Master’s Thesis

Underutilization of Palliative Care Related to the Associated Stigmatism:
Time to Change the Service Name within the Veterans Affairs Healthcare Setting

by

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Abstract

Advances in medicine and technology have transformed cancer into a chronic disease state: enabling earlier, treatable, diagnoses and longer lives. However, the focus in medicine remains in quantity of life: failing to address the multitude of stressors influencing quality of life. Quality of life considerations during treatment tend to focus on physical symptoms of disease or side effects of treatment, negating important quality of life interventions offered through Palliative Care. Palliative Care focuses on the psychosocial, emotional and spiritual aspect of living with cancer. Yet, it remains an untapped resource in the Veterans Affairs Healthcare System (VAHCS), often reserved until later or terminal stages of disease. However, Veterans and families begin to experience such stressors at the time of initial diagnosis, which negatively influences healing and overall quality of life. In an era, focusing on improved quality and overall outcomes, one must question the barriers to earlier initiation of services.

Keywords: palliative care, hospice, supportive care, cancer, chronic disease, barriers, quality of life, Veteran
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Chapter 1

**Introduction**

Advances in medicine and technology have enabled extension of life for Veterans living with chronic disease and illness. However, such extension often focuses on quantity of life, offering treatments that provide a few additional months or long-term control of disease. Less emphasis remains focused on the quality of life experienced during the treatment trajectory. Quality of life considerations during treatment tend to focus on physical symptoms of disease or side effects of treatment, such as pain, nausea, vomiting, or diarrhea. Important quality of life discussions or interventions focusing on stressors related to the psychosocial, emotional and spiritual aspects of living with the disease usually remain reserved until the late or terminal disease stages. However, Veterans and families begin to experience such stressors during initial diagnosis, which negatively influences healing and overall quality of life.

**Background**

Services offered to Veterans through Palliative Care include assessing and addressing the physical, psychosocial, spiritual, and financial aspects related to chronic illness and disease. Provided through a multidisciplinary team, the intent is to improve quality of life through recognition of barriers that increase levels of stress for that individual Veteran and family: Veteran-Centered Care (Sales, 2016). This service remains appropriate during all stages of chronic illness, provided simultaneously with curative treatments, regardless of life expectancy.

Historically, Palliative Care has equated to that of death and dying; providing a negative connotation. Therefore, providers tend to prolong implementation of services: confusing Palliative Care with that of Hospice Care (Ramchandran, 2013). The probable explanation for
such confusion relates to the introduction of Palliative Care within the oncology setting during the 1950’s, which molded the conceptual model (Clark, 2007). During this time, the focus of care centered on treating patients who maintained a potential for cure and sending those without such potential home to die (Clark, 2007). To compensate for the perception of abandonment, palliation of symptoms became the focus of care for this patient population. Overtime, Dr. Cicely Sanders and various leaders in the social aspects of death and dying began to raise awareness of unmet needs, the consequences thereof (Hui, 2013), and the term “palliative care,” surfaced. Created by Dr. Baulfor Mount, this term served to describe care provided within the hospice setting in Canada (Hui, 2013), hence the beginning of the associated stigmatism of the word “palliative” to death and dying.

In 1974, the concept of Hospice Care evolved in America, as a model of care to provide palliation of symptoms to terminal patients as they experienced a natural death within their home (Clark, 2007). By 1982, general medicine embraced the concept and founded the subspecialty of palliative medicine and Medicare established funding for Hospice services (Clark, 2007). In 1989, the World Health Organization (WHO) defined palliative care as “an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Hui, p.680, 2013). Yet, over the past 30 years, confusion among providers persists.

Various changes in terminology used to describe care provided within the hospice setting attempted to separate the confusion. Terms such as “terminal care,” “end-of-life care” or
“comfort care,” failed to provide more than synonyms lacking clear definition (Hui, 2013), and the term “palliation” remains associated with Hospice. Current National Comprehension Cancer Network (NCCN), National Cancer Institute (NCI), and the American Society of Clinical Oncology (ASCO) all maintain standards and guidelines, followed by the Veterans Healthcare System (VAHCS), to initiate Palliative Care Services at the diagnosis of cancer. However, orders for initiation at diagnosis remain extremely low, with an exception of end stage diagnosis (Ramchandran, 2013).

Other organizations or services experiencing resistance or decreased utilization transformed successfully through rebranding, such as nursing homes. Personal past experience and observations include a strong patient resistance to temporary nursing home placement post a hospital discharge. Patients often verbalize the nursing home as “the place to go and die,” as this is the memory of their parents, family, or friends. However, over the years nursing homes rebranded that image utilizing a new positive name, reflective of the care provided: “rehabilitation centers,” “extended care centers,” “assisted living facilities,” and “skilled nursing facilities.” While changes in health policy and reimbursement account for many of the changes, patients verbalize less resistance to continued care in these environments.

Significance

The consequences related to the negative connotation associated with the word “palliative” influences the ability of Veterans to experience improved quality of life. Current referral options, within the VAHCS electronic medical record (EMR), remain limited to choices of “Palliative Care” or “Hospice Care.” It remains personal belief that the negative stigmatism associated with the actual name of the service leads to underutilization and delay of appropriate
care: care that maintains potential to improve quality of life and overall outcomes for the Veteran and the facility. Although the current era of healthcare aims to improve quality of life and overall outcomes, the majority of providers continue to reserve initiation of Palliative Care until no further curative treatment options remain. In such era of healthcare, where evidence-based practice and quality outcomes take priority in selecting and directing implementation of care, one must ask why there remains resistance to earlier initiation.

Numerous studies demonstrating the benefits of early intervention remain available, such as the study completed by Temel and colleagues. Their randomized study showed the implementation of Palliative Care at diagnosis provided increased quality of life, decreased depressive syndromes, and a longer median survival, 11.6 months compared to 8.9 months (Temel, 2010), which remains longer than many costly approved chemotherapeutic options provide. This cohort of patients received less aggressive end of life therapy, yet reported experiencing longer quality of life.

This also implies cost saving measures for the facility, as patients receiving early interventions experienced decreased emergency room visits (Temel, 2010). Morrison and colleagues discovered a facility cost saving of approximately $5,000.00 per patients, related to decrease use of pharmaceuticals, laboratory testing, radiographic imaging, and intensive care stays when patients received Palliative Care (McGrath, 2013). Veterans and families that perceive increased quality of life are satisfied patients: increasing return business, word-of-mouth referral base, and facility satisfaction scores (Dunham & Pinczuk, 2015).
The body of nursing science will continue to advance, as nurses begin to embrace evidence-based practices associated with Palliative Care, advocate for early initiation of care, and participate in research to enhance the body of knowledge related to living with chronic disease.

**Purpose**

Intention serves to increase early initiation of appropriate care for Veterans living with a chronic diagnosis of cancer, by disassociating negativity, and replacing the word “palliative” with “best supportive” in the EMR to improve quality of life and overall outcomes.

Most providers continue to associate orders for Palliative Care with giving up: something difficult to grasp (Mulvihill, 2015). Many providers within the VAHCS are fellow comrades, they care for their patients, fight for their patients, and focus on keeping their patients alive to beat all odds. The current culture of healthcare perpetuates this belief with expectations that providers will heal and cure, increasing pressures to utilize all possible measures before surrendering to the disease. Yet, the dichotomy towards Palliative Care persists, because utilization of services creates a paradox.

Therefore, providing the same service line rebranded with a connotation of hope, enhancement and optimism enables an additional avenue for providers in their quest to heal and cure. The hypothesis being that, consultations to a rebranded service line will increase, regardless of stage, when providers associate positive outcomes with the service offered.
Chapter 2

Literature Review

The literature review of professional, peer-reviewed publications within the CINAHL® and ProQuest® databases included a search for publications between the years of 2005 to 2017 using key words, *palliative care, hospice care, psychosocial distress, utilization, rebranding*, and *barriers*. The search was then further refined using filters limiting publication dates 2011-2017, articles written in the English language, and those that included diagnoses of chronic disease and cancer. The reviews include selection of forty conceivable articles for utilization to support the benefit of Palliative Care in early disease and defend the need to rebrand the concept of delivery. Exclusion of articles for this review included those that remained personal opinions or editorials.

Most articles utilized “palliative care,” “Holistic Care,” “Hospice Care,” and “Supportive Care,” as if they were interchangeable terms. Although most articles confirmed the existence of confusion between Palliative Care and Hospice Care, and supported early initiation of care, only one systematic review provided a conceptual model, which included a new name for services provided to patients in early stages of disease (Hui, 2013). However, there remains a gap in the literature concerning the effects of changing the actual name of the service line.

A qualitative study conducted in Australia examined the utilization of Palliative Care in the emergency room setting in patients with advanced disease, and determined that a simple name change remained insufficient (Weil, 2015). While this study provided great insight regarding multidisciplinary perceptions and understanding of palliative care, and called for education of
providers, a name change was not included in the actual study to support such statement, decreasing validity of the statement.

A study conducted by Maciasz and colleagues related the underutilization of care to confusion and misperception regarding the meaning of services provided: equating Palliative Care with Hospice and misunderstandings regarding the delivery of concurrent care, implicating the term “palliative” as barrier perceived as distressing (Maciasz, 2013). Their randomized marketing study separated patients into one of four groups: supportive care, palliative care, patient-centered care, and traditional care. Patients in the supportive care group reported increased attitudes and favorable impressions of care (Maciasz, 2013). However, this study lacked evaluation or identification of the various modalities of care provided, which led to such increased attitudes. While their study maintained limitations, it supported the need to consider the negative connotation associated with the term “palliative” and to increase utilization by changing the name, not the service.

Rocque and Cleary (2013) further supported changing the name of palliative care in their randomized, controlled study. They noted the recent CanCors study, identified a 33-day median time from discussions regarding end of life care and actual death, and concluded this as multifactorial (Rocque, 2013). They noted reasons equating to the physicians poor judgement regarding life expectancy and fear of inducing psychological harm on the patient and family (Rocque, 2013). Rocque and Cleary (2013) discussed another study, conducted by the National Comprehensive Cancer Network (NCCN), which reported recent analysis of Hospice enrollment occurring 8-9 days prior to death, when benefit of care incudes a life expectancy of 6 months. Palliative care services remain appropriate for all stages of disease without life
expectancy restrictions and ease the psychological distress of transitioning into Hospice care. However, 70% of Americans lack knowledge regarding the differences between Palliative Care and Hospice Care (Rocque, 2013). When educated 92% of Americans concluded care Palliative Care remained an important aspect to improve quality of life (Rocque, 2013).

A national qualitative study completed in Canada by Wentlandt and colleagues (2011), surveyed 839 oncologists and experienced a 72% response rate, a significant sample size. They reported one third of the oncologists surveyed would utilize services earlier under the name “supportive care,” because the name “provided a favorable connotation” (Hannon, 2015).

Zimmermann and colleagues (2016) conducted a randomized controlled trial comparing early palliative care to standard care provided to patients with advanced stages of cancer. The trial included semi structured interviews that assessed personal perceptions and attitudes regarding palliative care. The study included 48 patients and 23 caregivers, divided with equal balance between the control and intervention groups, and offered perception clarity. Initial interviews in both groups revealed attitudes regarding palliative care that equated with fear, death, hopelessness, and dependency (Zimmermann, 2016). However, the intervention group reported increased quality of life and felt the term palliative carried a stigma, which needed renaming (Zimmermann, 2016). Sadly, the control group stated a name change remained pointless (Zimmerman, 2016), indicating initiation of care occurred too late. Their study recognized that patients, family, and providers all maintained negative attitudes toward palliative care. They recognized barriers regarding patient and family perceptions equating to the presentation of care conducted by providers: “I’m sorry, I think we’ve got to put her into palliative care,” and “We can’t do anything else, he’s in palliative care” (Zimmerman, 2016,
p10), which perpetuates the negative connotation. A prominent theme regarding the need to rebrand the service remained evident, “that shell of meaning that surrounds palliative care has to somehow change” (Zimmermann, 2016, pE22). Further supported with, “…a name that would outline what you’re actually trying to do” and “…it has to have this notion that it’s going to be help….to live longer” and “…make it less traumatic” (Zimmerman, 2016, pE24).

Caprio and colleagues (2016) conducted a retroactive qualitative review of Zimmermann’s study, and agreed changing the name to Supportive Care remained essential in breaking barriers associated with the negative connotation of the word palliative. Caprio (2016) further stated that regardless of the name utilized, the acceptance of care remained in the providers’ presentation to the patient: “stigma will persist if this type of care is recommended only as default treatment when curative or life-prolonging treatments are deemed ineffective” (Caprio, 2016). Suggesting the provision of services for all cancer patients regardless of a specific identified need; “no longer chosen….simply integrated into comprehensive oncology treatment that supports patients and caregivers” (Caprio, 2016, p712).

Sekelja and colleagues (2009) completed a qualitative study regarding Palliative Care services viewed by caregivers. Although recruitment of participants included those caring for patients with metastatic, end-stage disease, it provided insight regarding the potential benefit provided to caregivers and society. One participant stated, “I think I was more worried that, that the term ‘palliative care’ sort of drove home the point that he was in fact dying” (Sekelji, 2009, p 1225), supporting the negative connotation. Caregivers stated difficulty meeting their own psychological needs while trying to meet the physical needs of the patient, which feasibly relates to Maslow’s Hierarchy of Needs Model (Sekekji, 2009), and care assisted meeting both
the patient and caregivers needs. All the participants appreciated the emotional support and expressed gratitude for the bonds created with their caregiver (Sekelji, 2009). Memory bias may provide limitations for this study, as interviews took place 1-12 months after the patients’ death (Sekelji, 2009). However, the implied benefit to the caregiver during impending death and post death through visits, phone calls, and counselling assisted the entire family reach acceptance of death (Sekelkji, 2009).

No studies have evaluated the influence of rebranding palliative care in the VAHCS. This suggests the need to conduct a study to determine if rebranding within this setting would serve to increase early stage utilization. In the United States, MD Anderson reported increases in early stage initiation of care in the outpatient setting since changing their service name in 2007 to “supportive care” (Dalal, 2011). Their new “supportive care” service experienced a 41% referral increase after the name change and the referrals occurred earlier in the treatment trajectory (Dahl, 2011). Rhondali (2012) conducted an additional qualitative study at MD Anderson after the name change to Supportive Care. Utilizing semi-directed interviews with 17 staff medical oncologists, he reported the oncologists viewed the name change as lacking influence on referral patterns, however perceived their patients maintained a greater acceptance of care under this name. Perhaps this relates to a cognitive bias, as Dalal’s study confirmed otherwise.

A critical review of evidence supporting early integration of Palliative Care services, conducted by Salins (2016), describes multiple benefits of care. Each study reviewed supported improved quality of life, improvement of symptoms, improved perception of disease, and defined goals of care (Salins, 2016). However, the review failed to address barriers related
to delayed initiation of care, except for the relation of reimbursement of Palliative Care services falling under Medicare as Hospice Care.

In Rhondali’s study (2012), the oncologists described the Supportive Care team as capable of providing comprehensive symptom control, while their personal expertise maintained symptom management. Most oncologists identified the presence of uncontrolled or distressful symptoms, as the point of time to refer patients to Supportive Care (Rhondali, 2012). They acknowledged that by controlling their patients’ symptoms, they were able to provide increased dosing or extended duration of chemotherapy, which increased the potential to extend life (Rhondali, 2012). One provider discussed referring patients “earlier than when they need supportive help……to form a relationship with the supportive care physician…”(Rhondali, 2012, p401), which enabled smoother transitions in care. However, barriers to initiate care later in the disease trajectory persisted, as conversations regarding poor prognosis, remained difficult and provided the perception of their own failure. Rhondali (2012) suggests oncology training should include difficult conversations and a rotation within the palliative/supportive care setting, to increase personal comfort zones. Although this study represented the oncologists’ own perception of personal practice, it further described the benefit of changing the name for patients.

Despite availability of literature supporting a positive correlation between early integration of palliative care and improved outcomes, barriers related to the negative connotation persist. The name Palliative Care lingers in America, obstructing the provision of timely and appropriate access to care.
Chapter 3

**Method**

The method of study for this concept proposes development of a mixed study design, conducted over a 12-month period. This length of time remains necessary to obtain a large enough group of Veterans to provide adequate sample size to increase study rigor and reliability. Obtaining formal Institutional Review Board (IRB) approval remains indicated as post-study evaluation proposes the inclusion of protected health information (PHI) by accessing individual charts for the assessment of quality of life indicators and distribution of surveys.

**Study Design**

The NMVAHCS currently utilizes templated Cancer Survivorship Care Plans (CSCP) in the EMR system. The CSCP maintain automated features and decision tools prompting providers to implement delivery of care according to NCCN guidelines, which remain specific to the type and stage of disease specific to the Veteran. The provider driven CSCP auto populates orders and consultations based on each selection as indicated. Each selection maintains an embedded health factor or data point, which enables data retrieval from the Central Data Warehouse (CDW) for reporting purposes and automation of timely and appropriate survivorship care. The current CSCP prompts the provider to select consultations for “Palliative Care,” or “Hospice Care,” with the majority of providers negating either option in the absence of end-stage disease.

The proposed design includes inserting additional options for the provider to select, “Best Supportive Care” and “N/A,” and proposes a descriptor indicating the new service provided; “assesses and addresses the physical, psychosocial, and spiritual aspects of living with chronic
illness and disease, at any stage of the disease trajectory.” Selecting the “N/A” would populate a blank entry field for the provider to describe the reason care remained non-applicable (see Table 1 & 2). The section would remain a mandatory entry field, meaning one of the four options require selection before the provider finishes and signs the CSCP. Establishing this additional option will provide a means to assess if rebranding the name improves not only overall facility utilization, but will distinguish utilization of care at each specific stage of disease, allowing for recognition of statistical implications, relationships and provide construct validity. Inserting the mandatory data entry field to explain the providers reasoning of negating care will provide insight regarding barriers and development of future provider education.

Study design also proposes development of a pre and post implementation survey for the general surgeons to complete. This serves to provide information for qualitative study regarding the General Surgeon’s personal perceptions, confusion, knowledge, and personal bias concerning the appropriate indications for implementing Palliative Care prior to and after initiation of the stated CSCP changes. Surveying the providers will enable a survey sample representative of the population hypothesized as influenced by the negative connotation associated with the word “palliative.”

**Setting**

The setting remains a partially controlled, convenience sampling, with proposed participants for inclusion comprising of all Veterans diagnosed with gastrointestinal cancer receiving care within the Surgical Service of the New Mexico Veterans Affairs Healthcare Setting (NMVAHCS), in Albuquerque, NM, during Fiscal Year (FY) 2017. This group of participants’ remains selected, as they currently have mandated CSCPs, which service surgeons must
complete. Veterans diagnosed with cancer outside of gastrointestinal disease will remain excluded; as such, cancer diagnoses receive surgical care in other facility services or departments. The exclusion of Veterans diagnosed and treated for gastrointestinal cancer through the Gastrointestinal (GI) Service or Medical Oncology remains necessary, as these services currently lack a mandate to complete the CSCP. Veterans initially diagnosed with gastrointestinal cancer at an outside provider will also require exclusion. The VAHCS only provides care for eligible Veterans, so proposed data analysis lacks inclusion of civilians and patients under the age of 18 years. However, this proposed study design remains transferable to the private sector and requires consideration to improve utilization of care and elevation of health policy. The providers included in the study will represent all NMVAHCS Surgical Service General Surgeons caring for this patient population.

**Methods of Measurements**

As stated previously, each item selected in the CSCP maintains attached health factors that enable identification and collection of various data points. Specific data points propose to include: 1). the date of diagnosis, 2). the stage of disease, 3). the date of initial visit to Surgical Services, and 4). the date of consultation to either palliative care of best supportive care (see Table 3). The information remains accessible through reports generated that search for health factors captured in the CSCP. Generating this report pre and post initiation of the new branded name will provide information necessary for analysis. Baseline information for later comparison will include the number of consultations ordered to Palliative Care per disease stage during FY16; the period prior to initiation of this proposed change. One year after implementing the new “Best Supportive Care” option in the CSCP, September 30, 2017,
generating the same report will serve to compare results and indicate if a simple name change increased appropriate utilization of care.

The design also proposes assessing the Veterans’ perception of quality life pre and post initiation of “Best Supportive Care.” Retrieval of such information will occur through analysis of responses made to the DISTRESS tool, which remains housed in the CSCP (see Table 4). The design of this validated tool complies with the Commission on Cancer (CoC) standards for addressing the physical, psychological, social, and spiritual issues impacting quality of life in patients diagnosed with cancer (COC, 2014). This tool utilizes a Likert scale to assess personal reflection and attitudes related to the level of perceived distress experienced by the Veteran at that particular point of the treatment trajectory (Schwartz, 2014). Use of the Likert scale provides opportunity for construct validity and statistical analysis to develop reliability and validity of proposed measurement. Health factors attached to responses allow a mechanism to track and monitor reported perception, in each dimension of care, prior to and after initiation of interventions, as this remains a mandatory assessment in the CSCP by the surgeons at each follow up visit. Specific quality indicators will include the Veterans level of reported distress: “No distress,” “Slight Distress,” “Some Distress,” “Moderate Distress,” “Severe Distress,” or “Worst Distress.” Further quality indicators include identification of the specific area leading to level of reported distress: “physical,” “psychological,” “social,” or “spiritual.” Quality indicators will include narrowing down the specific identified need, such as: “pain,” “difficulty eating,” “depression,” “fear,” “transportation,” “loss of faith,” etc. (see Table 4).
Chapter 4

**Dissemination of Findings and Recommendations**

The topic of palliative care remains a highly published and studied content area in healthcare with identified benefits for the patient, facility, and society. Yet, there remains lack of consistent use or application in all stages of cancer. The current definition of palliative care, stated in the NCCN guidelines, includes delivery of Palliative Care services, at diagnosis, regardless of disease stage, provided with concurrent life prolonging treatments, at the initial visit, to foresee, avoid, and decrease stressors that impair quality of life (NCCN, 2016).

On-line evidence-based algorithms, published by the NCCN, assist providers in the screening and assessment process to recognize unmet or the potential of unmet needs. However, only 10% of oncology providers, from 21 of the 25 NCCN designated facilities, report using the Palliative Care Guidelines to direct care, leaving provision of care to provider discretion and inconsistencies in actual care provided (Rivera, 2015).

**Effects on Quality of Life**

Advances in medicine and technology continue to provide Veterans diagnosed with cancer a prolonged life expectancy: transforming cancer into a category of chronic disease. However, as with most chronic disease, maintaining extension of life requires lifestyle changes and treatment modalities that interrupt life: creating additional stressors and introducing symptom burden (Wysham, 2015). Initiating palliative care early in diagnosis enables improved quality of life by assessing and addressing the physical, psychosocial, emotional, and spiritual well-being of the Veteran.
Effects on Physical Well-Being

The physical stressors associated with a cancer diagnosis and its treatment cause interference with the ability to maintain optimal quality of life. Pain, from the actual disease or related cancer treatment, which lacks control, restricts the ability to remain active, leads to social isolation, and increases depression: negatively effecting quality of life (McPherson, 2013). Palliative care services enable identification of barriers leading to uncontrolled pain: fear of addiction, cultural beliefs, side effects, knowledge deficits, denial, and not wanting to bother the provider (McPherson, 2013). Many Veterans under report pain fearing that disclosure equates to the progression of disease, leads to termination of treatment, or another hospitalization and therefore, remain willing to tolerate the pain (Chen, 2012). Primary care providers and medical oncologists routinely assess pain levels, but accept reported levels as truths: negating the possibility of barriers (Beernaert, 2015). The most predominant reason cited for not initiating Palliative Care in a study conducted by Beernaert and colleagues, relates to the belief that care currently provided met their patient’s needs; that Palliative Care “lacked meaning,” and “not wanting to deprive patients and families hope” (Beernaert, 2015).

The Veteran population remains stoic: trained to ignore pain and persist in battle, which relates to the increased late stage disease diagnosis in the VAHCS and under reporting of pain, complicating adequate pain control. Palliative Care teams in the VAHCS understand approaches to assess pain in the Veteran, assess barriers, build rapport, and advocate for appropriate interventions (Woodall, 2016). As denial of pain leads to inappropriate coping such as recreational drug use or alcohol abuse and the increase incidence of suicide, especially in Veteran experiencing concurrent psychiatric disorders (Magruder, 2012). Removing the
social stigmatism associated with the word “palliative,” serves to improve quality of life by initiating care early and appropriately, perhaps even preventing suicide.

One intervention utilized in palliative care involves use of exercise. Many oncologists lack experience with the benefits of exercise and remain hesitant to recommend their patients to participate in exercise programs (Brown, 2014). However, research in this area validates enhancement of both physical and psychosocial dimensions of life: offering improved personal perception of quality (Haas, 2016). A landmark observational Cancer and Leukemia Group B (CALGB) study conducted by Meyerhardt and colleagues demonstrated a 50% increase in survival benefit in colon cancer patients participating in consistent exercise programs over the treatment trajectory (Meyerhardt, 2006). Ongoing exercise studies suggest a relationship between decreasing debilitating cardio toxic and neuropathic side effects of chemotherapy through aerobic exercise (Haas, 2016). These studies also imply actual suppression of cancer cell growth with concurrent aerobic activity (Haas, 2016), providing increased quality of life and survival benefit.

**Effects on Psychosocial Well Being**

The Veteran living with cancer experiences numerous psychosocial and emotional stressors influencing the ability to perceive positive quality life. However, many personal stressors remain undetected, as the provider concentrates assessment on the expected signs and symptoms of disease and Veterans fail to disclose issues themselves (Beernaert, 2014). Perhaps, this is because the majority of Veterans receiving care in the VAHCS are males, who remain less prone to discuss personal distress or anxiety openly, which remains especially true in older Veterans (Nedjat, 2015). Men in our society remain perceived as the stronger sex, not
expected to cry or display emotions, as doing so decreases their personal manhood. The barrier to accessing care becomes the social stigma (Tran, 2016). Veterans remain less apt to reveal issues, perceived as weaknesses in our society, without prompts from the provider. Oncologists and primary care providers lack the specialized training of palliative care teams, needed to discuss and draw out issues affecting well-being. Many Veterans will deny issues when the provider does inquire, although they may have admitted complications earlier to the nurse (Dinc, 2013). Perhaps, this relates to the art of nursing and the special bonds nurses create with their patients that build trusting relationships. Palliative Care teams maintain clinical expertise and training to develop such relationships, yet they remain untapped resources early in the disease process.

Veterans experiencing a diagnosis of colon cancer may experience a number of issues interfering with psychosocial wellbeing: urinary incontinence, fecal incontinence, impotence, decreased muscle mass, depression, fatigue, erectile dysfunction, and living with a permanent colostomy or ileostomy. The greatest symptom burden occurs early in the disease process, while trying to maintain normal life or sexual relationships. However, palliative care remains underutilized until end stages of disease. Providers’ reasoning relates to the misperception of services and negativity associated with the term “palliative,” stating phrases such as, “They are not ready for that” (Beernaert, 2015).

Palliative care teams address a variety of other issues affecting quality of life. For example, if the Veteran is the breadwinner supporting his family, stressors include worry regarding payment of their mortgage, utilities, or the purchase of food, while not bringing home a paycheck. Many Veterans live alone, estranged from family members, and lack social
resources needed for transportation to appointments and treatments. Initiating Palliative Care at the initial visit connects the Veteran to social workers, who remain knowledgeable of local resources, relieving such stressors and increasing adherence of scheduled appointments necessary for care.

As Veterans diagnosed with cancer, continue to experience increasingly longer survival, a better understanding and utilization of services earlier in the course of treatment remains imperative. Early referrals to appropriate care addresses the distinct individual needs, serves to reduce impact, improve well-being, and improve overall quality of life for the Veteran.

**Effects on Spiritual Well Being**

Veterans maintaining a religious affiliation, which includes regularly church attendance prior to the diagnosis of cancer, assert increased coping skills with decreased emotional distress (Zullig, 2014). However, many Veterans lack membership or affiliation in a spiritual setting, and experience a greater fear of death when diagnosed with life threatening diseases such as cancer, regardless of the disease stage (Zullig, 2014). Palliative Care assessments identify this Veteran population and connect them with appropriate Chaplin Services. Zullig and colleagues reported that 64% of Veterans studied perceived increased patient satisfaction when chaplain services were included in care (Zullig, 2014).

The multidisciplinary Palliative Care team in the VAHCS includes Chaplain Services. Although services remain available in all VAHCS settings, most Veterans lack awareness of care until approached with the option (Chang, 2012). Nurses must recognize the value of care, assess their patient’s individual spiritual needs, and advocate for appropriate services. Chaplain Services within the VAHCS remain unique. Veterans often struggle with spirituality issues
arising from combat: the emotional guilt of killing and associated war crimes (Chang, 2012). Many Veterans have never forgiven themselves for such actions. They suppress guilt until faced with a life threatening illness or disease (Chang, 2012). Initiating Palliative Care early in a cancer diagnosis allows Veterans the opportunity to seek self-forgiveness, peace, and harmony, which improves overall quality of life. Chaplains in the VAHCS remain highly specialized in the perspectives that cause spiritual distress in Veterans. They utilize approaches of religion, such as forgiveness of sins. However, they understand the value of allowing the Veteran to verbalize and validate life experiences in combat, which allows the Veteran to heal emotionally (Chang, 2014).

**Effect on Organizational Outcomes**

In 2012, the National Institute of Health (NIH) reported that 50% of healthcare spending occurs within the last year of life and represents care provided to only 5% of the American population (NIH, 2012). Over the last decade, the Institute of Medicine (IOM), now referred to as the Health and Medicine Division (HMD), called for improvements in quality care and demanded decreased healthcare spending in their annual reports. This led to implementation of evidence practices and changes in health policy, as healthcare began to evolve in the quest for means to meet such demands.

Aetna Compassionate Care Program reported decreased hospital admissions and length of stay experienced by patients enrolled. This led to decreased facility costs associated with end of life care by 22%, through the initiation of a structured Palliative Care Service, which is coordinated early and concurrently with treatment modalities (Parikh, 2013). Similar reports of savings equate to decreasing hospital costs by 9% to 24% when patients receive palliative care.
The structure of support provided a return of investment through establishing Palliative Care programs, which decrease unnecessary emergency room visits, hospital admissions, and hospital mortality (Snyder, 2015). Palliative Care programs identify patients’ needs and assist in the identification of realistic goals, through clarification and understanding of prognosis, and increasing the patients’ ability to cope with the diagnosis (Parikh, 2013).

Hospital based palliative care teams enable improved symptom management, survival, and patient satisfaction, while decreasing facility costs (Synder, 2015). The increased pressure to reduce hospital costs and improve quality outcomes, further supports the need to increase early access to palliative care. However, the majority of hospitals in the United States lack access to Palliative Care services in the outpatient setting (Dalal, 2011), where the majority of oncology therapy is provided. The majority of hospitals maintain access to inpatient Palliative care. However, the delivery of care in this setting focuses on preparation or transitions to end-of-life care (Beernaert, 2015).

**Implications for Advancing the Body of Nursing Knowledge**

Burden of chronic cancer diagnoses on society will continue as Veterans endure longer lives. While many providers lack a comprehensive understanding regarding the differences of Palliative Care and Hospice, oncology nurses remain well versed. Nurses must aim to improve quality of life by translating knowledge into evidence-based, cost-effective interventions, and advocate for the initiation of Palliative Care at diagnosis (Wysham, 2015). The majority of Veterans diagnosed with cancer experience symptoms from competing comorbidities: Post-Traumatic Stress Disorder (PTSD), Military Sexual Trauma (MST), depression, anxiety, obesity, diabetes, and chronic obstructive pulmonary disease (Tarleton, 2014). Understanding
the implications of comorbid disease and influences on the ability to maneuver the trajectory required of a cancer treatments, will enable nurses to improve overall outcomes for the Veteran, facility, and society.

This includes advocating for health policy changes to raise awareness regarding the associated benefits of early initiation of Palliative Care. The New Mexico 53rd Senate legislature is reviewing Senate Bill 173, during the 2017 first session. This Bill serves to establish a Palliative Care Advisory Council comprised of a multidisciplinary team of providers to increase access and decrease barriers associated with Palliative Care in the state. Nurses residing in the State of New Mexico must advocate for support of this Bill, and nurses in other states should team with stakeholders for initiation of similar legislative measures.

Other pertinent issues include advocating for health policy change that includes reimbursement of Palliative Care services through Medicare. In 1996, the Veterans Healthcare Eligibility Reform Act mandated the inclusion of Hospice and Palliative Care to all Veterans. However, access to such care remains limited to inpatient care, due to a lack of providers, despite the additional 2003 VAHCS Directive to increase care and form multidisciplinary teams of providers (Synder, 2015).

Although Palliative Care remains a covered service with the Veterans Healthcare System, the private sector lacks such coverage. Current reimbursement of services falls under the provision of Hospice Care, and excludes services outside this arena. Once again, the association of Palliative Care with end of life and confusion regarding the benefits of services provided. Although, the political agenda is gaining momentum through recognition of cost
saving, evidence-based, benefits related to early implementation (Parikh, 2013), nurses must advance this motion, take initiative, and advocate for policy change.

**Recommendations**

Several studies have compared the effectiveness of early palliative care interventions; however, limited information exists in the VAHCS. Additional work remains necessary to confirm the direct relationship between VAHCS provider perceptions as barriers to timely referrals. Studies should include the impact of early intervention on Veterans as they begin to engage in care, by monitoring their individual perceptions of distress along the treatment trajectory. Evaluation of such impact and the innovative approaches of managing stressors may have a larger organizational impact, as Veterans begin to engage in untapped resources.
Chapter 5

Conclusion

Barriers associated with the early initiation of palliative care directly relate to the confusion and negative connotation regarding the word “palliative” (Ramchandran, 2013). Perhaps, this correlates to the origin of the term; first coined by Dr. Mount to describe care provided within the Hospice setting (Hui, 2013). Although over the years, palliative care evolved to include services that improve quality of life throughout the disease trajectory, the term “palliative” remains associated with death and dying. This stigma creates barriers initiating early care, as providers’ state their patients “are not ready for that” (Beernaert, 2015). The associated negativity also obstructs initiating care when disease progresses, as providers struggle with personal perception of self, a feeling of failure, as if they are giving up by not providing a cure (Mulvihill, 2015). It also remains quite feasible that confusion persists within our society due to the manner that providers’ present palliative care “as the end of the line” (Hui, 2013).

These barriers linger, as oncology programs fail to provide actual training with rotations in the palliative care setting or experience conducting difficult conversations. The focus of medical training remains in quantity of life: curing and healing patients and negates stressors influencing quality of life. Quality of life concerns during treatment continue to center on the physical symptoms of disease or side effects of treatment, negating the psychosocial, emotional and spiritual influences. However, providers welcome the inclusion of such care when offered under rebranded, upbeat service lines, as demonstrated at MD Anderson and in the study conducted by Wentlandt and colleagues (2011). Physicians recognize the ability to keep
patients on treatment longer when they receive concurrent therapy, which enables the quest for cure.

Presenting the line of service, rebranded as “Best Supportive Care” maintains potential to disassociate the negative stigmatism and increase appropriate utilization of services. Services, which maintain the potential to increase the Veterans perceived quality of life, improve facility outcomes, and decrease the burden of chronic disease on society. Palliative Care assessments connect the Veteran to services, which run concurrent with the provision of curative treatment and allow the Veteran to experience improved quality of life. Quality of life, which remains defined by the Veteran, individualized by personal goals and expectations, through appropriate assessment of needs, and supported decision-making: Veteran-centered care.

As advances in medicine and technology continue to provide Veterans extension of life, organizations must recognize the value related to addressing stressors influencing quality of life. There becomes a need to promote education and awareness within the multidisciplinary team regarding the positive benefits, as relieving stressors provides meaningful care to the Veteran and family (Beernaert, 2015). Care initiated at diagnosis facilitates formation of realistic goals, enables acceptance of disease, and eases transitions of care (Salins, 2016). In the era, focusing on improved quality and overall outcomes, one must consider the barrier of terminology, and perhaps, recognize the time to change the service name.
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Appendix:

Table 1. Current Prompt for Care in the CSCP

<table>
<thead>
<tr>
<th>Prompt for Care</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care</td>
<td>Palliative care is provided to patients with a life expectancy of less than 6 months.</td>
</tr>
<tr>
<td>Hospice</td>
<td>Hospice care is provided to patients who are expected to die within the next 6 months.</td>
</tr>
</tbody>
</table>

Table 2. Proposed Changes of Prompt in the CSCP

<table>
<thead>
<tr>
<th>Consults for Additional Care</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Best Supportive Care (NEW)</td>
<td>Assesses and addresses the physical, psychosocial, and spiritual aspects of living with chronic illness and disease, at ANY stage of the disease trajectory.</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>Palliative care is provided to patients with a life expectancy of less than 6 months.</td>
</tr>
<tr>
<td>Hospice</td>
<td>Hospice care is provided to patients who are expected to die within the next 6 months.</td>
</tr>
<tr>
<td>N/A</td>
<td>Reason: Forced data entry box to reason for negating care</td>
</tr>
</tbody>
</table>

Table 3 Mechanism to Capture Date of Consult, Date of Diagnosis & Cancer Stage

Image of the interface showing the mechanism for capturing the date of consultation, date of diagnosis, and cancer stage.
Table 4. Psychosocial Distress Tool in the CSCP

Health factors drop based on selection for data collection through the CDW