

2018

Early Integration of Palliative Care for Patients Diagnosed With Life-limiting Illness

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Running head: EARLY IMPLEMENTATION OF PALLIATIVE CARE

EARLY INTEGRATION OF PALLIATIVE CARE FOR PATIENTS DIAGNOSED
WITH LIFE-LIMITING ILLNESS

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Submitted in partial fulfillment of
the requirement for the degree of
Doctor of Nursing Practice

AUGSBURG UNIVERSITY
MINNEAPOLIS, MINNESOTA

APRIL 28, 2018

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Presentations

Early Implementation of Palliative Care for Patients Diagnosed with Life-Limiting Illness

March 13, 2017

Palliative Care Team

Mayo Medical Center

Rochester, Minnesota

Early Implementation of Palliative Care for Patients Diagnosed with Life-Limiting Illness

March 27, 2017

Multi-disciplinary Collaborative Care Rounds

Mayo Medical Center

Rochester, MN

Dedication

To the patients I have and will serve during my life's work; these patients have inspired this important work.

Acknowledgements

With sincere gratitude and heartfelt thanks to the family and friends who believed in and supported my dreams and goals. None of this would have been possible without your continued patience and support. Special acknowledgement to my mother who raised me to be strong, independent, and hardworking; making me the accomplished woman I am today.

Abstract

There are numerous reasons conversations regarding the early implementation of palliative care for patients diagnosed with life-limiting illness do not occur early in the disease trajectory. A literature search was conducted to support the benefits of earlier implementation of palliative care, specifically, implementation by patient's primary care providers upon a qualifying disease diagnosis. The literature review revealed generous benefits of early implementation of palliative care and provided support for this scholarly project. For this scholarly project, a palliative care questionnaire and PowerPoint presentation were designed, administered, and presented to health care providers including nurse practitioners, physician assistants, pharmacists, and consultants who work in palliative care. The group was engaged in discussion/dialogue regarding the barriers to offering palliative care to patients who would benefit. The barriers include that many primary care providers are not comfortable initiating the conversation about palliative care, feel under-educated about the topic of palliative care, and do not want to take hope away from the patient by starting a conversation about palliative care. Information gathered from the questionnaire was used to create an educational pamphlet about which diseases qualify a patient for palliative care, why and how to have the conversation about palliative care, and resources available to further knowledge on the topic of palliative care. The goal of the scholarly project is to help primary care providers facilitate conversations, initiation, and the use of palliative care as part of the collaborative care team in patient care.

Key words: early, implementation, palliative care, life-limiting illness

Chapter One: Introduction

Death is an inevitable occurrence for all people. Those suffering from a life-limiting progressive disease have a death process that is drawn out along with side-effects that those suffering from life-limiting diseases need help managing. The occurrence of progressive life-limiting diseases and the end of life process can occur at any age and are frightening and overwhelming experiences to the patient and the patient's family. Patients facing life-limiting progressive disease management and end of life concerns can benefit from the early integration of a palliative care team (Matzo & Sherman, 2015). Palliative care offers many benefits such as providing symptom management associated with their life-limiting progressive disease and providing emotional, spiritual, and psychosocial support to the patient and the patient's family (Compassion Care Hospice, 2015). Palliative care needs to be in place through life-limiting disease diagnosis through progression to death. This scholarly project examines the benefits of early implementation of palliative care for the patient facing life-limiting progressive disease as initiated by the family nurse practitioners.

Palliative care (PC) is a relatively new program within the health care field. PC has grown over the last few decades since the 1980's and served over 1.65 million patients and families today (Matzo & Sherman, 2015). These numbers alone encourage the growth of the number and amount of PC services provided in the health care field (Matzo & Sherman, 2015). In accordance with Matzo and Sherman (2015) palliative care emphasizes relief from anguish by managing pain and other symptoms associated with the disease and dying process. Attention is given to the patient and patient's family to assist with emotional, spiritual, and practical needs through all stages of the illness.

Progressive life-limiting diseases can include but are not limited to cancer, Alzheimer's, end-stage renal disease, ALS ("Lou Gehrig's Disease"), stroke, cardiomyopathy, congestive heart failure, Parkinson's disease, emphysema, liver disease, and AIDS (Compassion Care Hospice, 2015). The progressive life-limiting disease is defined as an enduring disease or illness non-responsive to therapeutic management, which will result in patient fatality (Compassion Care Hospice, 2015).

Problem Statement

The problem for patients experiencing progressive life-limiting diseases and end of life issues is the lack of early implementation of palliative care behalf of the patient and the patient's family (Matzo & Sherman, 2015).

Purpose of the Scholarly Project

The purpose of this paper is to examine the benefits of early implementation of palliative care and hospice care for patients suffering from progressive life-limiting disease and end of life issues; along with examination the role of the family nurse practitioner and how they are in the position to initiate early implementation of PC for patients. The specific benefits being explored are the effects of early implementation of PC on symptom management during progressive life-limiting diseases along with facilitation of coping skills emotionally, spiritually, and psychosocially for the patient and the patient's family.

Clinical Questions

Clinical questions to be answered in this scholarly project are how the family nurse practitioner use their position to bring forth conversations and recommendations about early implementation of PC services in the primary care setting. Also, how do

patients suffering from a life-limiting disease and their families think of the early implementation of PC, can they articulate the benefits associated with symptom management and coping support emotionally, spiritually, and psychosocially.

Objectives

The objective of this project includes early implementation of palliative care for patients diagnosed with progressive life-limiting diseases and/or face end of life issues initiated by family nurse practitioners.

Patient Population and Healthcare Setting for Implementation of Project

The patient population for this project includes the adult population aged 18 years and older, who are suffering from a progressive life-limiting disease and/or face end of life issues. The healthcare setting for this project is a primary care setting.

Chapter Two: Literature Review

According to the World Health Organization (WHO) (2015), palliative care (PC) increases the quality life for patients suffering from progressive life-limiting disease and their families through symptom management and emotional support, along with decreasing emergency room visits and hospital admissions within the last ninety days before death. The WHO (2015) also predicts the need for PC will continuously increase as the population ages and enlarges. Currently, only a small portion, less than 15%, of the 40 million people in need of PC receive the care needed due to a lack of training and awareness within the health care system for the imperative need for PC (WHO, 2015). The WHO (2015) also recognizes strict regulations on pain relieving narcotics and other palliative medications as problematic to proper pain and symptom management within the palliative population. Facts like these support early implementation of palliative care in the primary care setting, ideally upon diagnosis of a life-limiting progressive disease. These facts also encourage the need for increased education about PC, how and when to implement PC, and the benefits PC provide to be readily available and expected for the family nurse practitioner in primary care to know and implement.

There are many benefits to having PC on board with a patient suffering from a life-limiting progressive disease. Back et al. (2014) argues there are three main reasons early implementation of palliative care is beneficial to patients suffering from life-limiting progressive diseases and their families. The first reason is symptom management such as pain, depression, and nausea along with building a rapport between the patient and care provider so other deeper issues can be approached and communicated at a later time (Back et al., 2014). Ferrell (2014) also supports symptom management as an

important trait of palliative care that also facilitates rapport between the patient, patient's family, and care providers. Back et al. (2014) argues symptom management facilitates patients to live at their fullest functional capacity increasing their quality of life. Studies done to examine the benefits of early PC and symptom management have shown patient's reporting better quality of life in the last few months of life. Better moods (less depression), less pain, less nausea, along with longer life expectancy on average of 2-3 months along with associated fewer uses of aggressive treatments, such as chemotherapy or radiation, in the last 60 days of life are reported (Glare, 2013). Glare (2013) hypothesizes early symptom management and less aggressive end of life treatments such as chemotherapy and radiation not only improve the patient's quality of life but lengthen the quantity their life through less exposure to toxic chemicals found in chemotherapy and radiation while also limiting side effects from treatment. Connor (2010) supports the early implementation of PC because symptoms are easier to manage if they never happen, symptom management prevents patients from enduring pain crisis and regression of coping skills while facilitating trust between the caregivers and the patient.

The second reason Back et al. (2014) argues early implementation of PC is beneficial to patients is because time is provided to establish rapport and trust between the patient, patient's family, and PC provider. A deeper personal connection facilitates discussions about end of life care, managing emotional distress, and acceptance of the prognosis of the life-limiting disease for the patient and their family (Back et al., 2014). Through an established relationship between the PC provider and the patient Back et al. (2014) states the PC provider can have difficult conversations with the patient regarding death and dying and their plans surrounding those topics. It is important for the PC

provider to reinforce difficult conversations about death and dying do not have to occur every day and the PC provider is there to empathize with and help the patient cope with issues about death and dying (Back et al., 2014). Through these conversations, the PC care provider acknowledges the patient's fears giving the patient a place and person to voice their fears too, and provides positive encouragement to the patient for partaking in uncomfortable conversations about death and dying (Back et al., 2014). A study by Wittenberg-Lyles, Goldsmith, & Ragan (2011) identified three types of journeys patients facing life-limiting progressive disease engage. The three types of journeys are: "(1) isolated journey, (2) rescued journey, and (3) comforted journey (p. 306-07). According to Wittenberg-Lyles, Goldsmith, & Ragan (2011) the isolated journey does not embrace the finality of the prognosis for the patient of the life-limiting progressive disease and energy and attention is solely focused on curative methods only, PC is often not engaged in patient care for support. Early implementation of PC should occur early in prognosis to save patients and their families from experiencing the isolated journey. Wittenberg-Lyles, Goldsmith, & Ragan (2011) indicate failing to initiate PC early on fosters false hope for the patient and patient's family and the longer the need for PC is ignored the harder it becomes for physicians to approach the subject with the patient and family. Wittenberg-Lyles, Goldsmith, & Ragan (2011) secondly discuss the "rescued journey" in which the need for PC intervention in patient care is evident and implemented, usually long after PC has been needed (p307). The focus of the patient care shift from "cure to care" and education about disease progression and what to expect with death and dying can occur (Wittenberg-Lyles, Goldsmith, & Ragan, 2011, p. 307). The boundaries of medicine are recognized, and false hopes eliminated, but the establishment of new hope can occur the

hope for what the patient and the patient's family wish for as they transition from "cure to care" and eventually death (Wittenberg-Lyles, Goldsmith, & Ragan, 2011). The last type of journey identified is the comforted journey. During the comforted journey, an openness and acceptance of disease diagnosis and prognosis is present from disease diagnosis, and the use of PC is embraced from diagnosis (Wittenberg-Lyles, Goldsmith, & Ragan, 2011). Wittenberg-Lyles, Goldsmith, & Ragan (2011) often argue the patient and the patient's family have time to accept the diagnosis and cope more appropriately with the comforted journey than patient's experiencing the isolated or rescued journeys. The comforted journey provides the PC team time with the patient to be able to establish a relationship and trust with the patient and patient's family allowing for smooth, consistent, honest, and open care for the patient. The comforted journey encourages the patient and the patient's family to be informed and help make decisions as part of the health care team. The family nurse practitioner can implement early palliative care when appropriate to facilitate patients and their families to experience the comforted journey that offers symptom management, open and honest conversations about diagnosis and prognosis, coping skills, and planning for death and dying.

In a study done by Beernaert et al., (2015) patients have personally expressed emotional distress from diagnosis through disease progressions such as stress, anxiety, or depression. Also, identified by Beernaert et al., (2015) is patient's feelings of social isolation because they fear friends and family do not understand the patient's situation, and they do not want to burden their friends and family with their problems. As life-limiting diseases progress, patients suffer more from side-effects of treatments or symptoms from their illness. Consequences such as the need to stay at home more for

comfort and familiarity, the need to stop working because side-effects or symptoms are so severe, or the loss of driving privileges because side-effects and symptoms do not allow the patient to drive anymore (Beernaert et al., 2015). Beernaert et al., (2015) also distinguishes when patients pursue aggressive treatments that require them to be hospitalized such as chemotherapy or radiation they feel ill prepared and undereducated about what to expect and how to proceed once they go home. These difficulties patients face with life-limiting disease diagnosis assert the need for early implementation of PC to help patients face these challenges and have access to a PC team that can provide answers and education to the patient and their families in the home setting (Beernaert et al., 2015).

Connor (2010) insists PC builds relationships with the patient and the patient's family because PC is an area in health care where palliative caregiving is a profession that asks the person to bring their whole selves to their craft and express true caring within the health care profession. Palliative care encourages care providers to become personally and emotionally invested in the patients they care for and the patient's family, though emotional investment is dangerous, it can also have many rewards (Connor, 2010). According to Connor (2010), psychological and social support are essential components of PC and the very diagnosis and circumstances patients facing life-limiting progressive diseases entitle them to mental health support. Often, addressing emotional, psychological, and spiritual needs are the most important aspects of care for a person facing life-limiting progressive disease as fears are addressed head on and opportunities for personal growth can present themselves. Connor (2010) proposes as death approaches a focusing of the mind may occur for the patient and issues that are important to the patient become the center of the patient's focus while non-important issues fade from the

forefront. Important emotional work that can ensue from the early implementation of PC includes the ability for the patient to get their affairs in order such as social responsibilities and funeral arrangements (Connor, 2010). The patient has a chance to close relationships with community and social relationships and has the chance to grieve being unable to continue their community and social obligations while receiving recognition from individuals in their community and social organizations of the death the patient is facing (Connor, 2010). The patient also has the chance to review one's life and recognize milestones and major events. These recollections and life stories are often recorded and reviewed by the patient for therapeutic use and left to the loved ones the patient is leaving behind (Connor, 2010). The patient is allowed the chance to forgive themselves for things they may have remorse for doing and to and learn to appreciate truly oneself (Connor, 2010). Patient's allow themselves to experience deep feelings and accept the love others give to them and may realize they have been worthy of that love the whole time (Connor, 2010). The patient is allowed the chance to find closure in personal relationships through forgiveness and acceptance, gratitude and love and the patient has the chance to say goodbye, hopefully releasing emotional pain and experiencing relief as the result (Connor, 2010). The patient comes to accept the finality of life and the temporariness of their life. With this acceptance, the patient is allowed to grieve what they will lose, and grieve the loss of one's self (Connor, 2010). The patient also strips away titles given to them in life (professional roles, social roles, social behavior) and find who they truly are at the core of themselves (Connor, 2010). The patient encounters the meaning of life as important to their journey, obtaining a sense of comfort among all the chaos surrounding them and realizes life will continue with or

without them (Connor, 2010). Finally, the patient can surrender and embrace the unknown. The family needs to let the patient know it is ok to transverse into death, and the patient needs to embrace stepping off the edge of life and enter the unknown that accompanies death (Connor, 2010). Connor (2010) stresses the early implementation of PC guides these emotional steps, going through all the steps can be a positive transformative process for the patient.

The last benefit according to Back et al. (2014) of early implementation of PC is the PC provider is available to be a communicator between the patient and the specialist in charge of the patients care. Whether the specialist is a hematologist, oncologist, cardiologist, nephrologist, pulmonologist, hepatologist, or an internal medicine physician PC assists with communication. The PC provider can also be a communicator between the specialist and the patient. In coordination with Back et al. (2014) the PC provider can relay the information from the patient's primary physician in a manner, the patient may be able to understand better. The PC provider can also repeat the information at different times on different occasions when the patient is ready to absorb and comprehend the implications of their diagnosis (Back et al., 2014). When the patient and patient's family is ready to comprehend the information about the diagnosis given to them it facilitates the patient's and patient's family's understanding of the diagnosis encouraging participation in care planning and emotional coping (Back et al., 2014). According to Back et al. (2014) the relationship between PC, the patient, and the specialist can work in the other direction also. Often specialists have incredibly busy schedules and see many patients and at times can become frustrated with patients when the patient is unable to absorb and understand the information the specialist is providing to the patient about their diagnosis

(Back et al., 2014). A specialist can also become frustrated with their patients when the patient has unrealistic expectations and hopes for a cure. PC can provide the bridge facilitating healthy communication between all parties the patient, the specialist, and PC so a communal understanding can be reached empowering a team approach can be taken to providing care to the patient with life-limiting progressive disease (Back et al., 2014). Glare (2013) also supports PC as an interpreter between the patient and the specialist. Glare (2013) states patients with early implementation of PC remember and understand their prognosis better than patients who only receive care from a specialist who only deals with the specific life-limiting disease and not the overall picture of the quality of life for the patient.

Connor (2010) stresses an additional benefit to the early implementation of PC is the deinstitutionalization of the health care system. PC allows the patient to remain in their home surrounded by familiar sights, sounds, and memories. A patient feels more in control in their home they do have to conform to an institution's rules or fear if they are emotional they are going to make someone uncomfortable by expressing their emotions. PC is set up to manage exacerbation of symptoms, preventing the need for emergency room visits or hospitalizations as the patient is undergoing normal life-limiting disease progression. PC is also family caregiver-oriented. PC encourages the family to learn how to provide care to their loved one and encourages active participation in the patient's care. Finally, care in the home is usually more cost effective to the patient and the patient's family than receiving a majority of care in an institution such as a hospital or nursing home (Connor, 2010).

Patients come to face the reality of their diagnosis at different times in their life-limiting illness trajectory; some patients prefer full disclosure from their care provider from the start, and some patients do not (Beernaert et al., 2015). Patients disclose they do not know what types of questions to ask their primary care providers about treatments, side-effects, symptoms, and course of the illness, and just what to expect in general (Beernaert et al., 2015). In the study by Beernaert et al., (2015) some patients even admit they do not understand their initial diagnosis and thorough explanation is not provided by their primary care provider. The study by Beernaert et al. (2015) concludes PC is needed to bridge the communication gap between the patient and the provider, often early in the life-limiting disease diagnosis as patients do not even fully understand their diagnosis at the beginning of their disease.

One additional benefit to the early implementation of PC is the correlation of less aggressive end of life treatments and a slightly longer life expectancy (Amano et al., 2015; Glare, 2013). Amano et al., (2015) classifies quality of life and less aggressive end of life care in the patient experiencing life-limiting progressive disease as: minimal or no medical interventions in the last weeks of life such as “emergency department visits, hospital and intensive care unit (ICU) admissions, death, and/or chemotherapy administration” (p. 270). Both Amano et al., (2015) and Glare (2013) conclude their studies regarding the early implementation of PC reduces the rate of patients undergoing chemotherapy in the last 60 days of life significantly. Both studies also found the early implementation of PC increases the use of hospice care within the last week of life for patients suffering from life-limiting diseases easing the transition from life to death. Amano et al. (2015) and Glare (2013) go on to further state patients using primary care

from a specialist in their illness and PC teams also have a mean survival rate of 2 to 3 months longer than patients who received care from their specialist alone. Amano et al., (2015) and Glare (2013) conclude from their studies, early implementation of PC is beneficial to patients facing life-limiting progressive disease, because they develop better coping skills, understanding of their illness and the disease trajectory, undergo less aggressive end of life treatment, and have an average longer life expectancy of 2-3 months than patients not receiving PC.

The many benefits of early implementation of PC are clearly evident and researched. So then, why does only 15% of the 40 million (WHO, 2015) patients in need of PC receive the care they need? There are many reasons identified in the literature as to why PC is not implemented early in the disease process. First and foremost, medicine and nursing are taught based upon the concept preservation of life is of the utmost importance, even if good intentions become twisted when preservation of life is most important, regardless of the effects on the patient undergoing treatments (Connor, 2010). Failure of medicine and technology become personal burdens to bear of physicians and nurses and feelings of failing the patient become overwhelming (Connor, 2010). An additional important reason PC is not implemented early is due to the human element of diagnosis with a life-limiting disease: avoidance and denial (Connor, 2010). American society is fascinated with violence and death, but yet avoids the topic of natural death at all costs, especially when it becomes personal and deals with one's self, people rather cling to the unrealistic belief of immortality (Connor, 2010). According to Connor (2010) the experience of denial can be a defense mechanism to protect one's self from overwhelming feelings of anxiety caused by a diagnosis of life-limiting disease. Connor

(2010) also proposes denial can act as a coping mechanism assisting the patient with emotional survival. Another reason early implementation of PC is avoided is because it takes away hope from the patient and their family; leaving the family nurse practitioner to handle patient's feelings of despair and hopelessness, often an uncomfortable situation for the family nurse practitioner (Pfeil, Laryionava, Reiter-Theil, Hiddemann, & Winkler, 2015). Pfeil et al. (2015) often found treatments having severe side effects prescribed for patients who request to undergo the treatments, even though the physician prescribing the treatment knows there will be no or minimalized effects from the treatment. Treatments are prescribed as a way to give the patient hope something may cure them and not to steal their courage to live life (Pfeil et al., 2015). Prescribers feel a life lived with side effects from treatments is better than a life lived with no hope (Pfeil et al., 2015).

An additional reason PC is not implemented early in life-limiting disease prognosis is the patient's lack of understanding of what PC is and means (Beernaert et al., 2014). Many patients associate PC with hospice care and do not know the difference between the two (Matzo & Sherman, 2015). Mayo Clinic (2015) identifies palliative care as appropriate for patients with a life expectancy of one to two years or less; the patient may also be currently actively pursuing treatment for their life-limiting progressive disease. Many patients do not realize the use of PC does not mean the withdrawal of treatment or care for their life-limiting progressive disease (Matzo & Sherman, 2015). Also, the relationship between the family nurse practitioner and patient also is not bonded strongly enough for either one of them to approach the subject of end of life care and the use of PC (Beernaert et al., 2014). Beernaert et al., (2014) identifies patients will not address issues concerning their diagnosis or end of life cares until symptoms, either

physical or emotional, have become unbearable. Beernaert et al., (2014) also identifies patients will not bring up specific topics regarding the end of life and PC or symptom management unless the family nurse practitioner specifically asks the patient to address certain issues. Patients express they know their family nurse practitioner is busy and feel like they should not burden them with their stories and their need to talk to someone; patients have expressed they rather tell someone they feel has the time to listen (Beernaert et al., 2014). Beernaert et al., (2014) indicates home visits would be a useful tool for educating patients about PC and the many benefits PC can offer to the patient and the patient's family.

According to Beernaert et al., (2014) another reason PC is not implemented early is because the family nurse practitioner feels unprepared, undereducated, and/or inexperienced on how or when to initiate discussion about PC. According to Beernaert et al., (2015) it is the responsibility of the family nurse practitioner, as the patient's primary caregiver, to address end of life issues and the need for PC in a timely fashion. Initiation of PC in a timely fashion allows for the coordination and continuity of care to the patient and the patient's family throughout the trajectory of the life-limiting disease process. In an additional article Beernaert et al., (2014) explores a lack of education about care options leaving family nurse practitioner feeling unprepared to lead discussions about PC. Beernaert et al., (2014) also recognizes family nurse practitioners are undereducated about the types of patients that qualify for PC. Family nurse practitioners rarely consider patients with organ failure or dementia as patients qualified for PC as opposed to patients suffering from cancer. In retrospect, the family nurse practitioner recognized patients suffering from organ failure or dementia would benefit from PC intervention.

Feelings of inexperience, under education, and unpreparedness to lead discussions about end of life care and integration of PC into a patient's plan of care add to a family nurse practitioner's overall feeling of discomfort with discussing death (Beeraert et al., 2014; Pfeil et al., 2015). Pfeil et al., (2015) reports primary care practitioners feel uncomfortable discussing death with their patients, especially when the patient is feeling well and is relatively symptom-free; the primary practitioner does not want to burden the patient with discussions about death. Pfeil et al., (2015) also discusses when a patient reaches a point where death will be imminent and PC would be the next logical step, the practitioner caring for the patient begins a ritual of separating themselves from the patient. In the mind of the practitioner when the provider-patient relationship shifts from curative to palliative it is easiest for the practitioner to separate themselves from the patient they were unable to cure, essentially abandoning the patient during their time of greatest need (Pfeil et al., 2015).

Palliative care is very much an interdisciplinary team effort to be able to provide holistic care to patients suffering from a life-limiting progressive disease. Connor (2010) adds, "physicians, nurses, social workers, mental health professionals, chaplains, therapists, pharmacists, and volunteers" (p. 8) constitute important team members for the holistic care of the patient using PC. Another barrier to the early implementation of PC by Beernaert et al., (2015) is difficulties in collaboration of care and continuity of care between the multidisciplinary teams caring for the patient facing life-limiting progressive disease. Often time the family nurse practitioner is the first one to identify how ill a patient is often referring the patient to a specialist in hopes of finding a treatment that will cure the patient. While the patient is undergoing care with the specialist the family nurse

practitioner loses contact with the patient and is unable to follow-up with the patient or be informed of the patient's well-being. The patient may be under the primary care of a specialist for weeks to months to a year or two, mostly exclusively using the specialist for all care needs even those non-acute care related facilitating discontinuity of care between multidisciplinary teams (Beernaert et al., 2014). After this period, when all options for the patient have been exhausted, the patient is sent back to the family nurse practitioner for disease symptom management, often it is late in the disease trajectory, and the patient does not receive the benefits of early implementation of PC (Beernaert et al., 2014).

Chapter Three: Nursing Theory

Patients living with and experiencing life-limiting progressive diseases are at a moment in their lives where one must face their mortality. Through personal experience, one knows dwelling upon the ending of one's life is not a pleasant experience one voluntarily engages in on a regular basis. Acknowledging one's death can bring feelings of vulnerability, anger, fear, despair, hopelessness, and incomplete accomplishments in life. At the point and time of facing one's impermanence, the patient's body, mind, and spirit all need to be nurtured to encourage the patient to find healing, wholeness, and acceptance with the stage they are at in their disease and life.

Nursing theorist Jean Watson recognizes through her work, nurturing a person as a whole mind, body, and spirit is essential for healing the patient. Watson (2003) reflects her fears that modern medicine and health care has lost touch with meaningful insight as to what it means to be human, and the core of our humanity is deteriorating. Watson (2003) fears on the path to reinventing and advancing medicine; medicine has forgotten humans find nurturing in and thrive on love, splendor, and depth of life. Despite the dehumanizing nature of modern medicine, Jean Watson calls for nurses caring for the ill to look into themselves and reflect upon the important caring work nurses perform day in and day out, and how nurses can bring humanity, caring, and love back into health care through nursing.

The essence of Watson's (2012) human caring theory centers on recognition of human self-determination, choice, and accountabilities, people are unquestionably connected with each other and with nature, acknowledgment and appreciation of all ways of knowing including intuition and all methods of discovery, and an open-minded

scientific worldview. Using these values and guidelines for nursing Watson (2012) is hopeful to bring art back into the practice of nursing to find new interpretations and representations of what it means to be human, to be a nurse, to be unwell, to be restored, and to give and get personal care. Jean Watson (2012) is still hopeful bringing back the art of nursing can assist the practice of nursing to rediscover their obligations to humans, humanity, and to human compassion and restorative processes; establishing a new philosophical foundation for nursing.

Many patients suffering from life-limiting progressive illnesses have their care managed by their primary care provider, most likely an advanced practice registered nurse. Advanced practice registered nurses are also essential to palliative home care, and provide care to patients and their families in their homes, striving to keep patients in the comfortable surroundings of their home by managing illness related exacerbations through palliative home care. Advanced practice registered nurses education and skill in caring for patients come from a unique perspective. A perspective rooted in holistic care that considers patients as a whole, family members as a whole, and tries to bring strength and healing to all of them through many modalities, and does not specifically focus on the medical model.

Jean Watson's theory of human caring provides the ideal-theoretic foundation behind the early integration of palliative care. In recognizing early a patient's need for palliative care, the patient can be nurtured mind, body, and spirit through the progression of their life-limiting progressive disease to hopefully find peace and wholeness within themselves to be able to transition from life to death with dignity and peace. To be able to provide this essential care to patients, Watson (2003) encourages the advanced practice

registered nurse to find their authentic selves. Only when a nurse knows oneself truly and deeply, are they able to provide and nurture patients the way the patient requires and can foster wholeness and healing to the mind, body, and spirit of the patient (Watson, 2012). Watson (2003) encourages nurses to evaluate one's thoughts and feelings towards the meaning of life and death as they work with patients experiencing vulnerability, uncertainties, and hopelessness. Watson (2003) calls upon nurses to provide compassionate care to patients by coming from a place of love, humanity, and connectedness and acceptance of the intricate web of life that connects us all together, human to human, human to nature, human to the cosmos. Acknowledging the brokenness within ourselves, others, and the world allows one to come from a place of suffering and to release one's self-yielding to the loving embrace of the universe and interconnectedness (Watson, 2003).

When one surrenders one's self to the connectedness of the universe, acknowledges the brokenness everyone comes from and grows from, and can surrender themselves to the importance of their work coming from a place of compassion, understanding and love. Only then one can engage in a truly meaningful relationship with their patient and enter a space where caring moments can occur. Watson (2012) describes caring moments in which the patient and the advanced practice registered nurse both bring their unique life experiences to each other and are influenced and affected by the basis of the relationship and link between them. The link between the patient and advanced practice registered nurse affects both profoundly and deeply leaving lasting impressions that affect their lives from here on out. The linking within this relationship uplifts the humanity and human dignity within the relationship bringing about the

restoration of inner peace, wholeness, and possibly healing. Watson (2003) also describes the caring relationship as energetic vibrations transcending time and space that exudes reciprocity and empathy between the two persons experiencing the moment, while connecting them with their humanity and the universe. The advanced practice registered nurse must enter their relationships with their patients with intentionality, and heart-centered compassionate caring intentions to guarantee the patient is in the best situation to access his or her inner curative resources, connecting to the universal source of healing where sometimes miracles can happen (Watson, 2012).

Along with the above factors for entering into a caring transformative relationship with patients, advanced practice registered nurses also need to incorporate the following factors according to Watson (2003) to create transformative caring relationships. All intentions and actions a person performs carries energy into their life and the lives of other, intentions, consciousness, and essential being can make a difference either for the better or worse, serenity and mindfulness in a caring moment perpetuates serenity and mindfulness throughout the caring moment. Caring and compassionate acts bring healing and wholeness to self and others, and finally, the practice of transformative caring in practice can overflow into our everyday lives affecting self and others in significant, meaningful ways.

Jean Watson's theory of human caring also includes carative factors, or factors that are important and need nurturing within one's self and in one's nursing practice to bring human caring to the highest quality it can be. These carative factors evolved into clinical caritas and provided the foundation of Watson's theory. The most notable highlight of the clinical caritas are as follows according to Cara (2003), bring forth a

caring intention presence full of love, be present and intentional at the moment in the care of the patient cultivating feelings of care. Also, create trusting valuable relationships with a genuine presence, support positive and negative feelings from patients, go beyond yourself and develop your personal spiritual practices allowing one to engage with others in a sensitive and compassionate way. Encourage the use of all ways of knowing, participate in genuine teaching and learning moments with patients, use healing environments at all levels mind, body, and spirit potentiating wholeness, love, humanity, and peace.

Watson (2003) reminds advanced practice registered nurses about important aspects of entering into a loving, trusting, and caring relationship with a patient. One must acknowledge other's talents, gifts, and contributions as these are indispensable to a person as a whole, speak and listen without drawing personal conclusions coming from a compassionate center to find shared meaning between the nurse and patient, and do not interrupt as telling one's story can be therapeutic in itself. Find stillness and a center within one's self for consideration, review, and clarity, a true human-to-human caring moment takes one to a place where self and work are no longer separate. Recognize everyone is a part of each other's journey and caring for and healing one's self can contribute to care and healing of the whole.

Through the use of Jean Watson's theory of human caring, advanced practice registered nurses can connect with their patients on a level where transpersonal caring moments affecting the patient and the nurse can occur. Transpersonal caring moments are critical to all patient care but essential in the care of patients diagnosed with and living with progressive life-limiting diseases. The early implementation of palliative care in

patients diagnosed with life-limiting disease allows advanced practice registered nurses in the primary care role and the palliative care role to establish these deep personal connections with their patients. In the process of fostering their relationships, the advanced practice registered nurse give their authentic self to the patient and the relationship, and the line between personal and work blurs and spills over into each other. Advanced practice nurses embracing and implementing Jean Watson's theory of human caring allow their patients the right to express their feelings and beliefs towards healing, wellness, and wholeness. Patients remain autonomous in decisions regarding their health care and enter into a relationship with the nurse that nurtures the patient's mind, body, and spirit. This allows the patient the ability to heal and find wholeness to the best of their ability in the face of their life-limiting illness while supporting the patient in finding meaning in their suffering, life, and death so they may pass from the world of the living into death in a peaceful, meaningful manner.

Chapter Four: Methodology and Evaluation

The goal of this scholarly project is to highlight the importance of palliative care in treating, supporting, and caring for the patient and their family holistically while living with life-limiting illness, and keeping the patient's perceptions about quality of life as the center focus. This project also highlights a gap within appropriate referral of patients with a life-limiting illness to palliative care programs. The overall focus is to educate primary providers on when it is appropriate to refer patients to palliative care as a collaborative approach to treating a patient and their life-limiting illness.

Through a systematic approach, a literature review was conducted focusing on scholarly articles about the importance of early integration of palliative care for patients diagnosed with a life-limiting illness and why primary health care providers hesitate to consult palliative care when appropriate. It was discovered that primary care providers, mainly, do not feel knowledgeable enough to have these delicate conversations with patients, and feel they will take away a patient's hope. Primary care providers avoid these conversations because patients may misconstrue involving palliative care as giving up on them. Primary health care providers also do not feel knowledgeable enough as to how to deal with the patient's or family's reactions. Finally, primary health care providers may not know enough about the differences between hospice care and palliative care, and often use hospice and palliative care interchangeably when they are two very different approaches to caring for patients.

Personal interviews were also carried out with the director of a palliative home care program. During the interview, the director shared what they thought the biggest barrier to patient referral for palliative care when they have the qualifying diagnosis of

life-limiting illness. Their response was lack of knowledge for health care providers as to what palliative care consists of, how it used in collaborative patient care, and all the benefits palliative care offers patients and their families. They also stated, for many health care providers, it is just easier to not have the conversation with the patient and to just keep feeding them hope with another medication here and another treatment there that might help, often overlooking the quality of life the patient will have after the medication or treatment. The director stated, in their opinion, most often, the health care provider does not want to admit defeat, that they are unable to heal the patient.

Lastly, personal experience as a registered nurse provides evidence in favor for education about the uses of palliative care, and how palliative care positively affects patient care and works collaboratively with the team. Through personal experience, there have been patients qualified for palliative care who were not offered this service because of a perceived lack of knowledge by provider about the role of palliative care.

Population

The population focus in this project is primary care nurse practitioners who manage and collaborate care for patients diagnosed with life-limiting illnesses. At the primary care level, nurse practitioners can implement palliative care consults in the early stages of life-limiting illness. Early implementation of palliative care allows the patient and their family to process their illness, and have time to make informed decisions about the type and aggressiveness of care to be received through the illness trajectory until death.

Setting

Education about how and when to implement palliative care, using an educational pamphlet, will occur as an informal meeting at a lunch and learn with primary care providers. An informal setting encourages questions and facilitates open and honest conversation about perceived barriers to implementation of palliative care in the early stages of life-limiting illness.

Tools

A general questionnaire was given to the family practice nurse practitioners [see Appendix C] to stimulate discussion about nurse practitioner's beliefs towards palliative care. Questions such as when palliative care should be used, if they have referred patients to palliative care, and if there were ever any times, they believed their patient should have had a palliative care referral, but they did not and perceived barriers. All questions answered remained anonymous to encourage open, honest answers. After all the questionnaires were returned, an informational pamphlet [see Appendix A] educating primary healthcare providers about why, when, and how to have the crucial conversation of palliative care with patients was presented at the meeting. A question and answer time was included at the end of the program.

Interventions

After collection of anonymous data in regard to palliative care was collected; education was provided to the family nurse practitioners. The education provided encourages and supports family nurse practitioners on how and when to have conversations with patients diagnosed with life-limiting illness. Early conversations and

integration of palliative care for patients diagnosed with life-limiting illness offers an additional layer of support, education, and time to allow the patient and their family to adjust to and accept a terminal diagnosis.

Outcome Evaluations

Overall, the education and pamphlet were well received, with additional pamphlets being provided to the nurse practitioners to bring back to their area of care with encouragement to share them with other primary care providers. The general questionnaires given to the primary care nurse practitioners will be used to evaluate if the educational pamphlet covers all pertinent topics as to why, when, and how to implement palliative care for appropriate patients. Early implementation of palliative care allows the patient and their family the resources to process their illness and have time to make informed decisions about the type and aggressiveness of future care.

Chapter 5: Significance and/or Implications

The focus of this scholarly project was to help initiate palliative care in the primary care setting, early in the disease process, for patients diagnosed with a life-limiting illness. Once a patient faces the diagnosis of a life-limiting illness, the discussion of extra layers of support for the patient should begin; including the consideration of palliative care and the additional level of support offered with the use of palliative care. One clinical question this scholarly project posed was do patients with life-limiting illness benefit from the early intervention of palliative care? The benefits of palliative care are numerous; an extensive literature review divulges that the earlier palliative care begins for patients with life-limiting illness, the more favorable the outcome for the patient and their family (Matzo & Sherman, 2015). Desirable outcomes for the patient and their family can include better coping, emotional, spiritual, and mental support for the patient and family, increases in quality of life, increases in life expectancy, symptom management such as pain, nausea, and depression, and referral for continued bereavement care if the family desires (Matzo & Sherman, 2015; Compassion Care Hospice, 2015).

The next clinical question stems from the first and identifies when does a patient qualify for palliative care? The answer to this question was variable, depending on the expert opinion consulted. Responses range from as soon as a patient is diagnosed with a life-limiting illness, to when symptoms begin to affect the quality of life, or when the patient deems the conversation about palliative care appropriate. This clinical question represents an area in need of consensus from primary care providers. Evidence from the literature review supports the initiation of palliative care as soon as diagnosis is made so

the patient and family become familiar with palliative care and the use and need for palliative care becomes progressive as the illness advances as well (Matzo & Sherman, 2015; Compassion Care Hospice, 2015).

Another clinical question this scholarly project posed was what are the barriers preventing primary care providers from beginning conversations about end-of-life and palliative care options with patients with a life-limiting illness? The earlier these discussions occur, the more time the patient and their family have to establish a relationship with interdisciplinary supportive teams such as palliative care (Ferrell, 2014). The answer to the clinical question about barriers was found to be multifactorial. Reasons ranged from feeling under-educated and ill-prepared to begin conversations about palliative care, to feeling the conversation is too drastic and takes away hope from a patient and their family, to not fully understanding how palliative care is different from hospice and the benefits offered by early involvement of palliative care (Matzo & Sherman, 2015; Compassion Care Hospice, 2015).

The last clinical question this scholarly project posed was what exactly is palliative care and how can it benefit the patient with a life-limiting illness? Palliative care, for this scholarly project, is defined as an interdisciplinary team that works in conjunction with the patient's healthcare team to ensure the emotional, spiritual, and practical needs of the patient and their families are met (Back et al., 2014; Connor, 2010). The goal of palliative care is to alleviate suffering from pain and symptoms associated with the life-limiting illness and the dying process. Palliative care is appropriate for any patient, at any age, at any stage of their disease, and is suitable if the patient chooses or does not choose to pursue treatment for their life-limiting illness.

An extensive literature review was completed to be able to support the clinical questions proposed by this scholarly project. A pamphlet was designed, see Appendix [A & B], using the knowledge gathered by the literature review. This pamphlet is a useful tool for the primary care provider and educates them about why to choose palliative care for their patients, who qualifies for palliative care, when patients are eligible for palliative care, and how to initiate conversations about palliative care with patients with life-limiting illness. A power point presentation was also designed to enhance education for primary care providers about palliative care. The power point presentation also supports the educational pamphlet created for education for primary care providers. The educational pamphlet and power point presentation used in conjunction were presented to several groups of professionals consisting of nurse practitioners, physician assistants, medical doctors, and pharmacists. A questionnaire was also used, see Appendix [C], to gather feedback about the presentation and offer suggestions for improvement and implementation of the project. The most common findings from the questionnaire were as follows: conversations regarding palliative care should be approached at diagnosis of the life-limiting illness; even if the patient may not be ready it is indispensable to begin these conversations early in the disease process. Early conversations about palliative care ensure the patient and their family are aware of the extra layer of support available to them with the use of palliative care. Time constraints for primary care providers is a significant factor limiting discussions about palliative care and result in the conversations being delayed and do not begin with the diagnosis of life-limiting illness. Appointment time with the patient is usually spent discussing other topics about their illness. Finally, it was a common finding the comfort level and education about palliative care for the

primary care provider is deficient and creates a barrier to broaching the subject of palliative care with patients with life-limiting illness and their families. Initial presentation of the educational pamphlet and power point presentation yielded feedback for improvements in the project, which were promptly incorporated. Visual changes to power point presentation, the addition of resources and education centers for primary care providers to use on the educational pamphlet, and additional professional contacts to present this scholarly project to were improvements for this project. Overall, feedback for the scholarly project was positive and encouraging to carry this work forward to make an impact in the primary care aspect of health care.

Doctorate of Nursing Practice Essentials

This scholarly project design is in alignment with The American Association of Colleges of Nursing (AACN) and eight nursing essentials for the Doctoral qualified nurse practitioner has set forth, as outlined in Appendix [D]. The eight nursing essentials guide the doctorate prepared nurse practitioner the ability to practice with interdisciplinary proficiency, work with complex information systems, aide in quality improvement projects in health care, as well as practice and advocate as patient safety specialists (AACN, 2006). The eight essentials of the AACN weave through the development, research, and implementation stages of this project.

Essential I Scientific Underpinning for Practice

This essential promotes using science-based perceptions to enrich and improve health care delivery, as well as enabling the ability to appraise results scientifically. The literature review for this scholarly project lifted essential one as the literature review

concludes several sources cite palliative care as an underused interdisciplinary patient care team and an area in health care delivery in need of increased education and use in the patient care setting. This scholarly project examines the urgency and barriers for early use of palliative care as the literature review reveals.

Essential II Organizational and Systems Leadership for Quality Improvement and Systems Thinking

This essential promotes responsibility of quality of health care delivered, as well as enhancing communication skills to lead to quality improvement, ethical decision making, and increased patient safety. This essential's presence was in the scholarly project through recognition of the responsibility of the primary care provider in delivering quality palliative and end of life care. Development and presentation of the palliative care pamphlet promoted education of primary care providers about palliative care and the ethical opportunity regarding decision making for patients with life-limiting illness.

Essential III Clinical Scholarship and Analytical Methods for Evidence-Based Practice

This essential encourages critical evaluation of current literature and evidence to conclude and initiate changes for best practice to promote safe, appropriate, competent, justifiable, and patient-centered care; allowing the researcher to circulate findings from evidence-based research, practice, and literature to enhance health outcomes. This essential's presence is in the literature review where evidence-based practice and literature is evaluated to support the need for early implementation of palliative care in

patients with life-limiting illness. Through the literature review, the completion of the educational pamphlet for primary care provider education regarding palliative care was able to be designed and implemented using evidence-based practice.

Essential IV Information Systems Technology and Patient Care Technology for the Improvement and Transformation of Health Care

This essential empowers evaluation of user health information sources for precision, correctness, and truthfulness. The development of this project required the evaluation of several health consumer websites with comparison against the evidence-based practice for precision, correctness, and truthfulness of the information provided to health information users in regard to palliative care. Information available to patients with life-limiting illness and primary care providers was evaluated for completion of this scholarly project.

Essential V Health Care Policy for Advocacy in Health Care

This essential enables the doctoral prepared nurse to evaluate health policies from multiple perspectives including the patient, nurse, and policymaker views. Also, maintaining the ability to educate from different perspectives about patient care outcomes while advocating for social justice, equity, and ethical health care for all. This essential presents in this scholarly project through the promotion of equal opportunity availability of palliative care to all patients diagnosed with a life-limiting illness as palliative care should be available to all patients with life-limiting illness ethically. This scholarly project promotes primary care providers to view health policies regarding palliative care

from a personal and professional perspective, as well as the aspect of interdisciplinary teams, and patient perspectives in regards to social justice and ethical healthcare for all.

Essential VI Inter-Professional Collaboration for Improving Patient and Population Health Outcomes

This essential promotes professional collaborative communication abilities to enable development and implementation of practice models. Essential VI presence in this scholarly project is through the development of the palliative care pamphlet (Appendix [A and B]), palliative care power point, and subsequent presentation of both pamphlet and power point to professional groups lifting collaborative communication between presenter and group. Feedback provided from interdisciplinary professions shaped and modified the project.

Essential VII Clinical Prevention and Population Health for Improving the Nation's Health

This essential assesses care models and tactics through the lens of community, environmental, cultural, and socioeconomic scopes of health. In this scholarly project, the current uses of palliative care were evaluated and compared as well as the average time frame in a person's illness palliative care begins. Overall, current care models and tactics reveal palliative care is an under-utilized healthcare resource with valuable potential for meaningful end of life care. This finding promotes the significance and assists with the development of this project and enforces the need for earlier implementation of palliative care in patients with a life-limiting illness.

Essential VIII Advanced Nursing Practice

This essential encourages developing and nourishing therapeutic connections and partnerships with patients and other professionals to aid in ideal health care and patient results. Essential VIII presents throughout the scholarly project by use of the primary care provider as the cornerstone for initiating palliative care for patients with life-limiting illness. The primary care provider is also integral to this scholarly project for maintaining collaborative care between interdisciplinary professions for the patient who qualifies for palliative care. The primary care provider nourishes a relationship between themselves and the patient, and the patient and the palliative care team (AACN, 2006).

Project Significance and Insights

Through the development of this scholarly project, many insights have come to light. The need for early introduction of palliative care for patients with life-limiting illness stimulates positive outcomes for the patient and their family. These positive outcomes include improved quality of life for the patient, increase in life expectancy, increase in management of bothersome disease and treatment associated symptoms such as pain, nausea, and depression. A decrease in hospitalizations, increases in disease and treatment knowledge, and increases in coping abilities are also optimistic effects witnessed with early use of palliative care (Back et al, 2014; Connor, 2010; & Ferrel, 2014). Another insight is increasing education for primary care providers about the benefits of palliative care and the role in patient care would be beneficial in improving primary care provider knowledge about palliative care and increase their awareness on the topic, therefore increasing comfort level talking about palliative care. The last insight gleaned from this scholarly project includes formal education and resources for primary

care providers on how to initiate and continue conversations about palliative care with their patients is essential to the early implementation of palliative care for the patient with the life-limiting illness.

Implications for Advanced Practice Nursing

It is the hope, with this scholarly project; future advanced practice nurses will become more comfortable with discussions regarding the use of palliative care for their patients with life-limiting illness. It is the desire that eventually, it will be commonplace for future nurse practitioners, and all their patients, have discussions about end of life desires and options well before the actual need to use them arises for the patient. Future plans include additional use of the educational pamphlet and power point presentation in the primary care setting as educational resources for primary care providers to use as assistance for when, for who, and how to implement palliative care. This scholarly project will be a keystone development in the early integration of palliative care for patients with life-limiting illness, and the use of palliative care for patients with life-limiting illness will become more common in health care. As a result, many patients will benefit from the services palliative care can offer as they face uncertain disease trajectories. Patients will feel supported to pursue treatment as desired without the fear of lacking health care support if they choose to or choose not to seek aggressive treatment for the course of their illness. Patients and their families will feel supported throughout the disease process mind, body, and spirit. Patients and families will be knowledgeable about their disease, the disease process, and all treatments available to them and their side effects. Hopefully, this work will help bridge the gap in healthcare between pursuing extension of life at any cost, and graceful acceptance of death as an unpreventable part of

life. This work will show patients they can choose which treatments they wish to pursue, and teach patients it is acceptable to say no to some treatments that will not have outcomes in alignment with their vision of how to treat their illness. There will be an emphasize that death can be an embraced dignified passageway from this life to the next with support along the pathway to make the transition as comfortable and easy as possible. The use of palliative care in the patient with life-limiting illness is important because the medical industry has become so focused on preservation of life at all costs, that many times the consequences and side effects of treatments far outweigh the quality of life some patient's lives end with.

Conclusions

In conclusion, end of life discussions can be difficult to initiate, but death is the one thing we all must face. Instead of death being a feared event where the discussion is avoided, healthcare industries must learn to bring it to the forefront of patient care and let the patient's vision and personal healthcare goals guide the healthcare services and treatments they receive. This scholarly project demonstrates the need for further education for primary care providers is essential regarding the appropriate use of palliative care. Education about how to have the discussion of palliative care with patients also needs to be available for primary care providers. Use of palliative care has shown numerous favorable outcomes for patients with life-limiting illness and their families. Health care needs to encompass nurturing a person as a whole mind, body, and spirit. Genuine connections are made through caring moments connecting health care provider and patient; establishing trust and enabling difficult conversations that ultimately have patient's best interest in mind. With knowledge, recognition of personal

wishes, and support systems death can be a distinguished final event in one's life that can embrace acceptance and peacefulness.

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Appendix A: Palliative Care Pamphlet

<p>How to talk to your patient about palliative care</p> <ul style="list-style-type: none">• Know what palliative care is and what palliative care is not• Know the benefits of palliative care• Emphasize the use of palliative care does not mean treatment cannot be pursued• Acknowledge death as a natural part of the life cycle• Identify personal biases against palliative care• Keep your patient's best interest in mind• Acknowledge life-preserving measures are often painful with undesirable side effects and may not align with patient's personal wishes• Expect a variety of emotions from your patient and their family• Acknowledge these conversations are difficult for patients and providers and may need to be discussed more than once• Be compassionate towards your patient and yourself—there is no one right way for these conversations to occur	<p>Be brave enough to start a conversation that matters.</p> <p><i>Margaret Wheatley</i></p>	<p>WOULD YOUR PATIENT BENEFIT FROM PALLIATIVE CARE?</p>  <p>The Power of <i>Palliative Care</i></p>
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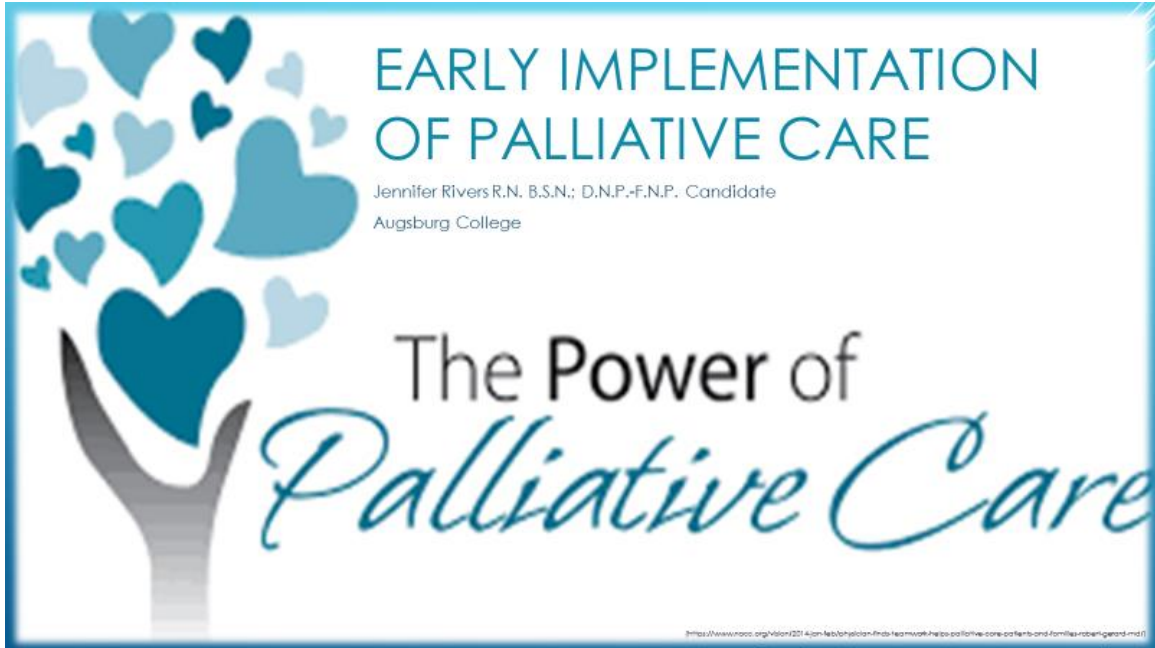
Appendix B: Palliative Care Pamphlet

	<h2>Does your patient qualify?</h2> <h3>What is life-limiting illness?</h3>	<h2>Benefits of early integration of palliative care</h2>
<h3>Palliative Care</h3>	<p>The life-limiting disease is defined as an enduring disease or illness non-responsive to therapeutic management, which will result in patient fatality.</p>	<p>Palliative care can...</p>
<p>Is appropriate for any patient at any stage of a life-limiting disease. The focus of palliative care is to alleviate suffering from pain and symptoms associated with the disease process and dying. Palliative care also supports the patient and the patient's family emotional, spiritual, and practical needs.</p>	<p>The surprise question can also be used to assess a patient for appropriate referral to palliative care. Ask yourself, would I be surprised if this patient died within the next year? If you can answer yes, this patient qualifies for palliative care.</p>	<ul style="list-style-type: none"> • Improve quality of life • Increase life expectancy • Manage symptoms such as pain, nausea, and depression • Decrease hospitalizations and emergency room visits • Increase knowledge about the illness and disease process for the patient • Decrease use of painful costly life-preserving measures • Increase patient comfort • Educate the patient and family how to manage disease exacerbations in the home • Support physical, mental, and spiritual aspects • Facilitate trust between patient and health care team • Increase coping abilities
	<h3>Life-limiting Illnesses</h3>	
<h3>Why Palliative Care?</h3>	<p>Life-limiting illnesses can include the following conditions: terminal cancer, <u>Alzheimers</u>, end-stage renal disease, <u>amyotrophic lateral sclerosis</u>, <u>cardiomyopathy</u>, congestive heart failure, Parkinson's disease, emphysema, chronic obstructive pulmonary disease, liver disease, and acquired immunodeficiency syndrome.</p>	
<p>Palliative care works collaboratively with the patient's health care team to ensure the best care for the patient. Palliative care is appropriate if the patient still wants to pursue treatment. Palliative care regards dying as a natural part of the life cycle, and focuses on the patient's ideals for quality of life, making them a priority, and helping the patient live well until death occurs.</p>		

Appendix D: Eight Essentials for Doctoral Nursing Programs in Accordance with
American Association of Colleges of Nursing

- I. Scientific Underpinning for Practice
- II. Organizational and Systems Leadership for Quality Improvement and Systems Thinking
- III. Clinical Scholarship and Analytical Methods for Evidence-Based Practice
- IV. Information Systems Technology and Patient Care Technology for the Improvement and Transformation of Health Care
- V. Health Care Policy for Advocacy in Health Care
- VI. Inter-Professional Collaboration for Improving Patient and Population Health Outcomes
- VII. Clinical Prevention and Population Health for Improving the Nation's Health
- VIII. Advanced Nursing Practice

Appendix E: Final Presentation Slides



- ▶ Define what palliative care is
- ▶ Define when palliative care is appropriate for a patient
- ▶ Identify barriers to implementation of palliative care
- ▶ Discuss the benefits of palliative care for patients with life-limiting illness
- ▶ Discuss Jean Watson's nursing theory and significance to project
- ▶ Evaluation of early implementation of palliative care project
- ▶ Identify and discuss the significance and implementation of this project

OBJECTIVES

- ▶ Palliative care, for this scholarly project, is defined as an interdisciplinary team that works in conjunction with the patient's healthcare team to ensure the emotional, spiritual, and practical needs of the patient and their families are met (Bock et al., 2014; Connor, 2010)
- ▶ Specialized medical care for individuals diagnosed with life-limiting disease, providing relief from symptoms, pain, and stress associated with the disease process, treating the whole person not just physical symptoms
- ▶ Live well and die well with disease, improve quality of life
- ▶ A specialized team of doctors, nurses, and specialists collaborating care with the patient's other doctors to add an extra layer of support for the patient and family
- ▶ Palliative care is appropriate at any age and any stage with serious illness (Birkenhagen, L. 2016)



(<http://www.chomp.org/what-we-do/palliative-care/#.WAmr5kxLcs>)

WHAT IS PALLIATIVE CARE?

Palliative care is commonly misunderstood and correlated with hospice care and the withdrawal of treatment and care

(Matzo & Sherman, 2015)

A patient under palliative care can still pursue aggressive treatment for their life-limiting illness and have a prognosis of 1-2 years of life, patients in hospice do not pursue aggressive treatments and death is imminent

(Mayo Clinic, 2014)

Palliative Care vs. Hospice Care



Palliative Care

Hospice Care

(<http://theapokavoice.com/which-is-appropriate-hospice-palliative>)

PALLIATIVE CARE IS NOT HOSPICE CARE

Life is Pleasant
Death is Peaceful
It's the transition that's troublesome...
Isaac Asimov

If you are living with any of the following...

- Cancer
- Lung disease (COPD, emphysema)
- Congestive heart failure
- End stage renal disease/kidney failure
- Liver failure
- Alzheimer's/Dementia
- ALS/Multiple Sclerosis, Parkinson's

If any of the following are impacting the quality of your life...

- Pain or discomfort
- Shortness of breath
- Fatigue, Anxiety, Depression
- Lack of appetite, Nausea
- Frequent hospitalizations
- Side effects of treatments
- Progressive health decline despite treatment
- Patient/family/caregiver stress
- Desire of patient and family to stop treatment
- Difficulty with decisions about aggressive treatments
- Uncertain goals of care

WHEN PALLIATIVE CARE IS APPROPRIATE

<https://www.residentialhomehealth.com/pain-and-symptom-management>

Dignity

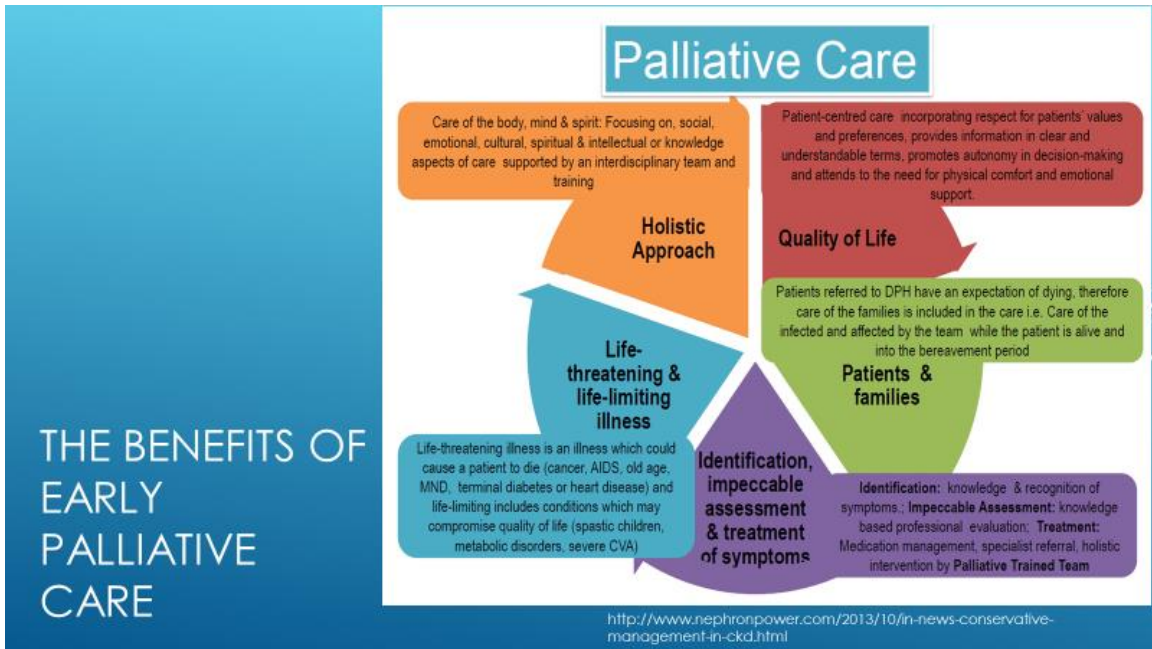
We never stop being human through the last stages of life. We never stop experiencing the full range of emotions. Palliative care is about dignity and respect. It is about quality of life in the final stages.

Source: Unknown



<https://www.oncology-central.com/2017/03/24/palliative-care-consults-improve-care-reduce-hospitalization-advanced-cancer-patients/>

THE BENEFITS OF EARLY IMPLEMENTATION OF PALLIATIVE CARE



- Relieve physical, emotional, and spiritual symptoms and distress
 - Improve patient-provider-family communication and decision-making
 - Reinforces transition management and continuity of care across health care settings
 - Enhanced quality of life
 - Decreased major depression
 - Decreased aggressive treatment
 - Less chemo
 - More likely to receive hospice in a timely fashion, less likely to be hospitalized in last month
 - Improved survival: 11.6 months vs. 8.9 months
(Temel, et al, 2010)
- THE BENEFITS OF EARLY IMPLEMENTATION OF PALLIATIVE CARE**

Human reactions of avoidance and denial of self-death
(Connor, 2010)

Medicine and nursing are based on the fundamental value of preservation of life
(Connor, 2010)

Fear of taking away hope from the patient
Feelings of failure on part of the family nurse practitioner (FNP), separation of relationship from patient as care shifts from curative to palliative
(Pfeil, Laryionava, Reiter-Theil, Hiddemann, & Winkler, 2015)

Role of the family nurse practitioner (FNP) and the relationship between the FNP and patient
Lack of education and inexperience on the part of the FNP
(Beernaert et al., 2014)

Difficulties with collaboration of continuing care between interdisciplinary teams
(Beernaert, 2015)

BARRIERS TO EARLY IMPLEMENTATION OF PALLIATIVE CARE

With the advancement of medicine, health care has lost its humanity

Love, splendor, and depth of life are what make life meaningful

Nurses are essential to bring humanity, love, compassion, and caring back to health care

Practice holistic care of the mind, body, and spirit
(Watson, 2003)



(<http://quoteigram.com/jean-watson-nursing-theorist-quotes/>)

JEAN WATSON'S THEORY OF HUMAN CARING AND PALLIATIVE CARE

The goals of Jean Watson's theory of human caring are closely aligned with the goals of palliative care

Care of the patient body, mind, and spirit along with care and support for family

+
**Caring is
 the essence of
 Nursing.**

MEDLINE UNIVERSITY
ADVANCING EDUCATION IN NURSING & HEALTHCARE

**Be brave enough
 to start a
 conversation
 that matters.**

Margaret Wheatley

(<https://s-media-cache-ak0.pinimg.com/originals/5d/61/b5/5d61b57f6a4979b75f1310913784bb15.jpg>)

JEAN WATSON'S THEORY OF HUMAN CARING AND PALLIATIVE CARE

Acknowledge the intricate web of life that connects human to human, human to nature, and human to the cosmos

Find your authentic self-by understanding your own brokenness to grow from and surrendering yourself to your work

Nurture your own mind, body, and spirit

Be present in the moment

Be prepared for transformative caring moments to occur at any time-affecting the patient and the caregiver in a meaningful manner-these relationships transcend time and space allowing inner peace, wholeness, and possibly healing to occur

Create a space that allows miracles to happen
 (Watson, 2003, 2012)

**"Realize deeply
 That the present moment
 is all you ever have."
 -Eckhart Tolle**

JEAN WATSON'S THEORY OF HUMAN CARING AND PALLIATIVE CARE

"Maybe this one moment, with this one person, is the very reason we're here on earth at this time." (Watson, 2003)

MISSION STATEMENT:
To provide high quality, customer-oriented and financially strong healthcare services that meet the needs of those we serve

(<http://jeanwatsoncaringtheory.weebly.com>)

JEAN WATSON'S THEORY OF HUMAN CARING AND PALLIATIVE CARE

Project: Where do current healthcare providers see limitations in the ability to talk about and implement palliative care for the patient with life-limiting illness in primary care?

Tools

- ▶ General questionnaire
 - ▶ When should palliative care be used?
 - ▶ Have you referred someone to palliative care, if so what prompted you to do so?
 - ▶ Have you ever believed someone should have had a palliative care consulted but it was not implemented? Can you share perceived barriers?

IMPLEMENTATION & EVALUATION

- ▶ Population
 - ▶ Primary care nurse practitioners who manage and collaborate care for patients diagnosed with life-limiting illness
- ▶ Setting
 - ▶ Informal meeting, lunch and learn, stimulating honest answers to questionnaire and stimulation of open, honest conversation



IMPLEMENTATION & EVALUATION

- ▶ Interventions
 - ▶ Pamphlet and PowerPoint reviewed by experts in palliative care
 - ▶ Provided expert opinion on where the "gaps" in knowledge lie, provided strengthening language and personal knowledge to promote importance of early palliative care and how to improve educational pamphlet
- ▶ Outcome evaluations
 - ▶ Well received
 - ▶ Educational pamphlet reviewed and updated to reflect responses from questionnaire

EVALUATION

<p>How to talk to your patient about palliative care</p> <ul style="list-style-type: none"> • Know what palliative care is and what it is not, as well as benefits for the patient and their family • Emphasize the use of palliative care does not mean treatment cannot be pursued • Acknowledge death as a natural part of the life-cycle • Identify personal biases • Keep your patient's best interest in mind • Acknowledge life-preserving measures are often painful with undesirable side effects and may not align with patient's personal wishes • Expect a variety of emotions from your patient and their family • Acknowledge these conversations are difficult for patients and providers and may need to be discussed more than once • Be compassionate towards your patient and yourself—there is no one right way for these conversations to occur 	<p><i>Be brave enough to start a conversation that matters</i></p> <p>~Margaret Heffley</p> <p>Resources for health care providers</p> <p>http://www.endoflife.northwestern.edu/index.cfm</p> <p>http://www.mn.hpc.org</p> <p>https://getpalliativecare.org/resources/clinicians</p>	<p>WOULD YOUR PATIENT BENEFIT FROM PALLIATIVE CARE?</p>  <p>The Power of Palliative Care</p>
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EVALUATION

 <p>Palliative Care</p> <p>It is appropriate for any patient at any stage of a life-limiting disease. The focus is to alleviate suffering from side effects and symptoms associated with the disease process and possible treatments. Palliative care also supports the patient and their families emotional, spiritual, and practical needs.</p>  <p>Why Palliative Care?</p> <p>Palliative care works collaboratively with the patient's health care team to ensure the best care for the patient. Palliative care is appropriate if the patient still wants to pursue treatment. Palliative care regards dying as a natural part of the life cycle, and focuses on the patient's ideas about quality of life, making them a priority and helping the patient live well until death occurs.</p>	<p>Does your patient qualify? What is life-limiting illness?</p> <p>The life-limiting disease or illness non-responsive to therapeutic management, which will result in patient fatality.</p> <p>Life-limiting Illnesses</p> <p>Life-limiting illnesses can include the following conditions: cancer, Alzheimer's, end-stage renal disease, amyotrophic lateral sclerosis, cardiomyopathy, congestive heart failure, Parkinson's disease, emphysema, chronic obstructive pulmonary disease, liver disease, and acquired immunodeficiency syndrome.</p> <p>Would I be surprised if this patient died within the next year? This surprise question can be used to assess a patient for appropriate referral to palliative care. If you can answer yes, this patient may qualify for palliative care.</p>	<p>Benefits of early integration of palliative care</p> <ul style="list-style-type: none"> • Improve quality of life • Increase life expectancy • Manage symptoms such as pain, nausea, and depression • Decrease hospitalizations and emergency room visits • Increase knowledge about the illness and disease process for the patient • Decrease use of painful medical procedures • Help the patient and family manage disease exacerbations in the home • Support physical, mental, and spiritual aspects of health • Facilitate trust between patient and health care teams • Increase coping abilities • Refer and offer bereavement support to the family
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EVALUATION

- ▶ II. Organizational and Systems Leadership for Quality Improvement and Systems Thinking-evidenced by this project in pursuit for accountability and quality improvement in health care
- ▶ VI. Inter-Professional Collaboration for Improving Patient and Population Health Outcomes-demonstrated by communication and collaborative skills in project implementation after extensive literature review, using interprofessional teams to generate changes in healthcare
- ▶ VIII. Advanced Nursing Practice-design, application and evaluation of intercessions based on nursing and science
(American Association of Colleges of Nursing, 2006)

EIGHT ESSENTIALS FOR DOCTORAL NURSING PROGRAMS IN ACCORDANCE WITH AMERICAN ASSOCIATION OF COLLEGES OF NURSING

- ▶ This project can be pivotal in providing education to primary care providers as to how, when, and why to have the crucial conversation of palliative care with their patients
- ▶ This project can facilitate patients diagnosed with a life-limiting illness in receiving additional support from palliative care early in their diagnosis

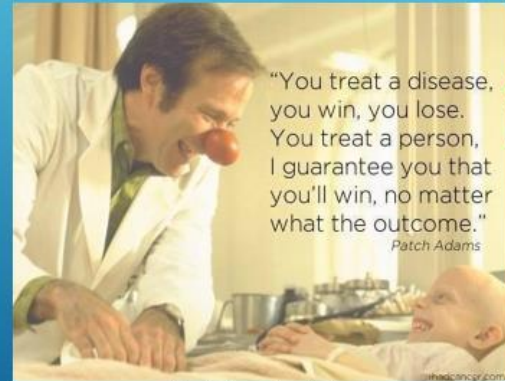


<http://wp.holytrinity3.ca/training-for-parish-palliative-care-volunteers/>

CONCLUSIONS

- ▶ The early implementation of palliative care is an essential component of interdisciplinary care for the patient and family with a life-limiting illness.
- ▶ Further resources and education for primary care providers is needed to help facilitate conversations and initiation of palliative care options for patients with life-limiting illness
- ▶ Additional education and communication skills regarding palliative care for the PCP and their patients will hopefully stem from this project

CONCLUSIONS



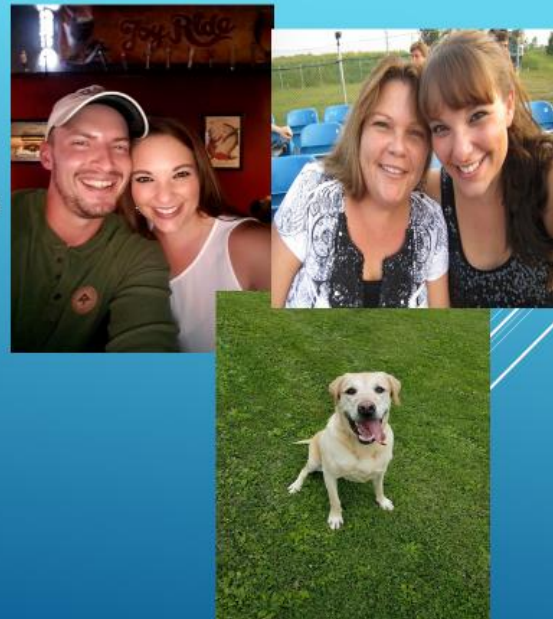
"You treat a disease, you win, you lose. You treat a person, I guarantee you that you'll win, no matter what the outcome."

Patch Adams

<https://twitter.com/paulinodoganis>

- ▶ To my preceptor and mentors who believed in my project and encouraged me every step of the way
- ▶ Inspired by the patients I have and will serve through my life's work as a nurse and nurse practitioner.
- ▶ To my family and friends, who have encouraged and believed in my dreams and supported me through school to achieve my goal of becoming a nurse practitioner.

DEDICATIONS



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