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DNP Final Project Report

An assessment to determine the need for a palliative care team to improve patient
satisfaction and decrease healthcare costs

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University of Kentucky

College of Nursing

Fall 2018

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Dedication

This DNP Project is dedicated to my amazing husband, Jeremy Weis, who reminded me to stay positive and focus on the light at the end of the tunnel. Thank you for your encouragement and endurance during this important journey of our life. Your patience during this time will never be forgotten.

Also dedicated to my three beautiful children, Samuel, Iris, and Nathalie Weis, who have been as understanding as children can be with a mother who works and goes to school full-time. Thank you for being with me through this voyage and allowing me to be a living example of the phrase “you never stop learning”. Thank you for your constant hugs, kisses, laughter, and love. I could not have asked for better cheerleaders, especially during this program. Remember always to make happy happen.

This is also for my amazing parents, Paul and Natalie MacDonald, who have always believed in me and supported my dreams. Every sacrifice you have made to get me to this point was not in vain. Thank you for giving me the opportunity to make you proud.

Each one of you play a significant role in my success and I am blessed to have you in my life. From the bottom of my heart, thank you!

Acknowledgements

I would first like to acknowledge being a Norton Healthcare Scholarship Recipient: This Doctor of Nursing Practice project and program of study was fully funded through the University of Kentucky College of Nursing and Norton Healthcare academic-practice partnership. I am honored and privileged to have been part of such a prestigious program.

Next, I would like to recognize my committee members, Dr. Julianne Ossege, Lynn Goranflo, and Nancy Kloha. Each of you have served as exceptional mentors and role models over the past three years. You are the leaders I aspire to be and thank you for holding me to the highest standards of excellence to make sure I reached my full potential.

Special thank you to my three supportive sisters who supplied laughs, listening ears, and quotes from our favorite old movies that allowed me to escape the seriousness of this program:

“Eunice? That's a person named Eunice?” - Barbara Streisand, *What's Up Doc?*, 1972

“Are you saying that I put an abnormal brain in a 7-foot-tall, 54-inch-wide

GORILLA!!!!???” – Gene Wilder, *Young Frankenstein*, 1974

Finally, I would like to recognize Betty Hayes, Amanda Wiggins, and my fellow DNP classmates. We have spent a long, arduous three years together full of laughter and tears, fond memories and epic meltdowns. Your continued support, encouragement, and alliance were pivotal to the successful completion of this journey.

Table of Contents

Acknowledgements.....	iii
List of Tables.....	v
List of Figures.....	vi
Abstract.....	1
Background.....	2
Theory.....	5
Purpose.....	6
Methods.....	7
Design.....	7
Setting.....	8
Sample.....	8
Measures.....	9
Data Collection.....	10
Results.....	12
Providers.....	12
ED utilization data.....	13
Discussion.....	14
Limitations.....	18
Implications for Practice.....	19
Recommendations for Future Studies.....	22
Conclusion.....	22
Appendices.....	24
Appendix A: IRB Approval Letter.....	24
Appendix B: NHORA Approval Letter.....	26
Appendix C: Consent to Email PCPs.....	27
Appendix D: Consent/Cover Letter to PCPs.....	28
Appendix E: Survey Sent to PCPs.....	30
Appendix F: ICD codes.....	31
References.....	36

List of Tables

Table 1: Provider survey and answers.....	39
Table 2: Patient demographics.....	40
Table 3: National Data.....	41
Table 4: This study's data compared to national data.....	42

List of Figures

Figure 1: Original palliative care model	43
Figure 2: Evidence-based updated model of palliative care.....	44
Figure 3: Cost per diagnosis of ED utilization data.....	45
Figure 4: Mean cost per patient.....	46

Abstract

Objective: The purpose of this project was to determine if there is a need for a palliative care team (PCT) to which primary care medical professionals can refer patients. The specific objectives of this project were: 1. To assess the knowledge of primary care providers regarding palliative care. 2. To assess the value and need for palliative care from the PCPs' perspective. 3. To evaluate the current ED utilization data for adults with serious chronic illness.

Methods: This was a descriptive study that involved an analysis of ED visit data for chronic illness, and a survey all PCPs employed at this healthcare system.

Results: Key findings showed that this population of providers were highly knowledgeable of palliative care (PC). The survey questions were answered correctly between 84%- 100% of the time. From this sample of PCPs, 89% felt that PC is needed and would refer their patients to a PCT if it were available. For the ED utilization data, revealed Caucasians and females were the most common users of the ED. Average LOS was approximately 4.45 days and HTN was the most common diagnosis. The admission rate for patients arriving through the ED was 63% (n = 1,524). Medicare was the primary payor for 57% (n = 1,375) of the population with a mean cost per patient of \$25,515.84. Total cost for the hospital system from October 1, 2017 through December 31, 2017 was \$58,430,933.75.

Conclusion: The evidence provided by this project demonstrates that PCPs have a high knowledge of PC and do find it to be of value for patients. Also, this study substantiates the evidence that patients are having complications from their chronic illnesses that bring them to the ED. These findings support palliative care as a necessary and valued modality of healthcare.

Background

Chronic illness affects many Americans at some point in their life, whether they are the one suffering from the illness or they are the caregivers of a loved one with the illness. A chronic illness is any diagnosis that “lasts longer than 6 months and requires ongoing care, cannot be cured, limits activity, and the associated symptoms lead to increased rates of morbidity and mortality” (Bushor et al. 2015, p 285). Chronic illnesses are associated with an estimated \$38 billion in unnecessary emergency department (ED) visits, \$25 billion in avoidable 30-day hospital readmissions, 67 million annual visits to the ED, and 836,000 annual unintentional 30-day readmissions (National Quality Forum, 2010). Current research continually proves that healthcare is inadequate for the problems that the seriously chronically ill patient can experience.

Chronic disease affects the majority of Americans, 51% of adults have at least one chronic condition, and 26% live with multiple chronic diseases (NCSL, 2013). The economic effects of chronic illnesses are not simply higher costs of health care but also include the decreased financial efficiency caused by higher rates of absences and poor job performances. A study by the Milken Institute found that the seven most common chronic diseases (cancer, diabetes, hypertension, stroke, heart disease, respiratory conditions, and mental disorder) cost the United States economy almost \$1.3 trillion annually, including \$277 billion for chronic illness treatments and \$1 trillion in lost productivity (DeVol et al., 2007).

When it comes to the last two months of life, 27% to 39% patients visit the ED at some point to receive relief from their symptoms (Murphy, et al. 2013). Common reasons that chronically ill patients are ultimately admitted to an inpatient setting include poor pain control, poor symptom management, an unexpected change in physical

condition, and overall caregiver burden (Murphy, et al. 2013). Indicators of poor-quality care are inadequately managed symptoms that result in ED visits, hospital and intensive care unit (ICU) admission, and possibly death (Earle, et al, 2003). Many studies consistently show that chronically ill patients often use health care resources, such as the ED, for management of their needs (Beckstrand et al., 2006; Bushor et al. 2015; Earle, et al, 2003; Hui et al. 2014; Murphy et al, 2013). Although most Americans would prefer to die at home, many continue to die with pain and poorly managed symptoms in a hospital setting (Beckstrand et al., 2006). More than 2.4 million deaths are annually recorded in the United States, and most of these deaths (80%) occur in hospitals (Murphy et al., 2013). Additionally, 20% of ICU patients die while hospitalized (Murphy et al., 2013).

Instead of realizing that death is a natural part of life, the majority of citizens in the United States deny death and won't accept that they will die at some point in their life. There is much reliance in believing that medical science can and will save us regardless of life's natural course. Frequently, healthcare providers perceive death as somehow failing to heal their patient rather than accepting the natural aspect of life. This tends to be manifested in a lack of discussions with patients regarding their end of life plan and wishes (End-of-Life Nursing Education Consortium, 2018). These discussions are missed opportunities to address the emotional, social, spiritual and physical pain with chronically ill patients and families. These conversations can improve quality of life for patients and families (National Hospice and Palliative Care Organization, n.d.).

Palliative care is a specialized modality of healthcare that focuses on providing relief from the symptoms and stress of a serious illness (The Center to Advance Palliative Care, n.d.). It is appropriate at any age, at any stage of illness, and can be offered together with curative treatment for any patient living with a serious illness

(CAPC, n.d.). Palliative care is a collaboration of doctors, nurses, social workers and others who work together to improve quality of life by: anticipating, preventing, and treating suffering; providing clarity on medical decisions; and by providing a plan of care for patients, families, and all medical providers (Dalal, et al, 2017).

According to the National Palliative Care Research Center (NPCRC) “palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness, whatever the diagnosis” (NPCRC, n.d.). Research findings demonstrate that initiating palliative care as early as possible in the outpatient setting is beneficial because it has been proven to decrease ED utilization and hospital admissions for those patients with life-limiting illness (Murphy, et al, 2013).

The former model of PC primarily included PC when death was imminent (Figure 1). The current updated, evidence-based model of PC involves PC at the time of diagnosis, but the involvement is not as prominent as it is near the end of the illness (Figure 2). There is a steady decline of traditional care while there is a steady increase in PC, which eventually converts into hospice care. Bereavement is also included for the surviving family and caregivers after the patient’s death. PC encompasses the broader population that could benefit from receiving this practice of care earlier in their illness or disease process (NHPCO, n.d.).

The objectives of palliative care are to improve the quality of a seriously ill person's life and to support that person and their family during and after treatment with an overall goal to create a plan of care for all involved (NPCRC, n.d.). Palliative care (PC) is a resource that can save patients the distress of needless procedures, medications, hospital

stays, and false hope that brings about unnecessary anxiety, pain, and fear (Aldridge et al, 2016).

However, at the healthcare system for this study, only two of the four hospitals have an inpatient PC team that is generally consulted too late in the disease progression, when further treatment is no longer an option and hospice is warranted. Hospice is a subdivision of palliative care that is specifically designed for patients who are in their last six months of life and have opted for no further treatments but want to focus on comfort from pain and anxiety (American Academy of Hospice and Palliative Medicine, n.d.). A primary palliative care team would be able to be involved throughout the course of the illness, rather than only being there for the end. In view of this, the intention of this study is to determine if there is a need for a palliative care team that can be consulted in the outpatient setting at the time of diagnosis, to improve patient quality of life and decrease overall healthcare costs.

Theory

The Human to Human Relationship Model, developed by Joyce Travelbee, is based on existentialism and its belief that humans are unique and irreplaceable, constantly growing, changing, facing conflicts and choices, and needing to accept accountability of these. This model, which is a major contribution to psychiatric and hospice nursing, can appropriately be utilized for all specialties in the nursing arena.

The Human to Human Relationship Model of Nursing has five phases.

- The inaugural meeting or original encounter
- Visibility of personal identities/ emerging identities.
- Empathy
- Sympathy
- Establishing mutual understanding and contact/ rapport (Nursing Theories, n.d.)

The role of nursing in Travelbee's theory is to help the patient find meaning in the experience of suffering, as well as help the patient maintain hope. It is necessary for the nurse to interact with the patient by using an authentic, humanistic approach. Patients are experiencing an imbalance of their health and the key to regain homeostasis is for the nurse to determine what has brought on this imbalance. By building a relationship that has followed the steps of interaction as Travelbee theorized, then the relationship can sustain through the illness and that connection will stimulate the nurse to go above and beyond for the patients that they have an emotional connection with. A nurse, that follows the seven basic concepts of Travelbee's theory will be able to assist the patient with their health issues and to accept and learn from it. This in turn will motivate the patient to change their behavior, maintain their health, and accept accountability for their actions that initiated the illness to begin with.

The main concept that is of the utmost importance of the Human to Human Theory is the maintaining of hope. A patient needs to have hope, whether its hope for a speedy recovery or hope for all their loved ones to be at their bedside as they take their final breath, because it gives them the faith and trust needed to not surrender to their illness, but to accept it.

Purpose

Research suggests assessing the need for a palliative care team (PCT) can be accomplished by studying the use of the ED, hospital admissions, hospital deaths, and medical procedures for the seriously chronically ill patient and totaling the overall costs (Beckstrand et al., 2006; Bushor et al. 2015; Earle, et al, 2003; Hui et al. 2014; Murphy et al, 2013). If the rates of hospital utilization and medical costs are higher than expected, a

PCT can be created that may help to cut these costs and improve patient symptom management, quality of life, and satisfaction. The specific objectives of this project were:

1. To assess the knowledge of primary care providers regarding palliative care.
2. To assess the value and need for palliative care from the PCPs' perspective.
3. To evaluate the current ED utilization data for adults with serious chronic illness.

This project's purpose is also pertinent to the local healthcare organization's mission that aims to provide quality health care to all those who are served in an approach that responds to the needs of the communities while honoring the faith heritage (Norton Healthcare. n.d.).

Completing this study will supply needed information to create a PCT for the patients who are diagnosed with a life-limiting chronic illness. By creating a healthcare organization that focuses on early PC, there could be a higher quality of overall care which has been proven to decrease healthcare costs, while increasing patient satisfaction, improving symptom management, quality of life, quality of death, and providing better managed care (Hui et al. 2014). When integrated with standard care at time of diagnosis, PC improves patient outcomes, including symptom burden, quality of life (QoL), and end-of-life care, all with lower associated costs (Dalal, et al, 2017). More importantly, the patient can be reassured that their pain, anxiety, dignity, and final wishes will be maintained.

Methods

Design

This was a descriptive study that analyzed ED utilization data and surveyed all primary care providers (PCPs) employed at this organization.

Setting

This project collected data at one institution with a network of five hospitals, and 30 physician practices. This is the largest healthcare system in Louisville, KY and the surrounding region.

Sample

There were two populations of interest. The first population was the PCPs working at this organization. Three hundred sixteen providers employed in the primary care offices were included in this study. Inclusion criteria for PCPs was comprised of all primary care providers that are licensed as either a medical doctor (MD), Doctor of Osteopathic Medicine (DO), nurse practitioner (NP), or physician assistant (PA); and see adult patients. Exclusion criteria were pediatric providers, any unlicensed professionals, and PCPs not employed by this system. PCPs' email addresses were obtained through the NHC human resources department (HR), and permission to use PCPs' email for this project was granted by HR personnel (Appendix C).

The second sample was comprised of ED utilization data. This data was from a 90-day timeframe, beginning October 1, 2017 through December 31, 2017, from all four major hospitals of this organization. Inclusion criteria were all adult patients seen in the ED with serious life-limiting illness diagnosis of congestive heart failure (CHF), hypertension (HTN), end-stage renal disease (ESR), chronic obstructive pulmonary disease (COPD), dementia, amyotrophic lateral sclerosis (ALS), acquired immunodeficiency syndrome (AIDS); human immunodeficiency virus (HIV), cerebral vascular accidents (CVA), and diabetes mellitus (DM) (Appendix F for specific ICD-10 codes). Exclusion criteria included any patients diagnosed with cancer or malignancies; gestational diabetic patients; pediatric patients under 18, and any patient who received a

new diagnosis of a life limiting chronic illness during that hospital visit. These medical records were excluded for the following reasons: their age and inability to make their own decisions without a guardian's involvement; cancer treatment for oncology patients generally include palliative care; and patients with diagnoses made with current hospital admission have yet to be seen by their PCPs. Also, excluded were any patients with alcohol or drug abuse as these patients generally require detoxification and rehabilitation with more involvement from the psychiatric team.

Measures

Providers' survey data was collected via Qualtrics (Qualtrics, 2018). Qualtrics is a secure, web-based application that is designed exclusively to support data capture for research studies and every effort was taken to safeguard data once received from Qualtrics.

The survey measured knowledge and perception of palliative care, involved 10 questions, and took approximately 5 minutes or less to complete (Appendix E). Questions 1-4 were true/false questions and were derived from the palliative care quiz for nursing (PCQN) (Ross et al, 1996). Three multiple-choice questions, 5-8, were derived from the survey created by the Italian Society of Palliative Care (SICP) and the Italian Society of General Practice (SIMG) which have been used in a study of Italian general practitioners (Beccaro et al, 2013). The last two questions were yes or no and were created by the primary investigator (PI). Additionally, the PI collected demographic data: years of experience, and license as MD, DO, NP, or PA.

ED utilization data: Data was requested through a collaboration with the healthcare's IT/ decision support/clinical effectiveness program. The 90-day review of the ED utilization data specified:

- Rates of admissions to ED
- If admitted to the hospital
- Rates of hospital deaths
- Admitting diagnosis of: CHF, HTN, ESR, COPD, dementia, ALS, AIDS, HIV, CVA, DM
- Total cost of hospital stays
- Length of stay
- Gender
- Age
- Ethnicity
- Insurance status

Data was gathered from all four hospitals within this system from October 1, 2017 to December 31, 2017.

Data Collection

Approvals from this healthcare's Office of Research and Administration (ORA) and the University of Kentucky Institutional Review Board (IRB) were obtained prior to data collection (Appendices A, B, & C).

Primary Care Providers: The PI requested and received email addresses from the institution's human resources department 9,516 were received. Each entry on this list supplied the employees' names, work locations, job titles, and the email addresses of a variety of staff from different areas of the healthcare network. Many were excluded due to their job title such as those that were staff registered nurses (RN), patient certified assistants (PCA), environmental services department (ESD) employees, human resources (HR), lab employees, medical care associates (MCA), and secretaries. Also excluded were any providers that worked in the hospital setting which included intensivists, hospitalists, nurse practitioners, physician's assistants, and certified nurse specialists (CNS). Furthermore, providers that were employed in specialty areas, such as maternity, spinal medicine, pediatrics, urology, and cardiology were excluded. The final sample of

MD, NP, DO, and PA providers included those employed in the primary care offices around the metropolitan area of this specific healthcare system. The final sample size consisted of 316 primary care provider email addresses. Providers' email addresses were stored in a file separate from data collected from Qualtrics. The providers' email addresses were used for the initial invitation to participate in the survey, then used once again for a reminder email that was sent two weeks after the original invitation. After the second emailing, the providers' email address list was destroyed.

The sample of 316 were sent a first email with a cover letter and informed consent, and a request to complete the survey on July 24, 2018. A second email reminder was sent on August 11, 2018. The survey closed on August 25, 2018.

Prior to administering surveys, consent for participation was obtained. The email contained a cover letter that provided potential participants the informed consent and a link to the survey (Appendix D). The informed consent provided a full explanation of the study provided, the time commitment required, the option to voluntarily participate or to withdraw at any time. It also provided information of the confidentiality associated with the study to protect their person from being identified. They were informed of their right to refuse to participate, absence of monetary gains or incentives, and methods of communicating concerns regarding the project. By clicking on the link provided, participants were able to continue to the survey and continuing to the survey constituted consent to participate.

The data from Qualtrics was electronically transposed onto a Microsoft excel spreadsheet for analysis in IBM SPSS version 23.0. All research reports were done in aggregate form and the data was stored separately on the healthcare's password protected and encrypted H drive.

ED utilization data: Data was requested through a collaboration with the healthcare's IT/ decision support/clinical effectiveness program. The 90-day review of the ED utilization data was specified for:

- Rates of admissions to ED
- If admitted to the hospital
- Rates of hospital deaths
- Admitting diagnosis of: CHF, HTN, ESR, COPD, dementia, ALS, AIDS, HIV, CVA, DM
- Total cost of hospital stays
- Length of stay
- Gender
- Age
- Ethnicity
- Insurance status

The data that was received from the healthcare's IT/ decision support/clinical effectiveness program contained deidentified information for 2,434 patients, however one patient was excluded due to being younger than 18 years of age. The final sample size totaled 2,433 patients.

Data were analyzed using descriptive statistics, including frequency distributions, means, and percentages.

Results

Providers

Of the 316 emails that were sent for the initial invitation to participate, 12 were not delivered due to email inboxes being full. For the reminder email sent, 13 emails were not delivered as one recipient was unknown and the 12 others for the same reason as the initial email. Thirty-eight responded to the survey and of those 37 submitted a completed survey making the response rate 11.7%. The professional title of participants

were 16 MDs, 3 DOs, and 18 FNPs. Of the 37 who responded, 54% (20) had less than 5 years' experience in their role.

Overall, the results of the survey showed that primary care providers are well educated about PC and how it can serve their patients. Survey knowledge questions were answered correctly between 84%- 100% of the time. When answers were cross-tabulated using the Chi square test against the specific role of the provider there was no significance in answers except for two.

The first question with a significant result asked, "Do you feel that a palliative care team, one you could refer outpatients to, is needed?" Four responded "maybe" and those four were MD titled. The second question of significance asked: If available, would you refer your patients to the palliative care team? Again, four responded "no" and again those four were MD titled. Both had a *P* value of 0.053. More importantly of the 36 who responded, 32 (89%) felt there was a need for PCT and would refer their patients if one was available.

Of the 37 who did participate, two personally took the time to comment. Both applauded the idea of a PCT, praised the project's objective, and offered help and guidance in whatever was needed to create a PCT.

ED Utilization Data

During the study timeframe 2,433 patients were seen in the Emergency Departments (ED) throughout the four major hospitals. Fifty-six percent of the sample were female ($n = 1,365$), 65% ($n = 1,581$) Caucasian, and the age range of the sample was between 18 through 101 years, with the mean of 61.6 ($sd = 16.8$). Of those, 909 were seen and discharged from the ED. The remaining 1,524 patients were admitted with an

average length of stay (LOS) of 4.45 days, for a grand total of 6,783 hospital days.

Twenty-six of these patients expired during their admission (Table 2).

Total cost, for all ED patients who were admitted from October 1, 2017 through December 31, 2017, was \$58,430,933.75 with a mean of \$25,515.84 per patient (Figure 4). Cerebral Vascular Accidents (CVA) were the most expensive diagnosis of \$62,828.96. Medicare was the payor for 57% (n = 1,375) of the population (Figure 3). The chief diagnosis was hypertension (HTN) in 37% (n = 910) with 60% (n = 544) of those patients being admitted. COPD was the second most common diagnosis at 22.9% (n = 556). African Americans had a higher rate of HTN per population, 41% (n = 321). Whether ED or inpatient, the mean cost of HTN was \$25,715.27 per patient.

Discussion

Key findings showed that this population of providers were highly knowledgeable of PC. This is dissimilar to those who have taken comparable surveys regarding PC and its need (Beccaro et al, 2013; Ross et al, 1996). For the true and false questions one through four, which were from the PCQN, this sample scored an average of 89%. Research indicated that the average for a sample of 155 registered nurses (RNs) was 76% correct which indicates that this population of PCPs is more informed of PC and its value (Ross et al, 1996). On questions five through eight, previous research of 1,489 Italian general practitioners that participated received a mean score of 48% (Beccaro et al, 2013), compared to the 80% received in this study. This sample was exceedingly more knowledgeable than providers in previous research from which the survey questions originated (Table 1), which could be contributed to recent increased advocacy and education for PC.

Eighty-nine percent of this sample of providers felt that PC is needed and would refer their patients to a PCT if it were available. This perception of PC is similar to data from the World Health Organization (WHO) which states that many providers do welcome PC into their practice, however PC continues to remain underutilized (WHO, 2018).

National patient data for a three-month time frame during 2015 shows that 34,236,000 patients utilized the ED (CDC, 2015). However, 17,336,000 shared the same primary diagnosis of the chronic illnesses from this study (CHF, HTN, ESR, COPD, dementia, ALS, AIDS, HIV, CVA, DM). From the national sample, patients were primarily Caucasians 74% (n = 12,854,000); 57.7% (n = 9,995,000) females; 46.7% (n = 8,093,000) were diagnosed with HTN; and 34.8% (n = 6,031,000) had Medicaid as the primary source of payment (CDC, 2015). The national mean costs per patient was \$10,885 with total costs of \$961,439,280 for a three-month timeframe (HCUP, 2018) and an average LOS of 4.6 (HCUP, 2018) (Figure 3).

These trends do correlate with the data from this project in that whites, females, and HTN are the most common users of the ED (Figure 4). Average LOS was approximately the same with 4.9 days of the nation compared to this study's average LOS at 4.45. While HTN was the most common diagnosis for both this study and nationally, the second most common for the nation at 21.6% (n = 14,945,000) was diabetes (CDC, 2015) while in this study the second most common diagnosis was COPD 23% (n = 566). This could be due to the large number of Kentuckians who are smokers. Kentucky is ranked second in the nation for smokers (UHF, 2015). Physiological, nicotine is a vasoconstrictor that can lead to HTN, which could explain this area's high rate of the disease. Furthermore, smoking is the primary cause for COPD, this creates a

vulnerable population susceptible to infectious agents and admitting these patients for close monitoring of oxygenation requirements is to ensure their safety and viability. This would also account for COPD being the second highest diagnosis in the ED in this study and increasing the mean cost per patient to \$25,515.84, which is \$14,630.84 higher than the national mean cost (HCUP, 2018).

National data shows that the average age was 73 for admissions compared to the average of 61.9 of this study (CDC, 2015). The younger age seen in this study could be attributed to Kentucky being the 6th unhealthiest state in the country (UNF, 2015).

The national admission rate for patients arriving through the ED has been reported as 10.5% (n = 1,820) compared to the 63% for this study (NCSL, 2013). This large contrast of admission rates could be due to Kentucky being ranked the fifth state in the country that has the highest preventable hospitalizations in the country (United Health Foundation, 2015), which can indicate problems with the state's access to primary health care and inadequacies in quality outpatient care (UHF, 2015). Preventable hospitalizations often take place for a failure to treat issues earlier in an outpatient setting and are also more common among the uninsured (UHF, 2015).

Research has shown that early PC can increase satisfaction and quality of life (QoL) thereby decreasing the ED usage. Chronically ill patients who are not well managed, which may be the case with those in this study with HTN who use the ED to manage symptoms. This also could indicate a decrease in their QoL. By integrating palliative care earlier in an illness progression, there could be a significant impact on decreasing unnecessary health care utilization for the patients like those in this study. Early PC is beneficial because it has been proven to reduce ER utilization and hospital admissions for those patients with life-limiting illness (Hui et al. 2014). The reduction of

ER utilization and improved symptom management outside a hospital setting can improve quality of life, quality of death, and decrease overall healthcare costs.

Palliative care, that is initiated at the time of diagnosis, can be delivered alongside treatments that aim to treat the underlying disease (Hawley, 2017). Both approaches are necessary and should have equal value. Research has shown that PCPs and patients often have sporadic conversations regarding goals of care. Unfortunately, they are commonly initiated late in the course of illness which contributes to poor outcomes, increased distress, and a failure to provide care that fulfills patients' wishes (Narang, Wright, & Nicholas, 2015). In comparison, when these discussions are early as is seen in palliative care, patients are more likely to receive goal-directed care that is less aggressive near death and have less hospitalizations, improved quality of life, and a greater likelihood of hospice enrollment (Mack, Weeks, Wright, Block, & Prigerson, 2010).

When discussing PC and advanced care planning (ACP), studies show that only 65% of physicians felt comfortable talking with their patients about this, while 44% of PCPs expressed a reluctance of bringing up the topic. (Snyder, Hazelett, Allen, & Radwany, 2012). These results are much higher than the 11% of providers from this study who expressed reluctance, suggesting the providers at this institution are comfortable discussing end of life care with their patients. Further research is needed to validate these findings.

Well-documented reasons for PCPs to be reluctant in discussing this are they believe that ACP and PC discussions take too much time, could cause distress and loss of hope, see a referral as an acknowledgement of failure, and they do not want to abandon their patient (Snyder et al, 2012; Beccaro et al, 2013; Ross et al, 1996). Although many

studies provide evidence that PCPs need to improve their knowledge of PC in order to enhance the quality of care physicians provide to pts (Davis, 2013; Snyder et al, 2012; Beccaro et al, 2013; Ross et al, 1996), for this sample that is not true as they have demonstrated that they are knowledgeable.

Limitations

The limitations of this study were few but of significance. The survey data is questionable due to the low response rate of 11.7% (n = 37) of the 316 providers invited. The response of the providers may have been skewed as those who chose to answer may be particularly interested in palliative care. Also, this survey was created from two different questionnaires. Questions one through four were from the PCQN that surveyed RNs and not providers, which could explain the difference in the average scores of 89% for the PCPs and 76% for the RNs. However, questions five through eight were from a survey that was designed specifically to test Italian providers. The cultural differences may have created the large difference between the scores. Also, the PCQN was from research obtained in 1996, the SKIP and SIMG from 2012. Since then promotion and education of PC has grown.

ED utilization information excluded any acute issues, such as injuries, accidents, or falls. This may have eliminated patients with acute problems directly related to a chronic disease itself or side effects of medications taken for chronic disease or illness.

Also, it is unknown if these ED patients were also being seen by a specialist, such as a pulmonologist seeing a COPD patient, for their chronic illness or if they were being managed by the primary care provider. Nevertheless, the patients were still being seen in the ED for unmanageable symptoms of their chronic illness. This implies that they have unmanageable symptoms.

An additional limitation is the fact that it is unknown if any of these visits are the same patient being seen multiple times during the three-month time study period, or if there were any 30-day readmissions. If this information was known, then this may have decreased the number of individuals seen but also would give further evidence that their illness is not being well managed.

A limitation of this general population should be addressed as this healthcare facility is located in an area of the country with a high incidence of smokers. This may reflect the high rate of COPD and HTN rates which were seen in this study. Perhaps in another area in the country, there would possibly be different chronic illnesses that could change the data.

Lastly, it is unknown if these individuals have any other comorbidities as many chronic illnesses can cause other chronic illnesses to arise, such as DM and renal disease, that would make them inter-related. This information would have given additional evidence regarding diagnosis, symptom management, and causes for increased LOS or costs.

Implications for Practice

The results of this study indicate that an early referral PCT could be beneficial to this community, especially with a focus on HTN and COPD. Providers are knowledgeable on what PC is and the benefits it can provide for patients, yet what is of more significance is that many PCPs who responded would integrate it into their practice for their chronically ill patients. Based on the ED utilization data, the need for PC exists. PCPs have the knowledge and the appreciation for utilization of a palliative care team. This supports development of a PC team to serve primary care patients with chronic diseases.

When surveying patients and their families regarding their chronic illness, research shows two major problems people face at the end of life are that quality care does not reach enough people (Dalal & Bruera, 2017), and the rising costs of health care (Dalal, et al, 2017). PC can help to resolve these two issues when integrated, along with traditional treatment, at the time of diagnosis. Patient savings could amount to \$2,300 to \$8,200 (Dalal, et al, 2017) if given the opportunity to have PC as a part of their healthcare team, which would help to relieve that financial burden and provide them with quality care throughout their illness.

Next steps could include creating a palliative care team (PCT) that a DNP prepared nurse practitioner could lead. This would require a thoughtful planned strategy to include gathering stakeholders and informing them of this project's results, providing education for patients and families, and for the providers who are skeptical about PC and its benefits. For the hospital leaders, administrators, and financial officers it would be necessary to present the evidence of how PC can improve services, decrease costs, increase patient satisfaction, use medical resources more efficiently and effectively, and promote this health system as a leader in healthcare. Evidence of importance to present to these stakeholders would be the cost for creating a functional PCT and the savings that would be recouped. To gain support from additional stakeholders, such as the patients, families, and providers, it would be necessary to hold educational sessions or forums explaining what PC is, how it differs from Hospice, what it can offer, how it improves patient satisfaction and increased QoL. These educational sessions have the goal of decreasing barriers, such as PCP, patient and family resistance. The biggest barriers would be a resistance to change which would require encouraging, listening and being available for discussions, concerns, and complaints from affected staff members. To

address the known unwillingness of PCPs to “share” patient and the known PCP feelings of abandoning their patient, as seen in the evidence (Hawley, 2017), any education or discussion would need to emphasize that PC is to augment care not take patients from providers and demonstrate how PC can increase patient satisfaction and allegiance to the provider especially when initiated in a timely fashion.

Estimated costs for a successful Palliative Care Program for one hospital in this healthcare system would be approximately \$714,000 annually. This would include a breakdown of the expenses of \$144,000 for office space, utilities, and supplies, and then an additional \$570,000 for staff of one physician, two nurse practitioners, a social worker, and ad hoc team members. The savings that could be gained from the creation of a palliative care team could be recouped through a decrease in the 30-day readmission rates, which hospitals do not get compensated for. This savings would justify the annual cost for a PCT. Although, this was not part of the study

Savings are higher when PC is involved earlier, the hospital cost savings with PC involvement ranges from 9%–32% (Dalal, et al, 2017). Patients with PC involvement had fewer ICU admissions, readmission rates, and approximately 32% reduction in total healthcare costs over 6 months post-discharge and a 50% reduction in daily charges, direct costs, and total costs of care for the PC patients (Scibetta, et, al. 2016).

Early palliative care is associated with less intensive medical care, improved quality outcomes, and cost savings (Scibetta, et, al. 2016). The mean total cost for medical care was \$10,801 with PC and \$16,165 without (Scibetta, et, al. 2016), which is an approximate savings of \$5,364 per patient. This would be assuming that the average

patient cost was \$16,165, however with the population in Kentucky the mean cost was \$25,715. Therefore, the savings could potentially be higher.

Recommendations for Future Studies

Recommendations for future studies would include an examination of the 30-day readmission rates with and without PC involvement. It would be beneficial to determine if readmission rates do decrease and provide the hospital with significant savings from 30-day readmissions.

Future studies could also focus on patient knowledge of PC and how they interpret the meaning of this specialized practice. It's not uncommon for patients, families, and even providers to interchange the terms palliative care and hospice, thinking that they are synonymous. Research investigating pre-education and post-education of PC would show evidence if patient education is effective in increasing the use of PC. Another study could be directed at evaluating the patients' feelings and thoughts regarding PC after it has been supplemented to their care team. This would be beneficial to verify if in fact PC does improve patient satisfaction, rather than only monitoring ER or hospital admissions.

Similarly, an evaluation of PCPs' feelings and thoughts regarding PC after it has been supplemented would help to understand their perspective of PC assisting in patients' care. Focus groups from PC supporters and non-supporters to discover their concerns, fears, and apprehensions would be helpful in determining how to best address these hesitations.

Conclusion

The evidence provided by this project demonstrates that PCPs have a high knowledge of PC and do find it to be of value. Also, there is evidence that patients are

having complications from their chronic illnesses that bring them to the ED. By integrating PC earlier in an illness progression, there could be a significant impact on decreasing unnecessary health care utilization across this healthcare system. PC is beneficial because it has been proven to reduce ED utilization and hospital admissions for those patients with life-limiting illness (Bushor, et al. 2015). The reduction of ED utilization and improved symptom management outside a hospital setting can improve quality of life, quality of death, and decrease overall healthcare costs. The value of early PC involvement is important for the patient and family to obtain the management and support they need to provide them with the best possible care and best possible outcomes that are available, but PC only provides benefits if utilized (Murphy, et al, 2013). Many healthcare facilities may not have a properly formed palliative care team for treating and caring for patients diagnosed with a life-limiting chronic illness.

This leaves many patients and providers without the proper resources that can help to avoid those unnecessary hospitalizations. A PCT can focus on relieving suffering and achieving the best possible quality care for patients and their caregivers, while assisting the primary care provider with the additional support of managing their patient's symptoms. Creating a PCT, one that primary care providers (PCPs) can refer chronically ill patients to early in the diagnosis, can provide a higher quality of overall care for all patients.

Appendix A: IRB Approval Letter



Research Office (RO)

224 E. Broadway
Louisville, KY 40202
Phone (502) 629-3501
Fax (502) 629-3480
nhora@nortonhealthcare.org
www.nortonhealthcare.org

April 25, 2018

Nathalie Weis, RN
3010 Boones Trace
Crestwood, KY 40014

RO# 18-N0081 / IRB# 43022/ An assessment to determine the need for a palliative care team to improve patient satisfaction and decrease healthcare costs

Dear Ms. Weis:

The Norton Healthcare Research Office (RO) is pleased to notify you that your application to conduct the above-mentioned research study in the following Norton Healthcare (NHC) facility has been approved.

- **Norton Community Medical Associates (NCMA)**

Please note: Additional institutional approvals, such as from practice managers, HR, and/or Norton Medical Group, may be necessary based upon the type of study you are conducting. It is your responsibility to work with your advisors to ensure that all institutional permissions have been obtained prior to initiating your research project.

The following items must be submitted to the RO if your study continues to be conducted in a NHC facility and are applicable to your study:

- **Annual Progress Report/Continuation Review form**
- **Annual Approval letters and current Informed Consent Forms approved by the IRB, if applicable**
- **Amendments and Amendment Approval letters**
- **Revised HIPAA documents such as revised Partial Waivers/Complete Waivers of authorization for each change in personnel**
- **Changes in the Conflict of Interest status**
- **Status change of study, i.e. closed to enrollment, study termination etc. To comply with HIPAA regulations:**
- **A copy of the Partial Waiver of Authorization must be filed with the medical record of every patient screened for the study, if applicable.**
- **For retrospective chart reviews, a copy of the Complete Waiver of Authorization must be filed with the medical record of every patient whose chart is reviewed for the study.**

For studies utilizing an Informed Consent Form, a signed copy of the Informed Consent Form and Research Authorization must be filed with the medical record of each subject enrolled in your study in a NHC facility.

If applicable, the Research Patient ID form must be submitted to NHC Research Billing daily with reportable activity. Please email the form to ResearchFinance@nortonhealthcare.org. Please contact Lori Gearhiser at 502-629-3558 for specific instructions regarding the notification of your subject enrollment at NHC.

If the study will include the use of sponsor provided and/or personal equipment of any type (for example: tablets, ECG machines, ePROs, personal laptops etc.), that equipment must be checked, tracked and/or inspected by Norton Healthcare's Clinical Engineering department prior to its use or placement in a patient care setting. Request an initial incoming inspection of the equipment as follows:

- Norton employed researchers – contact Clinical Engineering on NSITE at <http://nsite/departments/clinicalengineering/SitePages/Home.aspx>

Running head: PALLIATIVE CARE NEEDS ASSESSMENT

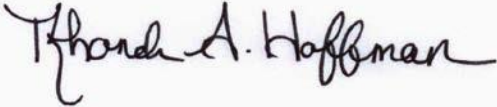
- Non-Norton employed researchers – contact Clinical Engineering by calling 502-629-3590

In the event your study will utilize personal and/or sponsor provided equipment, please ensure that you comply with the procedure outlined above.

We look forward to the successful completion of your study. If you have any further questions or need assistance, please contact the RO at (502) 629-3501.

Please let us know how we are doing. Follow the link <https://www.surveymonkey.com/s/NHORAsatisfaction> to complete the RO Satisfaction Survey in less than two minutes. Your feedback helps the RO improve the services we provide and meet the needs of the research community.

Sincerely,



Rhonda Hoffman
System Director Research

Norton Hospital Norton Children's Hospital Norton Audubon Hospital
Norton Women's and Children's Hospital Norton Immediate Care Centers Norton Brownsboro Hospital

Appendix B: NHORA Approval Letter



Initial Review

Approval Ends: 3/25/2019

IRB Number: 43022

TO: Nathalie Weis,
PI phone #: 5027584425
PI email: nmwe224@uky.edu

FROM: Chairperson/Vice Chairperson Medical Institutional Review Board (IRB)
SUBJECT: Approval of Protocol DATE: 3/28/2018

Initial Review

Approval Ends: IRB Number: 3/25/2019

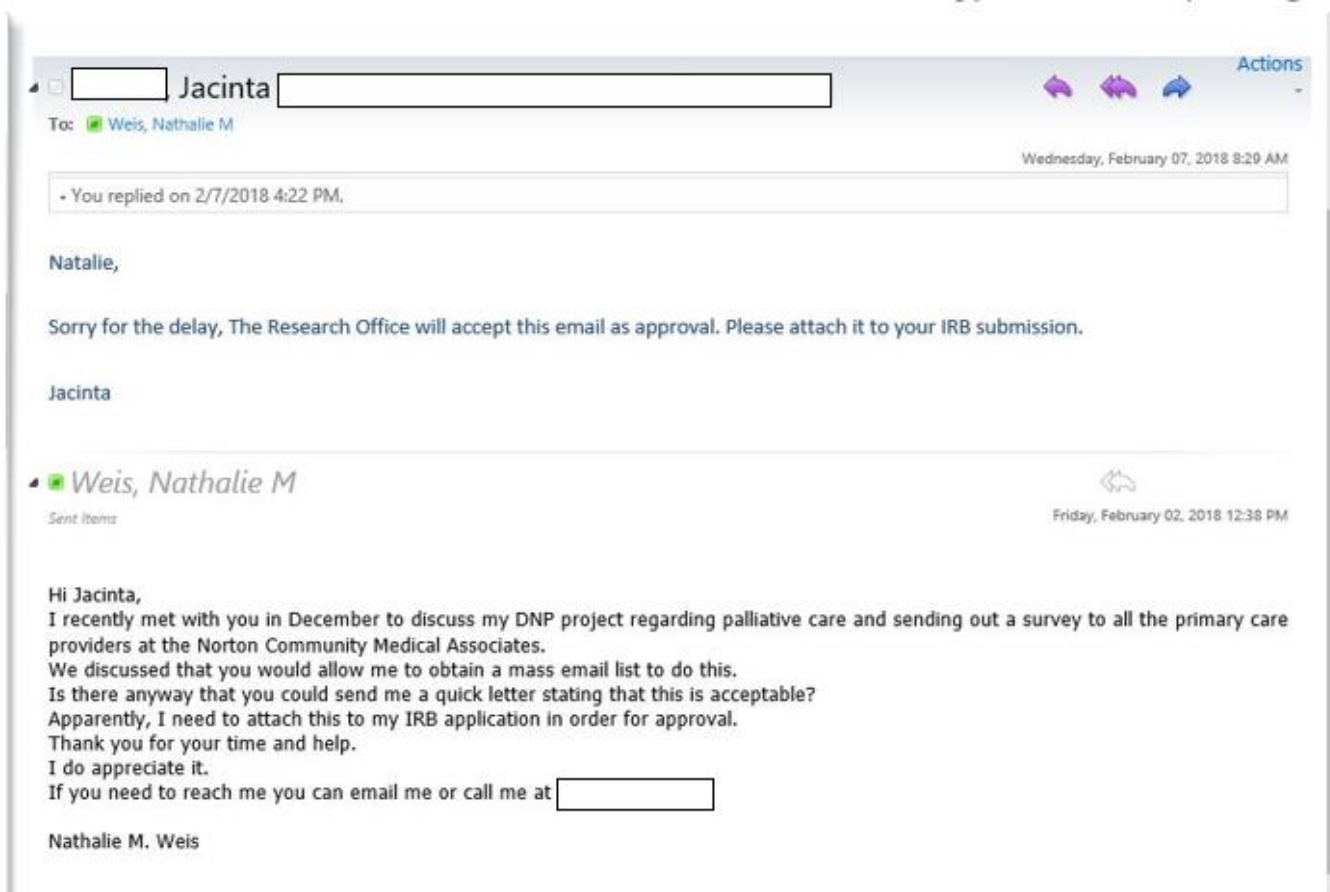
On 3/26/2018, the Medical Institutional Review Board approved your protocol entitled: An assessment to determine the need for a palliative care team to improve patient satisfaction and decrease healthcare costs

Approval is effective from 3/26/2018 until 3/25/2019 and extends to any consent/assent form, cover letter, and/or phone script. If applicable, the IRB approved consent/assent document(s) to be used when enrolling subjects can be found in the "All Attachments" menu item of your E-IRB application. [Note, subjects can only be enrolled using consent/assent forms which have a valid "IRB Approval" stamp unless special waiver has been obtained from the IRB.] Prior to the end of this period, you will be sent a Continuation Review Report Form which must be completed and submitted to the Office of Research Integrity so that the protocol can be reviewed and approved for the next period.

In implementing the research activities, you are responsible for complying with IRB decisions, conditions and requirements. The research procedures should be implemented as approved in the IRB protocol. It is the principal investigator's responsibility to ensure any changes planned for the research are submitted for review and approval by the IRB prior to implementation. Protocol changes made without prior IRB approval to eliminate apparent hazards to the subject(s) should be reported in writing immediately to the IRB. Furthermore, discontinuing a study or completion of a study is considered a change in the protocol's status and therefore the IRB should be promptly notified in writing.

For information describing investigator responsibilities after obtaining IRB approval, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" available in the online Office of Research Integrity's IRB Survival Handbook. Additional information regarding IRB review, federal regulations, and institutional policies may be found through ORI's web site. If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at 859-257-9428.

Appendix C: Consent to Email PCPs



Appendix D: Consent/Cover Letter to PCPs

<p>IRB Approval 3/26/2018 IRB # 43022 ID # 18070</p>
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Email to Participants and Consent Documentation Waiver Script

You are being invited to participate in a research study, An assessment to determine the need for a palliative care team. The purpose of this study will be to determine if there is a need for a palliative care team (PCT) to which primary care medical professionals can refer patients. The Principal Investigator is Nathalie M. Weis, a student in the Doctor of Nursing Practice Program at the University of Kentucky College of Nursing and employee at Norton Healthcare. If you agree to participate in the study, you will be asked to complete an online survey on Qualtrics that asks you to provide answers to nine questions, either true/ false, multiple choice, or yes/no. Completing the survey will take approximately 5 minutes. Your participation in this study is entirely voluntary. Your answers are important to us. Of course, you have a choice about whether to complete the survey/questionnaire or not, but if you do participate, you are free to skip any questions or discontinue at any time. There is no penalty for withdrawing and no benefits or services regularly afforded that you will be compromised by your participation status.

There is minimal risk with participation in the study. Qualtrics is a secure, web-based application designed exclusively to support data capture for research studies. We make every effort to safeguard your data once received on our servers via Qualtrics. Given the nature of online surveys, as with anything involving the internet, we can never guarantee the confidentiality of data still en-route to us.

The benefits that may be derived from this research include improving knowledge related to quality of care for patients with serious life-limiting illnesses through identification of possible treatment gaps or potential barriers. There is no direct benefit to you other than knowing you are informing this body of knowledge which could potentially improve patient care. Your responses will be anonymous. Records of your participation in this study will be kept confidential to the extent permitted by law. Results of this research will be reported as summarized data and will not contain any identifiable individual data. For this study, survey respondents will not be asked to provide a name, email address or any identifying information. There is no connection/link between the email addresses used when completing the survey and the responses.

Should you have any questions you may contact Nathalie M. Weis, the Principal Investigator, via email at nathalie.weis@nortonhealthcare.org or telephone at 502-758-4425. If providers are not able to reach the PI, then they can contact the advisor, Julie Ossege, PhD, FNP-BC, FNAP at julianne.ossege@uky.edu. If you have any complaints, suggestions, or questions about your rights as a volunteer, you are asked to contact the staff in the Office of Research Integrity at the University of Kentucky at 859-257-9428 or

toll free at 1-866-400-9428

Your completion of the survey will be considered your consent to participate in the study and your agreement that you have been sufficiently informed of the purpose of the study and any associated risks and benefits. If you agree to participate in the study, please click on the below link to access the survey.

SURVEY LINK WILL BE COPIED HERE

Thank you in advance for your assistance with this important project.

Appendix E: Survey Sent to PCPs

Primary Care Physician Questionnaire:

1-4 are true or false.

1. Palliative care and hospice care are virtually the same.
2. Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration.
3. The provision of palliative care requires emotional detachment.
4. The philosophy of palliative care is compatible with that of aggressive treatment.

5-8 are multiple choice; choose the best answer.

5. Which of the following definitions of palliative care do you consider the most appropriate?
 - a. A series of treatments aimed to bring the patient to a dignified end of life
 - b. Pain therapy, whether moderate or severe, in the incurable patient
 - c. The management of all symptoms affecting the incurable patient
 - d. Holistic care, which also incorporates support for the family, for patients not only at the end of life but also in the developmental stage of an incurable disease
 - e. Alternative treatments (e.g., homeopathy) for incurable patients and their families
6. In your opinion, which of the following objectives is consistent with the definition of palliative care?
 - a. To ensure the best quality of life of incurable patients
 - b. To alleviate pain
 - c. To relieve symptoms
 - d. To prolong as long as possible the patient's life
 - e. To cure the patient's illness
7. The most authoritative guidelines on health care planning recommend that palliative care should be provided by:
 - a. Specialized nursing staff
 - b. A specialized multi-professional palliative care team that includes the family's GP
 - c. GPs
 - d. Multi-professional hospital team led by a pain therapist
 - e. Specialized nursing staff in collaboration with an anesthetist
8. According to your experience, palliative care pathways require:
 - a. Treatments in accordance with the directives in the hospital discharge
 - b. Diagnosis and therapy based on past experience
 - c. An individual care plan.
 - d. Diagnosis and therapy centered on scientific evidence
 - e. High-performance technology

9 and 10 are yes or no

9. Do feel that a palliative care team, one you could refer outpatients to, is needed at Norton Healthcare?
10. If available, would you refer your patients to the palliative care team?

Appendix F: ICD Codes

Diagnosis	ICD-10 Code
Congestive Heart Failure	I50.1 Left ventricular failure, unspecified I50.2 Systolic (congestive) heart failure I50.20 Unspecified systolic (congestive) heart failure I50.22 Chronic systolic (congestive) heart failure I50.3 Diastolic (congestive) heart failure I50.30 Unspecified diastolic (congestive) heart failure I50.32 Chronic diastolic (congestive) heart failure I50.4 Combined systolic (congestive) and diastolic (congestive) heart failure I50.40 Unspecified combined systolic (congestive) and diastolic (congestive) heart failure I50.42 Chronic combined systolic (congestive) and diastolic (congestive) heart failure I50.9 Heart failure, unspecified
Hypertension	I10 Essential (primary) hypertension I11 Hypertensive heart disease I11.0 Hypertensive heart disease with heart failure I11.9 Hypertensive heart disease without heart failure I12 Hypertensive chronic kidney disease I12.0 Hypertensive chronic kidney disease with stage 5 chronic kidney disease or end stage renal disease I12.9 Hypertensive chronic kidney disease with stage 1 through stage 4 chronic kidney disease, or unspecified chronic kidney disease I13 Hypertensive heart and chronic kidney disease I13.0 Hypertensive heart and chronic kidney disease with heart failure and stage 1 through stage 4 chronic kidney disease, or unspecified chronic kidney disease I13.1 Hypertensive heart and chronic kidney disease without heart failure I13.10 with stage 1 through stage 4 chronic kidney disease, or unspecified chronic kidney disease I13.11 with stage 5 chronic kidney disease, or end stage renal disease I13.2 Hypertensive heart and chronic kidney disease with heart failure and with stage 5 chronic kidney disease, or end stage renal disease I15 Secondary hypertension I15.0 Renovascular hypertension I15.1 Hypertension secondary to other renal disorders I15.2 Hypertension secondary to endocrine disorders I15.8 Other secondary hypertension I15.9 Secondary hypertension, unspecified

	<p>I16 Hypertensive crisis I16.0 Hypertensive urgency I16.1 Hypertensive emergency I16.9 Hypertensive crisis, unspecified</p>
End stage renal failure	<p>N18 Chronic kidney disease (CKD) N18.6 End stage renal disease N18.9 Chronic kidney disease, unspecified</p>
Chronic Obstructive Pulmonary Disease	<p>J40 Bronchitis, not specified as acute or chronic J41 Simple and mucopurulent chronic bronchitis J41.0 Simple chronic bronchitis J41.1 Mucopurulent chronic bronchitis J41.8 Mixed simple and mucopurulent chronic bronchitis J42 Unspecified chronic bronchitis J43 Emphysema J43.0 Unilateral pulmonary emphysema [MacLeod's syndrome] J43.1 Panlobular emphysema J43.2 Centrilobular emphysema J43.8 Other emphysema J43.9 Emphysema, unspecified J44 Other chronic obstructive pulmonary disease J44.0 Chronic obstructive pulmonary disease with acute lower respiratory infection J44.1 Chronic obstructive pulmonary disease with (acute) exacerbation J44 Other chronic obstructive pulmonary disease J44.0 Chronic obstructive pulmonary disease with acute lower respiratory infection J44.1 Chronic obstructive pulmonary disease with (acute) exacerbation J44.9 Chronic obstructive pulmonary disease, unspecified J44.9 Chronic obstructive pulmonary disease, unspecified J45 Asthma J45.2 Mild intermittent asthma J45.20 uncomplicated J45.22 with status asthmaticus J45.3 Mild persistent asthma J45.30 uncomplicated J45.32 with status asthmaticus J45.4 Moderate persistent asthma J45.40 uncomplicated J60 Coalworker's pneumoconiosis J61 Pneumoconiosis due to asbestos and other... J62 Pneumoconiosis due to dust containing si... J63 Pneumoconiosis due to other inorganic du... J64 Unspecified pneumoconiosis J65 Pneumoconiosis associated with tuberculo...</p>

	<p>J66 Airway disease due to specific organic d... J67 Hypersensitivity pneumonitis due to orga... J68 Respiratory conditions due to inhalation... J69 Pneumonitis due to solids and liquids J70 Respiratory conditions due to other exte... J70.1Chronic and other pulmonary manifestations due to radiation J70.3Chronic drug-induced interstitial lung disorders J70.4Drug-induced interstitial lung disorders, unspecified J70.5Respiratory conditions due to smoke inhalation J70.8Respiratory conditions due to other specified external agents J70.9Respiratory conditions due to unspecified external agent</p>
Dementia	<p>F03 Unspecified dementia F03.90 without behavioral disturbance F03.91 with behavioral disturbance</p>
Amyotrophic Lateral Sclerosis (aka: Lou Gehrig's Disease)	<p>G12.21 Amyotrophic lateral sclerosis</p>
Acquired Immunodeficiency Syndrome	<p>D84.9 Immunodeficiency, unspecified</p>
Human Immunodeficiency Syndrome	<p>B20 Human immunodeficiency virus [HIV] disease</p>
Cerebral Vascular Accident (aka: Stroke)	<p>I63 Cerebral infarction I63.9 Cerebral infarction, unspecified G46 Vascular syndromes of brain in cerebrovascular diseases G46.0 Middle cerebral artery syndrome G46.1 Anterior cerebral artery syndrome G46.2 Posterior cerebral artery syndrome G46.3 Brain stem stroke syndrome G46.4 Cerebellar stroke syndrome G46.5 Pure motor lacunar syndrome G46.6 Pure sensory lacunar syndrome G46.7 Other lacunar syndromes G46.8 Other vascular syndromes of brain in cerebrovascular diseases Z86.73 Personal history of transient ischemic attack (TIA), and cerebral infarction without residual deficits</p>
Diabetes Mellitus: type 1	<p>E10.1 - Type 1 diabetes mellitus with ketoacidosis E10.10 - Type 1 diabetes mellitus with ketoacidosis without coma E10.11 - Type 1 diabetes mellitus with ketoacidosis with coma E10.2 - Type 1 diabetes mellitus with kidney complications E10.21 - Type 1 diabetes mellitus with diabetic nephropathy E10.22 - Type 1 diabetes mellitus with diabetic chronic kidney disease</p>

	<p>E10.29 - Type 1 diabetes mellitus with other diabetic kidney complication E10.4 - Type 1 diabetes mellitus with neurological complications E10.40 - Type 1 diabetes mellitus with diabetic neuropathy, unspecified E10.41 - Type 1 diabetes mellitus with diabetic mononeuropathy E10.42 - Type 1 diabetes mellitus with diabetic polyneuropathy E10.43 - Type 1 diabetes mellitus with diabetic autonomic (poly)neuropathy E10.44 - Type 1 diabetes mellitus with diabetic amyotrophy E10.49 - Type 1 diabetes mellitus with other diabetic neurological complication E10.5 - Type 1 diabetes mellitus with circulatory complications E10.51 - Type 1 diabetes mellitus with diabetic peripheral angiopathy without gangrene E10.52 - Type 1 diabetes mellitus with diabetic peripheral angiopathy with gangrene E10.59 - Type 1 diabetes mellitus with other circulatory complications E10.62 - Type 1 diabetes mellitus with skin complications E10.620 - Type 1 diabetes mellitus with diabetic dermatitis E10.621 - Type 1 diabetes mellitus with foot ulcer E10.622 - Type 1 diabetes mellitus with other skin ulcer E10.628 - Type 1 diabetes mellitus with other skin complications E10.64 - Type 1 diabetes mellitus with hypoglycemia E10.641 - Type 1 diabetes mellitus with hypoglycemia with coma E10.649 - Type 1 diabetes mellitus with hypoglycemia without coma E10.65 - Type 1 diabetes mellitus with hyperglycemia E10.69 - Type 1 diabetes mellitus with other specified complication E10.8 - Type 1 diabetes mellitus with unspecified complications E10.9 - Type 1 diabetes mellitus without complications</p>
<p>Diabetes Mellitus: type 2</p>	<p>E11.0 - Type 2 diabetes mellitus with hyperosmolarity E11.00 - Type 2 diabetes mellitus with hyperosmolarity without nonketotic hyperglycemic-hyperosmolar coma (NKHHC) E11.01 - Type 2 diabetes mellitus with hyperosmolarity with coma E11.1 - Type 2 diabetes mellitus with ketoacidosis E11.10 - Type 2 diabetes mellitus with ketoacidosis without coma E11.11 - Type 2 diabetes mellitus with ketoacidosis with coma E11.2 - Type 2 diabetes mellitus with kidney complications E11.21 - Type 2 diabetes mellitus with diabetic nephropathy E11.22 - Type 2 diabetes mellitus with diabetic chronic kidney disease</p>

	<p>E11.29 - Type 2 diabetes mellitus with other diabetic kidney complication</p> <p>E11.4 - Type 2 diabetes mellitus with neurological complications</p> <p>E11.40 - Type 2 diabetes mellitus with diabetic neuropathy, unspecified</p> <p>E11.41 - Type 2 diabetes mellitus with diabetic mononeuropathy</p> <p>E11.42 - Type 2 diabetes mellitus with diabetic polyneuropathy</p> <p>E11.43 - Type 2 diabetes mellitus with diabetic autonomic (poly)neuropathy</p> <p>E11.44 - Type 2 diabetes mellitus with diabetic amyotrophy</p> <p>E11.49 - Type 2 diabetes mellitus with other diabetic neurological complication</p> <p>E11.5 - Type 2 diabetes mellitus with circulatory complications</p> <p>E11.51 - Type 2 diabetes mellitus with diabetic peripheral angiopathy without gangrene</p> <p>E11.52 - Type 2 diabetes mellitus with diabetic peripheral angiopathy with gangrene</p> <p>E11.59 - Type 2 diabetes mellitus with other circulatory complications</p> <p>E11.6 - Type 2 diabetes mellitus with other specified complications</p> <p>E11.61 - Type 2 diabetes mellitus with diabetic arthropathy</p> <p>E11.610 - Type 2 diabetes mellitus with diabetic neuropathic arthropathy</p> <p>E11.618 - Type 2 diabetes mellitus with other diabetic arthropathy</p> <p>E11.62 - Type 2 diabetes mellitus with skin complications</p> <p>E11.620 - Type 2 diabetes mellitus with diabetic dermatitis</p> <p>E11.621 - Type 2 diabetes mellitus with foot ulcer</p> <p>E11.622 - Type 2 diabetes mellitus with other skin ulcer</p> <p>E11.628 - Type 2 diabetes mellitus with other skin complications</p> <p>E11.64 - Type 2 diabetes mellitus with hypoglycemia</p> <p>E11.641 - Type 2 diabetes mellitus with hypoglycemia with coma</p> <p>E11.649 - Type 2 diabetes mellitus with hypoglycemia without coma</p> <p>E11.65 - Type 2 diabetes mellitus with hyperglycemia</p> <p>E11.69 - Type 2 diabetes mellitus with other specified complication</p> <p>E11.8 - Type 2 diabetes mellitus with unspecified complications</p> <p>E11.9 - Type 2 diabetes mellitus without complications</p>
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Table 1: Provider survey and answers

Survey question	Sample answered correctly	PCQN answered correctly	SCIP and SIMG answered correctly
1. Palliative care and hospice care are virtually the same. answer <i>False</i>	89%	87%	
2. Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration. answer <i>False</i>	86%	85%	
3. The provision of palliative care requires emotional detachment. answer <i>False</i>	100%	85%	
4. The philosophy of palliative care is compatible with that of aggressive treatment. answer <i>True</i>	84%	47.7%	
5. Which of the following definitions of palliative care do you consider the most appropriate? answer <i>D. Holistic care, which also incorporates support for family, patients, not only for the end of life but also in the developmental stages of an incurable disease.</i>	86%		25.5%
6. In your opinion, which of the following objectives is consistent with the definition of palliative care? answer <i>To ensure the best quality of life of incurable patients.</i>	92%		40.6%
7. The most authoritative guidelines on health care planning recommend that palliative care should be provided by: answer <i>A specialized multiprofessional palliative care team that includes the family's GP.</i>	97%		65.5%
8. According to your experience, palliative care pathways require: answer <i>An individual care plan.</i>	45%		59.5%
9. If available, would you refer your patients to the palliative care team? answer <i>Yes</i>	89%		
10. What is your professional title? Answer <i>APRN</i>	49%		

Survey questions and answers from this study compared to results from research of the PCQN and the SCIP/SIMG

Table 2. Patient demographics

Characteristics	Mean (SD); range or n (%)
Age	61.6 (16.8); 18 - 101
Gender	
Female	1,365 (56.1%)
Male	1,068 (43.9%)
Race	
White	1,581 (65%)
Black	777 (31.9%)
Other	75 (3.1%)
Insurance status	
Medicare	1,375 (56.5%)
Private	450 (18.5%)
Medicaid	175 (7.2%)
Self-pay	65 (2.7%)
Other	52 (2.1%)
Hospirus Scatter Bed	4 (0.2%)
Diagnosis	
Hypertension	910 (37.4%)
COPD	556 (22.9%)
Diabetes	483 (19.9%)
Congestive Heart Failure	255 (10.5%)
Cerebral Vascular Accident	199 (8.2%)
Dementia	20 (0.8%)
HIV	8 (0.3%)
Renal Disease	2 (0.1%)
Patient Status	
Admitted to Hospital	1,524 (62.6%)
ED Visit and Discharged	909 (37.4%)
Expired	26 (0.01%)

Descriptive summary of the ED utilization data of study sample ($N = 2,433$)

A total of 2433 adults presented to the ED due to complications from CHF, HTN, ESR, COPD, dementia, ALS, AIDS, HIV, CVA, DM. The average age was 61.6 years (SD = 16.8).

Table 3: National Data

Characteristics	n (%) per 1,000 for the year 2015	n per 1,000 for three months
Gender		
Male	29,406 (42.4%)	7,352
Female	39,980 (57.6%)	9,995
Race		
White	51,414 (74%)	12,854
Black	15,908 (23%)	3,977
Other	2,063 (3%)	516
Insurance status		
Medicare	18,471	4,618
Medicaid	24,122 (34.8%)	6,031
Private	23,780	5,945
Self-pay	6,215	1,554
Other	2,780	695
Diagnosis		
Congestive Heart Failure	4,413 (6.4%)	1,103
COPD	7,251 (10.5%)	1,813
Dementia	1,712 (2.5%)	428
Cerebral Vascular Accident	4,002 (5.8%)	1,001
Diabetes	14,945 (21.6%)	3,736
HIV	566 (0.8%)	142
Hypertension	32,370 (46.7%)	8,093
Renal Disease	4,082 (5.9%)	1,021
Patient Status		
Emergency Department Visit and Discharge	69,341	17,335
Admitted to Hospital	7,280 (10.5%)	1,820
Expired	188(0.3%)	47

National data of ED usage in 2015 ($N = 69,341$ per 1,000 for 12 months; $N = 17,335$ per 1,000 for three months).

Centers for Disease Control and Prevention. (2015). *National Hospital Ambulatory Medical Care Survey: 2015 Emergency Department Summary Tables*. Data extracted for 69,341,000 patients with specific diagnoses of CHF, HTN, ESR, COPD, dementia, ALS, AIDS, HIV, CVA, DM.

Table 4: This study's data compared to national data

Characteristics	This study n (%)	National n (%) per 1,000 for three months	National data n (%) per 1,000 for the year 2015
Gender			
Female	1,365 (56.1%)	9,995 (57.6%)	39,980 (57.6%)
Male	1,068 (43.9%)	7,352 (42.4%)	29,406 (42.4%)
Race			
Caucasian	1,581 (65%)	12,854 (74%)	51,414 (74%)
African American	777 (31.9%)	3,977 (23%)	15,908 (23%)
Other	75 (3.1%)	516 (3%)	2,063 (3%)
Insurance status			
Medicare	1,375 (56.5%)	4,618 (26.7%)	18,471 (26.7%)
Private	450 (18.5%)	5,945 (34.3%)	23,780 (34.3%)
Medicaid	175 (7.2%)	6,031 (34.8%)	24,122 (34.8%)
Self-pay	65 (2.7%)	695 (4%)	2,780 (4%)
Other	52 (2.1%)	1,554 (9%)	6,215 (9%)
Hosparpus Scatter Bed	4 (0.2%)		
Diagnosis			
Hypertension	910 (37.4%)	8,093 (46.7%)	32,370 (46.7%)
COPD	556 (22.9%)	1,813 (10.5%)	7,251 (10.5%)
Diabetes	483 (19.9%)	3,736 (21.6%)	14,945 (21.6%)
Congestive Heart Failure	255 (10.5%)	1,103 (6.5%)	4,413 (6.5%)
Cerebral Vascular Accident	199 (8.2%)	1,001 (5.8%)	4,002 (5.8%)
Dementia	20 (0.8%)	428 (2.5%)	1,712 (2.5%)
HIV	8 (0.3%)	142 (0.8%)	566 (0.8%)
Renal Disease	2 (0.1%)	1,021 (5.9%)	4,082 (5.9%)
Patient Status			
Admitted to Hospital	1,524 (62.6%)	1,820 (10.5%)	7,280 (10.5%)
Emergency Department			
Visit	909 (37.4%)	15,515 (89.5%)	62,061 (89.5%)
and Discharge	26 (0.01%)	47 (0.3%)	188(0.3%)
Expired			

Table 4: ED utilization from this study compared to National data of ED usage in 2015 ($N = 69,341$ per 1,000 for 12 months; $N = 17,335$ per 1,000 for three months).

Centers for Disease Control and Prevention. (2015). *National Hospital Ambulatory Medical Care Survey: 2015 Emergency Department Summary Tables*. Data extracted for 69,341 patients with specific diagnoses of CHF, HTN, ESR, COPD, dementia, ALS, AIDS, HIV, CVA, DM.

Figure 1: Original palliative care model



Figure 2: Evidence-based updated model of palliative care

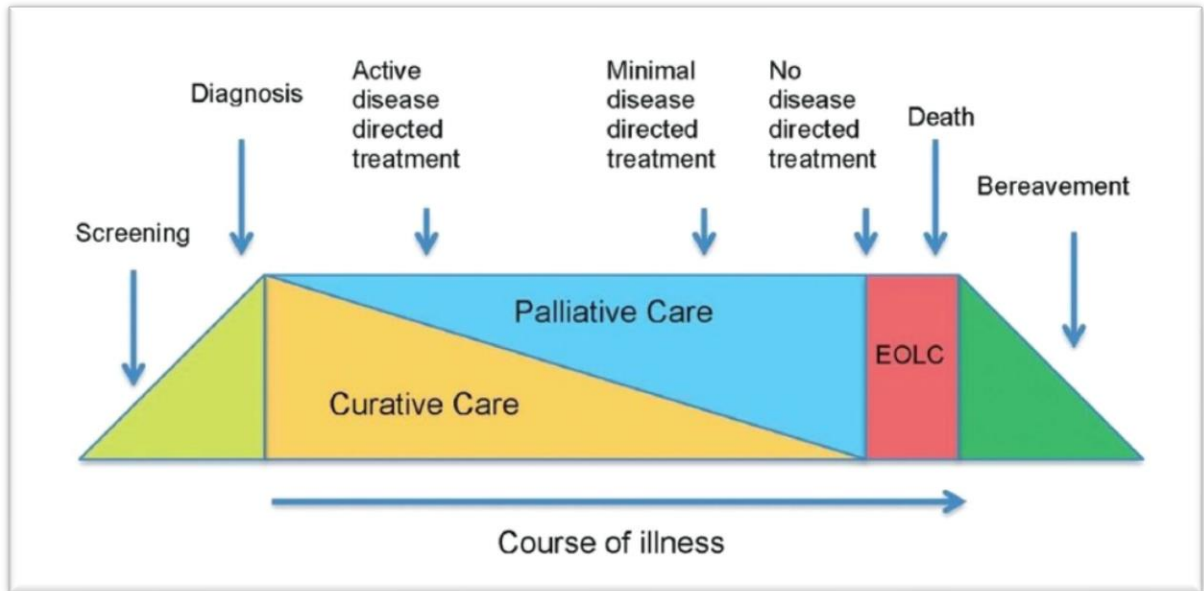


Figure 3: Cost per diagnosis of ED utilization data

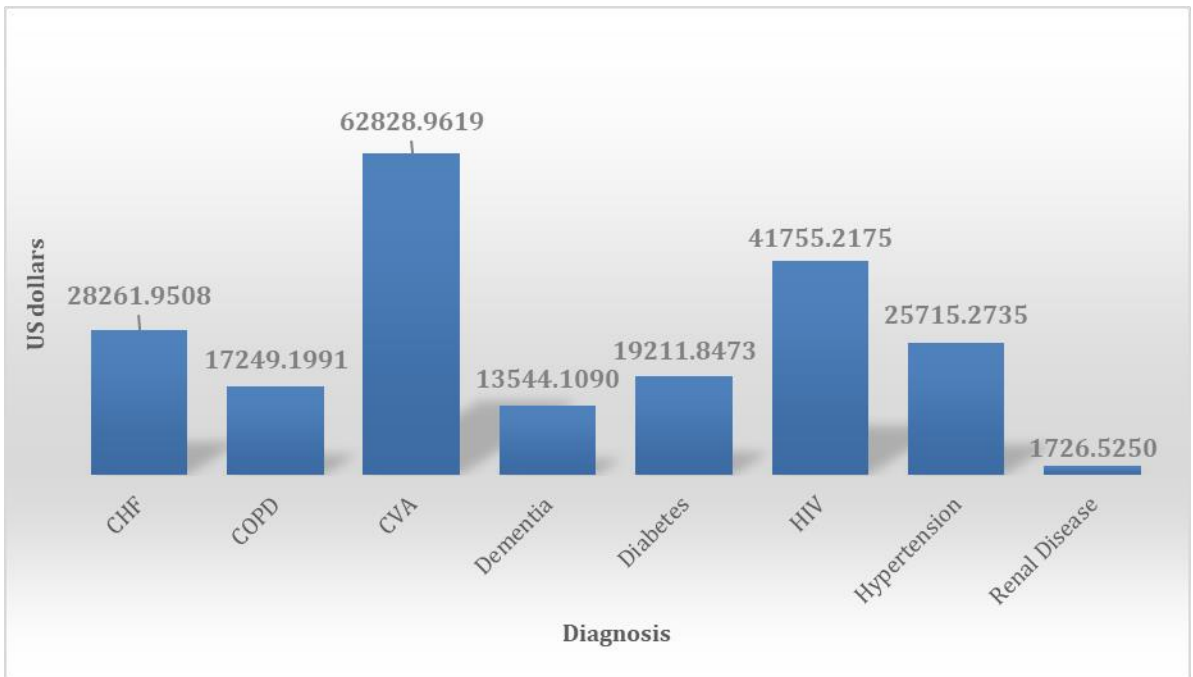


Figure 4: Mean cost per patient

