A New Understanding of Palliative Care

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A New Understanding of Palliative Care

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**Introduction**

**Purpose and Organization**

The purpose of this paper is to discuss palliative care and how it relates to chronic illness. It will include the current problems with palliative care as it is associated with chronic illness. The significance to nursing will be indicated and a review of literature will follow and then by a synthesis of the literature. A project proposal will follow the synthesis followed by an evaluation of the implemented project and conclusion.

**Problem/Purpose**

Palliative care is an important yet poorly understood field in modern medicine. Patients understand the value of a specialist, for example a cardiologist, and understand that said specialist completed years of specialized training to ensure the best outcomes for their patients and that it is best to seek out these specialists before symptoms become burdensome. The same cannot be said about palliative care. According to Strand, Kamdar, and Carey (2013), a “public opinion data commissioned in 2011 revealed that almost 80% of respondents lacked knowledge about the role of palliative care” (p.863) with the average patient equating palliative care to end of life or hospice care (Strand, Kamdar, and Carey, 2013). Problems exist within the medical community as well, with many physicians failing to suggest palliative care because of the fear that it signals the beginning of the end for their patients and would only cause distress for their patients (Strand, Kamdar, and Carey, 2013). With such misinformation, it is apparent why patients often do not utilize palliative care.

Contrary to popular opinion, palliative care is not for people who are at the end of their life; the purpose of palliative care is symptom management, psychosocial-spiritual support, and
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to aid in the facilitation of medical decisions (Buss, Rock, and McCathy, 2017). Palliative care identifies and addresses patient symptoms, whatever the cause, so that patient can have a better quality of life (QOL) (Buss, Rocks, McCathy, 2013). Any patient who experiences symptoms that make their daily life more difficult, such as people with chronic conditions, can benefit from palliative care. Patients with chronic conditions often have highly burdensome symptoms and evidence suggests that early palliative care in combination with traditional medical treatment can improve the quality of life for these patients (Strand, Kamdar, and Carey, 2013). Despite all of the benefits of palliative care, those with chronic conditions still experience barriers, and do not utilize palliative care (Strand, Kamdar, and Carey, 2013).

**Significance**

The significance to nursing is as follows: patients with chronic conditions who utilize palliative care have better control of their symptoms and a better quality of life. Furthermore incorporating palliative care would save money. According to Strand, Kamdar, and Carey (2013), it would save approximately “$1696 per admission for patients who survived hospitalization” (p.863). There is a growing number of patients with chronic conditions which means that palliative care has the potential to save thousands of dollars over a patient’s life while providing a better quality of life for patients.

**Objectives**

The objectives of project are to conduct a critical appraisal of the literature, develop and distribute a pamphlet of these findings to nurses, nursing students and patients in the difference significance and use of palliative care caring for chronic illness, and create and give a presentation of this material to junior nursing students.

**Summary**
Palliative care is a poorly understood and underutilized area of healthcare. Patients often falsely equate palliative care with hospice care and therefore view it as giving up. Providers often fail to suggest palliative care to their patients because of the fear that they are telling patients to give up hope. This is not the case, indeed palliative care exists to relieve the burden of symptoms and improve a patient’s quality of life. The purpose of this project is to educate both patients and nurses to dispel common misconception about palliative care and to encourage the use of palliative care before symptoms become unmanageable. A review of the literature was performed to identify common symptoms across multiple diagnoses that indicate a need for palliative care and indicate that palliative care is effective for the management of patient symptoms. This literature will be used to create both an educational pamphlet and PowerPoint for both nurses and patients.

**Review of Literature**

The Review of Literature was conducted using CINAHL and Pubmed using the Wright State University Database. Articles no older than five years were included in the review. Abstracts of the articles generated by a search and were if the abstract appeared to be pertain to the topic of this project, a reading of entire article was warranted. Once an article was selected, it was appraised using the Rapid Critical Appraisal tool. The level and quality of the articles can be found in Appendix B and a table of the review of the articles can be found in Appendix A. The results of the review have been organized into three categories: articles that indicate a need for palliative care, articles that explore the effects of palliative care on patients, and articles that explore the effects of palliative care on family members.

**Indicates a Need**
The following articles were found in the search of literature to study, examine, and discuss the need of palliative care in people with chronic conditions.

An article by Beernaert et al. (2016), a qualitative semi-structured interview, explored how seriously ill patients along with people in earlier phases of disease would benefit from early palliative care. The study took place in Belgium and included a sample size of 18 patients, six with cancer, six with dementia, three with Chronic Obstructive Pulmonary Disease (COPD), and another three with heart failure (Beernaert et al., 2016). Researchers found that patients, regardless of the diagnoses or stage of illness, reported symptoms such as pain, breathlessness, dry mouth, and cognitive impairment throughout the course of their illness and would also report difficulties with activities of daily living (Beernaert et al., 2016). Beyond physical symptoms, the patients reported increased psychological symptoms such as anxiety, distress, and depression as well as feelings of loneliness and decreased social interaction (Beernaert et al., 2016). The findings of this research suggest that no matter of the diagnosis or stage, patients experience symptoms that decrease their quality of life. Limitations of the study include that it was conducted using patients from another country’s model of healthcare and potential bias may have occurred because patients, particularly those with dementia, had difficulty remembering their earlier disease state (Beernaert et al., 2016).

The second article, by Koczywas et al., is a descriptive longitudinal study examining how symptoms, distress, and QOL data informed the development of an interdisciplinary, tailored palliative care intervention with patients with metastatic non-small cell lung cancer (2013). One hundred fourteen adult patients with stage IV non-small cell lung cancer, at least one month from diagnosis with no other cancer diagnosis within the past five years, were selected from a Medical Oncology Adult Ambulatory Care Unit in an National Cancer Institute (NCI)-designated
comprehensive cancer center (Koczywas et al., 2013). Patients were enrolled in usual care and had to self-report using Instrumental Activities of Daily Living Scale, The Blessed Orientation-Memory-Concentration Test, and the timed “Up and Go” test for physical mobility. In addition, researchers used the Medical Outcomes Study Social Activity Limitation Scale, The Medical Outcomes Study Social Support Survey: Emotional Information and Tangible subscales. Patients filled out these scales at 6 weeks, 12 weeks, and 24 weeks. Researchers found that when enrolled in usual care, “one third of patients had impaired physical mobility and 51% had at least one deficit in Instrumental Activities of Daily Living” (Koczywas et al., 2013, p.740). Physical symptoms such as pain, lack of appetite, shortness of breath, dry skin, lack of energy, and difficulty sleeping, had significant changes over time with the best time being 12 weeks (p=0.003) and the significantly worst physical symptoms at 24 weeks (Koczywas et al., 2013). As a result of the physical symptom, patients’ physical quality of life scores significantly decreased (p=0.036) between six and 24 weeks (Koczywas et al., 2013). Limitations for the study include that it was performed in one site and a portion of the data was self-reported which can create a bias.

The next article by Jorgenson, Sidebottom, Richards, and Kirven (2016), a qualitative study retrospective chart review, was aimed at describing the action of primary care providers for patients with heart failure in the intervention groups receiving palliative care of a larger randomized control trial (RCT) as well as examine actions for the subset of intervention patients with higher burden symptom. One hundred one patient charts from the intervention group of a larger RCT were reviewed from Abbot Northwestern Hospital in Minneapolis, Minnesota to examine the provider action and content of the inpatient palliative care consults and follow up visits (Jorgenson, Sidebottom, Richards, and Kirven, 2016). One third of the patients reported
having pain greater than a five on a scale from zero to ten, and 31 of the patients scored greater
or equal to a ten on the depression screening tool PHQ-9, and 1/3 of the patients had anxiety
scores greater than  or equal to five on the Edmonton Symptom Assessment System (ESAS)
(Jorgenson, Sidebottom, Richards, and Kirven, 2016). Limitations of this study include that
information in the study was gathered through documentation in the patients’ charts, which could
be have missing information. In addition, researchers did not know the stage of heart failure for
the charts being analyzed.

The fourth article, by Lofgren et al. (2015), is a qualitative survey of 15 patients with
HIV and all providers in Grady Memorial Hospital in Atlanta, Georgia (Lofgren et al., 2015).
Patients with a CD4-t cell count of less than 200 and either a known HIV diagnosis with fewer
than one follow up a year or a diagnosis of HIV within the last six months were surveyed with
the purpose of assessing the symptom burden and desired services of the patients versus the
perception of the healthcare providers (Lofgren et al., 2015). Patients were surveyed by a
researcher, while their physicians were provided the same survey to self administer (Lofgren et
al., 2015). Hospital physicians reported symptoms at a higher rate than the patients with
statistically significant symptoms being fatigue(p=0.04), sadness(p=.00), anxiety(p=.00), sexual
dysfunction(p=.00), and body image issues(p=.01), however pain was reported at an equal rate
for both physicians and patients (91% and 90%) (Lofgren at al., 2015). Patients rated needed
services higher than physicians with statistically significant differences being medical
care(p=.017), pharmacy(p=.001), social work(p=.003), physical therapy(p=.031), and
housing(p=.002) (Lofgren et al., 2015). Limitations for this study include that the study had a
rate of attrition greater than 20 percent, 15 subjects were recruited but ten completed the survey.
It was a single site study, and while all patients surveyed had low CD4+ counts, only 80% of the providers surveyed had treated patients with CD4 counts below 200 (Lofgren et al., 2015).

The next article, by Meffert, Hatami, Xander, and Becker (2015), is an epidemiological study aimed at identifying the percent of hospital patients with palliative care needs, in particular those with COPD (2015). The research was conducted and included any patient that was discharged or transferred within the hospital between January 2005 and May 2005; a total of 100,679 records were identified (Meffert, Matami, Xander, and Becker, 2015). Patients were electronically sampled and their attending physicians were sent a mandatory questionnaire to determine if that patient had palliative care needs (Meffert, Matami, Xander, and Becker, 2015). Researchers found that 1,455 of the patients admitted to the hospital had COPD and of those patients, 9.1% were considered by their physicians to have palliative care needs. Furthermore, those patients with palliative care needs had significantly longer hospital stays (13.7 days vs 10.3 days) (Meffert, Matami, Xander, and Becker, 2015). Limitations of the study include that the study was based on admissions, meaning that if a person were to have been admitted twice during the study period than that person would be counted as two points in the research. Lung function data was not provided to the researchers so there was no way to distinguish between early and late stage patients (Meffert, Matami, Xander, and Becker, 2015). Finally, the research took place in a foreign country with a different healthcare system.

The next article by Moens, Higginson, and Harding (2014), is a systematic review with the aim of describing and comparing the prevalence of seventeen palliative care problems across the four palliative care domains (Moens, Higginson, and Harding, 2014). The articles selected for this review were both quantitative and qualitative with a sample of adult patients with any of the following diagnoses: cancer, COPD, Acquired immunodeficiency syndrome (AIDS), end
stage renal disease (ESRD), chronic heart failure, Multiple Sclerosis (MS), Parkinson’s disease, Motor Neuron Disease, or dementia (Moens, Higginson, and Harding, 2015). The search focused on symptoms in the four domains of palliative care, including the various ways to phrase palliative care, and any disease that could require palliative care. Pain, anorexia, fatigue, dyspnea, and anxiety were reported with greater than 50% prevalence across several if not all disease processes (Moens, Higginson, and Harding, 2015). Limitations for this article include that each disease has its own specific symptoms that were not included in this study in order to get the most general problems across all disease processes.

An article by Simms, Higginson, and Harding (2011) is a systematic review of 27 original studies as well as seven secondary analysis of patient’s records. The aim of the study was to identify and appraise the evidence of palliative care related problems at the time of HIV diagnosis. The search terms “pain”, “symptoms”, “worry”, “well-being”, “support”, “peace”, “information” and “HIV”; 34 articles were selected for inclusion in the study (Simms, Higginson, and Harding, 2011). Researchers found that physical and psychological symptoms were highly prevalent amongst patients; pain(11-77%), weight loss(8-89%), fever(32-89%), diarrhea(6-54%), anxiety(36-95%), and depression(18-74%) (Simms, Higginson, and Harding, 2015). At diagnosis, patients experienced impaired well-being, frequent suicidal thoughts, and reduced peace and calmness (Simms, Higginson, and Harding, 2015). Limitations for this study include the epidemiological, social, and cultural environment were not considered in the review and some of the articles included in the review did not specify when the data was collected in relation to HIV diagnosis (Simms, Higginson, and Harding, 2015).

Effects of Palliative Care
The first article that will be discussed focuses on the effect of palliative care by Bekelman et al. (2014). The researchers conducted a prospective clinical trial with quantitative and qualitative methods pilot trial, for the purpose of determining the feasibility of Collaborative Care to Alleviate Symptoms and Adjust to Illness (CASA). The CASA was designed to improve symptoms and QOL by integrating palliative care and psychosocial care into chronic care, and identify necessary improvements (Bekelman et al., 2014). The pilot trial took place in outpatient clinics and inpatient medical units at the Denver VA Medical Center; 77 patients were approached to take place in the trial and 30 consented and passed the screening process (Bekelman et al., 2014). Patients were then randomized into the control or intervention, CASA, group. The CASA group included symptom management, psychosocial care, and collaborative while the control group was usual care (Bekelman et al., 2014). A completion rate of 94% informed the researchers that it was feasible to implement the CASA intervention and all but two patients reported positive experiences with CASA intervention (Bekelman et al., 2014). Patients also reported being happy with the format of the intervention which involved nurse phone calls, phone counseling, and weekly team meetings with palliative care specialists, cardiologists, and primary care providers to address the patients’ symptoms (Bekelman et al., 2014). Limitation include that changes in patterns and levels of symptoms would cause a change in the treatment regimen.

The next article by Ferrel et al. (2015), a perspective quasi-experimental designed study in outpatient thoracic surgery and medical oncology clinics, aimed to test the effect of interdisciplinary palliative care intervention in stage I-IV non-small cell lung cancer (2015). Five hundred forty-four patients with non-small cell lung cancer were enrolled in the clinical trial and were separated into the control, which receives usual care, and the intervention group, which
receives interdisciplinary care meetings, referrals, and four educational sessions (Ferrel et al., 2015). Ferrel et al. found the patients receiving the intervention had significantly higher scores for QOL symptoms including spiritual well-being on the Functional Assessment of Cancer Therapy-Lung (FACT-L) (p < .001), physical well-being (p < .001), emotional well-being (p < .001), functional well-being (p < .001), FACIT-Sp-12 (p = .001), meaning (p < .001), and psychological distress (p < .001) with benefits being seen primarily in those in the middle stage to late stages of disease (Ferrel et al., 2015). Limitations include the use of sequential designs which can create a bias as treatment or practice can change over time and the trial took place in one site.

The third article, by Kavalieratos et al., is a systematic review and meta-analysis of randomized controlled trials. Researchers included 43 RCTs of palliative care interventions in adults with life limiting illness (2016). Researchers examined 15 trials evaluating the QOL and found that “palliative care was associated with statistically significant and clinically meaningful improvement in QOL at one to three months”, “palliative care was associated with statistically and clinically significant reduction with symptom burden” (Kavalieratos et al., 2016, p.2107-2108). Of the five low risk trials that studied mood as opposed to physical symptoms, four found that palliative care was statistically significantly associated with improved mood (Kavalieratos et al., 2016). Limitations include that several trials found could not be included in the study because of gaps in the reported data, they were quasi-experimental in design, and trial duration and attrition rate were excluded from the review. In addition, the researchers did not distinguish between early palliative care and end of life care.

An article by Siousa et al., a systematic review of qualitative literature, aimed to identify empirically evaluated models of palliative care in cancer and chronic disease in Europe and
included 14 articles based on seven different models (2016). Articles that met specific inclusion criteria were then scored using the Hawker quality assessment tool and only those that scored above a 60% were included (Siouta et al., 2016). All of the studies included by the researchers focus on symptom treatment. In particular, the objective of these interventions was to improve physical symptoms such as difficulty breathing, pain, and gastrointestinal symptoms such as nausea and vomiting as well as diarrhea, emotional symptoms, including agitation, confusion, fear, and confusion (Siouta et al., 2016, p. 5). All but one study reviewed showed that a palliative care model produced better symptom control, QOL, communication, and more cost effective care (Siouta et al., 2016). Limitations include that the researchers focused on a broad topic that led to heterogeneous data that could only be used qualitatively.

The final article by Sun et al., a prospective sequential quasi-experimental design, aimed to describe spiritual well-being outcomes in a National Cancer Institution-supported Program Project, tested the effectiveness of an interdisciplinary palliative care intervention in lung cancer patient and their family caregivers (Sun et al., 2012). The study included 475 patients diagnosed with Stage I-IV non-small cell lung cancer and 345 family care givers from an NCI-designated comprehensive cancer center located in Southern California were enrolled either the control or intervention group (Sun et al., 2012). Those in the intervention group received a baseline QOL assessment and the results were used to create a palliative care plan suited to their specific needs (Sun et al., 2012). The intervention group then participated in weekly care meeting with every member of the care team and recommendations were made based on the meetings and included four educational session based on patient selected topics. Following intervention, patients rated their spiritual well-being using the FACIT-sp for patients and COH-QOL for the family care givers. Sun et al. found that patient and family members with no religious affiliation reported an
increased sense of harmony with oneself and patients with religious affiliations reported better outcomes on the faith subscale and found comfort and strength in their faith (2012). The intervention group scored significantly better for the Meaning/Peace subscale of FACIT (Sun et al., 2012). Limitations for this study include that it was a single site trial whereby spiritual care may vary depending on the site. Two different scales were used for patients and caregivers which made it difficult to compare the data.

**Palliative Care and Caregivers**

Several articles discussed the effects of palliative care on the caregivers of those with chronic illness. These include the articles by Kavalieratos, et al. (2016) and Sun et al. (2012) which have been discussed previously.

An article by Carson et al., a multicenter randomized clinical trial, included 365 caregivers of adult patients from four ICUs across the country were recruited and randomly assigned to either the palliative run meeting intervention group or the control group with which included ICU run meeting. Family caregivers’ anxiety and depression scored were rated on using the Hospital Anxiety and Depression Score (Carson et al., 2016). Carson et al. found no significant differences between the scores of the participants in the intervention or control group (2016). Limitation to this researchers include, according to the researchers, interventions may not have been enough to overcome the high levels of stress that the families were experiencing and instead of alleviating fears early meeting may have actually exacerbated them. In addition, blinding was not possible given the nature of the study.

**Synthesis**

**Indication of Need**
After reviewing and evaluating the literature, patients with various chronic illness have high symptom burdens resulting in a decreased quality of life; which indicates a need for palliative care (Beernaert et al., 2016, Koczymas et al., 2013, Jorgenson, Sidebottom, Richards, and Kirven, 2016, Lofgren et al., 2015, Meffert, Hatami, Xander, and Becker, 2015, Moens, Higginson, and Harding, 2014, and Simms, Higginson, and Harding, 2011). Moens, Higginson, and Harding (2014), a systematic review of multiple chronic diseases provides the strongest evidence for this claim. Researchers found that fatigue, anorexia, pain, dyspnea, and insomnia was reported with 50% prevalence in many diseases including cancer, AIDS, heart failure, end stage renal disease and COPD. These are significant and important findings because it demonstrates that patients with all different diseases suffer from similar symptoms. The remaining studies corroborate the findings of Moens, Higginson, and Harding (2014) but are either of a lesser level of evidence or focused on the symptoms of only one condition.

Simms, Higginson, and Harding (2011), another systematic review but focused on patients with HIV, reported that patients experience many distressing symptom such as pain, tiredness, weight-loss, fever, and skin problems. Pain is the only symptom that was found in both studies and therefore significant. The other symptoms reported are more specific to an HIV diagnosis but no less burdensome to the patient. Reported in Simms, Higginson, and Harding (2011) but not discussed previously is the psychological symptom burden, including impaired spiritual and psychological well-being as well as anxiety and suicidal ideation. Lofgren et al. (2015) also studied of HIV patients but is a lower level of evidence. However, these findings both corroborate with previous findings but are significant in that they highlight the discrepancy between the providers and the patients, although they do share some commonalities. Physicians rated symptoms: fatigue, sadness, anxiety, sexual dysfunction, and body image issues higher that
the patients with pain being the only symptom that patients and physicians rated evenly. However, physicians rated needed services much lower than patients. Research demonstrates that patients have needs beyond symptoms, though symptoms management is still prevalent and important albeit patients tend to under report their symptoms, that are not being met or readily recognized by their physicians and indicate the need for additional services of palliative care. Again pain is one of the most significant symptoms reported in all studies.

Beernaert et al. (2016), studied patients with various chronic diseases through the use of an interview which provides that patients the opportunity to be specific with the answers. Researchers found that patients had physical symptoms such as pain, breathlessness, dry mouth, and cognitive impairment and as a result of symptoms, patients struggle with day to day tasks resulting in a decrease in quality of life. Again, pain is the main symptom that has been present in all studies so far but this is the second time a respiratory symptom has been reported. In addition, all patients experienced an increase in psychological symptoms, similar to Simms, Higginson, and Harding as well as Lofgren et al.

Koczywas et al. (2013), a prospective longitudinal study conducted on cancer patients only, focused on the patients’ activities of daily living as well as their symptoms. Patients not receiving palliative care experienced a decline in physical well-being and had an increase in symptom scores. Again, this article demonstrates that the symptoms experienced by those with a chronic disease are severe enough that they negatively impact the patients’ lives and that the symptoms will become progressively worse without intervention.

Another prospective study by Meffet, Hatami, Xander, and Becker (2015), focused on patients with COPD. Researchers found that of the 14,055 of the COPD patients admitted into the hospital, 9.1% had palliative care needs. While these results may not seem significant this
was one hospital, in a relatively short time frame with only one disease of focus. These numbers would almost certainly be inflated if the inclusion criteria of the patient was expanded.

The final article, by Jorgenson, Sidebottom, Richards, and Kirven (2016), conducted a retrospective chart review on patients with heart failure to assess frequently reported symptoms. The most frequently reported were tiredness, shortness of breath, and drowsiness with pain and anxiety being reported in one third of all patients. Again these are symptoms that have been reported in patients with cancer, COPD, HIV, and are now being found in patients with heart failure.

Pain, respiratory related symptoms, and psychological symptoms are reported in all studies that focused on symptoms no matter the diagnosis. These are by no means the only symptoms experienced by those with chronic illness; many other symptoms were reported in individual studies based on the diagnosis but were not found across multiple diseases. These symptoms are no less significant than symptom like pain and dyspnea because they further add on to the patients’ symptom burden. An increase in symptom has been shown to decrease the patients’ quality of life and decrease their ability to perform activities of daily living. These findings support that patients, no matter the diagnosis, could benefit from palliative care to ease their symptom burden.

**Effects of palliative care**

Patients with chronic diseases experience a better quality of life when they receive palliative care (Bekelman et al., 2014, Ferrel et al., 2015, Kavalieratos et al., 2016, Lester et al. 2017, and Siouta et al., 2016).

The first article, by Kavalieratos et al. (2016) is a systematic review, with the aim of determining the association between palliative care and quality of life for people with life
limiting illness. The researchers examined 15 trials focused on QOL and palliative care was associated with statistically significant increases in QOL. In addition, palliative care relieved the patients’ symptom burdens. Twenty three trials found that palliative care significantly improved patient mood. Another systematic review completed by Siouta et al. (2016), but of qualitative studies and therefore a lower level study, also examined the effects of palliative care on chronic illness and cancer. Unlike the previously mentioned studies, this study is based in Europe and focused on symptom treatment, especially physical symptoms such as dyspnea, diarrhea, constipation, pain, and nausea as well as emotional symptoms such as agitation, confusion, fear, and delirium. All but one of the included studies found that palliative care produced better symptom control and increased QOL. These findings again corroborate with the previously studies which further supports that palliative care is effective in patients with different conditions.

A quasi-experimental study by Ferrel et al. (2015) sought to test the effect of concurrent palliative care intervention in patients with non-small cell lung cancer. The patients receiving palliative care had higher scores for QOL, symptoms, and spiritual well-being. These are important findings because they further demonstrate that palliative care improves symptoms and improve QOL.

A prospective clinical trial conducted by Bekelmen et al. (2014) both supports and adds to these findings because the study was focused on patients with heart failure. The purpose was to determine the feasibility and acceptability of CASA, designed to improve symptoms and quality of life. What the researchers discovered was that it was feasible to implement such care. All but two of the patients reported that they were happy with CASA. While Bekelmen et al. (2014) does not delve into symptoms, it does demonstrate that it is worthwhile to incorporate
palliative care into chronic care and that patients are happy with their outcomes utilizing palliative care.

Another prospective quasi-experimental study, by Sun et al. (2012) included both patients with cancer and their family caregivers. Patients receiving palliative care intervention reported better spirituality outcomes, no matter the religious affiliation, which has an impact on a patients QOL. Sun et al. (2012) is significant because it focuses on spirituality, a factor not studied any of the previously mentioned studies. These findings are important because QOL is not only based on physical symptoms and it is important that palliative care addresses, and as demonstrated improves, the spiritual aspects of QOL.

What these finding suggest is that palliative care, no matter the model or the disease that it is trying to combat, improves that patients QOL by improving physical, psychological, and spiritual symptoms. However, only a few are based off of RCTs so more RCTs are needed further support these findings. Despite this evidence it is still difficult to get palliative care for residents in nursing homes, arguably those with the greatest need, which may indicate why palliative care is not utilized despite the many benefits.

**Palliative Care and Caregivers**

The final article that will be discussed is a randomized controlled trial of family caregivers conducted by Carson et al. (2016). The aim of the study was to determine whether palliative care led informational and support meetings improved family anxiety and depression. The researchers found that there was no significant difference between the scores of the control and experimental group however, the researchers do propose that the palliative care meetings may have magnified existing fears of the family instead of relieving them. While these results do not to support palliative care meetings for the family it is important to recognize that the
family experiences their own unique but no less significant burdens and other previously mentioned studies do indicate that palliative care positively impacts caregivers. However, Carson et al. (2016) was the only study that focused on the caregiver and not the patients. Which indicates that there is a need for additional research conducted on the family in order to definitively know how palliative care affects their quality of life.

**Summary**

Patients with chronic illness have high symptom burden no matter their diagnosis. A patient with COPD, another with heart failure, and a third patient with cancer may all experience pain, depression, and dyspnea, as well as more diagnosis specific symptoms, which can negatively impact their quality of life. In addition, a high symptom burden is not solely associated with late stage chronic condition, researcher shows that symptoms are often present at diagnosis. Palliative care has been shown to decrease symptom burden and increase the patients’ quality of life. In some cases, research has shown that palliative care has improved well-being in the family care giver of the person with the chronic condition but more research is needed to know definitively. It is the purpose of this project to educate patients that they are not alone in their symptom burdens even if they do not have diagnosis that is readily associated with palliative care; it does not mean that their symptoms are less significant.

**Project Design**

Patients with chronic condition experience symptom burden that negatively impacts their lives but often minimize their symptoms and feel reluctant to seek treatment because they do not want to be a burden on their providers or family. Patients often conflate palliative care with hospice care and therefore do not seek treatment because they do not feel they are at the end of their life. It is the purpose of this project to develop an educational pamphlet to help patients
understand that palliative care is a valid option to manage their symptoms and increase the quality of their lives regardless of their diagnosis.

After the development and approval of the educational material, it will be distributed around medical offices around the Dayton area due to its abundance of high traffic hospitals. The population for this project is adults with chronic condition, especially cancer, COPD, and heart failure as those conditions were most frequently studied. Furthermore, the information found in this research will also be used to educate nursing student to displace any pre-existing misconceptions about palliative care and educate that on the benefits so that they will be able to better advocate for their patients with chronic conditions throughout their careers.

**Project Implementation**

An educational pamphlet will be created and distributed in the community and a post conference PowerPoint will be created to supplement the pamphlet and will be presented to medical surgical nursing students. The presentation for nursing students will include a pre presentation survey to determine the students’ preconceived ideas about palliative care and then a post survey to measures the students change in perception. The students will also report if they will advocate for palliative care for their patients in their future careers. The presentation and pamphlet will be distributed to all new nurse residents at a local healthcare organization.

**Definition of Terms**

Palliative Care—“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering of means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” (Eti, 2011, p.161)
Hospice Care- care for people at the end of life and is provided by a team of healthcare professionals who maximize comfort for a person who is terminally ill by reducing pain and addressing physical, psychological, social, and spiritual needs (Mayo Clinic, 2016, par 2)

Quality of Life- a broad concept that usually includes subjective evaluations of both positive and negative aspects of life (Centers for Disease Control and Prevention, 2016, par 2)

Chronic Disease-although the literature does not support a single uniform definition for chronic disease, recurrent themes include the non–self-limited nature, the association with persistent and recurring health problems, and a duration measured in months and years, not days and weeks (National Center for Chronic Disease Prevention and Health Promotion, 2013, par 1).

Ethical/Legal

The ethical issues involved in this study is that the personal information attached to the responses from the students. Responses will remain anonymous in order to protect the students.

Evaluation

To evaluate this project, the responses of the student will be examined before and after the presentation. The number of students with negative, positive, or no knowledge of palliative care will be documented and then the post-conference opinions of palliative care will be documented. Pre and post presentation values will be evaluated and the project will be successful if the students have a positive change in opinion palliative care and would advocate for palliative in their future careers. There is no way to evaluate the patients that pick up the educational pamphlet without potentially collecting private personal information.

Summary

The purpose of this project is to focus on nursing students’ preconceived ideas of palliative care of nursing students. Educational material will be provided and the students will
be asked to discuss their opinion on palliative given the new information. The same information will be distributed to the public. Results will be based on the change in opinion of the students from negative or indifferent to positive. A positive and opinion and if they would advocate for palliative care for their patients.

**Analysis of Project**

The information from the introduction, clinical importance, review of literature and the synthesis were incorporated into a PowerPoint to be presented to a group of nursing in their medical surgical rotation. The presentation occurred on November 7, 2017 to a group of 9 students and their clinical instructor. The presentation took approximately 30 minutes and the students were required to complete a pre and post presentation survey. The survey that consisted of 5 statements: I think that I have an understanding of palliative care, Hospice and palliative care are interchangeable terms for the same care, People with chronic conditions can benefit from palliative care, Only in the late stages of disease do patients experience burdensome symptoms, and I would encourage all of my patients with chronic diseases to consider palliative care. Students had to rate these statements on a scale of one to five with one being strongly disagree and five being strongly agree.

A handout that summarized all of the above information was created with the purpose of being distributed in physician offices for the education of patients. However, that did not end up coming to pass as physicians either were not responsive to communicating on the topic or were uninterested in having such material in their practice. Instead, that handout was supplied to the clinical instructor of the group of students that received the presentation. The clinical instructor was able to post that handout to the students’ Pilot page for them to look over and use as they felt
necessary. The newest dissemination of material will be to all new nurse residents during their orientation at a local healthcare organization.

**Pre-presentation Responses**

In response to the first statement: I have an understanding of palliative care, one student mildly disagreed, another two were neutral on the statement, and six mildly agreed. The second statement: Hospice and palliative care are interchangeable terms for the same care; three students strongly disagreed, three mildly disagreed, one was neutral, one mildly agreed, and one strongly agreed. Three people mildly agreed, and six strongly agreed with the statement people with chronic conditions can benefit from palliative care. Five students strongly disagreed, four mildly disagreed with the statement: only in the late stages of disease do patients experience burdensome symptoms. Two students were neutral, four mildly agreed, and three strongly agreed with the statement: I would encourage all of my patients with chronic diseases to consider palliative care.

**Post-Presentation Responses**

After the thirty minute presentation and discussion the students were asked to take the same survey and the results are as follows. All nine students strongly agreed with the statement, I think I have an understanding of palliative care. All nine student strongly disagreed with the statement that hospice and palliative care are the same thing. All nine strongly agreed that patients with chronic conditions can benefit from palliative care. The students unanimously strongly disagreed that only patients in the late stage of disease could benefit from palliative care. Finally, the nine students strongly agreed that that would encourage their patients with chronic diseases to consider palliative care.

**Summary**
Being that the students that were presented were in their second year of nursing school does mean that they already had more knowledge about palliative care and have already had some preconceived notions dismissed. As shown by the majority of students already agreeing or disagreeing, whichever was appropriate, with points that were going to be made in the presentation. However, most students did not have particularly strong option on the matter as evidenced by many answers of neutral and mildly agreeing and mildly disagreeing. Once the presentation was completed each student had much more strongly held opinions on the topic of palliative care and how it related to their patients with chronic diseases. This is significant because as these students become professionals they will take these opinions into their chosen fields. Some of them may work in areas where palliative care is already common, such as oncology and long term care, but some may go on to work in areas like ICUs or step down units where the focus is more on getting the patient better no matter what. They will be able to advocate for their patient’s quality of life in a setting that often values quantity of life over quality of life.

**Conclusion**

Unfortunately, palliative care is a poorly understood and underutilized specialty in the current healthcare world. Most patients equate palliative care with the end of life and therefore reject palliative care because they do not think they are at the end of their life. Many providers fear that if they suggest palliative care to their patients that the patients well interpret it as the provider saying to give up hope of treatment. Of course, none of this is true as the purpose of palliative care is to improve patients physical, spiritual, emotional, and mental well being all while continuing to pursue treatments. Palliative care exists to ensure that the patient is living their best quality of life. Patients with chronic conditions, no matter the diagnosis or stage, can
benefit from palliative care to relieve some of their symptom burden. Palliative care can also relieve some of the burdens of the caregiver, via taking care of the patient. However, very little research has been done specifically on how palliative care affects the family of a patient which indicates that further research needs to be done on this topic. Patients of course do not exist in a vacuum so it is important to consider those that are around them.

In the future, this project could be used for nursing students to educate them on palliative care and be an advocate for their patients, and not fail to suggest palliative care to a patient that could benefit from it. One of the roles of a nurse is to advocate for patients, and by being well informed on this topic, nurses can advocate that their patients can have a better quality while still receiving treatment. Of course, further research should be done to add on to the findings included in this paper to further solidify the point that palliative is a viable option for patients with chronic disease and that disease other than cancer have burdensome symptoms.
References


### Appendix A

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<tr>
<th>Article Citation</th>
<th>Purpose of Study</th>
<th>Setting</th>
<th>Sample</th>
<th>Designs</th>
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<tr>
<td>Beernae rt, K., et al., 2016</td>
<td>To explore how seriously ill patients and people in an earlier phase of disease would benefit from early palliative care.</td>
<td>Belgium, all interviews were conducted in the patients homes.</td>
<td>18 patients agreed to be interviewed. 6 had cancer, 6 had dementia, 3 had COPD, and 3 had heart failure.</td>
<td>Qualitative semi-structured interview</td>
<td>The researchers conducted the interviews in the patients’ homes and began the discussion with general questions about the person illness and then progressed to a more detailed section including care needs, care, and treatment. The interviews lasted between 4 minutes and 2 hours.</td>
<td>All patients, even those in the early stage of their disease, stated that physical symptoms such as pain, breathlessness, dry mouth, and cognitive impairment occurred throughout their illness and some even increased. As a result of their symptoms many experienced difficulty performing daily tasks. All of the patients stated increased psychological symptoms such as distress, anxiety, or depression. All patients experienced decreased social contact and feelings of loneliness. Patients also discussed miscommunications with their doctors, fears and concerns of what their eventual death will do to their family, and some cited financial difficulties.</td>
<td>The study had a small sample size and was conducted on patients in another country. Potential bias may have resulted for the patients’ inability to remember their earlier disease state correctly. No of the patients were selected as having either positive or negative experiences with their healthcare. Also the word “palliative care” was never used during the interview.</td>
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<td>Bekelme, D.B, et al., 2014</td>
<td>To determine the feasibility and acceptability of CASA (Collaborative Care to Alleviate Symptoms and Adjust to Illness), which was designed to improve symptoms and QOL by integrating palliative care and psychosocial care into chronic care, and identify necessary improvements</td>
<td>Outpatient clinics and inpatient medical units at the Denver VA Medical Center</td>
<td>30 patient with Heart Failure</td>
<td>Prospective clinical trial with quantitative and qualitative methods pilot trial</td>
<td>Of the 77 patients that were approached 30 patients consented and passed the screening. They were randomized into either the control or the CASA group. The CASA intervention included symptom management, psychosocial care, and collaborative care.</td>
<td>Based on a 94% completion rate, the researchers found that it was feasible to implement the CASA intervention. All but two patients reported positive experiences with CASA intervention. The also reported be happy with the format of the intervention which involved nurse phone visits, phone counseling, and weekly team meetings with palliative care specialists, cardiologists, and primary care providers to address the patients’ symptoms.</td>
<td>Changes in patterns and levels of symptoms would cause a change in the protocol to accommodate the variability.</td>
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<td>Carson, S. et al., 2016</td>
<td>To determine whether family information and educational support meetings led by palliative care physicians improve family anxiety and depression</td>
<td>4 different ICUs across the country from October 2010 to November 2014</td>
<td>Adult patient that required 7 days of mechanical ventilation</td>
<td>Multicenter randomized clinical trial</td>
<td>The surrogate decision makers of the hospitalized patients were randomly assigned to either the palliative run meeting or the control ICU run meeting and their scores of anxiety and depression were rated on using the Hospital Anxiety and Depression score.</td>
<td>There was not significant difference between the scores of the participants in the intervention or the control group.</td>
<td>According to the researchers the interventions may not have been enough to overcome the high levels of stress that the families were experiencing and the early meetings meant to alleviate fears may have actually exacerbated them. Limitations also include the inability to blind the participants.</td>
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<td>Ferrel, B., et al., 2015</td>
<td>The purpose of the study, according to the researcher, was to test the effect of a concurrent interdisciplinary palliative care intervention in stage I-IV non-small cell lung cancer</td>
<td>Outpatient thoracic surgery and medical oncology clinics</td>
<td>544 patients with non-small cell lung cancer</td>
<td>Perspective quasi experimental design</td>
<td>The patients were enrolled in the trial with the control group receiving usual care the intervention group receiving interdisciplinary care meeting, referrals, and, 4 educational sessions</td>
<td>Patients receiving the intervention had significantly higher scores for QOL, symptoms, spiritual well-being with benefits being seen primarily in those in the early stage of disease</td>
<td>Limitations include the use of sequential designs which can create a bias if treatment or practice changes over time. In addition, this trial only took place in one site.</td>
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<td>Kavalieratos, D., et al., 2016</td>
<td>To determine the association of palliative care and quality of life, symptom burden, survival, and other outcomes for people</td>
<td>Randomized clinical trial of palliative care interventions in adults with life limiting illness</td>
<td>Systematic review and meta-analysis of RCT</td>
<td>Two reviewers using EMBLINE, EMBASE, CINAHL, and the Cochrane CENTRAL</td>
<td>Fifteen trials evaluating QOL at 1-3 months palliative care was associated with significantly significant and clinically meaningful in QOL, palliative care was found to reduce symptom burden at 1-3 months, mixed review of 23 trials of mood- 7 trials are reported an improvement of mood with palliative care</td>
<td>Several trials could not be used because there were missing gaps in data, quasi-experimental studies were excluded, trial duration and attrition rate were excluded, review did not</td>
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<td>Koczyw as, M. et al., 2013</td>
<td>To describe how symptoms, distress, and Quality of Life data informed the development of an interdisciplinary, tailored palliative care intervention for patients with metastatic non—small-cell lung cancer (NSCLC)</td>
<td>Medical Oncology Adult Ambulatory Care Unit at an NCI-designated comprehensive cancer center</td>
<td>Patients 18 and older diagnosed with Stage IV non-small cell lung cancer at least one month from diagnosis with no other cancer diagnosis within the last five years</td>
<td>Prospective longitudinal study-descriptive</td>
<td>Patients were enrolled in the usual care and had to self-report using the Instrumental Activities of Daily Living Scale, The Blessed Orientation-Memory-Concentration Test, and the Timed &quot;Up and Go&quot; test for physical mobility. Also used was the Medical Outcomes Study Social Activity Limitations Scale, and The Medical Outcomes Study Social Support Survey: Emotional/Information and Tangible Subscales. All these scales were done at weeks 6, 12, and 24.</td>
<td>When enrolled in usual care, patients experienced a decline in physical well-being, activities of daily living and cognitive scores. They also had an increase in total symptom scores.</td>
<td>The study was performed in on site and portion of the data collected was self-reported.</td>
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<td>Jorgenson, A., Sidebottom, A.C., Richards, H., and Kirven, J., 2016</td>
<td>To describe the actions of PC providers for patients with heart failure in the intervention groups receiving palliative care and to examine actions for the subset of intervention patients with higher symptom burden</td>
<td>Abbott Northwestern Hospital, Minneapolis, Minnesota</td>
<td>101 patient charts with heart failure</td>
<td>Retrospective chart review</td>
<td>A retrospective chart review was used to examine the provider actions and content of the inpatient PC consults and follow up visits. Only the intervention group of a larger RCT was used.</td>
<td>The most frequently reported symptoms were tiredness, shortness of breath, drowsiness. Pain and anxiety was reported in one third of the patients and one third had moderate to high depression scores. 79% of the patients received a palliative care consult only and 21% received two or more visits. Providers made one order for 21% of patients with the main cause being pain.</td>
<td>Limitations include the fact that information was limited to documentation. The stages of heart failure were not made available</td>
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<td>Lofgren, S et al., 2015</td>
<td>To assess symptom burden and desired services of the patient and compare to the perceptions</td>
<td>Grady Memorial Hospital, Atlanta Georgia</td>
<td>Sample of 15 patients began the study with 10 completing the study</td>
<td>Survey of patients and healthcare providers</td>
<td>Patients that were deemed eligible were referred to the study by their healthcare team. The patients had to be at least 18 years old with a CD4- t cell count of less than 200 and either a known HIV diagnosis with</td>
<td>The researchers discovered that physicians reported symptoms more often than the patients did. The statistically significant symptoms were fatigue, sadness, anxiety, sexual dysfunction, and body image issues. The physicians had higher</td>
<td>Limitations include a rate of attrition greater than 20%. All of the patients that were surveyed had CD4 counts less than 200</td>
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<p>| of the healthcare provider | fewer than 1 follow up in 1 year or no history of outpatient HIV care, or diagnosis of HIV within the past 6 months. After the patients gave consent they were surveyed by the one of the physicians associated with the study. Additionally doctors within the Grady Hospital System were given the same survey to fill out. | scores on these symptoms than the patients. The only symptoms that patients scores were higher than the physician scores were dizziness, neuropathy, skin problems, and cough. However, services needed were compared it was shown that patients’ needs were far greater than the physicians estimated. That statistically significant differences are medical care, pharmacy, social work, physical therapy, and housing. The patients’ ranked this as being more important than the physicians. | while only 81% of the patients that the physicians treated had CD4 counts had less than 200. |</p>
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<tr>
<td>Meffet, C., Hatami, I, Xander, C., and Becker, G., 2015</td>
<td>To identify the percent of hospital patients with palliative care needs, in particular those with COPD.</td>
<td>University Medical Centre Freiburg, Freiburg Germany</td>
<td>Patients of the UMCF, with particular interest of those with COPD.</td>
<td>Prospective epidemiological study</td>
<td>Any patient that was discharged or transferred in the UMCF ward, electronic data sampling was mandatory by the attending physician. The physicians had to answer whether the patient in question had palliative care needs. 100,679 records were recorded over the course of the study.</td>
<td>1455 patients admitted to the UMCF during the study period had COPD and of those 9.1% were deemed to have palliative care needs by the attending physician. Those patients with palliative care needs had significantly longer stays in the hospital.</td>
<td>This study took place in a foreign country. The absence of lung function data did not allow for discrimination between those with differing severity of COPD. Patients that had multiple stays at the hospital were considered as separate cases.</td>
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<td>Moens, K., Higgins on, I.J., and Harding, R., 2014</td>
<td>To describe and compare the prevalence of seventeen palliative care-related problems across the four palliative care domains</td>
<td>Systematic review</td>
<td>Sample of any studies done on adult patients with either cancer, COPD, AIDS, ESRD, chronic HF, MS, Parkinson’s disease, motor neuron disease, or dementia</td>
<td>The researcher utilized three different databases, Medline, Embase, and PsychInfo. They searched three word word groups using the Boolean phrase OR and then combined them using AND. The first group consisted of symptom in the four domains of palliative care, the second group consisted of the various ways to word palliative care, and the third included diseases that could require palliative care</td>
<td>Most of the articles found focused on cancer and ESRD with very little being found for MS or MND. In addition most studies have tend to study physical and psychological symptoms and not social or spiritual. However, pain, anorexia, fatigue, dyspnea, and anxiety were found in all disease processes studied.</td>
<td>Each diagnosis included has its own highly specific symptoms that were not included in an attempt to get the most general problems across all disease.</td>
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<td>Simms, V.M., Higgins, I.J., and Harding, R., 2011</td>
<td>To identify and appraise the evidence of palliative care-related problems at HIV diagnosis</td>
<td>27 original studies and 7 secondary analysis of patient’s records</td>
<td>Systematic review</td>
<td>The search was completed using OVID Medline, PsycINFO, Embase, and Pubmed. The researchers used the terms pain, symptoms, worry, well-being, support, peace, and information. They conducted their research using the review question “what palliative-care related problems do adults experience at the time of HIV diagnosis?”</td>
<td>Physical and psychological symptoms were found to be highly prevalent (pain, weight loss, fever, diarrhea, anxiety, and depression). At diagnosis the patients experienced impaired well-being, frequent suicidal thoughts, and reduced peace and calmness. Participants also lacked emotional support and feared the reaction of their families.</td>
<td>Epidemiological, social, and cultural environment was not considered in the review. In some articles it was unclear when the data was collected in relation to diagnosis. There was no subgroup comparison.</td>
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<td>Siouta, N, et al., 2016</td>
<td>To identify an empirically evaluated models of PC in cancer and chronic diseases in Europe</td>
<td>14 studies with 7 different models</td>
<td>Qualitative literature systematic review</td>
<td>The search was conducted by two or the research members using the databases CENTRAL, Pubmed, EMBASE, CINAHL, AMED, BNI, Web of Science, and NIH Evidence. The articles that met the criteria were then scored using the Hawker quality assessment tool and only those that scored</td>
<td>All of the studies focused on symptom treatment and more specifically to improve physical symptoms including dyspnea, diarrhea, constipation, pain, and nausea. Also studied were emotional symptoms such as agitation, confusion, fear, and delirium. Timing of care included end of life care and care concurrent with healthcare. All but one study showed that a</td>
<td>Only six of the included articles were RCT which means that the conclusions drawn by the researchers are technically based on lower quality research. In addition the researchers</td>
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<td>Sun, V. et al., 2012</td>
<td>The aim of the analysis is to describe spiritual well-being outcomes in a National Cancer Institution-supported Program Project that tested the effectiveness of an inter disciplinary palliative care intervention in lung cancer</td>
<td>A NCI-designated comprehensive cancer center located in Southern California</td>
<td>475 patients diagnosed with Stage I-IV non-small cell lung cancer and 354 family caregivers</td>
<td>Prospective sequential quasi experimental design</td>
<td>Patients and family caregivers were enrolled in either the control group or the intervention. The patients in the intervention group received a baseline QOL assessment for both the patient and FCG with the results used to create a unique palliative care plan. The intervention group then participated in weekly care meeting with every member of the care team and recommendation were made based on the meetings. The final portion of the intervention included</td>
<td>Patient and family caregivers with no religious affiliation reported an increased sense of harmony with oneself. Patients with religious affiliations reported better outcomes on the faith subscale and finding comfort and strength in the faith. Generally, the intervention group significantly better for the Meaning/Peace subscale</td>
<td>The study was a single site trial which means that spiritual care may differ very depending on the site. There were two different scales used for the patients and family caregivers which make it difficult to compare the data. A bias may also result from the</td>
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<td>Patient in lung cancer patients and family caregivers.</td>
<td>Four educational session based on patient selected topics. Patients were asked to rate the spiritual well being using FACIT-sp for patients and COH-QOL-FCG.</td>
<td>Prospective sequential design.</td>
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