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Transitions in Palliative Care: Referral Time and Healthcare Utilization in Advanced Stage Colon, Rectal and Lung Cancer Patients.

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DOCTOR OF PHILOSOPHY IN NURSING

TRANSITION IN PALLIATIVE CARE:

REFERAL TIME AND HEALTHCARE UTILIZATION FOR ADVANCED STAGE COLON, RECTAL AND LUNG CANCER PATIENTS.

By

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ABSTRACT

Background: Despite lung, colon, and rectal cancer being the leading and third leading cause of cancer-related death among both men and women respectively, few studies have examined Palliative Care Consultation (PCC) on healthcare utilization (HCU) in individuals with advanced stage diagnosis in this disease cohort. Extant research shows advanced stage cancer patients receive aggressive treatments, within the last 30 days of life. Palliative care is linked to less aggressive cancer treatment, and palliative interventions applied early, at diagnosis of advanced cancer, is more favorable for improving symptom and disease management. Patients and family members with early PCC are better informed about treatment directives and end-of-life decisions. The American Nurses Association (ANA, 2017) recommends discussions of PC begin at diagnosis of a chronic illness; American Society for Clinical Oncology (ASCO, 2012) guidelines recommend PCR within 8 weeks of advanced cancer diagnosis.

Purpose: The purpose of this study was to examine the relationship among select socio-demographics, participant clinical characteristics, PCC time, healthcare utilization, and PCC to death for patients with PCC compared to no PCC, in a cancer patient cohort at an advanced stage in their disease process.

Methods: Descriptive correlational design using retrospective EHR data collected within the calendar year 2019-2020. Descriptive and inferential approaches were utilized to analyze the data.

Results: Bronchus/lung cancer, accounted for 74.7% (*n* = 71) of the sample; colon, rectosigmoid junction accounted for 25.3% (*n* = 24). Eighty percent (*n* = 76) of the participants had been diagnosed with stage IV and 20% (*n* = 19) stage III cancer. The average number of days from first PCC to death was 10 days, inferring that PC was being

utilized as hospice. Participants with stage IV diagnosis had less days from diagnosis to death. For patients with PCC, time from diagnosis to death was 445 days (*n* = 85), compared to 320 days for those with no PCC (*n* = 10). Also, participants who were White had more days from diagnosis to death, compared to those who were Hispanic or "other race;" and White participants were also more likely to get PCC. Overall, average number of ED, hospital, and clinic visits during the study period (3.72 visits) was reduced after PCC (0.16 visits); average acute care LOS (6.97 days) was reduced after PCC (0.76 days); and average ICU LOS for the study period (4.55 days) was reduced after PCC (0.51 days). However, none of the participants got PCC at the recommended time; at diagnosis or within 8 weeks of diagnosis.

Implications for Nursing Research: All clinicians who care for patients with chronic illnesses need to become more confident in having PC discussions with patients and advocating for physicians to do the same. State regulatory agencies need to ensure this by requiring mandatory EOL classes for licensure renewal, mandating the inclusion of more PC and EOL courses in nursing and medical curriculum. To ensure timely referrals and consults, health systems should implement a referral criterion for patients with advanced cancer diagnosis that automates a trigger system; this will ensure PCR and PCC is initiated outside of physician discretion; and remove the possibility of inequity in the referral process. Centers for Medicare, and Medicaid Service can build value-based reimbursement into existing programs to ensure dual-eligibility, not only by diagnosis of specific diseases. Preventable hospital admissions are often a consequence of poorly managed transitions in the illness trajectory, and delayed PCC leads to burdensome transitions for patients and their families.

DEDICATION

This dissertation is dedicated to:

My Parents, Charles, and Beatrice Lawani.

Itopa Lawani and Eddy Ojo, I did it for us, because you did not get a chance to.

We miss you.

Dr Patricia Roth, for recognizing my potential and helping me navigate the feelings of imposter syndrome. Thank you for your wit, kindness, encouragement, guidance, and compassion.

Samuel Lawani, for all you are and all you do for me, I am grateful.

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I give glory to God almighty for seeing me through this tedious, life changing, unique and rewarding experience to change my nursing lens, with exponential growth intellectually, professionally, and personally. To my parents: Charles and Beatrice Lawani, thank you for your support, prayers, and constant encouragement. I am grateful to God for keeping you two to share in the culmination of this experience with me. I am especially thankful for my brother Samuel Lawani, my entire family, far and near for the encouragement and understanding when I missed important events. Also, to my Godparents, Michael and Noja Uadiale, thank you for believing in me. My friends-Jason Vasquez and Susanne Carranza, for helping me laugh through the hard times and for coming hungry when I stress cooked, thank you!

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CHAPTER I

Introduction

The United States healthcare system does not currently meet the unique, individual needs of patients and families living with advanced-stage cancer. The culture of western medicine, focused on aggressive, disease-specific treatment, and aversion to End-of-Life (EOL) discussions neglects to consider the needs of the whole person, their values, culture, spiritual beliefs, and wishes about death and dying. This results in unnecessary, prolonged suffering, costly, and often futile interventions with medication side-effects giving rise to other adverse symptoms, repeated hospitalizations, and increased healthcare resource utilization. Diagnosis of any chronic illness is unsettling for patients and their families. It is an unpredictable time that requires many adjustments, role changes, education, and involves a new way of life. According to the World Health Organization (WHO, 2022), cancer is the leading cause of death in the world, accounting for over 10 million deaths alone in the year 2020. Given, a cancer diagnosis can be very debilitating; more so, an advanced stage diagnosis.

Innovation in modern medicine and pharmaceutical improvements over the years in the way cancer is treated has led to early diagnosis for some individuals, accordingly, some are living longer. Despite this achievement, chemotherapy and other therapeutic agents still only offer modest improvements in survival rates; this largely depends on the stage of cancer at diagnosis, as well as the type of cancer an individual is diagnosed with. Given, palliative care (PC) at advanced stage diagnosis can help with physical and psychosocial symptom improvements and improve quality of life for patients, to achieve quality, patient-centered care and have a meaningful effect, PC must be integrated in tandem with standard oncologic care early in the illness and treatment trajectory. Late delivery of PC undermines its true value and does not offer patients and families the full spectrum of care needed.

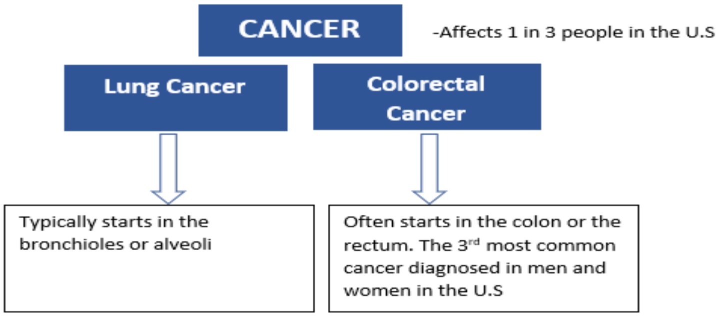
Background

Cancer

In the United States, cancer affects one in three people. It occurs when normal cells in the body grow excessively into tumors and become malignant (American Cancer Society, 2021). Cancer is the leading cause of death worldwide; the two most common causes of cancer-related deaths in 2020 were: lung cancer, accounting for1.80 million deaths; colon and rectum cancer, accounting for 916,000 deaths combined (WHO, 2022). In the United States, colorectal cancer is the third leading cause of cancer-related deaths in men and women respectively, and the second most common cause of cancer deaths when men and women are combined. Lung cancer, on the other hand, is the leading cause of cancer death among both men and women and accounts for almost 25% of all cancer deaths (American Cancer Society, 2021). Patients diagnosed with advanced-stage cancer often have high symptom burden, often unmanageable, in need of palliation. Add chemotherapy medications, radiation, and other routine cancer treatments, and the side-effects of disease and treatment combined increases the risk to changes in health seeking behavior and health service utilization. This burden is heavy both on patients, family, and clinicians alike. Despite these facts, few studies have examined the impact of Palliative Care Consult (PCC) time on Healthcare Utilization (HCU), as well as a comparison of outcomes for patients with PCC versus those with no PCC (Figure 1).

Figure 1

Cancer Prevalence



Note: From "Cancer Basics" by American Cancer Society.

Palliative Care

Palliative care (PC), as defined by the World Health Organization (WHO, 2012) is a holistic approach to patient care that improves the quality of life for patients with chronic illnesses, through the prevention and relief of suffering. The primary goal of PC is optimal management of symptoms and to treat patients with chronic illness from a physical, spiritual, and psychosocial point of view in addition to concurrent treatment of the chronic illness. Fallon and Hanks (2006) point out PC originated as a medical sub-specialty in 1987, based upon the work of Dame Cicely Saunders, who founded St. Christopher's Hospice, the first of its kind in 1963. Relative to her hospice work, Saunders sought to humanize, personalize, and de-institutionalize patients at the end of their lives. However, hospice care does not have the same meaning as PC. Hospice care is considered part of the longer continuum of PC that begins with the realization a patient has a life-limiting illness, progressed to the terminal level, with symptoms that can no longer be managed by medication (Smothers et al., 2019).

Considered the core ingredient of PC is the eminence of presence the clinician brings to the patient as they proactively provide resources to the patients to help navigate treatment. This infers a customized approach to both patient and family-centered care, not provider-oriented (Fallon & Hanks, 2006; Smothers et al., 2019), optimizing the overall health of the patient, not a one-size-fits-all. The overarching goal is biopsychosocial and physical symptom alleviation; although, spiritual concerns are emphasized in the care delivery process. Palliative care referral in the healthcare system is an indication a patient's illness or disease brings about symptoms more palliative in nature, either from the illness itself or a combination of the illness and medications utilized in treatment. It is founded on a philosophy that encourages sensitivity to cultural, sexual, religious, and other defining points of view of the person, with the aim of meeting them where they are in the illness transition trajectory (emotionally, psychologically, etc.), rather than where the physician or healthcare worker think they should be (Chick & Meleis, 1986; Fallon & Hanks, 2006; Meleis & Schumacher, 1994).

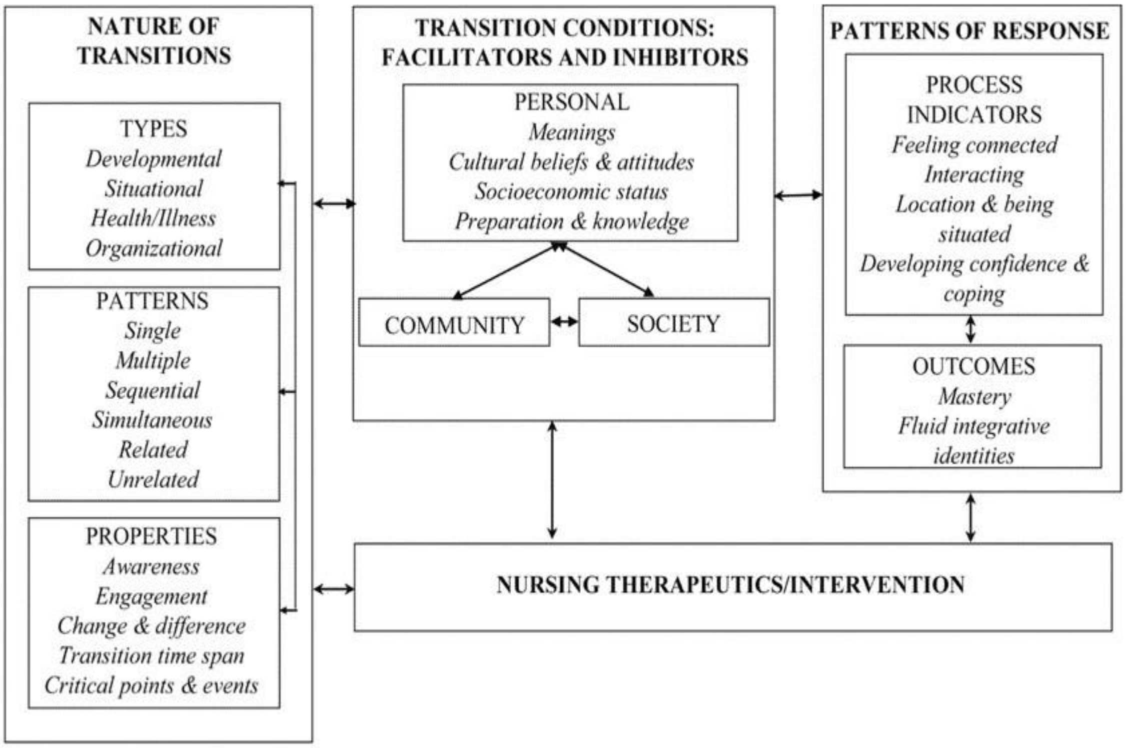
Transitions

Transitions was introduced into nursing practice by Meleis (1975), initially within the context of nursing role insufficiency. It blossomed into other aspects of nursing and was developed into a middle-range nursing theory (Figure 2) by Meleis et al., (2000). Meleis (2010) argues transitions is central to nursing, and although other disciplines focus on transitions itself, nursing plays a unique role in its ability to ease transitions towards health and wellbeing. In nursing and for the purpose of this study, transitions will be referred to in the context of health and is defined as a "passage or movement from one state, condition, or place to another" (Chick & Meleis,1986; Meleis & Schumacher, 1994).

Nursing involvement is critical in every aspect of patient care. In the case of transitions to PC, nursing education and understanding of PC, empathy, patient advocacy, and education are paramount for a successful transition. These skills are important to facilitate discussions and early recommendations to physicians about transitioning oncology patients into a PC program to ease suffering and prevent recurring hospital admissions. Limited research is available on this topic and within this context, especially as it relates to examining the relationship between PCC, healthcare utilization, and time between PCC and death, at an advanced stage in the disease process. More nursing education in this realm will lead to an anticipated outcome of increased nursing confidence, knowledge about PC, and advocacy for the inclusion of PC in the nursing curriculum to ensure proper education for patients and conversations related to a realistic understanding of disease progression. These conversations should occur, as early as possible to balance diagnosis with quality of life for patients and their caregivers.

Figure 2

Transitions: A Middle-Range Theory



Note: From "Experiencing Transitions: An Emerging middle-range theory," by Meleis, et. al (2000)

Problem Statement

The American Society for Clinical Oncology, in its special article by Smith et al. (2012), recommend PC interventions within 8 weeks of advanced cancer diagnosis, and the integration of PC into standard oncologic care throughout the illness and treatment trajectory. However, this is not often the practice. Patients diagnosed with advanced cancer often have a higher symptom burden; palliative care with this patient population involves open and honest goals of care conversations, advanced care planning (ACP), symptom management, control, and provision of patient-centered resources early in the illness trajectory. Non-adherence to this practice prolongs patient suffering and does not offer a holistic way of treatment. Patients are often unable to manage the increased symptom burden of disease, side effects of treatment, and other psychosocial unmet needs, leading to a disproportionate use of healthcare resources, and lack of preparedness for EOL.

Purpose of the Study

The purpose of this study is to examine the relationship among select socio-demographics, participant clinical characteristics, PCC time, healthcare utilization, and PCC to death for patients with PCC compared to no PCC, in a cancer patient cohort at an advanced stage in their disease process.

Specific Aims

This study seeks to address the following aims to provide a foundation to generate new scientific knowledge towards the integration of early PC with standard oncologic treatment for advanced-stage diagnosis.

Aim I. Describe select demographic (age, gender, race/ethnicity, marital status, insurance status, zip-code), healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), place of death, time between PCC and death, time from diagnosis to PCC, and time from diagnosis to death among a sample of Stage III and IV colon, rectal, and lung cancer patients receiving care from a large urban Southern California healthcare system

Aim II. Examine the relationships among select demographic, clinical characteristics, healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), place of death, time between PCC and death, time from diagnosis to PCC, and time from diagnosis to death

Aim III. Identify differences between participant clinical characteristics and healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), place of death, time between PCC and death, time from diagnosis to PCC, and time from diagnosis to death

Aim IV. Identify the amount of variance accounted for by select demographics, clinical characteristics, healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), place of death, time between PCC and death, time from diagnosis to PCC, and time from diagnosis to death**.**

Theoretical Underpinning

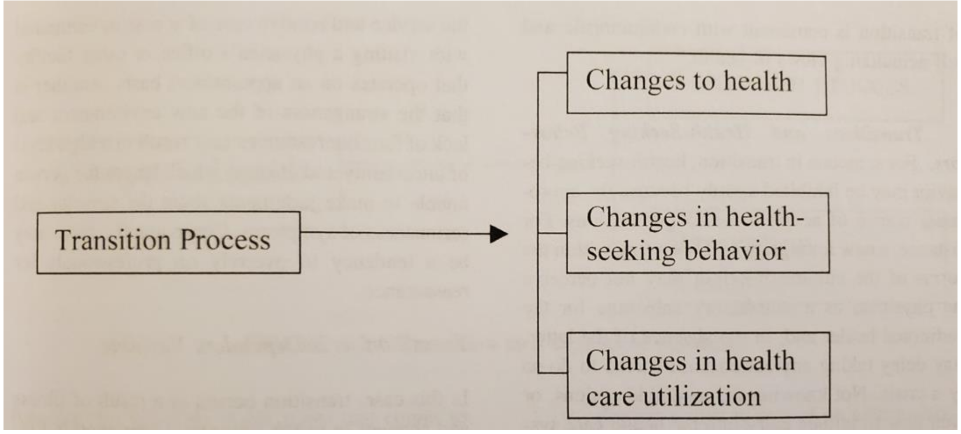
Afaf Meleis theory of Transitions is used as an underpinning for this study. According to Meleis (2010), transitions refer to both the process and outcome of complex person-environment interactions and occurs over time. When patients and their families are not properly cared for during the illness transitions trajectory, complications arise, leading to readmissions. The key to understanding transitions is the idea of “limina”-a space of separation where a person undergoes transitions. Transitions are elicited by critical events and changes in individuals or environments (Larkin et al., 2007).

Meleis (2010) describes transitions as the “business of nursing” because nurses spend most of their time caring for individuals who experience transitional changes that affect their health. Four major transitions identified by Meleis are developmental, situational, health and illness, and organizational transitions. For this study, only the health and illness transitions (Figure 3) will be utilized as an underpinning. This involves sudden changes related to moving from a well/healthy state to one of acute illness. These changes in health lead to changes in health seeking behaviors and HCU. Transitions in

PC relates to personal meaning in life, role changes, perception of end of treatment, and likelihood of death. How each person experiences transitions during the illness trajectory is unique because transitions are not linear. It is highly dependent on a person's culture, values, and socio-economic status. Socio-economic status (examined in this study in terms of zip code) is an important healthcare determinant, as it pertains to where and how much access an individual has to healthcare. This informs insurance status, quality of health, exposure to disease causing pathogens, environmental risk factors, as well as condition of healthcare facilities available in that environment. When patients with low socio-economic status seek healthcare, it is usually for an emergency, not for preventative care (Becker & Newsom, 2003).

Figure 3

Transition: Health and Illness



Note: From "Transitions: A nursing concern" by Chick & Meleis, 1986.

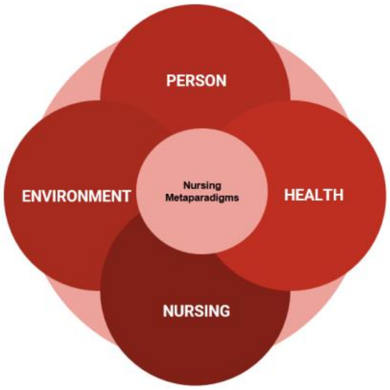
Often, health to illness transition is discussed solely from the perspective of when the clinician (physician or nurse) perceives a patient needs PC services. Both qualitative and quantitative data from the perspective of the patient are limited. More so, when healthcare workers are unsure about appropriate timing to initiate transitions to PC, the concept of transitions becomes problematic for the patient, often leading to unsuccessful transitions (Chick & Meleis, 1986).

Research Conceptual Framework

Jacqueline Fawcett (1984) grouped individual concepts to form the metaparadigms of nursing informing this study (Figure 4). A metaparadigm seeks to identify relevant phenomena in any discipline. The purpose of this framework using concepts from both Meleis, and Fawcett is to explore the different variables that facilitate or hinder transition to PC. Fawcett (1984) stated the foci and phenomenon of interest central in nursing are the person, in relation to their health, environment, and nursing, because these were the recurring themes found in the work of nurse scholars and nursing studies as it relates to the entirety of an individual. The person's behavior cannot be explained or predicted during periods of illness, but it can be described and influenced by environmental factors. The person is related to the nurse in the context of the effects of nursing interventions and therapeutics provided during a period of illness.

Figure 4

Nursing Metaparadigms

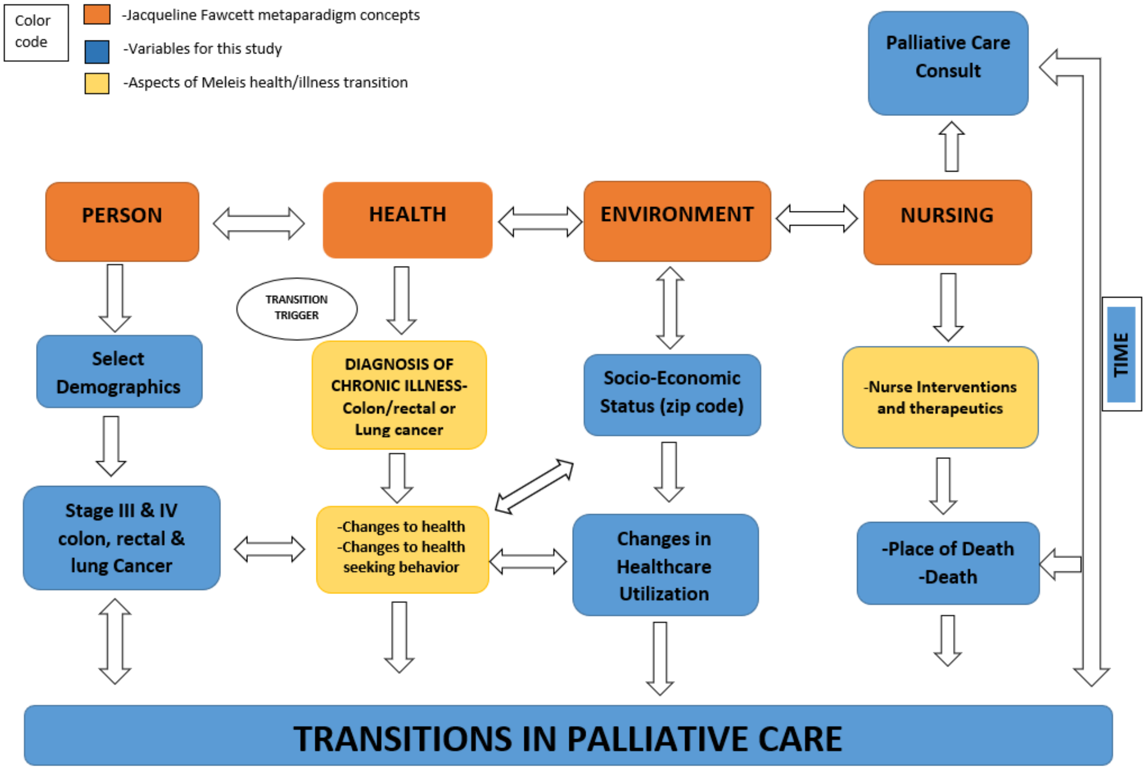


Note: From "The metaparadigm of nursing: present status and future refinements." By Fawcett, J. (1984).

For this study, stage III or IV diagnosis of colon, rectal, or lung cancer triggers a health/illness transitions trajectory according to Meleis, creating a change in the health of the person, as well as changes in their health seeking behavior. The individual is also influenced by environmental factors, to a large extent determined by socio-economic status, depicted by the variable "zip code" in this study (Chick & Meleis,1986; Meleis & Schumacher, 1994). This affects access to healthcare, the quality of care received, knowledge of the nurses, and availability of PC providers. All these factors combined shape the outcome of the patient and determine successful or unsuccessful transitions processes. The goal of this study is to ascertain the relationship among these variables. Do any exist? And if so, what is the significance of the relationship? The hypothesis for this study is: early PC referral and consult at diagnosis with stage III, or IV colon, rectal, or lung cancer will be associated with reduced healthcare utilization; including fewer emergency department visits, intensive care admissions and LOS, and hospitalizations in general for this patient cohort. Displayed in the model (figure 5) are the concepts of Fawcett's metaparadigms and Meleis' transition trigger of a cancer diagnosis. The variables to be examined and described for this study are also identified, in relation to Meleis and Fawcett's concepts. Early referral and consult for the purpose of this study is date of diagnosis to 8 weeks as recommended by ACSO (2012).

Figure 5

Conceptual Framework



Implications for Nursing Research

Prior to this study, anecdotal interviews were conducted with nurses (*n* = 5), as part of a qualitative analysis class project to identify barriers hindering PC referral at the bedside. These interviews revealed some nursing misconceptions about PC: *a*. there is a lack of clarity for nurses about the distinction between PC and Hospice, and the lines are blurred, *b.* nurses stated there is insufficient time dedicated to PC in the nursing school curriculum. This makes it difficult for nurses to advocate for PC referral and become comfortable having difficult advanced care planning conversations with patients and caregivers, *c*. there is no specific trigger-based referral system for patients needing PCC. As such, even when nurses attempt to advocate for patient referral due to clinical deterioration, the decision to refer patients is determined by physicians in most cases, who are reluctant to abandon treatment plans, and *d.* nurses interviewed stated physicians perceive they are fighting for the patients' best outcomes in their pursuit of standard oncologic care only; thus, even in the face of clinical deterioration, there is still a lack of referral. More qualitative research is needed from the nurse's perspective about barriers to PC in practice, as well as knowledge gaps that need to be filled for nurses to become better advocates.

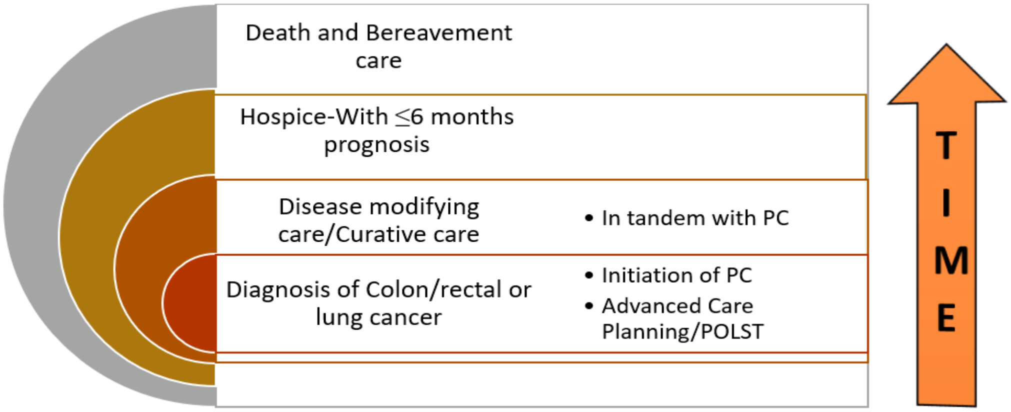
Woods et al. (2020) investigated the patient and provider perspective on PC in the emergency department with an aim to identify barriers that hinder early PCR and PC interventions in general. Their study developed two surveys: one for the patient and one for the providers (provider list included physician assistants, nurse practitioners, attending physicians, and emergency medicine residents). Results of the survey indicated 52% of providers felt their understanding of PC was a barrier. Also notable, despite presence of chronic illness and high frailty scores, only 20% of patients had PCC, even when 44% of patients indicated they needed more resources at home to help prevent hospitalization. In sum, the study revealed a dissonance between reported understanding of PC, compared to objective utilization (Woods et al., 2020).

Healthcare organizations can learn ways to optimize PCR by implementing a trigger system at diagnosis to ensure referral decision is not solely dependent on the order of a physician, because PC and curative care can, and should occur in tandem (Figure 6). To ensure comfort, function, and support for patients in this cohort, patients and their families must be able to understand their diagnosis, patterns of disease progression, symptom management, as well as the resources available to help. Identifying if a relationship exists between variables in this study will provide evidence educators can use to shift perceptions of nurses, physicians, and healthcare systems about the paramount need for early PCC.

In addition, healthcare organizations can use evidence presented in this study to create referral protocols and criteria. It will present the opportunity for health systems to understand the monetary value of investing in PC teams; this can increase patient satisfaction, quality of life, and educate the profession about the different ways to address health disparities and vulnerable populations. Dissemination of results from this study will add to the body of knowledge and propel the profession of nursing forward in the development of a robust PC curriculum for both graduate and undergraduate nursing programs. Given nurses are at the forefront of any direct patient improvement effort; PC education will equip bedside nurses to be prepared for difficult conversations.

Figure 6

Appropriate Initiation of PC Interventions



Note: Initiation of PC in tandem with standard oncology care.

CHAPTER II

Review of Literature

To ensure a detailed review of the literature the following steps were utilized. An electronic search of public databases and journal articles was conducted utilizing the following criteria. **Search Criteria.** Cumulative Index of Nursing and Allied Health Literature (CINAHL), Google Scholar, and PubMed were utilized to locate pertinent literature about the subject of transitions in PC in patients with colon, rectal, and lung cancer, the relationship between time of PCC and healthcare utilization in this patient cohort. These databases were searched using the Boolean phrase: palliative care referral, palliative care consultation, and healthcare utilization, lung cancer, colon cancer, rectal cancer, palliative care referral time to death, and early palliative care. Given the peculiarity of findings in this study, the term “different names of PC” was also included in the search for articles, as well as “perspectives about PC.” Search criteria included articles in journals, written in English, adult patient population, and full text available. Duplicates were removed from the results, and articles found were further screened to include factors that reflect the variables of this study in this patient cohort.

After completing an electronic database search, manual searches were performed from the reference list of some of the pertinent articles to further assist in the inclusion of a robust review. Research articles and studies found include systematic reviews, non-experimental, randomized clinical trials, qualitative and retrospective studies. This literature review focused primarily on the cancer landscape in the United States, although, a few corroboratory international articles were included. For this study, Palliative Care Referral (PCR) was utilized as a search term, in addition to Palliative Care consultation (PCC) because in the treatment trajectory, consultation does not often occur without a referral; sometimes, even with a referral, consultation may still not occur. Also, there exists some variance in the literature where studies indicate PCR but evaluate PCC. To address this, operational definitions have been provided later in this chapter.

Impact of Early Palliative Care Referral and Consultation

The influence of PCC time on healthcare utilization and patient quality of life cannot be underestimated. The Center to Advance Palliative Care (capc.org, 2018) states, PC reduces patient distress symptoms by 66%, drives high satisfaction and positive patient experiences by 93%, and reduces inpatient readmissions by 48%. Several studies have attempted to examine its impact and barriers to appropriate timing. Dunn et al. (2018) attempted to test the hypothesis that PC consultation (PCC) would be associated with reduced HCU for individuals in the last 2 months of life. Their study results found, for 92 veterans with PCC and interventions, lower emergency department and ICU admissions in the last 2 months of life. In a descriptive study using retrospective hospital data, Bharadwaj et al. (2016) measured the impact of early PC interventions on length of stay, readmissions, mortality, and intensive care unit (ICU) days. This study was conducted among seven hospitals and identified: PC services within 48 hours of hospitalization resulted in a shorter admission by 5 days, with decreased readmissions at 30, 60, and 90 days after a PC consult (61.5%, 47.0%, and 42.1%, respectively). Length of stay for the ICU patient also decreased by 1.5 days, with at least 40% in reduced cost to the patient.

Similarly, Delisle et al. (2019) in their retrospective study sought to illustrate the association between timing of PC and healthcare cost, utilization, and in-hospital deaths in patients with colorectal cancer. Timing of PC was defined as no involvement, late involvement (less than 14 days before death), early involvement (14 to 60 days before death), and very early involvement (> 60 days before death). The primary outcome was in-hospital deaths and EOL health care costs. Results from this study indicated patients with early PCC had significantly decreased odds of in-hospital death, decreased hospital cost, and lower healthcare utilization. Thus, integrating PC early with standard oncology care can improve patient quality of life. However, PC is progressively utilized late in the illness trajectory. Salins et al. (2016) sought to answer the question "does integration of early specialist palliative care in cancer care influence patient-related outcomes?" Their review of evidence revealed improvements in health-related quality of life (HRQOL), mood, depression, anxiety, and symptom control. Further, patients were better informed about EOL and made informed Advance Care Planning decisions.

Results from these studies support aggressive EOL measures are an inefficient use of healthcare resources, coupled with late PC integration. To this extent, Bhulani et al. (2018) surveyed cancer patients with PC and without PC. Of the 54,130 patients surveyed, 3,166 (5.8%) received PCC and 70% received it in the last 30 days of life. PC offered close to the end of life was not associated with reduced health care utilization or cost. The use of aggressive interventions in the last weeks of life indicates poor-quality care and has now been incorporated into the National Quality Forum and the American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative to serve as benchmarks to assess the quality of end-of-life care (Hui et al., 2014). In their retrospective study, Hui et al. (2014) sought to identify the association between timing of PCR and quality of EOL. Results indicated only 33% had early PCR (> 3 months before death). Earlier PCR was associated with fewer emergency room visits (39% vs 68%; *p* < .001), fewer hospitalizations (48% vs 81%; *p* < .003), and fewer hospital deaths (17% vs 31%; *p* < .004) in the last 30 days of life.

Temel et al. (2010, 2017) conducted a phase III randomized, controlled, single institution, nonblinded study with patients (*N* = 151) newly diagnosed with metastatic Non-Small Cell Lung Cancer (NSCLC). Patients were randomly assigned to early PC with standard oncology care or to standard oncology care. Results from the study indicated patients assigned to the PC intervention group had significantly higher QOL scores compared to patients receiving standard oncology care alone (*p* = .03). This classic study also demonstrated the palliative intervention group had fewer depressive symptoms (*p* = .01), as well as less aggressive EOL care (*p* =.05). Surprisingly, despite less aggressive EOL care, patients in the PC intervention group survived 2.7 months longer than those receiving standard oncology care alone. The patients with concurrent PC understood their ultimate prognosis and incurability more clearly as time went on, and those who understood their prognosis received less chemotherapy near the EOL.

The WHO (2014) describes PC as relevant early in the course of illness irrespective of curative or supportive care and interventions. Supporting PC for patients with life limiting chronic illnesses, the American Nurses Association (ANA, 2017) recommends discussions of PC should begin at diagnosis of a chronic illness. Corroborating with these sentiments, Smith et al. (2012) advocate for integration of PC in standard oncology care, stating patients with advanced cancer should receive dedicated PC services early in the disease course in addition to active curative treatment. Current research proposes the persistent need to improve access to PC, which includes better recognition of the need for PC, early referral time, early consultation, as well as the use of screening instruments and a referral criterion. A trigger system to refer patients with cancer will also aid in removing the dependence of PCR on clinicians, as this is often discretionary early in the illness trajectory. Although there is currently no description of essential components of highly successful concurrent standard oncologic care and PC, attempts are ongoing. Nonetheless, the key tenets of PC include open and honest communication about diagnosis, prognosis, medical appropriate goal setting, and symptom management. With that in mind, a good working list of components for healthcare organizations might include the following: a description of the diagnosis; an open and honest discussion of the prognosis (with a reasonable forecast of survival) and curability; including explicit discussion of the medically appropriate goals of treatment, and the possibility of frequent hospitalization. This will ensure patients are well informed to make decisions pertaining to their care; the staple of true patient-centered care. It must be pointed out there exists a variation in the definition of the term "early" as it relates to PCR and PCC. It ranged from time of diagnosis to advanced disease, to discontinuation of active treatment, and even death. This poor definition leaves PCR to clinician discretion; individual interpretation of the term "early" leads to complications in the referral and consultation process. Attached is a table with other studies indicating the role of early PCC (See Appendix 1).

Factors Complicating Early Palliative Care Referral and Consultation

Education. Emphasizing the pressing need to improve EOL care, the Institute of Medicine (IOM) in its report *Dying in America* stated there is insufficient knowledge about PC among clinicians who care for patients with advanced illness (IOM, 2014).

Marcella (2009) in a scoping review found three themes complicating transition to PC: Timing of transition, intrinsic nature of transition, and a lack of information surrounding transition to PC. According to her review, a survey of public perceptions of PC in Canada indicated only 50% of survey respondents had heard about PC. Upon further inquiry, only a third of the 50% could give some form of an accurate description of PC. Evident in the review of literature is the need to improve nursing education about PC, as well as documented patient experience in PC to understand the voice of the patient because each experience is multifaceted, complex, and non-linear.

Ronaldson and Devery (2001) posit patients need clear, honest, and understandable information at the point of diagnosis and transition to PC. Their qualitative study revealed a discrepancy between the pace of the referral process for the patients and the pace in the healthcare system. Themes in the study revealed events in the healthcare system often overtake the need for patient referral to PC and education due to increased pressure to discharge patients, a culture of aggressive curative care, and the need for available beds. This accounts for a lack in prognostic awareness, understanding of diagnosis, and the need for advance care planning. Also noteworthy, nurses stated patients were not often included in the decision for referral or lack of referral to PC, stating the patients were “talked into it”. This depicts a lack of education about the services PC offered, and resources available, posing more difficulty for patients who are already vulnerable (Ronaldson & Devery, 2001).

Perceptions of Palliative Care. Another confounding factor is misconstruing PC means Hospice, giving patients and clinicians the connotation that treatment must stop. Maciasz et al. (2013) assessed if the term PC affected patient views; by randomly surveying 169 patients with advanced cancer in 4 comparison groups: “supportive care vs PC, and patient-centered vs traditional.” Compared to PC, the term “supportive care” was associated with a better understanding, left a more favorable impression, and higher future perceived need of the service. Surprisingly, there were no difference in outcomes between “patient-centered vs traditional care.” Suffice to say, efforts to integrate PC in standard oncology care might require changing patient impressions through education, classes for patients with advanced cancer, or substituting the term PC. Similarly, Dalal et al. (2011) assessed the perception of PC by oncology professionals and its limitation on PCR specifically. After a name change from PC to “supportive care,” there was a 41% increase in PCC, mainly due to an increase in inpatient PCR. In addition, the study revealed a shorter duration from hospital registration to PCR, from advanced cancer diagnosis to PCR, and an overall survival rate from PCR. Supportive care was associated with more PCR.

Sorensen et al. (2019) conducted a survey to assess the opinions of specialized PC physicians to determine the characteristics associated with receiving early PCR, and to inquire their position about renaming PC to “supportive care.” Greater than 90% of the 71 physicians who responded supported early PCR in oncology and had a referral criterion; but only 20% received early referrals (with > 6-month prognosis). About 39% of these physicians also believed a name change would encourage early PCR. Zimmermann et al. (2016) surveyed patients and their caregivers to assess their attitudes about PC. Their study included a cluster randomized trial of early PC versus standard care. A total of 48 patients and 23 caregivers completed the interviews, indicating their initial perceptions of PC were of death, hopelessness, and EOL comfort care.

Surprisingly, patients stated their fears and perceptions about PC originated from interactions with clinicians. Nonetheless, patients in the intervention group developed a different perception of PC as “ongoing care” but required better explanations from clinicians.

As a result of the negative stigma of the name PC, health systems attempt to alter patient and family perceptions by using alternative terms, instead of ensuring proper patient and clinician education. As organizations put forward these varieties of terms without conceptual or functional definitions, interpretations of PC become problematic for both clinicians, patients, and families. This variance in terminology, combined with a lack of education and clarification further muddles the message about PC, deepens the divide, gap in knowledge, and complicates the referral process. For patients, it blurs the importance of the transitions points they may experience.

Conceptual Definitions

According to Polit and Beck (2021), concepts are abstract, and conceptual definitions present meaning of concepts used specific to a study. The following definitions are provided to clarify terminology within the context of this study.

Palliative care referral (PCR). Referral for the purpose of this study entails entering a provider (oncologist, general medicine, primary care) order for patient consultation with a palliative care physician or nurse.

Palliative Care Visits/Consult (PCC). Consultation between patients and palliative care physicians or palliative care registered nurses for goals of care discussions, initiation of PC services, interventions, and patient-specific resource determination.

Healthcare Utilization (HCU). Number of hospital visits- emergency department (ED) visits, clinic visits, acute care inpatient LOS (in days), and intensive care unit (ICU) LOS (in days).

Place of Death. Location of patient’s death i.e.-hospital, skilled nursing facility, hospice facility, patient's own home, unknown, etc.

Advanced Illness Management (AIM). A term used by healthcare systems tantamount to PC. For this study, AIM order and consult has been combined with PC order and consult. The responsibilities of both groups are the same, irrespective of the name difference.

Zip-Code. A postal code is utilized by the post office to identify geographic areas. This variable was initially used to examine access to PC.

CHAPTER III

Methodology

The purpose of this study was to examine the relationship among select socio-demographics, participant clinical characteristics, PCC time, healthcare utilization, and PCC to death for patients with PCC compared to no PCC, in a cancer patient cohort at an advanced stage in their disease process. In this chapter, the design, procedures, and protection of human subjects are presented.

Study Aims

Specific aims of the study are:

Aim I. Describe select demographic (age, gender, race/ethnicity, marital status, insurance status, socio-economic status), healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), place of death, time between PCC and death, time from diagnosis to PCC, and time from diagnosis to death among a sample of Stage III and IV colon, rectal, and lung cancer patients receiving care from a large urban Southern California healthcare system

Aim II. Examine the relationships among select demographic, clinical characteristics, healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), place of death, time between PCC and death, time from diagnosis to PCC, and time from diagnosis to death.

Aim III. Identify differences between select demographics, clinical characteristics, healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), place of death, time between PCC and death, time from diagnosis to PCC, and time from diagnosis to death.

Aim IV. Identify the amount of variance accounted for by select demographics, clinical characteristics, healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), place of death, time between PCC and death, time from diagnosis to PCC, and time from diagnosis to death

Study Design

A retrospective descriptive correlational design was used to examine the relationship among healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits), PCC time, place of death, time between PCC and death, and time of diagnosis. According to Plichta, Kelvin, and Munro (2013), descriptive studies have the primary purpose to describe the relationships between variables. The researcher collects information about study participants past or future status regarding variables of interest without interventions. This study is non-experimental, with the main purpose being to elucidate the relationship, rather than to support inferences of causality. Data for this study were collected retrospectively.

Sample and Setting

Sample. Data were obtained from a convenience sample of adults receiving health care services at a non-profit, Magnet® recognized, a healthcare system in Southern California. The community hospital system is an integrated, regional health care delivery system that originated in the early 1950s with a single hospital funded by a donation dedicated to Veterans. This system expanded to serve the community to include four acute care hospitals; three specialty hospitals; three affiliated medical groups; 24 medical centers; five urgent care centers; three skilled nursing facilities; two inpatient rehabilitation centers; home health, hospice, and home infusion programs; numerous outpatient facilities and programs; and a variety of other community health education programs and related services. Two of the four acute care hospitals are Magnet designated. The healthcare system also offers individual and group Health Maintenance Organization (HMO) coverage. Serving a population of approximately 3.3 million in Southern California, in 2017 this Healthcare System was licensed to operate 2,084 beds and had more than 2,600 affiliated surgeons and 18,000 employees.

Procedure. Data were extracted from 95 patients' EHR for the 2019-2020 calendar year. Inclusion Criteria. Decedent adults ages 21 years and older with a diagnosis of stage III and IV colon, rectosigmoid junction, bronchus, or lung cancer. Exclusion Criteria. Patients who did not meet inclusion criteria.

Sample Size Calculation. Several methods were used to estimate sample size. Using Tabachnick and Fidell's (2013) recommendation of $N > 50 + (8 \text{ x } m)$, we estimated a minimum sample size of $N = 139$ total participants with 15 predictor variables. An a priori power analysis was also conducted using G*Power 3.1 (Faul, Erdfelder, Lang, & Buchner, 2007) to test the difference between two independent group means using a two-tailed test, a medium effect size ($d = .50$), and an alpha of .05. Results showed a total sample of 139 participants with two approximately equal-sized groups of $n = 69$ was required to achieve a power of .80 with 15 predictor variables. For this study, total sample size was 95, below the sample size recommendation, requiring mostly non-parametric tests.

Measurement

The following are the independent variables analyzed for this study:

- PC and AIM Consultation

- PC and AIM order
- Days from Diagnosis to PCC
- Days from PCC to Death
- Stage III and IV diagnosis of colon, rectal (rectosigmoid junction), lung (bronchus) cancer
- Age-measured in years
- Gender-male/female
- Zip Code
- Race/Ethnicity
- Length of Stay-measured in days
- Discharge Disposition
    - Short-term acute care rehabilitation facility
    - Home/Self-care (routine)
    - Death
    - Home Health Service

The following are the dependent variables analyzed for this study:

- Time from diagnosis to PCC
- Time from PCC to death
- Time from diagnosis to death (for patients with PCC compared to those with no PCC)
- Utilization of healthcare services (ED visits, ICU LOS, Acute care LOS, clinic visits) for participants with PCC compared to those with no PCC.

Protocol and Procedure

Data Acquisition

Data collection and extraction occurred retrospectively. Health system leaders provided input on the best means of data collection based on their knowledge and relationship with said data, and health system analyst pulled data from EHR; data was then shared with the principal investigator via secured email. Using a master code list, data management began by deidentifying participants PHI to maintain privacy, confidentiality and limit the risk of unintentional sharing of PHI.

Analytic Approach

SPSS Statistics version 28 software was used for statistical analysis. The study aims, research questions, independent and dependent variables, and instruments of measurements were influenced by selected statistical tests to be performed. Descriptive statistics selected included the use of frequency distribution (cases and percentages) for categorical variables and measures of central tendencies (mean and standard deviation) and dispersions for continuous variables. Inferential statistics selected included the use of non-parametric tests to examine variance and explain relationships between variables.

Aim I. To address AIM I, descriptive statistics will be utilized to describe the sample and clinical characteristics.

Aim II. To address AIM II, Chi-Square test for independence and independent-sample t-test will be used to examine the strength of the relationship between variables.

Aim III. To address AIM III, Mann-Whitney U test will be utilized, given significant outliers and small sample size.

Aim IV. To address AIM IV, Kruskal-Wallis H test, Pearson’s or Spearman’s rho correlations, and Mann-Whitney U tests will be used to assess for variance between variables.

Human Subjects Protection

Institutional Review Board (IRB) approval for the protection of human subjects was obtained from the health system and the University of San Diego. There were minimal risks with this study, given retrospective analysis of secondary data. This study met exempt status per the University of San Diego IRB and the healthcare system IRB. Howbeit, coding of the sample was performed to minimize the risk of unintentional sharing of PHI.

CHAPTER IV

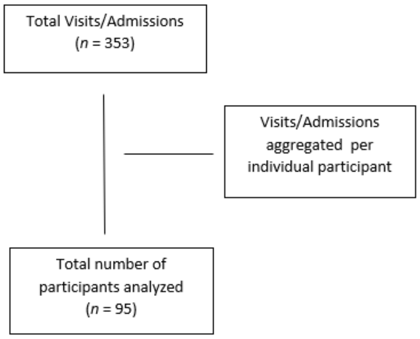
Results

The purpose of this study was to examine the relationships among PCC, healthcare utilization, select socio-demographics, and death among a sample of decedent patients diagnosed with Stage III and IV colon, rectal, and lung cancer, who received care from a large urban Southern California healthcare system. The primary outcomes of this study are a) time from initial diagnosis to PCC, b) time from first PCC to death, c) time from diagnosis to death, and d) utilization of healthcare services (ED, clinic, and inpatient visits) for those who got PCC compared to those who did not get PCC. The results are presented in this chapter for each specific aim.

Sample Characteristics. A total of 353 visits/admissions were provided and identified. Further analysis noted the sample was comprised of 95 individuals with multiple visits/admissions to various facilities (within the same healthcare system) post-diagnosis. A decision was made to analyze the data per individual and average visits/admissions per individual (Figure 7). For this study, *n* = 95 refers to the total number of individuals included in this study and represents individual cases for calendar year 2019-2020.

Figure 7

Analysis of Hospital Admissions/visits



Research Aim 1

The first aim was to describe variables in the study sample. These variables include select socio-demographics: age, gender, race/ethnicity, marital status, PCC location (facility where PCC occurred), insurance status, and zip code. Clinical characteristics include cancer site, stage of cancer diagnosis, healthcare utilization (ED visits, ICU LOS, Acute care LOS, clinic visits, visit type; calculated for all visits and post PCC visits) in patients with PCC vs no PCC, discharge disposition (at first visit and visit when PCC occurred), number of participants with PCC (at first visit and all visits during the study period), PC order (at first visit and all visits), location of death, time from initial diagnosis to first PCC, number of visits before first PCC, and time between first PCC and death, among a sample of Stage III and IV oncology patients receiving care from a large urban Southern California healthcare system.

Table 1 presents a description of study sample (*N* = 95). Mean age (in years) of the sample at stage III or IV diagnosis was 69.2 (*SD* = 13.18), evenly distributed by gender; 48.4% (*n* = 46) female, 51.6% (*n* = 49) male, with 50% (*n* = 47) married. The sample was diverse: White (41.1%, *n* = 39), “other” race (18.9%, *n* = 18), Asian (17.9%, *n* = 17), Hispanic (14.7%, *n* = 14), and African American (7.4%, *n* = 7). The most common type of insurance carrier at first visit was Medicare (57%, *n* = 53), followed by MediCal (21.5%, *n* = 20), and commercial coverage (21.5%, *n* = 20, Figure 8). Surprisingly, insurance carrier changed by the time of the first PCC visit: Medicare 56.6% (*n* = 47), MediCal 18.1% (*n* = 15), and commercial insurance 25.3% (*n* = 21, Figure 9). Essentially, fewer people used Medicare and MediCal at the time of first PC consult. Participants were evenly distributed across Central (26.7%, *n* = 24), East (24.4%, *n* = 22), North Central (21.1%, *n* = 19) and South (20%, *n* = 18) zip codes of San Diego County. Less than ten percent lived in North Coastal (1.1%, *n* = 1) and North Inland (4.4%, *n* = 4) zip codes or outside San Diego County (2.2%, *n* = 2). Diagnoses of lung and bronchus cancer were grouped as one category; rectosigmoid junction and colon were grouped together as well. The most common type of cancer was bronchus/lung cancer, accounting for 74.7% (*n* = 71) of the sample; colon, rectosigmoid junction sample 25.3% (*n* = 24). Eighty percent (*n* = 76) of the participants had been diagnosed with stage IV and 20% (*n* = 19) stage III cancer.

Location where participants were first seen as cancer patients included: emergency department 13.7% (*n* = 13), inpatient 69.5% (*n* = 66), and outpatient 16.8% (*n* = 16). Most first PC consultations occurred in the inpatient setting (76.5%, *n* = 65). During patients' first visits, 36.8% (*n* = 35) had a PC order, at the end of the study period, 91.6% (*n* = 87) had a PC order. Similarly, during patients' first visit 34.7% (*n* = 33) had a PCC, and at the end of the study period, 89.5% (*n* = 85) had a PCC. Discharge disposition for the first visit was notable, 34.7% (*n* = 33) of participants died, 65.3% (*n* = 62) were alive after the first visit; with 48.4% (*n* = 46) of participants who survived the first visit being discharged home, 10.5% (*n* = 10) to a home health service, 2.1% (*n* = 2) admitted to inpatient hospice, 3.2% (*n* = 3) discharged to a short-term acute care facility, and 1.2% (*n* = 1) discharged to a skilled nursing facility. After the first PCC, discharge disposition indicated remarkable changes including: 42.4% (*n* = 36) discharged home and 9.4% (*n* = 8) discharged home with home health service. Notably, 41.2% (*n* = 35) of participants died after the first PCC occurred regardless of when the visit happened (Figure 10). Of this number, only 85.7% (*n* = 30) got PCC, considering imminent death; 14.3% (*n* = 5) still did not get PCC (Table 1).

Over half 57.6% (*n* = 49) of all PCC occurred at site 3 (Table 2), 23.5% (*n* = 20) occurred at site 2, and 18.8% (*n* = 16) occurred at site 1. In congruence with existing research, there was a decrease in HCU; prior to PCC, the average number of ED, hospital, and clinic visits during the study period was 3.72 (*SD* = 5.35); however, after PCC, the average number of ED, hospital, and clinic visits was drastically reduced to an average of 0.16 visits. Likewise, the average acute care LOS (in days) for the study period was 6.97 (*SD* = 6.76); but after PCC, average number of days was reduced to 0.76 (*SD* = 2.67). Average intensive care unit (ICU) LOS for the study period was 4.55 (*SD* = 5.40); and after PCC it was 0.51 (*SD* = 0.51). The average time from the first PCC to death was about 10 days (*SD* = 23.03), indicating PCC interventions occurred close to death. Moreover, the average time (in days) from initial diagnosis to first PCC was 452.26 (*SD* = 687.42) days. Given most participants had multiple ED, hospital, and clinic visits throughout the study period, a set of timepoints were selected to determine the visit number when the first PCC occurred. About 58% (*n* = 49) of participants had their first PCC at visit 1, 9.4% (*n* = 8) at visit 2, 12.9% (*n* = 11) at visit 3, 5.9% (*n* = 5) at visit 4, 3.5% (*n* = 3) at visit 5, and 10.6% (*n* = 9) at visit 6 or more (Figure 11), also indicative of a late integration of PC interventions and services. Location of death includes: 22.1% (*n* = 21) died in a facility, and 77.9% (*n* = 74) died at an unknown location.

Figure 8

Insurance Use at Visit 1

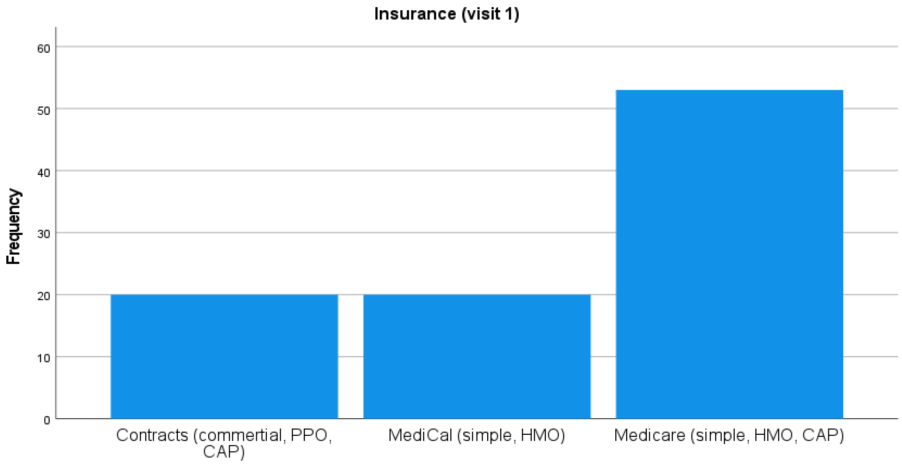


Figure 9

Insurance Use at First PCC

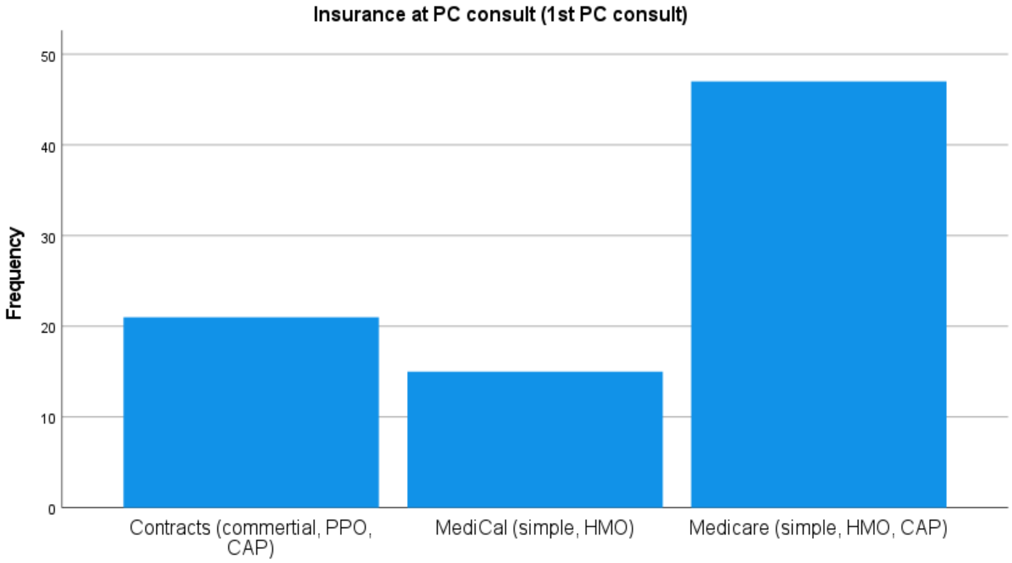


Figure 10

Discharge Disposition After First PCC

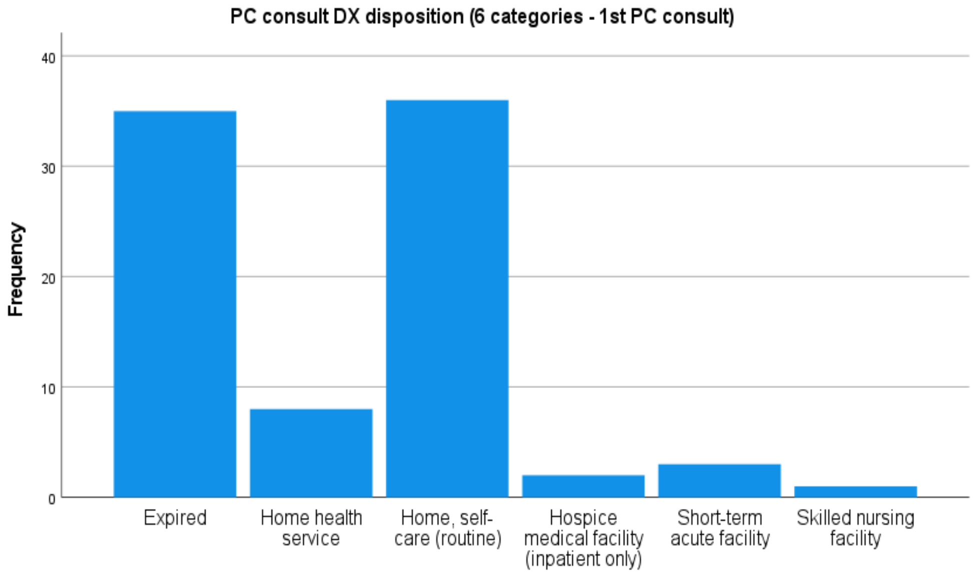


Figure 11

Participant Visit at First PCC

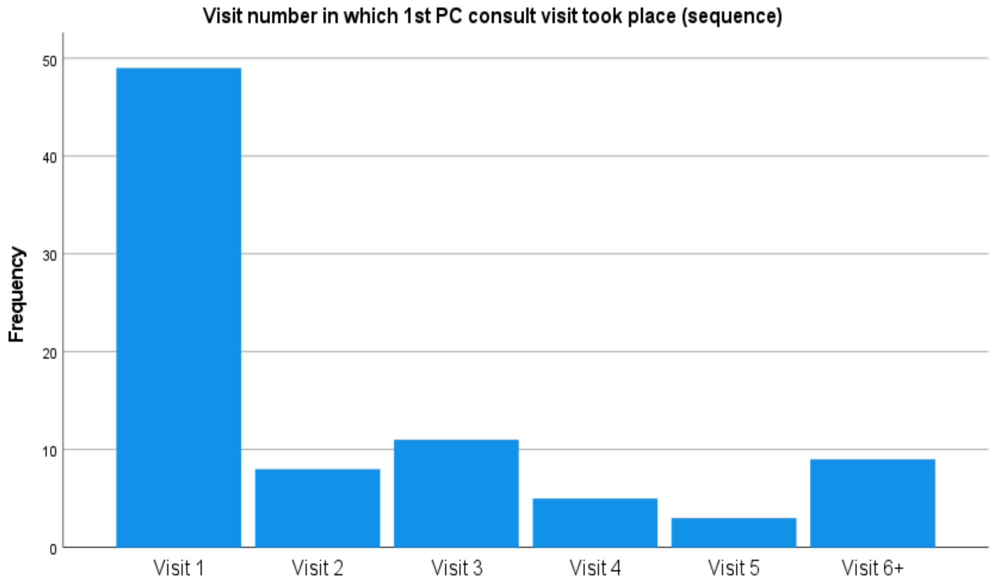


Table 1

Sociodemographic and Clinical Characteristics, Health Care Utilization, and Palliative Care Services Utilization of Study Population Overall and by Palliative Care Consult at Visit 1 (N = 95)

	Total		***PC Consult***		***No-PC Consult***			
Characteristic	***n***	***%***	***n***	***%***	***n***	***%***	χ^2	***p***
Gender							0.04	.830
Male	49	51.6	18	36.7	31	63.3		
Female	46	48.4	15	32.6	31	67.4		
Race							0.59	.989
White	39	41.1	14	35.9	25	64.1		
Black, African American	7	7.4	2	28.6	5	71.4		
Hispanic	14	14.7	4	28.6	10	71.4		
Asian	17	17.9	6	35.3	11	64.7		
Other Race	18	18.9	7	38.9	11	61.1		
Marital Status							3.95	.409
Married	47	50.0	14	29.8	33	70.2		
Single	23	24.5	8	34.8	15	65.2		
Divorced	6	6.4	3	50.0	3	50.0		
Separated	4	4.3	3	75.0	1	25.0		
Widow, widower	14	14.9	5	35.7	9	64.3		
Zip Code								
Central	24	26.7	7	29.2	17	70.8		
East	22	24.4	9	40.9	13	59.1		
North Central	19	21.1	5	26.3	14	73.7		
North Coastal	1	1.1	0	0.0	1	100.0		
North Inland	4	4.4	3	75.0	1	25.0		
South	18	20.0	6	33.3	12	66.7		
Outside SD County, Out of State	2	2.2	1	50.0	1	50.0		
Cancer Diagnosis							1.15	.219
Bronchus, Lung	71	74.7	22	31.0	49	69.0		
Colon, Rectosigmoid junction	24	25.3	11	45.8	13	54.2		
AJCC Stage							< .001	> .999
Stage III	19	20.0	7	36.8	12	63.2		
Stage IV	76	80.0	26	34.2	50	65.8		
PC Order at Visit 1[a]							82.57	**< .001**
Yes	35	36.8	33	94.3	2	5.7		
No	60	63.2	0	0.0	60	100.0		

	Total		***PC Consult***		***No-PC Consult***			
Characteristic	***n***	***%***	***n***	***%***	***n***	***%***	χ^2	***p***
PC Order at Remaining Visits (*n* = 62)[b]							10.53	**< .001**
Yes	52	83.9	0	0.0	52	100.0		
No	10	16.1	3	30.0	7	70.0		
PC Order for All Study Visits							3.13	**.047**
Yes	87	91.6	33	37.9	54	62.1		
No	8	8.4	0	0.0	8	100.0		
PC Consult at Visit 1							--	--
Yes	33	34.7	--	--	--	--		
No	62	65.3	--	--	--	--		
PC Consult at Remaining Visits							10.79	**.001**
Yes	54	77.1	2	3.7	52	96.3		
No	16	22.9	6	37.5	10	62.5		
PC Consult for All Study Visits							4.36	**.013**
Yes	85	89.5	33	38.8	52	61.2		
No	10	10.5	0	0.0	10	100.0		
Insurance at Visit 1							1.50	.462
Contracts (comm,, PPO, CAP)	20	21.5	6	30.0	14	70.0		
MediCal (simple, HMO)	20	21.5	5	25.0	15	75.0		
Medicare (simple, HMO, CAP)	53	57.0	21	39.6	32	60.4		
Insurance at 1st PC Consult							1.73	.434
Contracts (comm,, PPO, CAP)	21	25.3	6	28.6	15	71.4		
MediCal (simple, HMO)	15	18.1	5	33.3	10	66.7		
Medicare (simple, HMO, CAP)	47	56.6	21	44.7	26	55.3		
Visit Location at Visit 1							25.26	**< .001**
ED	13	13.7	0	0.0	13	100.0		
Inpatient	66	69.5	33	50.0	33	50.0		
Outpatient	16	16.8	0	0.0	16	100.0		
Visit Location of 1st PC Consult							18.12	**< .001**
ED	9	10.6	0	0.0	9	100.0		
Inpatient	65	76.5	33	50.8	32	49.2		
Outpatient	11	12.9	0	0.0	11	100.0		

Characteristic	*Total*		*PC Consult*		*No-PC Consult*		χ^2	*p*
	n	***%***	***n***	***%***	***n***	***%***		
Facility at Visit 1							0.57	.754
Site 1	21	22.1	8	38.1	13	61.9		
Site 2	29	30.5	11	37.9	18	62.1		
Site 3	45	47.4	14	31.1	31	68.9		
Facility of 1st PC Consult							10.75	**.004**
Site 1	16	18.8	8	50.0	8	50.0		
Site 2	20	23.5	13	65.0	7	35.0		
Site 3	49	57.6	12	24.5	37	75.5		
Discharge Disposition Visit 1							78.30	< **.001**
Expired	33	34.7	30	90.9	3	9.1		
Home, self-care (routine)	46	48.4	1	2.2	45	97.8		
Home health service	10	10.5	1	10.0	9	90.0		
Hospice (inpatient)	2	2.1	1	50.0	1	50.0		
Short-term acute facility	3	3.2	0	0.0	3	100.0		
Skilled nursing facility	1	1.1	0	0.0	1	100.0		
Discharge Disposition 1st PC Consult							69.21	< **.001**
Expired	35	41.2	30	85.7	5	14.3		
Home, self-care (routine)	36	42.4	0	0.0	36	100.0		
Home health service	8	9.4	1	12.5	7	87.5		
Hospice (inpatient)	2	2.4	1	50.0	1	50.0		
Short-term acute facility	3	3.5	0	0.0	3	100.0		
Skilled nursing facility	1	1.2	1	100.0	0	0.0		
Expired During Visit 1							66.63	< **.001**
Yes	33	34.7	30	90.9	3	9.1		
No	62	65.3	3	4.8	59	95.2		
Expired During 1st PC Consult							51.78	< **.001**
Yes	35	41.2	30	85.7	5	14.3		
No	50	58.8	3	6.0	47	94.0		
Location of Death							0.87	.351
In a facility	21	22.1	5	23.8	16	76.2		
Unknown	74	77.9	28	37.8	46	62.2		

	Total		***PC Consult***		***No-PC Consult***			
Characteristic	***n***	***%***	***n***	***%***	***n***	***%***	χ^2	***p***
Visit Number of 1st PC Consult							34.47	**< .001**
Visit 1	49	57.6	32	65.3	17	34.7		
Visit 2	8	9.4	0	0.0	8	100.0		
Visit 3	11	12.9	0	0.0	11	100.0		
Visit 4	5	5.9	0	0.0	5	100.0		
Visit 5	3	3.5	0	0.0	3	100.0		
Visit 6 or more	9	10.6	1	11.1	8	88.9		
	M	***SD***	***M***	***SD***	***M***	***SD***	***t***	***p***
Age at stage III-IV DX, years	69.28	13.18	71.52	11.50	68.10	13.94	-1.21	.231
	M	***SD***	***n***	***Mean Rank***	***n***	***Mean Rank***	***U***	***P*[d]**
No. ED, HOSP, clinic visits during study period	3.72	5.35	33	21.08	62	62.33	134.50	**< .001**
No. ED, HOSP, clinic visits post PC consult[c]	0.16	0.49	31	39.97	48	40.02	743.00	.986
Acute care LOS during study period, days	6.97	6.76	33	56.80	62	43.31	1313.50	**.023**
Acute care LOS post PC consult, days	0.76	2.67	31	38.44	48	41.01	695.50	.418
ICU LOS during study period, days	4.55	5.40	31	54.79	61	42.29	1202.50	**.033**
ICU LOS post PC consult, days	0.51	1.72	31	37.68	48	41.50	672.00	.211
Time initial DX to 1st PC consult, days	452.26	687.42	33	38.53	52	45.84	710.50	.183
Time 1st PC consult to death, days	10.11	23.03	32	40.05	49	41.62	753.50	.766
Time initial DX to death for those with no-PC consult, days (*n* = 10)	320.60	364.79	--	--	--	--	--	--
Time initial DX to death, days	445.63	660.01	33	43.17	62	50.57	863.50	.212

Note. AJCC, American Joint Commission on Cancer; BSN, bachelor's in nursing science; DX, diagnosis; ED, emergency department; HMO, Health Management Organization; HOS, hospital; ICU, intensive care unit; LOS, length of stay; PC, palliative care; PPO, preferred provider organization; SCV, Site 1; SGR, Site 2; SMH, Site 3; V1, visit 1. Fisher's Exact Test, unless otherwise specified. [a] Visit 1 refers to the 1st ED, hospital, or clinic visit since being diagnosed with stage 3 or 4 cancer at one of the participating hospitals. Visit 1 duration ranges from one to several days, depending on the visit type (ED, hospital, clinic). [b] Excludes participants who expired during Visit 1. [c] Post PC consult does not include the PC consult visit. [d] Asymptotic Sig. (2-sided test).

Research Aim 2

To examine the relationships among select socio-demographics, healthcare utilization, PCC, place of death, time between PCC and death, and time from diagnosis to death for participants with PCC and without PCC. To examine the relationships among categorical variables, a *Chi-square* test of independence was conducted between participants' sociodemographic and clinical characteristics, health care utilization, and PCC (yes, no) at the first visit (ED, clinic, or hospital visit) patients had following a stage III or IV cancer diagnosis (Table 1), and at all visits, participants had prior to death (Table 2). Not all expected cell frequencies were greater than five. Fisher's Exact Tests are reported for all variables unless otherwise specified. Yate's continuity corrections with asymptotic 2-sided significance are reported for 2 x 2 tables.

At the first visit (Table 1) there was a statistically significant association between PCC (at visit 1) and: PC order at visit 1, $\chi^2 = 82.57$, $p = < .001$, *Phi* = .955 large effect size (Cohen, 1988); PC order at remaining visits for ($n = 62$, given 33 participants died in the first visit), $\chi^2 = 10.53$, $p < .001$, *Phi* = .514 large effect; PC order at all study visits, $\chi^2 = 3.13$, $p = .077$, $p = .047$ Fisher's Exact, *Phi* = .221 small effect; PCC at remaining visits, $\chi^2 = 10.79$, $p < .001$, *Phi* = .446 medium effect; PCC at all visits, $\chi^2 = 4.36$, $p = .013$, *Phi* = .250 small effect; visit location at visit 1, Fisher's Exact $\chi^2 = 25.26$, $p < .001$, *Cramer's V* = .484 medium effect; visit location at first PCC (ED, inpatient, outpatient), Fisher's Exact $\chi^2 = 18.12$, $p < .001$, *Cramer's V* = .442 medium effect; facility at first PCC (site 1, site 2, site 3), Fisher's Exact $\chi^2 = 10.75$, $p = .004$, *Cramer's V* = .357 medium effect; discharge disposition at visit 1, Fisher's Exact $\chi^2 = 78.30$, $p < .001$, *Cramer's V* = .873 large effect; expired at visit 1, $\chi^2 = 66.63$, $p < .001$, *Phi* = .861 large effect; expired during visit when first PCC occurred, $\chi^2 = 51.78$, $p < .001$, *Phi* = .805 large effect; visit sequence before first PCC, Fisher's Exact $\chi^2 = 34.47$, $p < .001$, *Cramer's V* = .637 large effect.

Also, at the first visit, the following hypotheses were made: *1a*) Null: number of ED, hospital, outpatient visits during study period will not be significantly different after PCC.*1b*) Alternative: number of ED, hospital, clinic visits during study period will be significantly different after PCC. *2a*) Null: acute care LOS during study period will not be significantly different after PCC. *2b*) Alternative: number of acute care LOS will be significantly different after PCC. *3a*) Null: ICU LOS during study period will not be significantly different after PCC. *3b*) Alternative: number of ICU LOS will be significantly different after PCC. To address these assumptions, an independent sample Mann-Whitney U test was performed at two timepoints (study period, and post PCC). For hypothesis 1, we reject the null hypothesis, given asymptotic $p < .001$; for hypothesis 2, we also reject the null hypothesis given asymptotic $p = .023$; further, for hypothesis 3, we reject the hypothesis as well, given asymptotic $p = .033$. The null hypothesis for the Mann-Whitney U tests assumes the two samples (PCC yes & PCC no) come from the same population; that both groups will have the same median or mean rank due to the assumption the number of visits will be similar for both groups; but because the *p*-value is significant, we reject the null and accept the alternative hypothesis, the means or mean ranks are different.

All ED, Hospital, and Clinic Visits During the Study Period

At all visits (Table 2), there was a statistically significant association between getting a PCC and: race, Fisher's $\chi^2 = 8.28$, $p = .039$, *Cramer's V* = .289 large effect

(Figure 12); PC order (all visits), $\chi^2 = 64.24$, *p* <. 001, *Phi* = .884 large effect; PCC (visit 1), $\chi^2 = 4.36$, Fisher's *p* = .013, *Phi* = .250 small effect; PCC (remaining visits) $\chi^2 = 34.44$, *p* < .001, *Phi* = .750 large effect; facility at first visit, Fisher's $\chi^2 = 6.87$, *p* = .031, *Cramer's V* = .294 medium effect. No other significant associations exist.

Figure 12

PCC vs Race (All Study Visits)

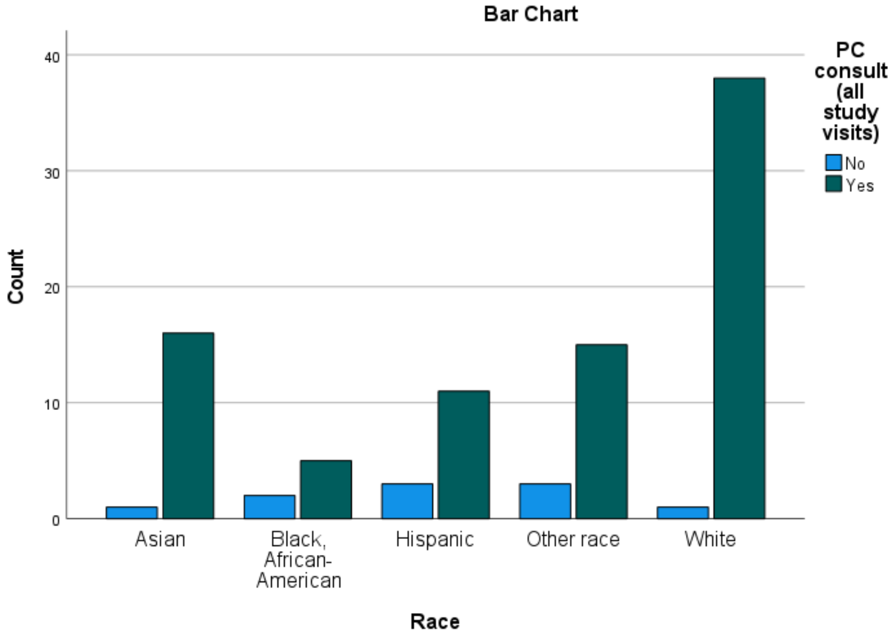


Table 2

Sociodemographic and Clinical Characteristics, Health Care Utilization, and Palliative Care Services Utilization of Study Population Overall and by Palliative Care Consult for All Visits (N = 95)

	Total		*PC Consult*		*No-PC Consult*			
Characteristic	***n***	***%***	***n***	***%***	***n***	***%***	χ^2	***p***
Gender							< .001	> .999
Male	49	51.6	44	89.8	5	10.2		
Female	46	48.4	41	89.1	5	10.9		
Race							8.28	**.039**
White	39	41.1	38	97.4	1	2.6		
Black, African American	7	7.4	5	71.4	2	28.6		
Hispanic	14	14.7	11	78.6	3	21.4		
Asian	17	17.9	16	94.1	1	5.9		
Other Race	18	18.9	15	83.3	3	16.7		
Marital Status							1.40	.865
Married	47	50.0	43	91.5	4	8.5		
Single	23	24.5	20	87.0	3	13.0		
Divorced	6	6.4	6	100.0	0	0.0		
Separated	4	4.3	4	100.0	0	0.0		
Widow, widower	14	14.9	12	85.7	2	14.3		
Zip Code							5.68	.463
Central	24	26.7	23	95.8	1	4.2		
East	22	24.4	17	77.3	5	22.7		
North Central	19	21.1	16	84.2	3	15.8		
North Coastal	1	1.1	1	100.0	0	0.0		
North Inland	4	4.4	4	100.0	0	0.0		
South	18	20.0	17	94.4	1	5.6		
Outside SD County, Out of State	2	2.2	2	100.0	0	0.0		
Cancer Diagnosis							< .001	> .999
Bronchus, Lung	71	74.7	63	88.7	8	11.3		
Colon, Rectosigmoid junction	24	25.3	22	91.7	2	8.3		
AJCC Stage							0.18	.413
Stage III	19	20.0	16	84.2	3	15.8		
Stage IV	76	80.0	69	90.8	7	9.2		
PC Order at Visit 1[a]							2.29	.086
Yes	35	36.8	34	97.1	1	2.9		
No	60	63.2	51	85.0	9	15.0		

	Total		***PC Consult***		***No-PC Consult***			
Characteristic	***n***	***%***	***n***	***%***	***n***	***%***	χ^2	***p***
PC Order at Remaining Visits (*n* = 62)[b]							22.74	**< .001**
Yes	52	83.9	51	98.1	1	1.9		
No	10	16.1	4	40.0	6	60.0		
PC Order for All Study Visits							64.24	**< .001**
Yes	87	91.6	85	97.7	2	2.3		
No	8	8.4	0	0.0	8	100.0		
PC Consult at Visit 1							4.36	**.013**
Yes	33	34.7	33	100.0	0	0.0		
No	62	65.3	52	83.9	10	16.1		
PC Consult at Remaining Visits							34.44	**< .001**
Yes	54	77.1	54	100.0	0	0.0		
No	16	22.9	6	37.5	10	62.5		
PC Consult for All Study Visits							--	--
Yes	85	89.5	--	--	--	--		
No	10	10.5	--	--	--	--		
Insurance at Visit 1							4.15	.125
Contracts (comm,, PPO, CAP)	20	21.5	20	100.0	0	0.0		
MediCal (simple, HMO)	20	21.5	16	80.0	4	20.0		
Medicare (simple, HMO, CAP)	53	57.0	47	88.7	6	11.3		
Insurance at 1st PC Consult							--	--[c]
Contracts (comm,, PPO, CAP)	21	25.3	21	100.0	0	0.0		
MediCal (simple, HMO)	15	18.1	15	100.0	0	0.0		
Medicare (simple, HMO, CAP)	47	56.6	47	100.0	0	0.0		
Visit Location at Visit 1							2.36	.297
ED	13	13.7	13	100.0	0	0.0		
Inpatient	66	69.5	59	89.4	7	10.6		
Outpatient	16	16.8	13	81.3	3	18.8		
Visit Location of 1st PC Consult							--	--[c]
ED	9	10.6	9	100.0	0	0.0		
Inpatient	65	76.5	65	100.0	0	0.0		
Outpatient	11	12.9	11	100.0	0	0.0		

Characteristic	*Total* *n*	*Total* %	*PC Consult* *n*	*PC Consult* %	*No-PC Consult* *n*	*No-PC Consult* %	χ^2	*p*
Facility at Visit 1							6.87	**.031**
Site 1	21	22.1	20	95.2	1	4.8		
Site 2	29	30.5	22	75.9	7	24.1		
Site 3	45	47.4	43	95.6	2	4.4		
Facility of 1st PC Consult							--	--[c]
Site 1	16	18.8	16	100.0	0	0.0		
Site 2	20	23.5	20	100.0	0	0.0		
Site 3	49	57.6	49	100.0	0	0.0		
Discharge Disposition Visit 1							5.57	.320
Expired	33	34.7	30	90.9	3	9.1		
Home, self-care (routine)	46	48.4	5	10.9	45	89.1		
Home health service	10	10.5	1	10.0	9	90.0		
Hospice (inpatient)	2	2.1	2	100.0	0	0.0		
Short-term acute facility	3	3.2	3	100.0	0	0.0		
Skilled nursing facility	1	1.1	0	0.0	1	100.0		
Discharge Disposition 1st PC Consult							--	--[c]
Expired	35	41.2	35	100.0	0	0.0		
Home, self-care (routine)	36	42.4	36	100.0	0	0.0		
Home health service	8	9.4	8	100.0	0	0.0		
Hospice (inpatient)	2	2.4	2	100.0	0	0.0		
Short-term acute facility	3	3.5	3	100.0	0	0.0		
Skilled nursing facility	1	1.2	1	100.0	0	0.0		
Expired During Visit 1							< .001	> .999
Yes	33	34.7	30	90.9	3	9.1		
No	62	65.3	55	88.7	7	11.3		
Expired During 1st PC Consult							--	--[c]
Yes	35	41.2	35	100.0	0	0.0		
No	50	58.8	50	100.0	0	0.0		
Location of Death							0.33	.450
In a facility	21	22.1	20	95.2	1	4.8		
Unknown	74	77.9	65	87.8	9	12.2		

	Total		*PC Consult*		*No-PC Consult*			
Characteristic	*n*	*%*	*n*	*%*	*n*	*%*	χ^2	*p*
Visit Number of 1st PC Consult							--	--[c]
Visit 1	49	57.6	49	100.00	0	0.0		
Visit 2	8	9.4	8	100.00	0	0.0		
Visit 3	11	12.9	11	100.00	0	0.0		
Visit 4	5	5.9	5	100.00	0	0.0		
Visit 5	3	3.5	3	100.00	0	0.0		
Visit 6 or more	9	10.6	9	100.00	0	0.0		
	M	*SD*	*M*	*SD*	*M*	*SD*	*t*	*p*
Age at stage III-IV DX, years	69.28	13.18	69.25	13.37	69.60	12.09	0.08	.937
	M	*SD*	*n*	*Mean Rank*	*n*	*Mean Rank*	*U*	*P*[d]
No. ED, HOSP, clinic visits during study period	3.72	5.35	85	47.61	10	51.35	391.50	.677
No. ED, HOSP, clinic visits post PC consult[e]	0.16	0.49	79	40.00	0	0.0	--	--
Acute care LOS during study period, days	6.97	6.76	85	49.05	10	39.05	514.50	.277
Acute care LOS post PC consult, days	0.76	2.67	79	40.00	0	0.0	--	--
ICU LOS during study period, days	4.55	5.40	82	46.98	10	42.60	449.00	.624
ICU LOS post PC consult, days	0.51	1.72	70	40.00	0	0.0	--	--
Time initial DX to 1st PC consult, days	452.26	687.42	85	43.00	0	0.0	--	--
Time 1st PC consult to death, days	10.11	23.03	81	41.00	0	0.0	--	--
Time initial DX to death for those with no-PC consult, days (*n* = 10)	320.60	364.79	--	--	--	--	--	--
Time initial DX to death, days	445.63	660.01	85	48.09	10	47.25	432.50	.928

Note. AJCC, American Joint Commission on Cancer; BSN, bachelor's in nursing science; DX, diagnosis; ED, emergency department; HMO, Health Management Organization; HOS, hospital; ICU, intensive care unit; LOS, length of stay; PC, palliative care; PPO, preferred provider organization; SCV, Site 1; SGR, Site 2; SMH, Site 3; V1, visit 1. Fisher's Exact Test, unless otherwise specified. [a] Visit 1 refers to the 1st ED, hospital, or clinic visit since being diagnosed with stage 3 or 4 cancer at one of the participating hospitals. Visit 1 duration ranges from one to several days, depending on the visit type (ED, hospital, clinic). [b] Excludes participants who expired during Visit 1. [c] Post PC consult does not include the PC consult visit. [d] Asymptotic Sig. (2-sided test).

Research Aim 3

To identify differences in clinical characteristics, healthcare utilization, place of death, time between PCC and death, time from initial diagnosis to first PCC, and time from diagnosis to death by group (PCC and without PCC). The outcome variable (number of days between cancer stage III or IV diagnosis and PCC) was not normally distributed for each level of the study's categorical variables; outliers existed, with small sample sizes and unbalanced groups. After performing a one-way test between sample analysis of variance assumptions, the non-parametric test option was chosen as the best choice. Therefore, Mann-Whitney U and Kruskal-Wallis H tests were conducted to identify significant differences in the number of days between participants' cancer diagnosis and receiving a PCC, in relation to the other variables (Table 3). With significant differences, post hoc tests were used to determine the groups enhancing the significance.

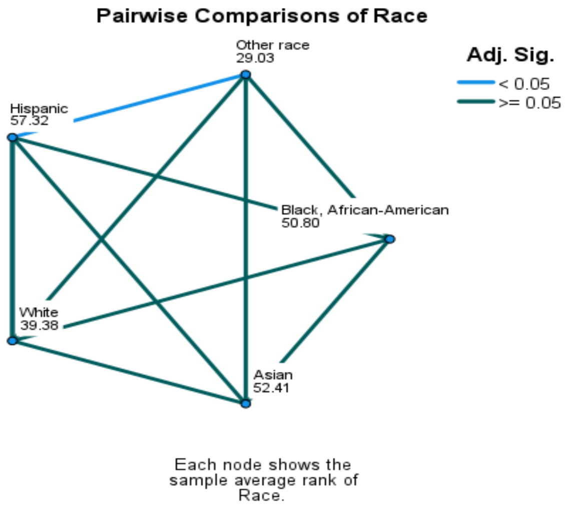
For categorical variables, if significant differences were found, effect size for significant differences (eta squared) was calculated and reported. Mann-Whitney U and Kruskal-Wallis H tests were also conducted to identify if there were significant differences in the number of days between participants' cancer diagnosis and receiving a PCC, and its influence on participants' gender, race, marital status, insurance (at first visit and first PCC), facility (at visit 1 and first PCC visit), zip code, cancer type, AJCC stage, PC order at first visit, PC order for all visits, PCC at first visit, PCC at all visits, visit location (at first visit and first PCC), discharge location (at visit 1 and visit of first PCC), number of visits before first PCC and location of death. Mean ranks were also compared for all variables. Time from cancer diagnosis to PCC varied by race $\chi^2(4) = 12.15$, *Adj. p*

= .016, $\varepsilon^2 = .145$; AJCC stage $U = 325.50$, Adj. $p = .011$, $r = .077$; number of visits $\chi^2(5) = 15.92$, *Adj.* $p = .007$, $\varepsilon^2 = .189$.

Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. The post hoc analysis indicated statistically significant differences in the number of days between a cancer diagnosis and PCC for race in two groups (Figure 13): Hispanic (*Mean rank* = 57.32) and other race (*Mean rank* = 29.03). Distribution scores were not similar.

Figure 13

Sociodemographic and Clinical Characteristics, Health Care Utilization, and Palliative Care Services Utilization of Study Population Overall and by Palliative Care Consult for All Visits (N = 95)



For AJCC cancer stage, the Mann-Whitney U test and Kruskal Wallis were run to determine the significant difference in the days from diagnosis to first PCC. The number of days from cancer diagnosis to PCC are statistically significant *Adj. p* = .011 for participants with stage III (*Mean rank = 57.16*), compared to those with stage IV (*Mean rank = 39.72*) diagnosis. There also exists statistical significance between days from diagnosis to PCC and number of participants visits (visit sequence) to the ED, hospital, or outpatient before first PCC χ^2 (5) = 15.92, *Adj. p* = .007, ε^2 = .189. Pairwise comparison (Figure 14) shows the two groups as visit 1 (*Mean rank* = 35.57) and visit 6 (*Mean rank* = 65.22).

Figure 14

Pairwise Comparison for Visit Sequence

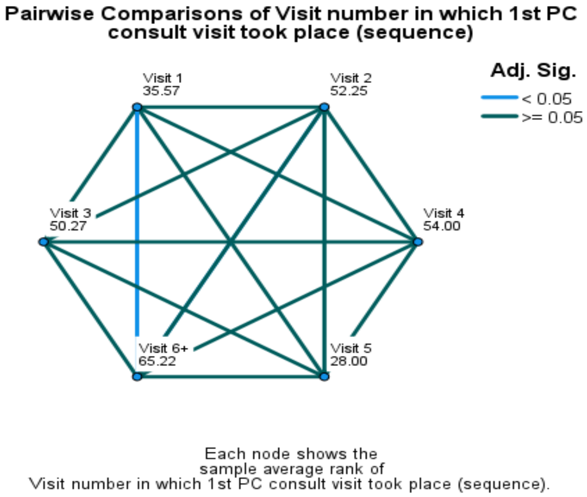


Table 3

Days from Stage III or IV Cancer Diagnosis to Palliative Care Consultation by Study Population Sociodemographic and Clinical Characteristics, Health Care Utilization, and Palliative Care Services Utilization (N = 85)

Characteristic	***n***	***Mean Rank***	***U***	***p***	***r***
Gender			820.50	.473	--
Male	44	41.15			
Female	41	44.99			
	n	***Mean Rank***	***H (df)***	***p***	ε^2
Race			12.15 (4)	**.016**	.145
White	38	39.38			
Black, African American	5	50.80			
Hispanic	11	57.32			
Asian	16	52.41			
Other Race	15	29.03			
Marital Status			9.28 (4)	.054	--
Married	43	50.27			
Single	20	35.03			
Divorced	6	27.17			
Separated	4	30.75			
Widow, widower	12	42.25			
Zip Code			8.14 (6)	.228	--
Central	23	39.96			
East	17	33.59			
North Central	16	44.44			
North Coastal	1	76.00			
North Inland	4	31.38			
South	17	47.12			
Outside SD County, Out of State	2	18.25			
	n	***Mean Rank***	***U***	***p***	***r***
Cancer Diagnosis			845.50	.126	--
Bronchus, Lung	63	40.58			
Colon, Rectosigmoid junction	22	49.93			
AJCC Stage			325.50	**.011**	.077
Stage III	16	57.16			
Stage IV	69	39.72			
PC Order at Visit 1[a]			709.50	.158	--
Yes	34	38.37			
No	51	46.09			

Characteristic	***n***	***Mean Rank***	***U***	***p***	***r***
PC Order at Remaining Visits			91.00	.721	--
Yes	51	27.78			
No	4	30.75			
PC Order for All Study Visits			--	--	--
Yes	85	43.00			
No	0	--			
PC Consult at Visit 1[a]			710.50	.183	--
Yes	33	38.53			
No	52	45.84			
PC Consult at Remaining Visits			234.00	.076	--
Yes	54	31.83			
No	6	18.50			
PC Consult for All Study Visits			--	--	--
Yes	85	43.00			
No	0	--			
	n	***Mean Rank***	***H (df)***	***p***	***ε^2***
Insurance at Visit 1			1.78 (2)	.410	--
Contracts (comm,, PPO, CAP)	20	44.53			
MediCal (simple, HMO)	16	43.09			
Medicare (simple, HMO, CAP)	47	40.55			
Insurance at 1st PC Consult			0.42 (2)	.810	--
Contracts (comm,, PPO, CAP)	21	45.40			
MediCal (simple, HMO)	15	46.83			
Medicare (simple, HMO, CAP)	47	38.94			
Visit Location at Visit 1			3.88 (2)	.144	--
ED	13	51.85			
Inpatient	59	43.29			
Outpatient	13	32.85			
Visit Location of 1st PC Consult			4.81 (2)	.090	--
ED	9	56.33			
Inpatient	65	43.02			
Outpatient	11	32.00			
Facility at Visit 1			0.89 (2)	.641	--
Site 1	20	41.53			
Site 2	22	39.64			
Site 3	43	45.41			
Facility of 1st PC Consult			1.20	.550	--
Site 1	16	38.66			
Site 2	20	40.45			
Site 3	49	45.46			

Characteristic	***n***	***Mean Rank***	***H (df)***	***p***	ε^2
Dis Disposition at Visit 1			6.44 (4)	.169	--
Expired	30	36.82			
Home, self-care (routine)	41	46.89			
Home health service	9	51.89			
Hospice (inpatient)	2	48.25			
Short-term acute facility	3	21.50			
Skilled nursing facility	0	--			
Dis Disposition of 1st PC Consult			7.39 (5)	.193	--
Expired	35	37.67			
Home, self-care (routine)	36	43.51			
Home health service	8	60.00			
Hospice (inpatient)	2	48.25			
Short-term acute facility	3	39.17			
Skilled nursing facility	1	76.00			
	n	***Mean Rank***	***U***	***p***	***r***
Expired During Visit 1			639.50	.088	--
Yes	30	36.82			
No	55	46.37			
Expired During 1st PC Consult			688.50	.096	--
Yes	35	37.67			
No	50	46.73			
Location of Death			664.50	.881	
In a facility	20	43.73			
Unknown	65	42.78			
	n	***Mean Rank***	***H (df)***	***p***	ε^2
Visit Number of 1st PC Consult			15.92	**.007**	.189
Visit 1	49	35.57			
Visit 2	8	52.25			
Visit 3	11	50.27			
Visit 4	5	54.00			
Visit 5	3	28.00			
Visit 6 or more	9	65.22			

Note. AJCC, American Joint Commission on Cancer; BSN, bachelor's in nursing science; DX, diagnosis; ED, emergency department; HMO, Health Management Organization; HOS, hospital; ICU, intensive care unit; LOS, length of stay; PC, palliative care; PPO, preferred provider organization; SCV, Site 1; SGR, Site 2; SMH, Site 3; V1, visit 1. Fisher's Exact Test, unless otherwise specified. [a] Visit 1 refers to the 1st ED, hospital, or clinic visit since being diagnosed with stage 3 or 4 cancer at one of the participating hospitals. Visit 1 duration ranges from one to several days, depending on the visit type (ED, hospital, clinic). [b] Excludes participants who expired during Visit 1. [c] Post PC consult does not include the PC consult visit. [d] Asymptotic Sig. (2-sided test).

Research Aim 4

Identify the amount of variance accounted for by select demographics, healthcare utilization, PCC, place of death, time from diagnosis to PCC, time from PCC to death, and time from diagnosis to death (for participants with PCC and without PCC). To address this aim, two assumptions were made: ***Assumption (a):*** No significant outliers: to determine the impact of outliers on results, the sample size, mean and 5% trimmed mean were considered. ***Assumption (b):*** Bivariate normality: To assess and report the statistical significance of Pearson's correlation coefficient, normality must exist in the sample; this assumption was difficult to assess, given a small sample size. After testing for normality, some variables were found to not be normally distributed and had significant outliers. To find the amount of variance shared by the significantly associated variables the formula r^2 *x 100* was utilized. This helped to identify important variables for the regression model; variables that explained the greatest amount (%) of variance in the outcome.

Kruskal Wallis and Mann-Whitney U tests were conducted because variables did not meet t-test assumptions. The distribution variables for the two groups (PCC vs. No PCC) were similar; therefore, inferences could not be made about the difference between groups. However, when examining the days from PCC to death by study population, and in terms of participants socio-demographics, clinical characteristics, discharge disposition, and sequence of visits; there was a statistically significant association for: zip-code χ^2 (6) = 12.78, $p = .047$, $\varepsilon^2 = .172$ relatively strong effect; facility at visit 1 $\chi^2 =$ 10.78, $p = .005$, $\varepsilon^2 = .135$ moderate effect; facility where first PCC occurred (Figure 15), χ^2 (2) = 10.52, $p = .005$, $\varepsilon^2 = .132$ moderate effect, location of death $U = 820.0$, $p = .020$, $r = .258$. (Table 4).

Figure 15

Pairwise Comparison

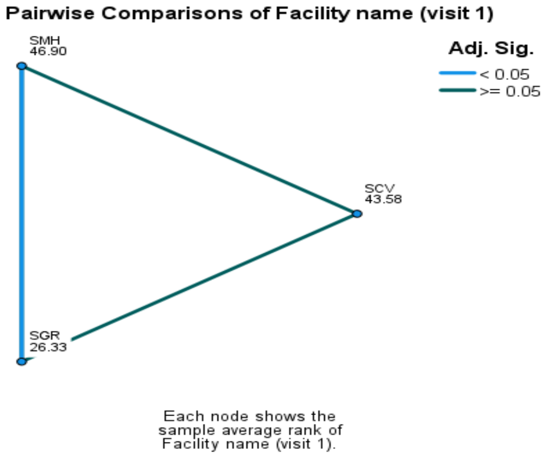


Table 4

Days from Palliative Care Consultation to Death by Study Population Sociodemographic and Clinical Characteristics, Health Care Utilization, and Palliative Care Services Utilization (N = 81)

Characteristic	***n***	***Mean Rank***	***U***	***p***	***r***
Gender			996.00	.094	--
Male	41	45.29			
Female	40	36.60			
	n	***Mean Rank***	***H (df)***	***p***	ε^2
Race			4.19 (4)	.380	--
White	36	37.00			
Black, African American	5	38.20			
Hispanic	11	52.95			
Asian	15	40.40			
Other Race	14	43.54			
Marital Status			4.77 (4)	.312	--
Married	40	45.39			
Single	20	37.08			
Divorced	5	30.00			
Separated	4	50.63			
Widow, widower	12	34.29			
Zip Code			12.78 (6)	**.047**	.172
Central	22	36.18			
East	15	25.57			
North Central	15	45.37			
North Coastal	1	9.00			
North Inland	4	39.13			
South	17	45.76			
Outside SD County, Out of State	2	61.25			
	n	***Mean Rank***	***U***	***p***	***r***
Cancer Diagnosis			616.50	.728	--
Bronchus, Lung	59	41.55			
Colon, Rectosigmoid junction	22	39.52			
AJCC Stage			578.00	.309	--
Stage III	15	35.47			
Stage IV	66	42.26			
	n	***Mean Rank***	***H (df)***	***p***	ε^2
PC Order at Visit 1[a]			769.50	.827	--
Yes	33	40.32			
No	48	41.47			

Characteristic	***n***	***Mean Rank***	***U***	***p***	***r***
PC Order at Remaining Visits			68.00	.333	--
Yes	48	25.92			
No	4	33.50			
PC Order for All Study Visits			--	--	--
Yes	81	41.00			
No	0	--			
PC Consult at Visit 1[a]			753.50	.766	--
Yes	32	40.05			
No	49	41.62			
PC Consult at Remaining Visits			137.50	.685	--
Yes	51	28.70			
No	6	31.58			
PC Consult for All Study Visits			--	--	--
Yes	81	41.00			
No	0	--			
	n	***Mean Rank***	***H (df)***	***p***	***ε^2***
Insurance at Visit 1			4.71 (2)	.095	--
Contracts (comm,, PPO, CAP)	20	49.30			
MediCal (simple, HMO)	15	39.37			
Medicare (simple, HMO, CAP)	44	35.99			
Insurance at 1st PC Consult			4.93 (2)	.085	--
Contracts (comm,, PPO, CAP)	20	49.30			
MediCal (simple, HMO)	14	40.46			
Medicare (simple, HMO, CAP)	45	35.72			
Visit Location at Visit 1			1.56 (2)	.458	--
ED	12	43.50			
Inpatient	56	38.96			
Outpatient	13	47.46			
Visit Location of 1st PC Consult			0.56 (2)	.756	--
ED	9	45.61			
Inpatient	62	39.98			
Outpatient	10	43.20			
Facility at Visit 1			10.78 (2)	**.005**	.135
Site 1	20	43.58			
Site 2	20	26.33			
Site 3	41	46.90			
Facility of 1st PC Consult			10.52 (2)	**.005**	.132
Site 1	16	27.50			
Site 2	0	--			
Site 3	46	32.89			

Characteristic	***n***	***Mean Rank***	***H (df)***	***p***	ε^2
Dis Disposition at Visit 1			1.70 (4)	.792	--
Expired	29	38.72			
Home, self-care (routine)	38	44.30			
Home health service	9	34.83			
Hospice (inpatient)	2	38.25			
Short-term acute facility	3	41.50			
Skilled nursing facility	0	--			
Dis Disposition of 1st PC Consult			8.39 (5)	.136	--
Expired	33	41.05			
Home, self-care (routine)	35	41.73			
Home health service	7	23.79			
Hospice (inpatient)	2	38.25			
Short-term acute facility	3	64.83			
Skilled nursing facility	1	68.50			
	n	***Mean Rank***	***U***	***p***	***r***
Expired During Visit 1			688.00	.512	--
Yes	29	38.72			
No	52	42.27			
Expired During 1st PC Consult			793.50	.988	--
Yes	33	41.05			
No	48	40.97			
Location of Death			820.00	**.020**	.258
In a facility	20	51.50			
Unknown	61	37.56			
	n	***Mean Rank***	***H (df)***	***p***	ε^2
Visit Number of 1st PC Consult			5.06	.409	--
Visit 1	48	39.29			
Visit 2	8	37.25			
Visit 3	10	45.60			
Visit 4	4	27.25			
Visit 5	3	59.00			
Visit 6 or more	8	49.38			

Note. AJCC, American Joint Commission on Cancer; BSN, bachelor's in nursing science; DX, diagnosis; ED, emergency department; HMO, Health Management Organization; HOS, hospital; ICU, intensive care unit; LOS, length of stay; PC, palliative care; PPO, preferred provider organization; SCV, Site 1; SGR, Site 2; SMH, Site 3; V1, visit 1. Fisher's Exact Test, unless otherwise specified. [a] Visit 1 refers to the 1st ED, hospital, or clinic visit since being diagnosed with stage 3 or 4 cancer at one of the participating hospitals. Visit 1 duration ranges from one to several days, depending on the visit type (ED, hospital, clinic). [b] Excludes participants who expired during Visit 1. [c] Post PC consult does not include the PC consult visit. [d] Asymptotic Sig. (2-sided test).

A Mann-Whitney U test and Kruskal Wallis test was performed to identify significant differences between days from cancer diagnosis to death for participants (with PCC vs. No PCC). No significant association existed between both groups; however, statistical significance existed in relation to socio-demographics of the participants. There was statistical significance between days from cancer diagnosis to death for: race χ^2 (4) = 12.18, p = .016, ε^2 = .130 moderate effect; marital status χ^2 (4) = 10.30, p = .036, ε^2 = .111; AJCC cancer stage U = 449.50, p = .011, r = .068; and for number of visits (visit sequence) before PCC χ^2 (5) = 15.55, p = .008, ε^2 = .187 (Table 5).

Table 5

Days from Stage III or IV Cancer Diagnosis to Death by Study Population Sociodemographic and Clinical Characteristics, Health Care Utilization, and Palliative Care Services Utilization (N = 95)

Characteristic	***n***	***Mean Rank***	***U***	***P***	***r***
Gender			1020.00	.426	--
Male	49	45.82			
Female	46	50.33			
	n	***Mean Rank***	***H (df)***	***p***	ε^2
Race			12.18 (4)	**.016**	.130
White	36	37.00			
Black, African American	5	38.20			
Hispanic	11	52.95			
Asian	15	40.40			
Other Race	14	43.54			
Marital Status			10.30 (4)	**.036**	.111
Married	40	45.39			
Single	20	37.08			
Divorced	5	30.00			
Separated	4	50.63			
Widow, widower	12	34.29			
Zip Code			7.87 (6)	.248	--
Central	22	36.18			
East	15	25.57			
North Central	15	45.37			
North Coastal	1	9.00			
North Inland	4	39.13			
South	17	45.76			
Outside SD County, Out of State	2	61.25			
	n	***Mean Rank***	***U***	***p***	***r***
Cancer Diagnosis			1000.00	.205	--
Bronchus, Lung	71	45.92			
Colon, Rectosigmoid junction	24	54.17			
AJCC Stage			449.50	**.011**	.068
Stage III	19	62.34			
Stage IV	76	44.41			
PC Order at Visit 1[a]			912.50	.289	--
Yes	35	44.07			
No	60	50.29			

Characteristic	***n***	***Mean Rank***	***U***	***p***	***r***
PC Order at Remaining Visits			289.00	.579	--
Yes	52	32.06			
No	10	28.60			
PC Order for All Study Visits			419.50	.338	--
Yes	87	48.82			
No	8	39.06			
PC Consult at Visit 1[a]			863.50	.212	--
Yes	33	43.17			
No	62	50.57			
PC Consult at Remaining Visits			535.00	.150	--
Yes	54	37.41			
No	16	29.06			
PC Consult for All Study Visits			432.50	.928	--
Yes	85	48.09			
No	10	47.25			
	n	***Mean Rank***	***H (df)***	***p***	ε^2
Insurance at Visit 1			0.48 (2)	.788	--
Contracts (comm,, PPO, CAP)	20	49.30			
MediCal (simple, HMO)	15	39.37			
Medicare (simple, HMO, CAP)	44	35.99			
Insurance at 1st PC Consult			1.59 (2)	.453	--
Contracts (comm,, PPO, CAP)	20	49.30			
MediCal (simple, HMO)	14	40.46			
Medicare (simple, HMO, CAP)	45	35.72			
Visit Location at Visit 1			2.81 (2)	.246	--
ED	12	43.50			
Inpatient	56	38.96			
Outpatient	13	47.46			
Visit Location of 1st PC Consult			4.65 (2)	.098	--
ED	9	45.61			
Inpatient	62	39.98			
Outpatient	10	43.20			
Facility at Visit 1			1.00 (2)	.605	--
Site 1	20	43.58			
Site 2	20	26.33			
Site 3	41	46.90			
Facility of 1st PC Consult			1.85 (2)	.396	--
Site 1	16	39.28			
Site 2	19	26.89			
Site 3	46	47.42			

Characteristic	***n***	***Mean Rank***	***H (df)***	***p***	ε^2
Dis Disposition at Visit 1			7.68 (5)	.175	--
Expired	29	38.72			
Home, self-care (routine)	38	44.30			
Home health service	9	34.83			
Hospice (inpatient)	2	38.25			
Short-term acute facility	3	41.50			
Skilled nursing facility	0	--			
Dis Disposition of 1st PC Consult			7.17 (5)	.208	--
Expired	33	41.05			
Home, self-care (routine)	35	41.73			
Home health service	7	23.79			
Hospice (inpatient)	2	38.25			
Short-term acute facility	3	64.83			
Skilled nursing facility	1	68.50			
	n	***Mean Rank***	***U***	***p***	***r***
Expired During Visit 1			828.00	.127	--
Yes	33	42.09			
No	62	51.15			
Expired During 1st PC Consult			687.50	.094	--
Yes	35	37.64			
No	50	46.75			
Location of Death			813.50	.743	--
In a facility	21	49.74			
Unknown	74	47.51			
	n	***Mean Rank***	***H (df)***	***p***	ε^2
Visit Number of 1st PC Consult			15.55 (5)	**.008**	.187
Visit 1	48	39.29			
Visit 2	8	37.25			
Visit 3	10	45.60			
Visit 4	4	27.25			
Visit 5	3	59.00			
Visit 6 or more	8	49.38			

Note. AJCC, American Joint Commission on Cancer; BSN, bachelor's in nursing science; DX, diagnosis; ED, emergency department; HMO, Health Management Organization; HOS, hospital; ICU, intensive care unit; LOS, length of stay; PC, palliative care; PPO, preferred provider organization; SCV, Site 1; SGR, Site 2; SMH, Site 3; V1, visit 1. Fisher's Exact Test, unless otherwise specified. [a] Visit 1 refers to the 1st ED, hospital, or clinic visit since being diagnosed with stage 3 or 4 cancer at one of the participating hospitals. Visit 1 duration ranges from one to several days, depending on the visit type (ED, hospital, clinic). [b] Excludes participants who expired during Visit 1. [c] Post PC consult does not include the PC consult visit. [d] Asymptotic Sig. (2-sided test).

Pearson’s or Spearman’s rho correlations were computed to assess the relationship between participants' socio-demographics, clinical characteristics, healthcare utilization, and PC utilization for the study period (Table 6). Results show none of the variables evaluated were significantly associated with patient's age at diagnosis; number of ED, inpatient, and outpatient visits post PCC; Acute care LOS post PC consult, and ICU LOS, post PC consult. Significant associations occurred between Days from cancer diagnosis to first PCC and number of ED, hospital, outpatient visits (all visits) $p < .001$; Days from first PCC to death and Acute care LOS (all visits) $p = .007$; Days from cancer diagnosis to death and number of ED, hospital, and outpatient visits (all visits) $p < .001$; and Days from cancer diagnosis to death and Days from initial cancer diagnosis to first PCC $p < .001$. As the average number of days increased from diagnosis to first PCC, so did the average number of ED, hospital, and outpatient visits. In order words, less diagnosis to PCC time would have reduced the HCU for this patient population.

Table 6

Intercorrelations for Sociodemographic and Clinical Characteristics, Health Care Utilization and Palliative Care Services Utilization (N = 95)

Characteristic	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1. Age at diagnosis	--									
2. No. of ED, HOSP and clinic visits, post PC consult	-0.13	--								
3. Acute care LOS, post PC consult	-0.06	0.61**	--							
4. ICU LOS, post PC consult	0.00	0.53**	0.95**	--						
5. No. of ED, HOSP and clinic visits, all visits	-0.24*	0.27*	0.34**	0.36**	--					
6. Acute care LOS, all visits	-0.03	-0.24*	-0.17	-0.15	-0.35**	--				
7. ICU LOS, all visits	0.11	-0.18	-0.10	-0.08	-0.33**	0.63**	--			
8. Days DX to 1st PC consult	-0.17	0.22	0.17	0.12	**0.35****	0.01	-0.09	--		
9. Days 1st PC consult to death	0.05	0.14	0.21	0.19	0.14	**0.30****	-0.02	-0.01	--	
10. Days DX to death	-0.16	0.22	0.16	0.12	**0.35****	0.03	-0.07	**0.99****	0.07	--

Note. ED, emergency department; ICU; intensive care unit; LOS, length of stay.

* < .05 (2-sided) ** < .01 (2-sided)

CHAPTER V

Discussion

The purpose of this study was to examine the relationship among select socio-demographics, participant clinical characteristics, PCC time from initial diagnosis, healthcare utilization, and PCC to death for participants with PCC compared to no PCC, in a cancer patient cohort at an advanced stage in their disease process. The conceptual framework for this study was derived from the literature and based on the concepts of Afaf Meleis's theory of Transitions and Jacqueline Fawcett's metaparadigms in nursing concept. Using aspects from both theories as an underpinning, other variables were used to construct a framework unique to this study. In this chapter, the study summary and findings, implications, and recommendations for the profession of nursing, healthcare systems, and health policy are presented. The recommendations, presented in this chapter, are proposed to address the needs of patients and families; nevertheless, these recommendations are also posited to encourage healthcare systems, policy makers, clinicians, public and private funding bodies, and interested healthcare advocates to enhance care delivery, as it pertains to providing care for those with advanced-stage illnesses at EOL.

Study Summary

This study used a retrospective descriptive correlational design. Retrospective data were extracted from the electronic health records (EHR) of deceased individuals older than 18 years, diagnosed with stage III and IV colon, rectal and lung cancer in a southern California healthcare system. For this study, participant variables were compared among two groups: those with PCC and those with no PCC. It was also important to examine the time from diagnosis to PCC to ascertain if PCC was provided "early" in the illness trajectory.

Cancer is the leading cause of death in the United States; early PC consult relieves suffering for patients, families, and improves quality of life for patients throughout the illness trajectory. In advanced cancer diagnosis, existing literature reveals, patients with early integration of PC interventions have reduced healthcare utilization, in terms of ED visits, and hospital admissions in general. However, palliative care is only reaching a fraction of the people who need it; even for those it reaches, as was the case in this study, it was much later in the illness trajectory, closer to death, as opposed to at diagnosis of advanced cancer, leading to burdensome EOL transitions for patients. Barring death from unexpected trauma, most deaths will be because of one or more diseases that must be managed. Ideally, healthcare should merge clinical care with social, psychosocial, cultural, and spiritual care to achieve the goal of patient-centered care. Nevertheless, many people, clinicians included, are still uncomfortable with end-of-life (EOL) discussions, and this is evident in the number of patients who die in hospitals and other healthcare facilities, despite the evidence 80% of people prefer to die at home (Smith et al., 2012).

The western culture of aversion to EOL discussion is evident in the way PC referrals are delayed in the clinical setting. Failure to deal with the reality of mortality leads to low quality of life for patients with advanced cancer diagnosis. Indeed, patients with advanced-stage cancer deal with many challenges during the illness trajectory: the high cost of healthcare, care disintegration, shortage of skilled clinicians, insurance navigation, etc. These are some of the issues beleaguering our healthcare system.

Palliative care is important for all patients with chronic illnesses, but in patients with advanced cancer diagnosis, it is even more paramount, as the burden of symptoms can be high, especially when combined with chemotherapy, radiation, etc., often producing side effects of their own.

Palliative care can and should be integrated in tandem with curative treatment. The primary goal of PC is to ensure patients have their needs met and to reduce barriers to treatment within the healthcare system. Access to healthcare resources specific to the patient and family needs, Advance care planning, psychosocial support, care transitions, care navigation, patient advocacy, education, and cultural inclusions in EOL discussions are some benefits of PC. In healthcare systems, clinical success should be measured by patient outcomes, not by process measures. However, there are no metrics required to measure and report on the quality of EOL care provided in clinical settings (IOM, 2014). As it pertains to PC success, as this study reveals, healthcare systems are still not "successful" when it comes to early PCR, PCC, patient, and clinician education about PC, all it entails, and the benefits it can bring to patients and families.

Study Findings

Study findings are explained by study outcomes followed by a discussion.

a) Time from initial diagnosis to PCC: this study found most participants had multiple hospital admissions after diagnosis of advanced cancer before PCC and interventions were initiated. Participants with stage IV diagnosis were also more likely to get PCC after diagnosis, even though late in the illness trajectory. There was also a significant association between race and time from diagnosis to PCC. Limited research exists to explain if Whites and Asians account for more PC patients. Although the sample in this study was small, it was diverse and representative of San Diego County. Specifically, according to the 2021 United States census bureau, Black/African Americans make up only 6.1% of the population in San Diego: White (62.0%), Asian (17.3%), and Hispanic (30.1%). White and "other" race were more likely to have PCC after initial diagnosis. It is critical healthcare systems ensure equity in PCC and referrals to reduce health disparities at EOL. This is synonymous with existing research where Black/African American patients are referred late to PC, indicating continued existence of disparities (Bhulani et al., 2018; Temel et al., 2010, 2017).

b) Time from first PCC to death: participants who visited site 3 at first visit (*Mean Rank*, 46.9) had more days from PCC to death, compared to site 1 (*Mean Rank*, 26.33) who had less days from PCC to death. The average number of days from first PCC to death was 10 days (*SD* = 23.03) for all visits combined which is similar to the national average length of stay in hospice. This depicts PC as being Hospice, further muddling the message about the true use of PC.

c) Time from diagnosis to death: patients with stage IV diagnosis had less days from diagnosis to death and most patients had multiple hospital visits before their first PCC. None of the patients got "early" PC integration (as indicated for the purpose of this study and as recommended) at diagnosis even though their disease was terminal; the average number of days from initial diagnosis to death for patients with PCC was 445, compared to 320 for those (*n* = 10) with no PCC during this study period. This is an important finding because stage IV cancer diagnosis is considered terminal with poor prognosis; a lack of PCC at this stage reveals a lack of understanding for PC; this negatively influences the health/illness transitions for patients. Also notable in this study, participants who were divorced had more time (days) from diagnosis to death, compared to those who were separated or married. This finding is contrary to research that suggests married cancer patients live longer than those who are single. Participants who were White (*Mean Rank* = 37) had more days from diagnosis to death, compared to those who were Hispanic (*Mean Rank* = 52.95), leaving room for health disparity concerns, some of which still plague our healthcare system.

d) Utilization of healthcare services (ED, clinic, and inpatient visits) for those who got PCC compared to those who did not get PCC: Before PCC, the average number of ED, hospital, and outpatient visits during the study period was 3.72; but after PCC, it was 0.16. Likewise, prior to PCC, the average number of days for Acute care LOS was 6.97, but after PCC, it was 0.76. Intensive care unit LOS prior to PCC was 4.55, after PCC integration, it was 0.51. This supports PC interventions reduce inpatient LOS and overall hospital admissions for critically ill patients.

A total of 91.6% of participants got a PC order, but only 89.5% of participants got PCC, as well as late during this study period. This means patients were either discharged or died before a consult could be completed. This could be due to limited-service hours, insufficient staff, or providers. Although the sample size for this study was relatively small, it provides pertinent evidence healthcare systems can use to reinforce the need for PC services. To an extent, findings from this study are not surprising, given the scope and benefits of PC and the late stage of disease at diagnosis (> 90% for lung and 22% for colon respectively). Notable in this study is for all patients, PC interventions were integrated very late, but HCU was still drastically reduced for those who were fortunate to enjoy the benefits of PC, indicating the critical need for strict PC criterion for referral in advanced illness. Preventable hospital admissions are often a consequence of poorly managed transitions in the illness trajectory; this warrants more attention, research, as well as more clinician education.

Implications for Nursing Profession and Research

Findings from this and other studies add to the evidence when PCC is offered late in the illness trajectory, transitions become more burdensome for patients and families. The barriers to PC are widespread among both developing and high-income countries. According to Meier et al. (2017), these barriers occur in five domains: lack of public and professional awareness of palliative care's benefits; workforce shortages and inadequate training; insufficient organizational capacity, due in part to misaligned (fee-for-service) payment programs; lack of regulatory requirements, oversight, and accreditation standards to ensure access and quality; and an inadequate evidence base to guide safe and effective practice. Results from this study have several implications for nurses, and indeed, all clinicians:

Education. It is expected for nurses and physicians to be well educated and informed about the distinction between PC and Hospice. But there exists frustration among clinicians about the mismatch between training and the complex needs of people being served. This does not ensure prompt recognition of patient need for PCC; as well as the appropriate time to advocate for a referral. Not only do results from this study indicate late integration of PCC; sadly, it shows PC being utilized as hospice in terms of the number of days from cancer diagnosis to PCC.

Every nurse and clinician has a stake in providing care for individuals with chronic illnesses- as a matter of professional commitment and responsibility. Healthcare and professional education for clinicians should not exist in silos. To this extent, all clinicians who care for patients with chronic illnesses need to become more confident in having PC discussions with patients and advocating for physicians to do the same. In addition, state regulatory agencies need to ensure this by requiring mandatory EOL classes for licensure renewal, mandating the inclusion of more PC and EOL courses in nursing and medical curriculum, as well as inclusion of related questions in licensure examinations.

Practice. Health systems also have a similar stake in ensuring high quality, sustainable care is provided to these patients; not just from a financial standpoint, but also one of compassion and empathy. To ensure timely referrals and consults, health systems should implement a referral criterion for patients with advanced cancer diagnosis that automates a trigger system. This criterion can be immersed into EHR software interface to trigger a referral to PC whenever a medical diagnosis of advanced cancer is documented. This will ensure early integration of PC services without provider discretion or lack of discretion about PCC being necessary or not. As this study found, patients with PC interventions live longer than patients without PCC. For health systems and clinicians alike, it is paramount that patient preferences are documented. Although treatment decisions for terminally ill patients can be complex, the potential benefits of PC are glaring. In this regard, it will benefit health systems to employ specialist PC team members to meet the needs of patients, standardize the consultation process and embed their services with oncologists, both to educate and to advocate for patients

The need for early referral and consults cannot be overemphasized. As indicated in this study, early PCC reduces HCU. Palliative care is useful for any serious illness and can be provided throughout the continuum of care. For patients with advanced cancer diagnosis, frequent assessment of physical, emotional, and psychosocial symptoms is needed, and must be communicated to ensure transparency, accountability in care, and should be measured by healthcare systems. Advanced cancer diagnosis necessitates ACP; this process can begin at any time for most adults, not only those who are ill. It can be difficult for patients and families to deal with ACP while also dealing with chronic illness and hospitalization. However, when patients are encouraged to complete and continuously review Advanced Directives during moments of good health, it slowly reinforces discussions with providers and family members and makes it less daunting. End-of-life preferences vary for most people, the ability to have these conversations early will remove the misconception only EOL patients need ACP.

Health Policy and Research. Improvements in PC cannot be conducted without state and federal policy support to train clinicians and ensure better EOL policies for patients. State and Federal regulatory agencies, in ongoing healthcare reform discussions, can help improve PC services by ensuring proper workforce training in specialty PC, as well as funding more research to advance PC. Pertaining to payment and reimbursement, the Centers for Medicare, and Medicaid Service (CMS) can build value-based reimbursement into existing programs to ensure dual-eligibility, not only by diagnosis of specific diseases. Hospital systems also need to be required to provide specialty PC services to their patients and acquire accreditation. The Joint Commission (TJC) currently offers “specialty advanced certification” in palliative care for hospital, hospice, and home health palliative care programs. The Community Health Accreditation Partner (CHAP) offers specialty palliative care certification to programs in the community, such as hospice, home health programs, and healthcare practices. When healthcare systems are held to this requirement, quality improvements and oversight can be managed by established accreditation bodies in addition to current practices and expectations. State public health agencies can then facilitate access to the public by developing referral sources in the community, disseminating emerging research, and collaborating with professional organizations at the grass-root levels to spread awareness.

***Federal*.** At the Federal level, the focus should be on investing in the training of health care professionals, supporting research to expand the evidence base, and ensuring the programs serving most people living with serious illness, particularly Medicare, incentivize and support access to quality palliative care. Incentives for patients can be in form of reduced co-pay for Medicare and MediCal patients who complete AD with their physicians. Bipartisan bills also help to ensure ongoing training of clinicians to ensure provider saturation given the current patient population with chronic illnesses.

The Palliative Care and Hospice Education Training Act (PCHETA), according to congress.gov, is a bill (H.R. 647) introduced in January 2019 in the 116th congress, which requires the Department of Health and Human Services (HHS) to take several actions pertaining to PC training: a) HHS must provide support for Palliative Care and Hospice Education Centers to improve the training of health professionals in palliative care and establish training for individuals preparing for advanced education nursing degrees, social work degrees, or advanced degrees in physician assistant studies in PC; b) HHS may provide support to medical schools, teaching hospitals, and graduate medical education programs to train physicians who plan to teach palliative medicine; c)HHS must provide Palliative Medicine and Hospice Academic Career Awards to individuals to promote their career development, support entities that operate a PC and Hospice Education Center, support individuals in specified fields who are pursuing an advanced degree in palliative care or related fields, and award grants to nursing programs to train students who want to provide palliative care.

In addition, this bill also requires the Agency for Healthcare Research and Quality (AHRQ) to provide a national education and awareness campaign to inform patients, families, and health professionals about the benefits of palliative care; as well as requiring The National Institutes of Health (NIH) to expand national research programs in palliative care (congress.gov). This bill passed the house in October 2019, was received in the Senate, and is currently pending. Should this bill pass in the Senate, PCHETA will promote education and research in palliative care and hospice, increase the number of palliative care professionals, and implement a public awareness campaign to educate the public on its extensive benefits; helping to reduce some of the barriers to quality, patient-centered PC.

State (CA). According to the California Department of Health and Human Services Agency (2018), in 2014, the state of California enacted a bill, SB1004, requiring Medi-Cal (partly funded by Federal Medicaid provisions) to include PC benefits. This bill made provision for eligible beneficiaries of Medi-Cal to access PC services concurrently with disease-targeted treatment, regardless of prognosis. Medi-Cal services are provided through contracts with distinct types of managed health care plans and prior to this bill, qualified low-income Medi-Cal beneficiaries received health care benefits but had to forgo ongoing disease-targeted treatment to receive hospice benefits. This legislation gave the California Department of Healthcare Services (DHCS) latitude to determine whether additional services will be covered under this benefit. Per this bill, the DHCS is required to: (1) Establish standards regarding palliative care services; (2) Determine the eligibility criteria for beneficiaries; and (3) Develop and provide technical assistance to the Medi-Cal managed care plans to ensure the delivery of palliative care services. The bill also specifies DHCS should consult with interested stakeholders as it moves forward with implementation.

In December 2018, the DHCS released an update to the bill informing Medi-Cal managed plans of their obligation to provide PC services under their contract relative to the provision of Early Periodic Screening, Diagnostic, and Treatment (EPSDT) services (California Legislative Information Text, 2021). Per this update, the provision of palliative care to qualifying members should not result in the elimination or reduction of any covered benefits or services under the plan contracts and should not affect a member's eligibility to receive any services, including home health services, for which the member would have been eligible in the absence of receiving palliative care. This update categorically stated PC can be provided in tandem with curative care and implemented payment through managed care and fee-for-service providers. The DHCS also contracted California State University Institute for Palliative Care to fund palliative care training for qualified Medi-Cal providers and their clinical staff. However, as of March 31, 2019, this contract had concluded, with a halt on new applications, further widening the gap in provider education; a disadvantage to clinicians who stand to gain from this education. Another disadvantage is the disease-specific eligibility criteria to qualify for PC: Congestive Heart Failure, Chronic, Obstructive Pulmonary Disease, Liver disease, and Advanced Cancer. Although the bill requires authorization and referral to PC for those who meet eligibility regardless of age, it neglects to consider individuals with other chronic illnesses who can benefit from PC.

Professional Nursing Organizations. The American Association of Colleges of Nursing (2021) in its new *Essentials*: *Core Competencies for Professional Nursing Education*, an educational framework for nurses, has delineated four spheres of future healthcare delivery: 1) disease prevention/promotion of health and well-being; 2) chronic disease care, which includes management of chronic diseases and prevention of negative sequelae; 3) regenerative or restorative care, which includes critical/trauma care, complex acute care, acute exacerbations of chronic conditions, and 4) hospice/ palliative/supportive care, which includes end-of-life care, as well as palliative and supportive care for individuals requiring extended care, those with complex, chronic disease states, or those requiring rehabilitative care.

Educational challenges associated with palliative care practice include the lack of preparatory education and exposure to palliative care principles within the nursing curriculum (ANA, 2017). To deliver quality care, clinicians must achieve competency and have standardized curriculums and expectations in social work, medicine, and nursing. To mitigate both the gaps in PC workforce and education, it is important to ensure clinicians across the disciplines have the basic skills necessary to initiate PC discussions and advance care planning. To this extent, licensing policies must require clinicians to engage in continuing education hours/credits to graduate, facilitate engagement with the core competencies, raise awareness, and promote professional capacity. Content about palliative care and palliative nursing can be included in any curriculum in academic and staff development settings. Provider discomfort about having difficult conversations or lack of knowledge should never be a deterrent to quality PC delivery.

In 2016, the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA) convened the Palliative and Hospice Nursing Professional Issues Panel (the Panel). The role of the Panel was to complete an environmental assessment, examine PC nursing within today's healthcare system, and identify steps and strategies for nurses to lead and transform PC (ANA, 2017). The Panel focused on discovering a future state for PC that promotes health equity and improves access, safety, and quality of PC. The following themes emerged during the panel deliberations: a) Palliative care has the potential to promote the health and well-being of all individuals and communities and therefore needs the attention and integration into practice by all nurses, no matter the practice area or population served; b) Nurses are leaders in developing, promoting, implementing, and sustaining interprofessional teamwork in palliative care; and c) Educational and other resources for palliative care exist, but are not widely known and remain hidden for many individuals and groups (ANA, 2017), including clinicians**.**

Meier et al. (2017), in their article *National Strategy for Palliative Care,* called for accountability in practice by Federal payors and other stakeholders like the Joint Commission by ensuring provider competencies to foster quality PC provision. Akin to New Zealand and Australia, they stressed the need for consistency in reimbursement (both on Federal and State levels), collaboration among stakeholders, and replacement of fee-for-service with value-based payment to providers. To ensure delivery of quality PC for individuals with chronic illnesses; access, education, cost, and investment in ongoing research is necessary.

Study Limitations

The findings in this study should be reviewed within the context of study limitations. This study was a retrospective review of patients' EHR records, raising concerns about potential selection bias; this study also did not have the benefit of randomization or intervention. Sample size was limited due to data timeline being only one calendar year; this led to a dataset that is not normally distributed, resulting in the use of mostly nonparametric tests.

Second, there was a lack of standardized practice within the PC team in the timing of PCC; practice rigor could be questionable. Also, given retrospective analysis, findings are not generalizable across organizations, and there is no establishment of a causal relationship. Future studies should employ longitudinal studies to reflect the full cancer journey of patients. Gathering HCU pattern could also be helpful to examine and describe if the providers/clinicians present at a particular time of the week influence and/confound results. Despite these limitations, findings from this study advance scientific knowledge regarding PCC, timing of PCC, and days between PCC and death among a sample of Stage III and IV oncology patients at an advanced stage in their disease process. Findings further clarify the relationships among PCC time, healthcare utilization, readmission rate post-diagnosis, select socio-demographics, and death among a sample of Stage III and IV oncology patients at an advanced stage in their disease process. Future research is needed to further understand strategies to overcome the barriers to implementing PCC at time of advanced cancer diagnosis.

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APPENDIX A

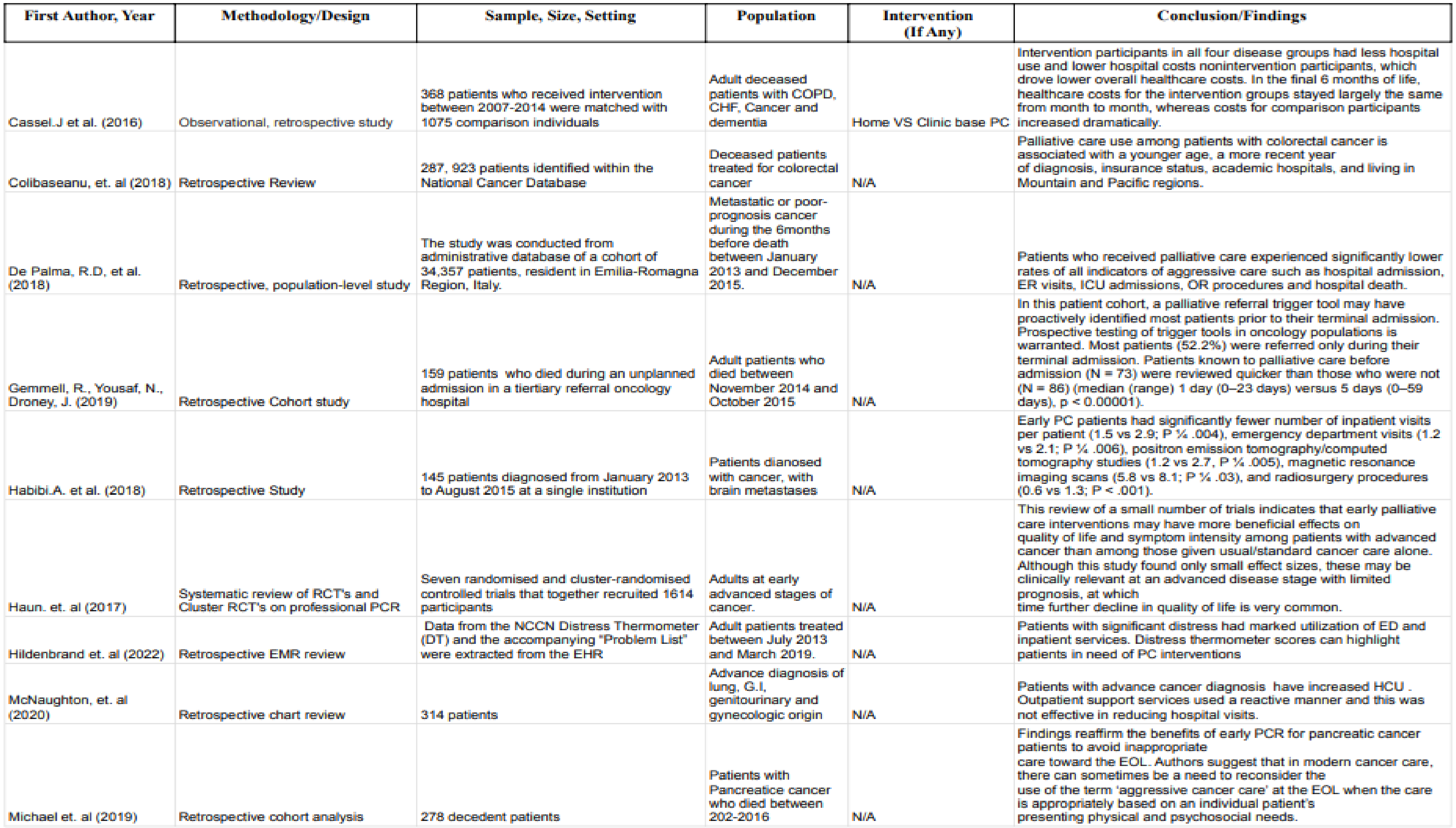
Study Variable Table

Category of Variable	Variables	Operational Definition	Level of Measurement
Independent Variables: Socio-demographics	Age, race, gender, insurance type, zip-code, visit type, facility, visit sequence	Age: length of time a person had lived at time of study. Race: self-identified category of people. Gender: biological/ self-identified sex. Health Insurance: primary insurance of participant Medicare, MediCal, Commercial). Visit Type: point of visit (ED, inpatient, clinic). Facility: health system location of care	Age: Ratio Race: Nominal Gender: Nominal Marital Status: Nominal Health Insurance: Nominal Facility: Nominal Visit Type: Nominal
Independent Variable: clinical characteristics	Stage III or IV diagnosis of colon, rectal or lung cancer	American Joint Commission on Cancer diagnosis of cancer. Defined ICD-10-CM primary site of diagnosis.	Nominal
Dependent Variable: Length of Stay (LOS)	Acute care LOS, ICU LOS	Number of days spent in acute care or intensive care unit (both account for inpatient visits)	Acute care LOS: Scale ICU LOS: Scale

Category of Variable	**Variables**	**Operational Definition**	**Level of Measurement**
Dependent Variable	Days from diagnosis to PCC	Number of days from first documented diagnosis of stage III or IV colon, rectal or lung cancer to first PCC	Scale
Dependent Variable	Days from diagnosis to death	Number of days from first documented diagnosis of stage III or IV colon, rectal or lung cancer to death	Scale
Dependent Variable	Days from PCC to death	Number of days from first PCC to death	Scale
Independent Variable: Discharge disposition	Discharge to home, death, discharge to facility	Anticipated status or location following inpatient admission, ED or clinic visit.	Nominal
Independent variable: marital status	Married, divorced, single, separated, widowed	Participant disclosed civil status with or without a significant other.	Nominal

APPENDIX B

Reference Matrix



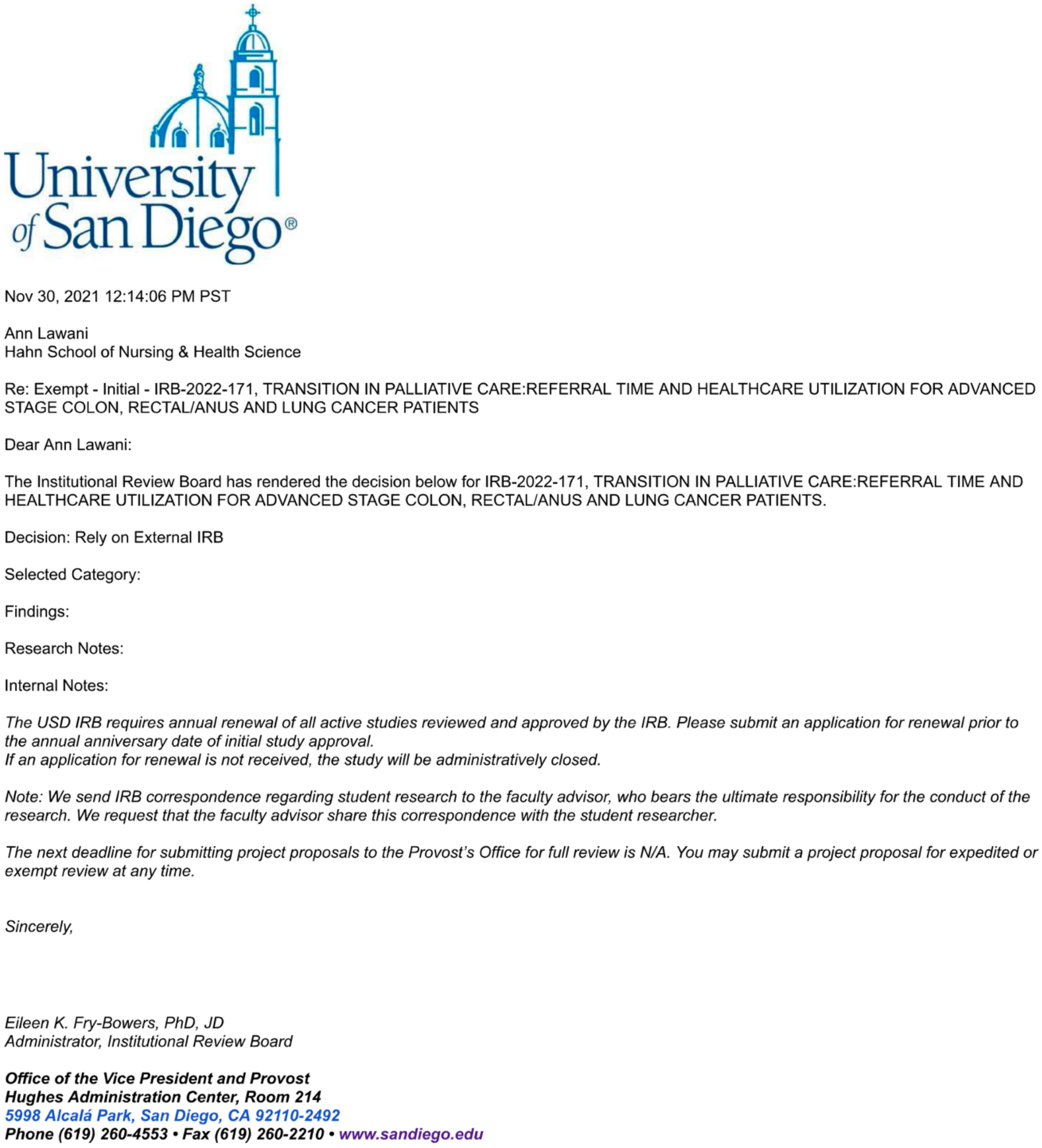
First Author, Year	Methodology/Design	Sample, Size, Setting	Population	Intervention (If Any)	Conclusion/Findings
Cassel.J et al. (2016)	Observational, retrospective study	368 patients who received intervention between 2007-2014 were matched with 1075 comparison individuals	Adult deceased patients with COPD, CHF, Cancer and dementia	Home VS Clinic base PC	Intervention participants in all four disease groups had less hospital use and lower hospital costs nonintervention participants, which drove lower overall healthcare costs. In the final 6 months of life, healthcare costs for the intervention groups stayed largely the same from month to month, whereas costs for comparison participants increased dramatically.
Colibaseanu, et. al (2018)	Retrospective Review	287, 923 patients identified within the National Cancer Database	Deceased patients treated for colorectal cancer	N/A	Palliative care use among patients with colorectal cancer is associated with a younger age, a more recent year of diagnosis, insurance status, academic hospitals, and living in Mountain and Pacific regions.
De Palma, R.D, et al. (2018)	Retrospective, population-level study	The study was conducted from administrative database of a cohort of 34,357 patients, resident in Emilia-Romagna Region, Italy.	Metastatic or poor-prognosis cancer during the 6months before death between January 2013 and December 2015.	N/A	Patients who received palliative care experienced significantly lower rates of all indicators of aggressive care such as hospital admission, ER visits, ICU admissions, OR procedures and hospital death.
Gemmell, R., Yousaf, N., Droney, J. (2019)	Retrospective Cohort study	159 patients who died during an unplanned admission in a tiertiary referral oncology hospital	Adult patients who died between November 2014 and October 2015	N/A	In this patient cohort, a palliative referral trigger tool may have proactively identified most patients prior to their terminal admission. Prospective testing of trigger tools in oncology populations is warranted. Most patients (52.2%) were referred only during their terminal admission. Patients known to palliative care before admission (N = 73) were reviewed quicker than those who were not (N = 86) (median (range) 1 day (0–23 days) versus 5 days (0–59 days), p < 0.00001).
Habibi.A. et al. (2018)	Retrospective Study	145 patients diagnosed from January 2013 to August 2015 at a single institution	Patients dianosed with cancer, with brain metastases	N/A	Early PC patients had significantly fewer number of inpatient visits per patient (1.5 vs 2.9; P ¼ .004), emergency department visits (1.2 vs 2.1; P ¼ .006), positron emission tomography/computed tomography studies (1.2 vs 2.7, P ¼ .005), magnetic resonance imaging scans (5.8 vs 8.1; P ¼ .03), and radiosurgery procedures (0.6 vs 1.3; P < .001).
Haun. et. al (2017)	Systematic review of RCT's and Cluster RCT's on professional PCR	Seven randomised and cluster-randomised controlled trials that together recruited 1614 participants	Adults at early advanced stages of cancer.	N/A	This review of a small number of trials indicates that early palliative care interventions may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone. Although this study found only small effect sizes, these may be clinically relevant at an advanced disease stage with limited prognosis, at which time further decline in quality of life is very common.
Hildenbrand et. al (2022)	Retrospective EMR review	Data from the NCCN Distress Thermometer (DT) and the accompanying "Problem List" were extracted from the EHR	Adult patients treated between July 2013 and March 2019.	N/A	Patients with significant distress had marked utilization of ED and inpatient services. Distress thermometer scores can highlight patients in need of PC interventions
McNaughton, et. al (2020)	Retrospective chart review	314 patients	Advance diagnosis of lung, G.I, genitourinary and gynecologic origin	N/A	Patients with advance cancer diagnosis have increased HCU . Outpatient support services used a reactive manner and this was not effective in reducing hospital visits.
Michael et. al (2019)	Retrospective cohort analysis	278 decedent patients	Patients with Pancreatice cancer who died between 202-2016	N/A	Findings reaffirm the benefits of early PCR for pancreatic cancer patients to avoid inappropriate care toward the EOL. Authors suggest that in modern cancer care, there can sometimes be a need to reconsider the use of the term 'aggressive cancer care' at the EOL when the care is appropriately based on an individual patient's presenting physical and psychosocial needs.

Reference Matrix Cont.

First Author, Year	Methodology/Design	Sample, Size, Setting	Population	Intervention (If Any)	Conclusion/Findings
Poulose, J., Kyung, Y., Neo, P. (2013)	Retrospective Analysis of referral to death interval	842 patients	Diagnosis of terminal cancer	N/A	Longer referral-to-death interval was associated with death outside the hospital for patients enrolled in a hospital-based service. The study highlights the importance of early referral in predicting the last place of care and location of death of palliative care patients.
Scarpi, et. al (2018)	Randomized Clinical Trial	186 patients	Gastric cancer patients	Standard oncology care alone vs Combination of oncology care with early PC in 1:1 randomized groups	Slight, albeit not significant, benefit from Early PC (EPC). Findings on E studies may be underestimated in the event of suboptimally managed issues: type of intervention, shared decision-making process between oncologists and PC physicians, risk of standard arm contamination, study duration, timeliness of assessment of primary outcomes, timeliness of cohort inception, and recruitment of patients with a significant symptom burden.
Urquhart, et. al (2015)	Longitudinal study	1885 decedents in Novia Scotia, Canada	Colorectal cancer	N/A	Identifying potential predictors of a short timeframe between cancer diagnosis and death may aid in the development of strategies to facilitate timely and appropriate PCR upon cancer diagnosis.
Vranas, K.C et al. (2020)	Retrospective cohort study	23,142 patients EMR from 132 VA medical centers	Stage IIIB/IV lung cancer between January 1, 2007, and December 31, 2013	N/A	Findings suggest that early PC referral is associated with less aggressive EOL care, ED visits, ICU admissions, which lead to reduced cost for patients.
Vasconcellos, et al. (2019)	Retrospective cohort study	228 patients EMR	G.I Tumors	N/A	Patients with advanced cancer and poor ECOG-PS had short survival after treatment with inpatient PC.Inpatient PC was associated with aggressive end-of-life care. Prognostic markers such as ECOG-PS, hypercalcemia and

APPENDIX C

USD IRB



University of San Diego

Nov 30, 2021 12:14:06 PM PST

Ann Lawani
Hahn School of Nursing & Health Science

Re: Exempt - Initial - IRB-2022-171, TRANSITION IN PALLIATIVE CARE:REFERRAL TIME AND HEALTHCARE UTILIZATION FOR ADVANCED STAGE COLON, RECTAL/ANUS AND LUNG CANCER PATIENTS

Dear Ann Lawani:

The Institutional Review Board has rendered the decision below for IRB-2022-171, TRANSITION IN PALLIATIVE CARE:REFERRAL TIME AND HEALTHCARE UTILIZATION FOR ADVANCED STAGE COLON, RECTAL/ANUS AND LUNG CANCER PATIENTS.

Decision: Rely on External IRB

Selected Category:

Findings:

Research Notes:

Internal Notes:

The USD IRB requires annual renewal of all active studies reviewed and approved by the IRB. Please submit an application for renewal prior to the annual anniversary date of initial study approval.
If an application for renewal is not received, the study will be administratively closed.

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited or exempt review at any time.

Sincerely,

Eileen K. Fry-Bowers, PhD, JD
Administrator, Institutional Review Board

Office of the Vice President and Provost
Hughes Administration Center, Room 214
5998 Alcalá Park, San Diego, CA 92110-2492
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USD IRB

University of San Diego®

Jan 20, 2022 9:27:13 AM PST

Ann Lawani

Hahn School of Nursing & Health Science

Re: Modification - IRB-2022-171 TRANSITION IN PALLIATIVE CARE:REFERRAL TIME AND HEALTHCARE UTILIZATION FOR ADVANCED STAGE COLON, RECTAL/ANUS AND LUNG CANCER PATIENTS

Dear Ann Lawani:

The Institutional Review Board has rendered the decision below forIRB-2022-171, TRANSITION IN PALLIATIVE CARE:REFERRAL TIME AND HEALTHCARE UTILIZATION FOR ADVANCED STAGE COLON, RECTAL/ANUS AND LUNG CANCER PATIENTS.

Decision: Approved

Findings:

Research Notes:

Internal Notes:

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