

CARING FOR THE SERIOUSLY ILL: DEVELOPING AN
INPATIENT PALLIATIVE CARE PROGRAM
AT A COMMUNITY HOSPITAL

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By
Andrea M. Martinez
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CERTIFICATION OF APPROVAL

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Signed Certification of Approval page is on file with the
University Library

Elizabeth Halifax, RN, PhD
Graduate Nursing Lecturer

Date

Janelle Culjis, RN, PhD, ANP
Director, ASBSN Program

Date

Connie Fairchilds, RN, MN, MBA
Graduate Nursing Lecturer

Date

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DEDICATION

This project is dedicated to my husband Victor and my children Sofia, Emily, and Jacob. I am so grateful for your love and support throughout my Master's program. To my children, thank you for keeping me balanced, inspired, and motivated to finish. To Victor, thank you for your continuous encouragement, your listening ear, and for the countless times you brought me coffee at midnight.

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ABSTRACT

Palliative care is an approach that improves the quality of life for patients and families coping with serious illness at any age and any stage of illness. Through the identification, assessment, and treatment of physical, psychosocial, and spiritual symptoms, palliative care aims to prevent and relieve suffering. The purpose of this paper is to propose a plan for the implementation of an inpatient palliative care program at a community hospital where no formal palliative care services exist. The need for formal palliative care services at this hospital was established and a literature review was undertaken to examine what is known about inpatient palliative care models. Existing research shows that palliative care positively impacts patients, their families, professional providers, and hospitals. An inpatient palliative care consultation service provided by an interdisciplinary team was determined to be the most appropriate model for this hospital. Spradley's theoretical change model was used as a framework to formulate a process by which an inpatient palliative care consultation service could be implemented. This process identified outcome measurements to determine the program's impact on patients, their family, the staff providing care, and the fiscal goals of the organization. Specific tools to measure clinical, customer, operational, and financial outcomes were evaluated and recommendations are given.

CHAPTER I
PALLIATIVE CARE: AN ESSENTIAL COMPONENT IN PROVIDING
QUALITY CARE

Approximately ninety million Americans are living with serious illnesses and that number is expected to double in the next twenty-five years (Center to Advance Palliative Care, 2011). Advances in modern medicine have shifted as conditions once considered terminal such as cancer, respiratory disease, and heart failure have become chronic conditions that people may live with for many years (Morrison & Meier, 2011). The need to address quality of life and relief of suffering is an essential goal of healthcare (Meghani, 2004). However, chronically ill patients frequently report inadequately controlled symptoms, disjointed care, and poor communication with healthcare providers (Center to Advance Palliative Care, 2011). Hospital nurses frequently charged with providing care for the chronically ill, often question goals of care and quality of life for their patients (Mahon & McAuley, 2010).

Palliative care is defined as an approach that aims to improve the quality of life of patients and families coping with life-threatening illnesses at any age and any stage of a serious illness. These aims are met through the prevention and relief of suffering by identifying, impeccably assessing, and treating physical, psychosocial, and spiritual symptoms without the intention of hastening or postponing death (World Health Organization, 2014; Center to Advance Palliative Care, 2014a). Inpatient palliative care is evolving to meet the needs of patients and families dealing with

serious illness, and has been shown to lower the cost of hospital care while offering additional benefits to healthcare providers (Digwood et al., 2011; Fillion, Dupuis, Tremblay, De Grace, & Breitbart, 2006; Morin, Saint-Laurent, Bresse, Dalbuiere, & Fillion, 2007; Morrison & Meier, 2011).

The project described here explored the potential benefits of developing an inpatient palliative care consultation service at a community hospital in California where there are no formal palliative care services. Currently, healthcare staff at this hospital attempt to meet the palliative care needs of patients through personal independent efforts and/or through consultations with ethics, social services, and chaplaincy personnel. Patient satisfaction data shows that this hospital scores below both the California and National averages on nurse communication, physician communication, and pain control (Centers for Medicare & Medicaid Services, 2015a). To understand the healthcare staffs' satisfaction with current palliative care practices, interviews with staff nurses, physicians, case managers, and specialists were undertaken to explore attitudes and concerns. These interviews revealed healthcare providers' dissatisfaction with discussions of goals of care and symptom management, and expressed frustrations with the disjointed support from ethics, pain management, and/or social services. In addition to meeting patient needs, this for-profit hospital is expected to meet corporate goals for quality care and financial expectations.

Having identified a gap in palliative care services at this hospital, a literature review was undertaken to examine the evidence regarding options to fill this gap. An

inpatient palliative care consultation service was identified as the most appropriate model for this community hospital. Spradley's change model is used as the framework to plan for and implement the change. Palliative care program clinical, customer, operational, and financial outcomes are identified and specific measurement tools are evaluated and recommended for use.

CHAPTER II

REVIEW OF THE LITERATURE

The purpose of this literature review is to identify what is known about the implementation and significance of inpatient palliative care programs. A main synthesis of themes from the literature are presented. The strengths and limitations of the literature reviewed are summarized and implications for nursing practice and future research are discussed.

Methods

A comprehensive literature search was accomplished using the CINAHL and Medline data bases. Search terms included palliative care, inpatient palliative care, palliative care consultation, palliative care models, and palliative care nursing. Both quantitative and qualitative articles in the English language published in the last 10 years were retrieved that addressed at least one of the following: (a) a definition of palliative care, (b) outcomes of palliative care, or (c) models of palliative care programs. Most literature addressing palliative care can be found in journals of oncology nursing, oncology medicine, palliative care medicine, palliative care nursing, and ethics.

Defining Palliative Care

The term *palliative* is derived from “palliate” which is defined as making a disease less severe without removing its cause (Palliate, 2014). Until the early 1990’s, the term *palliative care* was used in the United States to describe care of the

dying and was often used interchangeably used with the term *hospice care* (Meghani, 2004). Consequently, palliative care is often misunderstood as being the same as end-of-life care (Smith, Temin et al., 2012). Palliative care however, affirms life by supporting a seriously ill patient's goals and hopes for the future whether or not that person's death is imminent (National Palliative Care Research Center, 2014).

Palliative care does not intend to hasten or postpone death, it is defined as an approach to improve the quality of life of patients and families coping with life-threatening illnesses at any age and any stage of a serious illness through the prevention and relief of suffering by identifying, impeccably assessing, and treating physical, psychosocial, and spiritual symptoms (World Health Organization, 2014; Center to Advance Palliative Care, 2014a). Palliative care has three key attributes: patient and family centered holistic care, an interdisciplinary team approach, and effective communication (Weissman & Meier, 2011). It is appropriate as a main therapy or may be provided concurrently with other life-prolonging therapies, such as chemotherapy or radiation therapy for a multitude of individuals diagnosed with serious and chronic conditions such as cancer, congestive heart failure, and chronic obstructive pulmonary disease (Center to Advance Palliative Care, 2014a; Guo, Jacelon, & Marquard, 2012; Weissman & Meier, 2011; World Health Organization, 2014).

Inpatient Palliative Care Consultation Services

Palliative care in the acute-care setting is usually provided through inpatient units, inpatient consultation services, or outpatient clinics (Smith, Coyne, & Cassel,

2012). The most prevalent use of palliative care in hospitals is the use of specialty consultations to address symptoms that are difficult to manage, challenging family situations, and complex care decisions regarding life-sustaining treatments (National Consensus Project for Quality Palliative Care, 2013; Weissman & Meier, 2011).

Interdisciplinary teams of doctors, nurses, social workers, pharmacists, dieticians, and chaplains provide patient and family centered holistic care to assess and treat physical and psychosocial symptoms, guide goal-setting and decision-making, and provide a support system to help patients and their families achieve the best quality of life (Morrison & Meier, 2011; Strand, Kamdar, & Carey, 2013). Palliative care teams identify and address distressing symptoms such as pain, nausea, delirium, fatigue, depression, and dyspnea (Strand et al., 2013; Weissman & Meier, 2011). Inpatient consultancy services are easy to start and maintain, cost less than inpatient palliative care units (Smith, Coyne et al., 2012) and have the advantage of not being limited to one specific unit. Criteria for palliative care consults in the acute-care setting often include:

- a life-threatening or life-limiting condition(s) with difficult to manage physical or psychological symptoms,
- intensive care unit stay of greater than or equal to seven days,
- lack of clarity in the goals of care, and
- disagreements or uncertainty among the patient, healthcare team, or family regarding major medical decisions, resuscitation status, or use of alternative feeding or hydration (Weissman & Meier, 2011).

Inpatient Palliative Care Outcomes

Benefits of inpatient palliative care consultations are numerous and positively affect patients, families, healthcare providers, and medical institutions. Whether palliative care is combined with standard care or is the main focus of care, there are improvements in symptoms, quality of life, patient satisfaction, and coping abilities, along with a reduction in costs, suffering, distress, and caregiver burden (Digwood et al., 2011; May, Normand, & Morrison, 2014; Sanft & Von Roenn, 2009; Smith, Temin et al., 2012). Outcomes related to the integration of palliative care are hospital based, healthcare provider based, and/or patient and family based.

Hospital Based Outcomes

The sickest 10% of the United States population accounts for 64% of health care expenditures (Zuvekas & Cohen, 2007). Palliative care programs improve the quality, while lowering the cost of hospital care (Digwood et al., 2011; May et al., 2014; Morrison, Maroney-Galin, Kralovec, & Meier, 2005). Palliative care can shorten intensive care unit lengths of stay, decrease intensive care unit mortality, and reduce hospital costs (Digwood et al., 2011; May et al., 2014). In a retrospective electronic database review of 5,035 medical intensive care unit (MICU) discharges, Digwood and colleagues (2011) compared data on mortality and length of stay from the two years prior to and the two years after the opening of the palliative care unit (PCU). Results indicated that since the opening of the PCU, MICU mortality and length of stay significantly decreased (Digwood et al., 2011). Preliminary evidence from research exploring hospital palliative care consultations indicated that early

consultations in the emergency department were associated with significantly shorter lengths of stay averaging 3.6 days (Wu, Newman, Lasher, & Brody, 2013). May et al. (2014) completed a review of ten studies comparing the costs and/or cost-effectiveness of specialist hospital inpatient palliative care consultations and found a clear pattern of cost-savings. On average, palliative care was associated with cost savings to hospitals of approximately \$1,700 per admission for patients who survived hospitalization and \$5,000 per admission for patients who died during their stay. The decrease in cost was primarily related to reductions in intensive care, laboratory, radiology, and pharmacy services (May et al., 2014).

Healthcare Provider Based Outcomes

Healthcare providers encountering increased work demands and emotional stress related to the care of seriously ill patients have been shown to benefit when palliative care services are provided (Fillion, Dupuis, Tremblay, De Grace, & Breitbart, 2006; Morin, Saint-Laurent, Bresse, Dalbuires, & Fillion, 2007; Strand et al., 2013). Benefit was found to derive from effective communication among patients, families, and the interdisciplinary team. Though conversations with patients with serious illnesses can be emotionally intense, the palliative care team engages in patient-centered, empathetic communication that empowers patients and families to acknowledge the impact of the health condition on their life, set realistic goals, face challenges, and identify areas where they may need further support (Johnston, Milligan, Foster, & Kearney, 2012; Norton et al., 2013; Strand et al., 2013). This interdisciplinary collaboration, which fosters mutual trust and emotional support

among the palliative care team, has led palliative care providers, managers, and program coordinators to report positive effects including personal growth, increased confidence in clinical practice, increased job satisfaction, and improved staff retention (Fillion et al., 2006; Morin et al., 2007).

Patient and Family Based Outcomes

Much of the literature examined here describes how patients and families benefit from palliative care (Bronwyn-Long, Bekelman, & Make, 2014; Daveson, Benalia, Simon, & Higginson, 2011; Enguidanos, Housen, Penido, Mejia, & Miller, 2014). Improved communication through palliative care has shown to improve patient satisfaction, compliance with treatments, and health outcomes in seriously ill patients (Bays et al., 2014; Weissman, Morrison, & Meier, 2010).

A randomized control trial completed by Temel and colleagues (2011) aimed to explore the perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer (NSCLC) and to examine the effect of early standardized palliative care on these views over time. Participants (n=151) from a thoracic oncology clinic with newly diagnosed metastatic NSCLC were randomly assigned to either a standard oncology care group or early palliative care in addition to standard oncology care. Researchers found that patients who received the concurrent palliative care starting at the time of diagnosis had significantly higher quality of life scores, fewer depressive symptoms, less aggressive end of life care, better understanding of prognosis, and increased survival (Temel et al., 2011). Based on such evidence, consensus panels agree that palliative care should be considered

early in the course of illness in any patient with metastatic cancer and/or high symptom burden, to provide better patient and caregiver outcomes (Smith et al., 2012; Temel et al., 2011; Yoong et al., 2013). Further evidence supports the use of palliative care across a variety of inpatient and community settings to improve patient functioning and quality of life (Taylor, Bull, Zhong, Samsa, & Abernethy, 2013).

Families of the chronically ill often experience caregiver burden and have their own personal needs related to palliative care (Bausewein, Daveson, Benalia, Simon, & Higginson, 2011). Families describe the qualities of inpatient palliative care team interactions favorably when compared to those of other physicians and staff. These qualities include effective communication styles, better tone used in conversation, increased opportunity for exchange, more opportunities for questions, and improved access to the physicians (Enguidanos et al., 2014). Families further report benefits of palliative care in aiding to reduce the financial burden of medical care (Morrison et al., 2005).

Strengths and Limitations of the Literature

There is a breadth of research articles relating to “palliative care” from around the globe, with a general search of that topic in the CINAHL database yielding over 27,000 results. The topic is published in multiple professional disciplines, with the majority of articles using qualitative methodology. Limitations identified by researchers reflect practical and ethical considerations in collecting and analyzing data in a rapidly deteriorating and extremely sick patient population (May et al., 2014), and consequently much of the quantitative literature is retrospective.

Palliative care is under-theorized and most articles do not include theoretical frameworks that guide the development of the studies. Although there are numerous tools used to measure palliative care outcomes such as quality of life, symptom management, patient and family satisfaction, and provider satisfaction, there is not a specific consensus on which tools to utilize and further research is needed to identify which elements of data collection relate specific palliative care processes to clinical outcomes (Bausewein et al., 2011; Pelayo-Alvarez, Perez-Hoyos, & Agra-Varela, 2013; Weissman et al., 2010).

Implications for Nursing Practice

The literature demonstrates a positive relationship between palliative care and nursing practice (Fillion et al., 2006; Morin et al., 2007). Given the evidence that palliative care benefits hospitals, healthcare providers, and patients and family members, inpatient nursing staff would do well to advocate for palliative care programs. Benefits of palliative care have been maximized when referral has been initiated at the time of diagnosis of a serious illness has been made (Weissman & Meier, 2011).

Multi-disciplinary experts agree that comprehensive and timely interdisciplinary palliative care screening and assessments must be completed to develop the plan of care based on the identified and expressed values and goals of the patient (National Consensus Project for Quality Palliative Care, 2013; Weissman & Meier, 2011). Upon completion of initial palliative care assessments, it is recommended that nurses should complete a daily reassessment of moderate to severe

symptoms, a reassessment of all symptoms no less than every three days, and document symptom management plans for all moderate to severe symptoms (National Consensus Project for Quality Palliative Care, 2013; Weissman & Meier, 2011). Guidelines for nurses performing physical aspects of care include assessing and managing pain and/or other symptoms such as nausea or shortness of breath, based upon the best available evidence and developing treatment plans for the assessment and management of symptoms in the context of the disease, prognosis, and functional limitations of the patient (National Consensus Project for Quality Palliative Care, 2013).

Summary

Palliative care programs have positive effects on hospitals and healthcare providers, with research showing the most significant benefits accrue to patients and families (Bausewein et al., 2011; Bronwyn et al., 2014; Enguidanos et al., 2014). Research examined supports the effectiveness of achieving these benefits with inpatient palliative care services that provide cost-effective wide-reaching services. Further research is needed to determine the core components of palliative care interventions (Morin et al., 2007; Temel et al., 2011; Yoong et al., 2013) to address the identified disparities regarding palliative care education (Goldsmith, Dietrich, Du, & Morrison, 2008; Mahon & McAuley, 2010; Watts, 2014), and to validate palliative care outcome assessment tools (Bausewein et al., 2011; Pelayo-Alvarez et al., 2013; Weissman et al., 2010).

CHAPTER III
METHODOLOGY TO IMPLEMENT AN INPATIENT PALLIATIVE CARE
CONSULTATION SERVICE

An inpatient palliative care consultation service is being proposed at a 209-bed acute care hospital located in California's Central Valley, where there are currently no formal palliative care services available at the hospital. This hospital has been providing local, community-based hospital care for nearly 100 years. In the past ten years, the hospital has added a state-of-the-art cancer center, an open-heart surgery program, and additional critical care facilities. While this growth has provided more options for medical treatment at this hospital, seriously and chronically ill patients do not have access to adequate formal palliative care services. Currently, medical and nursing staff attempt to meet the palliative care needs of patients through personal independent efforts and/or various consultations with ethics, social services, and chaplaincy personnel. As a for-profit facility owned by an organization that operates multiple healthcare businesses including 79 hospitals, this hospital is expected to meet corporate expectations, such as cost controls that include adhering to maximum length-of-stay and cost-per-stay guidelines in addition to meeting patient needs. Evidence from the literature review above supports the implementation of a palliative care consultation service to advance corporate-set goals and improve patient care. This chapter will describe the strategies needed to

implement an inpatient palliative care consultation service at this community hospital and the theoretical change model that frames these changes.

Planning Change Using Spradley's Change Model

With its roots in Lewin's change theory (1951), Spradley's eight-step change model is a clear and systematic framework for inpatient palliative care program implementation at this community hospital (Spradley, 1980). Spradley's model calls for continuous monitoring throughout and after the change (Longo, 2013) and is organized much like the nursing process. The eight steps of Spradley's model are: (1) recognize the symptoms, (2) diagnose the problem, (3) analyze alternative solutions, (4) select the change, (5) plan the change, (6) implement the change, (7) evaluate the change, and (8) stabilize the change (Longo, 2013). Each step of this framework, and how it could be applied to the changes needed for this project are described below.

Recognizing the Symptoms

Spradley's first step in planned change is to recognize the symptoms by gathering evidence to support the need for change (Longo, 2013). The number of individuals living with serious illnesses in the U.S. is expected to continue to rise over the next several years (Center to Advance Palliative Care, 2014b). Advances in modern medicine have led to once terminal conditions such as cancer, respiratory disease, and heart failure becoming chronic conditions with many of these patients reporting inadequately controlled symptoms, disjointed care, and poor communication with healthcare providers (Center to Advance Palliative Care, 2011; Morrison & Meier, 2011). Healthcare teams caring for complex, seriously ill patients

report increased work demands, burnout, and emotional stress (Fillion, Dupuis, Tremblay, De Grace, & Breitbart, 2006; Morin, Saint-Laurent, Bresse, Dalbuiere, & Fillion, 2007; Strand, Kamdar, & Carey, 2013). Hospitals are impacted financially because of disproportionate spending on this patient population where the sickest 10% of the United States population accounts for 64% of health care expenditures (Zuvekas & Cohen, 2007). The evidence presented here effecting patients, healthcare providers, and hospitals indicates the need to improve patient care in the seriously ill.

Diagnosing the Problem

The need for palliative care services was diagnosed by analyzing research data from the literature and the hospital (Longo, 2013). The hospital corporation's nationally accepted "Palliative Care Screen" tool used at this corporation's facilities (Appendix A) was used to screen 415 of the hospital's adult inpatients in the Medical/Surgical, Progressive Care, and Critical Care units to identify patients who were eligible for palliative care during a two-week period in September 2015. Nearly 60% of inpatients screened positive for a palliative care consult in a hospital where no formal palliative care services were available. Patient satisfaction data shows that this hospital scores below both the California and National averages on nurse communication, physician communication, and pain control (Centers for Medicare & Medicaid Services, 2015a). Interviews with staff nurses, physicians, case managers, and specialists revealed the healthcare staff's frustrations of being unable to spend quality time with patients and their families to discuss goals of care, diagnoses, and symptom management. Feelings that current disjointed support from ethics, pain

management, and/or social services are dissatisfying for patients, families, and healthcare providers were also expressed.

This hospital participates in the Centers for Medicare and Medicaid Services (CMS) Value-Based Purchasing (VBP) program, a program where Medicare payments in the inpatient setting are subject to the hospital meeting predetermined levels of quality care (CMS, 2015b). Medicare payments may be earned by performing well in five weighted domains of care:

- patient experience of care 25%,
- safety 20%,
- efficiency 25%,
- outcomes 25%, and
- process, 5% (CMS, 2015b).

The absence of palliative care at this hospital may impact the patient experience of care. The CMS defines the *patient experience of care* as including nurse communication, physician communication, and pain management scores. The *efficiency* domain analyzes Medicare spending per beneficiary and calculates *excess days* as the number of days a patient remains in the hospital beyond the number expected for that patient stay based on diagnosis. Currently, excess days at this hospital are at 34%, much higher than the corporate goal of 25%. Additional local characteristics of this hospital's patient population that may contribute to higher *excess days* include diverse cultures, lower socioeconomic status, and the hospital's long history as a not-for-profit organization. Readmission rates are also high with the

majority of patients being re-admitted in the first 30 days after discharge often due to chronic illnesses including Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), and Cancer. On average, palliative care is associated with a cost savings to hospitals of approximately \$1700 per admission in patients who survive hospitalization and \$5000 per admission in patients who die during their stay (May, Normand, & Morrison, 2014). The decrease in cost is primarily related to reductions in intensive care, laboratory, radiology, and pharmacy services (May et al., 2014; Morrison et al., 2008). The hospital's clinical operations team aims to increase services provided at this hospital and has named palliative care a service need at this organization.

Analyzing Alternative Solutions and Selecting the Change

Analyzing alternative solutions and selecting the change involves brainstorming ideas, examining the risks and benefits of a change, and selecting the option most likely to succeed (Longo, 2013). One potential strategy is to not make any change to the current care of seriously ill patients at this organization. However, a decision that palliative care is needed has been made and a continued absence of palliative care services at this organization may contribute to inadequate or inappropriate patient care, dissatisfied patients and family members, burnt-out staff, and financial losses for the hospital. An alternative to a formal palliative care service is to provide palliative care education alone to healthcare staff. Many education resources exist, for example the American Association of Critical Care Nurses (AACN) recognizes the moral distress nurses often experience when caring for

seriously ill patients and those approaching end-of-life and in response, has developed an online education program “Promoting Excellence in Palliative and End-of-Life Care” (AACN, 2017). This online program uses patient simulation to educate nurses on focused assessments, nursing interventions, facilitating decision-making, communication skills, and techniques to lower the nurse’s stress levels. This nursing education approach could be beneficial to the hospital’s nursing staff but it would benefit nurses alone.

Palliative care in hospitals is usually provided through inpatient units or inpatient consultation services (Smith, Coyne, & Cassel, 2012). The most prevalent use of palliative care in hospitals is the use of specialty consultations from interdisciplinary teams (National Consensus Project for Quality Palliative Care, 2013; Weissman & Meier, 2011). Inpatient consult services are easier to start, maintain, and cost less than inpatient palliative care units (Smith, Coyne et al., 2012), in part because many members of an interdisciplinary palliative care team are already on-staff at the organization, including an ethicist, chaplains, case managers, social workers are already on-staff at the organization, and serve a broader population throughout the hospital as opposed to just one unit. An inpatient consultation service is therefore the most appropriate and feasible palliative care model for this hospital. It would provide benefits to all stakeholders using existing resources and expertise in a cost-effective way.

Planning the Change

Planning the change involves developing goals, objectives, timetables, resources, a budget, and an evaluation method (Longo, 2013). Following the organization's shared governance model, an interdisciplinary palliative care committee will be formed using a metamanagement framework that stresses teamwork, communication, and organizational flexibility (Longo, 2013). The committee will include members from nursing, medicine, administration, chaplaincy, ethics, dietary, pharmacy, information technology, and social services. The palliative care committee's overall responsibility will be to design and develop the Inpatient Palliative Care Consultation Service. The committee will develop an inpatient Palliative Care Services policy (see Appendix B) and determine the clinical focus, scope of service, desired outcomes, and formal business plan. Potential goals may include improving patient satisfaction scores, improving pain management scores, reducing excess days, reducing readmissions, and increasing staff retention and satisfaction. The palliative care committee will also be charged with developing a marketing plan, locating a home for the service, and developing an educational plan to ensure nursing staff, physicians, patients, and their families understand the service and its aims.

Implementing the Change

Implementing the change involves preparing a strategy to engage, educate, and support those who will be affected by the change (Longo, 2013). Preparing to implement a palliative care consultation program will require support from

information technology, nursing, medicine, education, billing, human resources, management, and administration departments. The strategy to successfully implement a palliative care program will rely on the palliative care committee's ability to support early adopters and effectively obtain buy-in for the change.

Engaging Those Affected by The Change

The development of an inpatient palliative care consultation service will impact different stakeholders including patients, primary healthcare staff, hospital support services, physicians, and administrative staff. Adopting a transformational leadership style with attributes including idealized influence, inspirational motivation, intellectual stimulation, and individual consideration have been found to be effective when working with large groups of people, and would be fitting when implementing palliative care at this organization (The Foundation for Nursing Leadership, 2015; Schwartz, Spencer, Wilson, & Wood, 2011).

Resistance to change is normal, and may be a result of lack of knowledge or the perception of implied criticism (Longo, 2015). To minimize the resistance to the implementation of a palliative care program, extensive education must be provided highlighting the strong evidence-based support for the change. The knowledge that when palliative care is combined with standard care or as the main focus of care there is an improvement in symptoms, quality of life, patient satisfaction, and coping abilities, along with a reduction in costs, suffering, distress, and caregiver burden should be emphasized (Digwood et al., 2011; May et al., 2014; Sanft & Von Roenn, 2009; Smith, Temin et al., 2012). Those resistant to palliative care may also be

unaware that the concept of palliative care has changed over time, and that rather than being synonymous with end of life, the modern definition of palliative care affirms life by supporting a seriously ill patient's goals and hopes for the future (National Palliative Care Research Center, 2014). Administrators who oppose the implementation of a palliative care program due to related program cost have also been identified.

Support and further engagement of early adopters (stakeholders who have bought into the need for this change) can be promoted through the use of a "change coach". For this project, the medical/oncology nurse manager has been identified as the change coach, and will be responsible for facilitating, guiding, and inspiring the group to accept change (Stefancyk, Hancock, & Meadows, 2013). The earliest adopters identified include the director of the cancer center and the organization's ethicist who have been invited to share in the planning process. This coaching approach to support the implementation of the palliative care consultation service complements the foundation of an interdisciplinary approach to palliative care and can be used throughout the implementation stage as additional early adopters are identified.

Educating Those Affected by The Change

Palliative care education that will include the concept of palliative care and the process of the consultation service will need to be provided at the appropriate level to all stakeholders affected by the changes. Learning is a lifelong process by which learners attain new skills, knowledge, and alter their thoughts, behaviors,

feelings, and attitudes as a result of experience (Bruangart, Braungart, & Gramet, 2014). Adult learners have been described as independent, task-oriented, self-directed learners who bring their own past experiences to the horizontal relationship between educator and learner (Knowles, Holton, & Swanson, 1998). Knowles' Theory of Andragogy will frame and inform the education of adult learners for this project.

In the early 1970's Malcolm Knowles introduced the concept of andragogy, a set of core adult learning principles, and the idea that children and adults learn differently (Knowles, Holton, & Swanson, 2015). Since its introduction, andragogy has been analyzed, debated, and critiqued. The Theory of Andragogy has been variously described as a set of guidelines, assumptions, and even a philosophy (Knowles et al., 2015). Knowles, Holton, and Swanson (2015) state that andragogy presents adult learners' core principles that guide educators in preparing and conducting adult learning to achieve a more effective adult learning process. Knowles, Holton, and Swanson (2015) further describe andragogy as a transactional model in that it addresses the learning transaction, not the goals of the transaction thus making it an appropriate framework for any adult learning transaction (Knowles et al., 2015).

The six core principles of andragogy are defined as (a) the learner's need to know, (b) self-concept of the learner, (c) prior experience of the learner, (d) readiness to learn, (e) orientation to learning, and (f) motivation to learn (Knowles et al., 2015). The learner's need to know principle is described as the need for the learner to

answer the why, what, and how parts of the learning transaction. The self-concept of the learner principle recognizes that adult learners are autonomous, self-directed learners, who are independently seeking information. The prior experience of the learner principle identifies, recognizes, and gives credit to the adult learner for their prior life experiences. The readiness to learn principle recognizes that an adult's readiness may be related to life events, situations, or a developmental task. The orientation to learning principle acknowledges that adults are life-centered and problem-center and seek to learn knowledge that can be applied in the present. The final core principle is the motivation to learn which recognizes that adults have both external and internal motivators for learning. These six core principles are at the center of the model surrounded by two outer rings identified as (a) individual and situational differences, and (b) goals and purposes for learning (Knowles et al., 2015). Individual and situational differences include subject matter differences, situation differences, and individual learner differences. Goals and purposes for learning include institutional growth, societal growth, and individual growth.

Andragogy works best in practice when it is modified to fit the individuality of the adult learners and the learning environment (Knowles et al., 2015). The core principles may not always occur together, especially in new educational subjects, but the teacher can work to develop an understanding of the learner and give guidance during the initial stages of learning (Mitchell & Courtney, 2005). Educational interventions that recognize that adult learners have differences are more likely to have positive outcomes (Mitchell & Courtney, 2005).

For the purpose of showing how this theory may be applied, this section will examine how education would be designed for one stakeholder group: nurses. An ideal application of Andragogy in a palliative care class for nurses at this hospital would take place in a classroom setting with small groups of nurses sitting round-table to discuss the implementation of a palliative care program. Prior to conducting the course the educator would obtain a baseline assessment of each nurse's knowledge of and prior experience with palliative care. During the course the educator would be a facilitator and provide facts on the concept itself or direction when needed. Because of the small group setting, each nurse would have the opportunity to share their experiences and discuss case studies. The palliative care policy, screening criteria, and consult process would be provided and reviewed to allow the nurses to familiarize themselves with the content. The computer applications could also be available in test mode for the nurses to practice initiating a consult based on assessment findings. The application of Knowles' core principles to educate stakeholders about palliative care in the acute care setting will facilitate the attainment of new skills and knowledge, and inform thoughts, behaviors, feelings, and attitudes towards palliative care.

Evaluating the Change

Evaluating the implementation of this project involves determining whether the objectives and outcomes are met (Longo, 2013). Outcome measurement has a major role in improving the quality, efficacy, and availability of palliative care programs (Bausewein, Daveson, Benalia, Simon, & Higginson, 2011), where quality

is a fundamental goal of palliative care (National Consensus Project for Quality Palliative Care, 2013). The consensus for key outcome measures of successful palliative care programs can be divided into four domains:

- operational metrics: the number of palliative care consults and referring physicians;
- clinical metrics: improvements in physical symptoms and quality of life;
- customer metrics: patient, family, and professional caregiver satisfaction; and
- financial metrics: length of stay, billing, and expenditure (Weissman & Meier, 2008).

The organization's palliative care program will be encouraged to collect and analyze data and report outcomes for each of the metrics (Weissman, Morrison, & Meier, 2010). Outcome measurement will be discussed further in chapter four of this paper.

Stabilizing the Change

Stabilizing the change refers to the intention to maintain and monitor the change (Longo, 2013). Sustainability of the palliative care consultation program after implementation will be dependent upon the direct benefits that the program has on hospital operations and stakeholders (Josland, Brennan, Anastasious, & Brown, 2012). The palliative care committee will need to determine the optimal meeting frequency to discuss the communication needs regarding consults, interventions, or outcomes measurements for both clinical and non-clinical stakeholders (Weissman, et al., 2010). The committee will also need to allow for an open exchange of ideas

among all involved in facilitating palliative care within the organization. Program successes should be celebrated as an entire organization to acknowledge the interdisciplinary nature of effective palliative care programs.

Summary

Inadequate care for chronically ill individuals, who often report disjointed care and poor symptom management, usually results in frequent, prolonged, and costly hospitalizations that leave hospital staff feeling inadequate and unsatisfied with the care they provide. This hospital's growth over the past decade has provided high quality medical care to its community, but it has not addressed the need for palliative care services for its chronically ill patients despite strong evidence that palliative care benefits hospitals, improves patient and family outcomes, and increases provider satisfaction. An inpatient palliative care consultation service has been identified as the optimal model for this organization. Spradley's change model has been described as a framework to implement a palliative care consultation service. Careful development of each of its eight steps can ascertain that chronically ill patients of this organization have the option to receive quality palliative care.

CHAPTER IV

PALLIATIVE CARE OUTCOMES MEASUREMENT

Measuring the effects of palliative care is necessary to ensure patients and families are receiving high quality care and to defend the need for palliative care services in the acute care setting, where finances and programs are closely monitored (Meier & Beresford, 2008). Data needs to be collected, analyzed, and reported to provide evidence of a palliative care program's impact and to aid in strategic planning and quality improvement (Weissman & Meier, 2009). Outcome measurement is essential in improving the quality, efficacy, and availability of palliative care programs (Bausewein, Daveson, Benalia, Simon, & Higginson, 2011). The consensus for key outcome measures of successful palliative care programs can be divided into four domains including:

- clinical metrics: improvements in physical symptoms and quality of life;
- customer metrics: patient, family, and professional caregiver satisfaction;
- operational metrics: the number of palliative care consults and referring physicians; and
- financial metrics: length of stay, billing, and expenditure (Weissman & Meier, 2008).

This chapter will discuss outcome measures in each of these domains as they relate to this hospital's proposed palliative care consultation service.

Clinical Outcomes

Clinical outcomes measure improvements in physical symptoms and quality of life for patients and their families and provide evidence of the impact of a hospital's palliative care consultation service (Weissman & Meier, 2008). When palliative care is combined with standard care or is the main focus of care it has been shown that there are improvements in symptoms, quality of life, patient satisfaction, and coping abilities, along with a reduction in costs, suffering, distress, and caregiver burden (Digwood et al., 2011; May, Normand, & Morrison, 2014; Sanft & Von Roenn, 2009; Smith, Temin et al., 2012). Recommended measurements for clinical data include documentation of symptom assessment and management and documentation of patient-centered goals of care discussion (Weissman, Morrison, & Meier, 2010).

Symptom Assessment and Management

Palliative care experts agree that symptoms should be assessed on initial consult, and then at least daily for moderate to severe symptoms, no less than every three days for all symptoms, and that symptom management plans be documented for all moderate to severe symptoms (Weissman et al., 2010). Many validated tools are available to evaluate pain and symptom management. While multiple tools are available and described in the literature, there is no consensus on which tools are best at measuring palliative care outcomes (Bausewein et al., 2011; Pelayo-Alvarez, Perez-Hoyos, & Agra-Varela, 2013; Weissman et al., 2010). Validated symptom assessment scales frequently used in palliative care include the Memorial Symptom

Assessment Scale, Palliative Outcome Scale version 2, and the Edmonton Symptom Assessment were chosen for their proven validity and analyzed for use in this hospital's palliative care program (Weissman et al., 2010).

The Memorial Symptom Assessment Scale (MSAS) is a patient-rated tool originally developed to provide a comprehensive analysis of 32 common symptoms experienced by cancer patients (Portenoy et al., 1994). The MSAS asks patients to read each symptom and rate:

- how often they experience the symptom in the past week (rarely, occasionally, frequently, or almost constantly),
- how severe it was (slight, moderate, severe, or very severe), and
- how much distress it caused (not at all, a little bit, somewhat, quite a bit, or very much).

Responses correlate to a number value, with total scores, facilitating the evaluation of symptom management. Although free, comprehensive, and detailed, the 96 response, two-page MSAS assessment is seen as a complicated tool for patients to complete because it is too long for seriously ill patients, causing fatigue and frustration.

The Palliative Outcome Scale version 2 (POS v2) is a two-page, 12 question tool that asks patients to report on their symptoms in the past three days (Cicely Saunders Institute, 2012). The tool is available in 11 languages and is free to use. Questions on the POS v2 cover specific symptoms such as pain and anxiety along with other broad topics such as question number 9: “over the past 3 days, how much time do you feel has been wasted on appointments relating to your healthcare, e.g.

waiting around for transport or repeating tests?” (Cicely Saunders Institute, 2012). Although a simple and easily accessible tool, the questions on the POS v2 are too broad of questions for the inpatient setting. Although proven effective to assess symptoms, this tool is not appropriate for measuring outcomes because questions are not scored, and therefore do not produce quantitative data.

The Edmonton Symptom Assessment System (ESAS) is a two-page tool designed to assess nine common symptoms by asking patients to rate their symptoms on a 0-10 scale and marking “where it is you hurt” on a body diagram (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991). The scales provide examples of symptom reporting such as zero representing “no pain” and ten representing “worst possible pain”. After patients complete the questionnaire independently or with help, staff are asked to input the data from the questions on to a graph to illustrate trends over periods of time. ESAS scores and graphs can be entered into the hospital’s electronic medical record to provide easily accessible data and reports to providers managing the patient’s symptoms. The ESAS (Appendix C) is recommended for use in this hospital. This tool is well written and simple to use for patients, caregivers, and staff. The data provided from the assessments can be tabulated for individual symptom scores and/or total scores, allowing clinical outcomes related to symptom management to be generated and used to compare initial symptom scores and analyze changes in symptom scores over time. The ESAS is also free and available in multiple languages including Spanish (Carvajal, Hribernik, Duarte, Sanz-Rubiales, & Centeno, 2013).

Documentation of Patient-Centered Goals of Care Discussion

Inpatient palliative care should include encouraging patients and their families to clarify goals of care and/or complex care decisions regarding life-sustaining treatments (National Consensus Project for Quality Palliative Care, 2013; Weissman & Meier, 2011). Palliative care practitioners should document conversations about diagnosis, treatment options, prognosis, identifying goals of treatment, plans to meet goals, preferred care setting, and advanced care planning (Weissman et al., 2010). Standardized initial consult forms and progress notes should be used to ensure that all elements of goals of care discussions are met and are accessible to all members of the interdisciplinary team. Data should then be collated to ensure documentation is complete and outcomes are being met.

Customer Outcomes

Customer outcomes refer to patient, family, and palliative care provider satisfaction (Weissman & Meier, 2008). Palliative care has been shown to increase patient satisfaction, compliance with treatments, and health outcomes in seriously ill patients (Bays et al., 2014; Weissman et al., 2010). Families of palliative care patients describe improved communication and better access to healthcare staff (Enguidanos, Housen, Penido, Mejia, & Miller, 2014). Palliative care providers report positive effects from palliative care programs including personal growth, increased confidence in clinical practice, increased job satisfaction, and improved staff retention (Fillion et al., 2006; Morin, Saint-Laurent, Bresse, Dalbuires, & Fillion,

2007). Customer satisfaction data can be obtained through a variety of tools and reports that this hospital already uses.

In addition to assessing symptom management using the ESAS as proposed, patient satisfaction can be measured by using the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) standardized surveys of patient's perceptions of care (CMS, 2015a). Questions from this survey offer options as answers; for example, "nurses always communicated well" and "patients report their pain was always well-controlled" (CMS, 2015a). This patient experience survey is required for all hospitals receiving federal funding from Medicare and Medicaid and is given to a select number of patients recently discharged from the hospital (CMS, 2015a). Although the HCAHPS survey is not restricted to Medicare beneficiaries, it is only given to patients after discharge, limiting customer satisfaction data collection for those patients who die in the hospital. The HCAPHS survey (see Appendix D) is recommended for use at this hospital to measure patient satisfaction because it is a validated tool that is already required of this hospital (CMS, 2015a).

The Family Satisfaction with End-of-Life Care (FAMCARE) scale is used to measure family caregiver satisfaction of palliative care services (Weissman et al., 2010). The original FAMCARE scale is a 20-item tool which asks family caregivers to rate how satisfied they are with care provided covering symptom management, inclusion in care, and emotional support provided. Responses are given using a numerical value with a maximum score of 100, with higher scores indicating more satisfaction with care. Researchers have found that shorter versions of the

FAMCARE scale, with 17, 10, or 5 questions are reliable tools to evaluate family satisfaction with palliative care services provided (Ornstein et al., 2015). The FAMCARE-2 scale (see Appendix E) is recommended for use at this hospital because it is shorter and more concise than the original FAMCARE scale, and refers to the team approach of palliative care rather than focusing primarily on care from doctors and nurses (Edmonton Zone Palliative Care Program, 2014).

There are validated and reliable palliative care provider satisfaction measurement tools available (Weissman et al., 2010). The Center to Advance Palliative Care (2017) provides examples of provider surveys including referring clinician and clinician satisfaction surveys. These surveys provide sample questions to ask regarding staff satisfaction with the palliative care services provided to patients. Provider satisfaction data can be collected from the hospital's annual staff and physician surveys results using current questions related to staff satisfaction of care provided to patients. Additional specific questions related to palliative care services can be added with administrative approval.

Operational Outcomes

Operational metrics describe the characteristics of the patients receiving palliative care services. The consensus recommendation from palliative care experts suggests that the following operational data should be the minimum collected to analyze inpatient palliative care include:

- patient age, gender, race/ethnicity,
- palliative care diagnosis,

- referring physician or group,
- hospital length of stay based on dates of hospital admission and discharge including disposition (inpatient death or discharge location), and
- number of hospice admissions and discharges (Weissman & Meier, 2009).

Hospital administrators or program directors may request additional data to sustain or grow their program. For this hospital, additional data to collect may include:

- amount of time lapsed between order for palliative care consult and initial consult completion,
- readmission rates of palliative care patients who are discharged from the hospital, and
- the number of positive palliative care screens compared to the number of consults ordered/completed.

Data to measure operational outcomes can be extracted in customized reports from the hospital's electronic medical record.

Financial Outcomes

Financial metrics include length of stay, billing, and expenditure (Weissman & Meier, 2008). On average, palliative care is associated with cost savings to hospitals primarily related to reductions in intensive care, laboratory, radiology, and pharmacy services (May et al., 2014). This hospital participates in the Centers for Medicare and Medicaid Services (CMS) Value-Based Purchasing (VBP) program, a program where Medicare payments in the inpatient setting are subject to the hospital meeting predetermined levels of quality care (CMS, 2015b). Medicare payments may

be earned by performing well in five weighted domains of care including patient experience of care, safety, efficiency, outcomes, and process (CMS, 2015b). Reports of lengths of stay, billing, expenditure, intensive care unit stays, and excess days for palliative care patients can be compared to data collected prior to the program implementation and to data collected on patients who screened positive for palliative care consultation but did not have a consultation referral ordered.

Summary

Key outcome measures of successful palliative care programs identified by expert consensus include clinical metrics, customer metrics, operational, and financial metrics (Weisman & Meier, 2008). Clinical outcomes measurement recommended here include symptom assessment and management using the Edmonton Symptom Assessment Scale and documentation of discussion of patient-centered goals of care using standardized initial consult and progress notes. Customer satisfaction data will be collected by administering HCAHPS, FAMCARE-2, and palliative care provider satisfaction surveys. Operational outcomes data collected will include length of stay and readmissions. Financial outcomes data related to value-based purchasing reimbursement and cost avoidance will be collected. Data collected will be used to determine the program's impact on patients, their family, the staff providing care, and the hospital's fiscal goals.

CHAPTER V

DISCUSSION AND RECOMMENDATIONS

The purpose of this project is to improve care of seriously ill patients in an acute-care hospital in California's Central Valley through the implementation of a palliative care consultation service. Inadequate care for chronically ill individuals, who often report disjointed care and poor symptom management, usually results in frequent, prolonged, and costly hospitalizations that leave hospital staff feeling inadequate and unsatisfied with the care they provide. This hospital's growth over the past decade has facilitated high quality medical care to its community, but it has not addressed the need for palliative care services for its chronically ill patients, despite strong evidence that palliative care benefits hospitals, improves patient and family outcomes, and increases provider satisfaction.

Recommended Project: Inpatient Palliative Care Consultation Service

The recommendation resulting from this project is to provide palliative care through specialty consultations by a palliative care team that include physicians, nurses, social workers, pharmacists, dietitians, therapists, ethicists, and chaplains. Research shows the most significant benefits of such a service accrue to patients and families but also positively impact healthcare providers and the financial health of the hospital (Bausewein, Daveson, Benalia, Simon, & Higginson, 2011; Bronwyn et al., 2014; Enguidanos, Housen, Penido, Mejia, & Miller, 2014). The palliative care team's primary roles are to address symptoms that are difficult to manage, broker challenging family situations, and facilitate complex care decisions regarding life-

sustaining treatments (National Consensus Project for Quality Palliative Care, 2013; Weissman & Meier, 2011). Current research indicates that an inpatient palliative care consultation service provided by interdisciplinary team can positively impact patients, their families, professional providers, and the organization. This model therefore has been identified as the optimal plan for this organization.

Strategies for Project Implementation

Strategies needed to implement an inpatient palliative care consultation service at this community hospital have been presented. Spradley's change model is recommended as a framework, with careful development of its eight steps to ensure that chronically ill patients have the option to receive quality palliative care. Key outcome measures of successful palliative care programs identified by expert consensus include clinical metrics, customer metrics, operational, and financial metrics (Weisman & Meier, 2008). Clinical outcomes measurement for this project will include symptom assessment and management using the Edmonton Symptom Assessment Scale and documentation of discussion of patient-centered goals of care using standardized initial consult and progress notes. Customer satisfaction data will be collected by administering HCAHPS, FAMCARE-2, and palliative care provider satisfaction surveys. Operational outcomes data collected will include length of stay and readmissions. Financial outcomes data related to value-based purchasing reimbursement and cost avoidance will be collected. Data collected will be used to determine the program's impact on patients, their family, the staff providing care, and the hospital's fiscal goals.

Strengths and Limitations of this Project

This inpatient palliative care consultation service project is designed for a community hospital in Central California where no formal palliative care services are available. This hospital is one of many healthcare organizations owned by a large for-profit business that sets corporate expectations for patient care, satisfaction scores, and budgeting. The corporate leadership understands the benefits of palliative care in the inpatient setting and local leadership has supported the need for palliative care services. Strengths of the project include the authors' experiential knowledge of the culture of this hospital and challenges associated with addressing the needs of seriously ill patients. The change model and outcome measurement tools recommended for this project were based on both research and intimate knowledge of the organization, but may not be generalizable to other organizations.

Implications for Future Research

Research is vital for the strategic planning, quality improvement, and demonstration of the impact of positive outcomes from inpatient palliative care programs to hospital administrators, payers, policymakers, and patients (Weissman et al., 2010). Further research is needed to determine the core components of palliative care interventions, including at what stage and in what setting are interventions most effective (Morin, Saint-Laurent, Bresse, Dalbuiere, & Fillion, 2007; Temel et al., 2011; Yoong et al., 2013). Significant disparities have also been identified highlighting the lack of public and educational access to inpatient palliative care services (Goldsmith, Dietrich, Du, & Morrison, 2008; Mahon & McAuley, 2010; Watts, 2014).

Additionally, researchers find a common theme of nurses confusing palliative care with hospice care and that nurses perceive palliative care to be focused on symptom management, end of life care, and frequently associate palliative care with cancer patients (Mahon & McAuley, 2010; Watts, 2014). Patients and families echo this lack of awareness of palliative care (Metzger, Norton, Quinn, & Gramling, 2013) and often feel a lack of preparedness for inpatient palliative care consultations (Enguidanos et al., 2014; Metzger et al., 2013). Further research is thus needed to address the knowledge deficits identified.

Implications for Nursing

Nurses, with their unique relationships with patients and families, are key stakeholders in promoting the implementation of palliative care services. In advocating for palliative care programs and the completion of comprehensive and timely interdisciplinary palliative care screening and assessments, a plan of care based on the identified and expressed values and goals of the patient can be achieved (National Consensus Project for Quality Palliative Care, 2013; Weissman & Meier, 2011). Knowledge of the impact of palliative care services and the role of nurses in providing this care is growing with research that reflects the multi-disciplinary nature of palliative care, and nurses have a key role to play in undertaking this research.

Conclusion

The purpose of this project was to propose an implementation plan for palliative care services at a hospital where no formal palliative care services exist. Research has shown that palliative care positively impacts patients, their families,

healthcare providers, and organizations. An inpatient palliative care consultation service was selected as the most appropriate model to deliver palliative care services at this hospital. Spradley's theoretical change model is used as the framework to develop the strategies for project implementation with the authors experiential knowledge of hospital culture identified as a strength. Specific tools and strategies for outcome measurement of clinical, customer, operation, and financial metrics were also discussed with recommendations given for this project.

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APPENDICES

APPENDIX A

PALLIATIVE CARE SCREEN

Palliative Care Screen

Date: _____

Patient Sticker: _____

1 PC risk factor: Palliative Care Consult Indicated
 >1 PC risk factor: Palliative Care Consult strongly indicated

Palliative Care Risk Factors	YES	NO	Comments/Questions
1. Admitted from: SNF, LTAC, Vent LTC, or home with failure to perform ADL's			
2. End Stage Illness: e.g. Dementia, COPD, CHF, Renal Failure, Cirrhosis, etc.			
3. Cancer: metastatic or advanced			
4. Severe symptoms despite initial treatment: e.g. N/V, dyspnea, pain, etc.			
5. Post arrest			
6. Readmission within 30 days			
7. Upgrade to ICU after being hospitalized > 5 days			
8. Palliative Care needs identified based on poor prognosis and complex care; e.g. considering trach or PEG			

Attending Physician decision for consult YES NO
 Attending Physician's Name: _____

APPENDIX B

INPATIENT PALLIATIVE CARE SERVICES POLICY

HOSPITAL MEDICAL CENTER DEPARTMENTAL MANUAL

Division: **Patient Care Services**

Department: **Administration**

Subject: **Palliative Care Services**

References:

National Comprehensive Cancer Network, “*Palliative Care: Clinical Practice Guidelines in Oncology*” v.1.2014; JCAHO RI.2.20, RI 2.30, 2.70, RI.2.80; Doctors Medical Center Patient Care Manual “*Palliative Care: Scope of Practice*” 04/25/14; National Consensus Project for Quality Palliative Care (2013). *Clinical practice guidelines for quality palliative care* (3rd ed.); Weissman, D., & Meier, D. (2011). *Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the center to advance palliative care*. *Journal of Palliative Medicine*, 14(1), 17-23.

Adopted:

Reviewed:

I. POLICY

It is the policy of Hospital Medical Center to provide high-quality health care services with competence and compassion to patients, their families, and the residents of our local community. Competent and compassionate health care includes palliative care; the comprehensive care and management of the physical, psychological, emotional, and spiritual needs of patients (of all ages) and their families with serious and/or life-limiting illness. Palliative care may be complementary to curative or life-prolonging therapies that are being used to meet patient-defined goals of care. Patients have the right to pain control and other measures to prevent or lessen suffering and discomfort. This right is not only legal; it flows from the core value of Christian compassion that shapes this hospital’s mission of healing. A tangible expression of that value and mission is the Palliative Care Team. Patients may request or consent to palliative care services at Hospital Medical Center either directly, by means of

an advance healthcare directive, or through a legally authorized surrogate decision-maker.

Patients suitable for palliative care services include:

- 1) Patients with debilitating, chronic, progressive, or life-threatening disease, who would like additional assistance with pain or other symptom control. Examples of such diseases include CHF, COPD, Dementia, Malignancies, Advancing Diabetes, Liver failure, Kidney disease and Neurological disease and injury,
- 2) Hospitalized patients wishing comfort measures only at the end of life. Comfort measures include pain management, respiratory and skin care and continuing emotional and spiritual support. In addition, assistance will be available regarding decisions about the setting for end of life care (i.e. whether in the hospital or in a long-term care setting) and
- 3) Patients unable to make their own decisions whose family must decide for them. These families sometimes struggle to balance the burdens and benefits to the patient of life-prolonging treatments on the one hand, and a desire to prevent and alleviate the suffering of their loved ones, on the other. The Palliative Care team will aid in examining and considering their treatment goals and choices, and in reaching consensus when family members disagree about the course of treatment that is best for the patient. In all instances, continued emotional, spiritual and practical help will be provided to these patients and families.

II. DEFINITIONS

- A. “Palliative Care” is an interdisciplinary team approach to provide holistic, supportive care to persons with life-threatening, debilitating, or advanced illness, and to their families. Its purpose is to prevent and relieve suffering through symptom control and to support the best achievable quality of life regardless of the stage of the disease. The interdisciplinary team whose skills are available to achieve this purpose include physicians, nurses, social workers, chaplains, dietitians, respiratory therapists and rehabilitation therapists.

III. PROCEDURE

- A. Upon admission, every patient will be screened for Palliative Care consult criteria. A palliative care consult is considered appropriate if screening nurse/physician finds at least one of the following true:

- a. Patient admitted from skilled nursing facility (SNF), long-term acute care (LTAC), ventilated long-term care, or home care with private-duty nursing with ADL dependencies
 - b. End-stage dementia, ALS, Parkinson's or MS
 - c. Large intracranial hemorrhage with anoxic encephalopathy or on a ventilator
 - d. Advanced or metastatic cancer
 - e. Admitted to the ICU post cardiac or respiratory arrest with neurological compromise
 - f. Admitted to the ICU with hospital length of stay (LOS) greater than 5 days or ICU readmission with same diagnosis in 30 days
 - g. Team perceives palliative care need based on poor prognosis and complex care; considering dialysis, tracheostomy or PEG tub placement
 - h. Patient/family concerns about course of disease, decision-making, or requests palliative care
- B. Upon physician referral, the palliative care team will work to:
- a. Optimize symptom control
 - b. Optimize functional status when appropriate
 - c. Promote the highest quality of life for patient and family
 - d. Educate patients and family to promote understanding of the underlying disease process and expected future course of the illness
 - e. Establish an environment that is comforting and healing
 - f. Plan for discharge to the appropriate level of care in a timely manner
 - g. Assist actively dying patients and their families to prepare for and manage life ending circumstances
 - h. Serve as educators and mentors for staff
 - i. Promote a system of care that fosters timely access to palliative care services
- C. The process of providing palliative care services includes:
- a. Assessments: Initial and subsequent assessments are carried out through patient and family interviews, review of medical records, discussion with other providers, physical examination, and review of laboratory, diagnostic tests and procedure results.
 - i. Assessment includes documentation of:
 1. Disease status/treatment history
 2. Functional status and expected prognosis
 3. Co-morbid medical and psychiatric disorders
 4. Physical, psychological, and spiritual symptoms and concerns
 5. Advanced care planning preferences/surrogate decision maker

- ii. All initial and ongoing assessment data are reviewed on a regular basis. Assessment findings are the basis for the care planning process.
 - b. After identifying the patient and family's goals, the palliative care team will make recommendations for symptom management. Referrals may be made to mental health, social services, hospice, interpreter services, and/or the dietician.
 - c. The Palliative Care team will provide daily follow-up if symptoms are not fully managed or if new issues arise; weekly follow-up if stable
- D. The Palliative Care team will meet monthly to review cases for the month, share data, identify opportunities for improved service and/or communication, and work to provide and improve continuity of care for those Palliative Care patients who have been discharged from the hospital.
- E. The Palliative Care Team will maintain patient care records for purposes of quality and outcomes review.
- F. The Palliative Care Team will provide educational programs to medical, nursing, and ancillary staff on palliative care standards and practice

APPENDIX C

EDMONTON SYMPTOM ASSESSMENT SYSTEM



Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

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

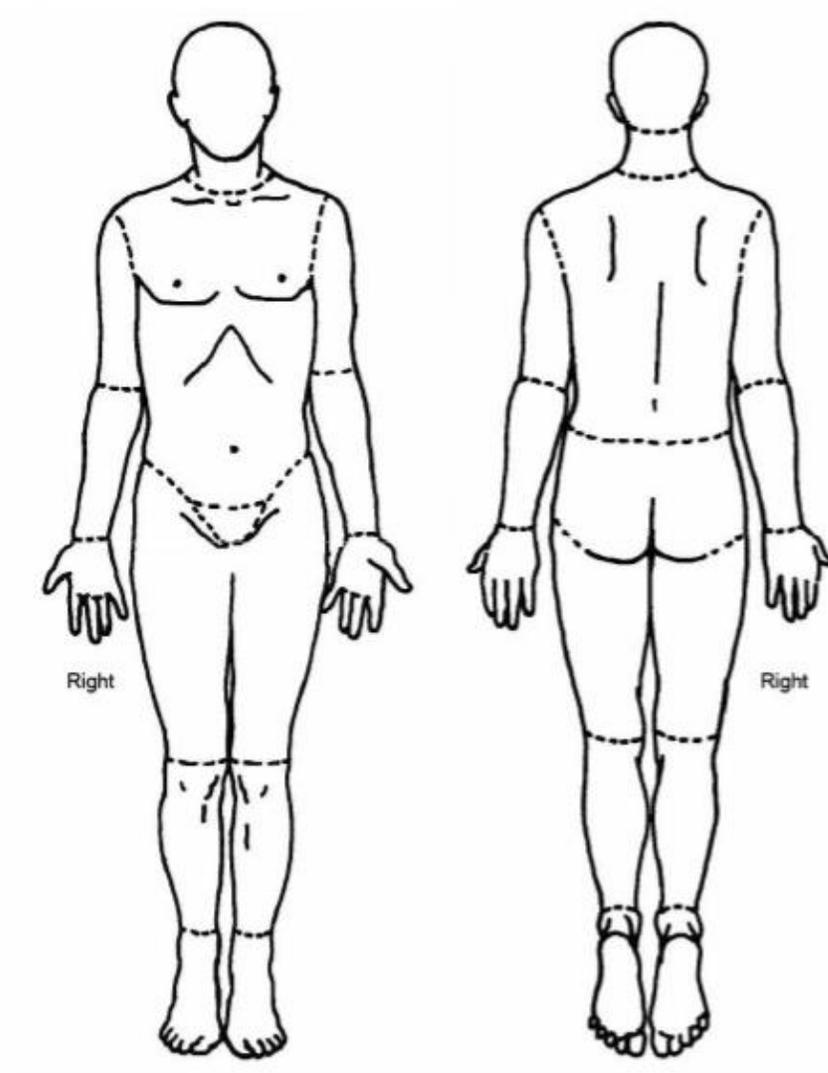
No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem <i>(for example constipation)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name _____
Date _____ Time _____

- Completed by (check one):
- Patient
 - Family caregiver
 - Health care professional caregiver
 - Caregiver-assisted

BODY DIAGRAM ON REVERSE SIDE

Please mark on these pictures where it is that you hurt:



APPENDIX D

HOSPITAL CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND
SYSTEMS (HCAHPS)

HCAHPS Survey

SURVEY INSTRUCTIONS

- ◆ You should only fill out this survey if you were the patient during the hospital stay named in the cover letter. Do not fill out this survey if you were not the patient.
- ◆ Answer all the questions by checking the box to the left of your answer.
- ◆ You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:
 - Yes
 - No → *If No, Go to Question 1*

*You may notice a number on the survey. This number is used to let us know if you returned your survey so we don't have to send you reminders.
Please note: Questions 1-25 in this survey are part of a national initiative to measure the quality of care in hospitals. OMB #0938-0981*

Please answer the questions in this survey about your stay at the hospital named on the cover letter. Do not include any other hospital stays in your answers.

YOUR CARE FROM NURSES

1. During this hospital stay, how often did nurses treat you with courtesy and respect?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
2. During this hospital stay, how often did nurses listen carefully to you?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always

3. During this hospital stay, how often did nurses explain things in a way you could understand?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
4. During this hospital stay, after you pressed the call button, how often did you get help as soon as you wanted it?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
 - ⁹ I never pressed the call button

YOUR CARE FROM DOCTORS

5. During this hospital stay, how often did doctors treat you with courtesy and respect?
- ¹ Never
² Sometimes
³ Usually
⁴ Always
6. During this hospital stay, how often did doctors listen carefully to you?
- ¹ Never
² Sometimes
³ Usually
⁴ Always
7. During this hospital stay, how often did doctors explain things in a way you could understand?
- ¹ Never
² Sometimes
³ Usually
⁴ Always

THE HOSPITAL ENVIRONMENT

8. During this hospital stay, how often were your room and bathroom kept clean?
- ¹ Never
² Sometimes
³ Usually
⁴ Always
9. During this hospital stay, how often was the area around your room quiet at night?
- ¹ Never
² Sometimes
³ Usually
⁴ Always

YOUR EXPERIENCES IN THIS HOSPITAL

10. During this hospital stay, did you need help from nurses or other hospital staff in getting to the bathroom or in using a bedpan?
- ¹ Yes
² No → If No, Go to Question 12
11. How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted?
- ¹ Never
² Sometimes
³ Usually
⁴ Always
12. During this hospital stay, did you need medicine for pain?
- ¹ Yes
² No → If No, Go to Question 15
13. During this hospital stay, how often was your pain well controlled?
- ¹ Never
² Sometimes
³ Usually
⁴ Always
14. During this hospital stay, how often did the hospital staff do everything they could to help you with your pain?
- ¹ Never
² Sometimes
³ Usually
⁴ Always

15. During this hospital stay, were you given any medicine that you had not taken before?

¹ Yes

² No → If No, Go to Question 18

16. Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?

¹ Never

² Sometimes

³ Usually

⁴ Always

17. Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?

¹ Never

² Sometimes

³ Usually

⁴ Always

WHEN YOU LEFT THE HOSPITAL

18. After you left the hospital, did you go directly to your own home, to someone else's home, or to another health facility?

¹ Own home

² Someone else's home

³ Another health facility → If Another, Go to Question 21

19. During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?

¹ Yes

² No

20. During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?

¹ Yes

² No

OVERALL RATING OF HOSPITAL

Please answer the following questions about your stay at the hospital named on the cover letter. Do not include any other hospital stays in your answers.

21. Using any number from 0 to 10, where 0 is the worst hospital possible and 10 is the best hospital possible, what number would you use to rate this hospital during your stay?

⁰ 0 Worst hospital possible

¹ 1

² 2

³ 3

⁴ 4

⁵ 5

⁶ 6

⁷ 7

⁸ 8

⁹ 9

¹⁰ 10 Best hospital possible

22. **Would you recommend this hospital to your friends and family?**

- 1 Definitely no
- 2 Probably no
- 3 Probably yes
- 4 Definitely yes

UNDERSTANDING YOUR CARE WHEN YOU LEFT THE HOSPITAL

23. **During this hospital stay, staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left.**

- 1 Strongly disagree
- 2 Disagree
- 3 Agree
- 4 Strongly agree

24. **When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.**

- 1 Strongly disagree
- 2 Disagree
- 3 Agree
- 4 Strongly agree

25. **When I left the hospital, I clearly understood the purpose for taking each of my medications.**

- 1 Strongly disagree
- 2 Disagree
- 3 Agree
- 4 Strongly agree
- 5 I was not given any medication when I left the hospital

ABOUT YOU

There are only a few remaining items left.

26. **During this hospital stay, were you admitted to this hospital through the Emergency Room?**

- 1 Yes
- 2 No

27. **In general, how would you rate your overall health?**

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

28. **In general, how would you rate your overall mental or emotional health?**

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

29. **What is the highest grade or level of school that you have completed?**

- 1 8th grade or less
- 2 Some high school, but did not graduate
- 3 High school graduate or GED
- 4 Some college or 2-year degree
- 5 4-year college graduate
- 6 More than 4-year college degree

30. Are you of Spanish, Hispanic or Latino origin or descent?
- ¹ No, not Spanish/Hispanic/Latino
 - ² Yes, Puerto Rican
 - ³ Yes, Mexican, Mexican American, Chicano
 - ⁴ Yes, Cuban
 - ⁵ Yes, other Spanish/Hispanic/Latino
31. What is your race? Please choose one or more.
- ¹ White
 - ² Black or African American
 - ³ Asian
 - ⁴ Native Hawaiian or other Pacific Islander
 - ⁵ American Indian or Alaska Native

32. What language do you mainly speak at home?
- ¹ English
 - ² Spanish
 - ³ Chinese
 - ⁴ Russian
 - ⁵ Vietnamese
 - ⁶ Portuguese
 - ⁹ Some other language (please print):

THANK YOU

Please return the completed survey in the postage-paid envelope.

[NAME OF SURVEY VENDOR OR SELF-ADMINISTERING HOSPITAL]

[RETURN ADDRESS OF SURVEY VENDOR OR SELF-ADMINISTERING HOSPITAL]

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APPENDIX E

FAMCARE-2

Instructions:

Think about the care that your family member has received on our Palliative Care Unit. Please answer the questions below indicating how satisfied you are with the care received: very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), very dissatisfied (VD), or not applicable (NA). Please circle the letters below that best match your experience. You may choose not to respond to some items. Patient* refers to your loved one who was cared for on the Palliative Care Unit. "Family" refers to you and others important to the patient.

How satisfied are you with:

1	The patient's comfort	VS	S	U	D	VD	NA
2	The way in which the patient's condition and likely progress have been explained by the palliative care team	VS	S	U	D	VD	NA
3	Information given about the side effects of treatment	VS	S	U	D	VD	NA
4	The way in which the palliative care team respects the patient's dignity	VS	S	U	D	VD	NA
5	Meetings with the palliative care team to discuss the patient's condition and plan of care	VS	S	U	D	VD	NA
6	Speed with which symptoms are treated	VS	S	U	D	VD	NA
7	Palliative care teams' attention to the patient's description of symptoms	VS	S	U	D	VD	NA
8	The way in which the patient's physical needs for comfort are met	VS	S	U	D	VD	NA
9	Availability of the palliative care teams to the family	VS	S	U	D	VD	NA
10	Emotional support provided to family members by the palliative care team	VS	S	U	D	VD	NA
11	The practical assistance provided by the palliative care team (e.g., bathing, home care, respite)	VS	S	U	D	VD	NA
12	The doctor's attention to the patient's symptoms	VS	S	U	D	VD	NA
13	The way the family is included in treatment and care decisions	VS	S	U	D	VD	NA
14	Information given about how to manage the patient's symptoms (e.g., pain, constipation)	VS	S	U	D	VD	NA
15	How effectively the palliative care team manages the patient's symptoms	VS	S	U	D	VD	NA
16	The palliative care team's response to changes in the patient's care needs	VS	S	U	D	VD	NA
17	Emotional support provided to the patient by the palliative care team	VS	S	U	D	VD	NA

Date: _____