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# Hospital-Based Palliative Care Programs: Perspectives Regarding Conceptualization and Accreditation

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# HOSPITAL-BASED PALLIATIVE CARE PROGRAMS: PERSPECTIVES REGARDING CONCEPTUALIZATION AND ACCREDITATION

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
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# Abstract

## HOSPITAL-BASED PALLIATIVE CARE PROGRAMS: PERSPECTIVES REGARDING CONCEPTUALIZATION AND ACCREDITATION

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Palliative care has been shown to improve symptoms and increase quality of life in people with a life-limiting illness. Despite growth in hospital-based palliative care programs throughout the United States, only 91 hospitals have obtained The Joint Commission’s Advanced Palliative Certification. The purpose of this descriptive study was to identify how programs that do not have The Joint Commission’s Advanced Palliative Care Certification defined and conceptualized palliative care. An additional focus was to identify the barriers these programs perceived or experienced that prevented them from obtaining the advanced palliative care certification. This research program began with an evolutionary concept analysis that identified how palliative care has changed through time. Following this was a review of existing definitions and theories of palliative care. Following a comparison of various standards for palliative care, the Trajectory of Quality Palliative Care Model was developed and used to guide this research study. Hospital-based palliative care programs listed as active on the Center to Advance Palliative Care’s (CAPC) National Palliative Care Registry were eligible. A total of 21 programs across the United States participated. Data collection was completed via phone interviews guided by the Hospital-Based Palliative Care Survey. Definitions of palliative care used by the programs within the data set were inconsistent but did follow components of the definitions used by the CAPC, National Quality Forum (NQF), National Hospice and Palliative Care Organization (NHPCO), and The Joint Commission. Findings also identified perceived barriers to achieving

The Joint Commission Advanced Palliative Care Certification: (a) not meeting the seven-days-per-week and on-call criteria, (b) recruitment and retention of staff, (c) allocating funding necessary to reach minimum staffing standards, and (d) hospital staff and consumer misunderstanding about palliative care. Evidence from this study provides a basis upon which further actions can be taken to address barriers to obtaining The Joint Commission's Advanced Palliative Care Certification. Finally, this research informs potential policy implication shifts related to education and research in palliative care along with workforce training, staffing standards, and financial resources to support high-quality palliative care.

# Chapter 1

## Overview of the Program of Research

Palliative care (PC), an often-misunderstood concept, is aimed at addressing symptoms early to facilitate longer survival and quality of life (QOL) improvement in patients (Davis, Strasser, Cherny, & Levan, 2015; Verret & Rohloff, 2013). Over 40 million people globally are in need of palliative care, but do not receive treatment (Worldwide Palliative Care Alliance, 2014). These individuals would have likely benefitted from palliative care, but services were not offered or were unavailable (Morrison & Meier, 2015; Worldwide Palliative Care Alliance, 2014). Low to middle-income countries make up 78% of the global population in need of palliative care at the end of life. However, the highest per capita rates of need are found in higher income countries that have greater access to palliative care services (Connor, 2014; Worldwide Palliative Care Alliance, 2014). The Centers for Medicare and Medicaid Services estimate that beneficiaries in the last year of life account for five percent of all medical spending (De Nardi, French, Jones, & McCauley, 2016; McGrath, Foote, & Frith, 2013; Hill, 2013). Conversely, when hospitals use palliative care effectively, the care can contribute to reductions in medical costs and hospital lengths (Khandelwal et al., 2016; McCarthy, Robinson, Huq, Philastre, & Fine, 2015). While palliative care interventions can improve patient symptomology and QOL, delays in referral and gaps in timely service delivery have been associated with healthcare provider (HCP) uncertainty, poor communication, decreased QOL, and conflicts over end-of-life care (Bakitas et al., 2015; Davis et al., 2015; Kamal et al., 2015; Riffin et al., 2015).

Access and delivery of palliative care services within the United States face significant challenges and insufficiencies (Bhatnagar & Gupta, 2015; McAteer & Wellberry, 2013). Rural communities have far less access to hospital-based palliative care programs than their urban counterparts (National Palliative Care Registry, 2015). Nationally, palliative care delivery is hindered by (a) policies establishing palliative care, (b) definitions that reflect clarity and consistent use of palliative care, (c) palliative care education for healthcare providers as well as for healthcare consumers and communities at large, (d) essential medications needed to deliver palliative care, and (e) organized programs and services to deliver palliative care (Connor, 2014; Hui et al., 2013; Van Mechelen et al., 2012; Worldwide Palliative Care Alliance, 2014). Though evidence-based standards of care and accreditation guidelines exist for hospital-based palliative care programs, only 91 hospitals out of 2,315 acute care hospitals within the United States currently hold The Joint Commission (TJC) Advanced Palliative Care certification. Sadly, of the 91 accredited hospitals, only 27 states are represented, severely compromising access to high-quality palliative care. Despite the growing numbers of hospital-based palliative care programs, a gap exists in literature related to the barriers to obtaining The Joint Commission’s Advanced Palliative Care Certification (Gadoud, Jenkins, & Hogg, 2013; Meier & Morrison, 2015; Riffin et al., 2015). Understanding the issues surrounding the ability of programs to obtain certification could assist in facilitating accreditation and improve access and patient outcomes.

## Introduction of Articles

This program of research began with an exploration of the concept of palliative care using Rodgers’ (2000) Evolutionary Concept Analysis method. This method was selected because over time, a concept can become associated with a certain set of behaviors or meanings and can become vague, ambiguous, or confused with other concepts (Rodgers, 1989). Using Rodgers’ guidelines, palliative care was explored within the healthcare setting from its origins in England in the 1960s through its evolution into the current healthcare specialty it is today within the United States. Results of the concept analysis are presented in Chapter two in *Palliative Care: An Evolutionary Concept Analysis.*

The next step in this program of research required a compilation of the various palliative care definitions in use in the United States. These definitions are summarized in Appendix A. The next step of this research program required a thorough analysis of palliative care standards in the United States. Further, the identification of standards for comparison in the *National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report* (National Quality Forum, 2006). The report details 38 preferred practices that further delineate high-quality palliative care (Appendix B). Prior to embarking on an original research study, an exploration of current palliative care theories was completed (Appendix C). The results of this analysis suggested a need for a new model to study palliative care. Results of the definition compilation, comparison of standards, and the concept analysis reported in Chapter two guided the development of the Trajectory of Quality Palliative Care Model (*Figure 1)*. This model then guided the next phase of this research.

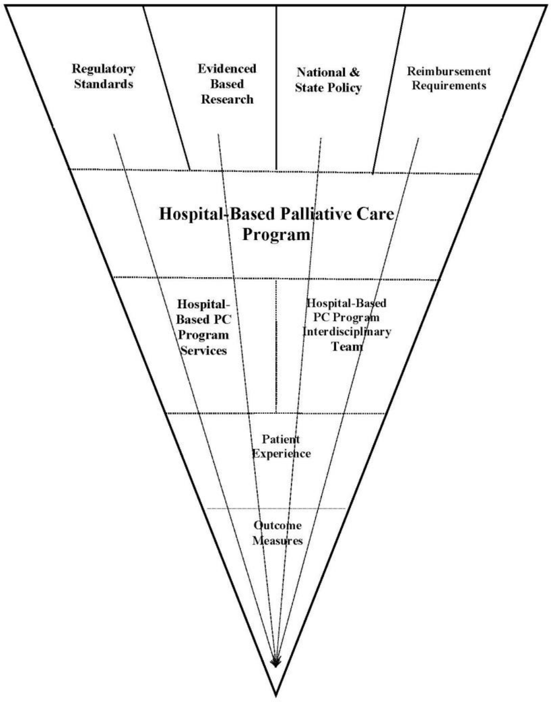


*Figure 1:* Trajectory of Quality Palliative Care (PC) Model

A descriptive study, *Hospital-Based Palliative Care Programs: Perspectives Regarding Conceptualization and Accreditation,* was completed using the aforementioned theoretical model and is contained in Chapter three. The study focused on how programs without The Joint Commission's Advanced Palliative Care Certification defined and conceptualized palliative care. Additional focus was dedicated to identifying what perceived barriers these programs experienced that dissuaded them from obtaining the Advanced Palliative Care Certification. Prior to initiating the study, Institutional Review Board approval (IRB# SP2018-99) was obtained (Appendix D). Participants were recruited from the Center to Advance Palliative Care Registry database. Those programs that were noted to be an active program but did not hold The Joint Commissions' Advanced Palliative Care Certification were recruited through phone calls, and study information was presented via a telephone script (Appendix E). Upon agreeing to participate, respondents were asked questions from the Hospital-Based Palliative Care Survey (Appendix F). The survey contained demographic information, questions related to how palliative care was defined and conceptualized by the individual programs and perceived barriers to obtaining The Joint Commission’s Advanced Palliative Care Certification. In addition, miscellaneous information was collected based on the respondents’ willingness to discuss their individual programs.

Chapter four provides a summary of this program of research and explores the strengths and limitations of the research. In addition, Chapter four includes recommendations and implications for policy, future research, and education.

# Chapter 2

# Palliative Care: An Evolutionary Concept Analysis

## Abstract

Palliative care is frequently confused with hospice care, resulting in delays in referrals that limit the effectiveness of palliative care services. Palliative care has evolved over the six decades following its inception. However, understanding of the concept of palliative care and its application to practice has not progressed. Clarification of the term palliative care is needed. An evolutionary concept analysis method was used to identify the progression of the concept and gain insight into the current state of palliative care within the healthcare environment. A history of the concept was examined, followed by identification of surrogate terms, attributes, antecedents, and consequences. An exemplar case and implications for further concept development are provided.

# Palliative Care: An Evolutionary Concept Analysis

Palliative care, first introduced in England in the 1960s, focused on treating persons with cancer in the hospital. When palliative care was introduced in the United States in 1973, it was a homecare-based program for persons with cancer at the end of life. This narrowed perspective of palliative care does not reflect current practice. Rodgers (2000) notes that, over time, concepts become ambiguous and vague, writing that "thinking that lies behind many regularly performed activities often takes place without awareness of it and so the use of the concepts take place without knowledge or clarity concerning the definition of the concept" (p. 83).

Today, palliative care encompasses all aspects of the healthcare environment and all life-limiting conditions. However, the definition of palliative care does not necessarily reflect this evolving concept. Rodgers (1989) maintains that concepts are refined and developed through the process of application. Because the practice of palliative care has significantly changed over time, an evolutionary concept analysis using Rodgers (2000) method was conducted to identify and understand changes of the concept.

## Background

Palliative care originated in England during the early 1960s when Dr. Cicely Saunders began the hospice movement. Her research involving 1000 patients led to the development of holistic pain management and addressed the needs of the dying patient in the hospital. In 1973, after hearing Dr. Saunders lecture on hospice care, Florence Wald, Dean of the Yale School of Nursing, assisted in the development of the first hospice program in the United States, serving patients with cancer at home (Connor, 2008; Silverman, 2011). The National Hospice Organization published "Standards of a Hospice Program" in 1979; the focus remained on terminally ill cancer patients. In 1999, the National Hospice Organization changed its name to the National Hospice and Palliative Care Organization to reflect the merging of traditional hospice with palliative care in the United States (Connor, 2008).

The concepts of palliative care and hospice were interchangeable until the establishment of the Hospice Medicare Benefit in 1982. At that time, Medicare became the prime insurance provider of hospice care in the United States (Connor, 2008; Mor & Teno, 2016). The provider was paid a set amount under the assumption that each hospice was in compliance with the Medicare Benefit Hospice standards of care. These standards were changed to the Medicare Conditions of Participation in 1985 (Connor, 2008; Mor & Teno, 2016). The standards included the stipulation that eligible patients have a diagnosis of an incurable malignant disease, a prognostication of life expectancy of 6 months or less by two physicians, and a waiver of all rights and privileges to receive curative treatments (Centers for Medicare and Medicaid Services, 2013).

The Hospice Medicare Benefit requirements created a difference in the paradigms of hospice and palliative care. As a result, the ethics committee of the American Geriatrics Society (AGS) developed a position paper on care of dying patients that called for "a modification of reimbursement policies to enhance the availability of palliative care" and a stance that care should be driven by need and not life expectancy or diagnosis (AGS Ethics Committee, 1995; Connor, 2008; Sachs, 1994). During this period, emerging technologies and improved medications increased life expectancy and varied expected disease trajectories.

By the end of the 20th century, palliative care was recognized as a specialty field within healthcare. The National Hospice and Palliative Care Organization (2015) set guidelines to assist clinicians in the prognostication for select non-cancer diagnosis for palliative care eligibility such as dementia, stroke, and heart failure. Palliative care began moving away from its traditional cancer care origins. Even though the focus of care was changing, most deaths continued to occur in hospital settings without hospice or palliative care, especially for people with non-cancer diagnosis.

In response to the large numbers of patients excluded from palliative care, the landmark SUPPORT study, funded by the Robert Wood Johnson Foundation (Connors et al., 1995), concluded that an intervention aimed at facilitating communication related to patient and family care preferences had no impact on the key outcome measures: Earlier writing of do not resuscitate orders, physician knowledge of their patients' preferences for cardiopulmonary resuscitation, number of days spent in intensive care before death, patient reports of moderate or severe pain, and use of hospital resources. The investigators suggested “more forceful measures” may be necessary (Connors et al., 1995; Covinsky, 2010). SUPPORT leaders noted that efforts to improve end-of-life care were inhibited by a medical structure that made it difficult to provide high quality end of life care. Therefore, the need for hospital-based palliative care programs was supported.

The findings of the SUPPORT study set the stage for an increase of palliative care programs throughout the United States in early 2000. During this time, the American Hospital Association began surveying hospitals throughout the United States for the availability of hospital-based palliative care programs. The results found 658 hospital-based palliative care programs were established in 2000. By 2006, that number had doubled to 1357 (American Hospital Association, 2012).

During this same time, The Joint Commission for Accreditation of Healthcare Organizations added the provisions of pain management and palliative care services to their 2000 accreditation survey (Gordon, Berry, & Dahl, 2000). The National Consensus Project for Quality

Palliative Care (NCP) represents an initiative to further define the value of palliative care and to improve upon the delivery of palliative care in the United States. In 2009, NCP said, “palliative care is appropriate for all stages for patients living with complex, chronic, life limiting condition” (National Consensus Project, 2009, p. 8). This viewpoint supports interdisciplinary teams working with patients throughout the trajectory of their disease process to improve patient outcomes and quality of life in conjunction with curative treatments.

Subsequently, the Affordable Care Act was passed in 2010 with the goal of expanding healthcare access to over 30 million Americans (Bergeron et al., 2016). The Act required the Center for Medicare and Medicaid Innovation to implement a five-year exploratory project that allowed patients to receive curative treatment as well as palliative and hospice care concurrently (Elmendorf, 2010). The pilot project, titled Medicare Care Choices Model (MCCM), projected to affect 150,000 patients, was limited to very specific terminal illnesses. There were no provisions for patients only requiring palliative services. (Center for Medicare Advocacy, 2015; Lupu, Ivanko, Insana, White, & Arnold, 2014; United States Department of Health & Human Services, 2015). As of April 2018, 44 of the original 141 hospices invited to participate withdrew from the program, citing reimbursement was insufficient to cover program costs. Enrollment in the program has been so low that quality measures related to the impact of MCCM on quality of life, patient and family satisfaction, and end of life outcomes have been postponed (Abt Associates, 2018).

The expression of the concept of palliative care has evolved over the past six decades. Unfortunately, the application of palliative care has remained stagnant. The application of palliative care as being synonymous with end-of-life care, bereavement care, or hospice has created confusion. Healthcare provider confusion of terminology decreases patients’ access to timely care (Fox et al., 2016; Pereira, 2017). In addition, practitioners are unaware as to what stage of illness patients must be at for these concepts apply. This lack of clarity has caused a delay in referrals and limits the effectiveness of palliative care and creates gaps in care for patients and families (Bhatnagar & Gupta, 2015; Connor, 2014).

## Method

Given the changes in palliative care over time, Rodgers (2000) evolutionary concept analysis was conducted to clarify current expression of the concept. Rodgers (2000) identified six primary activities of the evolutionary method of concept analysis (Table 2.1). These activities are not necessarily linear and can be conducted simultaneously. They may also be combined. For ease of reading, the activities of this analysis are presented according to activity and activities three and four combined.

Table 2.1

*Activities of Evolutionary Method of Concept Analysis (Rodgers, 2000)*

| Phases | Conceptual Definitions |
|---|---|
| Activity One | Identify the concept of interest and surrogate terms. |
| Activity Two | Identify and select an appropriate setting and sample for data collection. |
| Activity Three | Collect data relevant to identify attributes, contextual basis, including interdisciplinary, sociocultural, and antecedents and consequences. |
| Activity Four | Analyze data. |
| Activity Five | Identify an exemplar of the concept. |
| Activity Six | Identify implications for further development of the concept. |

### Activity One: Concept of Interest and Surrogate Terms

This activity focuses on the basic meaning of palliative, devoid of discipline specific constraints. Dictionaries, thesauri, and available literature were the sources of information. Palliative, for sentence structure purposes, can be an adjective or a noun. The etymology is

French and means “that relieves the symptoms of a disease or condition without dealing with the underlying cause” (“Palliative,” 2019, para. 1). In 1729, post-classical Latin *palliativus* had the meaning “that relieves the symptoms of a disease or condition without dealing with the underlying cause” as well (“Palliative,” 2019, para. 1.). A British source of the term has also been identified as a past participle stem of palliative to cloak or conceal (“Palliative,” 2019, para. 1).

Palliative is defined as “a treatment that gives temporary or symptomatic relief; something that serves to alleviate or mitigate pain, disease, suffering” (“Palliative,” 2019, para. 1). Two meanings were identified (“Palliative,” 2014, para. 1) with the first being “to care for the terminally ill and their families, especially care provided by an organized health service.” A second meaning is “alleviating the symptoms of a disease or disorder, especially one that is terminal, when a cure is not available” (“Palliative,” 2014, para. 2). Palliative is also defined as “one that palliates especially a palliative drug or medicine” (“Palliative,” 2011, para. 1). Taber’s Cyclopedic Medical Dictionary defines palliative as “relieving or alleviating without curing and an agent that alleviates or eases a painful or uncomfortable condition” (Venes & Taber, 2005, p. 1687). Key terms and definitions from major healthcare organizations are in Appendix A. A review of these definitions suggests that palliative care is focused on symptom management through the illness trajectory and is used along with curative therapies. There are some organizations that do use terms such as “through the dying process” and “bereavement care,” suggesting palliation is limited to hospice care.

Synonyms of palliative include alleviate, supportive, calming, and sub-curative and the antonym is painful (“Palliative,” 2014). The surrogate term for palliative is alleviative. Alleviate is defined as something which has an alleviating effect (“Alleviate,” 2019).

## Activity Two: Setting and Sample

The second activity in Rodger's method consists of identifying the appropriate realm for data collection. EBSCOhost was used to conduct a literature-based search and identify the sample. This setting was chosen due to the cross-section of discipline-specific journals represented. The term "palliative" was used as the initial search item. Searching years 1378-2015 revealed 642,663 results. The subject matter ranged from full scale testing of chemical dust palliatives (Rushing & Newman, 2009) to palliative business practices in managing instruments dynamically (Skidmore, 1997). A review of the dataset identified various definitions of the term palliative, but operationally, the definition was not supported. A secondary search using the term "palliative care" was completed, narrowing the scope and the time frame of the dataset to further delineate the concept. This search yielded 412,495 articles published between 2009-2019. A random sample of 30 articles published since 2015 was selected for definitions of palliative care. There was not a common definition for palliative care, but two themes emerged. First, palliative care may function concurrently with curative treatments. Additionally, palliative care is a holistic process aimed at relieving suffering and improving quality of life when facing a life-limiting illness.

## Activities Three and Four: Related Terms, Attributes, Antecedents, and Consequences and Analysis

The related term for palliative care is hospice care. The terms "hospice" and "palliative care" are used interchangeably in the literature. The substitution of terms creates confusion in practice. As a result, patients do not receive the full benefit of palliative care. Hospice care is appropriate when two physicians certify that the patient has less than six months to live. At this point, the patient stops receiving curative modalities and the goal of patient care moves to support, comfort, and quality of death or life remaining. Hospice is regulated by the Center for Medicare and Medicaid Services and has stringent conditions of participation in order for the healthcare provider to receive reimbursement. The goal of palliative care is to relieve suffering and improve quality of life; the current hospice model only aims at improving the quality of death and dying process. Therefore, all hospice care is palliative care, but not all palliative care is hospice.

Analysis of the etymology of palliative care literature led to definition of attributes. The attributes of palliative care are holistic, multidisciplinary, therapeutic, and patient-driven. Holistic patient care embraces the thought that each patient is unique in his or her needs, hopes, values, and preferences in terms of care planning and the meaning of health, illness, and death (Albaqawi, Butcon, & Molina, 2017; Desbiens, Gagnon, & Fillion, 2011). The patient's personal preference for spiritual practice is an integral component of holistic patient care (Albaqawi et al., 2017). Palliative care is delivered through a multidisciplinary team approach. Care teams can improve the provision of palliative care and reduce patient suffering and unmet needs, especially for symptom management and spiritual well-being (Kao, Hu, Chiu, & Chen, 2014). Through a therapeutic relationship, healthcare providers can partner with and empower patients to be better prepared for their illness trajectory. Ensuring the plan of care is patient-driven is critical as patients should be key decision makers in their care. Patient-driven care should be encouraged, regardless of the stage of the illness, until self-care deficits deem otherwise (Shiozaki, Burgomaster, & Lemonde, 2017).

To further delineate the concept, antecedents must be identified. Antecedents are those events that must happen prior to the occurrence of the concept. The antecedent is identified through examining the definitions and information gleaned from the literature. The antecedent for palliative care is a life-limiting illness. Historically, palliative care was a modality of treatment for terminal cancer patients (Connor, 2008; Hui et al., 2013; Van Mechelen, 2012). In recent years, palliative care has been extended to include chronic conditions such as heart failure in which the trajectory of the illness is uncertain (Campbell et al. 2018). In addition, strides are being made to use palliative care in neurodegenerative conditions and Parkinson's disease (Bouca-Machado, Lennaerts-Kats, Bloem, & Ferreira, 2018; Hussain, Allgar, & Oliver, 2018). At Beth Israel Medical Center in New York, patients who meet a specific set of criteria, including advanced illness and a week-long stay in the intensive care setting, are automatically referred to palliative care (Bush, 2012). The changes in palliative care and the Medicare’s MCCM program could change requisite antecedents in the future. Rather than life-limiting illness being the necessary antecedent for palliative care, an acute or chronic life-limiting condition may become the antecedent as practice and the concept of palliative care evolve.

Consequences are events that can occur as a result of the concept, in this case the concept of palliative care. The consequence of palliative care is better symptom management for relief of suffering, improved quality of life for the patient, and reduced healthcare costs. Patients receiving palliative care have improved quality of life, less depression, and reduced symptom burden (Kassa, Murugan, Sewdu, Hailu, & Woldeyohannes, 2014; Qadire & Khalaileh, 2014). In addition, there is a reduction in cost and improved utilization of healthcare resources (Khandelwal et al., 2016). Consequences of palliative care can also extend to the family members who demonstrate greater satisfaction with the quality of care and attention to caregiver needs (Naoki et al., 2018).

## Activity Five: Exemplar Case

The purpose of the exemplar case is to illustrate how a concept may be applied to a real-life situation (Rodgers, 2000). The following exemplar is provided for the concept of palliative care as applied in an acute care setting. Other conditions and settings may present differently.

Ms. H. is a 42-year-old female with end-stage heart failure. She was diagnosed nine months earlier when she came to the emergency room with severe shortness of breath and chest pain. Since diagnosis, she has been hospitalized multiple times and experienced excruciating pain throughout her body that cannot be explained. Ms. H. has had numerous appointments to see a physician at a major medical center for a possible heart transplant. However, her symptoms exacerbated, and she was readmitted to the hospital. During admission, the care team met to discuss her case. Her ejection fraction was 15% and she had severe fluid volume overload.

With another appointment scheduled for a heart transplant consultation, Ms. H. and her care team’s goal was to ensure she was well enough to attend the appointment. The social worker on the case suggested a palliative care consult be placed to help control pain and other symptoms to give the patient a respite. The team agreed, and the physician and primary nurse talked with the patient about the idea. Ms. H. agreed, and the palliative care physician saw her that afternoon. He spoke with Ms. H. at length and listened to her concerns. He prescribed a series of pain control medications with clear titration instructions. In addition, he prescribed medications to help with anxiety and breathing. Within four days Ms. H.'s pain was better; she was smiling and going outside in a wheelchair. She began to discuss with her primary nurse the fears that she has about her illness and how much she wants a new heart. In addition, the patient began to participate in physical therapy and eating meals in a chair. Upon discharge, she had follow-up appointments with the outpatient palliative care clinic and heart transplant consultation. Ms. H.

attended the consultation appointment and was placed on the heart transplant list. In addition, she was admitted and received a Left Ventricular Assist Device while awaiting transplant. Her physicians developed a plan to keep her medications within therapeutic range based on her condition. Throughout the months awaiting transplant, Ms. H. continued to go to the palliative care clinic. Over time, her medications were decreased, and her pain, anxiety, and breathing were well maintained. She had a marked decrease in pain and suffering and her quality of life was improved.

In the exemplar case provided, the antecedent (*i.e.* life-limiting diagnosis) is present. Attributes of palliative care are present as the multidisciplinary team developed a therapeutic relationship with Ms. H. and provided holistic care that encompassed physical and psychosocial needs. Communication among healthcare providers and consultation with the patient were evident, ensuring care was patient-driven. A consequence of the referral to palliative care is that Ms. H.'s symptoms were alleviated, and her quality of life was improved. Ms. H. was not considered a candidate for hospice care because she was not determined to have less than six-months to live. She received treatment that was palliative in nature based on the medications she received and the placement of the Left Ventricular Assist Device with the plan of care to be curative upon receiving a heart transplant. This exemplar case demonstrates the application of the concept palliative care.

## Activity Six: Implications

The final activity of an evolutionary concept analysis is to identify implications for further concept development (Rodgers, 2000). The concept of palliative care continues to be frequently confused with hospice care by healthcare providers and consumers. A standardized definition of palliative care is needed. Without a common definition, there can be no definitive practice standards. Inquiry into the perceptions of healthcare providers is the first step in refinement of the concept of palliative care. Without a clear understanding of palliative care, referrals either do not happen or are made too late for the patient to receive the full benefit of palliative care.

In addition, healthcare consumers may misinterpret a recommendation for palliative care as an indication that their condition is imminently terminal. Hesitancy of the part of consumers to accept palliative care may lead to worsening symptoms, decreased quality of life, and premature death. Inquiry into perceptions of palliative care by consumers is also needed.

Current palliative care studies focus on specific symptomology and the control of symptoms. The process of how palliative care is actualized in the acute care environment is not addressed. Inquiry into how acute care facilities implement palliative care is needed to change practice.

## Conclusion

This concept analysis provided an overview of the evolution of palliative care since its inception in the 1960s. Over the decades, palliative care, which began in an acute care setting, has moved to outpatient care. Starting as a program for persons with cancer, the concept was extended to others with terminal illnesses and eventually became synonymous with hospice care. More recently, palliative care has been expanded to include life-limiting conditions and occurs in various settings. However, multiple definitions have led to misinterpretation of the concept and inappropriate application. Education for healthcare providers practicing at the bedside is required so that patients can receive the full benefit of palliative care. Further inquiry into healthcare provider and consumer perceptions of palliative care is necessary to refine the concept and ensure it is appropriately applied in practice to improve the quality of life of many patients with a variety of life-limiting conditions.

# References

Abt Associates. (2018). Evaluation of the Medicare Care Choices Model. Retrieved from https://innovation.cms.gov/files/reports/mccm-firstannrpt.pdf

Albaqawi, H., Butcon, V., & Molina, R. (2017). Awareness of holistic care practices by intensive care nurses in north-western Saudi Arabia. *Saudi Medical Journal*, *38*(8), 826-831. https://doi.org/10.15537/smj.2017.8.20026

Alleviate. (2019). In *Oxford English dictionary* (3rd). [online version]. Retrieved from http://www.oed.com/view/Entry/5257?isAdvanced=false&amp;result=1&amp;rskey=o0M8Fb&amp;ER

American Academy of Hospice and Palliative Medicine. (2003). What is hospice and palliative care. Retrieved from www.aahpm.org

American Geriatric Society (AGS) Ethics Committee. (1995). The care of dying patients: A position statement from the American Geriatrics Society [Position Statement]. Retrieved from http://www.medicine.emory.edu/ger/bibliographies/geriatrics/bibliography71_files/The_care_of_dying_patients....pdf

American Hospital Association. (2012). *Palliative care services: Solutions for better patient care and today's healthcare delivery challenges.* (Signature Leadership Series). Chicago IL: Hospitals in Pursuit of Excellence.

Bergeron, C., Friedman, D., Sisson, D., Tanner, A., Kornegay, V. Owens, O.…Patterson, L. (2016). Awareness, perceptions, and communications needs about the Affordable Care Act across the life span. *American Journal of Health Education, 47*(2), 108-116. https://doi.org/10.1080/19325037.2015.1133341

Bhatnagar, S., & Gupta, M. (2015, Jan-Apr). Future of palliative medicine. *Indian Journal of Palliative Care*, *21*(1), 95-104. http://dx.doi.org/10.4103/0973-1075.150201

Bouca-Machado, R., Lennaerts-Kats, H., Bloem, B., & Ferreira, J. (2018). Why palliative care applies to Parkinson's disease. *Movement Disorders: Official Journal of the Movement Disorder Society, 33*(5). 750-753. https://doi.org/10.1002/mds.27309

Bush, H. (2012). The evolution of palliative care. *Patient Focus,* 38-41. Retrieved from www.hhnmag.com

Campbell, R., Petrie, M., Jackson, C., Jhund, P., Wright, A., Gardner, R.,…McMurray, J. (2018). Which patients with heart failure should receive specialist palliative care? *European Journal of Heart Failure 20*(9), 1338-1347. https://doi.org/10/1002/ejhf.1240

Center for Medicare Advocacy. (2015). Tinkering with hospice: The Medicare care choices model. Retrieved from www.medicareadvocacy.org

Centers for Medicare and Medicaid Services. (2013). *Medicare hospice benefit.* (Official Government Booklet No. 02154). Baltimore, MD: Department of Health and Human Services. (Medicare Hospice Benefit)

Center to Advance Palliative Care. (2014). About palliative care. Retrieved from www.capc.org/about/palliative-care/

Connors, A., Sawson, N., Desbiens, N., Fulkerson, W., Goldman, L., Knaus, W., Oye, R. (1995, November). A controlled trail to improve care for seriously ill hospitalized patients: The study to understand prognosis and preferences for outcomes and risks of treatment (SUPPORT). *Journal of the American Medical Association, 274,* 1591-1598. Retrieved from www.jama.com

Connor, S. (2008). Development of hospice and palliative care in the United States. *Omega: Journal of Death and Dying, 56*(1), 89-99. Retrieved from http://baywood.com

Connor, S. (2014). The global atlas of palliative care at the end of life: An advocacy tool. *European Journal of Palliative Care*, *21*, 180-183. Retrieved from www.ejpc.eu.com

Covinsky, K. (2010, November 29). The legacy of SUPPORT: 15 years later. Retrieved from http://www.geripal.org/2010/11/legacy-of-support-15-years-later.html

Desbiens, J., Gagnon, J., & Fillion, L. (2011). Development of a shared theory in palliative care to enhance nursing competence. *Journal of Advanced Nursing,* 2113-2124. doi:10.1111/j.1365-2648.2011.05917.x

Elmendorf, D. (2010). *Letter to the honorable Nancy Pelosi*. Washington DC: Congressional Budget Office.

Fox, S., Cashell, A., Kernhon, G., Lynch, M., McGlade, C.,O'Brien, T., O'Sullivan, S. Timmons, S. (2016). Interviews with Irish healthcare workers from different disciplines about palliative care for people with Parkinson's disease: A definite role but uncertainty around terminology and timing. *BMC Palliative Care, 15*(15), 1-10. doi:10.1186/s12904-016-0087-6

Gordon, D., Berry, P., & Dahl, J. (2000). JCAHO's new focus on pain: Implications for hospice and palliative nurses. *Journal of Hospice and Palliative Nursing, 2*(4), 135-142. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=shib&db=ccm&AN=107022350&site=eds-live

Hospice and Palliative Nursing Association. (2014). Palliative nursing an essential resource for hospice and palliative nurses. Retrieved from www.hpna.org

Hui, D., Cruz, M., Mori, M., Parson, H., Kwon, J., Torres-Vigil, I., . . . Bruera, E. (2013). Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks. *Support Care Cancer, 21*, 659-685. doi:10.1007/s00520-012-1564-y

Hussain, J., Allgar, V., & Oliver, D. (2018). Palliative care triggers in progressive neurodegenerative conditions: An evaluation using a multi-centre retrospective case record review and principle component analysis. *Palliative Medicine, 32*(4), 716-725. doi:10.1177/0269216318755884

Kao, C., Hu, W., Chui, T., & Chen, C. (2014). Effects of the hospital-based palliative care team on the care for cancer patients: An evaluation study. *International Journal of Nursing Studies*, *51*, 226-235. doi:10.1016/j.ijnurstu.2013.05.008

Kassa, H., Murugan, R., Zewdu, F., Hailu, M., & Woldeyohannes, D. (2014). Assessment of knowledge, attitude, practice, and associated factors towards palliative care among nurses working in selected hospitals, Addis Ababa, Ethiopia. *BioMed Central Palliative Care*, *13*(6), doi: 10.1186/1472-684X-13-6

Khandelwal, N., Benkeser, D., Coe, N. Engelberg, R., Teno, J., & Curtis, J. (2016). Patterns of cost for patients dying in the intensive care unit and implications for cost savings of palliative care interventions. *Journal of Palliative Medicine*, *19*(11), 1171-1187. http://dx.doi.org/10.1089/jpm.2016.0133

Lupu, D., Ivanko, B., Insana, F., White, P., & Arnold, R. (2014). Hospice innovation impediments: Can halfway efforts tame the terrible costs? *Journal of Palliative Medicine*, *17*, 1088-1090. http://dx.doi.org/10.1089/jpm.2014.0268

Mor, V., & Teno, J. (2016). Regulating and paying for hospice and palliative care: Reflections on the Medicare Hospice Benefit. *Journal of Health Politics, Policy and Law 41*(4), 697-716. doi:10.1215/03616878-3620893

Naoki, Y., Matsuda, Y., Maeda, I., Kamino, H., Kozaki, Y., Tokoro, A., . . . Takada, M. (2018). Association between family satisfaction and caregiver burden in cancer patients receiving outreach palliative care at home. *Palliative & Supportive Care, 16*(3), 260-268. doi: http://dx.doi.org/10.1017/S1478951517000232

National Council for Palliative Care. (2015). Palliative care explained. Retrieved from www.ncpc.org

National Hospice and Palliative Care Organization. (2015). An explanation of palliative care. Retrieved from www.nhpco.org

National Quality Forum. (2006). *A national framework and preferred practices for palliative and hospice care.* (Consensus Report No. 1-933875-06-2). Retrieved from https://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_Preferred_Practices_for_Palliative_and_Hospice_Care_Quality.aspx

Oncology Nursing Society. (2015, January 1). Position statement on palliative care. *Oncology Nursing Forum*, *42*, 11. Retrieved from www.ons.org

Palliative. (2019). In *Oxford English dictionary* (3rd). [online version]. Retrieved from http://oed.com/view/Entry/136403?redirectFrom=palliativeER

Palliative. (2014). In *Merriam-Webster unabridged dictionary*. [online version]. Retrieved from http://unabridged.merriam-webster.com/unabridged/Palliative

Palliative. (2011). In *The American heritage dictionary of English language.* [online version]. Retrieved from http://search.credoreference.com/content.entry/hmdictenglang/palliative/0

Pereira, D., Fernandes, J., Ferreira, L., Rabelo, R., Pessalacia, J., & Souza, R. (2017). Meanings of palliative care in the view of nurses and managers of primary healthcare. *Journal of Nursing UFPE, 11*(3), 1357-1364. doi:10.5205/reuol.10263-91568-1RV.1103sup201706

Qadire, M., & Khalaileh, M. (2014). Jordanian nurses knowledge and attitude regarding pain management. *Pain Management Nursing, 15*(1), 220-228. http://dx.doi.ord/10.1016/j.pmn.2012.08.006

Rodgers, B. L. (2000). *Concept development in nursing*. Philadelphia: Saunders.

Rushing, J., & Newman, K. (2009). Full-scale testing of chemical dust palliatives in a semi-controlled environment. *Journal of Materials in Civil Engineering, 21*(9), 454-459. doi:10.1061/(ASCE)0899-1561(2009)21:9(454)

Sachs, G. (1994). Improving care of the dying. *American Society on Aging, 18*(4), Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=shib&db=f5h&AN=9503030180&site=eds-live&scope=site

Shiozaki, L., Burgomaster, K., & Lemonde, M. (2017). Improving patient satisfaction: Lessons from a patient-driven care initiative in a community-based hospital. *Healthcare Quarter 20*(1), 62-66. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=shib&db=mdc&AN=28550703&site=eds-live

Silverman, J. (2011). Dame Cicely Saunders and the foundation of the hospice movement. *Hektoen International: A Journal of Medical Humanities, 2*(3), Retrieved from: hekint.org/2017/01/30/dame-cicely-saunders-and-the-foundation-of-the-hospice-movement/

Skidmore, D. (1997). Encouraging sustainable business practice through managing policies and instruments dynamically. *Business Strategy and the Environment*, *6*, 163-167. Retrieved from www.ebscohost.com

The Joint Commission. (2011). Joint commission certification for palliative care. Retrieved from www.jointcommission.org

United States Department of Health & Human Services. (2015). CMS announces Medicare care choices model awards. Retrieved from www.hhs.gov

Van Mechelen, W., Aertgeerts, B., Ceulaer, K., Thoonsen, B., Vermenhoven, F., Rijswijk, E., & Lepeleire, J. (2012). Defining the palliative care patient: A systematic review. *Palliative Medicine, 27*(3), 197-208. doi:10.1177/0269216311435268

Venes, D., & Taber, C.W. (2005). *Taber's Cyclopedia Medical Dictionary*. Ed. 21. Philadelphia: F.A. Davis.

World Health Organization. (2009). Definition of palliative care. Retrieved from http://www.who.int/cancer/palliative/definition/en/

Worldwide Palliative Care Alliance. (2014). Global atlas of palliative care. Retrieved from www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf.

Appendix A. Definitions and Key Terms for Palliative Care

| **Organization** | **Definition** | **Key Terms** |
|---|---|---|
| World Health Organization | Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with a 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. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organization, 2009). | • Palliative<br>• Life threatening-illness<br>• Relief of suffering<br>• Support<br>• Bereavement support<br>• Conjunction with other therapies |
| American Academy of Hospice and Palliative Medicine | Palliative care is comprehensive, specialized care provided by an interdisciplinary team to patients and families living with a life-threatening or severe advanced illness expected to progress toward dying and where care is particularly focused on alleviating suffering and promoting quality of life. Major concerns are pain and symptom management, information sharing and advanced care planning, psychosocial and spiritual support, and coordination of care (2003) | • Palliative<br>• Life-threatening or severe advanced illness<br>• Symptom management |
| Center to Advance Palliative Care | Palliative care, and the medical sub-specialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of palliative care | • Palliative<br>• Serious illness<br>• Relief from symptoms |

| Organization | Definition | Key Terms |
|---|---|---|
| | doctors, nurses, social workers and others who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment (2014). | • Support<br>• With curative therapy |
| National Consensus Project | Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice The following features characterize palliative care philosophy and delivery: Care is provided and services are coordinated by an interdisciplinary team; Patients, families, palliative and non-palliative healthcare providers collaborate and communicate about care needs; Services are available concurrently with or independent of curative or life-prolonging care; Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death (2013). | • Palliative<br>• Patient and family centered<br>• Holistic<br>• Support throughout continuum of illness<br>• Prevent suffering |
| National Quality Forum | Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy (2006) | • Palliative<br>• Patient and family centered<br>• Holistic<br>• Support throughout continuum of illness<br>• Prevent suffering |
| National Hospice and Palliative Care Organization | Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice. The following features characterize palliative care philosophy and delivery: Care is provided and services are coordinated by an interdisciplinary team; Patients, families, palliative and non-palliative healthcare providers collaborate and communicate about care needs; Services are available concurrently with or independent of curative or life- | • Palliative<br>• Patient and family centered<br>• Holistic<br>• Support throughout continuum of illness<br>• Prevent suffering |

| Organization | Definition | Key Terms |
|---|---|---|
| | prolonging care; Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death (2015). | |
| National Council for Palliative Care | Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. Palliative care aims to: Affirm life and regard dying as a normal process; Provide relief from pain and other distressing symptoms; Integrate the psychological and spiritual aspects of patient care; Offer a support system to help patients live as actively as possible until death; Offer a support system to help the family cope during the patient's illness and in their own bereavement (2015). | • Palliative<br>• Holistic<br>• Advanced progressive illness<br>• Regard dying as a normal process<br>• Relief from distressing symptoms<br>• Support system<br>• Bereavement support |
| Oncology Nursing Society | Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy (2015). | • Palliative<br>• Patient and family centered<br>• Holistic<br>• Support throughout continuum of illness<br>• Prevent suffering |
| Worldwide Hospice Palliative Care Alliance/ ehospice | Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patient's live as actively as possible until death; offers a support system to help the family cope during the patients | • Palliative<br>• Life threatening-illness<br>• Relief of suffering<br>• Support<br>• Bereavement support<br>• Conjunction with other therapies |

| Organization | Definition | Key Terms |
|---|---|---|
| | illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (2014). | |
| American Hospital Association | Palliative care specializes in taking care of patients with serious illness and focuses on providing relief from symptoms pain, and stress in order to improve the quality of life for patients and their families. The care is provided by an interdisciplinary team whose focus is: Assessment and treatment of a patient's physical and emotional/ spiritual distress; Communication and decision-making with patients and their families to establish achievable patient-centered goals of care; Coordination of transitions of care and support for practical needs of patients and families (2012). | • Palliative<br>• Serious-illness<br>• Relief from symptoms<br>• Patient-centered<br>• Transitions of care |
| Hospice and Palliative Nurses Association | Palliative care is patient- and family-centered care across the spectrum of illness. Palliative care begins with supportive care at the time of diagnosis of a serious or life-threatening illness and ends with bereavement care after death. Patient and family goals are supported throughout the course of illness, during the dying process, and after death, with respect to values, preferences, and beliefs. Palliative nursing is developmentally, culturally, ethnically, and spiritually appropriate. Palliative care relieves physical, psychological, emotional, and spiritual suffering of patients and families with serious or life-threatening illness. Palliative care is equitable, comprehensive, and reaches across health settings, with an emphasis on continuity, quality, safety, and access with attention to vulnerable populations and transitions of care. Services are available concurrently with or independent of curative or life-prolonging care. Palliative care is interdisciplinary and collaborative. Palliative care team members have clinical expertise and communication skills to educate patients | • Palliative<br>• Patient and family centered<br>• Serious or life-threatening illness<br>• Supportive<br>• Transitions of care<br>• Support through the dying process. |

| Organization | Definition | Key Terms |
|---|---|---|
| | about their disease, treatment options, and decision-making while maintaining confidentiality (2014). | |
| The Joint Commission | Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and any stage in a serious illness and can be provided along with curative treatment. The goal is to improve quality of life for both the patient and the family (2011). | • Palliative<br>• Support<br>• Any stage of serious illness<br>• Along with curative therapy |

## Chapter 3

# Hospital-Based Palliative Care Programs: Perspectives Regarding Conceptualization and Accreditation

## Abstract

Problem

Significant barriers to palliative care access continue to compromise quality of life for those who could benefit from palliative care services. Lack of well-defined parameters and regulations have contributed to palliative care programs that vary in their scope of practice and services to patients. Hospital-based palliative care programs with The Joint Commission’s Advanced Palliative Care Certification (APCC) remain low. A gap exists in the literature regarding what barriers preclude programs from obtaining certification.

Theory

The study is based on the Trajectory of Quality Palliative Care model that reflects palliative care patient outcomes that are based on regulatory standards, evidence-based research, national and state policy, and reimbursement requirements.

Design/Methods

The study uses a descriptive design to determine how hospital-based palliative care programs define and conceptualize palliative care and the barriers experienced by non-Joint Commission certified hospital-based palliative care programs in the United States. The target population includes a convenience sample of hospital-based palliative care programs in the United States (U.S.) that are listed on the Center to Advance Palliative Care (CAPC) National Palliative Care

Registry database as active hospital-based palliative care programs and do not hold The Joint Commission’s Advanced Palliative Care certification.

### Analysis

Frequencies and percentages were calculated for demographic data collected from the responses received from the Hospital-Based Palliative Care Survey. Content analysis was completed on the open-ended question with the survey and thematic analysis was completed on the miscellaneous data received from participant interviews.

### Results

The findings in this study identified perceived barriers to achieving The Joint Commission Advanced Palliative Care Certification including (a) not meeting the seven-days-per-week and on-call criteria, (b) recruitment and retention of staff, (c) funding necessary to reach minimum staffing standards, and (d) hospital staff and consumer misunderstanding about palliative care. The definitions of palliative care used by the programs within the data set were not consistent, but they did follow components from definitions used by the CAPC, National Quality Forum (NQF), National Hospice and Palliative Care Organization, and The Joint Commission.

*Keywords*: palliative care, hospital-based palliative care, barriers, accreditation standards

# Hospital-Based Palliative Care Programs: Perspectives Regarding Conceptualization and Accreditation

## Problem and Significance

The current United States healthcare environment continues to have significant barriers to palliative care palliative care access and delivery services (Bhatnagar & Gupta, 2015; Connor, 2014; McAteer & Wellberry, 2013). Hospital-based palliative care programs are even less common in rural communities. Nationally, 34% of rural hospitals provide palliative care compared to 72% of urban hospitals (National Palliative Care Registry, 2015). Appropriate care to patients in need of palliative care is hindered due to several insufficiencies: (a) policies establishing palliative care, (b) definitions that reflect clarity and consistent use of palliative care, (c) palliative care education for healthcare providers as well as for healthcare consumers and communities at large, (d) essential medications needed to deliver palliative care, and (e) organized programs and services to deliver palliative care (Connor, 2014; Hui et al., 2013; Van Mechelen et al., 2012). Palliative care as a healthcare specialty has vague parameters that are not regulated by policy; therefore, hospital-based palliative care programs vary in their scope of practice and services to patients (Arthur & Bruera, 2013; Epstein & Morrison, 2012; Hui et al., 2013; Van Mechelen et al., 2012). In addition, healthcare provider confusion of terminology and concepts creates delays in referrals, limits the effectiveness of palliative care, and creates gaps in care for patients and families (Pavlish & Ceronsky, 2009; Van Mechelen et al., 2012).

Palliative care has been shown to reduce symptom burden, hospitalization and medical costs, and improve mood and quality of life, but disparities exist in the abilities of patients to access these services (Bakitas et al., 2015; Davis, Strasser, Cherny, & Levan, 2015; Goldsmith, Dietrich, Du, & Morrison, 2008: Morrison et al., 2011; Riffin et al., 2015). Though evidence-based standards of care and accreditation guidelines exist for hospital-based palliative care programs, only 91 out of 2, 315 acute care hospitals within the United States currently hold The Joint Commission The Joint Commission Advanced Palliative Care certification (American Hospital Association, 2017; Get Palliative Care, 2018; National Consensus Project for Quality Palliative Care, 2013; The Joint Commission, 2015). The Joint Commission is a private, non-profit organization whose mission is to improve the safety and quality of care provided to the public through providing health accreditation and related services that support performance improvement in healthcare organizations (The Joint Commission, 2017). Unfortunately, of the 91 accredited hospitals, only 27 states are represented; therefore, access to high-quality palliative care is not consistent or possible in many areas of the United States. Despite the number of hospital-based palliative care programs offered in the acute care setting, a gap exists in the literature regarding the barriers that keep hospital-based palliative care programs from obtaining The Joint Commission Advanced Palliative Care certification (Gadoud, Jenkins, & Hogg, 2013; Goldsmith et al., 2008; Meier & Morrison, 2015; Riffin et al., 2015). Knowledge of these issues could facilitate efforts toward addressing barriers that currently stymie consistent delivery of high-quality palliative care. Removing these barriers could ultimately improve access and patient outcomes.

## Review of the Literature

### Conceptualization of Palliative Care

Palliative care originated in England in the early 1960s and was introduced in the United States in 1963 when Dr. Cicely Saunders presented a series of lectures on hospice care (Connor, 2008). These initial lectures led to the formation of the first hospice program in the United States in Branford, Connecticut in 1973 (Foley, 2000). The concepts of palliative care and hospice were interchangeable until the establishment of the Hospice Medicare Benefit in 1985. Per Medicare conditions of participation for hospice-specific care, a patient was required to have a diagnosis of an incurable, malignant disease; a prognostication of life expectancy of six months or less; and a waiver of all rights and privileges to receive curative treatments. The Hospice Medicare Benefit requirements created a marked difference in the paradigms of hospice and palliative care. Palliative care was now being recognized as a specialty field within healthcare. In response to these conditions, the literature in the 1990s suggested that availability of palliative care should be driven by need and not by life expectancy or diagnosis (Abyad, 1993; Addington-Hall, Fakhourg, & McCarthy, 1998; Connor, 2008). The National Hospice and Palliative Care Organization were created to assist clinicians in prognosis for select non-cancer diagnoses to determine palliative care eligibility. Even though the focus of care was changing from curative to end-of-life (EOL) care, most deaths for people with non-cancer diagnoses continued to occur in hospital settings without the benefits of hospice or palliative care. The concept of palliative care continued to evolve as a separate entity from EOL care with the development of the Center to Advance Palliative Care (CAPC) in 2000. The Center to Advance Palliative Care established a mission to provide technical support to hospitals to establish and sustain effective palliative care services (Larson, 2001). Also, in 2000, The Joint Commission added the provisions of pain management and palliative care services to their accreditation standards (Gordon, Berry, & Dahl, 2000). The National Consensus Project for Quality Palliative Care (NCPQPC), in 2001, began an initiative to further define the value of palliative care and to improve the delivery of palliative care in the United States. In 2009, NCP affirmed, “Palliative care is appropriate and should be available for all patients from the time of diagnosis with a life-threatening or debilitating condition (National Consensus Project, 2009, p. 11).” This approach suggested that palliative care teams should work with treatment teams to improve patient outcomes and quality of life in conjunction with curative treatments.

## Definitions

Various terms describe care received near or at the end of life. Hospice is end-of-life care given to a terminally ill patient with six months or less to live who no longer wishes to receive curative treatment. The goal of treatment is for patients to experience peace, comfort, and dignity throughout the dying process (Worldwide Palliative Care Alliance, 2014). A combination of national and worldwide organizational definitions for palliative care shows movement toward consistency since 2013. The National Consensus Project (NCP), National Hospice and Palliative Care Organization (NHPCO), and the Oncology Nursing Society (ONS) have adopted the 2015 National Quality Forum's (NQF) definition that defines palliative care as a patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering and supports patients and families throughout the continuum of illness to prevent suffering, thereby optimizing quality of life (National Quality Forum, 2006). On a global scale, the Worldwide Hospice Palliative Care Alliance (WHPCA) has adopted the World Health Organization's (WHO) 2009 definition that focuses on relief of suffering from a life-threatening illness and bereavement support for patients and families of the suffering patient. In addition, WHPCA’s definition of palliative care recognizes that palliative care can be received in conjunction with other therapies. The American Academy of Hospice and Palliative Medicine (2003) acknowledges that palliative care is a specialized treatment for patients with life-threatening illness, but their definition extends to include the expectation of illness progressing toward death. Serious illness is the focus of the Center to Advance Palliative Care (CAPC), American Hospital Association (AHA), Hospice and Palliative Nurses Association (HPNA), and The Joint

Commission. The American Academy of Hospice and Palliative Medicine (AAHPM) and HPNA add the caveat that the serious illness ends with bereavement care and support through the dying process; this is a source of much confusion and can affect who is and is not considered eligible for high-quality palliative care (AAHPM, 2003; HPNA, 2014). All definitions agree that care is delivered through a multi-disciplinary team approach that provides support to both patients and families. The essence of palliative care as defined by these organizations is an interdisciplinary support system which provides patients and families with holistic care to enhance quality of life and provide relief from suffering.

Although there are commonalities regarding perceptions about palliative care, ambiguity remains that contributes to confusion regarding the population served, appropriate referral criteria, policy and protocol development, and clinical and research practice (Arthur & Bruera, 2013; Epstein & Morrison, 2012; Hui et al., 2013; Van Mechelen et al., 2012). This lack of understanding adversely impacts patients, families, and the community at large (Hui et al., 2013).

## Policy Barriers

Lack of accessibility to high-quality palliative care has far reaching implications on global, national, and state levels. The WHO's recognition of palliative care as a basic human right has driven the development of palliative care policies worldwide (Connor, 2014; Worldwide Palliative Care Alliance, 2014). As cited in Worldwide Palliative Care Alliance (2014), the WHO public health model identifies policy components that are necessary for effective palliative care integration into a healthcare system. Integration requires that palliative care be a part of national health plans, policies, and regulations, including the funding and service delivery models that support palliative care delivery (Connor, 2014; Worldwide Palliative Care Alliance, 2014).

Within the United States, insufficient policies to guide and support palliative care have created difficulties for standardized, high-quality palliative care to develop. Barriers to policy development include a lack of understanding of the benefits of palliative care, fragmented healthcare systems, a need for greater research funding, a lack of adequate reimbursement for palliative care, and regulatory barriers (Aldridge et al., 2016; Connor, 2014; Robinson, Gott, Gardiner, & Ingleton, 2016). Luyirika et al. (2016) states that the lack of a policy framework is a limitation of the United States government's investment in developing palliative care services, leading to limited access, poor coordination, and inequities in service provisions as well as an inability to establish public and private partnerships to make services increasingly available. A national palliative care policy is essential in facilitating palliative care provisions that address relief of pain and other distressing symptoms at the time of diagnosis and through the disease trajectory (Aldridge et al., 2016; Klinger, Howell, Zakus, & Deber, 2014; Luyirika et al., 2016; Robinson et al., 2016; Schenker & Arnold, 2015).

In an effort to expand care access to over 30 million Americans, the Patient Protection and Affordable Care Act (ACA) was passed in March 2010 (Bergeron et al., 2016). The ACA required the Center for Medicare and Medicaid Innovation to implement a five-year exploratory project, which allowed patients to receive aggressive treatment as well as palliative and hospice care concurrently (Office of the Legislative Counsel, 2010). The pilot project titled, Medicare Care Choices Model (MCCM), has invited 141 Medicare-certified hospices to participate. The MCCM, however, has raised concerns (Center for Medicare Advocacy, 2015; Lupu, Ivanko, Insana, White, & Arnold, 2014; United States Department of Health & Human Services, 2015). Use of the term "curative" can cause confusion for patients and families and can give false hope. These patients have a terminal illness, and palliative treatments may lengthen life, but will not cure a terminal illness (Center for Medicare Advocacy, 2015; Lupu et al., 2014). The MCCM has no provisions for patients with other terminal illness such as end-stage renal disease or dementia, and there are no provisions for patients that require only palliative services. While formed to bring palliative care alongside curative care, the existing policy and the MCCM exploratory project specifically, can be a barrier due to inconsistent definitions of palliative care and may interfere with further policy development that could involve a broader and more open palliative care conception.

## Evidence-Based Practice Barriers

The WHO has identified the need for greater funding for palliative care research to strengthen clinical practice and improve healthcare delivery to maximize the quality of life for patients facing life-limiting conditions (Connor, 2014; Worldwide Palliative Care Alliance, 2014). Twelve research priorities identified for palliative care include (a) needs of family caregiver (Bergdahl, Benzein, Ternestedt, Elmberger, & Andershed, 2013; Brown & Vaughn, 2013; Enguidanos, Housen, Penido, Mejia, & Miller, 2014; Robinson, Gott, & Ingleton, 2014); (b) perspectives of patients (Hayle, Coventry, Green, & Caress, 2013; Morrison & Meier, 2015; Riffin et al., 2015); (c) culture and ethnicity (Evans et al., 2012; Koffman & Higginson, 2001; Riffin et al., 2015); (d) patient/family or patient/provider decision-making and communication (Enguidanos et al., 2014; Morrison & Meier, 2015; Richfield, Jones, & Alty, 2013); (e) perspectives of professional caregivers (Kamal et al., 2015; Pillemer et al., 2015; Riffin et al., 2015); (f) patient emotional and psychological status (Riffin et al., 2015; Ventura, Burney, Brooker, Fletcher, & Ricciardello, 2014); (g) economic research and cost effectiveness (Gomes, Calanzani, & Higginson, 2014; Riffin et al., 2015; (h) education, training, and curriculum development for healthcare providers (Hayle et al., 2013; Johnson, Gorman, Morse, Firth, &

Rushbrooke, 2013; Riffin et al., 2015); (i) spirituality and existential issues (Pringle, Johnston, & Buchanan, 2015; Riffin et al., 2015); (j) patterns of use, admittance, and referral (Hayle et al., 2013; Morrison & Meier, 2015; Richfield et al., 2013); (k) interdisciplinary approaches to delivering palliative care (Groh, Vyhnalek, Feddersen, Fuhrer, & Borasio, 2013; Morrison & Meier, 2015; Riffin et al., 2015); and (l) patient conditions other than cancer (Gelfman, Kalman, & Goldstein, 2014; Hayle et al., 2013; Morrison & Meier, 2015). The National Institutes of Health (NIH) funding of palliative care research has increased in recent years but gives less than one percent of its funds to palliative care research (Aldridge et al., 2016; Morrison & Meier, 2015). Barriers for research funding can be attributed to the structure of NIH institutes, which are often disease specific. Since palliative care is applicable to all chronic illnesses, it does not fit well into a particular institute’s scope of interest. In addition, there is no specific study section that reviews grant applications focused on palliative care. Existing sections currently have only one or two reviewers with expertise in palliative care research, which reduces the likelihood of palliative care grant proposals being funded (Aldridge et al., 2016). To facilitate support for national palliative care policy development, evidence-based standards of care are needed to create ubiquitous standards that can used across care settings to ensure that quality palliative care is being delivered.

## Standards of Practice for Palliative Care

Recommended standards of practice for hospital-based palliative care programs give a comprehensive view of high-quality palliative care. The National Consensus Project (NCP) has a mission of improving the quality of palliative care within the United States Clinical Practice Guidelines for Quality Palliative Care have evolved since 2004 to promote quality palliative care and foster high standards of practice across care settings with care domains that provide care precepts and give structure to clinical care programs (National Consensus Project for Quality Palliative Care, 2013). The National Quality Forum (NQF) adopted the Clinical Practice Guidelines for Quality Palliative Care within *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report* (National Quality Forum, 2006). The report details 38 preferred practices that further delineate high-quality palliative care. The Joint Commission's Advanced Palliative Care certification, developed in 2011, emphasizes a formal, organized palliative care program that is

> (a) led by an interdisciplinary team whose members possess the requisite expertise in palliative care; (b) reflects leadership endorsement and support of the program's goals for providing care, treatment, and services; (c) demonstrates a special focus on patient and family engagement; (d) has processes that support the coordination of care and communication among all care settings and providers; and (e) reflects the use of evidence-based national guidelines or expert consensus to guide patient care (The Joint Commission, April 21, 2017).

The Joint Commission Advanced Palliative Care certification is the only organization that requires a formal survey process and reported results of quality indicators (The Joint Commission, 2017). Performance measurement for process improvement was not addressed by NCP or NQF, and The Joint Commission added this component to their Advanced Palliative Care Certification process (Appendix B).

## Operational Barriers

Large hospitals (300 beds or greater) within the United States report 90% offer hospital-based palliative care programing (Dumanovsky et al., 2016). Accessibility to palliative care is inconsistent based on region and state and continues to be insufficient to meet the palliative care needs of the population (Centeno et al., 2016; Davis, Temel, Balboni, & Glare, 2015; Downing et al., 2016; Dumanovsky et al., 2016; Glass & Burgess, 2011). Even facilities reporting palliative care services do not always reach all patients in need due to problematic issues related to program protocols, funding, and staffing (Dumanovsky et al., 2016). Healthcare provider confusion of terminology and concepts creates delays in referrals, limits the effectiveness of palliative care, and creates gaps in care for patients and families (Pavlish & Ceronsky, 2009; Van Mechelen et al., 2012). Mahon and McAuley (2010) researched oncology nurses' understandings of palliative care and found that nurses’ understanding of palliative care focused on symptom management. Nurses could not distinguish between palliative care and hospice and believed that only patients who were near the end of life should receive palliative care.

Reported palliative care services can range from assistance with advanced directives, assistance with hospice referral, development of a comprehensive care plan, pain consultation, symptom management, and psychosocial support (Davis et al., 2015). Additional studies mentioned services at various hospitals were offered but did not provide details on what those services included (Centeno et al., 2016; Downing et al., 2016; Glass & Burgess, 2011). Credentialing for healthcare providers and hospital-based palliative care programs varied. Some programs have approximately half of their nurses and physicians certified whereas other programs had no requirements for staff certifications (Centeno et al., 2016; Davis et al., 2015; Downing et al., 2016; Glass & Burgess, 2011). Quality measures were inconsistent as well with programs reporting the desire to collect quality improvement data while others collected none (Centeno et al., 2016; Davis et al., 2015; Downing et al., 2016; Glass & Burgess, 2011). Specific program funding and reimbursement were not discussed in current studies (Centeno et al., 2016; Davis et al., 2015; Downing et al., 2016; Dumanovsky et al., 2016; Glass & Burgess, 2011).

Within the literature, one study was found that compared existing hospital-based palliative care programs with recommendations for palliative care programs (Hall, Rafalson, Mariano, & Michalek, 2016). A New York study of seven hospitals compared their hospital-based palliative care programs to the CAPC program recommendations. All hospitals reported being compliant with CAPC recommendations for hospital-based palliative care programs, including (a) integration of program into the management structure of the hospital; (b) program consultation services available to all hospital patients; (c) programs having designated funding for palliative care physicians, social workers, and chaplains are available to provide additional services; and (d) tracking for program operational, customer, clinical and financial metrics (Hall, Rafalson, Mariano, & Michalek, 2016). Recommendations have been made for ongoing development and expansion of quality hospital-based palliative care programs (Centeno et al., 2016; Davis et al., 2015; Downing et al., 2016; Glass & Burgess, 2011; Hall et al., 2016). No studies were found that demonstrate compliance with The Joint Commission Advanced Palliative Care certification.

## Summary

Palliative care has undergone tremendous growth in the past decade as a treatment specialty that can improve the quality of life of people living with serious illness with a focus on "providing…relief from the symptoms and stress of a serious illness" (Center to Advance Palliative Care, 2014, para. 1). Consistent education in palliative care delivery is necessary to ensure that healthcare providers can understand how services may help patients to receive appropriate care and alleviate unnecessary suffering (Covinsky, 2010; Karkada, Nayak, & Malathi, 2011; Kassa, Murugan, Sewdu, Hailu, & Woldeyohannes, 2014; Pfister et al., 2013; Qadire & Khalaileh, 2014). In addition, palliative care interventions can improve patient mood and quality of life, but healthcare providers barriers regarding confusion and conflicts about palliative and EOL care can result in delayed access to quality palliative care or EOL care (Bakitas et al., 2015; Davis et al., 2015; Goldsmith et al., 2008; Kamal et al., 2015; Morrison et al., 2011; Riffin et al., 2015).

Disparities exist in quality of palliative care due to a lack of consistent standards and variation of services based on state and region (Arthur & Bruera, 2013; Connor, 2014; Epstein & Morrison, 2012; Hui et al., 2013; Morrison & Meier, 2015; Van Mechelen et al., 2012). Opportunities for providing care are missed due to a lack of well-delineated delivery models that are easily measurable, efficient, and patient and family centered. Inconsistencies exist regarding implementation of services and hospital-based palliative care program outcome measurements and evidence-based, standards relative to palliative care (Kamal et al., 2015; Wysham & Kamal, 2016). The Joint Commission Advanced Palliative Care certification provides an evidence-based framework for hospital-based palliative care programs, but barriers to certification must be identified so that actions can be taken to support an integrated model of care that relieves unnecessary suffering of all patients in need.

## Theoretical Framework

Existing palliative care theoretical models focus on the time at which the patient enters the healthcare continuum, specifically, the time of diagnosis. These conceptual models do not consider what must occur to create a system that supports high-quality palliative care. Nursing theoretical models focus on the interdisciplinary team/patient relationship and how that impacts the patient’s experience. Even though these models address aspects of palliative care, certain elements from the literature are missing. Therefore, the Trajectory of Quality Palliative Care Model was developed to guide the current study.

Development of the Trajectory of Quality Palliative Care Model was influenced by Donabedian's structure-process-outcome model for evaluating quality in healthcare (Sund, Iwarsson, & Brandt, 2015). The measures of structure and process impact patient outcomes. Structure measures the characteristics and traits of the healthcare providers that include tools, resources, and physical and organizational environment (Peters, Mueller, Stoller, & Gupta, 2009; Sund et al., 2015). Process measures are the set of activities that occur between the healthcare provider and patient. Outcome measures represent the change in a patient's current and future health status due to care received (Peters et al., 2009; Sund et al., 2015).

The Trajectory of Quality Palliative Care Model (see Figure 1) is an inverted triangle. The top layers are macro-level components (regulatory standards, evidence-based research, national and state policy, and reimbursement requirements) from which critical elements are developed and disseminated to give shape to the beginnings of a high-quality hospital-based palliative care program. Dynamic integration of the macro-level components into micro-level components that focus on interdisciplinary actions facilitates operationalization of a hospital-based palliative care program that can positively impact patient experience and outcomes. The result of services provided through an interdisciplinary team approach impacts patient and family's quality of life. Variation likely exists in the quality of care patients receive throughout the United States due to low numbers of programs that have The Joint Commission Advanced Palliative Care certification. The barriers to utilizing best practices are unknown. As a result, access to high-quality palliative care in the United States is inequitable (Connor, 2014; Morrison & Meier, 2015). Through identifying hospital-based palliative care programs in the United States that do not have The Joint Commission Advanced Palliative certification and determining barriers that prevent obtaining certification, strategies can be developed to assist hospital-based palliative care programs to obtain certification and improve patient outcomes.

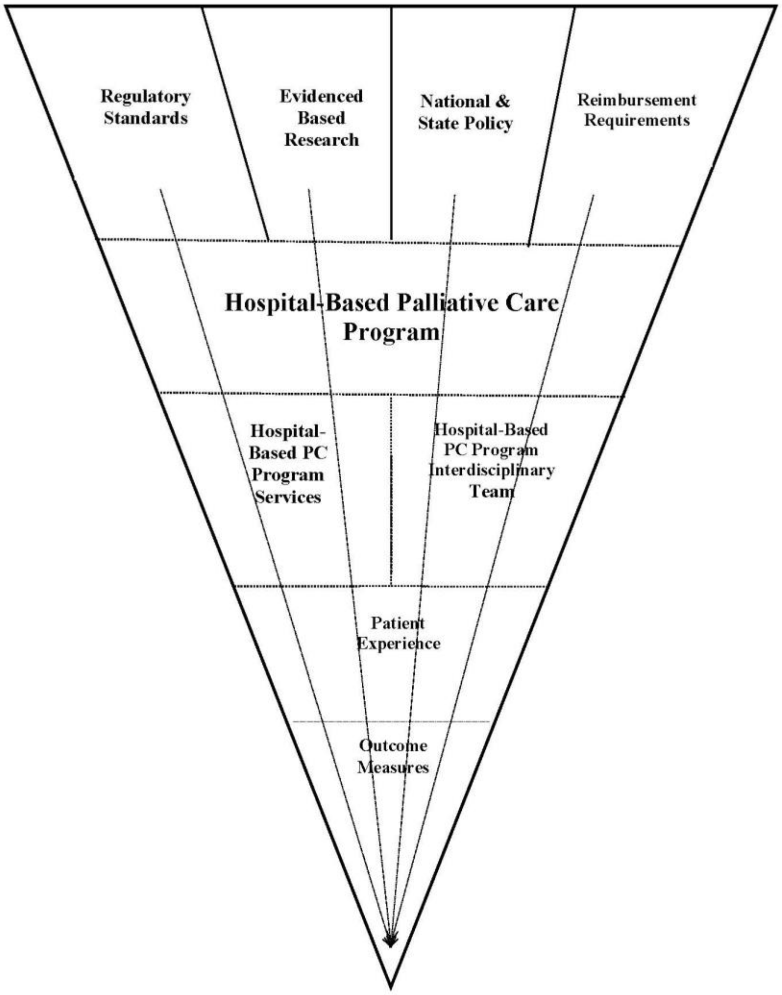


*Figure 1*. Trajectory of Quality Palliative Care Model

## Conceptual and Operational Definitions

Based on the findings from the literature, the definition of palliative care that guides this study is "Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering and supports patients and families throughout the continuum of illness to prevent suffering, thereby optimizing quality of life" (National Quality

Forum, 2006). In addition, congruence among model concepts that guide this study is essential. Table 3.1 depicts how model concepts and conceptual definitions demonstrate congruency among study components.

Table 3.1

*Model Concepts and Conceptual Definitions*

| Conceptual Model | Conceptual Definitions |
|---|---|
| Regulatory Standards | Standards of care based on evidence-based research that drive healthcare practice. |
| Evidence-Based Research | Evidence-based guidelines that promote safe and effective care and high-quality palliative care, foster consistence high standards of care, and encourage continuity of care (NCP, 2013; NQF, 2006; TJC, 2015). |
| National and State Policy | Policies that impact regulatory standards, evidence-based practice, and reimbursement requirements within the healthcare environment. |
| Reimbursement Requirements | The manner in which a program or project designs, executes, and controls to convert resources that include funding into desired services. |
| Hospital-based palliative care Program | The provision of palliative care services within an acute care hospital setting (Cox & Curtis, 2016; Hall et al., 2016; Morrison, 2013). |
| Hospital-based palliative care Services | Services available to patients in a hospital-based palliative care program. |
| Hospital-based palliative care Interdisciplinary Team | Different disciplines that work collaboratively to serve the needs of a patient. |
| Patient Experience | The measurement of the tangible and intangible effects (consequences) of a program or intervention on an individual or family. |
| Outcome Measures | "The continuous study and adaptation of a healthcare organization's functions and processes to increase the probability of achieving desired outcomes and to better meet the needs of patients and families" (TJC, 2015, p. PI-1). |

## Research Questions

The purpose of this study was to gain an understanding of how hospital-based palliative care programs define and conceptualize palliative care and to determine barriers hindering hospital-based palliative care programs from obtaining The Joint Commission Advanced Palliative Care certification. The following research questions guided this study:

1. How do hospital-based palliative care programs that do not have The Joint Commission Advanced Palliative Care certification define and conceptualize palliative care?
2. What are the factors and/or barriers that hospital-based palliative care programs have that impede achieving The Joint Commission Advanced Palliative Care certification?

## Design

The study used a descriptive design to determine barriers that exist in obtaining The Joint Commission Advanced Palliative Care certification as well as capturing how hospital-based palliative care programs define and conceptualize palliative care. Descriptive methods offer a comprehensive account of the phenomenon in question.

## Methods

### Sample

The target population for this study is all hospital-based palliative care programs in the United States that are listed on the CAPC National Palliative Care Registry database as active hospital-based palliative care programs, but do not currently hold The Joint Commission Advanced Palliative Care certification. The population included active hospital-based palliative care programs that provide palliative care services to patients in one or more locations and have been in business for at least three months (Center to Advance Palliative Care, 2017). The target population consisted of 530 hospital-based palliative care programs.

Sampling was conducted to recruit non-Joint Commission certified hospital-based palliative care programs using contact information provided by CAPC and institutional web sites. Telephone calls were made to the individual programs. The target population is not evenly distributed throughout the United States, which would make stratified or proportionate sampling an ineffective sampling strategy for this study (Creswell, 2014). A total of 21 programs were identified that represented the following United States Census Bureau regions (United States Census Bureau, 2015): Region One, northeast, 14.3%; Region Two, mid-west, 19.1%; Region Three, south, 33.3%, and Region Four, west, 33.3%.

## Protection of Human Subjects

The University of Texas at Tyler Institutional Review Board reviewed and approved the research protocol for this study. Each participant received verbal information from a telephone script (Appendix E) explaining the nature of the research, and the participant had the option to agree or not agree to participate. The benefit of participation was the opportunity to contribute to the body of knowledge related to improving access to quality palliative care.

## Instrument

The Hospital-Based Palliative Care Survey is a 12-item self-administered survey that includes open and closed-ended questions. Closed-ended questions collected demographic information (5 items) while open-ended questions collected information on how palliative care programs conceptualize and define palliative care (4 items) and barriers to obtaining The Joint Commission Advanced Palliative Care certification (3 items).

## Data Collection

Survey data were collected via telephone interviews by the primary researcher once participants agreed to participate. The conversation began with general information about the study that followed the telephone script (Appendix E). Interview notes were taken relating to each question answered. Miscellaneous data were collected that pertained to each program. Immediately after each phone interview, the data was entered into an Excel® spreadsheet for analysis. Each row on the spreadsheet represents an individual participant in the study, designated by a number ranging from one to 21, while each column represents the responses provided for the survey items. Data was saved on an encrypted and password-protected personal computer that can only be accessed by the researcher to protect confidentiality of data. Data saturation or redundancy was reached at the 21st interview.

## Analysis

Percentages and frequencies were collected for demographic data and content analysis was completed for open-ended survey questions (Drisko & Maschi, 2015). Thematic analysis was completed on the miscellaneous data received from participant interviews. (Braun & Clark, 2008).

## Procedures to Enhance Rigor

Credibility was demonstrated through use of the six-phase process of thematic analysis. The concepts were revised as data was read and reread, resulting in recoding and relabeling of themes and subthemes. This process continued until the final results provided the intended depth of insight into the data (Korstjens & Moser, 2018). Triangulation was accomplished through the collection of data from multiple hospital-based palliative care programs throughout the United States and from different levels of healthcare providers such as, a palliative care registered nurse or a licensed social worker (Korstjens & Moser, 2018).

Transferability was supported by allowing respondents to share their views on their individual hospital-based palliative care programs. No effort was made to make the data appear more similar or congruent than they were. Quotations were used as exemplars to illustrate the themes and show how the quotations and themes flow together (Korstjens & Moser, 2018). The respondent’s views were fully described to permit adequate comparisons with other respondent views. Results included “thick descriptions” of the participants’ responses so the readers can assess whether the findings are transferable to their own settings (Korstjens & Moser, 2018). The availability of research materials concerning all phases of the study are essential to the auditing process and in establishing confirmability. Clear and precise documentation throughout the study as well as the inclusion of the interview surveys with researcher notes, Excel® spreadsheet of all responses and use of a six-phase process for thematic analysis allows others to view the process by which the research study developed from conception to completion and assists in augmenting both dependability and confirmability (Braun & Clark, 2006; Korstjens & Moser, 2018).

## Data Management and Analysis

Two approaches were used to analyze qualitative data: content analysis and thematic analysis. Content analysis involved frequencies that were conducted on the following with regard to individual palliative care programs: mission and vision, how the program defines palliative care, program admission criteria, program priorities, barriers to achieving The Joint Commission's Advanced Palliative Care Certification, and resources needed to achieve The Joint Commission's Advanced Palliative Care Certification. Qualitative data falling under the miscellaneous information was thematically analyzed into sub-themes and themes (Braun & Clark, 2006) using a six-phase process (Figure 2).

| Phase | Description of the process |
|---|---|
| 1. Familiarizing yourself with your data | Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas. |
| 2. Generating initial codes | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. |
| 3. Searching for themes | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. Reviewing themes | Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic "map" of the analysis. |
| 5. Defining and naming themes | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. |
| 6. Producing the report | The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis. |

*Figure 2:* Six phases of thematic analysis

During interviews noted were taken by hand and then entered into an Excel® spreadsheet in preparation for the six-phase process of thematic analysis (Braun & Clarke, 2006). The phases served to bring clarity to the process while allowing the researcher to review the data multiple times to capture important elements that supported the research questions. Phase 1 entailed reading and re-reading the data and forming initial codes. Through reviewing the data an initial code list was generated (Phase Two/Table 3.2).

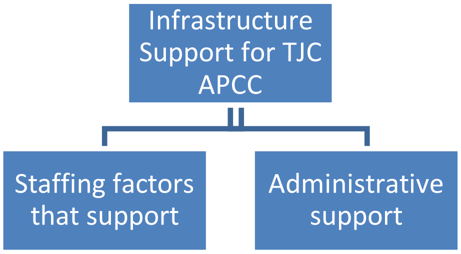
Table 3.2

*Phase 2: Initial Codes List*

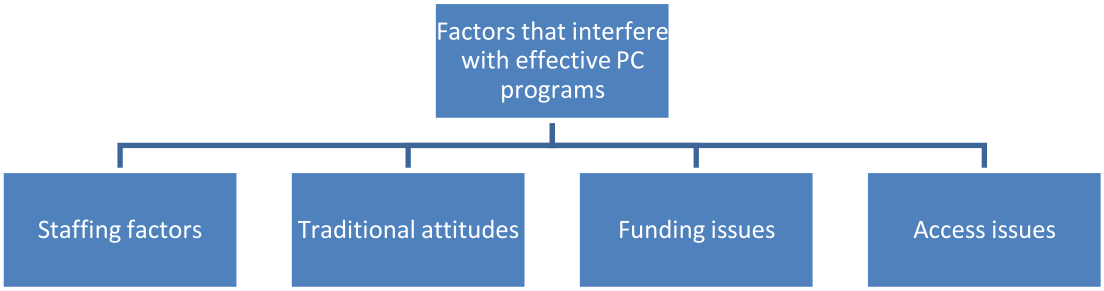
1. Skill mix
2. Professional Certification
3. Number of patients seen
4. Disposition and related challenges
5. Source of referral
6. Community service
7. Challenges incurred by the palliative care program
8. Inclusion criteria or trigger
9. Data collection
10. Administration and leadership
11. Culture
12. Program history
13. Day-to-day operation
14. Timely referral
15. Vacancies

The initial code list contained fifteen unique codes that were further refined in Phase 3 by narrowing the coded data into four preliminary themes (Figure 3).

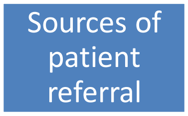
**Preliminary Theme 1**



**Preliminary Theme 2**



**Preliminary Theme 3**



**Preliminary Theme 4**

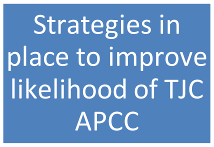


*Figure 3:* Phase 3: Searching for preliminary themes

During Phase 4, preliminary themes were reviewed for internal and external homogeneity, ensuring that each preliminary theme created meaning and definitive distinction between the different preliminary themes. Preliminary themes were also evaluated against the data set as a whole to ensure an accurate representation of the entire set. The outcome of Phase 4 was the identification of two broader themes (Figure 4). Sources of Patient Referral were important, but it did not cohere as a stand-alone theme and was reassigned as a sub-theme under Infrastructure Support in Phase 4. The name of this sub-theme was also changed to interdisciplinary teamwork due to the relationship component demonstrated in the dataset. The preliminary theme of Strategies in Place to Improve the Likelihood of The Joint Commission’s Advanced Palliative Care Certification was moved to Infrastructure Support and was added as the sub-theme of education and general support. These changes represent an important part of the infrastructure that contributed to the viability of the palliative care programs. Phase 5 involved determining if the research questions were answered through identification of the final themes. The determination was made that the two final themes addressed factors and challenges regarding The Joint Commission accreditation of hospital-based palliative care programs. Phase 6 involved writing up of the final report

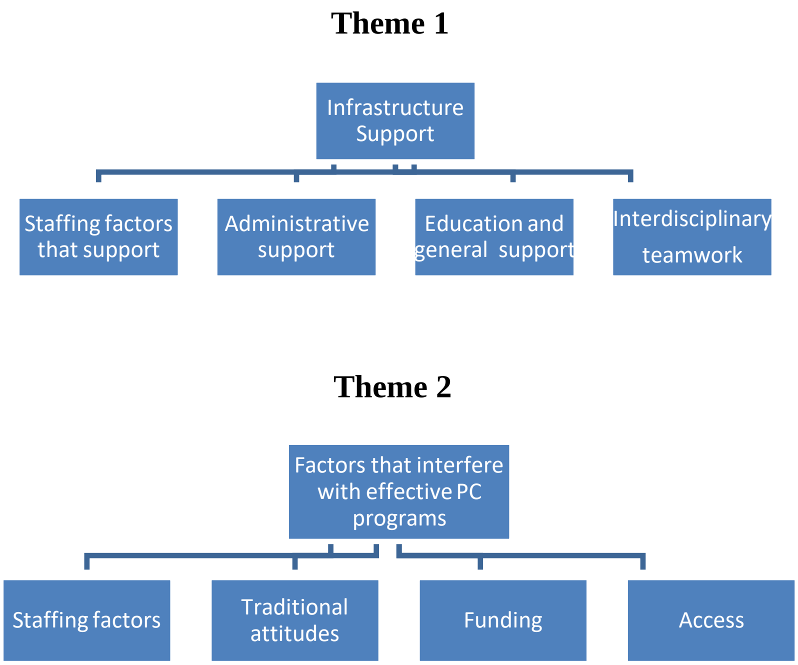


*Figure 4:* Phase 4: Reviewing and refining themes: Final thematic map

## Results

Results are divided into two major areas: a content analysis of responses that directly addressed interview guide questions, and a thematic analysis of responses that were labeled "miscellaneous" and did not directly pertain to the interview guide questions. A total of 32 programs were contacted with 21 programs responding for phone interviews that averaged 52 minutes in length. One to four attempts to contact each program were made. The response rate was 66%.

The title of the person completing the survey varied with the most common being Palliative Care Registered Nurse and Palliative Care Nurse Practitioner. Fifteen of the 21 participants were Registered Nurses and the remaining participants consisting of three social workers, one physician, one medical assistant, and a business support coordinator (Table 3.3). All of the participants completing the survey provided care for patients in the inpatient setting with five having additional outpatient responsibilities such as, outpatient appointments and assessments of patient. The sample as a whole had an average of 8.52 years of experience in palliative care with a range of 1 to 17 years.

Classifying the geographic location in which the palliative care programs operated required a consistent definition of urban and rural. Urban was defined as "…areas of 50,000 or more people" (United States Census Bureau, 2018, para. 1). Rural was defined as, "…all population housing, and territory not included within and urban area" (United States Census Bureau, 2018, para. 2). Some programs were described as urban but served rural areas (n=9). Urban programs represented 28% of the sample (n=6), rural programs were (n=6) 28%, and urban serving rural areas was the largest reported programmatic type at 44% (n=9). Hospital program bed sizes ranged from 29 beds to 619 beds and were organized into four categories: (a) less than 50 (5%), (b) between 50 and 150 (5%), (c) between 151-300 (43%), and (d) 301 and more (47%).

Table 3.3

*Demographics*

| Title of Person Responding to Interview | MD | RN | SW | Unlicensed Assistive Personnel | Region | Years of Experience | Hospital Bed Size |
|---|---|---|---|---|---|---|---|
| Palliative Care Medical Director | 1 | | | | 3 | 13 | 402 |
| Palliative Care Medical Assistant | | | | 1 | 4 | 5 | 318 |
| Palliative Care Program Manager | | 2 | 1 | | 3,4 | 10, 13, 17 | 326, 245, 300 |
| Director of Cancer Center and Hospice Program | | | 1 | | 4 | 9 | 114 |
| Palliative Care Coordinator | | 2 | | | 1, 4 | 12, 12 | 206, 211 |
| Palliative Care RN | | 4 | | | 1, 2, 3 | 1, 6, 7, 8 | 389, 321, 230, 449 |
| Care Management Nurse | | 1 | | | 1 | 13 | 29 |
| Palliative Care Clinical Manager and Inpatient Supportive Care Nurse | | 1 | | | 2 | 11 | 225 |
| Palliative Care Nurse Practitioner | | 3 | | | 2, 3, 4 | 7, 10, 15 | 184, 600, 283 |
| Director of Palliative Care and Hospice | | 2 | | | 3, 4 | 4, 8 | 619, 275 |
| Coordinator of Palliative Care | | 1 | | | 2 | 5 | 391 |
| Business Support Coordinator | | | | 1 | 4 | 3 | 212 |

## Content Analysis of Definitions, Admission Criteria, Mission, Barriers, and Resources

### Program definitions and criteria for palliative care admission.

Content analysis techniques applied to facility definitions revealed uniqueness as well as some commonalities. Seventy-six percent of the respondent answers contained phrases that addressed “symptom management” or “relief from symptoms.” The phrases “appropriate for patients with serious illness” or “providing care for patients with serious illness” occurred in 67% of the data set. The third most common phrase was “pain relief” and this represented 62% of the sample. Forty-three percent of the data set stated that palliative care can be received with curative treatments. Interventions to relieve stress  was noted  in 33% of the individual program’s definitions, and phrases that included “at any stage of illness” and “enhance” or “improve quality of life” were represented in 24% of the palliative care definitions. The remaining words and phrases that occurred less than 20% of the time represented how the programs would address patient and family care such as “offering an extra layer of support” or “providing comprehensive care.” The other terms existing less than 20% of the time were responses to the appropriateness of palliative care options, and these included “at any age,” “for which care is limited,” and “multiple hospital admissions.” Ninety-five percent of the programs had no inclusion criteria for patients to enter their program. One program in the sample had an inclusion criterion of a Glasgow Coma Scale of five or less but stated they try not to turn down any patients requesting services.

**Mission, vision, and program priorities.** The mission and vision of the hospital-based palliative care programs followed the respective parent hospital’s mission and vision with the exception of one program that followed the vision of an outpatient palliative care program that existed within a healthcare organization. “Quality of life” was the most common phrase (76%) noted as specific priorities for the palliative care programs. The words “improve” or “best possible”, occurred in 67% of the sample. Patients and families were mentioned 48% of the time and “symptom management” and “goals” were found in 29% of the respondents. The terms and phrases that were mentioned 10% of the time or less by the palliative care programs focused on individual program priorities and was reflective of the definitions of palliative care used by the hospital-based palliative care programs.

**Barriers to achieving The Joint Commission Advanced Palliative Care Certification.** Participants were asked what they perceived as barriers to achieving The Joint Commission Advanced Palliative Care Certification. The most common reasons were the inability to meet the "seven days a week" requirement or "on-call services" (57%). Staffing, as a barrier, was mentioned 12 times by the participants and represented three different types of barriers: physician recruitment (50%), inadequate staffing design (25%), and waiting on administrative funding (25%). Participants reported that physician recruitment was very difficult, and one position could take years to fill. These positions were often left vacant while one program reported using *locum tenens* to fill their physician vacancies. The respondent reported this was problematic because these temporary workers were not a part of the organization and did not have "buy-in" into the program. An inadequate staffing design represented programs that had only one staff member. In these programs, they often felt that the demand for palliative care could not be met. Even though administration had approved the positions, funding had not been allocated, and, therefore, the positions could not be filled. Ten percent of the program barriers centered around five areas: "significant confusion about what palliative care is," "current discussions about certification were occurring," "funding support was needed by administration," "programs were too small"; and "corporate mergers interfered with the certification process." The remaining five percent of responses focused on various organizational issues that prevented the palliative care programs from moving forward with The Joint Commission's Advanced Palliative Care Certification. Examples of these were: "administration reorganization and staff are unsure what will happen to the program," "the hospital that the program operates is not a Joint Commission accredited hospital," and "not valued by administration." One program stated that their organization is moving from The Joint Commission certification and preparing for a survey from an alternative accrediting organization.

**Resources needed to achieve The Joint Commission Advanced Palliative Care Certification.** Participants were asked what resources they would need to achieve The Joint Commission Advanced Palliative Care Certification. Thirty-three percent stated that they did not feel they had the administrative support needed to achieve The Joint Commission's Advanced Palliative Care Certification. Respondents from 10% of the programs felt that the certification was not necessary. Finally, a small percentage of the programs (5%) included the following reasons they were not currently certified: "certification for The Joint Commission's Advanced Palliative Care Certification was in progress," "certification was not a focus as much as expanding the outpatient division first," and an overall "lack of program growth."

## Thematic Analysis of Miscellaneous Data

From the twenty-one individual interviews, eight sub-themes evolved into two overall themes:  Infrastructure Support and Factors that Interfere with Effective Hospital-Based Palliative Care Program Practice (Figure 4). Staffing factors, administrative support, interdisciplinary teamwork, and education and general support were sub-themes that gave meaning to Infrastructure Support. Factors that Interfere with Effectiveness of palliative care Programs were informed by subthemes of staffing factors, traditional attitudes, funding, and access.

**Infrastructure support.** In this theme, participants reflected mostly on resources that contributed to The Joint Commission's Advanced Palliative Care Certification. The sub-themes included staffing factors, administrative support, education and general support, and interdisciplinary teamwork. Some sources of support did not reflect The Joint Commission's

Advance Palliative Care certification requirements but are worthy of mentioning here due to the fact this information contributed to the viability of the hospital-based palliative care programs. For example, respondents reported that they conducted one on one education sessions with bedside nurses on their respective units to help them understand palliative care. Another example was that four other programs held classes in the communities to assist with advanced care planning and group support. These two examples supported their palliative care programs, but The Joint Commission does not require these activities.

***Staffing factors.*** Data collated into the staffing factors sub-theme demonstrated a wide array of staffing mixes for hospital-based palliative care across the United States. The most commonly represented disciplines were registered nurses, nurse practitioners, and social workers. Physicians that saw patients represented 8 out of 21 programs in the data set. Two programs indicated that all of their staff had certifications in their respective fields, but this was not a consistent practice across all programs.

***Administrative support.*** Administrative support was seen as an important factor in the survival of the individual palliative care programs. The tone of this sub-theme was one of positive relationships and mutual trust in a caring environment. Participants shared patient stories and program data with administration that helped to validate the program's value in the organization. Two respondents reported that the hospital-based palliative care programs were "embedded into the culture of the organization." Other aspects of administrative support addressed having positive relationships and mutual trust with senior administration and using patient stories to keep palliative care programs at the forefront of the organization.

***Interdisciplinary teamwork.*** Interdisciplinary teamwork shows how the programs work within the acute care setting to receive patients and maintain the viability of the individual hospital-based palliative care programs. Participants reported that the majority of their referrals come from hospitalists and ICU intensivists. Multidisciplinary rounds occurred in some programs, but this was not a consistent practice. In many cases, an order was written by the physician for a consult, and the palliative care program admission process was initiated. It is worth noting that a relationship component was discovered in this sub-theme as well. Six respondents stated that they work closely with their hospitalists, social workers, and chaplains and emphasized the importance of maintaining good relationships with them. The passion in the respondents' tone of voice made it clear that the essence of interdisciplinary teamwork is partnering with other disciplines not employed by the hospital-based palliative care program to provide the best possible outcomes for the patient.

***Education and general support.*** Education represents the formal and informal education that hospital-based palliative care programs do for patients, families, and staff. Many of the programs conducted Respecting Choices classes to assist patients and families in advanced care planning. In addition, one palliative care nurse reported, "We do one on one education with bedside nurses as well as nurse interns. The ICU nurses especially reach out and ask questions about ways to help their patients." Another program reported that they offer advanced planning groups for healthcare professionals. General support encompasses groups offered to patients and families as well as home visits made to homebound patients in need. Support group topics can be as varied in topics to include something as specific as a particular form of cancer to something as general as family support. Both aspects of this sub-theme demonstrate a level of caring that enriches the individual hospital-based palliative care programs.

**Factors that interfere with effective hospital-based palliative care program practice.** The second theme explores Factors that Interfere with Effective hospital-based palliative care

Program Practice and therefore hinder the program from moving forward with The Joint Commission’s Advanced Palliative Care Certification. Four sub-themes emerged from this dataset; staffing factors, traditional attitudes, funding, and access.

***Staffing factors.*** Staffing factors had two distinct facets. The first revolved around human resource issues, such as (a) vacancies that are not being filled due to lack of interest in the position, (b) programs consisting of one staff member or no inpatient staff members, and (c) programs that have one staff member but spends about half of their time collecting data. Individual program issues include not enough staff to reach all of the referrals received. “We have 8 ICUs, and I cannot reach all the patients that I need to see.” One RN who was the only staff member for the hospital-based palliative care program stated she is “…currently meeting the needs and wishes of 0.5% of referred patients,” meaning that while more patients are being referred to the program, she can only see 0.5% of the patients referred to the hospital-based palliative care program.

One participant stated:

> I am the only staff in my program and in the first year, senior leadership wanted me to have 130 consults in the first 6 months. I received over 500. I had two physicians that were my support and mentors, but to this day, [the physicians] do not see patients in the hospital for palliative care consults.

The other facet of this sub-theme is maintaining the staff's physical, emotional, and spiritual wellbeing. One respondent stated, “Nurses burn out and leave.” Similar statements were made by two other nurses.

***Traditional attitudes.*** Traditional attitudes encompass the perception that palliative care is interchangeable with hospice. Participants reported that the majority of patients either die in the hospital or go to hospice. One participant stated that “current practice is that referrals are made too late to help the patient and this culture must change.” This perception was noted to adversely impact the referral of patients into hospital-based palliative care programs. Statements were made that encompassed the perception that palliative care is equated with end of life care. Many physicians do not want to refer patients to palliative care, or a hospitalist has a palliative care certification and will attempt to provide palliative care while attending to all of their other duties, so patients do not receive the full benefits of a palliative care program. A respondent stated that their biggest challenge was to have “…buy in support from our older oncologists. If you mention palliative care, they will tell us that you are not talking to our patients about hospice. We have done so much education, but their beliefs have not changed.” Participants reported that continued education of hospital staff and physicians are needed to change the current practice.

***Funding.*** Palliative care is not a revenue generator for hospitals and therefore funding is challenging. One program participant stated, “We try to keep our head in the sand, so administration forgets we have a budget when they are looking for money.” Other programs receive funds from community supporters but have no venue to develop their program. Also reflected in this sub-theme is that administration expresses value for the hospital-based palliative care programs, but funding for the programs to grow is not provided.

***Access.*** Access issues address primarily geographic factors. One program respondent stated there are two palliative care programs within their state and their catchment area includes the state below them: “Access is a huge issue.” While falling more within the realm of staffing factors, access is also limited due to the inability to meet high referral needs.

In summary, each program interviewed held a passion for the patients that they serve. In spite of the multiple challenges faced by program respondents, the implication was clear that the ultimate goal of each program was to do all they could do to positively impact patient care. All programs had factors represented under the themes of Infrastructure Support as well as Factors That Interfere with Effective Palliative Care Program Practices.

## Discussion

Understanding how hospital-based palliative care programs define and conceptualize palliative care and determining what barriers hinder hospital-based palliative care programs from obtaining The Joint Commission's Advanced Palliative Care certification were the goals of this study. Infrastructure Support and Factors That Interfere with Effective Palliative Care Programs were the two main themes that captured study results. The sub-themes that give meaning to Infrastructure Support were staffing factors, interdisciplinary teamwork, administrative support, and education and general support. Only 5 out of the 21 programs interviewed met the minimum staffing standards; this highlights a significant concern that palliative care programs do not meet national staffing recommendations, and the need for skilled providers continues to grow as the United States population ages (Dumanovsky, Rogers, Spargens, Morrison, and Meier, 2015; O'Mahony et al., 2018; Spetz et al., 2016). Even though 76% of the respondents reported inadequate staffing, interdisciplinary teamwork existed to some degree within each program. This data point illustrates how palliative care program staff works together or with hospital staff to meet the needs of patients and families. Teamwork is at the heart of palliative care and the driving force that maintains the programs viability, including receiving referrals from hospitalists and having family meetings to meet patient needs and goals (Ansari & Rassouli, 2018; Klarare, Hagelin, Furst, & Fossum, 2013). During the interview process it was clear that strong teamwork transcends the staffing challenges that the palliative care programs face. Participants' voices took on a passionate tone and the conversation became animated when talking about interdisciplinary teamwork.

The belief by study participants that administrative support along with characteristics of strong leadership are critical to the success of a palliative care program is validated in the literature (Hewison, Sawbridge, & Tooley, 2019; Klarare et al., 2013). These relationships supported the members of the palliative care programs and encouraged them to grow and develop and find innovative ways to serve patients and coworkers. Even though staffing was not always optimal, programs that reported strong interdisciplinary teamwork and administrative support reported positive aspects of their programs (Ali & Terry, 2017; Lin, Ma, Zhang, Li, & Jiang, 2018).

Education for patients, families, and healthcare providers regarding misconceptions about palliative care was provided by many of the hospital-based palliative care programs. This type of education provided by skilled practitioners about the meaning of palliative care can assist in providing clarity (Altaker, Howie-Esquivel, & Cataldo, 2018; Hawley, 2017). The activities conveyed in this sub-theme give meaning to the phrase "an extra layer of support" as stated in The Joint Commission's definition of palliative care (TJC, 2011; TJC, 2015).

Burnout was reported by respondents within the theme of Factors That Interfere with Effective Palliative Care Program Practice. Similar issues resulting from staffing factors such as a lack of workforce, staff turnover, and vacancy rates have also been reported (O'Mahony et al., 2018; Spetz et al., 2016). In addition, a lack of funding for staff often left minimal coverage for some of the palliative care programs. Palliative care programs that had no inpatient staff reported that in these cases, bedside nurses and hospitalists, were required to provide palliative services along with their other duties. High demand for palliative care services without funding for appropriate staffing levels leads to employee burnout (Hall et al., 2016; Klarare et al., 2013). Moreover, the question arises on how burnout impacts the quality of palliative care services and how can accreditation and regulatory policy improve access to high-quality palliative care. The average service penetration of palliative care programs within the United States is 5.0% as reported by the National Palliative Care Registry (National Palliative Care Registry, 2016). The sub-theme of access identified one palliative care program with a service penetration rates as low as 0.5% and reported that this was the largest and most frustrating challenge the program faces. Another respondent reported they were one of two palliative care programs in their state and could not meet patient care needs.

The need for a consistent definition of palliative care, avoiding the notion that palliative care is synonymous with end-of-life care, was reflected in the thematic subtheme of traditional attitudes and is supported by literature (Kennedy et al., 2019; Hawley, 2017; Shockney, 2018). The definitions of the individual programs did not closely follow TJC definition of palliative care but closely aligned with CAPC, NQF and NHPCO by specifically focusing on symptom management and relief from symptoms (76%) (CAPC, 2014; NHPCO, 2015; NQF, 2006). The Joint Commission ascribes to providing an extra layer of support and this was reflected in the dataset 10% of the time. In addition, enhancing or improving quality is part of the TJC and CAPC definition of palliative care, but in individual program definitions occurred only 24% of the time. Consistency in defining palliative care adds to the conceptualization of what high-quality palliative care programs entail. If the foundational component of defining the specialty area is not consistently communicated, then the programs themselves will not be consistent in quality, access, or services. Adherence to minimal standards of palliative care is likely to be more challenging with such diverse program definitions. Program respondents stated that the hospital-based palliative care programs are not effectively utilized because palliative care is equated to end-of-life care by hospital staff and physicians. As a result of these traditional attitudes, palliative care programs report that daily duties mainly include activities such as advanced care planning, discharge disposition, and end-of-life care. Patients can benefit from palliative care services much earlier in their disease trajectory, but, unfortunately, the trend is that patients do not receive palliative care services until they are close to death (Kennedy et al., 2019; Shockney, 2018). Referrals to palliative care should be done once a patient has been diagnosed with a chronic illness, but the misconception that palliative care cannot be received concurrently with curative treatment is cited as the most common reason for late referrals (Kennedy et al., 2019). As long as palliative care is synonymous with end-of-life care and is not a recognized specialty, its role in the acute care environment will be underappreciated and underused.

## Recommendations and Implications

Based on the findings of this study, recommendations for future research should focus on ways to overcome barriers to certification and to adequately educate healthcare providers and consumers. Staffing research can include determining what minimal staffing levels are needed and ways to prevent burnout in palliative care settings since burnout was shown to adversely impact nurse retention. Burnout is also important to study since this is known to impact quality of care rendered (Abbaszadeh, Elmi, Borhani, & Sefidkar, 2017; Liu, Zheng, Liu, & Yu, 2018). Additional research is needed to determine how accreditation and regulatory policy can improve access to high-quality palliative care.

The CAPC lists palliative care programs on their website, but because there are no governmental standards that dictate what minimal requirements must be in place to be called a palliative care program, it is unclear what a program may offer to consumers. This study showed that program conceptualization, staffing, and services varied significantly. Program variances can be misleading to healthcare providers and consumers who are seeking quality care through a palliative care program. Palliative care providers and leaders should identify areas of greatest concern and evaluate the impact of policies to support the development of high-quality hospital-based palliative care programs. Policy actions can include the development of governmental policies to integrate high-quality palliative care services into the acute care setting thereby facilitating timely palliative care referrals. The current palliative care environment requires provisions of adequate human and financial resources to meet the growing demand. Policy and budgeting by governmental agencies and institutions incorporating The Joint Commission's Advanced Palliative Care Certification standards are needed to maintain consistent high-quality palliative care. Federal bill H.R. 1666 (113th), Patient-Centered Quality Care for Life, was introduced in April 2013 with an aim to create a patient-centered quality initiative for seriously ill patients through quality of life education and awareness, workforce training, and palliative-care-focused research (Congress.Gov, 2014). This bill died in Congress January 2, 2015.

The development of regulatory and accreditation standards should place greater emphasis on palliative care education. Because of inconsistent understandings and definitions of palliative care, myths exist. Policy should establish standards that reflect consistent palliative care definitions and scope of practice in medical, nursing, and social work disciplines. Federal bill H.R. 1676 (115th), Palliative Care and Hospice Education and Training Act, was passed July 23, 2018, by the House but never passed by the Senate. The bill was reintroduced January 17, 2019, with no action reported. This bill provides for an increase in the number of faculty teaching palliative care in schools of medicine, nursing, social work, and physician assistant programs. The goal of the bill is to promote education and research and to support the development of faculty careers in academic palliative medicine (Congress.Gov, 2018). This bill does not have provisions for the acute care environment but does address policy to increase the amount of palliative care education received by students in their foundational training.

## Summary

The current study is a descriptive design to determine the barriers experienced by hospital-based palliative care programs in the United States that do not hold The Joint Commission’s Advanced Palliative Care certification. Palliative care is a treatment modality that can improve the quality of life for patients living with complex conditions and optimizes quality of life by anticipating, preventing, and treating suffering (National Consensus Project for Quality Palliative Care, 2013; National Hospices and Palliative Care Organization, 2015; National Quality Forum, 2006; Oncology Nursing Society, 2015). Significant barriers to palliative care access and quality service delivery within the United States healthcare continue to exist: (a) lack of policies establishing high-quality palliative care; (b) inconsistent conceptions and definitions of palliative care; (c) insufficient palliative care education for healthcare providers, healthcare consumers, and communities at large; and (d) lack of organized programs and services to deliver palliative care (Connor, 2014; Hui et al., 2013; Van Mechelen et al., 2012). Access to high-quality palliative care is not consistent or possible in many areas of the United States, and a gap exists in understanding the barriers that preclude programs from obtaining The Joint Commission’s certification (Gadoud et al., 2013; Goldsmith et al., 2008; Meier & Morrison, 2015; Riffin, 2015). The Trajectory of Quality Palliative Care Model can serve as a framework for this and related studies. The model serves as a framework to demonstrate how high-quality hospital-based palliative care programs in the US are congruent with (a) regulatory standards, (b) evidence-based research, (c) state and national policy, and (d) reimbursement requirements. Findings from this study contribute to scientific literature and provide a basis from which future actions can be taken to address barriers to obtaining The Joint Commission’s Advanced Palliative Care certification and to optimize quality of life for persons who qualify for palliative care. In addition, policy implications are identified related to education and research in palliative care as well as workforce training, staffing standards, and financial resources to support high-quality palliative care programs.

# References

Abbaszadeh, A., Elmi, A., Borhani, F., & Sefidkar, R. (2017). The relationship between “compassion fatigue” and “burnout” among nurses. *Annals of Tropical Medicine and Public Health, 10*, 869-873. DOI: 10.4103/ATMPH.ATMPH_234_17

Abyad, A. (1993). Palliative care: The future. *The American Journal of Hospice & Palliative Care*, 23-28. Retrieved from www.ajhpm.sagepub.com

Addington- Hall, J., Fakhoury, W., & McCarthy, M. (1998). Specialist palliative care in nonmalignant disease. *Palliative Medicine. 12,* 417-427. Retrieved from www.pmj.sagepub.com

Aldridge, M., Hasselaar, J., Garralda, E., Eerden, M., Stevenson, D., Kendrick, K., & Meier, D. (2016). Education, implementation, and policy barriers to greater integration of palliative care: A literature review. *Palliative Medicine*, *30*(3), 224-239. http://dx.doi.org/10.1177/0269216315606645

Altaker, K., Howie-Esquivel, J., & Cataldo, J. (2018). Relationships among palliative care, ethical climate, empowerment, and moral distress in intensive care unit nurses. *American Journal of Critical Care, 27*(4), 295-302. http://doi.org/10.4037/ajcc2018252

American Academy of Hospice and Palliative Medicine (AAHPM). (2003). What is hospice and palliative care. Retrieved from http://www.aahpm.org

American Hospital Association (AHA). (2012). *Palliative care services: Solutions for better patient care and today's healthcare delivery challenges.* (Signature Leadership Series). Chicago IL: Hospitals in Pursuit of Excellence.

American Hospital Association. (2017). *AHA hospital statistics: A comprehensive reference for analysis and comparison of hospital trend.* Chicago IL; Health Forum.

Ansari, M., & Rassouli, M. (2018). Team approach to palliative care: A narrative review. *Basic & Clinical Cancer Research.*, *10,* (1), 42-48. Retrieved from http://bccr.tums.ac.ir/index.php/bccrj/article/view/254

Arthur, J., & Bruera, E. (2013). Supportive and palliative care: A poorly understood science for the perioperative clinical. *Best Practice & Research Clinical Anesthesiology*, *27*, 563-573. http://dx.doi.org/10.1016/j.bpa.2013.10.006

Bakitas, M., Astin, M., Ceronsky, L., Clifford, K., Dionne-Odom, N., Emanuel, L., & Smith, T. (2015, October). Systematic review of palliative care in the rural setting. *Cancer Control*, *22*, 450-464. Retrieved from https://moffitt.org/publications/cancer-control-journal

Bergdahl, E., Benzein, E., Ternestedt, B., Elmberger, E., & Andershed, B. (2013). Co-creating possibilities for patients in palliative care to reach vital goals: A multiple case study of home-care nurse encounters. *Nursing Inquiry*, *20*, 341-351. http://dx.doi.org/10.111/nin.12022

Bergeron, C., Friedman, D., Sisson, D., Tanner, A., Kornegay, V. Owens, O.,…Patterson, L. (2016). Awareness, perceptions, and communications needs about the Affordable Care Act across the life span. *American Journal of Health Education, 47*(2), 108-116. https://doi.org/10.1080/19325037.2015.1133341

Bhatnagar, S., & Gupta, M. (2015, Jan-Apr). Future of palliative medicine. *Indian Journal of Palliative Care*, *21*(1), 95-104. http://dx.doi.org/10.4103/0973-1075.150201

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3,* 77-101. http://dx.doi.org/10.1191/1478088706qp063oa

Brown, M., & Vaughan, C. (2013). Care at the end of life: How policy and law support practice. *British Journal of Nursing, 22,* 580583. Retrieved from info.britishjournalofnursing.com

Centeno, C., Lynch, T., Garralda, E., Carrasco, J., Guillen-Grima, F., & Clark, D. (2016). Coverage and development of specialist palliative care services across the World Health Organization European region (2001-2012): Results from a European association for palliative care task force survey of 53 countries. *Palliative Medicine*, *30*, 351-362. http://dx.doi.org/10.1177/0269216315598671

Center for Medicare Advocacy (CMA). (2015). Tinkering with hospice: The Medicare care choices model. Retrieved from www.medicareadvocacy.org

Center to Advance Palliative Care (CAPC). (2014). About palliative care. Retrieved from www.capc.org/about/palliative-care/

Center to Advance Palliative Care (CAPC). (2017). National palliative care registry. Retrieved from https://registry.capc.org

Connor, S. (2008). Development of hospice and palliative care in the United States. *Omega: Journal of Death and Dying*, *56*(1), 89-99. Retrieved from http://baywood.com

Connor, S. (2014). The global atlas of palliative care at the end of life: An advocacy tool. *European Journal of Palliative Care*, *21*, 180-183. Retrieved from www.ejpc.eu.com

Covinsky, K. (2010, November 29). The legacy of SUPPORT: 15 years later. Retrieved from http://www.geripal.org/2010/11/legacy-of-support-15-years-later.html

Cox, C. E., & Curtis, J. R. (2016, February 1). Using technology to create a more humanistic approach to integrating palliative care into the intensive care unit. *American Journal of Respiratory and Critical Care Medicine*, *193*, 242-250. http://dx.doi.org/10.1164/rccm.201508-1628CP

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, California: Sage Publications.

Davis, M., Strasser, F., Cherny, N., & Levan, N. (2015). MASCC/ESMO/EAPC survey of palliative programs. *Support Care Cancer*, *23*, 1951-1968. http://dx.doi.org/101007/s00520-014-2543-2

Davis, M. P., Temel, J. S., Balboni, T., & Glare, P. (2015). A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illness. *Annals of Palliative Medicine, 4*, 99-121. http://dx.doi.org/10.3978/j.issn.2224-5820.2015.04.04

Desbiens, J., Gagnon, J., & Fillion, L. (2012). Development of a shared theory in palliative care to enhance nursing competence. *Journal of Advanced Nursing, 68*(9)2113-2124. doi:10.1111/j.1365-2648.2011.05917.x

Dobrina, R., Tenze, M., & Palese, A. (2014). An overview of hospice and palliative care nursing models and theories. *International Journal of Palliative Nursing, 20*(2), 75-81. Retrieved from www.ijpn.co.uk

Downing, J., Batuli, M., Kivumbi, G., Kabahweza, J., Grant, L., Murray, S., Leng, M. (2016). A palliative care link nurse programme in Mulago hospital, Uganda: An evaluation using mixed methods. *BMC Palliative Care, 15*(40), 1-13. http://dx.doi.org/10.1186/s12904-016-0115-6

Drisko J., & Maschi, T. (2015). Content analysis. Oxford Scholarship Online. http://dx.doi.org/10.1093/acprof:oso/9780190215491.001.0001

Dumanovsky, T., Rogers, M., Spragens, L., Morrison S., & Meier, D. (2015). Impact of staffing on access to palliative care in U.S. hospitals. *Journal of Palliative Medicine, 18*(12), 998-999. http://dx.doi.org/10.1089/jpm.2015.0436

Dumanovsky, T., Augustin, R., Rogers, M., Lettang, K., Meier, D., & Morrison, S. (2016). The growth of palliative care in US hospitals: A status report. *Journal of Palliative Medicine*, *19*, 8-15. http://dx.doi.org/10.1089/jpm.2015.0351

Enguidanos, S., Housen, P., Penido, M., Mejia, B., & Miller, J. (2014). Family members' perceptions of inpatient palliative care consult services: A qualitative study. *Palliative Medicine*, *28*, 42-48. http://dx.doi.org/10.1177/0269216313491620

Epstein, A., & Morrison, R. (2012). Palliative oncology: Identity progress and the path ahead. *Annals of Oncology*, *23*, iii43-iii48. http://dx.doi.org/10.1093/annonc/mds087

Evans, N, Menaca, A, Andrew, E, Koffman, J, Harding, R, Higginson, I, Pool, R., & Gysels, M. (2012). Systematic review of the primary research on minority ethnic groups and end-of-life care from the United Kingdom. *Journal of Pain and Symptom Management 43*(2), 261-286. http://doi.org/10.1016/j.jpainsymman2011.04.012

Foley, K. (2000). Dismantling the barriers: Providing palliative and pain care. *The Journal of the American Medical Association, 283*(1), April 12, 2014.

Gadoud, A., Jenkins, S., & Hogg, K. (2013). Palliative care for people with heart failure: Summary of current evidence and future direction. *Palliative Medicine*, *27*, 822-828. http://dx.doi.org/10.1177/0269216313494960

Gelfman, L., Kalman, J., & Goldstein, N. (2014). Engaging heart failure clinicians to increase palliative care referrals: Overcoming barriers improving techniques. *Journal of Palliative Medicine*, *17*, 753-760. http://dx.doi.org/10.1089/jpm.2013.0675

Get Palliative Care. (2018). Palliative Care Provider Directory. Retrieved from https://getpalliativecare.org/provider-directory/

Glass, A., & Burgess, M. (2011). A statewide status report on hospital-based palliative care program. *Journal of Palliative Medicine*, *14*, 809-809. http://dx.doi.org/10.1089/jpm.2010.0489

Goldsmith, B., Dietrich, J., Du, Q., & Morrison, S. (2008). Variability in access to hospital palliative care in the United States. *Journal of Palliative Medicine*, *11*, 1094-1102. http://dx.doi.org/10.1089/jpm.2008.0053

Gomes, B., Calanzani, N., & Higginson, I. (2014, March 12). Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers. *Journal of the American Medical Association*, *311*, 1060-1061. Retrieved from www.jama.org

Gordon, D., Berry, P., & Dahl, J. (2000). JCAHO's new focus on pain: Implications for hospice and palliative nurses. *Journal of Hospice and Palliative Nursing*, *2*(4), 135-142.

Congress.Gov. (2014). Federal Bill H.R. 1666 (113th). Retrieved from https://www.congress.gov/bill/113th-congress/house-bill/1666/all-actions?overview=closed

Congress.Gov. (2018). Federal Bill H.R. 1676 (115th). Retrieved from https://www.congress.gov/bill/115th-congress/house-bill/1676

Groh, G., Vyhnalek, B., Feddersen, B., Fuhrer, M., & Borasio, G. (2013). Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers. *Journal of Palliative Medicine*, *16*, 848-856. http://dx.doi.org/10.1089/jpm.2012.0491

Hall, K. L., Rafalson, L., Mariano, K., & Michalek, A. (2016). Evaluation of hospital-based palliative care programs. *American Journal of Hospice*, *33*(1), 77-83. http://dx.doi.org/10.1177/1049909114553460

Hawley, P. (2017). Barriers to access to palliative care. *Palliative Care: Research and Treatment*, 1-6. https://doi.org/10/1177/1178224216688887

Hayle, C., Coventry, P., Green, S., & Caress, A. (2013). Understanding the experience of patients with chronic obstructive pulmonary disease who access specialist palliative care: A qualitative study. *Palliative Medicine*, *27*, 861-868. http://dx.doi.org/10.1177/0269216313486719

Hewison, A., Sawbridge, Y., & Tooley L. (2019). Compassionate leadership in palliative and end-of-life care: A focus group study. *Leadership Health Service*, *32*(2), 264-279. http://dx.doi.org/10.1108/LHS-09-2018-0044

Hui, D., Cruz, M., Mori, M., Parson, H., Kwon, J., Torres-Vigil, I., & Bruera, E. (2013). Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks. *Support Care Cancer, 21*, 659-685. doi:10.1007/s00520-012-1564-y

Hospice and Palliative Nurses Association (HPNA). (2014). Palliative nursing an essential resource for hospice and palliative nurses. Retrieved from www.hpna.org

Johnson, L. A., Gorman, C., Morse, R., Firth, M., & Rushbrooke, S. (2013). Do communication skills training make a difference to patients' experiences of consultation in oncology and palliative services? *European Journal of Cancer Care*, *22*, 202-209. http://dx.doi.org/10.111/ecc.12014

Klarare, A., Hagelin, C., Furst, C., & Fossum, B. (2013). Team interactions I specialized palliative care teams: A qualitative study. *Journal of Palliative Medicine, 16*(9), 1062-1069. http://dx.doi.org/10.1089/jpm.2012.0622

Kamal, A., Hanson, L., Casarett, D., Dy, S., Pantilat, S., Lupu, D., & Abernethy, A. (2015, February). The quality imperative for palliative care. *Journal of Pain and Symptom Management, 49*, 243-253. http://dx.doi.org/10.1016/j.jpainsymman.2014.06.008

Karkada, S., Nayak, B., & Malathi, N.A. (2011). Awareness of palliative care among diploma nursing students. *Indian Journal of Palliative Care, 17*(1), 20-23. doi: 10.4103/0973-1075.78445

Kassa, H., Murugan, R., Zewdu, F., Hailu, M., & Woldeyohannes, D. (2014). Assessment of knowledge, attitude, practice, and associated factors towards palliative care among nurses working in selected hospitals, Addis Ababa, Ethiopia. *BioMed Central Palliative Care, 13*(6), doi: 10.1186/1472-684X-13-6

Kennedy, R., Abdullah, N., Bhadra, R., Bonsu, N., Fayezizadeh, F., & Ickes, H. (2019). Barriers to effective use of palliative care services in the acute care setting with emphasis on terminal noncancer diseases. *Indian Journal of Palliative Care, 25,* 203-209. doi: 10.4103/IJPC_201_18

Klinger, C., Howell, D., Zakus, D., & Deber, R. (2014). Barriers and facilitators to care for the terminally ill: A cross-country case comparison study of Canada England, Germany and the United States. *Palliative Medicine, 28*(2), 111-120. http:dx.doi.org/10.1177.0269216313493342

Koffman, J.,& Higginson, I. (2001). Accounts of carers' satisfaction with healthcare at the end of life: A comparison of first generation black Caribbean's and white patients with advanced disease. *Palliative Medicine, 15,* 337-345. Retrieved from jourmals.sagepub.com

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice, 24*(1), 120-124. https://doi.org/10.1080/13814788.2017.1375092

Larson, L. (2001). The humanity of palliative care. *Trustee, May*, 14-17. Retrieved from eds.a.ebscohost.com/eds/p*dfviewer/pdfviewer?vid=4&sid=44d57*a6-278c-45eb-b57f-5507914c8c3e%40sdc-v-sessmgr03

Lin, W., Ma, J., Zhang, Q., Li, J., & Jiang, F. (2018). How is benevolent leadership linked to employee creativity? The mediating role of leader-member exchange and moderating role of power distance orientation. *Journal of Business Ethics*, *152*, 1099-1115. https://doi.org/10.1007/s10551-016-3314-4

Liu, J., Zheng, J., Liu, K., & You, L. (2018). Relationship between work environments nurse outcomes and quality of care in ICUs. *Journal of Nursing Care Quality, 34*(3), 250-255. doi: 10.1097/NCQ.0000000000000374

Lupu, D., Ivanko, B., Insana, F., White, P., & Arnold, R. (2014). Hospice innovation impediments: Can halfway efforts tame the terrible costs? *Journal of Palliative Medicine, 17,* 1088-1090. http://dx.doi.org/10.1089/jpm.2014.0268

Luyirika, E., Namisango, E., Garanganga, E., Monjane, L., Ginindza, N., Madonsela, G., & Kiyange, F. (2016). Best practice in developing a national palliative care policy in resource limited settings: Lessons from five African countries. *ecancermedicalscience, 10*(652), 1-11. http://dx.doi.org/10.3332/ecancer.2016.652

Mahon, M., & McAuley, W. (2010). Oncology nurses' personal understandings about palliative care. *Oncology Nursing Forum*, *37*(3), 141-150. doi:10.1188/10.ONF.E141-E150

McAteer, R., & Wellberry, C. (2013). Palliative care: Benefits, barriers, and best practices. *American Family Physician, 88*(12), 811-813. Retrieved from www.aafp.org/afp

Meier, D., & Morrison, S. (2015, October 9). Palliative care: Continued progress but gaps remain. *Health Affairs Blog*. Retrieved from http://healthaffairs.org

Morrison, R. S. (2013, June). Models of palliative care delivery in the United States. *Current opinion in supportive palliative care*, *7,* 201-206. http://dx.doi.org/10.1097/SPC.0b013e32836103e5

Morrison, S., Dietrich, J., Ladwig, S., Quill, T., Sacco, J., Tangeman, J., & Meier, D. (2011). Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Affairs, 30*(3), 454-463. doi:10.1377/hlthaff.2010.0929

Morrison, R., & Meier, D. (2015). America's care of serious illness. Retrieved from www.npcrc.org

Murray, M. (2007). Crossing over: Transforming palliative care nursing services for the 21st century. *International Journal of Palliative Care Nursing*, *13*, 366-376. Retrieved from www.ijpn.co.uk

National Consensus Project (NCP). (2009). *Clinical practice guidelines for quality palliative care.* (Clinical Practice Guidelines No. 978-1-934654-11-8). Pittsburg, PA: National Consensus Project.

National Consensus Project for Quality Palliative Care (NCPQPC). (2013). Clinical practice guidelines for quality palliative care. Retrieved September 16, 2016, from www.nationalconsensusproject.org

National Council for Palliative Care (NCPC). (2015). Palliative care explained. Retrieved from www.ncpc.org

National Hospice and Palliative Care Organization (NHPCO). (2015). An explanation of palliative care. Retrieved from www.nhpco.org

National Palliative Care Registry. (2015). State Reports. Retrieved from www.registry.capc.org

National Quality Forum (NQF). (2006). *A national framework and preferred practices for palliative and hospice care.* (Consensus Report No. 1-933875-06-2). Washington, DC: National Quality Forum.

Office of the Legislative Counsel. (2010). Compilation of patient protection and affordable care act. Retrieved from www.senate.gov

O'Mahony, S., Levine, S., Baron, A., Johnson, T., Ansari, A., Leyva, I., Marschke, M., Szmuilowicz, E., & Deamant, C. (2018). Palliative workforce development and a regional training program. *American Journal of Hospice & Palliative Medicine, 35*(1), 138-143. http://dx.doi.org/10.1177/104990911668546

Oncology Nursing Society (ONS). (2015, January 1). Position statement on palliative care. *Oncology Nursing Forum*, *42*, 11. Retrieved from www.ons.org

Pavlish, C., & Ceronsky, L. (2009). Oncology nurses' perceptions of nursing roles and professional attributes in palliative care. *Clinical Journal of Oncology Nursing, 13*(4), 404-412. doi:10.1188/09.CJON.404-412

Peters, K., Mueller, B., Stoller, N., & Gupta, S. (2009). Structure-process-outcome quality measures. *Encyclopedia of Health Services Research.* http://dx.doi.org/10.4135/9781412971942.n378

Pfister, D., Markett, S., Muller, M., Muller, S., Rolke, R., Kern, M., & Radbrunch, L. (2013). German nursing home professionals' knowledge and specific self-efficacy related to palliative care. *Journal of Palliative Medicine*, *16*, 794-798. http://dx.doi.org/10.1089/jpm.2012.0586

Pillemer, K., Chen, E., Riffin, C., Prigerson, H., Schultz, L., & Reid, M. C. (2015). Practice-based research priorities for palliative care: Results from a research-to-practice consensus workshop. *American Journal of Public Health*, *105*, 2237-2244. http://dx.doi.org/10.2105/AJPH.2015.302675

Pringle, J., Johnston, B., & Buchanan, D. (2015). Dignity and patient-centered care for people with palliative care needs in the acute hospital setting: A systematic review. *Palliative Medicine*, *29*, 675-694. http://dx.doi.org/10.1177/0269216315575681

Qadire, M., & Khalaileh, M. (2014). Jordanian nurses knowledge and attitude regarding pain management. *Pain Management Nursing, 15*(1), 220-228. Http://dx.doi.ord/10.1016/j.pmn.2012.08.006

Reed, S. (2010). A unitary-caring conceptual model for advanced practice nursing in palliative care. *Holistic Nursing Practice*, *24*(1), 23-24. Retrieved from www.journals.sagepub.com

Richfield, E., Jones, E., & Alty, J. (2013). Palliative care for Parkinson's disease: A summary of the evidence and future directions. *Palliative Medicine*, *27*(9), 805-810. doi: 10.1177/0269216313495287

Riffin, C., Pillemer, K., Chen, E., Washington, M., Adelman, R., & Reid, M. (2015, January). Identifying key research priorities for future palliative care research using an innovative analytic approach. *American Journal of Public Health*, *105*, e15-e21. http://dx.doi.org/10.2105/AJPH.2014.302282

Robinson, J., Gott, M., & Ingleton, C. (2014). Patient and family experiences of palliative care in the hospital: What do we know? An integrative review. *Palliative Medicine*, *28*, 18-33. http://dx.doi.org/10.1177/0269216313487568

Schenker, Y., & Arnold, R. (2015, October 20). The next era of palliative care. *Journal of the American Medical Association, 314*, 1565-1566. Retrieved from www.JAMA.com

Shockney, L. D. (2018). The value of palliative care early in the treatment process. *Journal of Oncology, 9*, 20-23. Retrieved from jons-online.com

Spetz, J., Dudley, N., Trupin,, L., Rogers, M., Meier, D., & Dumanovsky, T. (2016). *Health Affairs; Chevy Chase, 35*(9), 1690-1697. http://dx.doi.org/10.1377/hlthaff.2016.0113

Sund, T., Iwarsson, S., & Brandt, A. (2015). The relationship between key elements of Donabedian's conceptual model within the field of assistive technology. *Assistive Technology, 271,* 485-490. http://dx.doi.org/10.3233/978-1-61499-566-1-485

The Joint Commission (TJC). (2015). 2015-2016 palliative care certification manual. Retrieved from www.jointcommission.org

The Joint Commission (TJC). (2011). Joint commission certification for palliative care. Retrieved from www.jointcommission.org

The Joint Commission (TJC). (2017). Disease-specific care advanced certification program. Retrieved from www.jointcommission.org/facts_about_palliative_care/

United States Census Bureau. (2015). Census regions and divisions of the United States. Retrieved from https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf

United States Census Bureau. (2018). Geography Program. Retrieved from https://census.gov/programs-surveys/geography/guidance/geo-areas/urban-rural.html

United States Department of Health & Human Services. (2015). CMS announces Medicare care choices model awards. Retrieved from www.hhs.gov

Van Mechelen, W., Aertgeerts, B., Ceulaer, K., Thoonsen, B., Vermenhoven, F., Rijswijk, E., & Lepeleire, J. (2012). Defining the palliative care patient: A systematic review. *Palliative Medicine, 27*(3), 197-208. doi: 10.1177/0269216311435268

Ventura, A., Burney, S., Brooker, J., Fletcher, J., & Ricciardello, L. (2014). Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers. *Palliative Medicine*, *28,* 391-404. http://dx.doi.org/10.1177/0269216313511141

World Health Organization (WHO). (2009). Definition of palliative care. Retrieved from http://www.who.int/cancer/palliative/definition/en/

Worldwide Palliative Care Alliance. (2014). Global atlas of palliative care. Retrieve from www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf.

Wysham, N., & Kamal, A. (2016, May). Integrating palliative care in the intensive care unit. *Annals of the American Thoracic Society*, *13*, 595-597. http://dx.doi.org/10.1513/AnnalsATS.201601-061ED

# Chapter 4

## Summary and Recommendations

The program of research presented in this portfolio began with an initial interest in palliative care in the hospital setting. It was noted that healthcare providers in the clinical setting referred to palliative care as a set of treatments that were appropriate at the end-of-life. This observation spurred an exploration into the literature related to healthcare providers' perceptions of palliative care. Results from the literature supported the observation that in the clinical setting palliative care is perceived to be an intervention that is appropriate at the end-of-life. An additional finding was that there was confusion and misconceptions about the definition of palliative care (Silva, Viana, & Lima, 2018; Tasseff, Tavernier, Watkins, & Neill, 2018). To obtain clarity and understanding of the meaning of palliative care, an evolutionary concept analysis was conducted and reported in the first manuscript titled, *Palliative Care; An Evolutionary Concept Analysis.* Given the changes of palliative over time, six primary activities of Rodgers' (2000) evolutionary method of concept analysis was used to gain a deeper understanding of the concept of palliative care. From this analysis, palliative care was found to be frequently confused with hospice care by healthcare providers and consumers. A standardized definition of palliative care is needed to clearly delineate the term and refine the application of the term in the clinical setting. Additionally, healthcare consumers misinterpret palliative care as a treatment modality at end of life. This misnomer creates a hesitancy to obtain services and can lead to decreased quality of life and premature death in patients who could benefit from palliative care. More research on the perceptions of healthcare consumers related to palliative care must be done. Due to the misconceptions on the part of healthcare providers and consumers, more research is also needed on how palliative care services are actualized in the hospital setting.

The next step in this program of research included identification of the definitions of palliative care by various healthcare organizations (Appendix A), comparing palliative care standards for care in the United States (Appendix B), and a comparison of current palliative care theories (Appendix C). The results of the definition compilation, comparison of standards, and the concept analysis reported in Chapter two led to the development of the Trajectory of Quality Palliative Care Model (Figure 1)

*Hospital-Based Palliative Care Programs: Perspectives Regarding Conceptualization and Accreditation,* contained in Chapter three, used the Trajectory of Quality Palliative Care Model to guide original research. The descriptive study described focused on how programs without The Joint Commission's Advanced Palliative Care Certification defined and conceptualized palliative care. The research also identified perceived barriers experienced by these programs in obtaining the Advanced Palliative Care Certification. Findings from this study indicate that the definitions of palliative care followed by the programs that participated in the study were not consistent, but they did follow components from national palliative care organizations. In addition, the study identified perceived barriers to achieving The Joint Commission's Advanced Palliative Care certification including (a) not meeting the seven-days-per-week and on-call criteria, (b) recruitment and retention of staff, (c) finding funding necessary to reach minimum staffing standards, and (d) hospital staff and consumer misunderstanding about palliative care.

Even though programs in this study were listed on the National Palliative Care Registry program conceptualization, staffing patterns and services varied significantly. Recommendations for further research based on study findings include identifying ways to overcome barriers to certification, adequate education for healthcare consumers and providers, and identifying minimum staffing levels that support the delivery of high-quality palliative care. Additional research is needed to determine how healthcare policy can improve access to high quality palliative care.

Policy implications from this study include integration of high-quality palliative care into the acute care setting in an effort to address access and timeliness of referral. Also, healthcare professionals need to create policies that address provisions for adequate human and financial resources to meet the growing demand for palliative care services. Additionally, more education and research in palliative care is needed as well as workforce training. Finally, governmental policy should establish standards that reflect consistent palliative care definitions and a shared scope of practice within healthcare disciplines.

A significant strength of this study is its ability to address a critical gap in understanding why more palliative care programs in the United States do not hold The Joint Commission Advanced Palliative Care certification. This information will provide regulatory agencies such as the Center to Advance Palliative Care and The Joint Commission, as well as legislators and policymakers, a more accurate picture of why hospital-based palliative care programs do not meet national standards for high-quality palliative care. Another strength is the stratification of sample selection throughout the United States. Limitations of this research study include: (a) some PC program respondents were reticent to discuss their program in-depth, and therefore some important information could have been missed, (b) program respondents to the interviews differed in disciplines, so perspectives regarding the interview guide questions varied as well and represented only the viewpoint of that one person and not necessarily the viewpoint of persons involved in the respective palliative care programs. All participants interviewed were active in direct patient care and could have been subject to self-report bias.

Palliative care is a treatment modality that reduces symptom burden, improves quality of life, and prevents suffering for people living with life-limiting conditions (Bakitas et al, 2015; Davis, Strasser, Cherny, & Levan 2015). Evidence from this study provides a basis from which further actions can be taken to address barriers to obtaining The Joint Commission’s Advanced Palliative Care Certification. Policy implications identified by this study could improve referrals to and administration of palliative care, patient and professional understanding of palliative care, and the appropriate funding and staffing needed to assist patients for whom palliative care is the best form of treatment.

# References

Bakitas, M., Astin, M., Ceronsky, L., Clifford, K., Dionne-Odom, N., Emanuel, L., Smith, T. (2015, October). Systematic review of palliative care in the rural setting. *Cancer Control, 22,* 450-464. Retrieved from https://moffitt.org/publications/cancer-control-journal

Bhatnagar, S., & Gupta, M. (2015, Jan-Apr). Future of palliative medicine. *Indian Journal of Palliative Care*, *21*(1), 95-104. http://dx.doi.org/10.4103/0973-1075.150201

Connor, S. (2014). The global atlas of palliative care at the end of life: An advocacy tool. *European Journal of Palliative Care*, *21,* 180-183. Retrieved from www.ejpc.eu.com

Davis, M., Strasser, F., Cherny, N., & Levan, N. (2015). MASCC/ESMO/EAPC survey of palliative programs. *Support Care Cancer*, *23*, 1951-1968. http://dx.doi.org/101007/s00520-014-2543-2

De Nardi, M., French, E., Jones, J., & McCauley, J. (2016). Medical spending of the US elderly. *Fiscal Studies, 37,* 717-747. Retrieved from https://www.ifs.org

Hui, D., Cruz, M., Mori, M., Parson, H., Kwon, J., Torres-Vigil, I., & Bruera, E. (2013). Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks. *Support Care Cancer, 21*, 659-685. doi:10.1007/s00520-012-1564-y

Kamal, A., Hanson, L., Casarett, D., Dy, S., Pantilat, S., Lupu, D., & Abernethy, A. (2015, February). The quality imperative for palliative care. *Journal of Pain and Symptom Management*, *49,* 243-253. http://dx.doi.org/10.1016/j.jpainsymman.2014.06.008

Khandelwal, N., Benkeser, D., Coe, N. Engelberg, R., Teno, J., & Curtis, J. (2016). Patterns of cost for patients dying in the intensive care unit and implications for cost savings of palliative care interventions. *Journal of Palliative Medicine, 19*(11), 1171-1187. http://dx.doi.org/10.1089/jpm.2016.0133

McAteer, R., & Wellberry, C. (2013). Palliative care: Benefits, barriers, and best practices. *American Family Physician, 88*(12), 811-813. Retrieved from www.aafp.org/afp

McCarthy, I., Robinson, C., Huq, S., Philastre, M., & Fine, R. (2015). Cost savings from palliative care teams and guidance for a financially viable palliative care program. *Health Research and Educational Trust, 50*(1), 217-236. https://dx.doi.org/10.1111/1475-6773.12203

McGrath, L., Foote, D., Frith, K., & Hill, M. (2013, August). Cost effectiveness of a palliative care program in a rural community hospital. *Nursing Economics, 31*(4), 176-183. Retrieved from www.nursingeconomics.net

Morrison, R., & Meier, D. (2015). America's care of serious illness. Retrieved from www.npcrc.org

National Palliative Care Registry. (2015). State Reports. Retrieved from www.registry.capc.org

National Quality Forum (NQF). (2006). *A national framework and preferred practices for palliative and hospice care.* (Consensus Report No. 1-933875-06-2). Washington, DC: National Quality Forum.

Riffin, C., Pillemer, K., Chen, E., Washington, M., Adelman, R., & Reid, M. (2015, January). Identifying key research priorities for future palliative care research using an innovative analytic approach. *American Journal of Public Health, 105*, e15-e21. http://dx.doi.org/10.2105/AJPH.2014.302282

Rodgers, B. L. (1989). Concepts, analysis and the development of nursing knowledge: The evolutionary cycle. *Journal of Advanced Nursing*, *14,* 33-335. Retrieved from https://onlinelibrary.wiley.com

Rodgers, B. L. (2000). *Concept development in nursing.* Philadelphia: Saunders.

Silva, H., Viana, G., & Lima, A. (2018). Interventions in palliative care: Knowledge and perception of nurses. *Journal of Nursing UFPE*, *12*(5), 1325-1330. https://doi.org/10.5205/1981-8963-v12i05a22653p1325-1330-2018

Tasseff, T., Tavernier, S., Watkins, P., & Neill, K. (2018). Exploring perceptions of palliative care among rural dwelling providers, nurses, and adults using a convergent parallel design. *Online Journal of Rural Nursing & Healthcare, 18*(2), 152-188. https://doi.org/10.14574/ojrnhc.v18i2.527

Van Mechelen, W., Aertgeerts, B., Ceulaer, K., Thoonsen, B., Vermenhoven, F., Rijswijk, E., & Lepeleire, J. (2012). Defining the palliative care patient: A systematic review. *Palliative Medicine, 27*(3), 197-208. doi:10.1177/0269216311435268

Worldwide Palliative Care Alliance. (2014). Global atlas of palliative care. Retrieve from www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf.

## Appendix A. Definitions of Palliative Care

| **Organization** | **Definition** | **Key Terms** |
|---|---|---|
| World Health Organization | Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with a 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. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organization, 2009). | • Palliative:<br>• Life threatening-illness:<br>• Relief of suffering:<br>• Support:<br>• Bereavement support:<br>• Conjunction with other therapies |
| American Academy of Hospice and Palliative Medicine | Palliative care is comprehensive, specialized care provided by an interdisciplinary team to patients and families living with a life-threatening or severe advanced illness expected to progress toward dying and where care is particularly focused on alleviating suffering and promoting quality of life. Major concerns are pain and symptom management, information sharing and advanced care planning, psychosocial and spiritual support, and coordination of care (2003) | • Palliative:<br>• Life-threatening or severe advanced illness:<br>• Symptom management |
| Center to Advance Palliative Care | Palliative care, and the medical sub-specialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment (2014). | • Palliative:<br>• Serious illness:<br>• Relief from symptoms:<br>• Support: |

| Organization | Definition | Key Terms |
|---|---|---|
| | | - With curative therapy |
| National Consensus Project | Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice<br>The following features characterize palliative care philosophy and delivery: Care is provided and services are coordinated by an interdisciplinary team; Patients, families, palliative and non-palliative healthcare providers collaborate and communicate about care needs; Services are available concurrently with or independent of curative or life-prolonging care; Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death (2013). | - Palliative:<br>- Patient and family centered:<br>- Holistic: Support throughout continuum of illness:<br>- Prevent suffering |
| National Quality Forum | Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy (2006) | - Palliative:<br>- Patient and family centered:<br>- Holistic:<br>- Support throughout continuum of illness:<br>- Prevent suffering |
| National Hospice and Palliative Care Organization | Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice.<br>The following features characterize palliative care philosophy and delivery:<br>Care is provided, and services are coordinated by an interdisciplinary team; Patients, families, palliative and non-palliative healthcare providers collaborate and communicate about care needs; Services are available concurrently with or independent of curative or | - Palliative:<br>- Patient and family centered:<br>- Holistic:<br>- Support throughout |

| Organization | Definition | Key Terms |
|---|---|---|
| | life-prolonging care; Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death (2015). | continuum of illness:<br>• Prevent suffering |
| National Council for Palliative Care | Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. Palliative care aims to: Affirm life and regard dying as a normal process; Provide relief from pain and other distressing symptoms; Integrate the psychological and spiritual aspects of patient care; Offer a support system to help patients live as actively as possible until death; Offer a support system to help the family cope during the patient's illness and in their own bereavement (NCPC, 2015). | • Palliative:<br>• Holistic:<br>• Advanced progressive illness:<br>• Regard dying as a normal process:<br>• Relief from distressing symptoms:<br>• Support system:<br>• Bereavement support |
| Oncology Nursing Society | Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy (2015). | • Palliative:<br>• Patient and family centered:<br>• Holistic:<br>• Support throughout continuum of illness:<br>• Prevent suffering |

| **Organization** | **Definition** | **Key Terms** |
|---|---|---|
| Worldwide Hospice Palliative Care Alliance/ ehospice | Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patient's live as actively as possible until death; offers a support system to help the family cope during the patients<br>illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better<br>understand and manage distressing clinical complications (2014). | • Palliative:<br>• Life threatening-illness:<br>• Relief of suffering:<br>• Support:<br>• Bereavement support:<br>• Conjunction with other therapies. |
| American Hospital Association | Palliative care specializes in taking care of patients with serious illness and focuses on providing relief from symptoms pain, and stress in order to improve the quality of life for patients and their families. The care is provided by an interdisciplinary team whose focus is: Assessment and treatment of a patient's physical and emotional/ spiritual distress; Communication and decision-making with patients and their families to establish achievable patient-centered goals of care; Coordination of transitions of care and support for practical needs of patients and families (2012). | • Palliative:<br>• Serious-illness:<br>• Relief from symptoms:<br>• Patient-centered:<br>• Transitions of care. |
| Hospice and Palliative Nurses Association | Palliative care is patient- and family-centered care across the spectrum of illness. Palliative care begins with supportive care at the time of diagnosis of a serious or life-threatening illness and ends with bereavement care after death. Patient and family goals are supported throughout the course of illness, during the dying process, and after death, with respect to values, preferences, and beliefs. Palliative nursing is developmentally, culturally, ethnically, and spiritually appropriate. Palliative care relieves physical, psychological, emotional, and spiritual suffering of patients and families with serious or life-threatening | • Palliative:<br>• Patient and family centered:<br>• Serious or life- |

| **Organization** | **Definition** | **Key Terms** |
|---|---|---|
| | illness. Palliative care is equitable, comprehensive, and reaches across health settings, with an emphasis on continuity, quality, safety, and access with attention to vulnerable populations and transitions of care. Services are available concurrently with or independent of curative or life-prolonging care. Palliative care is interdisciplinary and collaborative. Palliative care team members have clinical expertise and communication skills to educate patients about their disease, treatment options, and decision-making while maintaining confidentiality (2014). | threatening illness:<br>• Supportive:<br>• Transitions of care:<br>• Support through the dying process. |
| The Joint Commission | Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and any stage in a serious illness and can be provided along with curative treatment. The goal is to improve quality of life for both the patient and the family (2011). | • Palliative:<br>• Support:<br>• Any stage of serious illness:<br>• Along with curative therapy |

Appendix B. 2013 National Consensus Project Domains (NCP), 2006 National Quality Forum Preferred Practices (NQF), and 2016

The Joint Commission Advanced Palliative Care Certification Standards (TJC) Crosswalk

| **NCP Domains** | **NQF Preferred Practices** | **TJC Certification Standards** |
|---|---|---|
| **Domain 1:**<br>**General Structure of Care**<br>**Guideline 1.1:**<br>A comprehensive and timely interdisciplinary assessment of the patient and family forms the basis of the plan of care. | **Preferred Practice 1:**<br>Provide palliative and hospice care by an interdisciplinary team of skilled palliative care professionals, including for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).<br><br>**Preferred Practice 2:**<br>Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.<br><br>**Preferred Practice 3:**<br>Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.<br><br>**Preferred Practice 4:**<br>Provide adequate training and clinical support to assure that professional staff is confident in their ability to provide palliative care for patients.<br><br>**Preferred Practice 5:**<br>Hospice care and specialized palliative care professionals should be appropriately trained, | **Program Management (PCPM):**<br>**PCPM.1:**<br>The program leaders secure support from the organization.<br><br>**PCPM.2:**<br>The program defines its leadership roles.<br><br>**PCPM.3:**<br>The program uses clinical practices originating from evidence-based national guidelines or expert consensus to deliver or facilitate the delivery of clinical care, treatment, and services.<br><br>**PCPM.4:**<br>The program identifies and minimizes risks to patients.<br><br>**PCPM.5:**<br>The program has a process to address concerns or complaints patients have about the care, treatment, and services it provides.<br><br>**PCPM.6:**<br>Program leaders are responsible for selecting, orienting, educating, and retaining staff.<br><br>**PCPM.7:**<br>The program has an interdisciplinary team that includes healthcare professionals with the education and experience to provide the program's specialized care, treatment, and services that meet the needs of the patient and family. |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
|  | credentialed, and/or certified in their area of expertise. | **PCPM.8:**<br>The program promotes collaboration among program staff and with the organization staff who are involved in the patient's care. |
| **Guideline 1.2: General Processes of Care**<br>The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for patient-family decision making. Family is defined by the patient. | **Preferred Practice 6:**<br>Formulate, utilize and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.<br>**Preferred Practice 7:**<br>Ensure that on transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values and clinical information so that continuity of care and seamless follow-up are assured.<br>**Preferred Practice 8:**<br>Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and reintroduce the hospice option as the patient declines.<br>**Preferred Practice 9:** | **Program Management (PCPM):**<br>**PCPM.1:**<br>The program leaders secure support from the organization.<br>**PCPM.6:**<br>Program leaders are responsible for selecting, orienting, educating, and retaining staff.<br>**Provision of Care (PCPC)**<br>**PCPC.1:**<br>Patients and families know how to access and use the program's care,<br>treatment, and services.<br>**PCPC.2:**<br>The program communicates with patients and families and involves them in decision making.<br>**PCPC.3:**<br>The program tailors care, treatment, and services to meet the patient's<br>lifestyle, needs, and values.<br>**Information Management (PCIM)**<br>**PCIM.1:** |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
|  | Patient's and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare professionals' ability to discuss hospice as an option.<br>**Preferred Practice 10:**<br>Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.<br>**Preferred Practice 11:**<br>Provide education and support to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patients. | The organization maintains and protects the privacy and security of health information.<br>**PCIM.2:**<br>The program maintains complete and accurate medical records.<br>**PCIM.3:**<br>Continuity of information is maintained. |
| **Domain 2:**<br>**Physical Aspects of Care**<br>**Guideline 2.1:**<br>The interdisciplinary team assesses and manages pain and/or other physical symptoms and their subsequent effects based upon the best available evidence.<br>**Guideline 2.2:**<br>The assessment and management of symptoms and side | **Preferred Practice 12:**<br>Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.<br>Preferred Practice **1:3**<br>Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level acceptable to the patient and family. | **Provision of Care (PCPC)**<br>**PCPC.4:**<br>The interdisciplinary team assesses and reassesses the patient's needs.<br>**PCPC.5:**<br>The program provides care, treatment, and services according to the plan of care.<br>**Information Management (PCIM)**<br>**PCIM.1:**<br>The organization maintains and protects the privacy and security of health information.<br>**PCIM.2:** |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
| effects are contextualized to the disease status. | | The program maintains complete and accurate medical records.<br>**PCIM.3:**<br>Continuity of information is maintained. |
| **Domain 3: Psychological and Psychiatric Aspects of Care**<br>**Guideline 3.1**<br>The interdisciplinary team assesses and addresses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.<br>**Guideline 3.2**<br>A core component of the palliative care program is a grief and bereavement program available to patients and families, based on assessment of need. | **Preferred Practice 14:**<br>Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.<br>**Preferred Practice15:**<br>Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level acceptable to the patient and family.<br>**Preferred Practice 16:**<br>Assess and manage psychological reactions of patients and families to address emotional and functional impairment and loss, (including stress, anticipatory grief and coping), in a regular ongoing fashion.<br>**Preferred Practice 17:**<br>Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after the death of the patient. | **Provision of Care (PCPC)**<br>**PCPC.3:**<br>The program tailors care, treatment, and services to meet the patient's<br>lifestyle, needs, and values.<br>**PCPC.4:**<br>The interdisciplinary team assesses and reassesses the patient's needs.<br>**PCPC.5:**<br>The program provides care, treatment, and services according to the plan<br>of care.<br>**Information Management (PCIM)**<br>**PCIM.1:**<br>The organization maintains and protects the privacy and security of health information.<br>**PCIM.2:**<br>The program maintains complete and accurate medical records.<br>**PCIM.3:**<br>Continuity of information is maintained. |
| **Domain 4:** | **Preferred Practice 18:** | **Provision of Care (PCPC)** |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
| **Social Aspects of Care**<br>**Guideline 4.1:**<br>The interdisciplinary team assesses and addresses the social aspects of care to meet patient-family needs, promote patient-family goals, and maximize patient-family strengths and well-being.<br><br>**Guideline 4.2:**<br>A comprehensive, person-centered interdisciplinary assessment (as described in Domain 1, Guideline 1.1) identifies the social strengths, needs, and goals of each patient and family. | Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis, and advanced care planning, and offer support.<br><br>**Preferred Practice 19:**<br>Develop and implement a comprehensive social care plan which addresses the social, practical and legal needs of the patient and caregivers, including but not limited to: relationships, communication, existing social and cultural networks, decision-making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment. | **PCPC.3:**<br>The program tailors care, treatment, and services to meet the patient's lifestyle, needs, and values.<br><br>**PCPC.4:**<br>The interdisciplinary team assesses and reassesses the patient's needs.<br><br>**PCPC.5:**<br>The program provides care, treatment, and services according to the plan of care.<br><br>**PCPC.6:**<br>The patient's care is coordinated. |
| **Domain 5: Spiritual, Religious, and Existential Aspects of Care** | **Preferred Practice 20:**<br>Develop and document a plan based on assessment of religious, spiritual, and existential concerns using a structured instrument and integrate the information | **Program Management (PCPM):**<br>**PCPM.1:**<br>The program leaders secure support from the organization.<br><br>**PCPM.2:** |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
| **Guideline 5.1:**<br>The interdisciplinary team assesses and addresses spiritual, religious, and existential dimensions of care.<br>**Guideline 5.2:**<br>A spiritual assessment process, including spiritual screening, history questions, and a full spiritual assessment as indicated, is performed. This assessment identifies religious or spiritual/ existential background, preferences, and related beliefs, rituals, and practices of the patient and family; as well as symptoms, such as spiritual distress and/or pain, guilt, resentment, despair, and hopelessness. | obtained from the assessment into the palliative care plan.<br>**Preferred Practice 21:**<br>Provide information about the availability of spiritual care services and make spiritual care available either through organizational spiritual counseling or through the patient's own clergy relationships.<br>**Preferred Practice 22:**<br>Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.<br>**Preferred Practice 23**<br>Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy, and provide education and counseling related to end-of-life care. | The program defines its leadership roles.<br>**PCPM.3:**<br>The program uses clinical practices originating from evidence-based national guidelines or expert consensus to deliver or facilitate the delivery of clinical care, treatment, and services.<br>**PCPM.4:**<br>The program identifies and minimizes risks to patients.<br>**PCPM.5:**<br>The program has a process to address concerns or complaints patients have about the care, treatment, and services it provides.<br>**PCPM.6:**<br>Program leaders are responsible for selecting, orienting, educating, and retaining staff.<br>**PCPM.7:**<br>The program has an interdisciplinary team that includes healthcare professionals with the education and experience to provide the program's specialized care, treatment, and services that meet the needs of the patient and family.<br>**PCPM.8:**<br>The program promotes collaboration among program staff and with the organization staff who are involved in the patient's care.<br>**Provision of Care (PCPC)**<br>**PCPC.1:** |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
| **Guideline 5.3:**<br>The palliative care service facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death. | | Patients and families know how to access and use the program's care,<br>treatment, and services.<br><br>**PCPC.3:**<br>The program tailors care, treatment, and services to meet the patient's<br>lifestyle, needs, and values. |
| **Domain 6:**<br>**Cultural Aspects of Care**<br>**Guideline 6.1:**<br>The palliative care program serves each patient, family, and community in a culturally and linguistically appropriate manner.<br><br>**Guideline 6.2:**<br>The palliative care program strives to enhance its cultural and linguistic competence. | **Preferred Practice 24:**<br>Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including, but not limited to: locus of decision-making, preferences regarding disclosure of information, truth telling and decision-making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering and grieving, and funeral/burial rituals.<br><br>**Preferred Practice 25:**<br>Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language. | **Provision of Care (PCPC)**<br>**PCPC.4:**<br>The interdisciplinary team assesses and reassesses the patient's needs.<br><br>**Program Management (PCPM):**<br>**PCPM.6:**<br>Program leaders are responsible for selecting, orienting, educating, and retaining staff. |
| **Domain 7:** | **Preferred Practice 26:** | **Provision of Care (PCPC)** |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
| **Care of the Patient at the End of Life Guideline 7.1:**<br>The interdisciplinary team identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social. And cultural needs of patients and families.<br><br>**Guideline 7.2:**<br>The interdisciplinary team assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential symptoms, patent and family preferences for site | Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.<br><br>**Preferred Practice 27:**<br>The family is educated on a timely basis regarding signs and symptoms of imminent death in a developmentally, age, and culturally appropriate manner.<br><br>**Preferred Practice 28:**<br>As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for site of death and fulfill patient and family preferences when possible.<br><br>**Preferred Practice 29:**<br>Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns and fears about using narcotics and of analgesics hastening death.<br><br>**Preferred Practice 30:**<br>Treat the body post-death with respect according to the cultural and religious practices of the family and in accordance with local law. | **PCPC.2:**<br>The program communicates with patients and families and involves them in decision making<br><br>**PCPC.5:**<br>The program provides care, treatment, and services according to the plan<br>of care.<br><br>**Information Management (PCIM)**<br>**PCIM.1:**<br>The organization maintains and protects the privacy and security of health information.<br><br>**PCIM.2:**<br>The program maintains complete and accurate medical records.<br><br>**PCIM.3:**<br>Continuity of information is maintained. |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
| of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures.<br>**Guideline 7.3:**<br>Respectful post death care is delivered in a respectful manner that honors the patient and family culture and religious practices.<br>**Guideline 7.4**<br>An immediate bereavement plan is activated post death. | **Preferred Practice 31:**<br>Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death when the family remains the focus of care. | |
| **Domain 8:**<br>**Ethical and Legal Aspects of Care**<br>**Guideline 8.1:**<br>The patient or surrogate's goals, preferences, and choices are respected within the limits of applicable | **Preferred Practice 32:**<br>Document the designated surrogate/decision maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.<br>**Preferred Practice 33:**<br>Document the patient/surrogate preferences for goals of care, treatment options, and setting of | **Provision of Care (PCPC)**<br>**PCPC.2:**<br>The program communicates with patients and families and involves them in decision making<br>**PCPC.3:**<br>The program tailors care, treatment, and services to meet the patient's<br>lifestyle, needs, and values. |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
| state and federal law, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.<br>**Guideline 8.2:**<br>The palliative care program identifies, acknowledges, and addresses the complex ethical issues arising in the care of people with serious or life-threatening illness.<br>**Guideline 8.3:**<br>The provision of palliative care occurs in accordance with professional, state, and federal laws, regulations and | care at first assessment and at frequent intervals as conditions change.<br>**Preferred Practice 34:**<br>Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospitals.<br>**Preferred Practice 35:**<br>Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to Health Insurance Portability and Accountability Act (HIPAA) regulations, e.g., by Internet-based registries or electronic personal health records.<br>**Preferred Practice 36:**<br>Develop healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals, e.g., Respecting Choices, Community Conversations on Compassionate Care.<br>**Preferred Practice 37:**<br>Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life. | **Information Management (PCIM)**<br>**PCIM.1:**<br>The organization maintains and protects the privacy and security of health information.<br>**PCIM.2:**<br>The program maintains complete and accurate medical records.<br>**PCIM.3:**<br>Continuity of information is maintained. |

| NCP Domains | NQF Preferred Practices | TJC Certification Standards |
|---|---|---|
| current accepted standards of care. | **Preferred Practice 38:**<br>For minors with decision-making capacity, document the child’s views and preferences for medical care, including assent for treatment, and give appropriate weight in decision-making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child’s wishes differ from those of the adult decision maker. | |
| **None noted** | **None noted** | ***Performance Improvement (PCPI)**<br>**PCPI.1:**<br>The program plans an organized, comprehensive approach to performance improvement.<br>**Performance Improvement (PCPI)**<br>**PCPI.1:**<br>The program plans an organized, comprehensive approach to performance improvement.<br>**PCPI.2:**<br>The program collects data to monitor its performance.<br>**PCPI.3:**<br>The program analyzes and uses its data to identify opportunities for performance improvement.<br>**PCPI.4:**<br>The program addresses sentinel events that occur and takes steps to prevent future occurrences. |

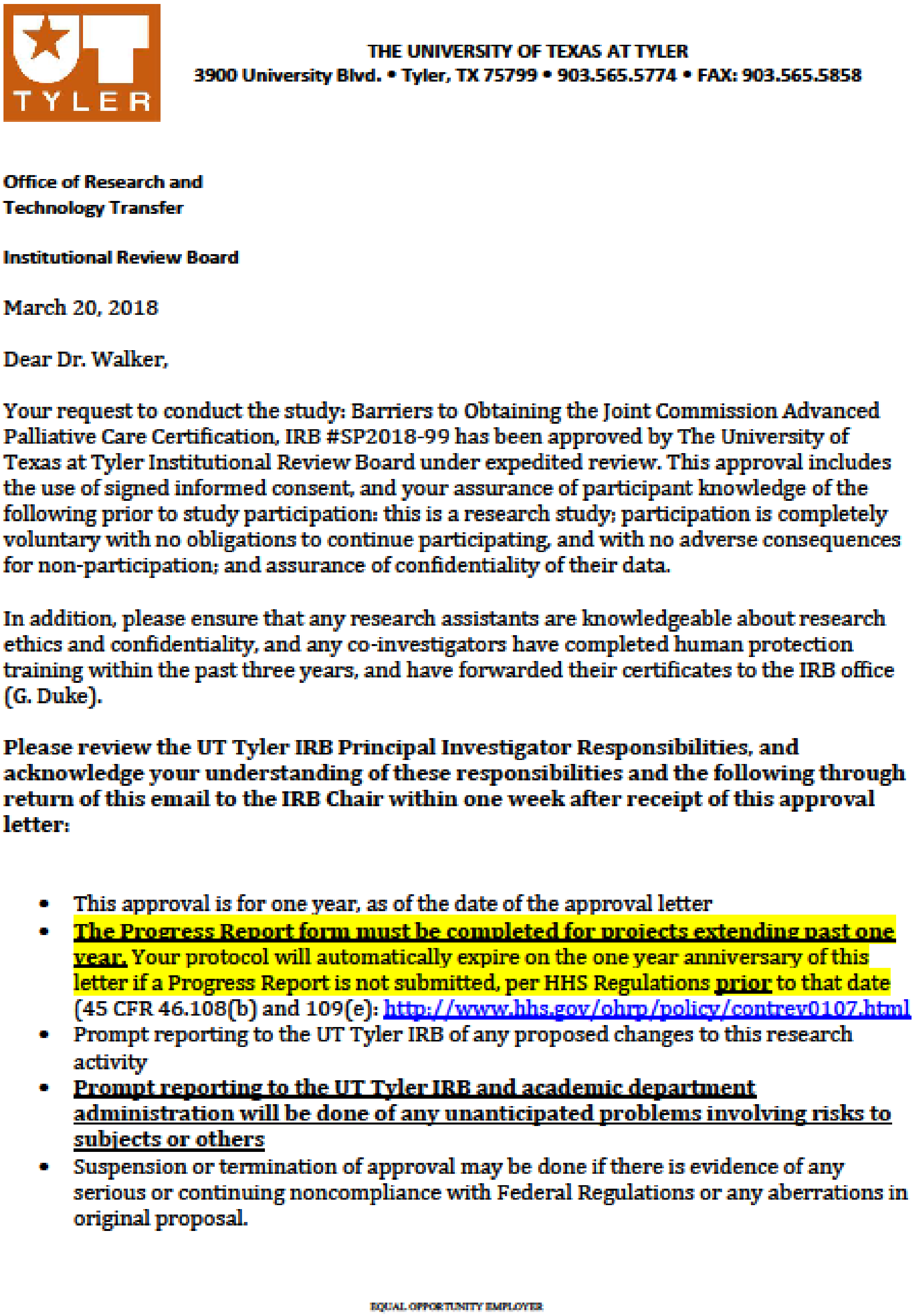
*Standards for performance improvement are noted in TJC but not with NCP Domains or NQF Preferred Practices.

Resources used to create this crosswalk are The National Consensus Project for Palliative Care 2013 *Clinical Practice Guidelines for Palliative Care*, the National Quality Forum 2006 *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report* and *The Joint Commission 2015–2016 Palliative Care Certification Manual*.

## Appendix C. Nursing Theoretical Models of Palliative Care

| **Name** | **Premise** |
|---|---|
| Transitions Model of Palliative Care (TMPC) | Emphasizes the interdisciplinary focus and holistic approach of palliative care within the context of chronic care management. Expected death rather than particular diagnosis defines the target population. Instead of time, patient response to the illness and needs mediate the transition to palliative care. Three general care patterns define care approaches: 1. Supported self-care 2. Episodic disease management and 3. Case management (Murray, 2007, p. 368) |
| Unitary Caring Model | The unitary-caring model article transforms ordinary standards of palliative care practice from national guidelines into a nursing values-based praxis of healing and caring. Integrating the values of caring, wholeness, pattern, meaning, relationship, consciousness, and transformation and transcendence into praxis upholds the worth of the profession and discipline of nursing (Reed, 2010, p. 30). |
| Shared Theory in Palliative Care | This theoretical development provides a framework to guide nurses in developing their competence to provide quality care to patients with life-threatening illness. The concepts of nursing competence, nursing self-competence, nursing interventions, palliative self-care behaviors, physical/emotional symptoms, and quality of life define the therapeutic relationship between the palliative care nurse and the patient with a life-threatening illness (Desbiens, Gagnon, & Fillion, 2012; Dobrina et al., 2014). |

# Appendix D. IRB Approval



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**Office of Research and**
**Technology Transfer**

**Institutional Review Board**

March 20, 2018

Dear Dr. Walker,

Your request to conduct the study: Barriers to Obtaining the Joint Commission Advanced Palliative Care Certification, IRB #SP2018-99 has been approved by The University of Texas at Tyler Institutional Review Board under expedited review. This approval includes the use of signed informed consent, and your assurance of participant knowledge of the following prior to study participation: this is a research study; participation is completely voluntary with no obligations to continue participating, and with no adverse consequences for non-participation; and assurance of confidentiality of their data.

In addition, please ensure that any research assistants are knowledgeable about research ethics and confidentiality, and any co-investigators have completed human protection training within the past three years, and have forwarded their certificates to the IRB office (G. Duke).

**Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:**

- This approval is for one year, as of the date of the approval letter
- **The Progress Report form must be completed for projects extending past one year.** Your protocol will automatically expire on the one year anniversary of this letter if a Progress Report is not submitted, per HHS Regulations **prior** to that date (45 CFR 46.108(b) and 109(e): http://www.hhs.gov/ohrp/policy/contrev0107.html
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- **Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others**
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.

EQUAL OPPORTUNITY EMPLOYER

# Appendix E. Telephone Script

Hello, my name is Karen Walker and I am PhD student at The University of Texas at Tyler and I am very interested in learning more about palliative care programs in the US and what prevents palliative care programs from obtaining certification.

This survey includes items dealing with The Joint Commission standards and any barriers you report that interfere with providing optimal care desired at your institution.

No identifying information regarding your program or institution is desired or requested, so your information will be anonymous.

Knowledge of these issues could facilitate efforts to improve access to quality palliative care that optimizes patient outcomes.

I would very much appreciate it if you could take about 15-20 minutes of your time to answer some questions for me.

However, please note your participation is 100% voluntary.

Know your identity but it would remain strictly confidential and only known to me. Your identity or that of the institution you represent would not be part of the data or results.

This study has been approved by The University of Texas at Tyler Institutional Review Board, and if you have any questions, please feel free to call contact me: kwalker@uttyler.edu or by phone (903)521-6854, or my dissertation chair: Dr. Gloria Duke:  gduke@uttyler.edu or by phone (903) 566-7023.

## Appendix F. Hospital-Based Palliative Care Program Survey

Please note: a confidential discussion about the items listed below can be arranged: please call me: 903-521-6854. Please understand this removes your anonymity, but rest assured I will be the only person that knows your identity, and no identifying information will ever be revealed.

1. What is the title of the person completing survey? (Please note that a nurse, physician or administrator should complete this survey.)

2. How long have you worked in a palliative care setting?

3. What state is your palliative care located? This does not serve as an identifying measure for your program as there are several programs from each state receiving surveys.

4. How would you classify the facility in which the palliative care program in your facility operates?
    a. Rural
    b. Urban
    c. Other or comments:

5. Number of beds in your acute care facility?
    d. <50
    e. 50-150
    f. 151-300
    g. 301+

6. What is the mission and vision of your palliative care program?

7. What is the vision of your palliative care program?

8. How is palliative care defined by your facility or inclusion criteria for patients to receive palliative care?

9. What are the priorities of your palliative care program?

10. What do you perceive to be the barriers in achieving The Joint Commission's Advanced Palliative Care certification? Please be as specific as possible and explain as much as possible.

11. What resources do you need to achieve The Joint Commission's Advanced Palliative Care certification? Please be as specific as possible.

12. What other factors have affected your program from not being certified? Please be as specific as possible.

# Appendix G. Biographical Sketch

| | |
|---|---|
| NAME<br>Karen L. Walker | POSITION TITLE<br>Doctoral Candidate, The University of Texas at Tyler<br>Clinical Instructor at The University of Texas at Tyler, School of Nursing, Tyler, TX |
| eRA COMMONS USER NAME (credential, e.g., agency login) | |

EDUCATION/TRAINING

| INSTITUTION AND LOCATION | DEGREE *(if applicable)* | MM/YY | FIELD OF STUDY |
|---|---|---|---|
| Wright State University | BSN | 06/96 | Nursing |
| University of Phoenix | MSN | 10/05 | Nursing Administration |
| University of Phoenix | MBA | 09/08 | Business Administration |
| University of Texas at Tyler | PhD | 12/19 | Nursing |

A. Personal Statement

B. Positions and Employment

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|---|---|
| 2015-Present | Clinical Instructor, The University of Texas at Tyler, Texas |
| 2012-2015 | Clinical Nurse Manager, East Texas Medical Center, Tyler, Texas |
| 2009-2015 | Registered Nurse, East Texas Medical Center, Tyler, Texas |
| 2007-2009 | Registered Nurse, South Texas Health System, McAllen, Texas |
| 2004-2007 | Clinical Nurse Manager, Premier Health Partners, Dayton, Ohio |
| 2000-2004 | Clinical Nurse Manager, The University of Cincinnati Hospital, Cincinnati, TX |
| 1996-2000 | Registered Nurse, Premier Health Partners, Dayton Ohio |