding of hospice palliative care would allow me to translate these urban experiences to rural and remote hospice palliative social work practice. It was through Victoria Hospice that I believed a practicum placement would be the most beneficial to my overall experiential learning with dying individuals and their bereaved families. Victoria Hospice has developed assessment tools and educational materials that are recognized and utilized in hospice palliative care facilities and societies throughout BC

(British Columbia Hospice Palliative Care Association, 2015). Psychosocial issues experienced at EOL are unique and this is an area of social work practice that will, in the coming years, be an expanding field for research and for specialized practice support, particularly for rural and remote communities.

Victoria Hospice is located in Victoria at the Royal Jubilee Hospital. Supervision and mentorship was provided by Michelle Dale, MSW, RSW. Ms. Dale is the Coordinator of the Psychosocial Services program at Victoria Hospice, and the in-patient unit counsellor. Ms. Dale reports to Wendy Wainwright, Director of Clinical Services. Ms. Dale is responsible for conducting assessments; counselling interventions; and evaluating the services required by patients and families (M. Dale, personal communication, October 7, 2015). She consults and collaborates with members of the hospice palliative interdisciplinary team at Victoria Hospice in-patient unit and links directly with agencies and organizations outside of Victoria Hospice Society with regards to palliative care (M. Dale, personal communication, October 7, 2015).

My practicum placement was completed between January 3 and April 15, 2016, during which time I was on site in the Psychosocial Service department Monday through Friday. I had direct contact with patients and families upon admission to the unit and continued supporting them until death. I attended medical "rounds" to gain information regarding the medical status of patients, attended in-service workshops for staff and volunteers, attended and facilitated patient-family conferences, and provided on-going EOL support for the patients and their families on a modest caseload. I also had the opportunity of shadowing the Palliative Response Team (PRT) in their home visits required by patients and families registered with the society. During those visits I was present for the pronouncement of death, pain management, and psychosocial support for both the patient and their family. I was able to follow several patients from their residence to the hospital unit for a continuity of psychosocial services until death.

Background Information on Victoria Hospice Society

The Victoria Hospice Society official website provides information on the history of the society's evolution as well as an overview of the programming utilized within the society's operations. Originally known as the Victoria Association for the Care of the Dying in 1978 (Victoria Hospice Society, 2014b), this community and volunteer based organization supported and cared for dying persons within the Greater Victoria area. The Victoria Hospice Society evolved from a pilot project funded in part by the BC's Ministry of Health. The information acquired from the project contributed to the formation and establishment of the Victoria Hospice Society in 1983 (Victoria Hospice Society, 2014b). Soon afterwards, the BC's Ministry of Health funded the Victoria Hospice Society in their endeavor to establish a seven-bed hospice palliative unit within the Royal Jubilee Hospital (Victoria Hospice Society, 2014b). The seven-bed hospital unit was expanded in 1994 and the Victoria Hospice Society became a registered charity in 1997. The Victoria Hospice Society's philosophy is to create a caring and compassion environment to provide comfort care for a natural death, and support to all those involved with a dying patient.

Patient Population

Victoria Hospice Society (2014b) serves individuals over the age of 19 living in the Greater Victoria area that are experiencing a life-limiting illness with a prognosis, generally, of less than six months. Victoria Hospice also provides bereavement services after death to family members and other individuals connected to the patient.

Hospice Services

The aim of the Victoria Hospice Society is to provide hospice palliative care to alleviate the physical and psychological symptoms of the dying individual (Victoria Hospice, 2014b). A 17-bed hospice palliative care in-patient unit, with trained hospice oriented staff, offers physical, emotional, social, and spiritual care to individuals during the dying process.

The hospice in-patient unit consists of seven acute-status beds, nine hospice-status beds, and one respite-status bed; all provide the same level of care but for different durations. An *acute palliative bed* provides pain and symptom management within a hospice hospital unit setting with "the goal of resolving the symptoms and the patient then returning home…[and/or]…support imminent death when care at home is no longer possible or is not wished for" (Victoria Hospice Society, 2013d, p. 4-5). This bed status is covered under the province of BC's Medical Service Plan (MSP). Alternatively, a *hospice palliative bed* provides:

> care for a patient who cannot continue at home or when a patient in an acute care bed in hospital or at Victoria Hospice is unable to return home. Prognosis is generally thought to be about six weeks. If the patient's condition stabilizes or improves after admission further planning may be done with consideration for discharge home or placement in an alternative community facility [i.e. Residential Care Facilities]. (Victoria Hospice, 2013d, p. 5)

Hospice palliative beds have a daily cost associated with them and they are partially covered by MSP. A client may also be eligible for financial assistance (i.e., rate reduction) for the balance of the service; however specific documentation is required (Government of British Columbia, 2016c). The third bed status is *respite*. Patients may stay for a week on the unit to provide their primary caregivers with an opportunity for respite. A per diem fee of $33.00 is charged in this instance (Government of British Columbia, 2016a). These *hospice palliative bed* options are available throughout BC in hospice palliative facilities, and costs associated with them are standard throughout BC (Government of British Columbia, 2016c). Most medications used in hospice palliative care are covered by the Government of BC if an individual is registered under the *Palliative Care Benefits Program* (Government of British Columbia, 2016b).

Victoria Hospice Society also maintains a Palliative Response Team (PRT) that "provides short-term crisis treatment for physical/emotional symptoms that might otherwise require hospital admission. The team is also available to help support a death at home" (Victoria Hospice, 2013c, p. 5) and for pronouncement of death when a death is expected at home. PRT is "staffed by a nurse and a counsellor, with backup from a palliative care physician" (Victoria Hospice, 2013c, p. 5). Nursing coverage is 24 hours a day with a Palliative Care Physician (PCP) available for consultation. A counsellor specializing in hospice palliative care accompanies the palliative nurse during a 12-hour day shift. The PRT provides daily contact with the patient and their caregivers for approximately five to ten days or "until symptoms have resolved, other plans have been made, or death has been supported at home" (Victoria Hospice, 2013d, p. 5). This service is available to all patients registered with Victoria Hospice. Additionally, a patient's General Physician or a Home and Community Care nurse may refer individuals to the PRT (Victoria Hospice, 2013d). Bereavement services are also offered to patients, their families, and others affected by an individual's death (Victoria Hospice Society, 2013b, p. 2). Bereavement services after death "include telephone support; counselling; a variety of bereavement groups; including drop-in and walking groups; education and referrals" (Victoria Hospice Society, 2013b, p. 2).

Victoria Hospice community counsellors provide support in care planning decisions, facilitate communication within families experiencing crisis, assist in funeral plans, wills, and other financial concerns. Hospice counsellors provide education and support regarding anticipatory grief, complicated grief, and support volunteers in their role with families.

Furthermore, the Victoria Hospice Society's trained volunteers are available for a variety of services. They provide:

- companionship for the patient, and at times provide respite so that a caregiver may take a break;
- offer Therapeutic Touch, Reflexology, and Reiki;
- perform small errands for patients and families;
- accompany patients to and from appointments and outings;
- provide services on the hospital unit when called upon; and,
- gather information regarding a patient's life history to create a "Life Story" memory CD to be shared with a person of their choosing.

Education and Research

In addition to direct patient services the Victoria Hospice Society provides education support for professionals interested in hospice palliative care through their Education and Research department. Clinical tools, research publications, courses, and student training for medical, nursing, counselling, social work, and other disciplines are available. For example, the Palliative Performance Scale (PPSv2), (Victoria Hospice Society, 2006) is a guide for assessing hospice palliative patients used by health care professionals throughout BC and parts of Canada. It was developed by the Victoria Hospice, specifically for patient admission requirements for hospice care (Victoria Hospice Society, 2006), it provides a basis for determining the level of functioning of an individual experiencing the dying process (Victoria Hospice Society, 2014d). This and other professional brochures and educational publications are accessible to professionals for free or for a minimal publication fee (Victoria Hospice Society, 2014d). The Victoria Hospice website provides educational information for patients and families free of charge (Victoria Hospice Society, 2014d; 2016b). Victoria Hospice Society staff is dedicated to the revision and updating of materials to support patients, caregivers, volunteers, and staff.

Funding

Hospice societies across the country and the world are heavily dependent upon volunteerism and private sector funding. Here in BC acute hospice palliative services are covered under Medical Service Plan (MSP). Professionals at Victoria Hospice are compensated through the Vancouver Island Health Authority (VIHA), while all other positions are of a volunteer nature. The Victoria Hospice Society "established the Victoria Hospice and Palliative Care Foundation in 1997" (Victoria Hospice Society, 2014a, para. 5), as a registered not-for-profit charity "to assume a primary fundraising role, and to provide investment, financial and stewardship of funds raised for Victoria Hospice operation" (Victoria Hospice Society, para. 5). The Victoria Hospice Society receives 50 percent of its funding through VIHA, while the remaining percentage of the operating funds are raised annually through fund raising events, private and corporate donations, and grants from foundations that support not-for-profit organizations (Victoria Hospice Society, 2014a).

Summary

In this chapter I introduced and described my reasons for pursuing a practicum placement at the Victoria Hospice Society, the necessities of quality hospice palliative care in Northern BC, and the evolution and services available through Victoria Hospice Society. In the following chapter I examine the theoretical orientation of the Victoria Hospice and provide a brief description of my own personal theoretical orientation and my position as it relates to my interactions with the individuals I serve as well as with other professionals.

Chapter Four – Theoretical Orientation

In this chapter I review and describe the theoretical orientation of the Victoria Hospice: a psychosocial, patient-family centered, *strengths-based model* within an interdisciplinary healthcare team. Furthermore, I discuss my personal theoretical orientation, a person-centered *biopsychosocial-spiritual* perspective within *structural social work theory* supported by my knowledge of classical homeopathy.

Theoretical orientations in social work provide foundations upon which professionals base best practice models and delivery of services. Mullaly (1997; 2007) suggests that social workers have two motivating factors within their own particular practice model: to create mutual trusting relationships with clients; and to develop one's sense of professional practice foundation through proven theories and methods in order to better serve the population in direct need of social supports. Students, under the guidance of a practicum supervisor, are challenged to effectively integrate theory while being reflective in practice.

Practice models are derived from our theoretical musings and "serve as intellectualized representations of reality, allowing us to study, envision and plan for change, and to manipulate our environment (social and physical)" (Byock, 1999, p. 83-84). Within palliative care models although no conceptual model may fully capture and address the human complexities of dying, as each experience is unique, a social worker should strive to conduct one's practice in a manner that reflects the full human experience of dying. Consideration for an effective practice model should take into account all aspects of "emotional, psychosocial, and psychospiritual states of persons living with physical discomfort, functional decline, and awareness of impending death" (Byock, 1999, p. 85). A patient-centered, family supported psychosocial practice model incorporates all the aforementioned aspects and provides a basic foundation for the complex human nature of dying with terminal illnesses while “acknowledg[ing] the difficult medical issues involved, and the often arduous and distressing natures of the patient’s experience, while not dismissing the potential value of this time in the life of the person and family” (Byock, 1999, p. 87). Reese and Sontag (2001) caution against the tendency to gravitate to the medical model by not taking into consideration the “biopsychosocial-spiritual perspective that may be more natural to social work” (Reese & Sontag, 2001, p. 171).

Victoria Hospice – Theoretical Orientation

Victoria Hospice practices within a psychosocial model that encourages patient and family involvement. This model supports the patient as the central decision-maker in their treatment and care, surrounded by family and supporting professionals in an interdisciplinary team (Victoria Hospice Society, 2015). A patient and family centered model recognizes team members do not focus “on their own professional values, approaches, and power, but rather on the family’s needs and preferences [and to] develop a plan of care. The care plan does not restrict intervention in any one dimension to any specific discipline, but identifies the [family centered] approach followed by all” (Oliver, Porock, Demiris, & Courtney, 2005, p. 270).

Victoria Hospice’s values and principles reinforce good quality of service within a holistic medical care team in order to “improve communication among colleagues, volunteers, patients, and families” (Victoria Hospice Society, 2003, p. 24). Further, Victoria Hospice recognizes that each death experience is unique to the individual and provides an opportunity, not only for the individual who is dying but also for those close to them to grow and understand the processes surrounding death (Chochinov, 2002; Sulmasy, 2002).

As previously mentioned Victoria Hospice reflects this sentiment and recognizes the dying individual at the center of the practice model by supporting family and all individuals connected, in a patient/family-centered *strengths-based model* of care. Utilizing a strengths-based perspective “recognizes human capacity, agency, and self-determination [by acknowledging] an individual or family system’s capacity to survive, regenerate, and grow out of crises and challenges in life” (Morgaine & Capous-Desyllas, 2014, p. 103). A hospice palliative social worker can assist the individual and support the family to identify their strengths they are viewed as the “experts” of their circumstances and lives (Davidson, 2014; DeJong & Miller, 1995; Mattaini & Meyer, 2002; Padesky & Mooney, 2012). This perspective, defined as one of the traditional social work theories, supports collaboration between the social worker, the patient and supporting family/friends to identify the connection between themselves and their environment, in order to access the appropriate resources (Morgaine & Capous-Desyllas, 2014). Morgaine and Capous-Desyllas reason “government mandates and funding issues often require social workers to collect extensive background information [thus it becomes] more probing of participant’s problems for bureaucratic reasons” (2014, p. 104). Maclean and Harrison (2011) support and maintain that a social worker must distance themselves from the bureaucratic structures that hinder patient and families in their quest for supports. As with some other organizations, this may not always be the case in hospice palliative settings due to funding structures set in place by health authorities.

Victoria Hospice’s practice model is operationalized within an interdisciplinary health team. Professionals within the hospice palliative interdisciplinary team strive to establish therapeutic relationships with patients and families. The interdisciplinary team recognizes the intrinsic worth of an individual by supporting a death that is dignified, while adhering to the medical ethical practices of benevolence and nonmaleficence (Chochinov, 2002; Victoria Hospice, 2015).

Personal Theoretical Orientation and Positioning

My interest in hospice palliative care came from my academic awareness and understanding of northern BC's unique challenges in the delivery of healthcare and supportive services for individuals aging and dying-in-place within rural and remote communities.

I practice from a person-centered biopsychosocial-spiritual perspective within *structural social work theory*, supported by my knowledge of classical homeopathy. The University of Northern British Columbia's (UNBC) School of Social Work is theoretically based upon structural social work. As a social worker practicing within a structural social work theory model, the goal is to "contribute to the transformation of liberal capitalist society to one that is more congruent with socialist principles" (Mullaly, 1997, p. 134). The theoretical underpinnings of structural social work are embedded in my practice and I tend to take into consideration the societal institutions and their oppressive influence on individual choices and, in this instance, the dying process within a medical structure. Rochford (1991) suggests "the experience of loss and grief is especially fitted for the teaching of theory and practice and for the educative process of putting a cognitive framework to personal experiences and feelings" (p. 79). Morgaine and Capous-Desyllas (2014) consider "the power hierarchies within and among institutions and structures result in inequality and oppression" (p. 111). Structural social work theory with a focus on anti-oppressive practice, guided my interactions with patients and families in their pursuit of alleviating suffering during the dying process. Social workers are in a position of power and influence and, as such, must put the patient and family ahead of themselves in decision-making to facilitate self-determination of the individual (Canadian Association of Social Workers, 2016).

My social work practice has been supported by my study and practice of classical homeopathy, a complimentary medical system that contends treating the physical and emotional expression of a disease in an individual with a similar homeopathic remedy likeness can be curative in nature (Hahnemann, 1996). I completed a three-year certificate course with the Vancouver Homeopathic Academy in 2000 (closed in 2015) that included pathology and physiology. Homeopathic consultation, through systematic interviewing, provides the foundation for my personal interviewing and intervention style. The information gathered during the homeopathic consultation assists in understanding the unique holistic expression of an individual and his/her disease process (Detinis, 1994; Hahnemann, 1996; Schmidt, n.d.). My 16 years of experience conducting homeopathic consultations, with or without the practice of prescribing homeopathic remedies, compliments my social work intervention style as I practice from a person-centered philosophy, while motivated by a biopsychosocial-spiritual model of care (Bassman, 1997; Eyles, Leydon, & Brien, 2012; Johannes, Townsend, & Ferris, 2013; Riebel, 1984). I pay special attention to language patterns, body language, and individualized physical symptom expression of disease while being comfortable with quiet observation. This compliments my social work education and intervention style, and I find it useful when interacting in a holistic manner, engaging in conversations that are supportive and curative in nature.

Additionally, I have a combined six years of volunteering and employment with the Canadian Red Cross' RespectED program: a violence and abuse prevention program addressing child abuse and maltreatment, bullying and harassment, and dating violence (Canadian Red Cross, 2016). This experienced exposed me to the issues of childhood sexual abuse and its prevalence. An estimated one in three women have been sexually abused as a child, and one in six men have also experienced sexual abuse during their childhood, although estimates vary (American College of Obstetricians and Gynecologists, & Committee on Health Care for Underserved Women, 2011; Denov, 2004; Field et al., 2001; Gallo-Silver & Weiner, 2006; Hume, 2000; Lisak, 1994). My knowledge of childhood sexual abuse at a prevention level fed my curiosity about the long-term effects of the experiences of childhood sexual abuse at EOL and how trauma is expressed through anxiety and Posttraumatic Stress Disorder (PTSD) in patients who are institutionalized at EOL (Callahan & Hilsenroth, 2005; Maschi, Baer, Morrissey, & Moreno, 2013; Sloane et al., 1995; Stausmire, 2004).

In preparing for my practicum I also enrolled in and completed the Victoria Hospice Society's *Psychosocial Care of the Dying and Bereaved* course offered in February 2015. The curriculum within this course confirmed my interests in hospice palliative care and my ability to engage in conversations regarding grief, bereavement, and the dying process. Furthermore, my undergraduate practicum experiences at the BC Cancer Agency's Centre for the North allowed me to research and understand the challenges faced in accessing care within northern BC.

Summary

In this chapter I introduced the Victoria Hospice Society's theoretical orientation and stated my theoretical orientation and experience to position myself within the practicum setting. I noted my practice positioning compliments Victoria Hospice Society's philosophical orientation. In the following chapter I provide a literature review of significant issues related to my experiences at the Victoria Hospice Society practicum site.

Chapter Five – Literature Review

This chapter is a literature review guided by my experiences and significant issues encountered during at my practicum at Victoria Hospice Society. It provides an overview of hospice palliative care definitions, interdisciplinary healthcare teams, the role of social worker within hospice palliative care services, family conferences, psychosocial issues at EOL, delirium at EOL, trauma at EOL, the manifestation of existential suffering at EOL, Palliative Sedation Therapy (PST) and Medical Assistance in Dying (MAiD), preferred place of death, spirituality in social work, and self-care and burnout prevention.

Definition of Hospice Palliative Care

The terms hospice and palliative are often used interchangeably when discussing EOL options and treatments (Canadian Hospice Palliative Care Association, 2015). For the purposes of my practicum placement experience, the definition of hospice care is that as offered by the Victoria Hospice Society within its' mission statement: "to enhance the quality of life for those facing advancing illness, death and bereavement through skilled and compassionate care, education, research and advocacy" (Victoria Hospice Society, 2013c, p. 5). Victoria Hospice Society's definition of hospice is congruent with the World Health Organization (WHO) (2015) definition of palliative care as:

> An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (para. 1)

The BC Ministry of Health in its document *Provincial Framework of End-of-Life Care* (2006) also combines the terms hospice and palliative to express end-of-life (EOL) care. For the purposes of this practicum report I use the term *hospice palliative care* to reflect the merging of the two terms (hospice and palliative) by the aforementioned governing bodies.

Interdisciplinary Healthcare Teams

Healthcare teams can be categorized into three different types to create a continuum of recognized team structures. Transdisciplinary, interdisciplinary, and multi-disciplinary healthcare team structures can be found in different settings. Each type of team varies in the degree of interaction between disciplines and their responsibilities to each other and to the patient (Hall & Weaver, 2001; Lemieux-Charles & McGuire, 2006). Transdisciplinary teams are at one end of the continuum, wherein the "roles of individual team members are blurred" (Hall & Weaver, 2001, p. 868). Each team member is familiar with and able to use the approach of the other team members and the team may include non-professionals. This team structure is "not often exemplified in health care" (Youngwerth & Twaddle, 2011, p. 650).

A multidisciplinary team structure, on the other hand, appears to be at the other end of the continuum with defined disciplinary roles that function independently, and the team relies on their expertise in those roles (Brown, Crawford, & Darongkamas, 2000; D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005). Youngwerth and Twaddle (2011) support this and offer, "multidisciplinary teams are typically hierarchical in structure, with the professional identities of the members placed above team membership" (p. 650). In such teams, "traditionally, it has been the physician who is responsible for prescribing the contribution other disciplines could make and for the coordination of services" (Hall & Weaver, 2001, p. 868). Interdisciplinary teams fall within the middle of this healthcare team continuum. In an interdisciplinary team all members interact and work collaboratively to ensure the safety and well-being of the patient (Hall & Weaver, 2001; McCALLIN & Bamford, 2007; Wittenberg-Lyles & Oliver, 2007; Youngwerth & Twaddle, 2011). Parker-

Oliver, Bronstein, and Kurzejeski (2005) define interdisciplinary collaboration as "an interpersonal process leading to attainment of specific goals that are not achievable by one team member alone" (p. 279). Interdisciplinary teams create a "synergy, which emerges from collaboration, identifying it as an active, ongoing, productive process" (Parker-Oliver, Bronstein, & Kurzejeski, 2005, p. 279).

Hospice palliative care facilities apparently prefer an interdisciplinary team approach when assigning roles and responsibilities, which in turn establishes a "flexible decision-making process [with] open communication patterns and leadership" (Leipzig et al., 2002, p. 1141). Successful collaboration between disciplines includes being responsible and accountable for the team's decisions and actions. Coordination and communication to define roles, assertiveness, autonomy, and mutual trust and respect, combine to establish a working relationship (Gaudet, Kelley, & Williams, 2014). In relation to healthcare interdisciplinary teams, Leipzig et al. (2002) suggest "interdisciplinary teamwork lowers hospital readmissions rates in comparison with lack of teamwork" (p. 1141). Interdisciplinary teamwork contributes to "the greatest reductions in readmissions rates occur[ing] when physicians, nurses, and social workers were most satisfied with their professional relationships on the team" (Leipzig et al., 2002, p. 1141).

As "hospice care is grounded in a holistic healthcare approach, taking into consideration and providing services that address the patient's biological psychological and social needs" (Wittenberg-Lyles & Oliver, 2007, p. 6), it is recommended that hospice palliative care facilities incorporate interdisciplinary healthcare teams to assist and be effective in the delivery of EOL services (Lawson, 2007). "Hospice interdisciplinary teams (IDTs) work together on a patient's plan of care, including developing and carrying out the plan of care as a collaborative effort" (Wittenberg-Lyles & Oliver, 2007, p. 6). Decision-making should not fall upon one person; an optimal healthcare interdisciplinary team should include physicians, nurses, social workers, and other healthcare professionals who can assist in the care plan and should consider all aspects of a patient's present situation while including them and their families/caregivers (Lawson, 2007).

Many hospice healthcare team structures face similar challenges due the medicalization and specialization of hospice palliative care services. One may find comfort within one's own discipline with its familiar interventions and vocabulary of each member (Hall & Weaver, 2001), yet interdisciplinary teams may encounter some or all of the following:

- lack of knowledge of other professionals' expertise;
- role blurring;
- conflicts arising from differences between professionals in values and theoretical base;
- value differences;
- theoretical differences;
- negative team norms (i.e.: bullying, harassment);
- lack of commitment to the team process;
- lack of willingness to share equally in the work of the team;
- scapegoating;
- power differentials on the team;
- client stereotyping;
- and, administrative issues (i.e.: discontinuing service due to lack of funding, downsizing). (Reese & Sontag, 2001)

The environment in which the hospice palliative healthcare team practices influences the leadership and practice of the team.

Lawson (2007) asserts teamwork is somewhat different in supporting the patient within their own home, compared to supporting a patient and family on a hospital unit. The medical expertise, interventions, and medications available in hospital are not always available or sustainable in a patient's home. Family involvement provides a "chance to hear the family story, input and ownership of patient/family concerns in the plan of care, opportunity to observe the team working together, and an opportunity for access to the team members who do not usually visit patients/families" (Parker-Oliver, Bronstein, & Kurzejeski, 2005, p. 274).

Social work within an interdisciplinary team structure is rewarding due to the collaboration of all disciplines. Yet one may conclude working within an interdisciplinary team is not without its challenges (Lemieux-Charles & McGuire, 2006; Oliver and Peck, 2006; Parker-Oliver, Bronstein & Kurzejeski, 2005). Reese and Sontag (2001) suggest "social workers may have a lack of understanding of the role of the other disciplines in hospice, and cultural differences between professions may be interpreted by social workers as personal deficits on the part of the other team members" (p. 167).

Role of Social Worker in Hospice Palliative Care

The role of a social worker within hospice palliative care is not apparent or clearly defined in the literature. Instead, I discovered specific competencies offered to guide a social worker within their hospice palliative care practice (Bosma et al., 2009; Christ & Sormanti, 2000; Sheldon, 2000). These competencies included "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). Bosma et al. (2009) further noted:

> these competencies can be used to facilitate the development of consistent practice goals and guidelines for social workers entering the [hospice palliative] field as well as those currently practicing in it. They are relevant across a range of practice locations and populations. Furthermore, social workers can draw on these competencies to clearly articulate their role and activities within interprofessional care teams, and to evaluate their contributions (p. 6).

Gwyther et al. (2005) support and categorize competencies within the realms of knowledge, skills, practice values and attitudes, and suggested further considerations for research. Particular attention was paid to intervention and treatment planning, noting social workers not only provide psychosocial support for the dying, but provide leadership and supervision for other disciplines (Gwyther et al., 2005). Gwyther et al. (2005) recommend these competencies should be noted in any social worker's practice as one may "inevitably work with clients facing acute and/or long term situations involving loss, life limiting illness, dying, death, grief, and/or bereavement" (p. 88). A social worker's knowledge in anticipatory grief and bereavement assists the patients and families before and after death, and other disciplines defer to social workers for direction in those aspects.

The role of social worker within a rural hospice palliative team must also be adaptable to each new client, being able to be part of the team while putting the patient's best interests at the center of the care plan (Sheldon, 2000). Hospice palliative social workers provide support to families anticipating a death and supporting them through the struggle, helping to recreate a functioning family unit while managing anxiety for both family and professionals by providing role modeling with regards to confidentiality and establishment of working boundaries (Sheldon, 2000; Quig, 1989). Lawson (2007) defines the role of social worker as a “team member who provides psychosocial support, facilitates family meetings between the pt/family and staff, with respect to clarification of goals and/or medical decision-making, and assists with complex discharge planning” (p. 4). Hospice palliative social workers continuously support and promote “patient self-determination [while] acting as a liaison between patient/family and health care providers” (Arnold, Artin, Griffin, Person, & Graham, 2007, p. 65).

Patient-family Conferences at EOL

Patient-Family conferences in a hospice palliative care setting are an “effective strategy to discuss goals of care, site of care options and care planning” (Hudson, Thomas, Quinn, & Aranda, 2009, p. 150). These meetings are an opportunity for patient and families to discuss their concerns with healthcare professionals regarding treatment and EOL issues. Hudson, Quinn, O’Hanlon, and Aranda (2008) suggest that family meetings are similar in structure to a single session of counselling in which the patient, caregiver, family members and health care professionals attend. Healthcare professionals that are not readily accessible due to other commitments are invited to share their knowledge with the patient, family and other healthcare professionals. In family meetings, health professionals are to present the medical facts of the diagnosis, understand the patient’s goal of care, and answer any questions or concerns the patient or anyone supporting them may have as to medications, treatment, or future plans for the patient while being culturally sensitive to the way in which information is shared (Candib, 2002; Csikai, 2004; Hebert, Schulz, Copeland, & Arnold, 2008; Hudson, Quinn, O’Hanlon, & Aranda, 2008; Hudson, Thomas, Quinn, & Aranda, 2009).

Healthcare professionals that are in direct contact with the patient and family should take advantage of these meetings as opportunities to gather information in order to better understand the family dynamics and to clarify goals of care (Oliver, Porock, Demiris, & Courtney, 2005). Family meetings may occur more than once, and at any time during the stay of the patient on the hospice hospital unit. During family meetings interdisciplinary team members should not focus on "their own professional values, approaches, and power, but rather on the family's needs and preferences" (Oliver, Porock, Demiris, & Courtney, 2005, p. 270).

Psychosocial Issues at EOL

Hospice palliative social workers encounter time constraints with patients and families at EOL due to physical deterioration of the patient and uncertainty as to length of time before death occurs. Nonetheless, a hospice palliative social worker considers and evaluates psychosocial issues in order to assist the patient to experience comfort and quality of life during EOL care. Psychosocial issues that social workers may encounter in patients include:

- diagnosable mental disorders – such as: anxiety disorders, clinical depression and other mood disorders, personality disorders, substance abuse;
- intrapersonal issues – such as: autonomy/control (self-determination), decision-making capacity, dignity, existential issues and spiritual beliefs, fear, grief, hopelessness, psychodynamic issues and counter-transference; and,
- interpersonal/environmental issues – such as: being a burden, cultural factors, financial variables, presence/absence of significant others, and pressure/coercion.

(Arnold et al., 2007; Casarett & Inouye, 2001; Kelly, McClement, & Chochinov, 2006; Mackelprang & Mackelprang, 2005; Pasacreta & Pickett, 1998; Pessin, Rosenfeld, & Breitbart, 2002; Vachon, Kristjanson, & Higginson, 1995; Werth, Gordon, & Johnson, 2002; Wilson, Graham, et al., 2004)

Crunkilton and Rubins (2009) assert it is a social worker's responsibility to "assess for caregiver distress and burden, as psychological distress experienced by family caregivers may have a serious effect on the mental health of the terminally ill patient" (p. 82). Psychological issues in caregivers may hinder the patient's quest for comfort care, as unresolved issues "can result in a family's inability to accept a terminal prognosis and insistence on aggressive treatment that neither the patient nor physician support" (Crunkilton & Rubins, 2009, p. 82).

Delirium at EOL

Delirium at EOL appears to be a major concern, particularly if the patient is experiencing agitation (Casarett & Inouye, 2001; Hosie, Davidson, Agar, Sanderson, & Phillips, 2012). "Delirium impacts upon the patient's ability to communicate, their decision-making capacity, functional ability, and quality of life" (Hosie, Davidson, Agar, Sanderson, & Phillips, 2012, p. 487). There are three distinct types of delirium: hyperactive, hypoactive and mixed. Hyperactive delirium is accompanied with hallucinations, delusions and restlessness (Casarett & Inouye, 2001). Hypoactive is defined as a delirium that is quiet and "a decreased level of consciousness with somnolence and can be mistaken for sedation due to opioids or obtundation in the last days of life" (Hosie et al., 2012, p. 487). Mixed delirium can have a combination of both hypoactive and hyperactive symptoms. The delirium can mirror a person's personality type and sometimes it is seen as an exacerbation of the dying process (Hosie et al., 2012). Medications, renal failure, or a urinary tract infection could be contributing to the delirium (Casarett & Inouye, 2001). Distinguishing delirium from other psychological disorders at EOL can be a complex and complicated process for those non-medical professionals who have little experience recognizing the signs and symptoms. Delirium can be a treatable condition that is relievable through antibiotics.

Trauma at EOL

Feldman, Sorocco, and Bratkovich (2013) state "84% of people encounter a traumatic event during their lives, and 15% to 24% of these develop posttraumatic stress disorder (PTSD)…[and] some may carry the effects of past trauma as they enter the last phase of life" (p. 233). Research into how trauma affects quality of living at EOL is limited with only a few research studies addressing this issue. Several researchers propose PTSD at end of life may be an accumulation of traumas experienced throughout one's lifetime (Feldman, 2011; Feldman & Periyakoil, 2006; Gallo-Silver & Weiner, 2006; Woods, 2003). These life traumas and experiences include "exposure to combat, exposure to disasters or violent crime victimization, refugee experience, and persons with a history of child abuse, sex abuse, or intimate partner violence" (Woods, 2003 p. 199).

The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, 2013) emphasizes the behavioural symptoms associated with Posttraumatic Stress Disorder (PTSD) and provides four diagnostic clusters when diagnosing this disorder (American Psychiatric Association [APA], 2013). These clusters include "exposure to a traumatic stressor that serves as the gatekeeper criterion, re-experiencing the trauma, numbing and avoidance (the latter added in DSM-IV), and increased arousal and vigilance" (Levin, Kleinman, & Adler, 2014, p. 146). The DSM-5 identifies sexual violence as a traumatic stressor. Sexual violence includes: "forced sexual penetration, alcohol/drug-facilitated sexual penetration, abusive sexual contact, noncontact sexual abuse, [and] sexual trafficking" (Levin et al., 2014, p. 149).

An examination of psychiatric diagnosis in terminal cancer patients provides EOL information for clinicians and social workers (Miovic & Block, 2007). Existing disorders may be exacerbated at EOL due to organic imbalances within bodily processes. For example, existing mental health issues can be accompanied by new symptoms of anxiety and depression. The challenge is then to identify existing mental health illness and separate these from new and persistent symptoms of EOL. Miovic and Block (2007) examined adjustment disorders, major depression, anxiety and PTSD, personality disorders, substance abuse, major mental illness (schizophrenia and bi-polar disorder), medication and treatment options and how each influences EOL care. PTSD in cancer care can be the direct result of a diagnosis and/or treatment "especially if the patient experiences unexpected and highly debilitating complications" (Miovic & Block, 2007, p. 1669). This may include the re-living of the treatment experiences, the manner in which the delivery of the diagnosis was presented, or similar institutional experiences in the past. Distress is expressed in dreams and flashbacks when exposed to similar stimuli in a medical setting; thus, the individual becomes hyper-vigilant and physically aroused. Miovic and Block (2007) explain:

> Patients with PTSD often present with high levels of anxiety, pronounced insomnia, frequent panic attacks, comorbid depression, excessive fear of medical recommendations, and avoidance of medical settings or procedures that trigger traumatic memories…[and]…risk factors for PTSD include prior history of traumatic exposure (such as physical or sexual abuse), negative interactions with physicians and nurses, and poor social or interpersonal support. (p. 1670)

EOL is a delicate and limited time for reviewing and addressing past traumas and many individuals may never be able to resolve traumatic experiences.

Existential Distress

Terminally ill and dying patients can maintain quality of life if pain and other symptoms are managed with the appropriate use of analgesics and adjuvants (Wrede-Seaman, 2001). Suffering, both physical and psychological, afflicts a person as a whole entity; we are “embodied, purposeful, thinking, feeling, emotional, reflective, relational human individual existing through time in a narrative sense” (Cassell & Rich, 2010, p. 436). Physical and psychological suffering “variously destroys the coherence, cohesiveness, and consistency of the whole. It is in this sense that the integrity of the person is threatened or destroyed” (Cassell & Rich, 2010, p. 436). Psycho-existential suffering issues contributing to the overall distress of a terminally ill and dying patient include “loss of autonomy, dependency, feelings of meaninglessness, and burden on others” (Morita, 2004, p. 446). Existential distress or the emotional/spiritual anguish that a terminally ill patient experiences at EOL may include the “concepts of loss of personal meaning, loss of purpose of life, fear of death, despair, anguish, hopelessness, being a burden to others, loss of dignity, helplessness and betrayal” (Bruce & Boston, 2011, p. 2734).

Kissane (2004) provides further insight into existential distress by theorizing the impact demoralization creates on a person’s ability to view one’s life and how that contributes to decisions at EOL. Demoralization is defined as “to deprive a person of spirit, courage or discipline; to reduce to a state of weakness or disorder” (Clarke & Kissane, 2002, p. 734). A person’s self-worth and self-esteem are directly compromised with a terminal illness and “demoralization adds to the distress of the symptoms and reduces a person’s coping capacity” (Clarke & Kissane, 2002, p. 737). Patients experience “frustration at persisting and intrusive symptoms, the inability to find relief, the loss of hope that things will ever be different, and the loneliness of the experience leads ruthlessly to demoralization – a form of personal suffering" (Clarke & Kissane, 2002, p. 738). The essence of the demoralization syndrome is "existential despair" (Parker, 2004). A request for MAiD may be motivated by a sense of feeling trapped inside a deteriorating body and therefore provides a way to control something that appears to be out of control (Albinsson & Strang, 2002). There is a distinction between a patient who is suicidal and one who is demoralized. Individuals who feel demoralized "may not be depressed and thus may be perceived by clinicians to rationally choose suicide as a merciful conclusion to their life" (Parker, 2004, p. 767). Clarke and Kissane (2002) propose that demoralization and depression can coexist and healthcare professionals fail to understand the underpinnings of the desire to die of someone suffering from existential distress. Professionals may consider demoralization and a syndrome of existential angst as a possible explanation of a patient's request and a desire for MAiD. Interdisciplinary hospice palliative healthcare teams will be challenged to identify and support those patients who feel demoralized and request medical assistance to die. Further research, screening tools, and supportive materials in this area would be useful to healthcare providers in their quest to support those patients considering MAiD (Kissane, Wein, Love, & Lee, 2004).

Palliative Sedation Therapy (PST) and Medical Assistance in Dying (MAiD)

Palliative Sedation Therapy (PST) and Medical Assistance in Dying (MAiD) are two palliative treatment options available to alleviate physical and psychological distress for patients who meet specific medical criteria. The following examines them separately.

Palliative Sedation Therapy (PST)

Palliative Sedation Therapy (PST), also referred to as "terminal, continuous, controlled, or deep-sleep sedation" (Bruce & Boston, 2011, p. 2734), is the intentional and continuous sedation of a dying patient to control physical and psychological suffering at EOL. PST provides a means to ease "uncontrollable refractory symptoms in the last days of life to the point of almost, or complete unconsciousness, and maintaining sedation until death – but not intentionally causing death" (Bruce & Boston, 2011, p. 2734). A refractory symptom is one that "cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness" (Rousseau, 2001, p. 151).

Medication and treatment options to alleviate pain and control symptoms should be explored first before considering PST (Wrede-Seaman, 2001). "The sedated patient dies within days to weeks of either the underlying disease, dehydration, starvation, or some other complication" (Taylor & McCann, 2005, p. 145). The patient who is experiencing uncontrollable suffering may contemplate and request a discontinuation of life supporting medications and treatments, which includes nutritional and hydration needs to sustain life (Taylor & McCann, 2005). In patients experiencing existential suffering and contemplating palliative sedation, the medical profession may view them as being "afflicted with a mental illness, and therefore lacking decisional capacity and acting irrationally" (Rich, 2014, p. 403). Rich (2014) further implies that mental health professionals may label patients expressing consideration of palliative sedation as "clinically depressed with suicidal ideation; and, therefore, without the ability to make a well-informed and authentic choice as to whether or not to go on living and endure refractory suffering until their disease progresses naturally to its fatal conclusion" (Rich, 2014, p. 403).

The following are consistent themes and considerations regarding PST guidelines noted in the literature:

> (a) the patient is terminally ill, (b) death is imminent and expected within hours or days, (c) the patient is suffering acute symptoms that are responding to therapy, (d) prompt intervention is required to alleviate refractory symptoms, (e) consent is obtained from the patient or his/her proxy, (f) the withdrawal of food and water is discussed, (g) families are informed that the patient will likely not regain consciousness and will die, (h) sedation is induced using a non-opioid drug to control the refractory symptoms and (i) causing death is not the intention even though it may not be possible to achieve adequate symptom control except at the risk of shortening the patient's life. (Bruce & Boston, 2011, p. 2736)

Taylor and McCann (2005) recommend alternate strategies for addressing existential distress should be considered before considering the option of palliative sedation. Pain and symptom management alleviating any physical suffering may in fact control psychological distress. Psychotherapy, spiritual counseling, supportive friendships with community connections, as well as conflict resolution interventions, should also be considered first before screening for possible motives for palliative sedation.

Victoria Hospice has specific guidelines with respect to the implementation of Palliative Sedation Therapy (PST). Patients must be competent to make the decision and families need a clear understanding of the request. Evidence is needed of ongoing distress experienced by the patient and family, and that this distress is intolerable and contributing to the patient's suffering. Strict psychological screening and monitoring is also required with informed un-coerced consent at the heart of the decision-making process. Additionally, information regarding the difference between PST and MAiD is required in order to distinguish the service being provided is correctly feasible at this point in the dying process (Victoria Hospice, 2016).

Medical Assistance in Dying (MAiD)

Medical Assistance in Dying (MAiD) was first defined under Quebec's *An Act respecting end-of-life care* (Quebec Official Publisher, 2013), and is currently defined as "care consisting in the administration by a physician of medications or substances to an end-of-life patient at the patient's request, in order to relieve their suffering by hastening death" (Government of Canada, 2016b, p. 10). The first reading of Bill C-14 (Government of Canada, 2016b), an amendment to the criminal code of Canada on April 14, 2016, placed pressure on Canada's healthcare system to incorporate MAiD by June 7, 2016. This amendment proposed exemptions from prosecution for the involvement of physicians, nurses, and pharmacists who participate in medical assistance in dying. It, however, did not include social workers (Canadian Association of Social Workers, 2016). On June 17, 2016, Bill C-14 received royal assent by the Parliament of Canada and became law, making MAiD legal in Canada. No amendments regarding the exemptions of particular medical professionals such as medical social workers, or mental health status that qualifies for assistance, were included in this bill (Canadian Association of Social Workers, 2016).

Hospice philosophy up to this point in time has not incorporated MAiD, as the direction had always been to provide comfort care up to a natural death (Mesler & Miller, 2000). It appears that hospice societies across Canada will need to review their policies regarding MAiD in order to provide a clear statement on whether or not they will provide the service to those patients who qualify.

Preferred Place of Death

Our social environment is situated in our home community's traditions and culture, and the characteristics of the people that we live with can influence our dying process (Howell et al., 2011; Hughes et al., 2004; Kelley, 2007; Zapf, 2009). A "shift from hospital to home-based death and dying is occurring in Canada and elsewhere" (Wilson, Cohen, et al., 2013, p. 502). Dying at home is becoming a choice for many individuals who have "incurable and usually long-term progressively disabling diseases" (Wilson, Truman, et al., 2009, p. 1756). To die at home can provide a secure attachment to the land and to those surrounding us during the dying process, contributing to a spiritual experience for all those involved. Yet there appears to be direct and indirect costs associated with deciding to stay in one's home to die (Wilson, Cohen, et al., 2013). Family members choosing to be caregivers experience a loss of income from both the dying person and the caregiver, adding to the overall stress that the family may be experiencing. Other factors such as "functional status, personal preferences, availability and contact with formal healthcare, the availability of informal and social support, and other factors related to culture and history" (Wilson, Truman, et al., 2009, p. 1753) contribute to the decision to die at home. The medical model of dying in a hospital is gradually being replaced by a resurgence of hospice programming and services (Gaudet, Kelley, & Williams, 2014). In Canada, hospitals, residential care homes, and hospices are all part of the "publicly funded health care system [and are the first choices] where health care professionals work and technologies are readily available to prevent or address unpleasant symptoms" (Wilson, Cohen, et al., 2013, p. 506). Wilson, Truman, et al. (2009) conclude "people who accessed community-based specialist palliative care having a seven times higher chance of dying at their usual residence" (p. 1753).

The BC provincial government supports the choice of dying at home by providing specific protocols for expected home deaths (Government of British Columbia, 2006). The reason for these protocols was to eliminate any unwarranted 911 calls, involvement of emergency personnel, and/or the coroner's office in an expected death. In order to alleviate any undue stress for the family upon death as well as to be cost effective in emergency services, documentation is put in place to create smoother transition in the utilization of funeral services (Grant, 1997). The coroner need not be called upon in an expected home death unless there are concerns with the circumstances or the cause of death. There is also no legal requirement in BC for pronouncement of death, family may or may not choose to have a physician or nurse to pronounce death at home. Ambulance paramedics are unable to pronounce death, and families should informed not to call 911 (Government of British Columbia, 2006).

In the event of an expected home death a *Notification of Expected Death* must be filled out and identify the person who is responsible for controlling the person's assets (Government of British Columbia, 2015). This person is usually the executor/executrix of the deceased's estate. In expected home deaths, the family must wait for at least one hour after breathing has ceased before contacting the funeral home for body removal. The funeral home will remove the body from the home once they have received notification. After the removal a physician must provide a medical certification of death before the body can be buried or cremated (Government of British Columbia, 2015). The funeral home must therefore pause for 48 hours before continuing with burial or cremation services.

As noted in Chapter Three, the Victoria Hospice's Palliative Response Team (PRT) provides support for people who want a home death. Pesut, Robinson, and Bottorff (2014) suggest that the availability of quality hospice palliative care is dependent on "the availability of specialist palliative care, including multidisciplinary teams with relevant expertise, hospice houses, and advanced pain and symptom management" (p. 128). There may be excellent health care providers available for consultation regarding home deaths in rural and remote communities, yet often these specialists are concentrated in urban centers and out of reach for residents outside such areas.

Spirituality in Social Work

In order to serve hospice palliative patients in a holistic manner, spirituality of both the patient and the worker must be acknowledged and examined (Carroll, 1998; Reese, 2001). Gilligan and Furness (2006) suggest a social worker must have an "understanding and appreciation of the impact of faith and belief" (p. 617). Interacting with patients at EOL provides an environment steeped in existential questioning of one's faith and understanding of the life and death cycle as "human beings have a desire to transcend hardship and suffering" (Kellehear, 2000, p. 150). A social worker, in the initial assessment of a patient will collect pertinent information regarding religious and spiritual practices yet may feel that they are not in a position to offer spiritual interventions (Reese, 2001; Reese & Raymer, 2004). A social worker, however, is in a position to support religious and spiritual beliefs of a dying person, as social work has "made claims about the 'pastoral' origins" (Kellehear, 2000, p. 154).

At EOL dying patients may experience "(a) being in the presences of the dead, (b) preparing to travel or change, (c) seeing a place, (d) choosing when to die, and (e) knowing the time of death" (Reese, 2001, p. 139). Reese (2001) also indicated patients may wish to discuss these experiences with hospice palliative professionals in order to acknowledge the experience and alleviate fear of the unknown. Furthermore, interventions regarding spirituality may include "reminiscing and life review" (Reese, 2001, p. 144). Sermabeikian

(1994) argues “spiritual bias can be just as harmful as racism or sexism” (p. 179), and Gilligan and Furness (2006) indicate many “social work professionals are inadequately prepared to undertake spiritually competent work with client and advocate the inclusion of relevant material within the social work curriculum” (p. 633). Reese (2001) believes that spirituality can be addressed by both student and practitioner and suggests the following areas need to be examined in order for social work to support spiritual interventions: “personal issues of the social worker which inhibit intervention in this area, clinical issues for clients which pose barriers, and proper documentation of spiritual interventions in patient charts” (p. 150). Interventions such as guided meditation and life review may provide enough support to alleviate death anxiety in a patient (Reese, 2001). It is important for a social worker not to impose their religious or spiritual beliefs, but to acknowledge and guide the dying patient in their own spiritual journey. The challenge for a social worker is to effectively “incorporate spiritual perspectives into social work practice” (Praglin, 2004, p. 78).

Self-care and Burnout Prevention

In order for a practitioner to be empathetic and attentive to the needs of individuals, a social worker must be aware of and understand the implications of burnout, compassion fatigue, and vicarious trauma (Huggard, 2011; Mathieu, 2009; Remen, 2011; Rosenbloom, Pratt, & Pearlman, 1995; Simons & Park-Lee, 2009). This awareness constitutes a basis for developing coping strategies needed to stay grounded and healthy for the people we serve. Coping strategies vary from person to person and can increase compassion satisfaction (Jones, 2005; Reese, Chan, Perry, Wiersgalla, & Schinger, 2005; Sanso et al., 2015). “Maintaining the balance between the output and input of energy in professional and personal lives of caregivers is an ongoing process” (Jones, 2005, p. 125).

A hospice palliative social worker is exposed to “existential issues, psychological challenges, and emotional distress that arise in patients facing the end of life” (Sanso et al., 2015, p. 200), and being exposed to these “situations in daily patient care have ethical implications” (Csikai, 2004, p. 69). Hospice palliative care is emotionally stressful; there are encounters of intense emotions experienced by patients, their families, acquaintances, and healthcare workers (Quinn-Lee, Olson-McBride, & Unterberger, 2014). Hospice palliative care professionals are exposed to “(a) death and dying, (b) grieving families, (c) personal grief, (d) traumatic stories, (e) observing physical pain in patients, (f) strong emotional states such as anger and depression, and (g) emotional and physical exhaustion” (Alkema, Linton, & Davies, 2008, p. 102).

Organizational and workplace factors may also exacerbate the overall levels of burnout experienced within the hospice palliative professions and include “(a) low salaries, (b) demanding schedules, (c) varying work shifts, (d) low social recognition, (e) lack of financial resources, (f) role ambiguity, and (g) difficult client behaviours” (Alkema, Linton, & Davies, 2008, p. 103). Professionals continuously exposed to such stressors “combined with an incapacity to disengage from the work and a restricted social support network, have a higher risk of presenting with compassion fatigue” (Vargas et al., 2015, p. 162). Rushton, Kaszniak, and Halifax (2013) recognize moral distress as a factor in health care professionals succumbing to burnout and compassion fatigue. Perspective taking or cognitive attunement, empathizing with the person in distress, our own memories regarding grief and loss, and how we react to other members on the interdisciplinary team all contribute to how one internalizes stress (Rushton, Kaszniak, & Halifax, 2013; Rushton et al., 2009). Furthermore, Rushton, Kaszniak, and Halifax (2009) contend that we should:

> Cultivate strategies to stabilize attention and affect, practice mindfulness, apply the GRACE process to support principled compassion, monitor somatic responses, cultivate compassionate intention, recognize empathic overarousal and personal distress, develop methods to foster reflection and inquiry [and] develop insight to distinguish self from other. [GRACE is an acronym for] Gather attention; Recall your intention; Attune to somatic, affective, and cognitive subjective content and then attune to the patient using perspectives taking, empathy, observation; Consider what will really serve through recalling intentions and allowing insight to arise; and Enact and considerately end the interaction. (p. 1084)

Summary

In this chapter, I reviewed the psychosocial issues pertinent to the practicum experience. These issues included the identification of the interdisciplinary healthcare team structure and the role of social worker within that structure; family conferences at EOL; psychosocial issues at EOL including trauma and existential distress; palliative sedation and MAID; preferred place of death; and self care and burnout prevention. In the next chapter, I describe my learning opportunities and how they contributed to my overall learning experience while at the Victoria Hospice Society's hospice hospital unit.

Chapter Six – Learning Experiences

The following quote describes my shift from curative cancer care to comfort hospice palliative care, and from rural and remote practice to an urban-based practice environment:

> The ambivalence that ensued as the author learned the culture and language of the hospital helped to create rich opportunities for reflection on current skills and knowledge. This led to a commitment to improve competence in area such as clinical documentation, cognitive-behavioural techniques, pain and symptom management, cultural awareness, and "knowing when there is a question to be asked"…the author also developed a renewed appreciation of the different pressures and responsibilities that physicians and nurses have in their work and the importance of engaging health care providers who have a history with the patient/family to provide continuity and minimize feelings of abandonment. The professional growth and increased understanding of the hospital system that occurred during was initiated by this transition in environments and scope of practice allowed the author to gain a respect for the quality services that can inform care of patients and families along the continuum of illness. (Lawson 2007, p. 5)

My practicum learning goals and activities were initially formulated based on my undergraduate practicum experiences and adapted for the Victoria Hospice Society practicum placement (see Appendix A – Learning Contract). Throughout my practicum, I reviewed the research literature relevant to the psychosocial issues I encountered, wrote daily entries in a journal documenting my practicum experiences in order to engage in critical self-reflective practice, and explored counseling materials relevant to dying, loss and grief. In this chapter, I describe my learning goals and objectives and the evaluation criteria for my experiences while at the Victoria Hospice's hospice hospital unit.

Goal: Increase Understanding of a Social Worker's Role in Interdisciplinary Hospice Palliative Healthcare Team

Increasing my knowledge of a social worker's role in an interdisciplinary hospice palliative healthcare team was my overall practicum goal. This goal was achieved by shadowing and observing my practicum supervisor in her routine contact with patients and families on the unit and in the community, at Family Conferencing meetings, as well as within interactions with the interdisciplinary healthcare team members. I attended daily medical "rounds" in order to become familiar with the medical and psychological status of patients. From these rounds I was eventually able to identify the needs of the patients and families on my caseload. I began to prioritize my day around the urgency of interventions. A social worker on a hospice unit provides support and counseling to patients and families to address psychosocial issues at EOL with consultation and support from other members on the interdisciplinary team. I supported patients who presented with delirium, dementia, depression, and addictions (alcohol, narcotics, and gambling).

In order to monitor and evaluate my progress I maintained a journal to document my experiences while engaging in self-reflective practice. I would journal every evening, documenting the events of the day and researched the outstanding issues that were relevant for that day. I also discussed with my supervisor and other team-members situations upon which I needed clarification. It was insightful to have several different views of the situation.

Goal: Increase Knowledge and Skills for Effective Interdisciplinary Collaboration

In order to increase my knowledge and hone my skills for effective interdisciplinary collaboration I shadowed various team members within the interdisciplinary healthcare team to better understand their roles. During my practicum, I was able to shadow the hospice palliative physicians attending patients and families and was privy to discussions regarding medications and treatment options. It was useful to observe the delivery of a terminal medical prognosis by physicians and attending residents. Pain and symptom management were first and forefront in the physicians' discussions with patients and families. It was beneficial for me to observe the gentleness and candidness of physicians' conversations with patients and families; this was an opportunity to witness how medical information was delivered and clarified. The availability of other medical professionals such as family physicians, cancer care physicians, and anesthesiologists provided an additional level of support for the patient when addressing pain management. Unfortunately I was not present for those consultations.

It was through collaboration and consultation with team members that I shaped and formulated my impressions of interdisciplinary teamwork and its effectiveness for the benefit of the dying patient. I did take every opportunity to assist and collaborate with the nursing staff by being available when transferring patients from room to room or assisting them in personal care for the patient. The nurses' empathetic and caring attitude was evident in their interactions with patients and families and I strove to learn from their example. The nurses approached me whenever they felt a family member could use emotional support.

I included these experiences within my daily journal entries, researching medications and treatment options in order to be familiar with procedures offered to patients. When discussing treatment options with patients at EOL an understanding of the differences between curative and palliative treatments is imperative in order to convey that information. Chemotherapy and radiation therapy are used for alleviating symptoms, reducing inflammation, and slowing the advancement of the growth of tumors. A patient and family may confuse the differences between curative and palliative.

Goal: To Develop Practice Skills in the Area of Psychosocial Hospice Palliative Service Delivery, Being Mindful of Culturally Relevant Protocols

My goal to develop practice skills in the area of psychosocial hospice palliative service delivery was accomplished by reviewing the relevant Victoria Hospice resources, shadowing my practicum supervisor, and eventually managing a caseload. The application of a psychosocial delivery model, within the context of clinical practice, should be mindful of incorporating culturally relevant procedures and protocols to treatment and care of hospice patients. After two and a half weeks of shadowing my supervisor I was able to manage a supervised caseload that involved the assessment of newly admitted patients and support their families engaged in their direct care. My caseload consisted of seven to eight patients and their families and supporting caregivers. This number varied from week to week, depending on where in the dying process the patient presented.

The majority of my time was devoted to interactions and interventions with patients and families on my caseload. Through the use of family genograms, the Palliative Performance Scale (PPSv2) (Victoria Hospice Society, 2006), and a psychosocial assessment form, I gathered information for the Victoria Hospice psychosocial services program (see Appendix B – Psychosocial Assessment). My gathering of this information with new patients and families provided the basis for the clinical team and bereavement services to determine whether or not bereavement services were required by family members after the death of a patient. The Psychosocial Assessment form of the Psychosocial Program covers practical considerations, in particular Power of Attorney documentation, Representation Agreements, Last Will and Testaments, funeral planning, and financial/housing/employment concerns. Patient assessment topics included: life review, cultural beliefs and practices relevant to care, community supports, strengths/coping and decision-making styles/self care, fears/concerns, and intimacy/sexual issues. Family dynamics were considered, particularly in terms of past losses and anticipated losses. The psychosocial assessment contains a section pertaining to the patient's caregiver, family members, and support persons, in relation to bereavement risks. A Bereavement Risk Assessment Tool provides an instrument for evaluation of risks and includes 11 areas of consideration: kinship; caregiver; mental health; coping; spirituality/religion; concurrent stressors; previous bereavements; supports and relationships; children and youth (less than age 19); circumstances involving the patient, the care, or the death; and protective factors supporting positive bereavement outcomes. The gathering of information for intake and allowing for patient and family to be settled and comfortable was at times a delicate process. There were two different incidences in which I felt that I was intruding and took it as a learning moment. I strove to collect pertinent information from the patient and family to be an organic process and not to have an agenda.

Assessing a family's strengths and deficits provided a basis for addressing psychosocial issues at EOL. I experienced patients with symptoms of depression, existential distress, PTSD, hoarding, anticipatory grief, dementia, delirium, addictions, and mental disabilities. I provided information to family members in how to access funeral services, financial assistance, and I supported patients in their wish to die at hospice. I also had the privilege of supporting two patients and their families with a "celebration of life". Friends and family were able to attend a quiet gathering on the unit to pay their respects and to celebrate a life well lived.

I also shadowed the Palliative Response Team (PRT) on four separate occasions. Each occasion provided an opportunity to experience a different team dynamic of counselor and nurse. The work was collaborative and supportive in nature as they addressed patient and families needs in the community. I was able to be present at three pronouncements of death, witness the involvement of the coroner when 911 was contacted at time of death, and observe and assist the team with pain and symptom crisis. I was able to follow and support three patients on my caseload, from their homes onto the hospice unit, providing a consistent psychosocial care approach for the patient and their family.

Goal: Acquire Knowledge of Policies/Protocols/Procedures/Programs

In order to achieve my goal of acquiring knowledge with regards to Victoria Hospice's protocols, policies and procedures, programs and interventions, I reviewed available manuals and existing information for psychosocial programming and services, particularly in relation to intake, referrals, assessments, and counseling provided to registered hospice patients.

Patient-family conferences provided an avenue for patients to ask questions and clarify their decisions around goals of care. The research suggests that family caregivers acquire a sense of relief as "an opportunity to discuss feelings with a health professional reduces psychosocial distress" (Hudson, Quinn, O'Hanlon, & Aranda, 2008, p. 5) while having their concerns addressed during patient-family conferences. In this way the patient and family were incorporated into the interdisciplinary team. Several patients and family caregivers shared with me that EOL conversations are difficult and usually their questions revolved around the estimated length of time the patient had to live. Hebert et al. (2008) suggest this area of conversation appears to be difficult for families due to the uncertainty surrounding physical symptoms and how they are interpreted, not only by themselves but by physicians and hospice staff. Family conferences provided an opportunity to "inform, deliberate, clarify and set goals for future care, based on discussions between health professionals and the patient and family" (Hudson, Quinn, O'Hanlon, & Aranda, 2008, p. 8), which helped in my opinion to alleviate the anxiety and stress the patient and family had regarding medical information and psychosocial issues. There is also a need to be culturally sensitive when discussing EOL issues within family conferences while "recognizing that we, to, are culture-bound in our approach, and that our assumptions about truth telling and the end of life are not universally applicable or appropriate" (Candib, 2002, p. 226).

I was able to observe Patient and Family Conferences and to facilitate three in a format similar to family conferencing in child protection. The Victoria Hospice Society's Patient and Family Conferences provided an opportunity to gather information and observe the interaction and functioning of patients and families (see Appendix C – Patient and Family Conference). It was during these Patient and Family Conferences that I truly came to understand that the dying patient is the director of their own care and healthcare providers take a supportive role. A family conference format is an avenue for patients and families to ask questions regarding medications, clarifying medical treatments, discuss future plans for discharge if the patient physically stabilizes in their pain and disease, taking into consideration the ability of the caregivers to provide quality care. I was involved with two patients who stabilized in their symptoms and, through a nurse liaison, were found alternative placement in residential care facilities. Several families expressed gratitude for having the opportunity to voice their concerns and question medical staff in order to clarify their goals of care.

One of the projects that I was assigned while at Victoria Hospice was to review existing information/documentation with regards to Wills and estates, and anticipatory grief, in order to create pamphlets for patients and families on these topics. With the supervision of my practicum supervisor and the input from the psychosocial program staff I created a pamphlet on "*Making a Will*" (see Appendix D – Making a Will). I was also able to reformat the existing information on anticipatory grief and to provide support in the revision of that material.

Goal: Self-care and Coping Strategies

Social work, described by some, is an emotionally stressful profession. Being exposed to individuals who are dealing with mental health and addictions, financial constraints, child welfare concerns, and end of life decisions can place a social worker in an emotionally vulnerable position. Being aware of the effects of burnout and compassion fatigue, one of my goals while at practicum was to develop appropriate self-care and coping strategies to maintain mental, emotional, physical and spiritual health. Balance between one's personal and professional lives indicates how well a social worker will cope with the stresses of EOL care (Jones, 2005).

In January 2016, as an extra supportive activity to my practicum, I enrolled and completed a four-week on-line course offered by the University of British Columbia (UBC). The course facilitated by Lynda Monk, MSW, RSW, CPCC, addressed burnout, compassion fatigue, and vicarious trauma. This allowed me an opportunity in the evenings to engage in discussion with other professionals within an on-line format. The materials used throughout the course were effective in assisting me identify compassion fatigue and vicarious trauma while offering various coping strategies.

Several family situations during my practicum presented an opportunity to identify and confront my "triggers". Furthermore, I felt that moving to a different city isolated me from familiar and comfortable living arrangements. I experienced a shift from comfort to discomfort. This shift appeared to parallel a patient's journey onto the hospice unit, and my personal feelings towards my family members filtered through into my professional life. The longings for emotional connection to the people I loved and cared for were paralleling the experience of the patients in their dying process. The anticipatory grief of many families fed into my own perceived losses. It was the realization that although I was being empathetic and compassionate towards patients and families, this was not my family and I needed to distance myself from their grief in order to remain emotionally healthy and be consistent in my interventions. I continued to make connections in various ways with the patients and families but understood that in order to serve them to the best of my ability I need to maintain my professionalism. Our personalities provide an insight into how we cope, "extroverted workers need to verbally express their emotions more than introverts, who need to be sure they have adequate time alone to reflect" (Jones, 2005, p. 126). I experienced the need between the two, having to verbally debrief the circumstances of a patient, while also having to withdraw from the situation in order to reflect on my experiences. Journaling my experiences provided an opportunity to release emotions and reflect on my practice.

In order to develop an ongoing self-care regime I engaged in regular physical exercise, enjoying a half hour walk to and from practicum each day. I blended suggested coping strategies from other team members to create my own "letting go" ritual at the end of the day (Jones, 2005) creating a transition from professional to personal life that was crucial for maintaining my mental, emotional, and spiritual well-being. I painted with watercolors, wrote poetry, and enrolled in an "infused glass" class to create pieces of glass art. My modest basement suite was three blocks away from the ocean and I frequently walked on the beach looking for sea glass and observed wild life, taking the time to perform a walking meditation and to practice being mindful.

Connection to my family was also important to my emotional well-being and I frequently used Skype in order to have conversations with my husband, my adult children, friends, and colleagues. Self-awareness provides the basic understanding of our own traits and motives for one choosing to engage in hospice palliative social work.

Goal: Understanding Palliative Sedation Therapy (PST) and Treatment Options

The goal that was in the forefront of all my interactions with patients and families was to develop an understanding of Palliative Sedation Therapy (PST), Medical Assistance in Dying (MAiD), and other treatment options to alleviate pain and suffering. I reviewed *Preparing for Death: A Guide for Caregivers,* and *A Caregiver's Guide: A Handbook about End-of-Life Care* (Macmillan, Peden, Hopkinson, & Hycha, 2014), a comprehensive handbook of caregiving at EOL used by the Victoria Hospice's bereavement services. This handbook covered the physical changes expected at EOL, and provided practical suggestions for caregivers (Macmillan, Peden, Hopkinson, & Hycha, 2014).

All registered hospice patients are provided with a binder, *Palliative Care at Home*, outlining the Victoria Hospice's services. This binder outlines information to patients and family on practical matters, how to document medications, and procedures for dying at home (Victoria Hospice Society, 2013b). I found this binder useful in understanding the services provided by the Victoria Hospice to patients and families, before, during, and after death.

I also reviewed the Victoria Hospice *Palliative Sedation Therapy (PST) Worksheet* (see Appendix E – Palliative Sedation Therapy (PST) worksheet) to understand the diagnostic criteria of palliative sedation. The Palliative Care Team is consulted to evaluate the request of the patient and family. The patient's illness status as well as the duration of sedation is considered, a flow chart and a decision-making framework are included in the Palliative Sedation Therapy worksheet assist the team in analyzing the request and initiating PST. There is on-going assessment of the patient's circumstances and strict procedural protocols in place for patients who meet the criteria.

There were several patients and families who requested MAiD. I did not have any requests from patients, however, was privy to conversations between team members during medical rounds, and with patients and families when physicians clarified Victoria Hospice policies regarding MAiD. Victoria Hospice does not have protocols or procedures in place to assess a patient who requests MAiD. The hospice staff and volunteers were instructed to inform patients they would have to apply through the courts to access MAiD. Although the Victoria Hospice Society's philosophy emphasizes comfort care towards a natural death, MAiD may become an option for patients on the hospice unit once legislation clearly defines the parameters for eligibility.

Summary

In this chapter I identified and described my learning goals and objectives for my practicum at the Victoria Hospice and I believe I exceeded my own expectations of acquiring knowledge as to the role of social worker in an interdisciplinary hospice palliative care team. Learning opportunities to examine roles, understand psychosocial and physical issues at EOL, and collaborate with other health care disciplines were present on a daily basis. In the following chapter I will offer implications for social work practice based upon my experiences.

Chapter Seven – Implications and Recommendations for Practice

My experiences at Victoria Hospice exceeded my learning expectations; being physically, emotionally, and spiritually present with dying patients and their families provided a rich learning environment that is not fully accessible to graduate level social work students in northern BC. This practicum placement assisted me in understanding my role as a social worker within an interdisciplinary hospice palliative social work team, and contributed to the overall formation of my personal practice techniques and style.

The following passage from Debra Parker-Oliver's (2016) commentary amply reflects my experiences at the Victoria Hospice:

> I was privileged to listen to my staff reflect on their experiences with patients transitioning from this life to another. As they debriefed following the death of patients, they shared stories with me regarding how it went, what the problems were, how they felt. I had heard the pride and frustration they experienced with the clinical details of managing pain, alleviating anxiety, managing secretions, and educating and supporting families through the long hours of vigilant waiting. (p. 337)

Although I was not in an administrator or counsellor position at the Victoria Hospice, the staff 's, and families' stories influenced my overall learning experience and personal growth within hospice palliative care. In order to understand the implications these experiences have on my personal social work practice I turned to the research literature for clarification and to support of my learning. The challenge was to connect the literature to the human experience while being acutely aware that academic knowledge is not the only way in which to view a situation. Experiential learning provides an avenue to practice social work in a supervised structured environment. This chapter provides implications and recommendations for hospice palliative social work based upon my experiences.

Implications for Social Work Practice

My practicum confirmed social workers are an important component of an interdisciplinary team and a necessity within hospice palliative care. Social workers are in a position to assist families in establishing new roles and identities before and after a death in the family due to their knowledge of “counseling, family systems, community resources, and psychosocial assessments” (Bosma et al., 2009, p. 84). Coincidently, social workers have “specialized training and clinical experience in crisis intervention, including individual and family counseling and is skilled at making assessments and referrals” (Quig, 1989, p. 22), all of which are beneficial when supporting patients and families facing death.

Social workers engaging in an initial psychosocial assessment in hospice palliative care, and subsequent interactions thereafter, gather pertinent information needed to support patients and families in the dying process. The timing of acquiring the necessary information provided a challenge at times for me, particularly when the patient entered hospice in a critical state and/or a patient and family were reluctant to discuss particular aspects of the psychosocial evaluation pertaining to practical matters. My skill in acquiring information evolved to include casual informal conversations in order to complete necessary hospice evaluation forms. This skill continues to strengthen as I pursue professional duties in hospice palliative care in other settings. I found a familiarity and ease, as well as sensitivity, is needed when discussing the practical matters during these initial interactions and assessments. This sensitivity coupled with an understanding of cultural norms surrounding death rituals and funerals provided a base for my interactions with patients and families when discussing EOL issues. Their wishes surrounding last moments before death and moving of the deceased varied. Again, being culturally sensitive within hospice palliative social work develops from exposure to numerous opportunities in experiencing cultural rituals and spiritual beliefs surrounding death not familiar to one's own culture.

Hospice palliative interdisciplinary healthcare team philosophy revolves around the principles of holistic care, self-determination of the patient and their families, comfort care, and understanding that death is part of the human development continuum (Oliver & Peck, 2006). Interdisciplinary teams exemplify the service delivery option that best suits healthcare in hospice palliative environments. Csikai recommends "interdisciplinary discussion and problem solving may provide guidance to hospice professionals to preserve patient autonomy and to support families simultaneously" (2004, p. 68).

Victoria Hospice provided an example of a team that was well versed in their disciplines, and exhibited a team that engaged in shared decision-making (D'Amour et al., 2005). Communication and collaboration between disciplines were observed and were an essential component to the successful functioning of the interdisciplinary team. The establishment of clear goals and roles, mutual respect and trust between team members, team structure, and organizational support assisted the team to work effectively (Csikai, 2004). I observed the nurses within their duties on the hospice unit were responsible for discharge planning, making arrangements for transportation to and from residences, assessing equipment needs, and in the event of a death, arranging for body transfer to a funeral home. As a hospice palliative social worker in a smaller community I may have those responsibilities, freeing up the nursing staff to continue with personal care for the patients. One of my disadvantages within this team setting was my lack of knowledge regarding medical terminology, treatment options, and medications commonly used in pain management in hospice palliative care. It was through conversations with nurses and physicians, along with reviewing medical information in articles and books provided to patients and families that I was able to become informed about possible treatment options.

Recommendations for Social Work Practice

During my practicum tenure at the Victoria Hospice several situations provided an opportunity to ponder what I would recommend for social work practice in hospice palliative care in northern BC. Several issues came to mind, but the most pressing, in my opinion were the following: loss and grief curriculum for social work undergraduates, interdisciplinary healthcare team project availability, availability of suitable practicum placements for students pursuing specialization in hospice palliative social work, and information and discussion surrounding MAiD, both for students and for practicing social workers.

Social Work Curriculum

Social workers in any stream of social work will encounter clients who have been affected by grief and loss and as such should receive instruction in that area (Christ & Sormanti, 2000; Gwyther et al., 2005; Sermabeikian, 1994). Social work students should be provided opportunities to cultivate being present and compassionate with dying individuals while recognizing their own grief responses and support self-care is important to their well-being (Rushton et al., 2009). Incorporating identified competencies in social work curriculum provides a basic understanding of the role of a social worker in social palliative care, further research and support in this area continues to be challenging as there are few social workers in northern BC who specialize in hospice palliative care (Bosma, 2009; Gwyther et al., 2005). Undergraduate and graduate courses addressing cultural competency with emphasis on Aboriginal, First Nation, Metis and Inuit culture should become mandatory for social workers, nurses, and all medical professionals, in order to implement holistic practice interventions for indigenous peoples.

Discussion and curriculum addressing compassion resilience, compassion fatigue, burnout, vicarious trauma, secondary traumatic stress, and compassion satisfaction, needs to be implemented during undergraduate practicum support sessions for students, supervisors, and organizations to understand the implications of these syndromes on personal and professional levels.

Interdisciplinary Healthcare Team Projects

Opportunities for undergraduate and graduate social work students to participate in interdisciplinary healthcare team projects, incorporating all disciplines (i.e. social work, nursing, medicine), and reinforced by supervision and support from experienced members of established interdisciplinary healthcare teams, should be considered in an academic setting in order to foster cooperative and effective interdisciplinary teamwork (Charles et al., 2006). Reese and Sontag (2001) stress members on an interdisciplinary healthcare team "lack knowledge of the other professions' expertise, skills, training, values, and theory. This is the result of training health care professionals in isolation from each other" (p. 168). Presently medical and nursing graduate students are enticed to northern regions by a recruitment program through the Rural Coordination Center of BC (Rural Coordination Center of BC, 2016). A similar program to recruit social workers to northern BC may be a starting point to establish practice and knowledge in hospice palliative social work. Reese and Raymer (2004) recommend implementing reasonable and attractive salaries for social workers educated and experienced in hospice palliative programming while maintaining supervision from another social worker. In rural and remote settings generalist social workers must have knowledge of the Palliative Care Benefits, Compassionate Care Benefits and other programming to support and guide the individual and their families through the bureaucracy of dying while supporting the patient's right to self-determination.

Practicum Placements

Social work practice is founded on apprenticeship structures, incorporating supervision for students during practicum placements (Bogo & McKnight, 2006; Bruce & Austin, 2001; Ingram, 2013; Maidment & Beddoe, 2012; Noble & Irwin, 2006; O'Donoghue, 2015). As noted previously, a larger number of seniors are aging and dying in place and therefore more social workers with knowledge of EOL issues are going to be needed to support patients and families experiencing EOL issues in rural and remote communities. Practicum placements within hospice palliative settings will be further required in order to provide optimal learning opportunities for social work students.

Discussions and Information on MAiD

Canada is now in a position to legally offer MAiD to those individuals who are experiencing intolerable suffering and wish to end their life (Government of Canada, 2016b). Open discussion regarding MAiD and being informed of the legislation and how it affects social workers is recommended for undergraduate and graduate social work students. Practicing social workers have an obligation and duty to support individuals who pursue this palliative treatment option. Social workers are reminded of their ethical and moral obligations to uphold a patient's right to self-determination, and to honor the patient's decisions regarding MAiD. To view the situation objectively and not to impose their beliefs will be an ongoing challenge as legislation on MAiD is challenged and/or upheld.

Summary

In this chapter I addressed the implications my practicum experiences will have on my personal social work practice and provided recommendations for social work practice based upon these experiences. In the next, and final chapter of my practicum report, I will provide an overall summary of my report and my concluding thoughts.

Chapter Eight – Conclusion

In this chapter I will summarize my practicum report and include my concluding thoughts regarding my placement and its impact on my social work practice.

In Chapter One I introduced my reasons for pursuing a practicum placement at Victoria Hospice and outlined the structure of this report. Hospice palliative care in BC is a growing practice area in social work due to the aging population and will need experienced hospice palliative social workers to assist in the evaluation and support of patients and family experiencing terminal illnesses. By pursing a practicum placement in an established and recognized hospice palliative interdisciplinary healthcare team it allowed me to experience first hand the challenges patients and family experience during the dying process.

I examined the shift in aging demographics in Canada and British Columbia in Chapter Two, and identified the challenges northern BC citizens experience in the delivery of services and hospice palliative services for rural and remote Aboriginal communities in BC. Culturally relevant, trauma sensitive practice is essential and appropriate practice at EOL and needs to be implemented for elders and their families who have experienced Indian Residential Schools.

In Chapter Three I provided a detailed description of the practicum site and services provided by the Victoria Hospice Society. Information regarding patient population demographics, hospice services, education and research, and funding were included in this chapter.

Chapter Four describes the theoretical orientation of Victoria Hospice as strength-based family centered and my own person-centered orientation. I believe my personal orientation blended well with Victoria Hospice's theoretical orientation and philosophy of comfort care to death.

Chapter Five provided a comprehensive literature review that encompasses the relevant hospice palliative issues I experienced during my practicum. I provided a definition of hospice palliative care that I referred to throughout my report. Included in my literature review were the following topics: interdisciplinary healthcare teams, role of social worker in hospice palliative care, Family Conferencing at EOL, psychosocial issues at EOL, delirium at EOL, trauma at EOL, existential distress at EOL, Palliative Sedation Therapy and Medical Assistance in Dying (MAiD), preferred place of death, spirituality in social work, and, self-care and burnout prevention.

Chapter Six discussed my learning goals and experiences and what insights I have gained from them. Through the use of my evaluation criteria I was able to critically review and challenge my assumptions of a social worker's role within a hospice palliative healthcare team. I was able to develop a layperson's understanding of PST and other treatment options offered by Victoria Hospice by reviewing and integrating documents and literature. I described the development of my self-care routine, and was able to practice my social work skills in the delivery of a biopsychosocial-spiritual delivery model for patients and families experiencing death.

Chapter Seven states the implications of my practicum experiences for my professional social work practice and recommendations for practice. Opportunities for collaborative hospice palliative healthcare team projects and additions to undergraduate and graduate social work curriculum regarding loss and grief are two of the recommendations set out in this chapter.

My experiences at Victoria Hospice supported my assumptions of hospice palliative facilities as environments rich with learning opportunities for social work practicum students. The interdisciplinary team environment within Victoria Hospice provided an example of collaboration and cooperation between disciplines with an allocated social worker position within the team. I learned alongside knowledgeable professionals from all healthcare disciplines. Shadowing the PRT response team was invaluable as this team can be duplicated and supported in rural and remote settings. These experiences supported and confirmed my literature review with regards to optimal team structure for hospice palliative care.

Each patient I followed and supported was unique in their disease process and life circumstances, leaving me saturated in my learning while providing an environment to hone my social work and counselling skills. I was present for a patient's death, observing and supporting the process while being conscious of the circumstances by which I was there. On several occasions I was present at pronouncement of death and able to pay my last respects to the person I had been serving. I supported two families and their network of friends in organizing a "celebration of life". I was able to recognize my own emotional "triggers" and created a self-care regime. These experiences and more continue to influence my own decisions, both professionally and personally, regarding EOL and generated an interest in cumulative, lifelong trauma and how it manifests at EOL. Acquiring knowledge of trauma at EOL will assist me in recognizing and discerning treatment options for intolerable emotional symptoms.

I will be forever grateful for the opportunity to fulfill my MSW requirements at the Victoria Hospice for my MSW practicum, and I feel honored by those patients, families, and professionals who allowed me into their private and professional lives to observe EOL challenges. This practicum has changed the way I perceive life and death and because of this it is my wish to die at home at the time of my choosing, surrounded by the people that I love and who love me, to be pain and anxiety free, and to be joyful of a life well lived (Parker-Oliver, 2016).

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Appendix A

Learning Goals and Objectives

Learning Goals	Objectives and activities	Monitoring/ evaluation criteria
Increase understanding of a social worker's role in a interdisciplinary hospice palliative healthcare team	Observe and shadow other discipline members within the interdisciplinary team to better understand their roles Collaborate and consult with other team members to establish effective and respectful relationships	Participate in all interdisciplinary hospice palliative healthcare team meetings, includin "rounds" Maintain a journal to document learning experiences within the practicum setting – engage in critical self-reflective practices
Increase knowledge and skills for effective interdisciplinary collaboration	Observe and shadow other discipline members within th interdisciplinary healthcare team to better understand thei roles Collaborate and consult with other team members to establish effective and respect ful relationships	Maintain a journal to document learning experiences within the practicum setting i order to engage in critical sel reflective practices.
To develop practice skills in th area of psychosocial hospice palliative service delivery, bei mindful of culturally relevant protocols	Review resources related to th application of psychosocial delivery model within the context of clinical practice Explore how social workers incorporate culturally relevan procedures and protocols to treatment and care of hospice patients Gain an understanding of cultural competency in social work practice	Manage a supervised caseloa that involves assessment, development of treatment plans, treatment and case closure Maintain a journal to docume learning experiences regardin cultural competency Shadow the Palliative Response Team (PRT) in thei community services to patien
Gain knowledge about Victori Hospice's protocols, policies and procedures, programs and interventions	Review manuals regarding psychosocial programming in relation to intake, referrals, assessments, counselling sessions, and other services	Become familiar with documentation requirements surrounding intake, assessme and development of treatmen plans

	provided to hospice patients Review and become familiar.	Journal experiences and engage in discussions with team members
Protocols, policy, procedure continued from previous page	…documentation associated with policy and procedures around referrals Examine the strengths of the organization and the effectiveness of the interventions	
Develop appropriate self-care and coping strategies to maintain mental and emotional health in my practice	Engage in self-care activities in order to maintain mental, emotional, physical and spiritual health in order to support staff and patients in healthy interactions	Journal daily and explore Different self-care strategies Engage in a regular physical exercise routine Engage in discussions with practicum supervisor and othe staff members in order to debrief stressful situations Utilize relaxation techniques Enroll in a 4-week on-line Burnout prevention course
Develop an understanding of Palliative sedation, medical assistance in dying (MAID) and other treatment options available during the dying process	Review any relevant documer ation regarding protocols and procedures regarding palliativ sedation and MAID	Be present and discuss treatment options as well as Practical issues with patients Develop a lay-person's understanding of the dying process by becoming familiar with diagnostic criteria and medical terminology

Appendix B

Victoria Hospice

Psychosocial Assessment

____
(Print patient name or place patient label here)

TEAM ALERT Date of First Assessment:__________ initial: ______

____
____
____

PRACTICAL CONSIDERATIONS

P.O.A.: enduring / bank / other: ____________________ Who is POA?__________

Decision Maker: ____________________ Relationship ____________ Rep Agreement: yes no

Financial Support/Pensions: Income Assist ☐ CPP (disability) ☐ DVA ☐ Other__________

Financial/Housing/Employment concerns: ______________________________

______________________________ No financial concerns apparent ☐

Last Will & Testament: Discussed ☐ Estate Plan package given ☐ Will Completed ☐

Funeral Planning: Discussed ☐ F/M Plan package given ☐ Funeral Home__________

TIME OF DEATH

Pt's preference of location: Home ☐ VHS unit ☐ Other__________ Date __________ PPS ___

Home ☐ VHS unit ☐ Other__________ Date __________ PPS ___

Details ______________________________

Family/others requesting to be present at time of death ______________________________

Special requests/rituals for time of death ______________________________

SPIRITUAL CARE

Religious/Spiritual affiliation ______________________________

Patient's description of their Spirituality ______________________________

____
____
______________________________ Referral for Spiritual Care ☐ Date__________

INFORMATION GIVEN: (to whom)

- ☐ Anticipatory Grief ______________________________
- ☐ Children & Grief ______________________________
- ☐ When Death Occurs ______________________________
- ☐ Final Gifts ______________________________
- ☐ Other

Patient Assessment

Life Review (careers, interests, etc.)

Cultural Beliefs & Practices Relevant to Care

Community Supports

Strengths / Coping and Decision-making Styles / Self Care

Current Awareness of Illness / Goals / Expectations / Hopes

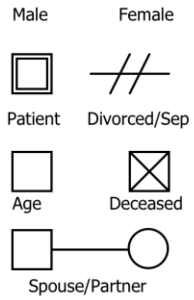
Fears / Concerns

Intimacy / Sexuality Issues

Losses experienced by Patient and Family

Anticipated losses

FAMILY MAP



CAREGIVER ASSESSMENT

Primary Caregiver Name ____________________________ Relationship ________ Employed ______

Physical/Psych/Medical ____

____

Strengths/Coping/Self Care ____

____

Concurrent Demands ____

Hopes/Fears/Other ____

Other Caregiver Name ____________________________ Relationship ________ Employed ______

Physical/Psych/Medical ____

____

Strengths/Coping/Self Care ____

____

Concurrent Demands ____

Hopes/Fears/Other ____

FAMILY FUNCTIONING (communication patterns, decision making, family roles, etc.)

____

____

____

____

Bereavement Risk Assessment Tool (rev 2008)

I. Kinship

☐ a) spouse/partner of patient or deceased
☐ b) parent/parental figure of patient or deceased

II Caregiver

☐ person who provides or plans ongoing physical and/or emotional care

III. Mental Health

☐ a) significant mental illness (eg major depression, schizophrenia, anxiety disorder)
☐ b) significant mental disability (eg developmental, dementia, stroke, head injury)

IV. Coping

☐ a) substance abuse / addiction (specify)
☐ b) considered suicide (no plan, no previous attempt)
☐ c) has suicide plan and a means to carry it out OR has made previous attempt
☐ d) self-expressed concerns regarding own coping, now or in future
☐ e) heightened emotional states (anger, guilt, anxiety) as typical response to stressors
☐ f) yearning/pining for the deceased OR persistent disturbing thoughts/images > 3 months*
☐ g) declines available resources or support
☐ h) inability to experience grief feelings or acknowledge reality of the death > 3 months*

V. Spirituality / Religion

☐ significant challenge to fundamental beliefs / loss of meaning or faith / spiritual distress

VI. Concurrent Stressors

☐ a) two or more competing demands (eg single parenting, work, other caregiving)
☐ b) insufficient financial, practical or physical resources (eg ? income, no childcare, illness)
☐ c) recent non-death losses (eg divorce, unemployment, moving, retirement)
☐ d) significant other with life-threatening illness / injury (other than patient/deceased)

VII. Previous Bereavements

☐ a) unresolved previous bereavement(s)
☐ b) death of other significant person within 1 year (from time of patient's death)
☐ c) cumulative grief from > 2 OTHER deaths over past 3 years
☐ d) death or loss of parent/parental figure during own childhood (less than age 19)

VIII. Supports & Relationships

☐ a) lack of social support/social isolation (eg perceived lack of support, housebound)
☐ b) cultural or language barriers to support
☐ c) longstanding or current discordant relationship(s) within the family
☐ d) relational difficulties with patient/deceased (eg verbal/emotional/physical abuse)

IX. Children & Youth (less than age 19)

☐ a) death of parent, parental figure or sibling*
☐ b) demonstration of extreme behaviours or symptoms (eg separation anxiety+, nightmares)
☐ c) parent expresses concern regarding his/her ability to support child's grief
☐ d) parent/parental figure significantly compromised by his/her own grief

X. Circumstances Involving the Patient, the Care, or the Death

☐ a) patient/deceased less than age 35
☐ b) lack of preparedness for the death (as perceived or demonstrated by bereaved)*
☐ c) distress witnessing the death OR death perceived as preventable*
☐ d) violent, traumatic OR unexplained death (eg accident, suicide, unknown cause)*
☐ e) significant anger with OTHER health care providers (eg "my GP missed the diagnosis")
☐ f) significant anger with OUR hospice palliative care program (eg "you killed my wife")

XI. Protective Factors Supporting Positive Bereavement Outcome

☐ a) internalized belief in own ability to cope effectively
☐ b) perceives AND is willing to access strong social support network
☐ c) predisposed to high level of optimism/positive state of mind
☐ d) spiritual/religious beliefs that assist in coping with the death

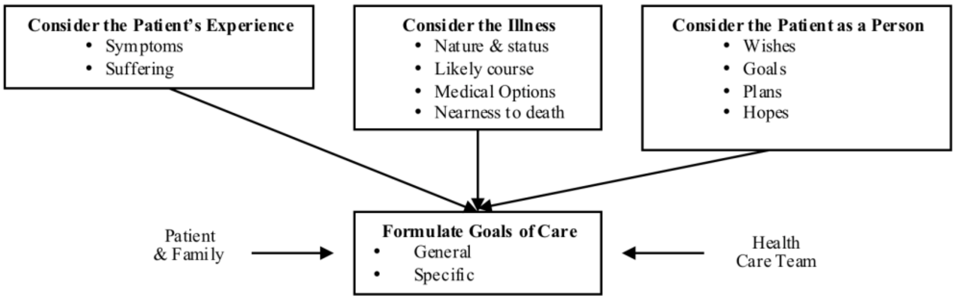
Notes to Bereavement: ____________________

(S:) Jan 2008

Appendix C

VICTORIA HOSPICE

Latimer Ethical Decision Model



Consider the Patient's Experience
- Symptoms
- Suffering

Consider the Illness
- Nature & status
- Likely course
- Medical Options
- Nearness to death

Consider the Patient as a Person
- Wishes
- Goals
- Plans
- Hopes

Patient & Family → **Formulate Goals of Care** ← Health Care Team
- General
- Specific

PATIENT & FAMILY CONFERENCE

Date: _____________ **Time:** ____________

Present: ____

____

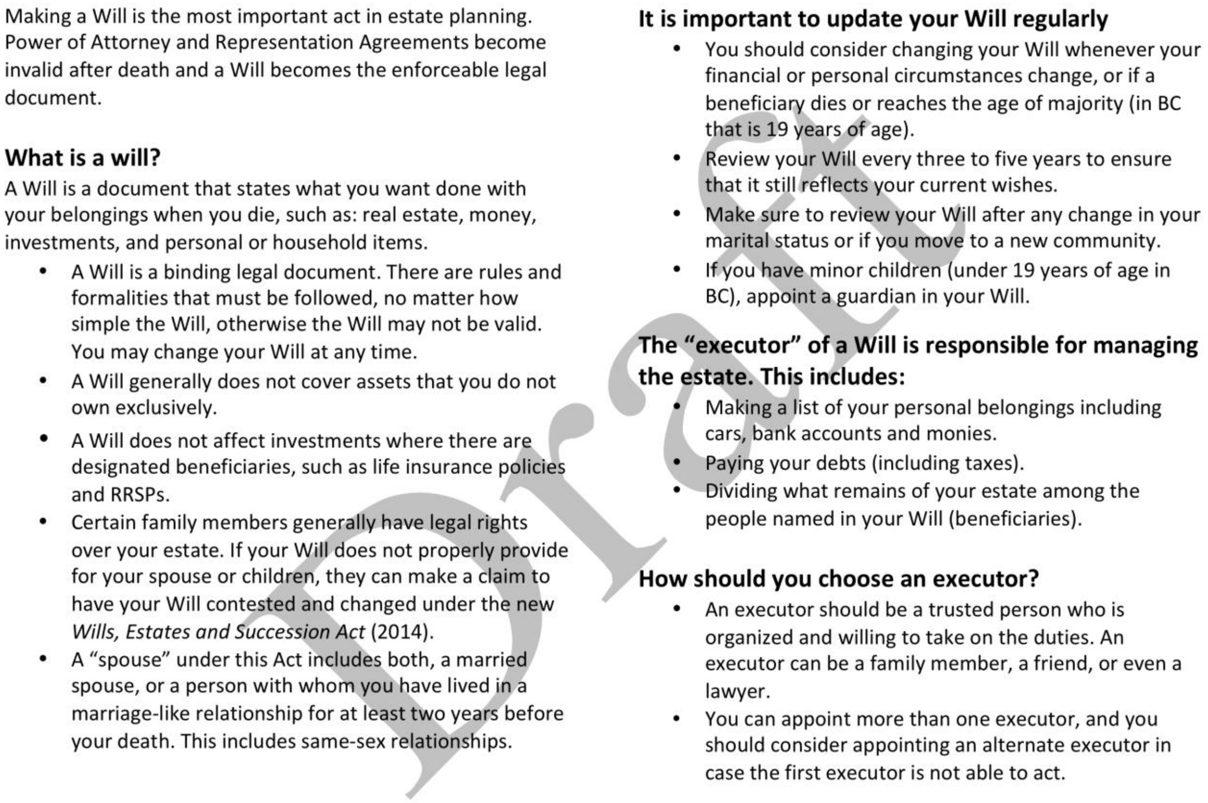
____

Goals of This Conference	Post Conference Goals
Patient:	
Family:	
Team:	

Speaker	**Discussion**

Appendix D

Making A Will



Making a Will is the most important act in estate planning. Power of Attorney and Representation Agreements become invalid after death and a Will becomes the enforceable legal document.

What is a will?

A Will is a document that states what you want done with your belongings when you die, such as: real estate, money, investments, and personal or household items.

- A Will is a binding legal document. There are rules and formalities that must be followed, no matter how simple the Will, otherwise the Will may not be valid. You may change your Will at any time.
- A Will generally does not cover assets that you do not own exclusively.
- A Will does not affect investments where there are designated beneficiaries, such as life insurance policies and RRSPs.
- Certain family members generally have legal rights over your estate. If your Will does not properly provide for your spouse or children, they can make a claim to have your Will contested and changed under the new *Wills, Estates and Succession Act* (2014).
- A "spouse" under this Act includes both, a married spouse, or a person with whom you have lived in a marriage-like relationship for at least two years before your death. This includes same-sex relationships.

It is important to update your Will regularly

- You should consider changing your Will whenever your financial or personal circumstances change, or if a beneficiary dies or reaches the age of majority (in BC that is 19 years of age).
- Review your Will every three to five years to ensure that it still reflects your current wishes.
- Make sure to review your Will after any change in your marital status or if you move to a new community.
- If you have minor children (under 19 years of age in BC), appoint a guardian in your Will.

The "executor" of a Will is responsible for managing the estate. This includes:

- Making a list of your personal belongings including cars, bank accounts and monies.
- Paying your debts (including taxes).
- Dividing what remains of your estate among the people named in your Will (beneficiaries).

How should you choose an executor?

- An executor should be a trusted person who is organized and willing to take on the duties. An executor can be a family member, a friend, or even a lawyer.
- You can appoint more than one executor, and you should consider appointing an alternate executor in case the first executor is not able to act.

Where should you keep your Will?

- It is advised that you give a copy of your Will to your executor and keep a copy for yourself in a safe place.

What happens if you do not make a Will?

- When there is no Will you are said to die "intestate", and your net estate will be managed by a person, usually a family member if there is one.
- If no family member is available then the courts appoints someone, or the Public Guardian and Trustee of British Columbia, will distribute your belongings according to rules set out in the new *Wills, Estates and Succession Act* (2014). In this case, next of kin must apply to the Supreme Court of British Columbia, Probate Division, to be appointed as Estate Administrator.
- The estate will go to the government if no relatives can be found to administer it. ***It is strongly recommended that you have an up-to-date Will, no matter what you own.***

A simple Will is available from Victoria Hospice. It requires two witnesses to your signature. It is intended for those people who do not own property, do not have investments, or do not have dependent children. If you are unable to sign the Will because of illness or disability, you can ask someone to sign it for you in front of you, and in front of the two witnesses. Medical staff and hospice volunteers are not allowed to act as witnesses.

Resources:

An estate planning resource list, is available from Victoria Hospice at www.victoriahospice.org

For information regarding CPP Death Benefits please visit the Service Canada office at 1401 Douglas Street, Victoria, BC or call: 1-800-277-9914

Access Pro Bono: volunteer lawyers help low-income seniors (ages 55+) and people with terminal illnesses to prepare a Will: 604-424-9600

The Canadian Bar Association's Dial-a-Law:
Toll free: 1-800-565-5297

Law Students' Legal Advice Program Clinics:
604-822-5791

Lawyer Referral Service Toll free: 1-800-663-1919

Society of Notaries Public of BC
Toll free: 1-800-663-0343

You can also search on-line for Province of British Columbia's website on Wills and Estate Planning at:

http://www2.gov.bc.ca/gov/content/family-social-supports/seniors/financial-legal-matters/wills-and-estate-planning

Appendix E

Victoria Hospice

PALLIATIVE SEDATION THERAPY (PST) Worksheet

- Palliative Sedation Therapy (PST) is defined as the use of specific sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness using appropriate drugs carefully titrated to the alleviation of distress.
  - ➢ *Sedation is commensurate and proportionate to the patient's level of distress.*
  - ➢ *Medications are titrated to symptom relief, not sedation level. (appendix I, II)*
- Palliative Sedation Therapy is distinct from Physician Assisted Suicide (PAS) and Euthanasia in that there is no intention to hasten death.
- Consequential Sedation is an unintended, but possibly expected side effect of some drugs used in symptom control. Usually temporary until tolerance develops or dose is adjusted, but could be persistent (see Appendix II). Consequential Sedation is not Palliative Sedation Therapy.

ASSESSMENT date ____ / ____ / ____ PPS ______%

PT LABEL

Diagnosis____

Refractory symptom(s) ______________________________

____

____

initials -
PCP

____ Estimated nearness to death in days ☐ 0-3 ☐ 4-7 ☐ >7 (*check one*)
____ VHS Palliative sedation framework has been used (*appendix V)*
____ ☐ Patient is competent ☐ Patient is incompetent (*check one*)
____ ☐ Informed consent obtained from patient ☐ TSDM (*check one*)
____ A DNR / No CPR / or AND (Allow Natural Death) order is in effect
____ Patient and family demonstrate a clear understanding of PST as distinct from Physician Assisted Suicide and/or Euthanasia

PALLIATIVE CARE TEAM CONSULTATION (as appropriate, please include names)

PCP(s)____ GP____

CNL/CRC_______________________________________ MRN/LPN_______________________________________

Counsellor_____________________________________ Spiritual Care___________________________________

Other (i.e., HCCN, Consulting Physicians) ____

TENSION POINT(S) IDENTIFIED Indicates possible need to notify clinical managers to ensure team support and resources

Patient / Family
- ☐ Patient/family/team do not demonstrate clear understanding of PST as distinct from Physician Assisted Suicide and Euthanasia
- ☐ Evidence of ongoing family distress around PST despite alleviation of patient's refractory symptom
- ☐ Patient/family dissatisfied with PST

Patient's Illness Status
- ☐ Anticipated nearness to death is greater than 7 days
- ☐ Existential suffering is sole refractory symptom
- ☐ PPS > 20
- ☐ Administering PST to a patient who currently has oral intake.

Procedural
- ☐ Requirement for rapid initiation of PST
- ☐ PST initiation delayed
- ☐ Prolonged titration period or unexpected amount of medication required to alleviate patient's refractory symptom
- ☐ Unexpected duration of PST (short or lengthy)

Team and Team Resources
- ☐ Team consensus not achieved
- ☐ Adequate PRT resources not available to support PST in the home.
- ☐ Adequate interdisciplinary staffing not available
- ☐ PST initiated in the home
- ☐ PCP and PRT unable to make joint visit

Other tension point(s) identified:____

Name of clinical manager(s), if notified____

FAMILY MEETING participants and date (if held)____

____

DECISION REGARDING PST ☐ proceed ☐ not at this time

INITIATION, TITRATION and MONITORING

PCP

DOCUMENT in Physician's Progress Notes
- ☐ refractory symptoms and patient/family goals
- ☐ PST criteria met/not met using VHS PST Framework
- ☐ informed consent to proceed obtained
- ☐ conclusion of any hydration & nutrition discussion (*appendix III*)
- ☐ communication with patient/family regarding patient's prognosis and the anticipated impact of PST on ability to communicate, etc.
- ☐ communication with patient's GP, on-call PCP, interdisciplinary care team as appropriate
- ☐ assessment of patient/family (daily)

MEDICATIONS
- ☐ nonessential medications discontinued
- ☐ ongoing and anticipated symptom management (pain, nausea, delirium, dyspnea, etc.)
- ☐ PST orders (appendix IV)
    - ✓ *Initial titration is based on the level of symptom relief, level of sedation, and medication side effects*
    - ✓ *Sedation is commensurate and proportionate to the patient's level of distress.*
    - ✓ *Medications are titrated to symptom relief, not sedation level.* (*appendix I, II*)

NURSING
- ☐ Daily documentation of current plan in Progress Notes

COUNSELLING
- ☐ document summary of family meeting (if held)
- ☐ initiate counselling PST flowsheet and document daily
- ☐ daily documentation of counselling plan in Progress Notes
- ☐ assess and attend to team process daily

Date and time of Death: ________________day of ______________________, 20______ at _____________

Current team members assess for need/type of followup (debriefing, personal reflection, etc.)

initials –
counsellor

_____ BRAT completed
_____ PST worksheet photocopied and given to Medical Director's assistant (to include in database)
_____ Consideration of need for debriefing at Tuesday rounds or PRT daily rounds
_____ Debriefing occurs as required and relevant points documented

Comments on this patient's PST and suggested feedback to be completed by any member of the palliative care team. This is to material for staff debriefing, if needed, or for future PST procedures. Attach additional notes as required or speak directly to cli managers.

Appendix I

SEDATION SCALE (1)

Consciousness Scale for Palliative Care (CSPC) – NB: Not appropriate for patients with profound visual/hearing loss.

Level	Level of Consciousness
1	Awake
2	Awakens when called by his/her name and stays awake during conversation
3	Awakens when called by his/her name but falls asleep during conversation
4	Reacts with movement or brief eye opening, but without eye contact, when called by his/her name
5	Reacts to trapezius muscle pinching
6	Does not react

(1) Goncalves F, et al. Consciousness Scale for Palliative Care (CSPC) Palliative Med 2008 Sep;22(6):724-9

Appendix II

MEDICATION REVIEW FOR PALLIATIVE SEDATION THERAPY (2)

Generally four drug classes:

Benzodiazepines (anxiolytic sedatives)
Neuroleptics (sedating antipsychotics)
Barbiturates
General anaesthetics

- Medications are used with the intent to cause sedation. They should be used concurrently with medications targeting the refractory symptoms (e.g., continue opioids for pain or dyspnea; antipsychotics for delirium).
- Note that opioids, although may be used concurrently for symptom control, are NOT used to cause sedation.
- May need more than one of the four drug classes listed above to achieve adequate sedation.

Midazolam – Generally drug of first choice
Initial loading dose of 1-5 mg followed by infusion of 1-5 mg/hr
Titrate infusion up q 30-60 min depending on patient comfort
Caution: Paradoxical behaviour or excitement, Hiccups, NV, Rapid induction of depressed respiration

Antipsychotics - Sedating neuroleptics preferred (methotrimeprazine)
Particularly useful if agitated delirium a feature.
Methotrimeprazine (Nozinan) dose: 10-15 mg sc q4h titrated up to 25-100 mg

Barbiturates - Used less often if benzodiazepines not effective or contraindicated
Phenobarbital dosage: start 60-120 mg sc q8h; titrate up to 120-140 q8h and PRN

Anesthetics - Used rarely and under direction of palliative care consultant and/or anaesthetist
Propofol dose 0.3-3.0 mg/kg/hr

Medication	Initial or Loading Dose (mg)	Titration	Usual Maintenance Dose	Route of Administration	Advantages	Disadvantages
Midazolam	1-5 mg	q30-60 min	30-100 mg/day (higher doses reported)	usual subcut	Rapid effect Anxiolytic Antiseizure	- Paradoxical agitation - Resp depression - Tachyphylaxis
Lorazepam	1-4 mg	q4h and titrate based on prn doses	1-4 mg q4h and prn	usual subcut also SL or IV	Easily administered at home Anxiolytic Antiseizure	- Paradoxical agitation - Resp depression
Methotrimiprazine	10-15 mg	q4h and titrate based on prn doses	25-100 mg q4h regularly and prn	usual subcut also IV	Rx delirium and nausea	- Extrapyramidal symptoms - Lowers seize threshold
Phenobarbital	60-120 mg	q8h and titrate based on prn doses	30-240 mg q8h and prn	usual subcut	Inexpensive Highly sedating; often useful when others have failed	- Difficult to obtain from community pharmacies - Multiple drug interactions - Tachyphylaxis
Propofol	20-50 mg (may need to be repeated)		0.3-3.0 mg/kg/hr	IV	Rapidly titrated	- Expensive - Probable anaesthetist consult - IV access required

(2) Muller-Busch HC. Outcome With Sedation in Palliative Care. Forum – European Association for Palliative Care Sep;2007

Appendix III

NUTRITION/HYDRATION
“The ethical aspects of sedation are separate and distinct from the ethical aspects of hydration; thus, the decision whether or not to withhold or withdraw nutrition and/or hydration should be discussed separately from the decision to initiate PST.” (3)

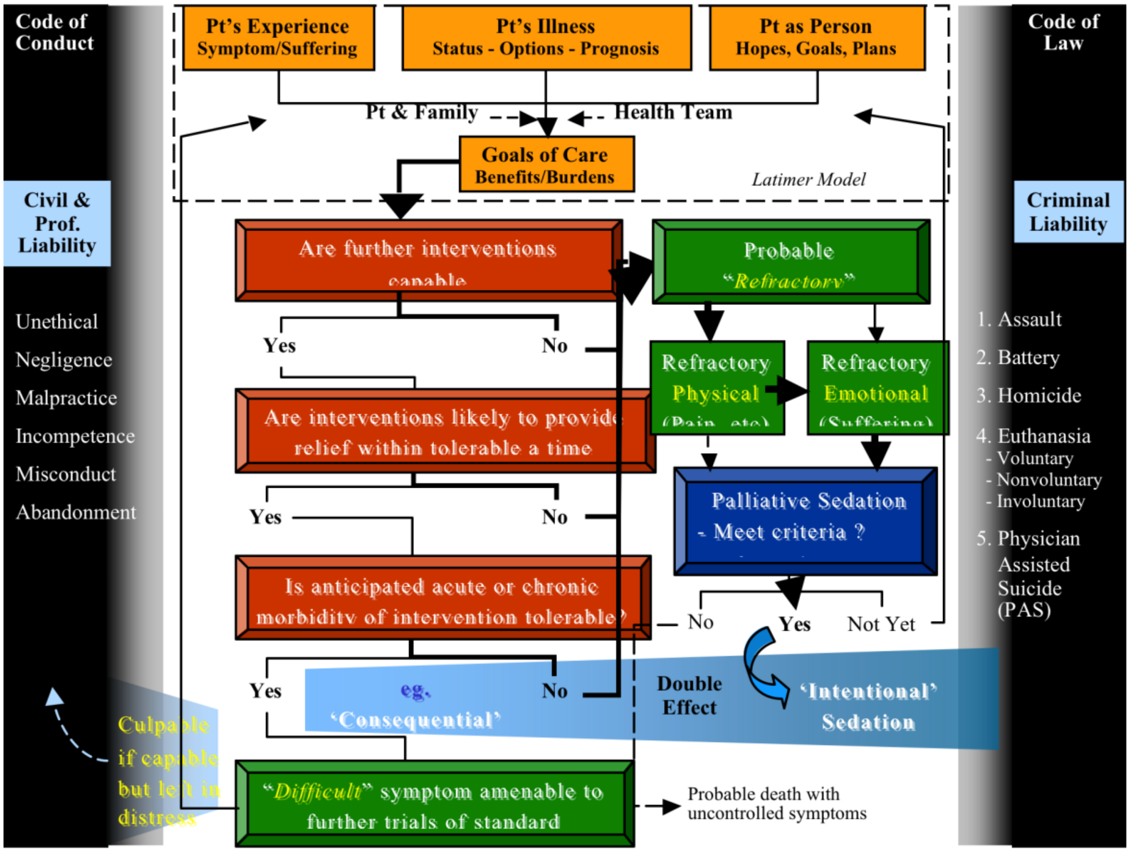
Task Group recommendation:

- Consider if transient sedation or patient has a life-expectancy of >1-2 weeks.
- Artificial hydration probably not to be initiated in the imminently dying.

(1) De Graeff A, Dean M. Palliative Sedation Therapy in the Last Weeks of Life: A Literature Review and Recommendations for Standards. Journal of Palliative Medicine 2007; 10: 67-85

Appendix IV

PS Table Framework and Guideline for Palliative Sedation (4)



(2) Downing, M, Wainwright W. Medical Care of the Dying. 2006 Victoria Hospice Society Learning Center for Palliative Ca
Canada 2002; 605-639

Appendix V – PS Decision Making Framework from "Medical Care of the Dying" (2)

Framework and Guideline for Use of Palliative Sedation

Goals for Relief of Intractable Symptoms

- To provide relief of intractable distress in the dying through use of palliative sedation and other treatment, as requested by the patient, when no other interventions will provide acceptable comfort
- To provide palliative sedation within an acceptable ethical (96) and legal context in the use of sedation at end-of-life, recognizing clear differences between Palliative Sedation (PS) and Physician-Assisted Suicide (PAS)
- To assess patient's symptoms and suffering to differentiate difficult but treatable issues from those which are refractory to treatment or which have unacceptable consequences to the patient in attaining relief
- To respect patient's desires and requests after considering potential advantages and disadvantages of palliative sedation
- To distinguish between intentional Palliative Sedation (PS) and Consequential Sedation (CS)
- To assess, assist and support families in understanding and coping with issues related to sedation at end-of-life
- To develop care plan with and receive orders from the Palliative Care Physician, Family Physician or other specialist
- To monitor the effects of PS, if implemented, and adjust accordingly within care plan

Assessment and Investigation (Record assessment results for each category in patient chart)

1. Use Latimer's **ethical** decision-making model (53) for assessment in three areas as follows:
   a. Illness – functional status (PPS)(28); extent of disease; available treatment options if any; prognosis; nearness to death
   b. Symptoms and suffering – degree of pain, etc. on NRS 0–10/10 scale; impact on quality of life; existential or other suffering (69,99,109–112), demoralization (97), loss of dignity (98)
   c. Person – goals, desires, hopes, plans in light of current symptoms and future; advanced care plan if completed
2. Assess **decision-making** capacity of patient and determine Temporary Substitute Decision-Maker (TSDM)
3. **'Symptom'** assessment for possible refractory symptoms should be carried out by a specialist skilled in symptomatic management (67, 100). The Palliative Care Physician (PCP) will determine whether a difficult (treatable) or refractory symptom exists through appropriate physical, treatment history, possible investigations, available options, etc; and also if available treatment could relieve distress within acceptable time frame and with acceptable adverse effects as determined by patient. If no palliative specialist is available, the physician is advised to discuss by phone with PCP
4. **'Suffering'** assessment by inter-professional team as available and appropriate by PCP, Family physician, nursing, counselling, spiritual care and other (as appropriate) including severity, type(s) of suffering, possible interventions and outcomes as acceptable to patient – respecting right of privacy, confidentiality, non-intrusiveness
5. **Family** assessment of impact on them of continuing current care without full symptom relief, as well as potential impact of using palliative sedation for treatment
6. Determination of **other** relevant issues and consequences** including temporary vs. sustained PS, no resuscitation, hydration, etc. (N.B. see discussion in text)
7. Clarity among all that **resuscitation** would not be appropriate nor carried out if and when the patient dies***

Recording

1. PCP will record all relevant factors above to provide clear rationale, process, ethical and acceptable medical process
2. Second medical consultation by another PCP, Family Physician or specialist is advisable to corroborate refractory state

PS Criteria for Inclusion and Exclusion

INCLUSION Criteria, based on BC Ministry of Attorney General Policy (101)

- Administration of drugs designed for pain control in dosages which the physician knows will hasten death … is based upon intention, in the case of palliative care to ease pain, which has effect of hastening death, whereas in assisted suicide intent is undeniably to cause death
- Terminally ill and near death with no hope of recovery
- Ethical medical practices are followed
- Patient's condition associated with severe and unrelenting suffering
- Registered with a palliative care program or palliative care treatment plan

EXCLUSION Criteria

- Does not meet all five inclusion criteria for PS
- Not requested or evidence of ambivalence
- If TSDM requesting, lack of clarity that acting as patient would want, given current situation
- Misperceptions persist e.g. thinking PS is in fact PAS

Treatment and Monitoring

1. PCP responsible for final **decision** to proceed, after consultation with team and final informed request by patient or TSDM
2. There are several **drugs** which can be used for palliative sedation as seen in PS Table 2, with midazolam being the most common at 50%, methotrimeprazine 30% and lorazepam 22%(66,102). In some cases, a combination of drugs such as midazolam and phenobarbital may be required (103,104)
3. Medication orders for PS to include drug(s), dose, route, frequency and specific method for titration including possible use of dose range and use of PRNs or BTDs
4. Dosage needs to be **proportionate** and commensurate with distress but also caution in using too low of a dose which could disinhibit or aggravate restlessness, confusion or provide only partial relief (103,113)
5. PCP and nursing to continually **monitor** degree of sedation and relief obtained, and adjust dosing accordingly for effective but not excessive sedation. Monitor sedation level with tool such as Communication Capacity Scale (121,122) or RAAS (123)
6. Attend to **other** factors such as pain, skin care, incontinence, respiratory secretions, fever, etc. as well as support to family
7. PCP and nursing to determine which other medications for symptom relief to be continued or stopped
8. Frequent **discussion** by health professional team with the TSDM and family is important for reassurance, support, feedback and ongoing decision-making