

An Exploration of Palliative Care Providers' Lived Experiences of Implementing the
Gold Standards Framework in Oncology Care from a Hospital-Based, Outpatient
Palliative Care Setting.

by

Melanie Dissanayake

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Abstract

Palliative care aims to address the needs of patients and family members who are dealing with a life-altering illness. The Gold Standards Framework (GSF), consisting of 7 key components (Communication, Coordination, Control of Symptoms, Continuity of Care, Continued Learning, Carer Support and Care in the Dying Phase), is a tool implemented in palliative care to ensure such objectives are met. Therefore, through an in-depth qualitative analysis, this thesis examined the lived experiences of 6 palliative care providers on implementing the GSF in oncology care from a hospital-based, outpatient palliative care setting. The GSF facilitated the interpretation of the results according to each component of the framework and 11 subthemes emerged. This study highlights the facilitators and barriers that impact the implementation of the GSF in a hospital-based, outpatient setting. This study has implications for palliative care practice, policy, education and research to help strengthen the development of sustainable palliative care.

Keywords: cancer, palliative care, Gold Standards Framework, healthcare providers, palliative

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An Exploration of Palliative Care Providers' Lived Experiences of Implementing the
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Chapter One: Introduction

Dealing with a life-altering illness, such as cancer, can be an extremely terrifying experience for patients, as there can be physical, spiritual and psychosocial suffering (Rome, Luminais, Bourgeois, & Blais, 2011). The patients' experience of illness also has a profound impact on family members who are affected by a variety of challenges whether directly or indirectly related to a patient's illness (Rome et al., 2011). One existing approach to dealing with cancer is palliative care, a specialized type of health care that is directed at addressing the overall needs of patients and family members involved with a life-altering illness (Clark, 2007; Meier, 2006; Sepulveda, Martin, Yoshida, & Ulrich, 2002). Palliative care is defined as medical care that focuses on improving the quality of a patient's life by targeting the spiritual, physical and psychosocial aspects of care with the support of a multidisciplinary health team (Clark, 2007; Meier, 2006; Sepulveda et al., 2002). Palliative care was chiefly developed for patients with advanced cancer (Canadian Cancer Society (CCS), 2016). Therefore, this type of care is largely delivered to approximately 80-85% of patients with advanced stages of cancer (Cancer Care Ontario (CCO), 2016). The primary goal of palliative care is to relieve the sufferings of patients through anticipating, preventing, diagnosing and treating symptoms that may be experienced, while simultaneously providing support to family members on determining what type of medical care is appropriate, as aligned with the patients' care goals (Clark, 2007; Meier, 2006; Sepulveda et al, 2002). Additionally,

through such initiatives of support, palliative care providers aspire to optimize the overall quality of life for patients who are approaching the end-of-life, and family members who may experience the burdens associated to this process. (Badger et al., 2012; Walshe, Caress, Chew-Graham, & Todd 2008).

1.1 Background on the Gold Standards Framework

In order to meet the various objectives of palliative care, there are tools in place for palliative care providers so optimized levels of care for patients and family members can be achieved. Additionally, such palliative care tools implemented to target optimal delivery of care are provided by CCO, Ontario's governmental advisor on cancer systems, which is recognized for improving cancer services through innovation and evidenced-based approaches in cancer care (CCO, 2016; Evans et al., 2015). CCO is responsible for fostering integrated cancer care and aims to target optimal care through: a.) driving endless improvement for the prevention and screening of cancer, b) overseeing funding (\$1.5 billion) for hospitals along with other cancer care providers, c) collaborating with cancer care professionals to develop and execute the highest quality improvements and measures in cancer care and, d) establishing standards/guidelines for improved delivery of patient care (CCO, 2017; Evans et al., 2015). Currently, one prominent tool instructed by CCO for implementation in palliative care by palliative care providers is the Gold Standards Framework (GSF) (CCO, 2016).

The GSF (further explored in the literature review) is a systematic, evidenced-based guideline to direct frontline care providers on how to implement palliative care (Badger et al., 2012; Dale et al., 2009; Klinger, Howell, Zakus, & Deber, 2014; Shaw, Clifford, Thomas, & Meehan, 2010). The GSF is defined within the literature as a model

that enables good practice, and provides the right protocols to raise the level of care to the highest standard for all (Badger et al., 2012; Walshe et al., 2008).

This framework is comprised of seven key components (7C's), including: Communication, Coordination, Control of symptoms, Continuity, Continued learning, Carer support and Care in the dying phase (Hansford & Meehan, 2007). Consequently, the GSF is considered to be highly effective because the incorporation of these key components within palliative care impact the organization and quality of care for patients who are approaching the end-of-life (Shaw et al., 2010).

1.1.1 Gold Standards Framework in Palliative Care Practice

A vast majority of the literature on the implementation of the GSF in palliative care state there are various benefits for both palliative care providers who implement the components of the GSF and patients who receive GSF guided palliative care. For palliative care providers, the two most common areas where improvement has been found is in communication and coordination, notably between all professional disciplines involved in the comprehensive approach entailed in palliative care (Hansford & Meehan, 2007; Munday, Mahmood, Dale, & King, 2007; Walshe et al., 2008). In relation to patients, much of the literature states that there is an improvement in patient outcomes with respect to a “personalized approach” to care (further explored in the literature review) (Hansford & Meehan, 2007; Walshe et al., 2008). Although there have been benefits associated with utilizing the GSF as a tool in palliative care, studies indicate that some challenges may arise if healthcare practices do not implement the GSF to the full extent. Consequently, there is a chance that ideal outcomes associated with implementing

the GSF may not be achieved (Badger et al., 2012; Klinger et al., 2014; Shaw et al., 2010).

1.2 Current Gaps and Significance

Although there is a body of literature on the implementation of the GSF within hospital and community settings in palliative care, much of the literature conducted on implementing the GSF has been completed outside of Canada. Specifically, most studies have been completed within the United Kingdom, possibly due to the framework being chiefly developed there. Although the existing literature may be informational to Canadian practices who desire to implement the GSF in a standardized manner, healthcare systems in the UK and Canada may vary. As a result, the implementation of the GSF within a Canadian healthcare setting may differ from the implementation of the GSF within a UK healthcare setting, due to varying organizational factors. A few studies were completed on the delivery of palliative care in an outpatient setting within Canada. However, there are no studies which focus on the perspectives of palliative care providers regarding the implementation of the GSF from a hospital-based, outpatient palliative care setting, in the Durham Region. Most importantly, CCO, a partner with Lakeridge Health (LH), has instituted the implementation of this tool in all settings of palliative care, therefore exploration into the experiences of implementing this tool is necessary, to examine its impact.

It is important to understand palliative care providers' experiences of implementing the GSF in relation to the delivery of outpatient palliative care within a hospital setting. Palliative care providers are responsible for providing care to patients who face a life-altering illness such as cancer, and therefore can use the GSF as a

guideline to deliver care at the highest standard possible (Walshe et al., 2008). Many palliative care research studies indicate that patients prefer to die at home rather than within an inpatient (hospital/clinical) setting (Gomes et al., 2012; Gomes, Calazani, Gysels, Hall, & Higginson, 2013; Wheatly & Baker, 2007). However, although outpatient palliative care services continue to operate, it is estimated that 64.9% of patients diagnosed with cancer still spend their remaining days of life and/or die within hospital care (Health Quality Ontario, 2016).

Therefore, gaining insight into palliative care providers' experiences of implementing the GSF will further inform an understanding of barriers to and facilitators of implementation, in a hospital-based, outpatient palliative care setting. Additionally, insight from palliative care providers' experiences into how practice might be improved will help teams within these settings better utilize this framework to strengthen the delivery of outpatient palliative care. This will advance the state of knowledge in palliative care because it will not only bring awareness to the experiences of palliative care providers who administer this type of care, but also build knowledge into ways these experiences can be improved. Consequently, both patients and family members may benefit from positive developments. This will aid in increasing the levels of care that is being delivered to patients and also provide efficient support for family members who may be burdened and worried about caring for a loved one alone.

Research studies also indicate that optimal palliative care services within hospitals have the potential to accrue large savings (Fine, 2004; Hodgson, 2012). In comparison to regular hospital care, it is estimated that hospital-based, palliative care programs operated by palliative care teams can save the Canadian healthcare system around \$7,000 to

\$8,000 dollars per patient (Hodgson, 2012). The reason behind this is hospital-based, palliative care services can impact the cost of end-of-life care by a 50% reduction through: eliminating duplicated diagnostic testing, decreasing Intensive Care Unit admissions, and reducing interventional procedures (Hodgson, 2012). This can be highly advantageous to the Canadian healthcare system, as these savings can be allocated to different aspects of healthcare, which are in need of more funding (Hodgson, 2012). Therefore, this may also identify the importance of having the availability of excellent hospital-based, outpatient palliative care programs. Subsequently, this can help increase the need for policy and funding initiatives to continually support this in Ontario.

As the aging population continues to accelerate due to the era of the baby boomers, a rapid increase in deaths including those related to cancer, is to be expected. There are now more demands that need to be met by palliative care teams, especially as it is estimated that there will be a 40% projected increase in cancer diagnoses over the next 15 years (CCS, 2016; Fine, 2004; Gott & Ingleton, 2011; Wilson & Woytowich, 2014). As this occurs, many more individuals will be affected by cancer and may require the use of hospital-based, outpatient palliative care services administered by outpatient palliative care teams (CCO, 2016; Fine, 2004). Therefore, this study focuses on the importance of understanding how the GSF is executed within a hospital-based, outpatient palliative care from palliative care providers' perspectives. Consequently, this can strengthen the delivery of care provided by hospital-based, outpatient palliative care teams, benefit patients by optimizing levels of care through enhancing their quality of life and lastly, have a tremendous financial benefit on the Canadian healthcare system (Fine, 2004; Hansford & Meehan, 2007; Hodgson, 2012).

1.3 Research Question

As a result of the existing gaps within Canadian literature on the implementation of the Gold Standards Framework in palliative care, the research question is: What are the lived experiences of palliative care providers in implementing the Gold Standards Framework in oncology care, from a hospital-based, outpatient palliative care setting?

Sub questions will primarily focus on each palliative care providers' experiences in relation to: (a) their experiences in implementing the GSF in hospital-based, outpatient care, (b) how improvements made from the GSF are sustained, (c) factors (barriers and facilitators) that may impact how the GSF is practically implemented in hospital-based, outpatient palliative care, and (d) if needed, any recommendations to practically support the implementation of the GSF in relation to the delivery of optimal palliative care from a hospital-based, outpatient setting.

1.4 Purpose of the Study

The primary purpose of this study is to explore the lived experiences of palliative care providers in implementing the GSF in oncology care, from a hospital-based, outpatient palliative care setting. Through the conceptual underpinnings of the GSF (further discussed in Chapter 2), and the methodology of Interpretative Phenomenological Analysis (further discussed in Chapter 3), this qualitative study will provide insight into the experiences of palliative care providers and identify both the facilitators to and barriers of implementing the GSF within the context of a Canadian healthcare setting. Additionally, the expectation of this study is to help determine how the 7 core components of the GSF can be executed at optimal levels by palliative care providers to not only benefit their daily experiences in delivering hospital-based,

outpatient palliative care but to also support the ideal delivery of care for patients seeking this approach.

1.5 Summary of Introduction

To summarize, I provided a brief overview of the GSF and the research question for this study in Chapter One. In Chapter Two, I have described the concepts presented in Chapter One by imparting a most up-to-date review of the supporting literature. Then in Chapter 3, I have described the methodology and methods taken to conduct this study, by providing details about characteristics of the sample, data collection and data analysis. In Chapter Four, I have presented the findings of the study. I have reviewed and discussed the findings in depth, in relation to the theoretical underpinnings of the GSF in Chapter Five. Finally, in Chapter Six, I have provided a conclusion and explained the study's strengths and limitations along with implications for practice, policy, education and research.

Chapter Two: Literature Review

An in-depth analysis of numerous peer reviewed articles and grey literature provided evidence to support this study. The primary goal of the literature review is to analyze current findings about the phenomenon of interest and critically assess such findings in relation to the perspective taken by the researcher. Firstly, I provide the search and selection criteria. Then I provide literature pertaining to both palliative care and the GSF, and lastly, a summary of the major findings.

2.1 Search and Selection Criteria

Search engines that were used to gather all relevant articles related to palliative care and the GSF included PubMed and Scholars Portal Journal. The terms used within both search engines included: Gold Standards Framework, palliative, palliative care, cancer, end-of-life care, palliative care providers, and supportive care. These search engines were chosen to not only provide an easier way to access peer-reviewed journal articles from a variety of scholarly organizations, but also provide a large selection of articles relevant to the research topic. PubMed provided sources, which contained similar key words that were used to locate peer reviewed articles. Apart from the keywords that were initially used, terms associated with the research topic were identified to grasp a clearer understanding of palliative care in the literature. Scholars Portal Journal provided a variety of credible sources that went beyond the keywords that were used. This enabled me to identify peer reviewed journals that had different perspectives on the research topic in comparison to PubMed. The keywords that were carefully chosen had specific relevance to the research topic. Therefore, the use of these keywords enabled my ability to find a vast majority of relevant data pertaining to the proposed research question. The

goal was to make sure that no important articles were missed due to a lack of specificity in the search process. The inclusion criteria for the selection of articles included: articles relevant to populations in palliative care, journal articles published in English, inclusion of both perspectives namely palliative care providers and/or palliative patients, palliative care in hospitals, nursing homes and primary care trusts, GSF literature from the year 2002 onwards and patients diagnosed with the chronic ailment of cancer alone. The exclusion criteria included: essays, common diseases in palliative care not including cancer, and articles published in languages other than English.

The rationale behind choosing the inclusion criteria was to enhance my ability to gain a clearer understanding of the literature as pertaining to the research question. With relevance to the GSF, only reviewing published articles after the year 2002 was significant, as this framework was first implemented throughout palliative care beginning in 2001 and onwards. There was also an importance in including articles surrounding both the perspectives of palliative care providers and patients involved with palliative care, the GSF, and cancer, as it enabled me to retrieve much more literature for my review in relation to the research topic. In this literature review, essays were not considered, as empirical evidence was desired. Therefore, only published and/or peer reviewed articles along with grey literature on the topic of research were examined. For purpose of comprehension, maintaining specificity to the English language was also critical. Therefore, published articles written in other languages were excluded from this literature review. Similarly, articles published on palliative care in relation to chronic diseases other than cancer such as dementia and chronic obstructive pulmonary disease were excluded, as the primary disease of focus was cancer. Overall, the articles used

within this literature review were selected to help increase knowledge on the topic, build the overall argument, and most importantly to construct the literature review in a logical and systematic way.

In the next section, I provide an overview of the current literature on palliative care, the GSF, and its implementation in palliative care practice.

2.2 Palliative Care

2.2.1 Background/Evolution of Palliative Care

Palliative care evolved from the “hospice” movement guided by Dame Cicely Saunders (Kastenbaum, 2009). In the 1960’s Saunders, a medical nurse, social worker and physician by profession, emphasized the importance of assessing end-of-life care needs that patients with advanced malignant disease were experiencing. In the early 1950’s professional interest in cancer care chiefly concentrated on curative treatments (Richmond, 2005). As a result, patients dying from advanced stages of cancer commonly experienced severe neglect as abandonment by physicians was common when curative treatments options were no longer available. For this reason, Saunders opened St. Christopher’s hospice, the world’s first ever modern hospice in the United Kingdom in 1967 (Humphreys, 2002). The purpose of this institution was to combine teaching, research and clinical care in aiding the advancement of pain management for patients in the dying phase of their illness. Saunders was a professional in various healthcare disciplines (nurse, social worker, and physician) therefore she was liberated from viewing a patient through one healthcare provider standpoint. Consequently, her perspective on hospice care highlighted the importance of care contributions from providers of diverse healthcare backgrounds. Saunders’ greatest contribution is the idea that “total pain” is

inclusive of every dimension where distress can occur across physical, social, emotional, and spiritual dimensions, a concept that is now considered as the very essence of palliative care (Richmond, 2005).

As the evolution of the hospice movement continued to accelerate, expansion at international levels occurred as well. Within North America, specifically Canada, a urologic-oncologist physician, Dr. Balfour Mount took an interest in the alternative approach to the typical medical management for cancer care (Kastenbaum, 2009). In the 1970's, Dr. Balfour Mount suggested the term palliative care as derived from the Latin word 'pallium,' meaning cloak. The etymology of the word from his perspective meant, "to improve the quality of." The term palliative care also was introduced in Canada at a similar time when the importance of prioritizing symptom and pain management was being identified in various Canadian cancer treatment centers. Expansion of palliative care continued to occur and a national body was founded in 1991 named the Canadian Palliative Care Association and presently identified as the Canadian Hospice Palliative Care Association. Dr. Balfour Mount's contributions to palliative care enabled a global fight for palliative care service provisions within hospitals and most importantly in home settings. More than 40 years later since the conception of the term "palliative care," it is officially considered a right for every Canadian to die in the utmost comfort, away from physical, psychosocial, spiritual and emotional distress through the support of compassionate and respectful care (Richmond, 2005). Palliative care is the provision of interventions to reduce suffering and has been proven to be beneficial to patients diagnosed with any life-limiting illness. Consequently, Canada is currently recognized globally as a leader in supporting the provision of palliative care services.

2.2.2 Definition of Palliative Care

As stated above, palliative care is defined as a type of medical care intended to relieve suffering and impart support towards patients facing a life limiting disease by targeting the spiritual, physical, and psychosocial aspects of care, through a multidisciplinary palliative care approach (Clark, 2007; Meier, 2006; Spulveda, Marlin, Yoshida, & Ullrich, 2002)

2.3 Palliative Care and Cancer

Presently, the chronic illness of cancer exists as the leading cause of death within Canada, i.e., approximately 30% of all Canadian deaths each year are related to cancer (CCS, 2016). It is estimated that 2 out of every 5 Canadians will be diagnosed with cancer while the probability of death stands at 1 out of every 4 individuals (CCS, 2016). Cancer as a terminal illness can be excruciatingly debilitating on an individual because of associated physical, psychosocial and emotional consequences (Clark, 2007). When dealing with such a disease, there is strong evidence to support that palliative care helps individuals with life-altering illnesses on a comprehensive level (Hansford & Meehan, 2007; Munday et al., 2007; Walshe et al., 2008). The purpose of palliative care is to provide an enhanced quality of life for patients and family members journeying through the illness trajectory.

As declared by World Health Organization, the intent of palliative care is to: assert life while considering the process of dying as normal, incorporate the spiritual and psychosocial dimensions into patients journey of systematic care, positively impact the trajectory of illness and enrich the quality of life, offer methods of pain relief and comfort from symptoms that may be distressing and lastly, offer a system of support for patients

and family members to cope with illness and bereavement (Sepulveda et al., 2002). Consequently, palliative care has the power to influence the chances of patient survival while also enabling patients to receive a comfortable and peaceful death if desired (Brurera & Yennurajalingam, 2012). There are benefits associated with including palliative care in cancer care. Pain and symptom management along with addressing psychosocial dimensions are considered to be helpful for patients diagnosed with cancer.

2.3.1 Pain and symptom management

Pain is considered a very stressful experience. Therefore, the alleviation of suffering from pain is considered the primary goal of palliative care when attending to patients diagnosed with cancer (Kastenbaum, 2009; Temel et al., 2010). A normal accompaniment of experiencing cancer is pain as 20-50% of individuals diagnosed with cancer endure pain in the period of diagnosis and about 75% at the terminal stage (Plaisia & Syrigos, 2005). Common pain symptoms experienced by patients with cancer include: nausea, vomiting, delirium, breathlessness and fatigue (Fineberg, Wegner, & Brown-Saltzman, 2006; Solano, Gomes, & Higginson, 2006; Temel et al., 2010). The superior knowledge in pain control along with the optimal use of medications has developed over the years and has been a contributing factor to success in palliative care treatment for pain (Kastenbaum, 2009). A systematic literature review conducted by Higginson & Evans (2010) was completed to assess the efficiency of specialist palliative care teams in improving the health outcomes of patients diagnosed with advanced stages of cancer. These authors indicated that specialist palliative care teams were the most effective for improving patient outcomes in the domains of anxiety, pain and symptom control, and reduced hospital admissions. Similarly, a randomized control trial conducted by Temel et

al. (2010) aimed to assess the effectiveness of introducing palliative care early within the illness trajectory for patients diagnosed with metastatic non-small-cell lung cancer. From 2006 to 2009, patients with newly diagnosed non-small-cell lung cancer were given palliative care service and oncologic care in comparison to a control group who only received oncologic care. These researchers found that patients who received early palliative care reported better symptom management, a higher survival rate (3 months) and an improvement in quality of life and mood, in comparison to those who only had oncologic care.

2.3.2 Psychosocial Care

To accomplish the provision of good palliative care, along with pain and symptom management, it is imperative that the psychosocial needs of individuals diagnosed with cancer, also are addressed (Kastenbaum, 2009; Mistry, Bainbridge, Bryant, Tan Toyofuku, & Seow, 2015; Rome et al., 2011; Sampson, Finlay, Byrne, Snow, & Nelson, 2014). The psychosocial care of an individual is inclusive of psychological experiences, values, culture, spiritual beliefs and social factors (Legg, 2010). Approaching these domains are inherent to patients' ability to achieve a higher level of contentment when dealing with the illness of cancer. The psychosocial state of a patient can influence their sensitivity to physical pain (Kastenbaum, 2009). Additionally, effective care management for a patient's psychosocial domains can help reduce the stress of other cancer related symptoms. Therefore, palliative care aims to address these domains in order to help patients receive the highest form of care when dealing with cancer (Kastenbaum, 2009; Rome et al., 2011; Sampson et al., 2014). This was supported by a qualitative study conducted by Mistry et al. (2015) which examined the perspectives

of palliative care providers on end-of-life care. Through semi-structured interviews, the authors purposed to delineate what matters the most when delivering optimal care for those approaching the end-of-life. Mistry et al. (2015) revealed that addressing a patient's non-physical needs by means of having the patient's wishes fulfilled, was the highest response from palliative care providers on achieving the best quality of care. The authors concluded that palliative care providers must consistently: recognize a patient focused care pathway, maintain a comprehensive outlook on care and be dedicated to a patient's journey, as this plays a critical role in supporting a positive experience for those approaching the end of life (Mistry et al., 2015). Similarly, these results were supported by another study conducted by Sampson et al. (2014) which, aimed to establish benefits associated to experiencing palliative care from patients' perspectives. This was done through the analysis of free text responses from patients detailing their comprehensive experiences in palliative care. The authors indicated that there was an overall positive response to administering palliative care. More importantly, the authors indicated that the most significant aspect of care felt by patients was the emotional care experience with domains relative to restorative care, renewal, refuge, and respect (Sampson et al., 2014).

In summary, it is important to note that palliative care includes addressing all aspects of care relative to both physical and psychosocial dimensions of a person's life. Additionally this is accomplished because of the unique multidisciplinary approach palliative care incorporates relative to a comprehensive delivery of care (Rome et al., 2011; Sampson et al., 2014; Tuggey & Lewin, 2014)

2.4 Palliative Care Delivery

2.4.1. A Multidisciplinary Approach

As indicated by many studies, a multidisciplinary approach is an essential component of palliative care for patients diagnosed with cancer (Chirgwin, et al., 2010; Sampson et al., 2014; Tuggey & Lewin, 2014). Such an approach involves a set team of palliative care specialists from various healthcare backgrounds, who are trained to provide the best possible methods to influence the quality of life for patients desiring palliative care (Brurera & Yennurajalingam, 2012; Horovath, et al., 2010; Tuggey & Lewin, 2014). Although the composition of palliative care teams may vary between institutions, specialist palliative care teams may consist of a primary oncologist, palliative care trained registered nurse, social workers, a pharmacist, an occupational therapist, a physiotherapist, a grief counsellor and a chaplain (Brurera & Yennurajalingam, 2012; Tuggey & Lewin, 2014). A multidisciplinary approach to care by clinicians include: to investigate and discuss appropriate treatment options for patients, recognize patients care goals and enable continuing education on and/or topics associated to palliative care among healthcare professionals. In studies examining the treatment of invasive cancers, multidisciplinary care have been shown to have several benefits. A retrospective study conducted by Dillman & Chico (2005) analyzed cancer survival rates of patients who experienced multidisciplinary care at a large community hospital and those that did not. In a before (1986-1991) and after (1992-1999) series, the study indicated that 5 year survival rates for invasive cancers (breast, lung, prostate) increased between consecutive periods from 63% to 71%. The researchers reported that the addition of various professional disciplines involved in patients' care impacted such rates. Similarly, another retrospective study conducted by Stephens et al. (2006) looked at the impact of a

multidisciplinary approach on surgical outcomes of esophageal cancer. The authors indicated that individuals who received a multidisciplinary approach to care had a lower operative mortality rate along with a higher survival rate in comparison to groups who experienced care at the hands of surgeons working independently. Therefore, it is important to note that the incorporation of various professionals among healthcare disciplines not only brings more knowledge and complementary skills to complex cases but it also is instrumental in delivering comprehensive care to influence ideal patient outcomes of providing high quality care in congruence with patients' wishes (Stephens et al., 2006).

Through a multidisciplinary approach the physical, emotional, psychosocial, and spiritual support of a patient's care are recognized and addressed (Horovath et al., 2010; Silbermann et al., 2013; Spruyt, 2014; Tuggey & Lewin, 2014). The unity of diverse backgrounds involving clinicians within a palliative care team has a larger potential to strengthen comprehensive care because complex aspects of patient care can be addressed through team communication (Chirgwin, et al., 2010; Dillman & Chico, 2005; Hong, Wright, Gagliardi, & Paszat, 2010; Sampson et al., 2014; Tuggey & Lewin, 2014). Subsequently, multidisciplinary team meetings have been considered beneficial to generating comprehensive multidisciplinary care for patients (Chirgwin et al., 2010; Horovath et al., 2010; Silbermann et al., 2013; Spruyt, 2014; Tuggey & Lewin, 2014). A study conducted by Chirgwin et al. (2010) aimed to evaluate the impact of multidisciplinary team meetings on performance outcomes for patients diagnosed with advanced breast cancer. Through questionnaires, multidisciplinary team members from two health services for advanced breast cancer were instructed to rate the performance of

multidisciplinary team meetings on patient care from the perspectives of five different areas including: palliative care, medical management, psychosocial care, community care and benefits gained for multidisciplinary team members (Chirgwin et al., 2010). Results by Chirgwin et al. (2010) showed that a majority of members rated the use of multidisciplinary team meetings to be highly contributive to medical management and palliative care. Another interesting finding by these authors identified that most multidisciplinary team members viewed these team meetings as being important for patients in relation to the awareness of various services available, support in care, pertinent referrals and most importantly referral efficiency. The authors concluded that the involvement of multidisciplinary team meetings in cancer care provides an important contribution to the logistics behind comprehensive support for patients in palliative care (Chirgwin et al., 2010).

It is also important to note that all healthcare professionals involved in primary care should be aware of initiating discussions around palliative care towards patients who may require it (Shadd, et al., 2013). Although palliative care may most often take a multidisciplinary approach with palliative care specialists, resorting to specialized palliative care teams may limit the capacity of palliative care delivery for many patients who are not able to have access to these teams (rural areas). Ensuring that all members in primary care are able to support the delivery of palliative care at its initial stages can help patients' jumpstart their journey to experiencing exceptional end-of-life care (Shadd, et al., 2013). Education on palliative care for all primary caregivers must be considered essential to enable this (Pallium Canada (PC), 2018).

2.4.2 Common Settings of Palliative Care Delivery

In Ontario, the delivery of palliative care can occur in multiple settings (Seow, Barbera, Howell, & Dy, 2010). Depending on the situation of a patient, palliative care can be delivered in hospitals (inpatient or outpatient), residential hospices and patient homes (Government of Canada (GOC), 2016). In most cases, hospital-based, inpatient palliative care is designated for patients who are approaching the end of life with 3-6 months to live, and choose to die within a hospital setting (Canadian Hospice Palliative Care Association [CHPCA], 2014). Although hospitals are considered institutions able to provide immediate assistance, such places are not the ideal locations for comfort in the end-of-life process (GOC, 2016). For this purpose, hospital-based, outpatient palliative care is available for patients. Care is provided within a clinic like setting for patients who desire to live at home while receiving palliative care but also have the option to visit a hospital facility when seeking out additional help if necessary (CHPCA, 2014; LH, 2017). The main goal of such clinics is managing physical and emotional symptoms (anxiety/depression), assisting with community supports, and promoting the provision of advanced care planning (CHPCA, 2014; LH, 2017). Residential hospices also are available; they provide a home like setting for individuals facing a terminal illness, but patients still have access to constant care by professionals (e.g. nurse, physician, social work) when needed (CHPCA, 2014). The largest preference for the delivery of palliative care is within a patient's home; 75% of Canadians prefer to end life within their homes (CHPCA, 2014; Health Quality Ontario, 2016). Not only is this approach beneficial to patients but to the Canadian government as the cost of palliative care provision in the home (\$4,700) is approximately one quarter of the cost compared to acute hospital care

costs (\$19,000) (CHPCA, 2014). However, achieving optimal care for individuals in a home setting can sometimes be problematic, since receiving care regularly can vary due to a high dependency on community supports/organizations (CHPCA, 2014).

2.4.3 Community Supports for Cancer Care in Ontario

Within Ontario, there are 14 geographically outlined Local Health Integration Networks (LHIN) where healthcare services are organized and delivered to patients based on their location of residence (DeMiglio & Williams, 2014). Formerly, each LHIN was associated with a community care access center (CCAC); funding was designated to CCAC's within particular geographic areas from the Ministry of Health and Long Term Care (DeMiglio & Williams, 2014). With this funding, CCAC's were responsible for providing care support within the community, for example, patients diagnosed with cancer who wanted to receive palliative care support within a home setting (DeMiglio & Williams, 2014; Evans et al., 2015). Subsequently, most individuals diagnosed with cancer, who are interested in receiving outpatient palliative care usually depend on CCAC for home care support (CHPCA, 2014). In December 2016, *The Patients First Act* was passed with implementations and transitions beginning in June of 2017. The formation of this *Act* enables the coordination and provision of home care (formerly CCAC's responsibility) to be solely under the responsibility of each LHIN (LHIN, 2017). The main purpose behind passing *The Patients First Act* is to achieve the provision of a tightly coordinated and integrated, patient-centered health care system for individuals seeking care, while also eliminating excess administrative costs with idea that these savings be reinvested into patient care (LHIN, 2017).

However, it is important to note that many organizations supporting cancer care (CCO, LHIN, and Hospice Palliative Care Ontario (HPCO)) still continue to operate in silos. The delivery of optimal integrated cancer care relies highly on the communication and coordination between the hospital and the various cancer care organizations (Evans et al., 2015). Additionally, most of the time, hospital-based, outpatient palliative care services assist with the coordination of these supports (CHPCA, 2014; LH, 2017). Problematic issues can arise as many of these organizations operate in silos, thereby resulting in inadequate person-centered care approaches (DeMiglio & Williams, 2014; Evans et al., 2015). Therefore, it is vital that all organizations associated with cancer care work in a collaborative and coordinated manner to influence high impact palliative care service delivery. This can be achieved through remarkable integration across palliative care providers, implementing framework/models to maintain universal standards of care, and remaining focused on person-centered approaches,

2.5 Common Frameworks/Models Used Within the Delivery of Palliative Care

There are various palliative care model/frameworks available for palliative care providers to utilize in order to support the most efficient and successful delivery of care towards patients in need. The most common frameworks implemented in palliative care are outlined below.

2.5.1 TLC Model of Palliative Care in the Elderly

The TLC model of palliative care in the elderly was designed specifically for the older adult seeking palliative care as a form of healthcare for a life-altering illness (Jerant, Azari, Nesbitt & Meyers, 2004). In this model of palliative care, the main objective is to ameliorate burdens associated with spiritual and physical suffering during

the aging process (Jerant et al., 2004). A focus of the model is timely interventions involving a proactive method to prevent delayed, unnecessary suffering. One of the aims of this model is to incorporate a patient's wishes. Underpinning the model is the recognition that curative and palliative measure have the potential to evolve over time (Comart, Mahler, Schreiber, Rockett, Jones, & Morris, 2013). Although this framework is found to be a beneficial tool in palliative care, it is important to note that this model focuses solely on palliative care for the elderly rather than all persons seeking palliative care.

2.5.2 Liverpool Care Pathway

The Liverpool Care Pathway (LCP) was designed as a standardized approach for generalist staffs caring for patients who are close to death (within a period of 48 hours) (Ellershaw & Ward, 2003; Thomas, 2003). The LCP mainly focuses on ensuring consistency of care in patients' final days which includes assessing the administration of current medications, identifying ways of informing family of impending death, assessing spiritual needs and finalizing decisions to abort inappropriate interventions such as urine samples, blood tests and monitoring vital signs (Jack, Gambles, Murphy, & Ellershaw 2003; Thomas, 2003). Additionally the aims of the LCP framework are to support cost-effective healthcare through the avoidance of crisis interventions, the provision of appropriate drug prescriptions and the prevention of unnecessary hospital admissions (Chan & Webster, 2010; Ellershaw & Ward, 2003; Jack et al., 2003). Although the LCP framework is considered an excellent tool for palliative care providers to implement, there has been much criticism on the framework, being a deemed a "pathway to euthanasia" (Knights, Woods, & Barclay, 2013). A review conducted by Baroness

Neuberger as cited by Knights et al. (2013), in England suggested that the framework firstly compromised patients' autonomy, secondly, promoted the financial gains of NHS trusts by means of incentive payments for using the tool and lastly, was primarily used to free up hospital beds, thereby neglecting patient safety along with quality of care. Consequently, the British government instructed hospitals to discontinue the use of the LCP framework. However, this tool is still being used in other countries such as The Netherlands, Argentina, Slovenia, India and Norway. Knights et al (2013) states that the LCP is best applied with patients during their last 48 hours of life and therefore may not be the most appropriate framework for individuals receiving palliative care for over longer periods of time. For this purpose, the GSF(discussed further) is another common tool in palliative care that is most applicable to patients requiring palliative care for longer periods of time including months and/or days (Thomas, 2003). The use of this framework has been instituted by CCO to be implemented as a tool within palliative care thereby giving rise to the need to evaluate its implementation in the context of Canadian healthcare, specifically within a hospital-based, outpatient setting.

2.6 Gold Standards Framework (GSF)

2.6.1 Definition and Background

It is important to critically analyze the Gold Standards Framework (GSF) and define what the GSF is intended to do. The GSF is defined in the literature as a model that enables the best standards of practice be provided to the highest degree with respect to all individuals approaching the end of life regardless of diagnosis (Hansford & Meehan, 2007). Dr. Keri Thomas, a general practitioner with focused interest in palliative care, initiated the development of the GSF to be originally used in primary care (Hansford &

Meehan, 2007; Shaw et al., 2010). After its implementation in 2001, the GSF was refined in 2004 so adaptation in various settings of palliative care delivery could occur, particularly with specific emphasis on end-of-life-care (Hansford & Meehan, 2007). The principal focus of utilizing the GSF is to enable frontline healthcare providers deliver palliative care at an exceptional standard. As such, implementation of this tool within palliative care is rapidly growing in many hospitals, hospices, long-term homes and care homes (Meier, 2011). Currently, one third of care facilities within the UK have taken up the GSF within cancer care and internationally, many countries including New Zealand, United States, Canada and Australia have also adopted this framework as a tool within the delivery of palliative care (Meier, 2011).

2.6.2 Aim of the Gold Standards Framework

The central aim of the GSF is to enhance palliative care for individuals approaching the end of life by formalising the highest standard of practice (Hansford & Meehan, 2007; Thomas, 2003). The GSF was developed as an approach to support the achievement of an exemplary standard of care; the needs of patients were analyzed through a holistic perspective with the expectation that the physical, spiritual and/or psychosocial dimensions of need could be properly recognized and addressed. The development of the GSF was influenced by the areas of human need as identified by Maslow, which includes physiological, safety, social, esteem and self-actualisation needs (Thomas, 2003). Patients' needs have mainly been identified at two levels, namely the inner and outer level. Thomas (2003) states that the inner level consists of the structure of service provision in any required area including access to: 24-hour care, out-of-hours care, support for family, necessary equipment and drugs, information transfers and advice

from specialists. Thomas (2003) then goes on to describe the outer level. Thomas (2006) describes this as aspects of relationships and the importance behind patient bonds with palliative care providers and family, noting this as extremely crucial in each patient's healthcare journey.

The dominant strength of the GSF is the ability to improve communication and organizational methods thereby positively affecting patients' quality of life (Hansford & Meehan, 2007). There are five main goals that the GSF aims to meet so that patients in the remainder of their last months of life are able to live to the highest standard possible and anticipate a peaceful death (Hansford & Meehan, 2007; Shaw et al., 2010). These goals are to i).ensuring symptom control, ii) recognize and enable preference for life and death, iii) reassure support and security through efficient advanced care planning, iv) ensure carers are supported through increased communication and proactively addressing any issues, and v) educate staff consistently thereby increasing knowledge and confidence in care (Hansford & Meehan, 2007; Shaw et al., 2010). These goals support the entire realm of care, which the GSF aims to address, not only for practitioners to provide, but also, most importantly for patients to benefit from.

The GSF also provides the use of the "GSF Prognostic Indicator Guidance" which directs palliative care providers to primarily focus on the question "Would you be surprised if this patient were to die in the next few months, weeks, days"? (GSF, 2016). Through specific clinical indicators such as: decreased functional performance, metastatic cancer, decreased response to treatments and reversibility, palliative care providers are enabled to gain a better indication of patients' status in relation to the cancer illness trajectory. Simultaneously, through the use of the GSF, palliative care providers are then

directed to optimize patient quality of care, through three processes, which are to: i) identify those who are in need of palliative care, ii) assess symptoms along with preferential issues of patients and, iii) plan care with emphasis on limiting future complications in care that may arise (Hansford & Meehan, 2007; Shaw et al., 2010; Thomas, 2003). This process enables practitioners to grasp what the ideal form of care consists of and furthermore describes the necessary steps to achieve this level of care (Shaw et al., 2010).

2.6.3 Levels of Adoption and 7 C's

In order for practitioners to follow the steps noted above, there are four “levels of adoption,” which incorporate seven key components as outlined by the framework. These seven areas, known as the “7 C's”, ranging from C1 to C7 include: communication, co-ordination, control of symptoms, continuity of care, continued learning, carer support, and care in the dying phase (Hansford & Meehan, 2007; King, Thomas, Martin, Bell & Farrell, 2005, Thomas, 2003).

Level 1 (C1&C2): Communication (C1) entails the incorporation of patient involvement through every stage of the illness trajectory in relation to patient preference of care. Communication also entails regular palliative care provider meetings to help improve information flow between all providers associated with a patient's care (Amass, 2006; King et al., 2005). Co-ordination (C2) entails the nomination of a GSF coordinator that is accountable in ensuring that proper utilization and implementation of the GSF is carried out amongst any designated palliative healthcare team (Hansford & Meehan, 2007).

Level 2 (C3, C4, & C5): Control of symptoms (C3) includes accurately assessing all patient symptoms whether being physical, spiritual, social or psychological with aim to effectively monitor and control in present and anticipatory situations (Hansford & Meehan, 2007). Continuity of care (C4) entails the maintenance of information transfers between health agencies (out-of-hours doctors, nurses, support workers) through handover forms so that the most up-to-date information is available (King et al., 2005). Continued learning (C5) entails the active commitment of primary health care teams to learning about end-of-life care in all aspects so that maximum benefit is achieved for practitioners and patients (Hansford & Meehan, 2007; King et al., 2005; Wee & Hughes, 2007).

Level 3 (C6 & C7): Carer support (C6) covers the provision of support through the emotional, practical, and bereavement aspects of end-of-life care (Hansford & Meehan, 2007). Lastly, care in the dying phase (C7) ensures appropriate care for those in the terminal phase of illness where all aspects of care for patient and family members are considered systematically (Hansford & Meehan, 2007). Such considerations include bereavement communication, psychological support, stopping drug interventions that may not be essential, and religious support (Hansford & Meehan, 2007; King et al., 2005).

Level 4: At this level, there is a focus on sustainability of prior improvements gained from the GSF's seven key components of care.

Each area of care targeted by the GSF is of significant importance, not only for palliative care providers who administer palliative care but also patients, the recipients of care (Shaw et al., 2010; Thomas & Free, 2006; Walshe, et al., 2008). King et al. (2005)

indicates that the most important reason behind why facilities implement the GSF is to improve team communication and ensure consistency in standard levels of palliative care. Greater understanding of patient and family needs relative to care also is a benefit from the uptake of the GSF in palliative care (Badger et al., 2012; Hansford & Meehan, 2007; Thomas, 2003). Therefore, the GSF is deemed to be pivotal in ensuring the delivery of exemplary palliative care for patients facing the life altering illness of cancer (Badger et al., 2012; Hansford & Meehan, 2007; Thomas, 2003).

2.7 Implementing the GSF in Palliative Care

2.7.1 Impact of the Gold Standards Framework on Palliative Care Providers

Increased Communication

An increase in communication amongst palliative care team members from all disciplines is the top recognized change by palliative care providers in relation to the implementation of the GSF in palliative care (Badger et al., 2012; Dale et al., 2009; King et al., 2005; Mahmood- Yousuf, King, & Dale, 2008; Shaw et al., 2010; Thomas & Noble, 2007; Walshe et al., 2008). The impact of multidisciplinary meetings between members of palliative care teams helped initiate more communication as detailed aspects of care regarding patients was discussed (King et al. 2005). Enhanced communication influenced a shared vision amongst palliative care team members where uniformity, acknowledgement and decision-making involving the whole team could occur (Munday et al., 2007). A study conducted by Mahmood-Yousuf et al. (2008) focused solely on the aspects of communication and inter-professional relationships in palliative care teams after the adoption of the GSF. This qualitative study was based on thirty-eight semi-structured interviews from general practitioners, framework facilitators, and district

nurses, with the aim to understand their experiences of utilizing the framework. The study found that the benefits acquired through multidisciplinary meetings promoted the engagement of discussion relative to patient care. Mahmood-Yousuf et al. (2008) discovered that before the application of the GSF in palliative care practices, general practitioners were less aware that nurses relied on information from them after patient meetings. However, after the application of the GSF, district nurses saw an increase in knowledge transfer from general practitioners. The authors indicated that this allowed district nurses to be up-to-date on information and better prepared when meeting patients to discuss care. Consequently, this was instrumental in strengthening patient-provider relationships (Mahmood-Yousuf et al., 2008). The authors also discovered that if patients and district nurses built relationships earlier within a patient's disease trajectory, patients were more likely to engage in discussion regarding emotional and spiritual needs. As a result this positively influenced the overall palliative care of a patient seeking this approach (Mahmood-Yousuf et al., 2008).

Increased Co-ordination

Within palliative care, the purpose of implementing the GSF is to facilitate the best quality of care so that all patients who desire this care are able to receive it at the highest standard possible. As coordinating processes to carry out palliative care can be challenging, studies have indicated that the implementation of the GSF enables smooth coordination not only between palliative care providers, but also with the provision of support services primarily due to the selection of GSF coordinator (Dale et al., 2009; King et al., 2005; Shaw et al., 2010). A qualitative study conducted by King et al. (2005) aimed to analyze the differences within levels of the delivery of palliative care through

evaluating the implementation of the GSF, between hospitals that did and did not utilize the framework in daily practice. As a result, the authors indicated that coordination among palliative care providers' was significantly increased in hospitals who implemented the GSF in daily practice than in comparison to those who did not. (King et al., 2005). Through 68 semi-structured interviews conducted by telephone, the authors found that an increase within coordination among healthcare teams occurred mainly due to the clear selection of a GSF coordinator, whose role was at most times filled by a district nurse with interest in palliative care (King et al., 2005). The selection of a GSF coordinator ensured that there was a daily, formal responsibility around managing various issues experienced by patients and providers in palliative care (King et al., 2005). Additionally, many general practitioners and nurses felt a sense of support from the GSF co-ordinators, which impacted the progresses made in the delivery of palliative care (King et al., 2005).

2.7.2 The Impact of the Gold Standards Framework on Patients and Care Givers *Increased levels of care*

The literature review revealed several studies where patient quality of life was improved through the enactment of the GSF model in daily practice (Badger, et al., 2012; Hansford & Meehan, 2007; Munday et al., 2007). In addition, levels of standard palliative care towards patients and caregivers were shown to increase notably through patient support and satisfaction as a result of adhering to patients' goals of care (Badger et al., 2012; King et al, 2005; Munday, et al., 2007; Shaw et al., 2010). Incorporating all components of the framework (7C's) proved to be beneficial to patient outcomes in palliative care (Badger, et al., 2012; Hansford & Meehan, 2007; Kelt, Munday & Dale, 2008; Munday et al., 2007). This was demonstrated through a qualitative study conducted

by Kelt et al. (2008). Patients and caregivers who had received palliative care as guided by the GSF not only reported positive experiences in relation to coordination of care services, but most importantly with patient support. Kelt et al. (2008) indicate that in particular, a large number of patients felt that many of their physical and psychosocial needs were met because palliative care providers who utilized the GSF were able to provide a “personalized” approach to care. Additionally, many patients felt their care plans were acknowledged earlier within the illness trajectory. Therefore, this resulted in the experience of high-quality palliative care (Kelt et al., 2008).

Patients’ awareness also increased with the implementation of the GSF for example this was seen from an increased use of cancer and/or support care registers among palliative care providers (King et al., 2005; Petrova et al., 2010; Shaw et al., 2010). Cancer care registers and support care registers enabled palliative care providers to be more aware of patients’ information thereby, enabling the provision of increased consistency in palliative care (King et al, 2005). Through the implementation of the GSF there was an increased awareness of patients requiring palliative care. Consequently, regular conversations between palliative care providers and patients/family members were made possible and discussions on advanced care planning were initiated (King et al., 2005; Shaw et al., 2010). Additionally, this resulted in palliative care providers understanding the importance of recognizing and discussing patients’ final wishes on desired places of death (King et al., 2005; Shaw et al., 2010). A systematic review conducted by Bell, Somogyi-Zalud and Masaki (2010) analyzed palliative care patients preferred places of death in comparison to actual places of death. The authors concluded that it is important for palliative care providers to inquire about, and communicate with

patients on preferred places of death because a lack of inquiry could most likely lead to higher admittance rates to emergency departments, thereby contradicting the sole purpose of palliative care within a preferred environment. Hansford and Meehan (2007) also state the grave importance behind discussions on advanced care planning. The authors emphasize that these conversations facilitate increased knowledge, awareness, and recognition amongst palliative care providers, consequently deeming the appropriate direction and levels of care desired by patients.

2.8 Challenges/Barriers Associated with Implementing the Gold Standards Framework

Evidence suggests that the GSF supplies the necessary tools to support the efficiency of care, especially when executed entirely (Hansford & Meehan, 2007; Shaw et al, 2010; Walshe et al., 2008). However, while there are benefits in communication and coordination with implementing the GSF, studies also indicate that issues can arise in these areas depending on how and to what extent healthcare practices implement the GSF (Mahmood-Yousuf et al., 2008; Shaw et al. 2010; Street & Blackford, 2001; Walshe et al., 2008). Subsequently, if the GSF is not implemented to the full extent, this can impact whether or not care is delivered to patients and family members (Shaw et al., 2010; Spruyt, 2011; Street & Blackford, 2001; Walshe et al., 2008). Communication and coordination between palliative care providers can be challenging at times, therefore, various studies indicated a need to support stronger inter-professional collaboration amongst palliative care team members relative to understanding the responsibility of roles in palliative care (Badger et al., 2012; Klinger et al., 2014; Shaw et al., 2010). For instance, a qualitative study by Walshe et al. (2008) identified how wrongful assumptions of the roles and responsibilities of nurses within palliative care teams resulted in an

adverse effect on their daily workload. Walshe et al. (2008) indicated that improper coordination between members of a palliative care team meant that a majority of the time, district nurses were left to do all the work with respect to addressing patients' needs. Moreover, they found that general practitioners never voluntarily reported on the impact of the GSF on their workloads. This may suggest that general practitioners assumed nurses were responsible for completing all the main work involved within GSF, such as maintaining patient care, identifying patient preferences, patient-referrals, and engaging in patient follow-ups (Walshe et al., 2008). Therefore, ambiguity amongst palliative care team members with respect to not properly understanding each other's roles and responsibilities can be harmful to patient care, as misunderstandings can lead to patients being neglected, with negative impact on patient outcomes (Shaw et al., 2010; Walshe et al., 2008).

Similarly, the same negative aspect found in implementing the GSF was supported from two different studies by King et al. (2005) and another by Mahmood-Yousuf et al. (2008), which indicated concerns surrounding district nurses and workloads. Findings by King et al. (2005) indicated that the need to monitor and maintain all palliative care concerns was deemed fulfilling for district nurses however responding to clinical facets of care and being held responsible for all aspects of the framework was perceived as daunting. Another interesting finding by the authors was the administrative staff who decided to take on any additional workloads, did not mention this as a problem (King et al., 2005). This finding suggests, enlisting administrative staff to handle excessive workloads could be a viable option for practices implementing the GSF and thereby decrease stress on district nurses (GSF coordinators).

Another challenge/barrier to implementing the GSF was identified by Walshe et al., (2008). The authors identified many practitioners only implemented parts of the framework that were deemed beneficial to the needs of their respective practices, while neglecting the implementation of the framework as a whole. Walshe et al. (2008) suggests that this can negatively impact patient care. Findings by Shaw et al. (2010) support this study, such that the authors indicate variability in implementing the GSF can negatively impact palliative care. Palliative care teams may participate in a cherry-picking approach and avoid challenging aspects of the GSF Shaw et al. (2010) emphasizes that this approach can enable providers to drift away from aspired palliative care goals associated to implementing the GSF, and therefore impact how palliative care is delivered. Such challenges in implementation can make it difficult for researchers to accurately evaluate the implementation of the GSF and precisely understand which areas of the GSF need improvement as not all practices may implement the framework in its entirety (Shaw et al., 2010; Walshe et al., 2008). While research on the GSF has indicated some challenges and barriers relative to implementation primarily in the UK, a limitation that currently exists is the paucity of evidence on what type of challenges take place within the context of the Canadian healthcare system. Therefore, this study aimed to identify whether or not there are challenges with implementing the GSF in hospital-based, outpatient oncology care and if there are, what these challenges may be.

2.9 Summary of Key Findings

The provision of palliative care provides a relief in suffering and supports patients facing a life limiting disease by targeting the spiritual, physical, and psychosocial aspects of care, using a multidisciplinary approach. The analysis of existing literature

surrounding palliative care continuously describes the focus of palliative care on the quality of living, rather than the quantity of life (Badger et al., 2012; Shaw et al., 2010; Street & Blackford, 2001; Walshe et al., 2008). To support the delivery of high quality palliative care, palliative care providers implement frameworks/models to assist in recognizing and addressing patients' physical and psychosocial needs. The GSF is currently being implemented in palliative care service delivery as instituted by CCO.

The literature review revealed evidence that enactment of the GSF model resulted in improving patient quality outcomes (Badger et al., 2012; Hansford & Meehan, 2007; Munday et al., 2007) Study results indicate that the GSF is an excellent tool which can be used to facilitate optimal palliative care for cancer patients by adhering to the components of the framework, notably the 7 C's (Communication, Coordination, Continuity of Care, Control of Symptoms, Continued learning, Carer Support and Care in the dying phase) However, various studies indicate that even though the GSF is being implemented, not all individuals facing cancer are receiving the desired care. This may be due to inadequacies in areas such as communication and coordination as a result of how multidisciplinary team members are executing the GSF (Badger et al., 2012; Klinger et al., 2014; Shaw et al., 2010). Consequently, numerous published journal articles surrounding the GSF model in palliative care have explored potential ways to improve the utilization of this framework so that patients can receive desired care from palliative care providers in a more organized and systematic manner (Shaw et al., 2010; Walshe et al., 2008)

Although there is a plethora of palliative care literature, which explored the implementation of the GSF in palliative care, most of these studies were conducted

outside of Canada, primarily within the United Kingdom (UK) (King et al., 2005; Munday et al., 2007; Shaw et al., 2008; Walshe et al., 2008). The rationale for this may be due to the GSF's origin in the UK during 2001, with implementation around 2002. More recently, researchers outside the UK have begun using this framework (Meier, 2011). As the healthcare systems in the UK and Canada vary, Canadian palliative care teams may face different challenges and therefore, such challenges may not have been examined or addressed within previous studies (Brown, 2003).

Within Canadian literature on palliative care, a small number of research studies have examined how palliative care is delivered within an outpatient setting (Cross, 2013; Mistry et al., 2015). However, there is a gap in the literature because these studies have not examined the delivery of palliative care through the analysis of implementing the GSF, from the perspective of palliative care providers in a hospital-based, outpatient palliative care setting (Cross, 2013; Mistry et al., 2015). Additionally, it is vital to examine the experiences of palliative care providers because implementation of the GSF has been currently instituted by CCO, a partner with LH. Furthermore, another existing gap in the literature includes a lack of Canadian studies, which use qualitative approaches to explore palliative care providers' experiences in implementing the GSF in hospital-based, outpatient palliative care.

Therefore, this study fills in these gaps presented in the literature by asking the following question: What are the lived experiences of palliative care providers in implementing the Gold Standards Framework in oncology care, from a hospital-based, outpatient palliative care setting? Using the conceptual underpinnings of the 7 core components (7C's) from the GSF, in this study I examined palliative care providers lived

experiences in implementing the GSF in palliative care in a hospital-based, outpatient setting. This study builds upon the existing literature regarding the implementation of the GSF specifically, within the context of the Canadian healthcare system. I will discuss the methodological approach of this study in the next chapter.

Chapter Three: Methodology and Methods

In this chapter, I outline the research methodology and methods I used for this study. I outline the research processes created and implemented in order to answer the research question to meet the overall purpose of the study.

3.1 Study Purpose and Design

The primary purpose of this study was to explore the lived experiences of palliative care providers in implementing the GSF in oncology care, from a hospital-based, outpatient palliative care setting. This is to gain an understanding of the facilitators and barriers to implementing the GSF in this setting, such that the exploration of lived experiences can be used as a foundation to further strengthen participants' practices in order to optimize the delivery of palliative care for patients in need. Furthermore, it is hoped that these experiences will provide an insight into what supports are needed for palliative care providers to fully implement the core components of the framework to meet the standards of excellence in palliative care that support positive patient outcomes.

To answer the research question, I used an interpretative phenomenological approach to explore the perspectives of palliative care providers who used the GSF in a hospital-based, outpatient palliative care setting, notably LH. The study received ethical approval from the University of Ontario Institute of Technology (UOIT) and LH. Participants were recruited once they met the eligibility criteria. Following recruitment, participants signed consent forms, which provided details about the study. In-depth interviews were conducted with participants and digitally recorded. Data were transcribed and analyzed in keeping with the interpretative phenomenological methodology chosen

for this study. The methodology and methods of this research study are explained in further detail throughout the next sections of this chapter.

3.2 Interpretative Phenomenological Analysis

In keeping with Cresswell's description of phenomenology, a qualitative research approach was taken within this study to gain an in-depth understanding of the nature of the phenomenon and answer the research question. Jonathan Smith's Interpretative Phenomenological Analysis (IPA) was applied within this study. Smith's (2009) approach to IPA was informed by Martin Heidegger's philosophical views. Heidegger's philosophical underpinnings are concerned with existence itself and its relation to contextualizing experience (Pietkiewicz & Smith, 2012). Heidegger developed the term "hermeneutics," which is the theory of interpretation (Gill, 2014; Pietkiewicz & Smith, 2012). In this theory, he elucidated the importance of interpretation when analyzing the experiences of human beings in relation to a phenomenon (Gill, 2014). As this research study took an interpretative approach, I examined the lived experiences of palliative care providers in implementing the GSF such that I as the researcher took an interpretive stance to examine these experiences. Heidegger also stressed that individuals are "always already in an environing world" and that individuals' culture and traditions have an impact on how they fathom an experience (Pietkiewicz & Smith, 2012). Heidegger applied the concept of inter-subjectivity to his view of the "person" as he deemed 'relatedness' to the world as a crucial part of the nature of individuals (Dallmayr, 1980; Pietkiewicz & Smith, 2012). The concept of inter-subjectivity describes how individuals relate and communicate to make sense of each other (Dallmayr, 1980). Smith's IPA is not only strongly informed by Martin Heidegger's philosophical views but also incorporates

them within his methodology (Larkin & Thompson, 2011; Smith & Osborn, 2003; Smith, Flowers, & Larkin, 2009).

IPA is a qualitative methodology that is utilized in research to gain an understanding into participants' subjective realities through personal interpretations surrounding their lived experiences, along with identifying the meanings that are attached to these experiences (Smith, 2011). It is unique because it combines phenomenology, hermeneutics and idiography together within one methodology (Smith, 2004; Smith et al., 2009). Firstly, IPA is highly phenomenological. By using this approach the researcher gains an understanding of the individual's experience and perspective. Secondly, IPA is interpretative because it relies on the ability of a researcher to acquire access into a participant's world to accurately make sense of participants' experiences within their personal and social world (Smith, 2004). Therefore, it emphasizes the research exercise as a dynamic process, which demands an active researcher role (Larkin & Thompson, 2011; Smith et al., 2009). Smith and Osborn (2003) state that when aiming to get an insider perspective on how each participant senses meaning of their experience, the researchers can only have access to this by including their own perceptions otherwise known as a two-stage interpretation process (Larkin & Thompson, 2011). This process is also known as double hermeneutics; the text attributable to the research participant and the text brought by the researcher co-inform one another throughout the research process (Smith & Osborn, 2003). Double hermeneutics is the incorporation of the researcher's own preconceived assumptions, values, and beliefs based on prior experiences surrounding the proposed research inquiry (Smith & Osborn, 2003). Because I employed methods in keeping with double hermeneutics, I did not need to bracket my

preconceptions, for example, one preconception was that there was low awareness regarding implementation of the GSF from a hospital-based, outpatient palliative care setting. Along with these existing preconceptions, I (as the researcher), decoded meaning that was made by palliative care providers within this study through the process of interpretative activity, such that I made sense of each participant, making sense of their own experiences (Smith & Osborn, 2013). This was done through understanding each palliative care provider's exploration of their experiences related to how they incorporated the seven components (7 C's) of the GSF when administering palliative care. Lastly, IPA is highly idiographic such that there is an in-depth analysis of each case through examining each participant's experiences in a unique context (Gill, 2014; Smith et al., 2009). As this occurs, a comprehensive analysis of each participant's experiences is ascertained before moving on to the next participant.

The utilization of the IPA methodology means the researcher has a theoretical responsibility to research participants as well (Smith et al., 2009). In the application of the IPA methodology, the researcher understands that each participant is a cognitive, linguistic, affective and physical being (Smith et al., 2009). As my pre-existing knowledge and inferences surrounding the proposed phenomenon of interest were already noted, being aware of these experiences surrounding palliative care enabled me to develop more insight into each participant's experiences. Therefore, I was able to further engage with every participant by grasping a detailed account into the experiences within their personal and social world through accessing my personal familial experiences with receiving palliative care from palliative care providers (Smith & Osborn, 2003; Smith, 2011).

Within this study, I proposed to understand and interpret meaning behind the lived experiences of every participant, utilizing the three main components of IPA (phenomenology, hermeneutics, and idiography). Through this methodological approach, I wholly grasp an in-depth perception into each subjective experience along with how each participant has made sense of these experiences (Smith & Osborn, 2003; Smith et al., 2009).

3.3 Research Setting

This research study took place at LH in Ontario, Canada, a partner of Cancer Care Ontario (CCO). This study focused on the lived experiences of palliative care providers in implementing the GSF in oncology care from a hospital-based, outpatient setting. Therefore, this setting was chosen because CCO has instituted the utilization of the GSF as a tool in the delivery of palliative care. Additionally, there are no previous research studies, which examined the lived experiences of palliative care providers in implementing the GSF within a Canadian context from a hospital-based, outpatient palliative care setting.

3.4 Study Participants

3.4.1 Ethics and Research Approval

As this research study involved human participants, ethics approval was required. Ethics approval helps preserve the rights, dignity, welfare and safety of the participants who volunteer for any research study while protecting the researcher's rights to conduct a legitimate investigation. As such, ethical approval for this study was gained from both the UOIT Research Ethics Board (REB) (*REB #14051*) on August 10th 2016 (Appendix A) along with LH's REB (*REB 2016-025*) on October 17th 2016 (Appendix B).

3.4.2 Inclusion Criteria

As several authors note, palliative care teams deal with all patients regardless of the chronic illness they are experiencing (Gardiner, Cobb, Gott, & Ingleton, 2011; Nelson & Hope, 2012). Therefore, the inclusion criteria for palliative care providers within this research study was that they: (a) were currently working on the outpatient palliative care team within LH (b) were currently administering palliative care to patients diagnosed with any form of malignant cancer and c) consented to participate in the study.

3.4.3 Exclusion Criteria

Palliative care providers who did not meet all of the inclusion criteria were not able to participate in this study.

3.4.4 Sample and Sample Size

In order to select participants, Smith and Osborn (2003) suggest that purposive sampling techniques will ensure a homogenous sample of participants. In the literature, purposive sampling is defined as the selection of participants who share commonalities surrounding characteristics and experiences relative to the phenomenon of interest (Smith & Osborn, 2003). Therefore, palliative care providers of a hospital-based, outpatient palliative care team who has implemented the GSF and its respective components were an appropriate sample because of their ability to answer the research question.

As IPA involves a detailed examination of the experiences of participants, Smith and Osborn (2003) recommend a smaller sample size ranging from 6-10 participants as an appropriate sample size to enable researchers to properly explore each case with the necessary rigor, time and energy. As a result, the researcher is able to thoroughly explore each participants' verbatim accounts in extensive detail on a case-by case analysis, being

provided the opportunity to investigate the similarities and differences between each participants' responses (Pietkiewicz & Smith, 2012). Based on Smith and Osborn's recommendations (2003), I selected a sample size of 6-10 participants from a total of 13 physicians and 4 registered nurses, which comprised the outpatient palliative care team. I was able to recruit six participants from this sample.

3.4.5 Recruitment Strategy

In order to access participants for this study, I provided a recruitment email to the receptionist of the outpatient palliative care program. To protect the anonymity of participants within this study, I provided the receptionist with a confidentiality agreement (Appendix C) form, which was signed by myself, the principal investigator, and the receptionist. Once this occurred, the recruitment email (Appendix D) was sent out biweekly (November 2016- February 2017) to all palliative care providers on LH's outpatient palliative care team, consisting of 4 registered nurses and 13 physicians. Through the recruitment email, I informed all individuals who were interested in participating within the study to contact me (as the primary researcher). Subsequently, I contacted the participants and provided further details about the study. I invited participants who met the eligibility criteria to a scheduled interview. I scheduled interview times with the participant based on the next available library booking times.

I provided the participants of this study a consent form (Appendix E) informing them of the purpose, procedures, benefits, discomforts and compensation associated with this study. The participants were informed that they would be audio recorded throughout the interview and of those who had access to the audio recordings/data, including where they were stored. Participation within this study was completely voluntary and

participants were aware they could withdraw from the study at any time without experiencing any consequences to their employment. Participants were informed they had the right to not answer or discuss any questions that they felt uncomfortable with and would not experience any consequences as a result.

Preceding the interview, I provided participants the opportunity to ask questions concerning any aspects related to the research study. Once these questions were asked, participants were then asked to read and sign the written consent form so that they could participate in the interview. Each participant signed two consent forms: I retained a copy while the participant retained one as well.

Participants' data were kept confidentially and their anonymity was maintained through the use of pseudonyms. The principal investigator and I only had access to the data collected within this study as it was entered into a password-protected computer and saved as a password-protected file. I gave an ID code to each participant before the interview along with a pseudonym to ensure that all the legitimate names of participants were not disclosed. Participants were informed that all recordings and transcriptions would be kept for a period of 5 years after the completion of the research study and notified that after the 5 year period all confidential data would be destroyed either through shredding (paper format) or reformatting, rewriting and/or deleting (electronic format). Participants were also informed that all the information they provided for the purpose of this study would remain confidential and thereby only be utilized to inform the research study.

3.5 Data Collection

Data collection commenced from November 2016- February 2017. The interview setting, interview rationale and steps taken throughout the interview process are outlined below.

3.5.1 Interview Setting

Pietkiewicz and Smith (2012) suggested that the best areas to complete an interview are within a private or semi-private setting. Pietkiewicz and Smith (2012) indicated this is a prime choice for data collection because it allows the researcher to engage in dialogue with their participants in real time and away from a majority of distractions. In keeping with the recommendations by Pietkiewicz and Smith (2012), I conducted all the interviews within a quiet area, in the main library, located within the research site. As stated on the recruitment email, the average time designated for individual in-depth interviews ranged from 45 minutes to one hour, therefore, I booked the library room for one hour.

3.5.2 Interview Rationale

In keeping with Smith's IPA methodology, I collected data through individual, in-depth semi-structured interviews with palliative care providers working as members of an outpatient palliative care team. Smith and Osborn (2003) suggests that this method of data collection enable the researcher and participant to engage in dialogue on a more flexible level. Subsequently, the initial questions asked by the researcher can be directed into other areas of interest in light of participants responses, and thereby enable the researcher to probe into areas of interest that have been brought up by participants (Smith & Osborn, 2003). This process enables researchers to be aware of other issues and

concerns of participants relative to the phenomenon of interest, as well as collect richer data (Smith & Osborn, 2003). Smith and Osborn (2003) suggest the use of an interview guide (Appendix F) to help the researcher gain control of the interview and maintain focus on the research inquiry. As suggested by Smith and Osborn (2003), throughout the interview process of this research study, I utilized an interview guide to help promote a natural flow of conversation between each participant (palliative care provider) and myself. A few key prepared questions were asked so that there was structure within each interview, but also enough room for conversation to develop and further explore the proposed research inquiry with participants. As the prime goal was to elicit a rich and detailed amount of data from each participant, sub questions were created. As Gill (2014) and Pietkiewicz and Smith (2012) note, this assists the researcher to focus on exploring individual interpretations, sensory perceptions and mental phenomena such as thoughts, recollections and associations in relation to the research question.

3.5.3 Interview Process

After completing the consent process, I asked the participant to fill out a sociodemographic form (Appendix G). The sole purpose of the socio-demographic form was to describe the characteristics of participants within this research study. Once the process of filling out the socio-demographic forms was completed, I gave the participant a choice of selecting an identification pseudonym, which I then noted down. After the participant chose a pseudonym, I turned on the audio recording device and reminded each participant that no identifying information would be used within the research study. Each participant was also informed about various ethical principles relative to this study such as maintenance of anonymity as well as data confidentiality before I conducted the

individual semi-structured interview. According to Kaiser (2009), this is a fundamental aspect of the informed consent process. The interview process commenced and I asked questions from the interview question guide. I also kept a notebook to record any points that stood out to me such as body language or important points brought up by the participant that needed to be discussed further. There was no set time limit for participants' responses during each interview and participants were given the opportunity to speak freely even if there was deviation from the interview question being asked. As stated in the consent form, participants were given the right to not answer or discuss any questions that they felt uncomfortable with, as well as terminating the interview at any time. However, six participants completed the study and each interview was approximately an hour in duration. Once the interview was completed, I turned the recording device off. I thanked each participant for his/her participation in the study and I gave each participant a 15-dollar Tim Hortons gift card as a token of appreciation for his/her valuable contribution. Once I was alone, I composed brief summaries pertaining to my thoughts on the interview. The main purpose of these summaries was to allow me to reflect back on the interviews before I started the process of transcribing data. Upon the completion of each summary post-interview, I uploaded each recording to a password-protected computer. Subsequently, each recording was deleted from the audio recording device to comply with ethics requirements from LH REB.

3.6 Data Analysis

3.6.1 Data Transcription

Before data analysis ensued, I transcribed all interview audio recordings verbatim into written text. Bowling and Ebrahim (2005) recommend researchers transcribe their own data as this enables researchers to become familiar with the data and its contents. Therefore, I transcribed all the interviews with the purpose of becoming familiar with and able to absorb the data. I reviewed each interview audio recording on the same day and transcribed the data within 7 days of the initial interview date (stated on consent form). Prior to data transcription, I considered qualitative software packages such as NVivo to be part of the research study, however it is important to note that such qualitative software packages are helpful for studies that contain a large amount of participants and consequently large amounts of data (Bender, 2009). Therefore, because my study consisted of six participants, I used Microsoft word to arrange and store the data. I noted participants' chosen pseudonyms on each transcript to preserve their confidentiality and anonymity within the study. In order to further preserve the anonymity of participants, I chose a pseudonym to replace any names that were mentioned within the various interview audio recordings as well.

3.6.2 Analytical Process

As noted above, the process of data analysis within this study was guided by Jonathan Smith's (2009) IPA such that there is a detailed description of the concepts and procedures that should be taken in order to qualitatively analyze data in an accurate manner, according to this methodological approach. Once data transcription ensued, an idiographic approach was taken such that I took a case-by-case approach by closely

reading and listening to each participant's transcript and audio recording. This was done so that I could further reflect on the data collected, while simultaneously annotating important points and looking for emerging themes, before moving on to the next participant (Smith & Osborn, 2009). Smith and Osborn (2003) suggest that this process helps to further develop notes into concise themes, which will grasp the essential quality of each of the participant's responses. In this study I used the 7 C's notably: communication, coordination, control of symptoms, continuity of care, continued learning, carer support and care in dying phase of the GSF to guide data analysis within each transcript. In keeping with the suggested methods of Smith and Osborn (2003) and Smith et al., (2009), I looked for commonalities between emerging themes within each component of the framework according to conceptual similarities (Smith & Osborn, 2003; Smith et al., 2009). In keeping with the analytic processes outlined by Smith and Osborn (2003), I clustered related or connected themes by giving each group of themes a descriptive label, thus creating sub-themes in the process. The authors suggest this will help to identify the major and minor themes that have occurred as a result of the whole interview process with all the participants. As suggested by Pietkiewicz and Smith (2012), once I completed the interpretive process, a final analysis of the texts occurred, and a final table of sub-themes was subsumed under each component of the GSF; these are discussed further in the findings section of the thesis.

3.7 Achieving Scientific Rigour

In lieu of stating limitations, Webb (1992) suggests that the identification of evaluative criteria is important, prior to conducting a qualitative research study. Webb (1992) states this is necessary as rigour is established differently in qualitative research.

Therefore, several evaluative criteria were applied in order to assess the authenticity of the findings of my qualitative inquiry. I adopted Guba and Lincoln's trustworthiness criteria and applied it as closely as possible to my research inquiry (Guba & Lincoln, 1994). This criterion of rigour is commonly used to address the credibility, transferability, dependability and confirmability of a qualitative inquiry.

In keeping with the first principle of the trustworthiness criteria, I applied credibility to my research inquiry. Anney (2014) and Shenton (2004) define credibility as placing confidence in the authenticity of the research findings. In keeping with Anney (2014) and Shenton (2004) recommendations to ensure credibility, I welcomed peer scrutiny of this research study by academic associates or colleagues. According to Shenton (2004), this is in-order to help see new perspectives to the study, which I may not have initially noticed. Guba (1981) also notes that this is instrumental in establishing authenticity in the criteria of credibility. Member checks are also encouraged to ensure consistency in the findings of this kind of qualitative research inquiry as well (Guba, 1981). Therefore, after collecting the data from each participant (palliative care provider), I gave each participant the option to review completed data transcriptions for assessment to ensure that these results are true reflections of their responses.

In keeping with the second principle of the trustworthiness criteria, I applied transferability to my research inquiry. Shenton (2004) defines transferability, as the ability to demonstrate that the research study can be applied to a different setting with the potential for different populations. To ensure transferability in my research inquiry, a thick description technique was used (Lincoln & Guba, 1985). I used the technique of thick descriptions such that I provided very comprehensive details of the research

processes (methodology choice, inclusion/exclusion criteria, location, and methods) that were completed within this study (Guba, 1981). As a result, I was able to provide a complete overview of the research context and ensure transferability in this study.

In keeping with the third principle of the trustworthiness criteria, I applied dependability to my research inquiry. Guba (1981) defines dependability as a method to ensure that the processes of the research study are stable over time. To ensure dependability in my research study, I used external auditors. Lincoln and Guba (1985) define external auditors as researchers not involved in the research process, which examine and aid in the evaluation of whether or not the interpretations and conclusions of the results are reinforced by the data (Shenton, 2004). My supervisory committee was instrumental in regularly providing me with many reviews of my interpretations and conclusions. Consequently the provision of ongoing feedback challenged me to frequently revise my work so that dependability was ensured within my study.

In keeping with the last principle of the trustworthiness criteria, I applied confirmability to my research inquiry. Anney (2014) defines confirmability as the process of ensuring the findings of the study are clearly developed from the data and is not shaped by the researcher's own characteristics, preferences and/or interests. In my research study, I ensured confirmability by using the technique of journal reflexivity. In keeping with the recommendation by Anney (2014), I kept a reflexive journal throughout the research process to ensure that the results of my study were derived from the data presented by participants and were not based solely on my thoughts or imaginations. This ensured that the study outcomes truly represent the results of each participant's thoughts and experiences subsequently limiting any researcher bias (Anney, 2014; Guba, 1981;

Shenton, 2004). For instance, at the beginning of this study, I assumed that poor patient care was solely aligned with palliative care provider support. However, during data analysis, participant experiences informed my understanding; existing contextual factors (limited provider capacity) greatly contributes to the amount of regular support which palliative patients may receive. Noting my assumptions allowed me to understand my position/stance on this issue, such that I could apply the criteria of confirmability to this study.

In the next chapter, Chapter Four, I present the findings of my study and identify the emerging themes that were derived from the data.

Chapter Four: Results

In this chapter, I provide an overview of the research results obtained from participant interviews. Six palliative care providers described their lived experiences in implementing the Gold Standard Framework (GSF) in oncology care, from a hospital-based outpatient setting. Firstly, the results of participant recruitment are discussed, followed by a description of participant demographic data and characteristics of the sample. Lastly, a detailed description of the qualitative results from participant interviews that were analyzed using the 7C's of the GSF Framework (Communication, Coordination, Control of Symptoms, Continuity of Care, Continued Learning, Carer Support and Care in the Dying Phase) will be discussed.

4.1 Results of Participant Recruitment

The recruitment of participants for data collection ensued from November 2016-February 2017. A recruitment email was sent out biweekly to all palliative care providers on LH's outpatient palliative care team, consisting of 4 registered nurses and 13 physicians. Of the 17 palliative care providers on the outpatient palliative care team who were eligible to participate in the study, 6 palliative care providers consented to participate in the study and provided their experiences in implementing the GSF within a hospital-based outpatient palliative care setting. Therefore the final sample of the study consisted of six participants.

4.2 Participant Demographics

A self-reported socio-demographics form was provided to each participant. Socio-demographic data were collected to help describe the characteristics of the sample in the study. The socio-demographic data (table 1 below) revealed the ages of

participants, which ranged from 38-60 years old, with a numerical mean age of 49 years. Two males and four females participated in this study. Five of the participants were physicians and one participant was a registered nurse (RN). The number of years that participants worked in the field of oncology ranged from 4 to 18 years with a mean of 9 years. The number of years that participants worked within hospital-based, outpatient palliative care ranged from 1 to 18 years with a mean of 8.2 years. Of the 6 participants in the study, 3 participants were employed full time and 3 participants were employed part time.

Participant Demographics	
Gender	2 males; 4 females
Age	Range: 38-60 yrs. Mean: 49 yrs.
Role on Hospital-Based, Outpatient Team	5 Physicians; 1 Registered Nurse
Number of Years Working in Oncology	Range: 4-18 yrs. Mean: 9 yrs.
Number of Years Working in Palliative Care from an Outpatient Setting	Range: 1-18 yrs. Mean: 8.2 yrs.
Employment Status	3 Full Time; 3 Part Time

Table 1.

4.3 Results of Participant Interviews

Data were analyzed according to the 7 C's of the GSF namely (Communication, Coordination, Control of Symptoms, Continuity of Care, Continued Learning, Carer Support and Care in the Dying Phase). The GSF facilitated the interpretation of the results which are presented under each of the seven components of the framework. The 7

C's were used as a guide for data analysis. Interview data, from which the 6 themes emerged are used to illustrate the themes.

4.4 Communication

Palliative care providers described the importance of 'Communication' in palliative care, which is the first component of the GSF. Three key themes emerged under communication. They were: Inter-Professional Communication, Establishing Patient Rapport and Advance Care Planning. Furthermore, participants felt that enacting these themes helped facilitate the first component of the GSF.

4.4.1 Inter-professional Communication

Participants identified the impact of strong inter-professional communication between the varying healthcare disciplines in the delivery of palliative care from LH's outpatient setting and the consequence on patient-focused outcomes.

Inter-professional communication among the varying healthcare disciplines in palliative care is described in the following exemplar,

I think, this team does a very good job through inter-professional rounds through the daily work in the clinic. When you are in the clinic you are there, working with a nurse, the patients and the family. There is very good communication with the secretary you know we have good access to ancillary services, pharmacy, social work, and I think all of that works well (6, L. 31-36)

and,

Sitting down and having those inter-professional rounds together are very helpful for me when we have a problematic case, when that is actually discussed amongst the team even though I have never seen the patient or know the patient. When the time comes where I become the provider for that patient I have an understanding of what's been happening that may not necessarily be easily gleaned from the notation so that's definitely one of the things that is helpful in me providing the care (4, L.272-277)

Here the participants speak to the impact of team discussions with inter-professionals of the outpatient palliative care team. The participants emphasize the necessity of such discussions, as these are beneficial in helping the team administer optimized levels of care with palliative patients as indicated in the overall use of the GSF. Similarly, another participant speaks to the impact of strong inter-professional communication in the following quote,

R: We had a patient who was end stage with a line mass that was impinging on the superior vena cava (SVC) and was a potential SVC syndrome who did not at that time want any palliative treatment, no radiation, no chemo, nothing. So supportive care was what we were seeing her for, but in my experience working in a multidisciplinary team, when the family phoned in to say that she was very symptomatic, could not breathe and they were starting to panic, I looked at the whole picture in our centralized data base from all the disciplines and determined that radiation was offered on the front palliative radiation to the mass in her chest, to try and control the potential for SVC obstruction, so I called the patient's radiation oncologist and the palliative care doctor and we conferenced to decide did the patient need to come in for urgent palliative RAD and the radiation oncologist called the patient directly and then we called the patient directly and we made a plan how we are going to treat her. So rather than just assume that this was supportive care only, we made sure that we were clear about the patients' goals of care and that all disciplines had a chance to discuss whether there could be an adjustment in the plan of care so that she got what she had wanted for her quality of life, so it was a continuum to make sure that all members weighed in and that the patients adjusting needs were then re-evaluated to make sure that those were her goals of care currently.

M: Did you find that you were able to communicate well and that's what helped you determine what these goals were?

R: Yes, absolutely, we had open dialogue with radiation oncology, with medical oncology, with social work, and then our palliative care team were able to discuss between them whether they felt she needed to come in today to be seen as opposed to perhaps a home visit for supportive care from our physicians (1, L.67-88)

In the aforementioned quote, the participant provides an in-depth, first-hand experience on how quick thinking supported by inter-professional communication amongst varying disciplines in palliative care enabled an optimized level of care for a patient in an

emergency state. A high level of strong inter-professional communication propagates enriched patient care, thereby eliminating barriers in achieving patient care goals.

Similarly, another participant speaks to the impact of inter-professional communication on comprehensive care in the following excerpt,

We can do advanced care planning, and symptom control. We are one of the specialties that does it the best because we do it more holistically through communication with various professions involved, and also if the patient is not going to get better, we are there for the end (3, L. 440-443)

Here the participant reveals the strength behind strong inter-professional communication and how this enables the ability to provide a comprehensive approach to care for palliative patients. A main component of engaging in the palliative care journey for patients is the experience of a comprehensive approach to care which involves all spectrums of health in a patients care trajectory (Brennan, 2013). Similarly, in the following quote, another participant speaks to the comprehensive provision of care by establishing the strength behind communicating with healthcare disciplines separate from LH's outpatient team namely, Community Care Access Center (CCAC).

So the things that we have you know set up is for communication is getting more providers at the table not just within our team, so like CCAC case coordinators are now attending the monthly palliative care rounds that we do together so we go over cases and we actually review problematic cases that we are finding and therefore getting a better continuum and coordination of services between our team and the teams that are actually at the household so that's one of the key things that we have found very helpful (4, L.154-159)

Here the participant describes how elevated levels of inter-professional communication with disciplines outside of the hospital facilitate a stronger continuum of care for palliative patients. The CCAC¹ is responsible for coordinating care outside of the hospital for palliative patients. However, when there is a lack of communication around

¹ As a reminder, the CCAC and the LHIN is now considered one entity

the provision of care, outcomes may result in frantic phone-calls, visits to the outpatient palliative clinic or even worse, reliance on emergency department services. Similarly, another participant provides her experience on CCAC relations with the hospital-based, outpatient team in the following excerpt,

We do have monthly meetings where we try to talk and CCAC does attend a portion of it and we bring up issues but let's be honest we are not able to bring all the issues that occurred in the last month so we bring up just a few key things (5, L. 633-636)

Here, this participant acknowledges that inter-professional communication between healthcare disciplines from CCAC and palliative care providers of the hospital-based, outpatient team exists. However, due to many care concerns, the ability to have a full discussion around patient care is limited. The inability to sufficiently address all gaps in patient care increases the risk of providing poor quality palliative care for such patients within a home setting, thus resulting in a frequent need for emergency services (Shaw et al., 2005). Subsequently, both the hospital and patients are affected; the outcome of unnecessary, recurrent emergency visits leads to an intensified strain on healthcare budgets and patients do not receive their envisioned goals of care.

4.4.2 Establishing Patient Rapport

In this study, there was an overall consensus by participants on the importance of establishing patient rapport through communication. Many participants felt that taking time to build a solid rapport with patients played an integral role in laying the groundwork for continued effective communication onwards in the patient's care trajectory. One participant elaborates further on this in the following quote,

We had one fellow that came in and said that he would like physician assisted suicide because he didn't want to suffer. After the appointment, we changed his medications around, he saw social work and said if he could just get his pain

under control that he'd be happier, so then he wouldn't want physician assisted death. So once he went home he was reluctant to call and he was running low on one medication so he called me the day before yesterday and he said I need a refill, and I hate to bug you but what do you think about this, and I said no that's fine we will do that, but I want you to call me back in two days' time or sooner if it's not working. So he called me first thing this morning and he said, I know you are so busy and I really didn't want to call but you said it wouldn't be bothering you if I asked. I said, I most certainly am not bothered in the least, that is what we are here for, what is it? He said I think I have too much now and I was just going to take it but you said to call anytime and it would be okay. So I said yes we can decrease it that's fine. He said I am sorry to be a bother, and I said this is what we are here for, you are not bothering us! The reassurance that their concerns are going to be addressed without repercussions of being a bother, because I think a lot of the population, the older population are worried that they just zip up their lips and don't bother people, be a man, you don't need pain killers, just put up with the pain, and it will be alright, so the way you set up that rapport right on the onset, that you expect this to be a process, a recipe if you will with different ingredients for every person and we are not going to get it right the first time, it's going to take a little bit of trial and error to figure out what the right amounts for you are, because we have to go safely low and raise it slow and he said I remember you said that so now we need to lower it back down, so I said perfect! (1, L. 427-447)

The participant speaks to the importance of providing dependable support to patients thus encouraging them to rely on palliative care providers at any time. The provision of this type of dependability in care can lead to patients feeling secure throughout their care journey. Similarly in the next excerpt, a participant provides an in-depth, first-hand experience on the effect of instantly establishing patient rapport through effective communication.

This young man is 19 years old, and had testicular cancer. Testicular cancer causes lots of pain, very severe pain, so he was diagnosed, he was in chemo but with excruciating pain, so he was referred to us and the first thing he said to the doctor was "No I don't want to go" and they had to insist it is about pain control they are not going to talk about anything else but pain, so that's what we did, we talked, he became in remission. Once he was in remission and his chemo worked, the medication went down to zero, so we lost him but he came back about 3 or 4 years after, and he started to have pain and he knew the cancer came back. The first thing he asked is "I want to see palliative care" because he knew if he doesn't want to talk about death we won't talk about it but he wanted to have symptom control and you know it was me that saw him the first time after the

cancer started back again and I said you know “ we are going to talk about your pain but if you want to talk about anything else you know we can, so how are you managing” and at some point you know he said “ I think I am not doing very well” so I said “ How can we prepare and what do you want to do next” (3, L. 446-459)

Here, the participant indicates the comfort and security a patient felt in receiving palliative care when navigating through being diagnosed with cancer for a second time. It is evident that focusing on person-centered care with the patient helped shape the patient’s perspective with relying on palliative care for support throughout the care trajectory even after a substantial period of time. Establishing a therapeutic relationship with patients can convey consistency, dependability and competence in care (Belcher & Jones, 2009). Another participant speaks further to this in the following excerpt,

I do a lot of teaching in terms of what to expect going forward because some people know they are going to die, they don’t know what that is going to look like, they don’t realize that, that’s going to mean over time it’s going to get harder and harder to walk and then it gets harder and harder to stand. They don’t know that, they know they are going to die, they have no idea on how that is going to look, they think that like on TV the person is still doing something and the next day, they are not talking but it prepares them for the fact that it is going to get more difficult for me to walk but I will tell the doctor about it and there may be things that she can do to help. She may put in a PT (physiotherapist) to do an assessment for a walker, she may put in an OT (occupational therapist) to put in an assessment for equipment for the home, things like that, so I do a lot of teaching on what it’s going to look like and what to expect and I do a lot of teaching on when it is appropriate to contact us and when you should contact us immediately, but all that takes time and they are so overwhelmed so sometimes you just repeat yourself for a few visits and then it’s like a well-oiled machine and they just call every month at that time to renew their meds, it gets better (5, L. 817-830)

Patients with low health literacy may tend to ask fewer questions regarding palliative care, as a result of being unaware of what palliative care entails (Schapira, 2008). In the above quote, the participant indicates that by establishing patient rapport and being consistent through effective communication, patients may feel more inclined to seek, rely

and/or follow palliative care provider directions of care efficiently. Similarly, another participant speaks further to this in the following excerpt,

There isn't somebody just sitting here reading prescriptions and it takes time, and it takes time for it to be delivered, so not letting stuff run low or out, creating an avenue for open communication between the patient and us without fear that we are going to get mad that they are bugging us, because I get told, I know you are busy, I don't want to bug you. So setting up that rapport up front. We are a team and we want to hear from you if things are not working right and reinforcing that with every phone call (1, L. 418-423)

Here, the participant speaks to the impact of establishing a strong patient rapport through active communication as this empowers patients to rely further on palliative care providers when in need of direction to receiving palliative care. Consequently, patients can experience better treatment outcomes, as the provision of a strong clinician-patient relationship is deemed influential in patient satisfaction and compliance with palliative care provider healthcare recommendations (Bakic-Miric & Bakic, 2008).

4.4.3 Advance Care Planning

Participants emphasized the importance of communicating with palliative patients about advance care planning. One participant speaks to this in the following excerpt,

If you have the conversation [advance care planning] before, you get that [emergency visits] less and less, so probably earlier in my career I did more home visits, did more regular visits, I had to get comfortable with what I was doing, and now I have the conversation early and hopefully have the symptom kit in early and have the supports in early, so that I don't get panic calls, so that's the ideal situation (2, L.376-379)

The same participant elaborates further,

Having that [advance care planning] discussion early so you don't have to go through the emergency. I have admitted patients directly, to a hospital bed, because that was the plan, so just like if you have your birth plan, you have your death plan (2, L.463-467)

In the above quote, the participant speaks to the importance of being able to communicate about advanced care planning and subsequently outlining a solid plan of care.

Discussions beforehand with palliative patients' on what should be done in a case of an emergency will permit for the recognition of their envisioned goals of care. Similarly, another participant speaks further on this in the following excerpt,

You have the conversations about advanced care planning and there is always that sense of hope that they will continue to get better in some way or prolong their life in some way, and therefore when it comes to an acute illness that makes them dramatically worse, the discussions always have to take place. Do you want to stay home and have this be your last illness or do you want to go to the hospital, find out what's going on and reverse the process (4, L. 231-235)

Here the participant speaks to why communication with patients on advanced care planning should occur. Advance care planning is extremely important as palliative care patients may lose their ability to make rational decisions in the midst of a pain crisis. Such conversations may be beneficial towards helping palliative patients feel autonomous and in control even through the very last stages of life, thus avoiding a dying experience that negates their wishes. In a slightly different vein, one participant acknowledges the positive impact of using the prognostic indicator guidance from the GSF on having conversations about advance care planning in the following excerpt,

I spoke to patients about advanced care planning, understanding where they are at with the disease. Where it was most helpful is when there was a crisis maybe 2 or 3 weeks after we had conversation, so I was glad that I had the framework, that guided me to have that conversation with the patient earlier, so I think the patient was still in shock, but I think when we started to talk, they were not completely surprised, that this was happening, so I think that's the best thing to really guide, I use it [prognostic indicator guidance] to guide me when to talk to the patient about when things are not going that good, and what would be plan A and plan B, and we go from there. I used to always say let's hope for the best, but if the worst would come, what plan would we have? (3, L. 33-43)

and,

It [prognostic indicator guidance] gave me an insight, into the fact that I needed to talk about advance care, well advanced care planning, about the care plan (3, L. 80-81)

Here the participant speaks to the impact that utilizing the prognostic indicator guidance can have on conversing and creating an advanced care plan with palliative patients. The purpose of utilizing the prognostic indicator guidance is to help physicians anticipate the likely needs of patients. Consequently, this can lead to proactive care aligned with the patient's care goals such that optimized standards of care which are administered throughout the end-of-life process.

In summary, participants noted the importance and impact of communication in palliative care with respect to inter-professional communication, establishing a patient rapport and advance care planning. The themes emerging from the first component of the GSF will be examined further throughout the next chapter.

4.5 Coordination

It is important to note that the second component of the GSF is 'Coordination'. However, the responses, which participants provided, did not identify with this component of the GSF in terms of the frameworks' definition. Coordination in the GSF is defined as the nomination of a GSF coordinator that is accountable in ensuring that proper utilization and implementation of the GSF is carried out amongst any designated palliative healthcare team. Participants identified that coordination is an essential component to enabling high quality, person-centered palliative care. Although participants' responses did not identify with the exact definition provided by the GSF, participants noted how coordination of palliative care was established through strong inter-professional communication with fellow team members and allied health.

Therefore, such integrated care is instrumental in enabling patients to experience the ideal palliative care journey. Further exploration in to this component will be discussed in chapter 5.

4.6 Control of Symptoms

The major theme that emerged from the third component of the GSF was pain and symptom management. Additionally, participants felt that providing pain and symptom management helped facilitate the component of “control of symptoms” from the GSF.

4.6.1 Pain and Symptom Management

Participants provided their perspectives on the role of palliative care in controlling symptoms and by means of which pain and symptom management occurred for palliative patients diagnosed with cancer. One participant describes her perspective on what palliative care entails relative to symptom control in the following,

Palliative care essentially, is symptomatic control, caring of the whole person to improve the quality of life when they have a life limiting condition that’s incurable, but life limiting could still mean years, this person could have lived till 90 (5, L. 277-280)

When incorporated properly into a patient’s trajectory of care, pain and symptom management can enable patients to experience a higher quality of life, which is a fundamental aspect of palliative care. In the next quote, the same participant goes on to describe this further,

We have patients who are still working, who we are following. They have an incurable diagnosis; it is affecting their life. We keep controlling their symptoms; it’s improving their quality of life so that they can function (5, L. 289-291)

Effective symptom control can have a great impact on a patient's quality of life.

Adhering to patient care goals relative to pain and symptom management can exacerbate optimal results over time. In a slightly different way, another participant provides her experience on how anticipated pain and symptom management is tackled in the following quote,

If we know that we may be potentially heading to that [symptomatic] direction, we put it in something called an SRK kit which are medications that the home care nurses can initiate in the event that the patient is no longer able to swallow or becoming symptomatic, this really helps (1 L. 307-310)

This participant speaks to supplying a Symptom Relief Kit (SRK) for palliative patients in need of urgent aid in a home setting. An essential component of palliative care is foreseeing patients' pain needs when dealing with pain management and other symptom control. Similarly, in the following quote, another participant provides his opinion on the Symptom Relief Kit and its benefits towards patients relative to pain and symptom management,

With palliative care we have a symptom relief kit that's available now, so if you have it in the home you can actually utilize different things when you need it quickly (2, L. 354-355)

Enabling the use of an SRK for pain and symptom management can aid in preventing outpatient clinic visits or emergency visits to the hospital. Consequently this can be beneficial to patients who desire to be aligned with their anticipated goal of care of remaining within a home setting. This is essential as the majority of palliative care patients aspire to remain/die within a home setting when requiring care (CCO, 2017). In a slightly different vein, palliative care providers recognized that utilizing the Edmonton Symptom Assessment System (ESAS), a significant symptom assessment tool, was

highly effective in pain and symptom management for palliative patients. Participants indicated the benefits in the following quotes:

I think that palliative care team does a good job. Most of us will use the ESAS scoring system, to look at, monitoring control of symptoms and that is something that is more formalized where all of the LH palliative care patients when they come into register for their appointment. They are doing a computerized ESAS scores so that we can compare over time (6, L. 38-42)

and,

But certainly symptom control is something that I talk to them about and in here we use a lot of the Edmonton scale, when we ask them those questions (3, L. 500-502)

and,

Well I think the ESAS helps a lot because it opens the conversation about symptoms and with the talk about that. It also helps them focus where their concerns are because sometimes you are super overwhelmed and that helps me identify what is stressing the patient and what is stressing the caregiver. It also gives us something, like these ten things we review at every visit. It adds to the symptom management, every visit you come back you do the ESAS and I can see exactly what is going on with your pain, I can see exactly what your perception of your shortness of breath is so its adds to pain management so you can see and we can chart it like there is a flow chart I can see the numbers going up and down so that helps a lot. (5, L 531-538)

and,

I think you know we focus a lot on control of symptoms and I think our ESAS scoring assessment is our way of sort of continuing to come back to that (6, L. 266-267)

Having the availability of an assessment tool such as the ESAS enables palliative care providers to efficiently measure and monitor pain and other symptoms. Consequently this enables palliative care providers to communicate with patients on current and anticipated preferences of pain and symptom management. Similarly in the next quote, another principal symptom assessment tool is discussed. Here the participant speaks to the relevance of utilizing, the palliative performance scale (PPS) concurrently with the GSF.

With palliative care, we use the palliative performance scale (PPS), I always go back and use it all the time and sort of look the subtleties, that's really where the framework is important, you might be able to do the general comments and generalities but then it gets into the subtle details and you sort of have to go back and have a look at it again (2, L.110- 114)

This participant notes the significance of implementing the GSF jointly with the PPS in relation to being thorough when attending to patients' pain and symptom management concerns, thereby resulting in a gold standard of care. This further emphasizes the importance of utilizing pain assessment tools along with the GSF to help control patients' pain symptoms.

Participants commonly expressed the importance of advocating the use of pain medication for anticipated pain in palliative patients in order to induce symptom control.

One participant speaks to this in the following excerpt,

I think I find that we talk to them about pain and symptom management and I will tell them certain symptoms I will not be able to manage without medication. There is only so much I can do for pain, I mean you can do some relaxation distraction but I mean if you are in severe cancer pain I need to do pain meds, so this helps getting things under control and so I talk to them about the different ways the pain medication can be delivered (5, L. 492-497)

Here the participant indicates that anticipating patient pain symptoms can aid in effective symptom control. Ensuring that palliative patients receive adequate pain and symptom management is a fundamental element of the GSF.

In summary, participants in the study felt that their biggest role in providing palliative care related to pain and symptom control. Given that the participants of my study were primarily physicians (and one nurse), it is not surprising that pain and symptom management were central to their practice. Participants also deemed the use of tools such as the ESAS or PPS as being beneficial towards the assessment of pain and other symptoms that palliative patients face; in-order to provide a gold standard of care when implementing the GSF.

4.7 Continuity of Care

The participants in this study spoke to how they ensured a continuum of care to palliative patients from a hospital-based outpatient palliative care setting. Participants noted various factors that either facilitated or acted as barriers to palliative patients in experiencing appropriate levels in the continuum of care. Therefore, there were three key themes that emerged from the fourth component of the GSF namely: Reliable Access, Electronic Maintenance of Patient Records and Inadequate Community Support.

4.7.1 Reliable Access

Participants expressed that the ability for palliative patients to have reliable access to palliative services 24/7 from LH facilitated a continuity of care. Various participants speak to this in the following quotes:

It really gives them reassurance that we have this under control, and this is what we would do. This is how you get in touch with us if anything was to go wrong and if you needed more from us, this is how we would go about it, I guess that helps, dealing with the symptoms help, and with continuity, we cover this 24 hours a day (5, L.69-73)

and,

M: You feel like there is not enough support?

E: No, it's a 24/7 service (2, L. 287-288)

and,

Any time we have had anybody that is phoning in urgently, making sure that their needs are met urgently, we have people available so we will page them and they will call us back, they will phone the patient directly (1, L.103-106)

and,

We have 24/7 access to us, which I think is huge. A lot of the time the nurse is on the phone supporting the caregiver. They get to know some of them really, really well and then after hours, on call it's us and I think sometimes that's the call you get in the evening too or at 2 o'clock in the morning and it's not necessarily somebody needs something but somebody needs to talk to somebody (6, L.79-83)

These participants point to the importance of creating a comfortable atmosphere for palliative patients to rely on palliative care providers with regards to the provision of healthcare support in all spectrums of care; physical, psychosocial and emotional (CCO,

2017). Ensuring reliable access enables palliative patients to experience a consistency in support at all times. Consequently, this ensures a continuum of care for palliative patients in all environments both at home and/or within a hospital facility. In a slightly different way, another participant details how reliable access enables continuity of patient care.

This experience is further addressed in the following excerpt,

For some patients who are not as sure, I kind of look at their bottle and I say okay they take x amount a day, so I tell them when you have ten left in the jar, call and sometimes people say you know what, I'll call when I am close to running out and they don't really kind of think about the fact that oh yeah when I am down to 10 I only have three days left, because 10 seems like a lot of pills. So sometimes I give very specific instructions to patients I think might not have a good handle on it. Other patients are like, I've had an accountant once who literally had everything marked down to the tee and had clear inventory of everything. In that case I knew he knew when to call when he was within a few days of running out. Other patients are just overwhelmed, so I say when there is x amount of pills you call and leave a voice mail and we will take care of it (5, L. 480-489)

Here the participant's experience speaks to the strength of this hospital-based outpatient palliative care facility and the ability to provide prompt medical care with simple needs such as patient medication refills. Ensuring reliable access to exemplary care enables palliative patients care needs to be met in a timely manner while also instilling a sense of confidence in the access to the 24/7 palliative care services provided by this palliative care facility. Similarly another participant describes the strength of this facility with access to care, resulting in decreased wait times for patients seeking palliative care services. This is explained further in the following quote,

I think that in a lot of places, the barrier is access to palliative care appointments and teams I think our statistics are really good that we get our waiting times are really short and we do get people in and when somebody needs an urgent appointment they get in, so I think you know that is a good part for us (6, L. 409-413)

Access to quality palliative care at the time a patient needs it, still remains a significant barrier when seeking this comprehensive approach to care (CCS, 2016). This participant provides her experience on how this facility tries to eliminate this barrier by prioritizing a decrease in wait times for palliative patients. Taking steps to ensure that such barriers are eliminated can place more focus on guaranteeing patients experience the best quality of life and care satisfaction, promised through palliative care. Alternatively, another participant speaks to how a reliable access to palliative care services within the facility can also be of benefit towards in-home care providers in the following quote,

Sometimes the nurses [from CCAC] can be inexperienced and then they are overwhelmed. It's scary to see someone dying and it's a life and death thing, so you really get scared. So they call in and you get a lot of education from our nurses over the phone and our nurses do make it a point to try and education and support because they want these people to be functioning autonomously (5, L. 584-588)

This participant speaks to the impact that outpatient palliative care nurses on the phones can have on new or inexperienced caregivers providing palliative care for patients in need. Adequacy in meeting palliative care needs within a home environment may influence a decrease in unnecessary emergency visits/stays, thereby enhancing the institution's cost-saving measures (Riley & Lubutiz, 2010).

4.7.2 Electronic Maintenance of Patient Records

Participants identified how the electronic maintenance of patient records enabled continuity in patient care. Specifically, one participant described the impact of this system on palliative care provider relations in following quote,

We have a very good, electronic medical records system to be able to allow that communication piece and continuity piece to be between our team members much stronger (4, L. 161-162)

Having up-to-date, electronic information on each patient was identified as an advantage when approaching the provision of palliative care. Consequently, this strengthens the potential for patients to experience a continuance in palliative care across-the-board.

Another participant elaborates further on this in the following quote,

We have a main database of information in our computer systems that all disciplines including allied health enter information into. So by collecting that information, we have a solid understanding of what the patients goals for care are, what the teams understanding of the plan of care is to meet those goals, so that regardless of who access the information we are all on the same page and meeting the common expectation of where we are going with this patient's care. So it is helpful in the sense that we are all understanding, that what the patient wants is our goal of care and with the exception of, making sure the patient is safe, making sure that the care is appropriate and that we are considering quality of life, that is sort of the Gold Standard that we are all following in a centralized location for information (1, L. 56-64)

The same participant adds,

We have obviously our documentation with screens which are geared to keeping the other members of the team up-to-date. We have a telephone triage system so we have a nurse on the phones Monday to Friday sitting there collecting that information from phone calls and updating our system. We have also email for transfer accountability so if we are sending an email to update the team that we include all members of the team so that everybody is on the same page and we get responses back (1 L. 94-100)

This participant speaks to how the electronic documentation of patient's health information assists all health care disciplines involved in a patient's palliative care journey to be up-to-date with regards to a patient's care status. Ultimately, this can benefit with expediting continuity in patient-centered care. This illustrates how this technological method contributes a unique opportunity for palliative care providers of varying professional disciplines to be "on the same page" and minimize the frustrations associated with having several healthcare providers involved in a patients care journey. Similarly, another participant speaks more on this in the following quote,

As a team we are on call 24 hours a day and I think nobody wants to be on-call but we are. But the benefit of that is that the patients know they are not completely on their own, meaning you might not be able to reach me even though you see me more often, but if you are in crisis on a Saturday night, midnight you can call, and my colleague will have access to the charts, because we access remotely through the computer right from home. We can just look up the last time she saw the doctor so and so this is what they did, this is the issue and they will make whatever changes they need to make and put it in the chart meaning. The next time they see me, I will be aware of whatever things will be changed (5 L. 514-519)

Here, the participant indicates that the ability to easily access patient records electronically permits palliative care providers to remain informed by gaining a comprehensive up-to-date overview on a palliative patient's healthcare status. Subsequently, the treatment needs of patients are met efficiently and effectively, resulting in optimized patient care and patient satisfaction.

4.7.3 Inadequate Community Support

Participants in this study felt that there was not enough support by community agencies in the provision of palliative care to patients outside of the hospital-based, outpatient facility (LH). One participant speaks to this in the following quote,

It's a vicious cycle, and why do people go to the hospital? It's because they don't have the supports at home, so it comes back to being at home (2, L. 455-456)

The same participant elaborates further,

We go back to the thought of if we had put in the supports right you might live longer so that does happen, so the person might have not been doing well at home, and why aren't they doing well at home well maybe because there weren't enough supports, then you put them in hospital and they live longer, because you actually gave them the support they needed (2, L. 472-476)

In the above quote, the participant speaks to the impact of unsupportive care within a home environment and the consequences on patient care. Another participant speaks further on this in the following quote,

I think there are gaps in care for the home visits to people. The patients who progress from outpatient ambulatory to end of life in the home; there is a huge gap on the care that is provided to them. They are told that they will receive support in the home, but I don't think it is enough, I don't think it's enough to keep our patients out of the emergency and I don't think it's enough support to keep them from wanting to be on the palliative care floor, because they are not coping, and I don't know what the answer is, but they are told if you want to pass away at home we will make that happen, but what we don't tell them is that they are going to be required to do some of this care, and not everybody is geared for it. We don't have enough hospital beds to keep up with the patients who can't cope at home, where symptoms aren't managed well at home, and I don't think we have enough home support to keep people in the home, if they are wanting to manage the physical care, the emotional support, I don't think it's there, I don't think we are touching the surface of what they need, because a lot of phone calls we get are just fear and anxiety and the nurses have been and they are not due to come back for a couple of days and they are petrified to be the person holding that ball of care for that loved one and not nursing or medically versed in any way but yet they say how can I do this by myself, you said there would be support for me to do this, but nobody is here, where are they? (1, L. 454-469)

This participant speaks to how family members within a home setting feel isolated and distressed due to inadequate community support, resulting in frantic phone calls to nurses in the outpatient clinic. Patient care can be very emotional, stressful and demanding on family members who are living with an individual dealing with a life-limiting illness such as cancer. Additionally, such actions contribute to the experience of caregiver burnout (Berry, Dalwadi & Jacobson, 2017). Ultimately, this can have long lasting effects on patient's goals of care to die at home. This is elaborated further in the following quote,

A lot of times there are patients, so compared to say being in the hospital where if something is going on, they have got access to the doctor 24/7. For example if we need a change in medication, it is going to take 10 minutes to get that ordered and to get that there, whereas I think at home they are looking at 40 hours of support a week for somebody who is in the final stages of dying, a lot of times that is just not enough and I think that's why a lot of the times, even if their wishes were to try to die at home they end up being admitted to the hospital because there is a lack of support (6, L. 100-106)

This participant speaks to inadequate community supports as a main factor of why palliative patients engage within dying experiences contrary to their wishes. Adhering to patients dying wishes nearing end of life is a main goal, not only of the GSF, but also palliative care as a whole. Therefore, high levels of consistent and reliable support in all spectrums of a patient palliative care journey are required to achieve quality care at the end of life. In a slightly different but similar vein, another participant provides his input on how discrepancies in community care frequently occur and thereby result in poor patient satisfaction. This is elaborated further on in the following quote,

The outpatient palliative care team in the hospital is under a different organization than CCAC. CCAC manages all the outpatient nursing that goes to the home and outpatient services that go to the home, and therefore what we might think is important and helpful is not necessarily what happens as a result (4, L. 289-292)

This participant adds further,

CCAC manages all the non-physician services at the home, we are the physicians that go and do visits at the home so we order things but again we don't have, because of a different organization depending on the budget, depending on who is the coordinator, the patient may not get the kind of care that they actually need so that's one barrier that's not easily fixed, that's more a systemic problem (4, L. 294-298)

This participant speaks to the need for systematic reform relative to care organizations operating in silos, notably LH and services provided by the CCAC. The participant attributes this as an extensive factor that influences the realistic level of care provided to palliative patients who have a preference to die at home. The same participant speaks to budget constraints as another factor that exacerbates the discrepancies associated with inadequate community support in the following quote,

Well the reality is the supports are not there, so they [patients] are saying this is what we want but on the other hand CCAC doesn't have the resources to do it, so that's a combination of a lack of continuity because hospitals do something, they

are a different organization, different funding envelope and CCAC is a different organization, different envelope and so that's the lack of continuity between the two and then you know just the resources that you would expect if you had a priority of doing something of reducing stays in hospital, that funding should also be near it and the support of that happening in the outpatient setting (4, L. 447-454)

This participant speaks to the importance of sufficient community care funding to enable high quality care for palliative patients in a home setting. Consequently, a lack thereof impacts hospital resources; a vicious cycle of frequent hospital visits is exacerbated thus more funding is spent on unnecessary emergency visits and in-patient stays, which is costly. Another participant goes on to explain the effects of insufficient funding to support outpatient care in the following quote,

If there were the [financial] resources available so that we could look at defined objectives, and here, we are sitting around a table trying to identify what the problems are but we are not hearing from the outside world (6, L. 548-550)

The same participant elaborates further in the following interview excerpt,

I think as a physician our goals are trying to provide the best quality of care period. We do realize that there are fiscal constraints and you try to work within that system as best you can and then as a physician in the hospital. We are also trying to work in the cooperate structure to try to align our goals with what the cooperate goals are because otherwise you are not going to go anywhere if you have a goal that is completely maligned with their goals, it's not going to work but sometimes you feel like you can't really get accomplished what you want to get accomplished because you are trying to do all those things! And then you end up sacrificing what you really want for something that could be wishy, washy because that is all you can do with the resources you have (6, L.655-663)

As dying is an integral part of life, resources to support this process are necessary. In the above quotes, the participant speaks to the impact of insufficient financial resources. A lack of resources due to insufficient funding impacts the provision of high quality palliative care. Consequently, patients suffer the most by not receiving excellent

standards of palliative care at the end-of-life because of such financial discrepancies in funding.

In summary, participants indicated how a reliable access to palliative care services and the electronic maintenance of patient records helped facilitate continuity of care. Participants also expressed that inadequate community support from care provision agencies provided by the CCAC stands as a barrier to a continuum of patient care. Adequate support aids in limiting the gap between a palliative patient's preferred and actual place of death. Furthermore, adhering to patient preferences is a core element of the GSF. Therefore, the barriers around providing a continuum of care from community support agencies should be addressed. This will be discussed further in the next chapter.

4.8 Continued Learning

Participants in this study discussed various aspects surrounding the component of 'continued learning'. Two themes emerged under 'continued learning' including the importance of employing a standardized approach and the consequence of poor educational supports. Furthermore, participants felt that the occurrence of discrepancies in these areas regarding continued learning served as barriers to implementing the GSF as a whole from a hospital-based, outpatient palliative care setting.

4.8.1 Standardized Approach

Participants outlined the need for a standardized approach to implementing the GSF in the delivery of palliative care from a hospital-based, outpatient palliative care setting. This is elaborated further on in the following quotes,

It would be nice to be able to say we are following a gold standard in our approach to providing this care rather than a lot of it is individualized. Here we

have a team so I think we are fortunate because we are sharing ideas and trying to do things in a similar way but it's not so set (6, L. 529-541)

and,

So I think it would be great if we had this standardized approach, what they have been able to do in England has been fantastic, they have been able to have this across the whole country and be able to do this, for how many, I don't know how many years they did it, but for us I mean just having it within the hospital itself implemented by all physicians would be a huge first step (4, L. 18-22)

and,

I think just a standardized approach to implementing the framework, and even guidelines in general, that's what we lack, and part of that is because physicians and NPs are pretty autonomous people and they don't like to be told what to do, but if you can base it on research and science, and convince people of that I think it will be better implemented (2, L. 638-641)

In the above exemplars, the participants note the impact that standardizing the implementation of the GSF amongst all practicing palliative care providers can have on the delivery of palliative care. Having a set standard to implementing tools instituted for exemplary patient care could limit variations in care provision from one palliative care provider to the next. Other participants speak further on this in the following excerpts,

I think, this allows us to have a common vocabulary that we would then be able to communicate amongst all providers, and therefore it would allow much more. It's not going to be seamless but a lot better transfer of accountability from one provider to the next as a result so now having the lack of a framework in a standardized way that we work in, we all are kind of doing what we think is best practice. We will do it, however because all of us are going to be different providers. We have certain things that we do a little bit differently which is something that is a risk for the patient in terms of gaps of the care they would receive as a result (4, L.64-71)

And,

I think working in a team. It would be preferable that everybody would know about it [GSF] and use it [GSF] the same or we each have our style, but I think this is the gap here is that just a few physicians know about the framework and they don't really use it. We don't really use it at the potential that we could use it, because it's not a team thing it's more of an individual use (3, L. 134-138)

Here, these participants reveal that inadequate knowledge about the GSF among palliative care providers can be detrimental, as their potential to deliver optimized care

can be compromised. Limiting such barriers in acquiring knowledge about the GSF can bring about many benefits. One participant speaks further to the benefits associated with all palliative care providers systematically implementing the GSF in the following quote,

It impacts patients because I think if we would all use the gold standards framework, systematically, with all our patients I think the patient satisfaction of all our patients would be much, much better and also the team satisfaction! Because when you have the impression of a work well done it boosts your morale (3, L.376-379)

A universal approach to implementing the GSF in hospital-based outpatient palliative care delivery can facilitate an easier approach to exchanging expertise amongst palliative care providers. Furthermore, not only can this boost patient care satisfaction but also encourage feelings of camaraderie amongst team members as stated above. Additionally, another participant provides her recommendation on how to support a more standardized approach of implementing the GSF in the following excerpt,

I think just bring it up; I think the best thing to do is a short presentation, just to kind of bring it up. A lot of us will go to a talk and hear something and then it will stick and now it changes how we practice. Just the fact how we brought it up in depth today will continue to change the way I frame things and I am sure anyone else you talk to that will change as well, just the awareness, because I don't think any of these concepts are foreign and if you don't do it then this highlights what needs to be done (5, L.913-918)

In the above excerpt, the participant indicates that more formal discussions with palliative care providers surrounding the implementation of the GSF may help raise awareness on the use of the GSF in the delivery of palliative care. Consequently, ensuring a standardized approach to implementing the GSF can be beneficial on the levels of consistency associated to the delivery of palliative care to patients seeking this comprehensive approach in dealing with a life-limiting illness.

4.8.2 Poor Educational Supports

Participants spoke to the importance of strong educational supports for providers implementing the GSF in palliative care. One participant speaks to this in the following excerpt,

You have to educate on what it is and also how to implement it [GSF]. Exactly how you do this [implement the GSF], and you have to know why you do this (3, L.539-540)

Here this participant reveals there is grave importance in supportive education regarding implementing the GSF in hospital-based outpatient care. Another participant describes why educational support for implementing the GSF is important in the following interview excerpt,

We have no direction like that in the sense, these are the standardized processes that will work in your organization, instead we have, ok, these are the principles go ahead and implement them. So that's the problem, because everybody is making the wheels somewhat in order to implement something that we are told to do and so once you do that, the processes are being different from one organization to the next, you will have gaps, you will have barriers, and you will have different language, different vocabulary (4, L.392-397)

Here this participant indicates that poor educational support on how to implement instituted tools like the GSF can cause ambiguity in the proper delivery of palliative care towards patients in need. On the other hand, other participants elaborate on the effects improper educational support can have on palliative care providers in the following excerpts,

It is based on the UK framework but I mean they actually have resources defined in each of the areas of the framework so it's great to say I want to look at control of symptoms, but where do I go in the Canadian supports? It's an idea but where is the information? I want to look at continued learning, where do I go, in palliative care supports that I can go to get help? (6, L. 522-526)

And,

D: Cancer Care Ontario and at some point the LHIN too

M: So you are finding, that they are not providing the supports for you to actually carry this out?

D: No, it seems that the entire burden is on us and now we have to deal with implementing the framework (3, L. 414-416)

Here the participants indicate the burden that is experienced with the lack of direction and/or educational supports for implementing the GSF in a hospital-based, outpatient palliative care setting. It is evident the feelings of abandonment regarding the provision of educational support to implement the GSF stems further than at a local level. This is elaborated further on in the following quote,

I think that our team, yes we can do this [implement GSF] but if it would come from CCO to give some education conferences, or something around that. If it is very important and they promote it, why don't they organize something, but I find sometimes they want to implement this, but they don't follow up with this, they don't give any resources, they don't give any education, okay here's the list you have to do it and that's it! (3, L. 366-370)

The same participant goes on to emphasize this point,

So it's the education of the team, now if it's mandated by CCO, why haven't we received some push through them on that? (3, 520-521)

Here this participant reveals that higher institutions associated with mandating the implementation of the GSF are responsible for organizing such educational supports. Addressing the gaps in educational support at a broader level can provide the necessary support for palliative care providers to feel secure in implementing the GSF with confidence and competency. Ultimately, this will result in coordinated, high-quality, patient-centered care.

In summary, participants attributed the lack of a standardized approach towards implementing the GSF and poor educational supports as reasons to why this component was not fully sustained within the realm of delivering optimal palliative care, according to the GSF. Additionally, participants felt that by ensuring this, there would be

consistency in levels of palliative care delivery in a hospital-based, outpatient setting. Therefore, this further emphasizes the need for educational resources to be available for palliative care providers to assist in the implementation of the GSF.

4.9 Carer Support

Participants noted that the component ‘carer support’ was critical to optimizing a patient’s palliative care experience. The theme ‘active family involvement’ emerged from participants’ responses in the study. Additionally, participants felt that actively involving loved ones within a patient’s palliative care journey facilitated the component of ‘carer support’ from the GSF.

4.9.1 Active Family Involvement

One participant describes their experience of providing carer support in the following excerpt,

I find when I talk to patients and family members, they are very appreciative of knowing this is what we expect next. The patient will be sleeping most of the time, the breathing might change after that, things like that, so having that kind of end of life prognosis and vision for them, they find much more sense of control that they can have as a result. They can anticipate and know what decisions need to be made at the time because they themselves can understand the process that is going on (4, L. 330-335)

Here, this participant speaks to helping carers develop confidence in accurate decision-making by preparing them to have realistic expectations throughout the end of life process. Similarly another participant speaks about active family involvement in the following quote,

I knew that this patient could die very, very quickly, so I asked to speak to her family and she said “they are coming, but you don’t need to speak to them.” By the next day she was starting to be confused, so I knew to speak to the husband, he knew that she was very sick, I gave him the diagnosis and we discussed about no resuscitation, and so she died in a couple days (3 L. 69-74)

The same participant went on to add,

You know there is a trust that has developed with the patient and the family and that doesn't take long, it could be just an admission, like with that patient, it's not with that patient that I developed the relationship it's really with the family, because the second day she was confused and I couldn't really have conversations that were helpful with her. We tried to reverse her confusion but it was due to the lack of oxygen and so we sat down with the family and explained everything and they were conscious that she would not be on life support (3, L. 125-131)

In the above excerpts, the participant speaks to a first-hand experience on the impact of initiating family involvement for a patient diagnosed with cancer. The participant emphasizes the importance of establishing a trusting relationship with family members as this results in alleviating worries or burdens associated to dealing with a patient's last days of life. In a slightly different vein, another participant speaks to the impacts of active family involvement throughout a patient's palliative care experience in the following quote,

Sometimes, I come in and I think settling down the caregiver who is really burnt out is going to be my priority and once I get that settled down and we can back track and start talking about symptom control and other things (5, L 32-34)

The same participants elaborates further in the following,

I take a moment to address what they [caregivers] are going through, because then it makes the rest of the visit easier when they feel like you have acknowledged the caregiver but also given them a few ideas as to what you might be able to do for them. For instance put in more CCAC, you know acknowledging they are going through a lot but you know telling them there are going to be options before you can move on with other things because otherwise the level of stress could be potentially really high (5, L. 45-49)

In the above quotes, the participant speaks to the power of recognizing the caregiver's role by acknowledging hidden feelings of caregiver burnout. The participant speaks to active family involvement by showing awareness on the complexities family members may feel in association with a palliative patient's care journey. By acknowledging such

complexities, family members feel encouraged to continue with being actively involved in a loved one's journey in obtaining high quality palliative care.

In summary, participants in the study acknowledged active family involvement as an imperative aspect of carer support in palliative care. Meeting the demands of caregivers and decreasing stress in tense instances are a crucial part of enabling a gold standard of care as indicated through the implementation of the GSF.

4.10 Care in the Dying Phase

The participants in this study spoke to the importance of being able to recognize that the palliative patient is entering the dying phase so they can take appropriate measures to meet care standards within this last stage of a patient's life. Participants acknowledged considering comfort measures as a key theme within this last component of the GSF, citing that this facilitated the assurance of 'Care in the dying phase' for palliative patients.

4.10.1 Comfort Measures

Participants in this study elaborate further on establishing comfort measures in the following excerpts,

We will put in home oxygen. You know we have people doing drainages, have catheters, we do all the supportive things so we can keep them out of the emergency (1, L.558-559)

and,

You know the care in the dying phase, you have to tell the family, you may have doubt at some point that you or your loved one took the right decision or that you visualized how it was going to be. You know, someone with delirium in the home, this is very, very tough but this is what the patient wants, so then let's consider palliative sedation (3, 640-643)

and,

In most cases you can use palliative sedation, or some other form to calm them and make this a comfortable death, and I know that sounds strange but people want to be comfortable (2, 292-293)

Here the participants speak to the means of medical actions taken by palliative care providers to ensure comfort measures for patients are achieved. Another participant shares her experience of this in the following quote,

Towards the dying phase we do a lot of medication review so I tell patients as you change the focus, what we are looking after also changes so this medication, which now you know is still helpful in the dying phase, may not be nearly as helpful. It may not change your symptom one way or another but maybe just adding to your pill burden, an extra pill that you have to swallow at a time you are really tired, really weak, and it's effortful. So I always offer, anytime you reach that stage talk to us and we can do every few days or every week or every month, however or whatever is appropriate, we can do a medication review and go through and say this is what you are taking this one for I recommend that you take it. It's still up to the patient to say you know what, I don't want it and I just let them know if you stop taking it maybe you will get dizzy but again your call so we go through it and I'll say this cholesterol medication you have been taking for the last ten years you are not going to feel any different without it and so some patients are happy to get rid of some pills that are unnecessary (5, L. 497-509)

Here the participant speaks to medication review as an aspect of comfort measures and the importance of review as a mechanism for ensuring medication management is still aligned with the patient's care goals. Another participant speaks about his experience on conversing about comfort measures in the following quote,

That's what the daughter said to me today, "it's actually selfish of me to want her to live, because she wants to die", like her mom wants to die, she's 91, all her friends are gone and she doesn't have any interest in life, but her daughter says "I am selfish, I want her to live, but I understand she doesn't want to", and that's exactly what I tell people, "perfect you said that", because I think it shows how much care you have for your loved ones because if you say listen, if you die to day I would be sad but I would be happy that she is happy and comfortable, because again it depends on your belief system. If she wants to be with her husband, that's a happy time, so why would you want her to suffer here? So you will miss her and be sad but you will be happy that she is now comfortable, so if you have enough discussion around that people usually will understand that (2, L. 335-344)

Here the participant speaks to being forthcoming about having frequent discussions with family members on raising awareness about care and comfort measures, when approaching the dying phase. Addressing such topics can ensure a “good death” for a palliative patient because loved ones are reminded of the care goals consistent with the patients’ dying wishes.

In summary, the participants of this study described their lived experiences related to considering comfort measures, thereby being a key theme associated to the last component of the GSF. Achieving the highest quality of life through any stage of a patient’s palliative care experience is the ultimate goal of the GSF, especially in the last moments of life. Therefore, participants recognized discussing and considering comfort measures for palliative patients as an integral factor to quintessentially achieving this.

4.11 Summary of Results

To summarize this chapter, I indicated the results of participant recruitment, demographics and interviews. The results of participants’ interviews were analyzed according to the GSF and emerging themes from each component of the GSF were identified. Participants in this study spoke positively about the GSF and revealed in depth what factors facilitated or acted as barriers relative to an exceptional implementation of the framework within LH’s outpatient, palliative care setting. In the following chapter, I provide a discussion of the themes that emerged from each component of the GSF as a result of participants’ experiences with implementing the GSF in a hospital-based, outpatient palliative care setting. Table 2 provides a summary of these themes:

Table 2 Summary of Emerging Themes	
Gold Standards Framework Components	Emerging Themes
Communication	<ul style="list-style-type: none"> • Inter-professional Communication • Establishing Patient Rapport • Advance Care Planning
Coordination	<ul style="list-style-type: none"> • (Explored in Chapter 5)
Control of Symptoms	<ul style="list-style-type: none"> • Pain and Symptom Management
Continuity of Care	<ul style="list-style-type: none"> • Reliable Access • Electronic Maintenance of Patient Records • Inadequate Community Support
Continued Learning	<ul style="list-style-type: none"> • Standardized Approach • Poor Educational Supports
Carer Support	<ul style="list-style-type: none"> • Active Family Involvement
Care in the Dying Phase	<ul style="list-style-type: none"> • Comfort Measures

Chapter Five: Discussion

The primary purpose of this study was to explore the lived experiences of palliative care providers in implementing the GSF (with its respective components) in oncology, from a hospital-based, outpatient palliative care setting. The data analysis and interpretation of the results were guided by the conceptual underpinnings of the GSF (Communication, Coordination, Control of Symptoms, Continuity in Care, Continued Learning, Carer Support and Care in the Dying Phase) with the purpose of exploring the barriers and facilitators of implementation in the context of Canadian healthcare. Therefore, in this chapter, I provide a discussion of the findings and compare these findings to current research.

5.1 Communication

The first component of the GSF, communication, is described as the incorporation of patient involvement through every stage of the illness trajectory relative to patient preference of care. Communication also entails regular palliative care provider meetings to help improve information flow between all providers associated with patients' care (Amass, 2006; Hansford & Meehan, 2007; King et al., 2005).

Participants' responses coincided with the description of this component. The first sub-theme to emerge under the communication component of the GSF through participant responses was the theme of *inter-professional communication*. Shaw et al. (2005) defines inter-professional communication as the sharing of knowledge and information between healthcare disciplines, which constitutes a central element in supporting an optimized level of quality care for palliative patients. Participants were in agreement on the importance of inter-professional communication amongst all healthcare

disciplines within LH's hospital-based, outpatient palliative care setting, such that it was crucial in contributing to patients receiving optimized levels of palliative care. This finding is substantiated by the literature on the component of communication from the GSF as well (Badger et al., 2012; Dale et al., 2009; King et al., 2005; Mahmood- Yousuf et al., 2008; Shaw et al., 2010; Thomas & Noble, 2007; Walshe et al., 2008). Participants felt that there was strong sense of inter-professional communication amongst healthcare disciplines through team discussions during inter-professional rounds. Participants also felt that discussions of problematic cases with healthcare providers responsible for care outside of the hospital (CCAC) lead to a better understanding of how to actively approach and consistently contribute to a continuum in excellent standards of patient care. However, participants felt that there was a need for more frequent discussions between LH's palliative care providers and healthcare disciplines from CCAC in order to continuously maximize exemplary standards of care for palliative patients. These findings are consistent with a qualitative study conducted in the United Kingdom by Mahmood-Yousuf and Munday (2008) who found inter-professional collaboration in palliative care to be greatly impacted through effective communication as a result of implementing the GSF. Additionally, the authors also identified similar findings such that consistencies in improvement of patient care could have been improved through frequent multidisciplinary meetings with all healthcare providers involved in each patient's palliative care journey. In this present study, participants felt that interacting in inter-professional communications with other healthcare disciplines associated with a patient's palliative care journey consistently helped facilitate the component of communication. Incorporating various healthcare professionals in the provision of palliative treatment is

instrumental in the delivery of comprehensive care as increased knowledge and complementary skills from each discipline influences ideal patient outcomes (Stephens et al., 2006)

Establishing patient rapport was the second sub-theme that emerged from this study. Schapira (2008) defines establishing patient rapport as the process of building trust and understanding between palliative patients and clinicians early on during patient encounters in order to solidify a strong clinician-patient relationship. Participants in this present study echoed the same attitude. Participants indicated that establishing patient rapport was integral to effective communication at the beginning of the palliative care experiences and throughout the care trajectory. For instance, one participant spoke of the impact that establishing patient rapport had on one of her patients in treatment for testicular cancer. She indicated establishing rapport at the onset of her encounter with the patient enabled a sense of trust, which provided the opening for the patient to discuss some of the myths and anxieties associated with palliative care. The participant reported that establishing rapport through the duration of her encounters resulted in the initial request for palliative care by the patient when the cancer returned 4 years later. Other participants also reported that establishing patient rapport built a sense of dependence and security for patients when dealing with cancer, such that each patient was more inclined to seek and rely on palliative care providers for direction in the palliative care journey. Patients with high health literacy were more likely to experience better patient-focused care; generally there is greater inclination to access support services due to a better understanding of what their chronic disease entails (Altin & Stock, 2016). Belcher and Jones (2009) indicated that the effect of establishing a strong rapport conveyed

consistency, dependability and competence in all aspects of palliative care, thereby enhancing patient-focused outcomes. Additionally, Bakic-Miric & Bakic, (2008) indicated a strong clinician-patient relationship improved patient-satisfaction as compliance with palliative care provider recommendations enhanced exceptional levels of care. There was an overall consensus by participants that establishing patient rapport was necessary to strengthen communication with patients and labeled this as a crucial factor that facilitated the component of communication from the GSF.

The third and final sub-theme to emerge was the theme of *advance care planning*. Thomas (2006) described advance care planning as a conversation between clinicians and patients about future directions and priorities for care. Participants were in agreement that enacting advance care planning enhanced communication. Participants reported the importance of communicating with patients about outlining a solid care plan in order to legitimize and carry out patient's care wishes in anticipated circumstances. Clarifying patient wishes and needs for anticipatory situations highly impacts optimal patient-focused outcomes because envisioned goals of care are respected (Quinn & Thomas, 2017). Participants also described the beneficial impact of communicating on advance care planning such that patients felt autonomous and in control through the ability to make decisions beforehand, in preparation for emergency situations. Some participants said the identification of the prognostic indicator guidance was a tool that helped develop conversations on advanced care planning. For example, one participant indicated that utilizing this tool guided her conversation with a patient when a crisis occurred three weeks later, the participant was able to provide proactive care that was aligned with the patient's envisioned goals. This finding was consistent with a prospective, cross sectional

study completed by O’Callaghan, Laking, Frey, Robinson, and Gott (2014) who found that utilizing the prognostic indicator guidance tool early on during patient screening in palliative care within a hospital setting enabled better identification of patients’ unrecognized and anticipatory needs. Consequently, patients were more likely to experience better healthcare outcomes as a result of this (O’Callaghan et al., 2014). Overall, participants reported that advance care planning was an integral factor in limiting adverse outcomes for patients in anticipatory circumstances. Therefore, participants emphasized that enacting advance care planning with patients and clinicians facilitated communication.

5.2 Coordination

The second component of the GSF coordination, is described as the nomination of a GSF coordinator who is accountable in ensuring that proper utilization and implementation of the GSF is carried out amongst any designated palliative healthcare team (Hansford & Meehan, 2007).

Participants’ in this study were not aware of an elected GSF coordinator in LH’s outpatient palliative care setting. However, it is important to note that participants related to the aspect of inter-professional communication as the mechanism, which established coordinated care services for palliative care patients in LH’s outpatient palliative care setting. Brazil (2017), identifies communication amongst teams as a method of establishing coordinated care. Although this is beneficial in administering integrated palliative care, in order to fully implement the framework, an elected champion or coordinator with strong understanding of the GSF may be instrumental in supporting the uptake of this component within an outpatient palliative care setting.

As previously stated in the literature review, various studies conducted in the United Kingdom on the implementation of the GSF identified the beneficial impact of having such a member within the palliative care team (Dale et al., 2009; King et al., 2005; Shaw et al., 2010). Absence of a GSF coordinator at LH may have influenced full integration of the model by participants. Therefore, to experience the full impact of implementing the GSF from a hospital-based outpatient palliative care setting, I would recommend that a coordinator be elected so that clinician-clinician and clinician-patient relationships associated with the delivery and reception of palliative care can be enhanced (Dale et al., 2009, Quinn & Thomas, 2017).

5.3 Control of Symptoms

Control of symptoms, the third component of the GSF, is described as the process of accurately assessing all patient symptoms whether being physical, spiritual, social or psychological with aim to effectively monitor and control in present and anticipatory situations (Hansford & Meehan, 2007).

Participants' responses coincided with the description of this component and the only sub-theme that emerged from participant responses was *pain and symptom management*.

Participants in this study felt that their most important role as palliative care providers was to provide pain and symptom management for patients. Pain is identified as a multidimensional experience with respect to cognitive, sensory, behavioral and affective dimensions (Wilkie & Ezenwa, 2012). Around 75% of individuals journeying through cancer experience pain and it can be intensively severe for such patients at the end-of-life (Plaisia & Syrigos, 2005; Wilkie & Ezenwa, 2012). Sufficient pain and

symptom management is a critical component of palliative care (Kastenbaum, 2009; Temel et al., 2010; Wilkie & Ezenwa, 2012). Patients facing the life-altering illness of cancer experience common pain symptoms such as nausea, vomiting, delirium, breathlessness and fatigue (Fineberg, Wegner, & Brown-Saltzman, 2006; Solano, Gomes, & Higginson, 2006; Temel et al., 2010). The ability to provide care through extensive knowledge and research on limiting such pain symptoms has been a contributing factor to creating success in palliative care treatment (Kastenbaum, 2009). There was a recurrent notation by participants on the ability to improve the quality of life for palliative patients through actively taking initiative to effectively manage pain and symptoms associated to cancer. For example, one participant spoke about the effect that controlling pain and symptoms for patients had on their quality of life. She indicated that this enabled patients to experience optimal results over time such that many were still able to lead as normal of a life as possible. This was not only a fundamental aspect of the GSF, but also the foundation of what providing palliative care entailed. This finding was consistent with a randomized control study done by Temel et al. (2010) who found that patients who received palliative care experienced better symptom management and a greater improvement in quality of life resulting in a higher survival rate than those who did not experience palliative care.

Participants spoke to methods by which pain and symptoms were assessed and managed. Participants mentioned the provision of a Symptom Relief Kit (SRK) within the home setting helped patients to have access to aid in urgent situations. A SRK is a standardized package consisting of the necessary medical supplies and medications that is provided to patients nearing end of life, to relieve symptoms that are rapidly escalating or

unanticipated (LHIN, 2017). As foreseeing patients' pain needs in anticipatory circumstances was an essential element of controlling symptoms, participants felt that ordering a SRK was essential to maximizing pain and symptom management. It was important to note that for the SRK to be administered, a nurse within the home setting must be present. Participants also spoke about discrepancies around the availability of care services within patients' homes resulting in the need for unnecessary visits to the emergency department for symptomatic control. This aspect of palliative care will be discussed in further detail below under continuity of care.

Participants also mentioned the utilization of the Edmonton Symptom Assessment System tool (ESAS) and Palliative Performance Scale (PPS) tool to be beneficial in pain and symptom management for palliative patients as well. The ESAS is a validated assessment tool with a rating scale ranging from 1-10 (absent to worse possible), that was created to help palliative clinicians expedite understanding on nine prevalent symptoms that the majority of cancer patients face namely: pain, drowsiness, nausea, shortness of breath, appetite, anxiety, depression and well-being (Richardson & Jones, 2009). Participants felt that the utilization of the ESAS tool on every patient encounter enabled a stronger understanding each patient's symptom experience and consequently helped managed pain symptoms. This finding was consistent with a systematic review of the literature conducted by Richardson and Jones (2009) who discovered the use of the ESAS tool to be reliable in improving clinical encounters for patients in palliative care. Richardson and Jones (2009) indicated that a consequence of utilizing this tool for patients was higher patient satisfaction. However, the authors also mentioned that results required sound clinical judgment by palliative care providers to interpret the score and

subsequently give relevant levels of attention to induce such a consequence.

Another frequently used assessment scale that participants felt strengthen pain and symptom management for patients was the PPS. The PPS is described as a valid, functional assessment scale that is utilized to measure the progressive decline of palliative patients approaching end-of-life (Lau, Downing, Lesperance, Karlson, Kuziemsy & Yang, 2009). The scale focuses on physical performance through observable parameters (ambulation, activity/evidence of disease, self-care, intake, conscious level) and is measured in decrement levels of 10% from healthy (100%) to death (0%) (Lau et al. 2009). Participants felt that incorporating this scale in patient assessments helped provide a good physical description of the patients functioning levels. This finding was consistent with a study conducted by Lau et al. (2009) who found that use of the PPS amongst palliative care providers was indeed impactful in indicating survival rates for patients enlisted in palliative care. As indicating survival rates can be variable in palliative care, the authors emphasized the use of this tool to help palliative care providers grasp a strong understanding of how to accurately approach patient care with respect to the use of this scale (Lau et al., 2009). The GSF supports the use of assessment scales to help manage pain symptoms for patients (Hall, Goddard, Stewart, & Higginson, 2011).

5.4 Continuity of Care

The component of continuity of care from the GSF is described as the maintenance of information transfers between health agencies (out-of-hours doctors, nurses, support workers) through handover forms so that the most up-to-date information is available (Hansford & Meehan, 2007; King et al., 2005).

The first sub-theme to emerge from participant responses to the notion of continuity of care was *Reliable Access*. Participants discussed reliable access as a key factor to supporting continuity of care. There was an overall consensus by participants on the positive impact of providing reliable access to palliative care services in the hospital. For instance, one participant indicated that the provision of 24/7 access to palliative care services through the telephone triage and after hours, on-call system, enabled patients to feel well supported at all times. The participant indicated that patients were able to have their concerns addressed by nurses during outpatient clinic hours and through all hour/on-call requests for home visits by physicians when seeking emergent palliative care. This was beneficial because the majority of palliative care patients prefer to spend their remaining days of life within a home setting (Gomes et al., 2012; Gomes et al., 2013; Wheatly & Baker, 2007) The opportunity for patients to have all concerns addressed from the comfort of their homes decreased their anxiety and stress that may be felt when not receiving care in an inpatient setting. Subsequently, this can decrease the demand for unnecessary emergency service visits, thereby enhancing the ability to increase the institution's cost saving measures (Riley and Lubitz, 2010). This finding was consistent with the findings of a study conducted by Bunn, Byrne and Kendall (2004) who assessed the use of the telephone consultation system on patient satisfaction. The researchers found this system to be effective in limiting GP out-of-hour visits and the need for emergency services by patients (Bunn et al., 2004). Participants in this present study also reported that the provision of reliable access facilitated a decrease in wait times for patients seeking palliative care. Participants felt this this encouraged patients to experience a better quality of life and patient-care satisfaction as promised by this

comprehensive approach of palliative care. Although the findings of this present study supported the provision of reliable access to palliative care services from a hospital-based, outpatient care setting, this did not corroborate with existing literature presented currently in Canadian palliative care research (CCS, 2016; Collier, 2011; Hawley, 2017). For example the Canadian Cancer Society reported that 40% of Canadians diagnosed with cancer do not obtain a palliative assessment within the last year of living (CCS, 2016). Therefore, improving reliable access to services for all patients seeking palliative care in Canada will permit more patients to experience a better quality of life throughout the illness trajectory (CCS, 2016). Thus, governmental action should be taken to ensure consistent access to palliative care services are available for all individuals seeking this comprehensive approach to care (CCS, 2016).

The second sub-theme to emerge from the data on continuity of care was *electronic maintenance of patient records*. Participants did not identify the use of handover forms as recommended in the conceptual description of continuity of care from the GSF. However, participants did identify the impact of electronically maintaining patient records as a more modern method towards facilitating continuity in patient care. Electronic medical record technology is described as a system that enables healthcare providers to easily access patients' current healthcare information (Manca, 2015). In this present study, participants echoed the benefits of being able to electronically access a patient's chart information. For example, one participant identified the impact of the electronic system on allowing clinicians from all healthcare disciplines to be up-to-date on each palliative patient's care status. The participant felt this facilitated the experience of improved quality of care for palliative patients ranging from one palliative care

provider to the next. This unique technological method provided a way for palliative care providers to gain a comprehensive, up-to-date overview of a patient's goals of care and status, thereby impacting higher patient focused outcomes in all outpatient settings (hospital/home). Findings from a cross sectional study conducted by Kern, Barron, Dhopeswarkar, Edwards, and Kaushal (2013) supported these findings; they found there was a positive outcome between the use of up-to-date electronic medical records and the provision of quality patient care. Subsequently, the findings indicated that the electronically maintaining patient records provided opportunities to share and exchange patients' information and thereby impact positive patient engagement (Kern et al., 2013).

Inadequate community support was the last sub-theme to emerge as related to continuity of care. Mainly, participants described this as unsupportive care for palliative patients who had a preference to remain in a home environment. There was an overall consensus by participants that the frequent occurrence of this existed as a barrier to patients receiving optimal hospital-based, outpatient palliative care resulting in dying experiences contrary to patient wishes. A paradox around patient dying wishes currently exists (Thomas, 2003). Many patients prefer to spend their remaining days of life at home however, around 75% of individuals approach the end of life within an inpatient hospital setting (CHPCA, 2014). For example, one participant identified the impact of inadequate community support on patient care and the vicious cycle created with this barrier which, resulted in unnecessary visits to the emergency department for symptomatic relief. This finding was consistent with findings from Barbera, Taylor and Dudgeon (2010), which examined the most common reasons why cancer patients visit the emergency department nearing the end of life. Through a descriptive, retrospective cohort study, these authors

identified symptomatic control as the main reason for unnecessary emergency department visits (Barbera et al., 2010). A Symptom Relief Kit (SRK) was provided to palliative patients with the aim of reducing adverse outcomes in anticipatory circumstances. However, it was necessary for homecare nurses to be present in the home to administer symptom relief/support as directed by the SRK. Many participants described a lack in homecare support from community agencies (CCAC) as an extensive factor contributing to the increase of frantic phone calls to nurses and physicians in the outpatient clinic, especially by concerned family members/friends. Inadequate homecare support in dealing with patients seeking palliative care can be demanding on family members/friends. Moreover, an unsupportive environment for care can cause these patients to feel isolated and distressed thereby resulting in the dependency on emergency services. Participants advocated for the provision of more in-home support by nurses and PSWs to help patients experience a better quality of care nearing the end of life. This finding was consistent with a retrospective cohort study conducted by Seow et al., (2016) which examined the impact of increased homecare nursing on reducing visits to the emergency department for cancer patients nearing the end-of-life. Seow et al. (2016) found that cancer patients who received frequent in-home nursing care with a consistent rate of over 5 hours a week was associated with a 41% decrease in emergency department visits. This study emphasized the need for stronger community support for cancer patients choosing to spend their remaining days of life at home as more support resulted in decreased emergency department visits (Seow et al., 2016).

Participants identified resource and budget constraints as another possible systemic factor to the provision of inadequate community support. For instance,

participants spoke to different funding envelopes for the hospital and CCAC as a systemic barrier to enhancing quality of care for palliative patients with a preference to die at home. Participants identified more governmental funding to support the delivery of palliative care and, palliative care services operating uniformly (CCO, LHIN, RPC, OPCN) as a potential way to limiting this factor. Current governmental actions to improve care through effective change such as the *Patients First Act* which focuses on achieving the provision of a tightly coordinated and integrated, patient-centered health care system while also eliminating excess administrative costs with hopes to be reinvested into patient care, is a step towards improving the healthcare system (LHIN, 2017). However as the implementation of the GSF in Canadian healthcare is new, future research should focus on the integration of this approach in the healthcare system. Dying is an integral part of life and sufficient resources to support this process are highly necessary (Fine, 2004). Subsequently, an improvement in continuity of palliative care in all settings can result in better allocation of healthcare dollars thereby being mutually beneficial to both patients receiving care and savings for the Canadian healthcare system (CCS, 2016; Fine, 2004; Hodgson, 2012).

5.5 Continued Learning

The component of continued learning in the GSF is described as primary health care teams being actively committed to learning about end-of-life care in all aspects, so that maximum benefit is achieved for practitioners and patients (Hansford & Meehan, 2007; King et al., 2005; Wee & Hughes, 2007).

Participants' responses coincided with the description of this component such that there was particular focus on methods to improve implementing the GSF from a hospital-

based, outpatient palliative care setting. Two sub-themes emerged from the data. The first sub-theme to emerge from participant responses on continued learning was the need for a *standardized approach* to implementing the GSF in hospital-based, outpatient palliative care. Participants identified the implementation of the GSF as an individualized process in this setting of care, thereby being a significant barrier. There was an overall consensus by participants that a universal and team approach to implementing the GSF could establish the same vocabulary amongst providers and limit variations in care provision from one provider to the next. Subsequently, there is mutual benefit for both providers and patients; palliative care providers would experience better team satisfaction and palliative patients would experience better patient care satisfaction. According to the Canadian Cancer Society (2016), there is a lack of common frameworks currently implemented in palliative care to ensure the delivery of high quality palliative care. The GSF is an evidenced based framework that has been proven to increase patient care satisfaction through helping healthcare providers identify individuals requiring palliative care along with its comprehensive approach to meeting palliative patient needs (Hansford & Meehan, 2007; Thomas, 2003). As the GSF is instituted by CCO to be utilized within palliative care, it is vital that healthcare disciplines associated with this comprehensive approach of care are aware of its benefits and take initiative to implement the GSF (CCO, 2017 Hansford & Meehan, 2007; Shaw et al., 2010).

The second sub-theme to emerge from participants' responses to the notion of continued learning was *poor educational supports* for providers. To provide effective palliative care for patients, it is essential that healthcare providers of all disciplines are educated on the appropriate standard of care (CCS, 2016). Participants felt that there was

not enough educational resources to guide providers on how to implement the GSF, thereby acting as a barrier to continued learning. For instance, one participant felt the lack of direction on how to accurately implement the GSF resulted in variations of palliative care between providers. The participant indicated that this factor had the potential to exacerbate gaps and barriers around the provision of palliative care. Similarly, another participant spoke of the impact of educating providers on the importance of the GSF and how it was useful in delivering a comprehensive and patient-focused standard of care. Through strong educational programs such as training modules and/or conferences, palliative care providers can be better prepared to deliver high quality care according to this framework. For example, Pallium Canada provides a Learning Essential Approaches to Palliative Care Course (LEAP course) that emphasizes beneficial tools such as the GSF, ESAS and PPS which can be informational on delivering high quality palliative care (PC, 2018). Additionally, a study conducted by Dale et al. (2009) identified the positive impact of teaching healthcare providers about utilizing the GSF in palliative care. Questionnaires on the provision of palliative care were sent out to healthcare providers prior to and subsequent to training on implementing the GSF. The authors found that the greater majority of individuals who participated, indicated a large improvement in the uptake of methods associated with providing high quality palliative care for cancer patients (Dale et al., 2009). Another significant finding for healthcare providers was the improvement in gaining confidence to evaluate, report and address the psychosocial and physical areas of patient care (Dale et al., 2009). As the objective of palliative care is to administer comprehensive care to patients, the implementation of this evidence-based framework (GSF) can wholly support palliative care providers on

achieving this goal successfully (Dale et al., 2009; Hansford & Meehan, 2007; Thomas, 2003). In this present study, it was evident that although the GSF was theoretically provided to palliative care providers, the educational supports to realistically enable the effective uptake of the GSF in daily palliative care practice was lacking.

5.6 Carer Support

The component of carer support from the GSF is described as the provision of support through the emotional, practical, and bereavement aspects of end-of-life care (Hansford & Meehan, 2007).

The responses from participants in this study coincided with the description of this component from the GSF and the sub-theme of *active family involvement* emerged from the data. The life altering illness of cancer not only affects patients but also caregivers (Sklenarova et al., 2015). Subsequently, it is essential to recognize that informal caregivers are a primary source of support for patients who are severely affected by a cancer diagnosis (Lambert, et al., 2012). In this present study, participants agreed on the importance of having family members involved in the physical and psychosocial aspects of palliative care for patients dealing with cancer. Participants found that by actively involving family members in a patients care journey, carers were provided with realistic expectations throughout the end-of-life process. This form of support also enabled carers to develop confidence in making decisions associated with the patients care. This finding was supported by a study conducted by Sklenarova et al. (2015) whereby the authors examined the unmet needs of cancer caregivers. The authors found that the majority of their participants had unmet needs for supportive care with regards to fears surrounding a patient's condition and obtaining disease related information. The

authors concluded that healthcare providers should be aware and proactive in systematically addressing carers' information, healthcare service, and emotional needs to enhance levels of emotional and practical support throughout a patient's end-of-life process (Sklennerova et al., 2015). Participants in this present study also indicated the importance of recognizing when carers were experiencing caregiver burnout. This finding was consistent with the literature on informal caregivers through a qualitative study done by Joad, Mayamol and Chaturvedi (2011). This study examined the needs of caregivers for patients diagnosed with cancer. Through semi-structured interviews, participants were asked about the physical and psychosocial aspects of caregiving. Joad et al. (2011) found that many participants did not have prior experience on providing care thereby experiencing high levels of caregiver burnout. The authors concluded that actively recognizing caregivers' psychological and emotional needs could be beneficial in optimizing support for such individuals. Participants in this study described the necessity behind actively involving family members in a patient's trajectory of care subsequently acknowledging this as a facilitator to achieving the component of carer support from the GSF (Joad et al., 2011).

5.7 Care in the Dying Phase

The component of care in the dying phase from the GSF is described as ensuring appropriate care for those in the terminal phase of illness are provided, where all aspects of care for patient and family members are considered systematically (Hansford & Meehan, 2007). Such considerations include bereavement communication, psychological support, stopping drug interventions that may not be essential, and religious support (Hansford & Meehan, 2007; King et al., 2005).

The only sub-theme associated with care in the dying phase was assessing *comfort measures*. Achieving the utmost quality of life for patients through any stage of a patient's palliative care journey is the most fundamental goal of implementing the GSF. Participants in this present study indicated that considering comfort measures facilitated the last component of the GSF. Participants mainly indicated the consideration of comfort measures in providing symptom and pain relief. A reason for comfort measures relative to the physical aspect of care being discussed as so important could have been because participants in the study consisted of physicians and nurses. For example, one participant discussed the advantages of conducting a medication review. The participant indicated the significance of removing unnecessary medications in order to alleviate the burdens of high medicinal intake, with the hopes of enhancing a patient's quality of life. This participant acknowledged that many patients preferred minimal use of medications while approaching the last days of life. This finding was consistent with a cross-sectional study conducted by Fede et al. (2010) which examined the proportion of cancer patients taking unnecessary medication throughout the last days of life. The authors discovered that many cancer patients in the last stages of life take unnecessary medications, which can inhibit patients' comfort measures. These authors concluded that a thorough review of medications could limit this outcome for patients facing cancer as many cancer patients experience intense weakness and difficulty swallowing in the last days of life. Furthermore, such patients who receive numerous medications can experience adverse drug interactions and this also can affect patients' quality of life (Abel et al, 2013). By taking initiative to perform medication reconciliation, palliative care providers can

contribute to enhancing stronger patient-centered care resulting in high quality outcomes for palliative patients (Fede et al., 2010).

Participants in this present study also spoke about introducing palliative sedation as a measure of comfort for patients suffering in the immediate last days of life. Palliative sedation is described as the use of various medications in order to induce a decrease in awareness to relieve unbearable suffering in the last days of life (Olsen, Swetz & Mueller, 2010). Participants reported taking this measure of comfort for palliative patients enabled a better quality of life for patients approaching the end of life process. Furthermore, participants identified patients being comfortable with the application of this measure nearing the end of life as this enabled patients to remain within a home settings thereby being aligned with their goals of care. This finding was consistent with a cross sectional study conducted by Sanjo et al. (2007), which aimed to identify cancer care preference nearing the end of life and associations with the concept of a “good death”. The authors found that 75% of the general population and 85% of bereaved families preferred the use of palliative sedation (Sanjo et al., 2007). They concluded that this measure of comfort was associated with the experience of a “good death” such that patients could experience death within a home environment (Sanjo et al., 2007). It was important for palliative care providers to raise awareness on this measure of comfort for patients who seek to receive a relief in suffering throughout the very last days of life (Olsen et al., 2010). Since Canadians prefer to approach the end-of-life at home, palliative sedation is a viable option for achieving this outcome. Subsequently patients dying wishes can be honoured.

5.8 Summary of Findings

In this chapter, I discussed the emerging sub-themes identified from the data presented in chapter 4. I compared these findings with the existing research in palliative care being organized according to the conceptual underpinnings of each component from the GSF. Firstly, under the component of ‘communication,’ participants’ perceived *inter-professional communication, establishing patient rapport and advanced care planning* as facilitators to enabling overall communication in the delivery of optimal palliative care. The literature supports these areas in communication as vital elements to optimizing patient-focused outcomes in the delivery of palliative care. Secondly, under the component of ‘coordination,’ palliative care providers indicated the lack of an elected GSF coordinator. The various literature on the implementation of the GSF suggest the selection of a GSF coordinator, as this has the potential to impact clinician-clinician and clinician-patient relationships. Thirdly, under the component of ‘control of symptoms,’ palliative care providers identified *pain and symptom management* as their most important role in the delivery of palliative care from a hospital-based outpatient care setting. Participants also described the use of various assessment tools such as the ESAS and PPS as tools which helped facilitated this aspect of the GSF. Fourthly, under the component of ‘continuity of care,’ participants felt the provision of *reliable access* and *electronically maintaining patient records* as methods to facilitating a continuum of care for palliative patients. Although these aspects were beneficial to enabling continuity in care, participants also identified *inadequate community support* as a barrier to supporting palliative patients with a preference to die within a home setting. As described earlier within this chapter, the literature identifies this as a possible reason to why there is an

increase in emergency department visits by palliative patients throughout the last months of life. Increasing in-home support would be a potential way to eliminate such occurrences. Fifthly, under the component of ‘continued learning,’ participants attributed the lack of a *standardized approach* towards implementing the GSF and *poor educational supports* as barriers to why this component was not fully sustained within the realm of delivering optimal palliative care, according to the GSF. There was an overall consensus by participants that the provision of more educational supports to support providers would limit these barriers. Sixthly, under the component of ‘carer support,’ participants acknowledged *active family involvement* as an imperative aspect to facilitating this component from the framework. The literature supports this such that many studies indicate the inclusion of family members in a patient’s trajectory of care as crucial to establishing a gold standard of care. Lastly, under the component of ‘care in the dying’ phase, participants recognized discussing and considering *comfort measures* for palliative patients as an integral factor to achieving the “gold standard” of care in the last days of life. Participants noted being mindful of patients’ requests of care with respect to comfort measures as a factor which facilitated this component of the framework.

In the next chapter, I provide a conclusion to this study and identify implications and potential recommendations to help strengthen the delivery of palliative care from a hospital-based outpatient palliative care setting.

Chapter Six: Conclusion

In this final chapter, chapter six, I discuss the strengths and limitations of my study. Next I provide the implications and recommendations for practice, policy, education and research.

6.1 Strengths

This study's strengths lie in the chosen methodology. Taking a qualitative approach using IPA allowed me to gather rich and detailed data surrounding the lived experiences of palliative care providers in implementing the GSF from a hospital-based outpatient palliative care setting. Subsequently, I was able to make meaning and interpret the responses given by participants on the research question thereby allowing me to generate sub-themes under the each component of the GSF. Combining phenomenology, hermeneutics and an idiographic approach on each participant's responses enabled me to grasp further insight into how these lived experiences of implementing the GSF could be enhanced in hospital-based, outpatient care, within the context of the Canadian healthcare setting. It is important to note that many studies completed on the implementation of the GSF were conducted in the United Kingdom. Moreover, there is a lack of qualitative studies on how the GSF is implemented within a Canadian healthcare setting. This study addressed the gaps presented in the literature and provided information regarding the barriers and facilitators in implementing the GSF, from a hospital-based, outpatient setting.

The use of the GSF to guide data analysis and the interpretation of the results was considered another strength of this study. As the purpose of the study was to examine the lived experiences of palliative care providers in implementing the GSF with oncology

patients in a hospital-based outpatient setting, examining participants' responses according to each component of the GSF allowed a thorough investigation regarding how we might enhance palliative care practice so that patient-focused outcomes are achieved. Furthermore, using the conceptual underpinnings of each component in the GSF allowed me to gage a realistic viewpoint of palliative care practice within the context of Canadian healthcare. Through this, I was able to identify facilitators to and barriers of implementation within each component of the GSF and clarify ways for palliative care providers to strengthen patient-focused care.

6.2 Limitations

A limitation for this study was the sample size (six participants). Due to time constraints, there was less time to involve more participants in the study. However, I was able to conduct individual, in-depth interviews with participants, which generated new findings on the lived experiences of these participants. Additionally, the majority of the participants in this study were physicians. Although this aspect of the study cannot be controlled, the inclusion of more nurses to provide detailed accounts of their experiences would have enhanced my understanding on the overall implementation of the GSF. Another limitation impacting the study choosing participants from only one healthcare setting. However, this qualitative study provided valuable information on two different healthcare professionals which, is not generalizable to the entire palliative care provider population but rather identified potential areas where experiences can be enhanced.

6.3 Implications and Recommendations

6.3.1 Practice

The results of my study emphasized the benefits associated with implementing the GSF in hospital-based, outpatient palliative care. Furthermore, the results of my study illuminated areas of the framework that can be improved to enhance palliative care practice. Current developments in palliative care within Ontario concentrate on creating high quality, patient-focused care that is sustainable and accessible (OPCN, 2017). This is through the creation of a more integrated, person-centered, health care system, which can influence the achievement of optimal palliative patient-care outcomes (CCO, 2017; LHIN, 2017; OPCN, 2017). This study highlights areas for improvement with regards to the practical aspects of providing high quality palliative care in accordance with implementing the GSF. For instance, many participants spoke about the need for greater community supports towards patients who prefer to die at home. Therefore, this study highlighted the need for greater advocacy on more in-home supports for patients, which would reduce their stress and anxiety, as well as improve their quality of life. It is important to also note that many patients may require culturally competent care as cultural diversity is prominent in Ontario. With the provision of more in-home support, palliative patients are able to adhere to their cultural beliefs, rituals and practices if they have the opportunity to die at home, rather than within a hospital setting.

Many participants identified barriers in provision of community support as a contributing factor to frantic calls to LH's outpatient clinic and frequent emergency department visits. A result of frequent unnecessary visits to the emergency department results in higher costs utilized for assistance with symptomatic relief. Through the provision of more in-home support provided by the LHIN's associated to each district in

Ontario, many more patients can experience high quality palliative care in the comfort of their own homes. This could result in less dependence on emergency department services nearing the end-of-life, thereby successfully impacting both patients and the Canadian healthcare system. Currently, Hodgson (2012) found that community-based palliative care services impacted the cost of end-of-life care by a 50% reduction through: eliminating duplicated diagnostic testing, decreasing Intensive Care Unit admissions, and reducing interventional procedures. Implementing changes to provide more community support for patients who have a preference to remain within a home setting can be highly advantageous to the Canadian healthcare system; savings accumulated from limiting emergency department interventions can propagate cost saving measures and be allocated to different aspects of healthcare requiring more funding (CHPCA, 2017). Therefore I would recommend the provision of supplementary funding initiatives to sustain in-home care as this is essential to supporting the delivery of exemplary palliative care services for patients preferring to approach the end-of-life within a home setting.

6.3.2 Policy

My study also illuminates the strength of successful hospital-based, outpatient palliative care programs/services. Through the analysis of the GSF, I was able to identify the impact and benefits of this type of hospital-based service. The provision of 24/7 reliable accesses toward patients desiring to spend their remaining days of life within a home setting encourages patient-focused care. Furthermore, for most patients, this highly aligns with their envisioned goals of care thereby resulting in patient-focused outcomes. Therefore I would recommend stronger policy initiatives to support the establishment of more outpatient, palliative care programs in hospitals across Ontario, as well as funding

initiatives to support the continuous operation of these programs/services. This would be beneficial in the delivery of high quality palliative care for residents in Ontario. Such provisions allow patients to feel comfortable and safe in accessing immediate care such that patients' questions/concerns can be addressed by nurses in functioning outpatient clinics. The addition of hospices in the community to support the provision of palliative care would also be helpful toward the delivery of high quality care, as this may alleviate caregiver burden/burnout. It is estimated that 84% of the population seeking palliative care have been hospitalized within six months of death (CHPCA, 2017). Furthermore, it is important to note that the elderly population (65 and up) represent the fastest growing age bracket and by 2061, it is estimated that 11 million to 15.9 million individuals will be considered seniors. With such accelerations in the baby boomer population combined with the known projected increases in cancer diagnosis over the coming years (40%), it is estimated that there will be a greater reliance on palliative care services (CHPCA, 2017). Therefore, strengthening the operation of hospital-based, outpatient palliative care services and establishing hospices within the community increases the potential for patients to experience high-quality, patient-focused care; there is less reliance on emergency department services and a decreased need for emergency hospitalizations.

6.3.3 Education

Awareness on the GSF as a tool to be implemented in palliative care will enable palliative care providers to deliver high quality, person-centered care to residents in Ontario. Many participants in this study identified a lack of knowledge on the GSF as a barrier to proper implementation. It is essential that institutions focused on promoting palliative care through the implementations of tools like the GSF, provide educational

supports for palliative care providers to gain further understanding on how to implement the GSF in palliative care settings. Educational supports on implementing the GSF enable palliative care providers to be aware of tools available to impact the delivery of high quality, person-centered care. Subsequently, palliative care providers will not only be knowledgeable on the GSF and its implementation but also be able to share expertise with other health professionals on ways to support such improvements in care. This can have the potential to increase collaboration amongst palliative care providers, with the shared goal of providing best practices in palliative care. Therefore, I would recommend the provision of more educational resources such as training modules or presentations on implementing the GSF in palliative care for palliative care providers. Additionally, this would be beneficial for palliative care team members by increasing their awareness, knowledge and skills on implementing the GSF.

6.3.4 Research

Based on the results of this study, future research could include an exploration of the experiences of palliative care providers in implementing the GSF from a hospital-based, outpatient setting within a different location in Ontario. I would recommend engaging a diverse sample of healthcare providers to get a more comprehensive idea on the impact of implementing the GSF which was limited in this study. Comparisons of palliative care providers' lived experiences could be made to identify possible areas in care where strengths and challenges may occur. Using multiple methods of data collection would also provide more insight and comprehensive results by triangulating the data, which, would strengthen the validity of the study. Additionally, this study also did not include the lived experiences of palliative patients' and caregivers' accounts of

care. Therefore, the addition of exploring patient and caregivers experiences could be included in order to examine different perspectives from all groups involved in the care trajectory, in relation to the conceptual underpinnings of the GSF.

6.4 Conclusion

The purpose of my research was to investigate the lived experiences of palliative care providers in implementing the GSF in oncology care, from a hospital-based, outpatient palliative care setting. Through this study, I was able to identify facilitators and barriers of implementing the GSF within the context of the Canadian healthcare setting. Subsequently, I was able to answer the research question that I initially set out to explore at the beginning of this study. Furthermore, using the GSF, I was able to identify the areas of strength and the areas for improvement, needed to solidify the delivery of high quality, patient-centered, palliative care. As palliative care is a developing field in healthcare, it is important to understand the importance of limiting gaps in patient care so there is success in addressing patients' envisioned goals of care and achieving patient-focused outcomes. Maintaining universal standards of care through the implementation of the GSF accompanied with adhering to patients' needs and preferences will support this goal.

Appendix A: UOIT REB Approval Form

2/27/2018

University of Ontario Institute of Technology Mail - Research Ethics Board Approval Notice



Melanie Dissanayake <melanie.dissanayake@uoit.net>

Research Ethics Board Approval Notice

1 message

researchethics@uoit.ca <researchethics@uoit.ca>

Wed, Aug 10, 2016 at 5:25 PM

To: "Dr. Manon Lemonde (Primary Investigator)" <manon.lemonde@uoit.ca>, "Ms. Melanie Dissanayake (Student Lead)"

<melanie.dissanayake@uoit.net>

Cc: researchethics@uoit.ca

Date: August 10, 2016

To: Manon Lemonde

From: Shirley Van Nuland, REB Chair

Title: Utilizing the Gold Standards Framework as a tool in hospital-based, out-patient palliative care: An exploration of palliative care providers' experiences in oncology

Decision: APPROVED

Current Expiry: August 01, 2017

Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the research proposal cited above. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 (2014)) and the UOIT Research Ethics Policy and Procedures. You are required to adhere to the protocol as last reviewed and approved by the REB.

Continuing Review Requirements (forms can be found on the [UOIT website](#)):

- **Renewal Request Form:** All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed within 30 days of the expiry date will be automatically suspended by the REB; projects not renewed within 60 days of the expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form:** Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or Unexpected Events Form:** Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form:** This form must be completed when the research study is concluded.

Always quote your REB file number (**114051**) on future correspondence. We wish you success with your study.

REB Chair

Ethics and Compliance Officer

<https://mail.google.com/mail/u/0/?ui=2&ik=2374e5bceb&jsver=IEEF798Mfw.en.&view=pt&ui%20cb&search=query&th=1567658957995a1&siml=15676589...> 1/2

Appendix B: Lakeridge Health REB Approval Form



Lakeridge
Health

1 Hospital Court
Oshawa, ON
L1G 2B9

NOTIFICATION OF RESEARCH STUDY TO COMMENCE

To the Principal Investigator:
Manon Lemonde
Lakeridge Health

cc: LH Programs: DRCC

attach: Research Team Form

From: Vice President, Research
Lakeridge Health
(for Administrative Approval)

Chair, Lakeridge Health Research Ethics Board
(for Research Ethics Board Approval)

RI-ID#: 2016-025

Study Title: Utilizing the Gold Standards Framework as a tool in hospital-based, out-patient palliative care: An exploration of palliative care providers' experiences in oncology

All research studies must receive both Administrative Approval and Research Ethics Board Approval prior to commencement. Administrative Approval requires approval of the department impact, resource utilization (including sufficient funds to cover all expenses related to the study), and execution of a research Contract/Agreement. The above named study has been approved for administrative and resource utilization merit by Lakeridge Health under the current funding agreement. Any changes to the agreed funding, or protocol revisions that have an impact on resources, will require re-approval.

Please feel free to contact the Research Liaison if there are any questions.

Sincerely,

Barry R. Guppy, MD, MPA, FRCPC
Vice President, Research
Lakeridge Health

2016-10-12

Date



In addition to Administrative Approval, the above named study has been approved for ethical and scientific merit by the Research Ethics Board (REB). This research study may now commence, contingent upon the following:

(i) As a reminder, the REB and LH operate in compliance with applicable laws and regulations including, but not limited to, the International Conference on Harmonization for Good Clinical Practice (ICH/GCP) Guidelines as set forth in Part C Division 5 under the Canadian Food and Drugs Act and the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans Version 2 (TCPS). Lakeridge Health is registered with the U.S. Department of Health & Human Service under IRB registration number IRB00003507. As the Principal Investigator, you are responsible for the ethical conduct of all research team members during the course of the study, and for cooperating with monitoring activities determined by the REB. As such, you and your Research Team (see attached) agree to undertake the study in conformity with the approved protocol, and to immediately report to the REB:

- any revisions, additions, deletions or other amendments via the *Amendment/Revised Consent Form*;
- any local, and specifically relevant external serious adverse events via the *Internal Serious Adverse Event (SAE) Report Form*; and
- any deviation or new information with respect to the protocol via the *Protocol Deviation Form*

(ii) In the event of confidentiality concerns or privacy breach, such as inappropriate and/or unauthorized use of information, you are to immediately report these to both the REB and to the LH Privacy Officer (in accordance with Ontario health privacy legislation – *Personal Health Information Protection Act, 2004*) via the *Privacy Breach Report Form*.

(iii) As the Principal Investigator, you are further expected to submit:

- an annual progress report and annual re-approval via the *Annual Report/Re-Approval Form* if the study is expected to continue beyond the Expiry Date; and
- a *Study Closure Form* along with a copy of the final report when the study has been completed.

Contact Information:

CONTACT	NAME	PHONE
Principal Investigator	Manon Lemonde	905.576.8711 x2342
LH Research Department	Research Liaison	905.576.8711 x2745
Research Ethics Board	Chair	905.576.8711



1 Hospital Court
Oshawa, ON
L1G 2B9

REB Meeting Date: September 12, 2016

REB Review Type: A Full Board Meeting
 The Chair with Notification to All Board Members

REB Approval Date: September 12, 2016

REB Approval Expiry Date: September 12, 2017

The Research Ethics Board has received the following documentation for study entitled:

"Utilizing the Gold Standards Framework as a tool in hospital-based, out-patient palliative care:
An exploration of palliative care providers' experiences in oncology"

Documents approved until the expiry date noted above:

- Protocol Version 1 dated August 26, 2016
- Consent Form Version 1 dated August 26, 2016
- Recruitment Script - Email Version 1 dated August 26, 2016
- Palliative Care Provider Socio-demographics Form Version 1 dated August 26, 2016
- Interview Guide Version 1 dated August 26, 2016

Documents Acknowledged:

- UOIT REB Approval Letter



Lakeridge
Health

1 Hospital Court
Oshawa, ON
L1G 2B9

Signed: _____

John Montgomery, BA, LLB
Chair, LH-REB

Please quote your file number (2016-025) on all future correspondence.

Notification of Research Study to Commence Release Date: October 17, 2016

Appendix C: Confidentiality Form



Title: Utilizing the Gold Standards Framework as a tool in hospital-based, outpatient palliative care: An exploration of palliative care providers' experiences in oncology

Administrative Assistant Statement of Confidentiality

I Tina Doucet-Black am assisting Melanie Dissanayake in her study: "Utilizing the Gold Standards Framework as a tool in hospital-based, outpatient palliative care: An exploration of palliative care providers' experiences in oncology" with participant recruitment

As an administrative assistant I am acknowledging that:

- I will maintain the anonymity of all participants involved in this research study.
- I understand that information (names/emails) regarding all participants is to be held in strictest confidence and is not to be discussed outside of the research group.

In signing my name below, I agree to the above statements.

Administrative Assistant Signature: Tina Doucet-Black Date: November 1, 2016

I have fully explained the issues of confidentiality, integrity of data and security issues to the above Administrative Assistant.

Principal Investigator Signature: Manon Lemond Date: Nov. 1, 2016

Appendix D: Lakeridge Health Recruitment Email Script



Utilizing the Gold Standards Framework as a tool in hospital-based, outpatient palliative care: An exploration of palliative care providers' experiences in oncology

Melanie Dissanayake, Faculty of Health Sciences,

University of Ontario Institute of Technology

Email Subject Line: A study on implementing the Gold Standards Framework in hospital-based, outpatient palliative care.

I am writing to invite you to participate in a research study. As a master's student from the faculty of health sciences at the University of Ontario Institute of Technology (UOIT), I am currently conducting a research study under the supervision of Dr. Manon Lemonde, RN, PhD from UOIT. This study has been approved by the UOIT Research Ethics Board REB (#14051) on August 10, 2016 and Lakeridge Health Research Ethics Board REB (#2016-025) on October 17th, 2016.

The purpose of this study is to explore the experiences of palliative care providers on implementing the Gold Standards Framework in hospital-based, outpatient palliative care. Particularly, we want to gain an in-depth understanding from palliative care providers' lived experiences on what factors may impact the implementation of this framework in hospital-based, outpatient palliative care, specifically in the Durham Region. You are eligible to participate in this study because you are part of the outpatient palliative care team at Lakeridge Health Oshawa and currently administer palliative care to patients diagnosed with cancer.

We would like to audio record your interview. Participation in this study would take approximately 45 to 60 minutes of your time. In appreciation of your time commitment, you will be given a \$15 Tim Hortons gift card.

The risks involved in participating in this study are minimal and it is not likely that there will be any harms or discomforts as a result of your participation in this study. You do not have to answer any question that you do not want to. To protect your privacy, all data collected during the interviews will be kept confidentially and will only be accessed by the researcher and research supervisor associated with this study. Additionally, pseudonyms will be used and thereby your name will not be presented on any data, for the purpose of your privacy. Therefore, as your information will be kept confidential and anonymous throughout this study, your decision to participate will in no way impact your employment or future employment opportunities.

Remember, this is completely voluntary, and you can answer only those questions that you are comfortable with. If you decide to be part of the study, you can stop (withdraw) from the interview for any reason even after signing the consent form. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you provided will be destroyed unless you indicate otherwise.

Thank you for your consideration. If you would like to participate or have any questions about the study, please feel free to email me at: melanie.dissanayake@uoit.net or contact me at: 416-904-3875.

Sincerely,

Melanie Dissanayake

Appendix E: Participant Consent Form



Consent Form

Title: Utilizing the Gold Standards Framework as a tool in hospital-based, outpatient palliative care: An exploration of palliative care providers' experiences in oncology

You are invited to participate in the research study as part of a master's project. Please read this form carefully, and feel free to ask the researcher any questions you might have concerning the study. This study has been approved by the UOIT Research Ethics Board REB # 14051 on August 10, 2016 and by the Lakeridge Health Research Ethics Board (2016-025) on (October 17th, 2016).

Researcher(s):

Student Researcher: Melanie Dissanayake MHSc. (Cand.)
melanie.dissanayake@uoit.net
416-904-3875

Principal Investigator, Faculty Supervisor: Manon Lemonde RN, PhD.
(Associate Professor/Research Associate) manon.lemonde@uoit.ca /
mlemonde@lakeridgehealth.on.ca
905-721-8668 (2706) /905-576-8711 (2342)

Purpose and Procedure:

The purpose of the study is to explore the experiences of palliative care providers on implementing the Gold Standards Framework in hospital-based, outpatient palliative care. Your participation involves completing a socio-demographic form and taking part in a semi-structured interview consisting of open-ended questions, where you can speak with the researcher about your experiences. The interviews are audio-recorded and will be transcribed verbatim; the researcher may also take notes by hand during the interview. It is anticipated that the interview may take approximately from 45-60 minutes to complete.

Following the completion of the interview, it will be transcribed and available for you to review within seven (7) days. You will have an opportunity to review the transcript, at

your discretion, either in person or via email to confirm meaning in statements and to provide additional information or comments, as you deem necessary. If you decide to review the transcript, it is appreciated to send your comments, changes, or approval to the researcher within seven (7) days. If a subsequent meeting is to occur in person, it will take place on a different, mutually agreeable date and time. This process may need to occur more than once, which is at your discretion, to ensure that meaning has been accurately captured and your experience sufficiently described in as much detail as possible.

Potential Benefits:

There are no direct benefits to you from participating in this research; however, this research can be used to inform palliative care practices and support the importance of having strong hospital-based, outpatient palliative care programs.

Potential Risk or Discomforts:

The risks involved in participating in this study are minimal and it is not likely that there will be any harms or discomforts as a result of your participation in this study. You do not have to answer any question that you do not want to. All data collected during the interviews are confidential and will only be accessed by the members on the research team listed on this consent form.

Confidentiality:

Transcripts will be transcribed on Google Docs via Google Apps for Education (UOITnet server) and will therefore only be accessible to the student researcher, faculty supervisor/principal investigator, and participant (if desired) via the shareable link. Your privacy shall be respected. All information and data collected will be kept completely confidential. Your names, and contact information will not appear on any forms or on any type of publication. Moreover, information about your identity will not be shared or published without your permission unless required by law. Therefore, as your information will be kept confidential and anonymous throughout this study, your decision to participate will in no way impact your employment or future employment opportunities. All recordings and transcriptions will be kept for 5 years after the completion of the research study. After the 5 year period, all data will be destroyed in a proper manner. Any confidential research data and records in paper format will be shredded. Confidential research data and records in electronic format will be destroyed by reformatting, rewriting or deleting. All the information provided by you will remain confidential and will only be utilized for the purpose of this research. For further information about security of data within Google Apps for Education, please visit <https://support.google.com/work/answer/6056693>

Right to Withdraw:

Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research supervisor. If you decide to be part of the study, you can

stop (withdraw) from the interview for any reason even after signing the consent form. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you provided will be destroyed unless you indicate otherwise.

Compensation:

You will receive a \$15 Tim Hortons gift card upon the completion of your interview.

Participant Concerns and Reporting:

If you have any questions concerning the research study, please contact the researcher at melanie.dissanayake@uoit.net. Should you have any questions or concerns regarding your rights as a participant in this research study, or if you wish to speak to someone who is not related to the study, you may contact the Research Ethics Board through the Compliance Office at researchethics@uoit.ca or (905) 721-8668 x 3693 and/or the Chair of the Research Ethics Board of Lakeridge Health at (905) 576-8711 ext. 2745. By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Dissemination of Results:

A hard copy of the thesis research will be given to Lakeridge Health Oshawa. The results of the study may be published or presented at professional meetings, or journals as well.

Consent to Participate:

- I have read this consent form and understand the study being described
- I have had an opportunity to ask questions about my involvement in this study and to receive additional details I requested
- I agree that data collected during my interview will be kept for a maximum period of 5 years by the researcher
- I freely consent to participate in the research study, understanding that I may discontinue participation from the interview even after signing the consent form without penalty.

_____	_____
Participant Full Name	Date
_____	_____
Participant Signature	Date
_____	_____
Researcher Signature	Date

No, I do not want to receive a copy of the interview transcription.

Yes, I would like to receive a copy of the interview transcription.
Email: _____

***YOU WILL BE PROVIDED A COPY OF THIS CONSENT FORM FOR YOUR OWN
RECORDS***

Appendix F: Interview Guide

Interview Guide

1. Tell me about your experiences surrounding the implementation of the Gold Standards Framework in outpatient palliative care, specifically in this hospital setting. (*Probes below*)
 - a. What are these experiences like for you?
2. Tell me about your experiences on how implementing the Gold Standards Framework affects the way you provide hospital-based, outpatient palliative care?
 - a. What are these experiences like for you?
3. In what ways does the use of the Gold Standards Framework help you ensure that the improvements in the levels of care (7 C's/key tasks) delivered to oncology palliative care patients in a hospital-based, outpatient setting are sustained?
 - a. What are some of your memorable experiences detailing this?
4. Tell me your experiences about facilitators that you have found which affects how you practically implement elements of this framework in the delivery of palliative care? What are these experiences like for you?
5. Tell me your experiences about barriers that you have found which affects how you practically implement elements of this framework? What are these experiences like for you?
 - a. (If barriers exist) What measures should be taken to limit these barriers?
6. In your opinion what can enhance your experiences on implementing the Gold Standards Framework in hospital-based, outpatient palliative care?
 - a. In what ways do you think this would have an impact on the delivery of palliative care from this hospital-based, outpatient palliative care setting?
7. Is there anything else that you feel I should know in relation to your experiences surrounding the implementation of the GSF within hospital-based, outpatient palliative care?

Appendix G: Participant Socio-Demographics Form



**Lakeridge
Health**

Palliative Care Provider Socio-demographics Form

Participant ID: _____

Gender: Female Male

Age: _____

Highest Level of Education:

Baccalaureate Degree Master's Degree

College Diploma Doctorate Degree

Other (Please Specify): _____

My years of working in oncology are _____ years

My years of working within hospital-based, outpatient palliative care are _____ years

My role on Lakeridge Health Oshawa's hospital-based, outpatient palliative care team is: _____

Employment Status: Full-Time

Part-Time

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