

Quality of Care for Cancer Patients

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### Abstract

Research has shown that patients treatment plans depend on open and honest communication from their providers regarding their health care. Providers felt that it is important to have early end of life discussions with cancer patients. Some of the barriers to having early end of life discussions with cancer patients were comfort level, lack of training in medical school, and lack of communication skills. Cancer patients felt that there are gaps to receiving quality of care, some of these gaps included comfort level, open and honest communication, and knowledge level of diagnosis. The data collection and analysis has shown that there are barriers to having early end of life discussions. It is hoped that this paper would have the information and data collected for future projects to be developed.

### Early End of Life Discussions for Cancer Patients

Research has shown that when patients know their disease process, treatment, outcomes and prognosis and their wishes for end-of-life care, it prevents unnecessary treatment being provided and promotes quality of care (Isler, 2017). Cancer patients' quality of life depends on social support, spirituality and their health care provider's honest communication (Isler, 2017). Understanding barriers to early discussions, developing tools, and educating health care providers may make them more comfortable having early end-of-life discussions with cancer patients. Early end-of-life discussions may promote quality of care for the patients and their families. It can also decrease health care spending due to less unwanted and unnecessary treatment being provided.

### Overview

#### Background

Cancer is a major public health concern and is the second leading cause of death in the United States. According to the National Center for Health Statistics in 2016, there were 1,685,210 new cancer diagnoses, and 595,690 cancer deaths were projected to occur in 2017 affecting the United States (Siegel, Miller & (Ahmedin, 2016). The International Agency for Research on Cancer estimates that the number of new cancer cases will rise by 75 percent over the next two decades (Carlson, 2016). Between 20 and 50 percent of patients with incurable cancers receive chemotherapy within 30 days of their death which often leads to increased utilization of acute services (Wright, Baohui, Keating, Weeks, & Prigerson, 2014). There are an estimated 1,299 hospital admissions per year due to adverse drug related problems in cancer patients. The incidence of unplanned hospital admissions in 2014 was 12.4 percent among cancer patients;

approximately half of these were preventable events (Chan, Soh, Yuko, Yu-Chu, & Chiang, 2014).

Studies show that 50% of initial end-of-life discussions take place in the hospital rather than in the outpatient setting (Victoria & Patel, 2016). Patients are often under educated on the scope of treatments to which they were consenting, and, therefore, may have unrealistic expectations of treatment. In a study of patients with metastatic cancer, 69 % with lung cancer and 81% with colorectal cancer were unaware that chemotherapy was palliative rather than curative (Victoria & Patel, 2016).

According to the medical expenditure panel survey, 64% of health care spending is concentrated on 10 percent of the population with most of the money spent at the end-of-life. Increases in health care spending may be related to patients not being given the information they need to make informed decisions. By law, health care providers must offer patients with a terminal illness six month or less to live information about palliative care and end-of-life care to make informed decisions (Salima, Rafat, Adnan, Kashmira, & Ambreen 2017). End-of- life discussions often take place much too late during the disease process of terminal illnesses (Salima, Rafat, Adnan, Kashmira, & Ambreen 2017). These are hard topics for family providers to discuss with patients, and many times these conversations are deferred to the oncologist who may give false hope through continued cancer treatment (Salima, Rafat, Adnan, Kashmira, & Ambreen 2017).

Cancer patients must deal with the symptoms and effects of the disease, while dealing with the side effects of treatment. This can negatively affect their quality of life. Counseling and education with the patient and family regarding the disease process, treatment options, prognosis,

the side effects of treatment options and outcomes can decrease emergency room visits and hospital admissions, which in turn can save time and health care costs (Salima, Rafat, Adnan, Kashmira, & Ambreen 2017). Health care professionals need to be aware of cancer patients' physical well-being and their psychosocial emotions as this can predict how well they will progress in the treatment process (Salima, Rafat, Adnan, Kashmira, & Ambreen 2017).

### **Stakeholders**

In this capstone project about cancer patients and quality of care, there were many different stakeholders to consider. The primary stakeholders that were involved included family practitioners, oncologists, cancer patients, their families, palliative care, hospice staff, and community members. Government representatives were beneficial stakeholders in helping to identify the amount of money that is spent on care at the end-of-life regarding cancer patients. Earlier conversations about end-of-life care would potentially benefit stakeholders by decreasing healthcare expenditures through less use of non-beneficial treatments for terminal disease and improved quality of life for the patient. Earlier conversations with the patient on goals of care could potentially impact what they would accept for cancer treatment, and how aggressive care would be at the end-of-life.

Family practitioner perspectives were important to understand. Implementation ideas for this project were based on different experiences that were done with cancer patient, their families, and from the engagement of these stakeholders. This included finding out how end-of-life care was addressed with cancer patients, which identified current trends in cancer care management. It was beneficial to understand what they were comfortable discussing and when they refer their patient to oncology for further conversations. The oncologists were one of the

key stakeholders as this is their specialty. Assessing how oncologists treat and educate patients on the treatment options and side effects, as well as how they diagnosis and communicate with cancer patients was important. Current cancer patients engaged in the project by talking about their experiences. All these stakeholders were valuable in helping to evaluate and improve the design process by experiences and knowledge.

### **Problem Statement**

Cancer patients' quality of life depends on social support, spirituality and their health care provider's honest communication (Isler, 2017). Cancer affects people of all ages, races and genders and the number of patients living with cancer continues to increase. Education and tools for health care providers to feel comfortable with having early end-of-life discussions may improve quality of care and quality of life for cancer patients, may affect treatment choices of cancer patients, as well as decrease health care spending related to unnecessary testing and treatment being provided for terminal cancer patients. Literature shows that there is a gap in early end-of-life conversations, without patients having full information on all treatment options available and goals of care (Isler, 2017). Patients many times do not have enough information to accurately make informed decisions on the best treatment options. Once these gaps are identified through a community assessment, the information will be shared with other health care providers, and further studies and tools can be developed.

The problem to be addressed for this capstone project was "How do early end-of-life discussions with health care providers impact the treatment choices of cancer patients?"

### **Purpose Statement**

The purpose of this project was to understand the barriers through community



assessments to providers and patients having early end-of-life discussions. This was a critical step towards a future project to create and provide an evidence-based education program.

Assessing the barriers to early end-of-life discussions can help to develop tools for health care providers feeling comfortable having early end-of-life discussions. This project can help to guide the best treatment choices for cancer patients to promote quality of care.

### **Outcomes**

The outcomes for this project include: 1.) Identify the barriers health care providers have towards end-of life discussions with patients. 2.) Identify the barriers patients have when having end-of-life discussions with health care professionals. The outcomes information was obtained through a community assessment using surveys with people who have been diagnosed with cancer and health care providers. Health care providers were included to help collect data regarding if health care providers were discussing treatment options, outcomes, prognosis and end-of-life wishes early in the disease process. The survey questionnaire for health care providers helped to identify the barriers to, attitudes towards, and their comfort level in having early end-of-life discussions with cancer patients.

The provider questionnaire had questions such as “How comfortable are you at having early end-of-life discussions with cancer patients?” “How important do you feel it is for health care providers to have early end-of-life discussions?” The cancer patient survey questionnaire had questions such as “Are there barriers to having end-of-life discussions?” How much did your financial and spiritual beliefs affect your treatment choices?” How well did your provider discuss your treatment options?” How important is it to know your treatment options and outcomes?” These questions helped to gather information on the barriers to early end-of-life

discussions and the affects they had on treatment choices. The survey questions helped to gather information on cancer patient's perspectives of quality of care for end-of-life and barriers to health care providers and cancer patients having early end-of-life discussions.

## **Review of the Literature**

### **Search Strategy**

A variety of search terms were used including cancer, pain, suffering, nausea, fatigue, quality of life, experiences, oncologists, primary care providers, palliative and early end-of-life discussions. Data bases that were searched were Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed and ProQuest Nursing and Allied Health Source. The inclusion criteria included oncologists, health care providers, quality of life, cancer patients, early end-of-life discussions, the highest level of evidence and research-based material. The exclusion criteria included non-human research, oral presentations, physicians that are not oncologists or health care providers, the wrong patient population, and articles published before 2013. The time frame of articles ranged from 2013-2018. There were nine final articles within the inclusion criteria and the levels of evidence ranged from level II-VI. Articles included in the search have reliable current information regarding cancer patients' and quality of care. Research contained reliable studies with information on cancer patients' wishes for quality of care. They include many reliable cancer statistics. They contain some financial data related to health care savings. Information found promoted having early end-of-life discussions for quality of care for cancer patients. Articles contained evidence of health care provider's lack of knowledge and many experience discomforts having early end of life discussions with end-of-life goals.

### **Early End of Life Discussions to Promote Quality of Care**

According to the American Cancer Society in 2015 there were 1,658,370 people that were diagnosed with cancer. Only 36 % of cancer patients were enrolled in appropriate hospice programs. Health care providers should take time to address their cancer patient's end-of-life goals in the outpatient clinical setting. A study conducted by Mack, Weeks, Wright, Block, and Prigerson (2010) found that patients who have early end-of-life discussions within the last 30 days of their life were less likely to receive chemotherapy within 14 days of their death. A study conducted by Brom, Onwuteaka-Philipsen, Wuderove, & Pasman, (2016) found that people who received palliative care were less likely to receive chemotherapy within 60 days of their death. In the Greer (2012) study, patients met with a palliative care team member shortly after being diagnosed and then monthly in the outpatient clinic. The palliative care team focused on understanding their illness, coping mechanisms, symptom management, decision making, planning and referral (Brom, Onwuteaka-Philipsen, Waddesdon, & Pasman, 2016).

A cross-sectional survey that was conducted from April 2011 through November 2013 with 2,467 participants had an 89.3% participation rate and included patients diagnosed as terminal and unresponsive to current treatment. Only 7.8% of the respondents reported having had end-of-life discussions with their physician (Tang, Liu, Hiu, Hsieh, & Tsai, 2014).

In this section of the literature review there was evidence that early end-of-life discussions can promote quality of care for cancer patients, and prevent unnecessary or unwanted treatment from being provided. Health care providers having open and honest discussions with cancer patients early in their diagnosis of cancer can make it easier for cancer patients to make decisions regarding their treatment choices and wishes for their health care.

### **Health care providers lack of knowledge**

Literature review indicated that there is a lack of knowledge and training for health care providers on how to initiate and have early end-of life discussions and develop end-of-life care goals (Miller et al., 2015). Many health care providers have a lack of comfort discussing end-of-life issues or care. Early advanced planning regarding patient's wishes can help achieve the patients' wishes that are to be followed when they are faced with a diagnosis of terminal cancer (Miller et al., 2015).

Terminal illness can be an uncomfortable topic to discuss, but it is important to make cancer patients aware of their disease and prognosis. Increasing health care provider's knowledge of the barriers to having early discussions can increase the quality of care at the end-of-life.

### **Cancer Patients View of Quality of Care**

Cancer patients who are faced with making end-of-life decisions can experience many psychological emotions such as anxiety, depression, fear, and worrisome stress while some may experience peace and spirituality (Rand, Shea, & Cripe, 2016). At many time points, patients will often have to make decisions and review goals of care as they go through cancer treatments. Studies have shown that early end-of-life discussions regarding cancer patient's goals can help patients feel more comfortable with the decisions they make about treatment options offered and can help decrease the psychological burden of making end-of-life decisions (Rand, Shea, & Cripe, 2016).

In an interview with 63 cancer participants regarding their life goals, the top three goals were meaningful experiences, social connection, and altruism at the end-of-life (Rand, Shea, &

Cripe, 2016). In these interviews, patients separated their treatment options from their life goals. Many of these patients did not see their diagnosis as a serious life-threatening disease. Most of the patients surveyed had goals to live longer and find a cure for their cancer. Results of the study were that 82.26% of patients were highly optimistic of surviving a year compared with their oncologists mean of 42.50% of the patient surviving an estimated 355 days (Rand, Shea, & Cripe, 2016).

It is estimated that 18-30 % of cancer patients spend time in the intensive care unit. The mortality rate of cancer patients' in the ICU is 27-43% (Miller et al., 2015). In a study done with 38 cancer patients in the intensive care unit, researchers found a statistically significant correlation between quality of life, pain, support, and religiosity (Miller et al., 2015). One important concept for health care providers and cancer patients is to have discussions related to their disease process and making sure that they understand their prognosis to promote quality of care. Another important concept for health care providers and cancer patients is to have goals of care discussions to promote quality of care and prevent intensive care admissions if unwanted.

These studies and statistics show that cancer patient's views of the treatment choices they have made may be different from their health care provider's reason for offering various treatment options. Honest, early conversations regarding prognosis for treatment options being provided could help prevent unwanted hospitalizations, and unrealistic views for a cure.

### **Health care savings**

Hospitals with palliative care programs have decreased length of stay, fewer intensive care unit admissions, and decreased pharmacy and laboratory expenses. In a study by Parikh, Kirch, Smith & Temel, (2013) they estimated \$2,500 in net costs savings per admission.

Palliative care accessed in an outpatient setting saves costs in decreased hospital admissions and emergency room visits (Parikh et.al, 2013).

Initiating a program with penalties for readmissions to the hospital for cancer patients with the same symptoms and discussing with the patient the option of not readmitting to the hospital but instead enrolling to hospice program could increase quality of care for cancer patients too. Early discussions regarding patient's wishes for treatment and care regarding cancer diagnosis can prevent unwanted treatment and improve quality of care given too as perceived by the cancer patient. Health care providers initiating conversations regarding support programs available can help decrease cancer patients spending unnecessary time in the hospitals and may decrease unneeded health care spending.

### **Impact of Palliative Care**

Studies have shown that early palliative care consultation can improve quality of life and reduce health care spending. There are individuals that argue that early end-of-life discussions and palliative care options should be required to be discussed in serious illness (Parikh, Kirch, Smith, & Temel, 2013).

The current standard of medical practice is to offer palliative care services through hospice or inpatient status after life-prolonging treatment options have failed or at the time of a medical crisis (Parikh et al., 2013). The problem with this practice is that it ignores most individuals facing life threatening diseases such as advanced cancer. Many studies show that initiating palliative care at time of cancer diagnosis can improve one's understanding of prognosis and improve a cancer patient's quality of life (Parikh et al., 2013). Recent studies have

shown that patients with metastatic cancer report that they will be cured with chemotherapy and radiation (Parikh et al., 2013).

Encouraging providers to use palliative care programs at the time of a cancer diagnosis for serious illnesses, such as cancer, could increase quality of care for cancer patients. If Medicare, hospitals and insurance companies would provide and pay practice incentives to health care providers for having early end-of-life discussions, this may increase the number of early end-of-life discussions and enable patients to be more engaged in determining what they would accept for treatment and at end-of-life. Medicare does provide reimbursement to encourage providers to counsel patients about their goals and options throughout their disease process (Parikh, Kirch, Smith, & Temel, 2013).

### **Summary**

Statistics and literature have shown that there is a gap in care without early end-of-life discussions; the goal of this project was to identify potential barriers from stakeholders. Building on these results, a potential future project could be for education and development of tools to help health care providers feel comfortable having early end-of-life discussions with cancer patients. Patients with cancer often feel that their providers do not provide all information about their diagnosis, treatment options, and prognosis making it difficult for them to know what they are agreeing to with treatment, or if there are other options available; patients want their providers to be open and have honest conversations with them. Early conversations about goals of care, treatment options, and end-of-life would allow patients to be better informed and participate in determining treatment and aggressiveness of care. Early discussions can improve a patient's quality of life.

### **Theoretical Framework**

The Iowa Model of Evidence-Based Practice to Promote Quality of care is the practice model that fit most closely with this capstone project. The parts of this model that will be used will be guidance it gives for nurses and other clinicians in making decisions regarding practices that effect patient outcomes. It helped guide the process of identifying knowledge barriers and knowledge triggers regarding increased early discussions for cancer patients. One strategy would be developing ways to help health care providers feel comfortable having early end-of- life discussions as well as promoting quality of care. A second knowledge focused trigger would be increased education for patients and families on having open and honest discussions with their health care providers through community assessments. Communication between the family, patient and provider were important characteristics in providing quality care. Understanding, supporting, and respecting patient and families decisions are an important role in providing quality care.

Application of the practice model was to evaluate the main barriers relating to the lack of having early end-of-life discussions with cancer patients. Another step will be getting the stakeholders involved in the process by forming a team to initiate the project. It may be necessary to base the community assessment on other types of evidence such as scientific research, case studies and expert opinions.

### **Organizational Assessment**

The health care facility that was utilized for this project in northeast Nebraska has a



mission to serve Christ by providing exemplary medical services in an environment of love and care. This mission statement was a core value that drove and underpinned all elements of this project. This project included collecting information from survey tools to indicate the barriers to having early end-of-life discussions. Understanding their comfort level and the potential barriers to early conversations helped to increase the health care providers comfort level of initiating and having early end-of-life discussions to promote quality of care for cancer patients. Making health care providers aware of the barriers to early conversations could help decrease the barriers, and in turn increase early conversations. The health care facility strives to find ways to improve on providing high quality care for patients' and families. The health care facility was open for changes that can improve the services they offer and provide to patients, families and the community. They have many new projects and changes that their employees adapt to often; some are to stay in compliance with the health care regulation laws.

Anticipated barriers to the project included the possibility of provider resistance to having early end-of-life discussions with patients, emotional discomfort related to the topic from the patient perspective, and differences in personal beliefs and values between the patient and provider.

A facilitator of this project was helping to increase the Hospital Consumer Assessment of Health Care Providers and Systems (HCAHPS) quality scores of the organization. This tool is a standardized survey that collects data on patient hospital experiences. There are questions related to communication with providers and transition to different care stages. This project can help to improve these scores by finding the barriers to early conversations for cancer patients to make the most informed decision regarding their health care. This education could help lead to improved patient care, decision making, and ease the uncertainties cancer patients and families

may have regarding their health and treatment. This project of evaluating and providing study results to providers and patients about the barriers to discussing end-of-life decisions could help make treatment choices and options easier for cancer patients and families.

### **Methodology**

Methods used in this capstone project were done through implementing a community assessment process by collecting quantitative and qualitative data through surveys on the importance of and barriers to having early end-of- life discussions between cancer patients and health care providers that would help to guide the best treatment options for the cancer patients and promote quality of care.

### **Setting**

The setting for this project was a 227-bed acute health care facility in a Midwestern rural community that serves the northeast Nebraska and surrounding communities. This facility offers services such as inpatient and outpatient treatment, general surgery, orthopedic surgery, rehabilitation services, hospice, home health care, pulmonology, cardiovascular services and cancer services. The organization employs a variety of family practice providers, surgeons, hospitalists, and specialty providers. The organization provides cancer services and treatments to many cancer patients in northeast Nebraska and the surrounding geographical areas. A variety of services such as imaging, pathology medical oncology, radiation oncology, and surgical services throughout the health care facility. The health care facility also offers supportive services before, during, and after diagnosis. Staff included five providers including an oncologist, two radiation oncologists, a nurse practitioner, and a physician's assistant as well as a nurse navigator. The cancer center provides a safe environment for chemotherapy and radiation services. An

comfortable environment for support services at time of diagnosis and throughout the disease process is provided at the cancer center. Approximately twenty to thirty health care providers are employed by or affiliated with this facility that were potential candidates for this project. Letters of support from the governing bodies was obtained prior to initiation of this project.

### **Sampling**

Participants in this project were cancer patients, primary care providers, and oncologists. For this project, the goal sample size was 20 cancer patients and 20 provider participants.

The inclusion criteria for cancer patients were individuals that have a cancer diagnosis were within the ages of nineteen to ninety-nine; able to sign informed consent; individuals that could verbally communicate; and were able to speak and write in English to answer survey questions. The inclusion criteria for provider participants included primary care providers and oncologists; individuals that could verbally communicate; and were able to write in English to answer survey questions.

The exclusion criteria for cancer patients were people without a cancer diagnosis; individuals that were younger than nineteen and older than ninety-nine; individuals that were unable to verbally communicate; and people that did not speak or write in English. Exclusion criteria for health care providers included staff that were not primary care providers or oncologists; individuals that were unable to verbally communicate; and those that did not speak or write in English.

Recruitment strategies included seeking guidance from the staff at the health care center, including the oncology nurse navigator, in selecting patients with a cancer diagnosis that met inclusion criteria and were good candidates for surveying. The recruitment of primary care

providers and oncologists surveyed included working with medical staff and administrative staff at the health care facility to determine those that met the inclusion criteria. Follow up contact was conducted through face to face interaction, email, or by telephone to see if they were interested in participating in this project.

Surveys were delivered by electronic method through email and hand delivered with instructions to return to the researcher. The diversity of participants and different geographical locations could have potentially influenced the results. Spiritual, personal values and beliefs could have also affected the results.

### **Implementation**

Implementation began with an introduction to the staff at a Midwestern Health Care Facility to explain the project. The process involved establishing a working relationship with a contact person at the facility to be able to use as a resource for completion of the steps of the implementation phase. The first step was working with the contact person at the facility to identify and select potential participants in the first month. A meeting was set up with the prospective participants to explain and discuss the project with them between month one and month two. Informed consent was obtained from all participants who were willing to participate before the surveys were distributed.

Surveys were distributed either by electronic method through email, or hand delivered to participants that have signed the informed consent including patients and health care providers that met the inclusion criteria. The surveys were distributed to the eligible participants during month two and three of the project. The data was collected, analyzed and recorded on tables and charts included in this paper.

## **Measurement Instrumentation**

### **Instrumentation tools to be used in project.**

Data collection tools used are attached in (*Appendix D-E*) reflecting the survey questions to measure the outcomes of this capstone. The survey tool developed for cancer patients and health care providers collected descriptive, qualitative and quantitative data, including responses to the inclusion criteria for the project. The first question asked in the cancer patient tool made sure that the participants were appropriate for the project. Most of the survey questions in the cancer patient's tool were closed-ended to make it easy and less time consuming for the participants to complete. The surveys contain mostly questions with a scale for simple number responses. The survey tool developed for the providers assessed their comfort level in having close-ended questions on barriers to having end-of-life discussions with cancer patients. The questions were targeted to get a variety of provider's perspectives on the importance of early goals of care and end-of-life discussions for cancer patients. The tools could be emailed, or printed, and then distributed to be filled out with pens, and then mailed back to researcher. A strength is that these surveys could also be sent through emails if preferred by participants.

The survey tools were developed by this author based on the review of literature to collect information with the inclusion criteria in mind. There was no established validity and reliability related to the tools. The questions were developed to collect information to evaluate if early end-of-life discussions are an area in health care that could use improvement. The questions were developed as easy to understand to collect information on early end-of-life

discussions. The surveys collected suggested some solutions on how to improve the educational gap of having early end-of-life discussions. The surveys were evaluated by a statistician as well.

### **Data Collection Procedures**

Data collection began with the distribution of surveys to participants through email and hand delivery. Method of delivery for each participant was determined at the enrollment process of the project. Instructions were included on how to return them to this researcher via email, postal mail, or given back in person to this researcher with each participant at the enrollment process. It was important to evaluate the progress of the project to monitor the progress of the surveys and the outcomes for the barriers and the educational needs by organizing and evaluating the data collected through the completed survey. Monitoring included observing for any distress, concerns or comments about the surveys. Emotional support and education on surveys was given as needed throughout the project

### **Timeline.**

Month one included engaging the stakeholders, providing education on the project to prospective participants, and finding a contact person at the settings. Month two included screening and enrolling eligible participants, obtaining informed consent, and distributing the surveys to the participants. Month three involved data entry, cleaning the data and reviewing the data for common themes and barriers. A plan was developed to distribute the information to the stakeholders. Recommendations were made for future studies for education and tool development. (*Appendix G timeline*).

### **Pre-intervention.**

The pre-intervention phase took place at the beginning of this project and continued through month one. This included gaining permission to use the facilities listed above in the setting section. Engaging with stakeholders regarding this project through meetings and phone conversations was important. It consisted of establishing a relationship with a staff member at each the facilities to use as a resource and contact person. A facility contact person was able to assist in the project of setting a date for a meeting and assisted in finding and recruiting eligible participants. The number of potential participants was accounted for at this phase. Participants were evaluated to make sure they met the inclusion criteria to participate in the project.

### **Intervention.**

Several steps were critical to this project's success. Screening and enrolling the eligible subjects was conducted. Informed consent was obtained, and the distribution of the surveys to the participants was done (*Surveys in Appendix D-E*). Surveys were electronically distributed to some of the participants, with instructions to return to the researcher electronically. Some of the surveys were directly distributed by hand and returned from subjects as paper forms to this researcher or clinical staff. Data was evaluated to assess what the barriers were in having end-of-life discussions with cancer patients and how early goals of care conversations affect treatment choices of cancer patients.

### **Ethical Considerations/Protection of Human Subjects**

Institutional Review Board (IRB) approval was obtained prior to initiating the project. The level of Institutional Review Board (IRB) was expedited with less than minimal risks for human subjects who choose to participate in this project. There were no known conflicts of interest.

Informed consent was obtained from each participant prior to involvement in the project. Data was collected through surveys, and recorded in tables (*Appendix E-F*); data integrity was reliable and accuracy maintained. Data was analyzed using qualitative and quantitative methods, then verified for accuracy and completeness. Health Insurance Portability and Accountability Act (HIPAA) was the guide in this project to protect all participant private health information. Patient information was d-identified using numbers to ensure absence of personal identifying information. All data with patient identifiers were destroyed immediately after being assigned an d-identifying number in appropriate locked shred bins at the health settings. The electronic surveys were stored in a file of a password protected computer. Paper surveys were stored in a locked storage space. Privacy and confidentiality was a maintained throughout this project.

### **Data Analysis**

The quantitative and qualitative data was evaluated and prioritized to assess where the largest barriers were to having early end-of-life discussions and the effect on the treatment choices of cancer patients.

Data responses to the surveys were organized in the tables developed for organization. The respondents answered questions with a score of 0-3, with 0 meaning no importance and 3 meaning high importance. There were also yes and no questions on the patient surveys regarding if they had a cancer diagnosis, and if they thought there were gaps to obtaining quality of care. The providers questionnaire also had yes and no questions regarding if education and educational tools on the end-of-life discussions could help guide these conversations. There also was a yes or no question regarding if the providers felt that there are gaps in guiding cancer patients treatment

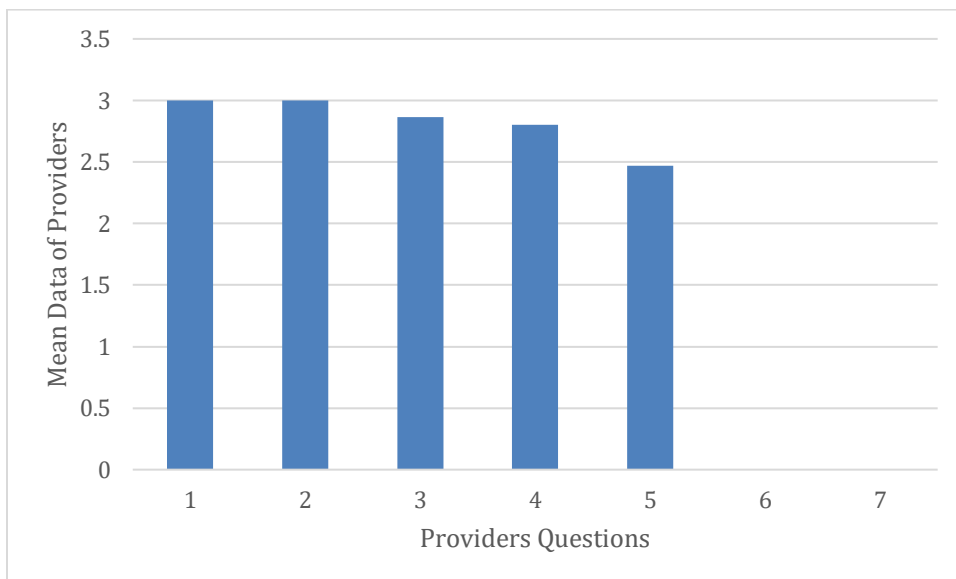


options. The data was sorted, calculated and recorded in an Excel software program. A statistician assisted with data analysis.

## Results

Provider enrollment goal was a total of 20 participants; a total of 15 providers participated in this study. The goal of 20 cancer patients was reached for this study.

**Figure 1.** Mean Data Analysis Providers

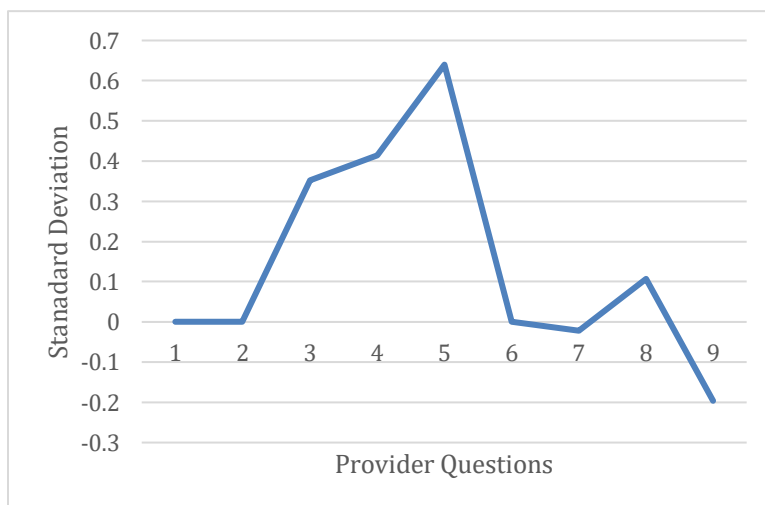


As shown in *figure 1*. Fifteen providers surveyed reported high importance to having end-of-life discussions with cancer patients (  $M=3$ ). Providers also scored discussing the cancer diagnosis with the patients as high importance (  $M=3$ ), while discussing treatment options equaled ( $M= 2.9$ ). Providers felt strongly about there being a need for more training in medical school on having end of life discussions ( $M=2.8$ ). Comfort level of having early end of life discussions was rated above moderate importance as a ( $M= 2.5$ ). Fifteen providers answered yes to there being a need for more education such as in-services and conferences on having end of life discussions. Fifteen providers answered yes to there being a need for an increase in

educational tools on how to have these tough conversations. Fifteen providers reported that there are gaps in providing quality of care to helping guide a patient in their treatment choices.

Providers identified that there are barriers to having early end-of-life discussions as being there is a need for increased education in medical training, that providers are not always comfortable having early end-of-life discussions, and felt that having education tools to guide these conversations would be beneficial in health care. Providers also felt that it is important to be open and honest with patients to help guide their treatment plans.

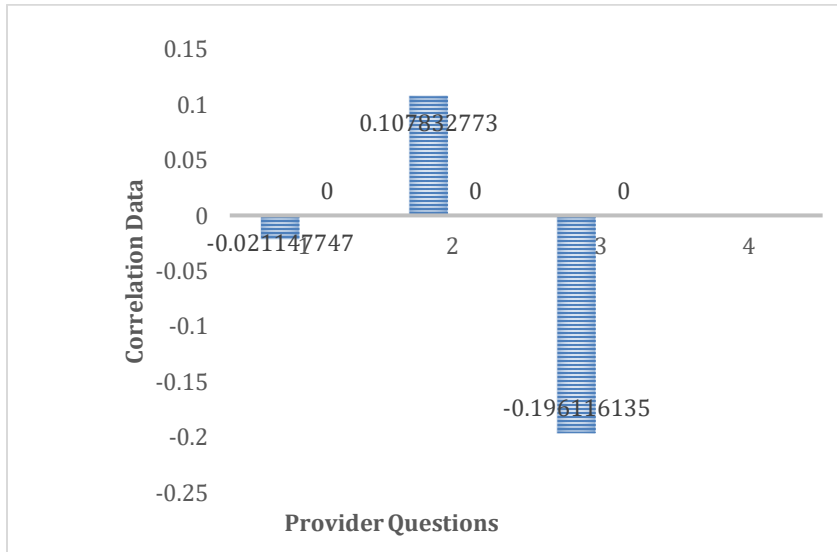
**Figure 2.** Provider Comfort Level of Discussing Treatment Options



*Figure 2.* Shows that the standard deviation results of the questions ranged from 0-0.6. The results of the data collected revealed that most of the providers answered most of the survey questions with a score of 2.5 to 3 as high importance. Providers felt strongly that there were barriers to having early end-of-life discussions and gaps in providing quality of care to patients. The gaps that were reported were that there is not enough education on end-of-life discussions in medical schooling and that there is a need for the development of educational tools on how to

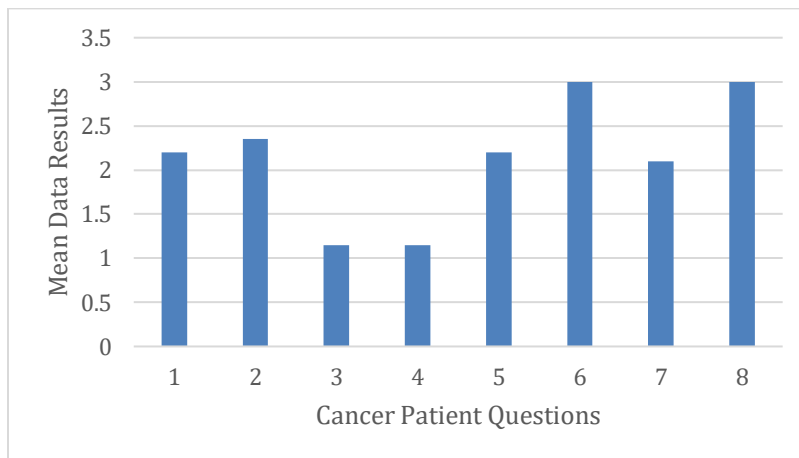
have these difficult discussions. Fifteen providers also scored being open and honest with patients about diagnosis, treatment options and plans as high importance.

**Figure 3.** Correlation Provider Data



*Figure 3.* Indicated that the comfort level of discussing treatment options with patients, and there being a need for increased training in schools had a positive correlation of 0.1. From the data collected the comfort level of discussing treatment options had a negative correlation of .02. The correlation data revealed that the importance of discussing treatment options with patients and the need for training had a negative correlation of 0.2. This data illustrates that there is a need for increased training for providers to be comfortable in having end-of-life discussions.

**Figure 4.** Mean Data Analysis of Cancer Patient Data



*Figure 4.* Revealed that patients feel that it is important to be aware of the outcomes of their treatment choices, and receive open and honest communication from their providers ( $M=3$ ). Cancer patients felt that there are barriers to having early end-of-life discussions ( $M=2.35$ ). A couple of identified barriers were on providers having not discussed their treatment options fully and honestly with them, and the lack of being aware of community resources for the support of cancer patients ( $M=2.2$ ). An identified barrier was the comfort level of cancer patients having end-of-life discussions with their provider ( $M= 2.1$ ). Beliefs and finances did not really affect their decisions about treatment choices ( $M=1.15$ ). Thirteen out of twenty patients (65%) believed that there are gaps in obtaining quality of care.

**Figure 5.** Cancer Patients Standard Deviation

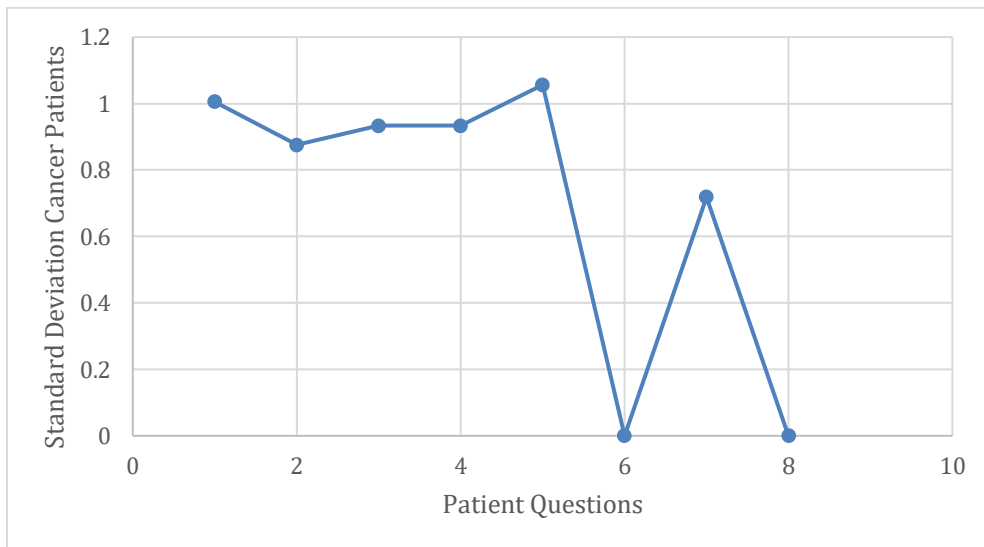


Figure 5. Indicated that the standard deviations did not vary much with the questions 0-1.5. Many of the patients scored majority of the questions with a three meaning high importance. There was little deviation in the data collected from cancer patients surveys.

**Figure 6.** Patient Correlation Data

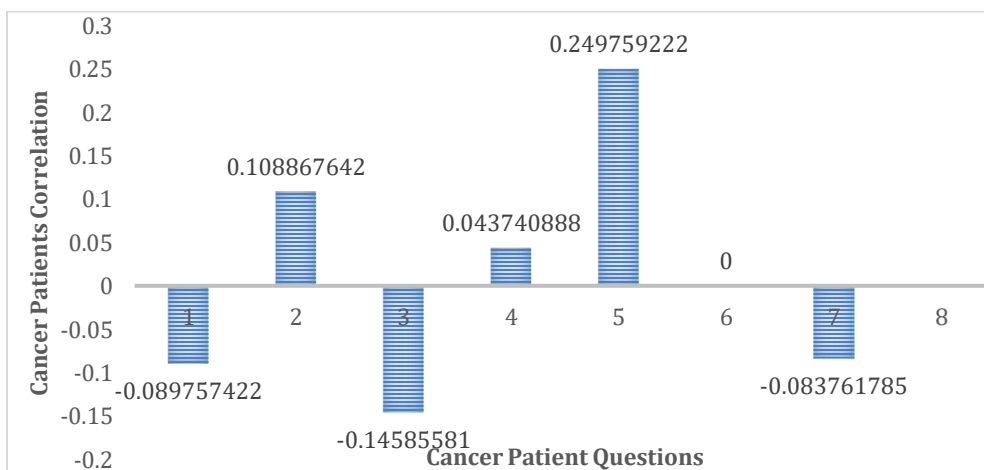


Figure 6. Revealed that the comfort level of having early end of life discussions and barriers to having end of life discussions had a positive correlation of 0.1. Being aware of the community resources and support and comfort level of having early end of life discussions had a positive correlation of 0.2. Comfort level of having early end-of-life discussions and treatment options had a positive correlation of .04. Treatment options and spiritual beliefs had a negative correlation of -.08. Treatment options and financial concerns had a negative correlation of -.15. Communication and honesty had no correlation.

## **Discussion**

The providers suggested increased education in medical provider education and training to be able to communicate better with patients and families.. Providers thought that having simulated practice sessions and mentor programs on end-of-life discussions with patients and families could increase the quality of patient care for cancer patients. Some of the providers implied that encouraging increased education on palliative care programs to medical providers and oncology providers could increase comfort level of tough conversations. Having early end-of-life discussions for providers was found to be uncomfortable due to the lack of education on early end-of-life discussions, and the lack of educational tools and resources available to help guide these conversations.

The majority of the patients (sixty-five percent) believe that there are barriers to having early end-of-life discussions. This is a large percentage of the participants and plays a major role in the perception of the quality of care these patients may receive. This result also indirectly affects the open and honest communication, the outcomes, and the decisions cancer patients make regarding their treatment choices. Barriers identified were that cancer patients wanted to be

aware of the resources and knowing their outcomes was shown to be important to these cancer patients, which may directly impact the way these patient perceive their quality of life. There are barriers to having early end of life discussions and understanding treatment options and outcomes in this population.

### **Limitations**

Limitations of the study included that only fifteen providers were surveyed versus the original planned twenty. There were not an adequate amount of eligible providers in the health care system to meet the target enrollment goal. The Midwestern health care system selected could have been expanded to include a couple other health care practices to have possibly included the original twenty providers. Providers were primary care, oncologists and patients were from one health care system in a Midwestern community; results are limited to this site and are not generalizable. The survey tools were developed specifically for the project and have not been tested for psychometric properties.

### **Plan for Sustainability**

The initial project used surveys of patients and providers to find barriers to early end-of-life discussions and how these conversations affect treatment choices of cancer patients were completed. The outcomes of this project will be shared as a foundation for a future study developing educational tools that could be developed to address barriers identified in this project. The plan will be to share the information and results in this study at a medical staff board meeting at the Midwestern health care facility. Having stakeholders engaged in the project so they understand the importance of these conversations helped to sustain the project. There may be a person at one of the settings that want to remain engaged in the project to continue it.

Another part of the plan for sustaining this project will be to continue educating providers and patients in practice on the importance of these early end-of-life discussions. The health care providers that participate in this project may continue to use what they learn from the project in their practices, and patients may have a better understanding of the need for these conversations.

### **Nursing Implications for Practice**

Nursing implications for practice were to actively work with the stakeholders to identify potential barriers to early end-of-life discussions, and the importance of early discussions on patient treatment choices and quality of life. Sharing the results with stakeholders will provide them with insight and hopefully a better understanding on the importance of early end-of-life discussions. Health care providers will then have a better understanding of the barriers to early conversations, that patients identify there are barriers, to look for education on how to overcome these barriers, and how to incorporate early conversations in their daily practice through the sharing of the results of the surveys. It is hoped that cancer patients will understand the barriers and be comfortable discussing treatment choices and their wishes for end-of-life with their providers by sharing the results of the surveys and community assessment. With this researcher sharing the findings from this project with administrations, health care providers, cancer patients and families, it is hoped that this will translate to improved discussions and quality of care for some cancer patients. Sharing information from this project would hopefully initiate more education on end of life discussions into medical training.

### **Conclusion**

The purpose of this community needs assessment project was to gain baseline information on potential barriers to early end-of-life discussions to increase awareness, and so



that future educational tools can be developed to increase comfort and the number of early end-of-life discussions. The patients and providers surveyed both identified barriers to communication about treatment options, outcomes and honest communication. The goal of this project was to gain some insight on what the barriers are to having early end of life discussions to promote quality of care for cancer patients. Open and honest communication between the provider and cancer patient can help guide the cancer patient's treatment choices to receive quality of care based on their goals and wishes. These early discussions could increase the chances of cancer patients having their end-of-life wishes respected and followed by providers and family members.

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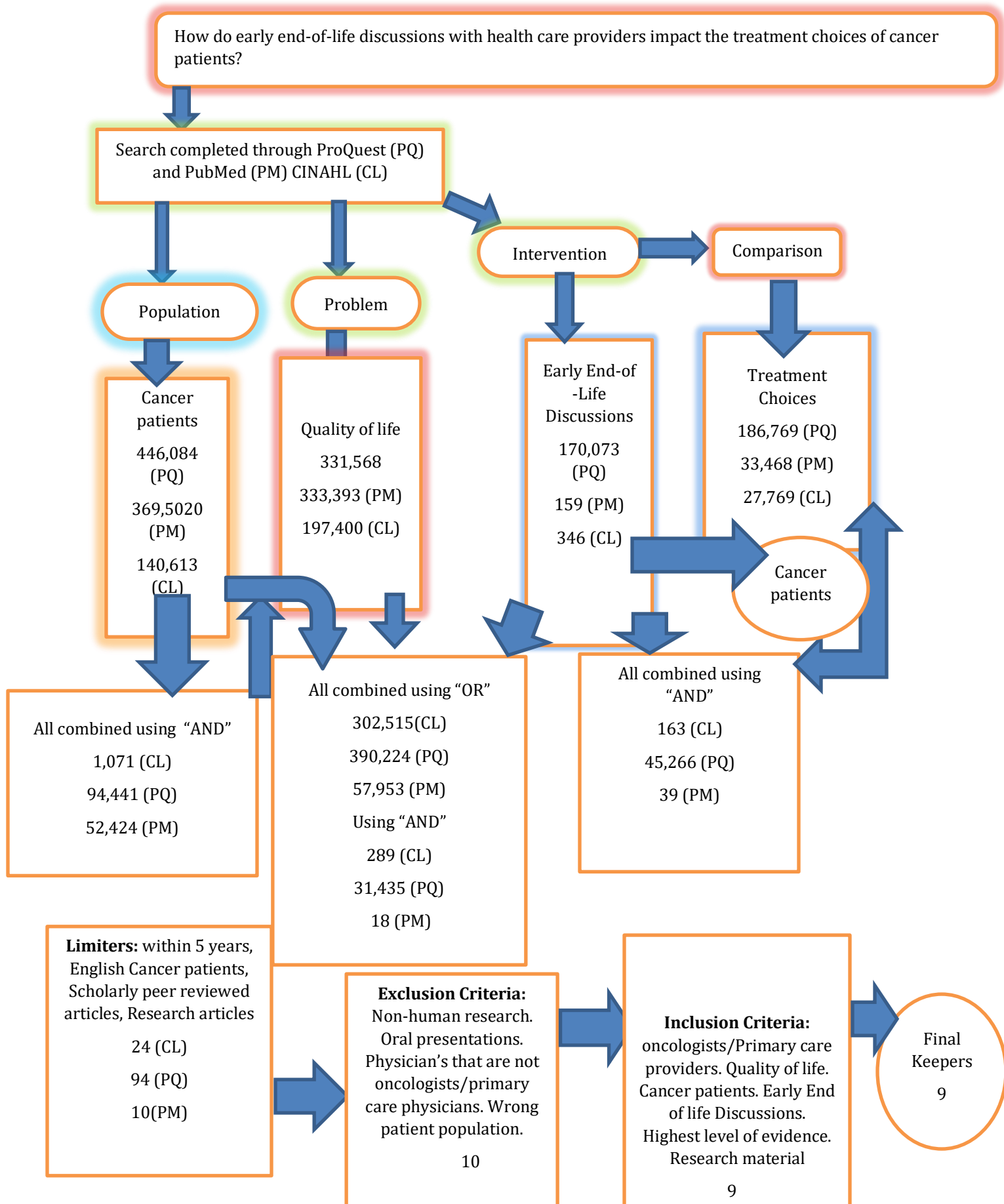
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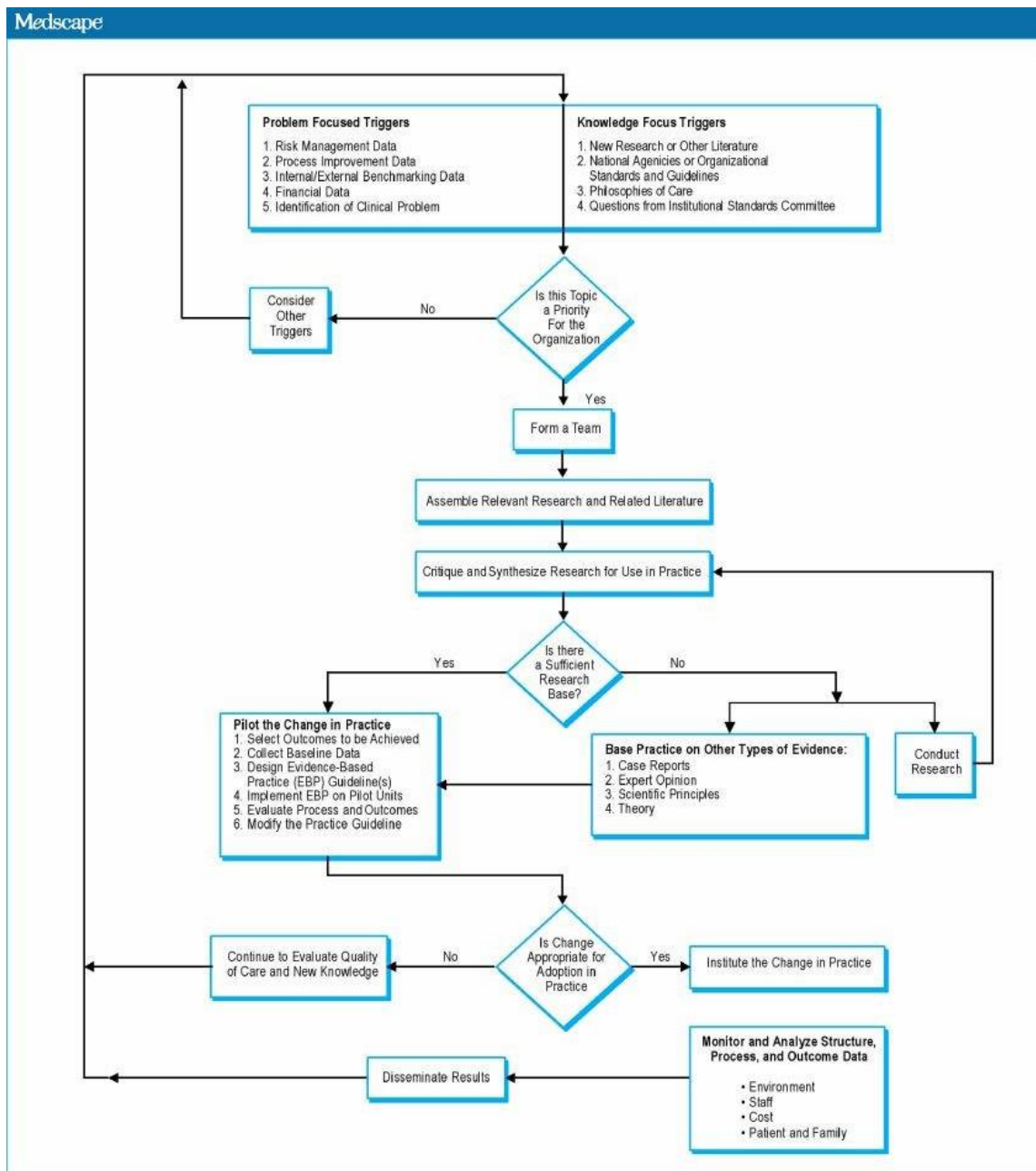
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**Appendix A: Literature Search Trail**



**Appendix B: Iowa Model of Research-Based Practice to Promote Quality Care**



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**Appendix C: Reference Matrix**

**PICO**

**How does early end of life discussions impact the treatment choices of cancer patients?**

| Citation/ Level of Evidence  | Participant s/Setting/ Sample size   | Purpose/Bac kground  | Methods/Design & Limitations  | Findings/Summar y Strengths/Weakne ss   | Applicability to Own Research   |
|--|--|--|---|---|---|
| <p>Brom, L., Onwuteaka-Philipsen, B., Widdershoven, G. A., &amp; Pasman, H. R. (2016). Mechanisms that contribute to the tendency to continue chemotherapy in patients with advanced cancer. qualitative observations in the clinical setting. <i>Supportive Care in Cancer</i>, 24(3), 1317-1325. doi:http://dx.doi.org .methodistlibrary.id m.oclc.org/10.1007/ s00520-015-2910-7</p> <p>Level of evidence: Qualitative observation study in a clinical setting, Level IV.</p> | <p>The sample size was small with only 28 patients. The sample size included 18 patients with advanced glioblastoma, and 10 with metastatic colorectal cancer (stage IV). The setting was conducted in outpatient clinic at a university hospital.</p> | <p>The purpose of the study was to describe mechanisms that lead to the tendency to continue chemotherapy in patients with advanced cancer. The purpose was clearly stated in the article.</p> | <p>A longitudinal qualitative study was conducted. The study was conducted through observation in an outpatient oncology clinic. The participants were observed in an outpatient clinical setting from first treatment to last treatment, or until they died. The researcher had informal conversations with patient and relatives in the waiting rooms after their first appointment was made. The researcher also had conversations with physicians before and after visits. The researcher audiotaped some patient visits with</p> | <p>The findings indicated that most patients continued treatment till the last treatment, or they passed away.</p> <p>They concluded that there were not many conversations between the physician and patients on treatment benefits, risks and options in this outpatient clinical setting</p> <p>The conclusion from observational data was that physicians are not comfortable in early end of life discussions, and physicians need to have more individualized conversations with patients.</p> <p>The study only had one researcher who</p> | <p>This article addresses the need for more discussions in the clinical setting for treatment options for cancer patients. There is a need for education on early end of life discussions to help physicians feel comfortable having these conversations. This is one of the concepts that will be presented to the stakeholders to make them aware of the need for early end of life discussions to promote quality of life for cancer patients.</p> |

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|   |   |  | <p>the physician. Recruitment and inclusion were used to collect data. Inclusion data 2013 or later. Patients had to be over 18.</p>   | <p>observed 28 patients in an outpatient setting. There could have been some research bias with only one researcher.</p> <p>It had many participants drop out before the study was conducted.</p>                                    |  |
| <p>Isler, A. (2017). Palliative and hospice care versus standard care on quality of life and suffering <i>Kentucky Nurse</i>, 65 (3) 6-7.</p> <p>Level VI</p> | <p>Evidence form the opinion of authorities and /or reports of expert opinions</p>                                    | <p>To promote having early end of the life discussions with patients to promote spirituality, trust and quality of life.</p>                         | <p>An observational survey study was conducted with patients with cancer and other terminal illnesses. Inclusion data 2013 or later.</p> <p>Included other terminal illnesses not just cancer.</p> | <p>Studies show that patients want their physician to be have open and honest communication with them.</p> <p>Cancer patients depend on their relationship of trust and honesty with their physician to promote quality of life.</p> | <p>This article addresses that having early end of life discussions promotes patient and provider trust.</p> <p>It also promotes spirituality and quality of life when physicians provide open and honest communication.</p> <p>These are important concepts to be addressed in my capstone project.</p> |
| <p>Miller, S.J, Desai, N., Pattison, N., Droney, J.M., Kling, A., Farqunar-Smith, P., &amp; Gruber,P.C. (2015) Quality of transition to the end of</p>        | <p>Quantitative and qualitative methods were used.</p> <p>Sample size was 85 patients in intensive care settings.</p> | <p>Purpose is to make physicians, medical staff and patients and families on the importance of addressing end of life care at the beginning of a</p> | <p>Key words were palliative care, communication, cancer, end of life care.</p> <p>This study was undertaken on a medical unit where patients were admitted to a special cancer</p>                | <p>There were 85 patients and of these patients 44.7 % of them transferred to EOLC during their ICU stay.</p> <p>The results were significantly positive that when patients have collaborative teamwork with the</p>                 | <p>This study showed that there needs to be better developmental tools and education is needed to address end of life wishes early in the disease process.</p>   |



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| <p>life care for cancer patients in the intensive care unit. <i>Annals of Intensive Care Unit 5 (1)</i>, 1-11. Doi:<a href="http://dx.doi.org/10.1186/13613-0515-0059-7">http://dx.doi.org/10.1186/13613-0515-0059-7</a></p> <p>Level IV<br/>Quantitative and qualitative.</p>   |  | <p>cancer diagnosis.</p>   | <p>hospital intensive care unit (ICU). They were observed over 6 months. Quantitative and qualitative methods were used to explore quality of transition to end of life (EOLC) by using documentary evidence. The clinical parameters in ICU on admission were reviewed to determine if they could be used to identify patients who were likely to transition to EOLC during their ICU stay.</p> | <p>physician, nursing staff, patient and family they can make better decisions regarding their end of life care.</p> <p>51.4% and 40.5 % of patients were unable to discuss transition to end of life care and do not resuscitate status due to a decline in status before these conversations happened.</p> <p>76.3 % of patients died from cancer in the ICU.</p>                              | <p>There are some significant statistics in this article that can be used in my project.</p>  |
| <p>Parikh, R. B., A.B., Kirch, R. A., J.D., Smith, T. J., M.D., &amp; Temel, J. S., M.D. (2013). Early specialty palliative care -- translating data in oncology into practice. <i>The New England Journal of Medicine</i>, 369(24), 2347-51. Retrieved from <a href="https://methodistlibrary.idm.oclc.org/login?url=https://search-">https://methodistlibrary.idm.oclc.org/login?url=https://search-</a></p> | <p>Evidence Analyzes Randomized Studies of 151 patients within 8 weeks after diagnosis of metastatic lung cancer. There are other randomized trials done by other researchers in this article. The study took place in the outpatient settings, in</p> | <p>Purpose: To educate the public and medical providers on the palliative care programs that are available. To educate on when it is the right time to initiate these programs to promote quality of care.</p> | <p>Search terms used Palliative care/ quality of life /cancer patients were clearly defined.</p> <p>Inclusion criteria included articles 2014 or later.</p> <p>Randomized studies were conducted to see what the level of knowledge is in the outpatient settings on palliative care programs</p>  | <p>The article explains that palliative care is an under used service in medicine.</p> <p>That there needs to be more early conversations with patients and that providers need to feel comfortable having these conversations.</p> <p>One study estimated that palliative care consults save about \$2500 in net savings per patient admission and reduce overall outpatient costs by 33 %.</p> | <p>This article shows that there is a lack of knowledge in the public about palliative care programs.</p> <p>It also shows that there are health care savings happen with palliative care programs in place .</p> <p>These will be positive aspects of research for my project.</p> |

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| <p><a href="http://proquest-com.methodistlibrary.idm.oclc.org/docview/1467731511?accountid=58689">proquest-com.methodistlibrary.idm.oclc.org/docview/1467731511?accountid=58689</a></p> <p>Level II</p> | <p>their homes and in hospital settings.</p>  |   |   | <p>Randomized trials have shown improved quality of life from palliative care consults</p>   |  |
| <p>Pham, B., &amp; Krahn, M. (2014). End-of-Life Care Interventions: An Economic Analysis. <i>Ontario Health Technology Assessment Series</i>, 14(18), 1–70.</p> <p>Level IV</p>                        | <p>Qualitative study.</p> <p>The data was collected through multiple sources such as systemic reviews, linked health administration data bases, surveys, planning documents, expert input and literature reviews.</p> | <p>The purpose was clearly stated.</p> <p>The purpose of the article is to bring awareness of the cost effectiveness of end of life care.</p> | <p>The data bases searched were Ovid MEDLINE Other Non-Indexed Citations, Ovid Embase, and the Centre for Reviews and Dissemination/International Agency for Health Technology Assessment, for studies published from January 1, 2000, to October 22, 2013.</p> <p>Six studies qualified for the inclusion criteria. One systemic review and 5 cost-effectiveness studies</p> | <p>The conclusion was clearly stated. The finding was identified as palliative care, or in-home end of life care reduces health care costs.</p> <p>The conceptual underpinning is to support assessing cancer patients that are receiving radiation to assess if increasing or decreasing their quality of life.</p> | <p>This study also supports my topic in that early palliative care discussions can decrease health care costs.</p> <p>It also addresses that continued radiation treatment can decrease a cancer patients' quality of life.</p> <p>This is a topic that I plan to include in my proposal to my stakeholders of prolonged treatment can decrease a cancer</p> |

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|   |   |  |  |   | patients' quality of life.   |
| <p>Rand, K.L, D.A. Shea, A.M. &amp; Cripe, L.D. (2016). Life and treatment goals of patients with advanced cancer incurable cancer. <i>Supportive Care in Cancer</i> 24(7), 2953-2962. Doi:<a href="http://dx.doi.org/10.1007/15005205-016-31136">http://dx.doi.org/10.1007/15005205-016-31136</a>.</p>   | <p>Interviews were conducted, and the participants prognosis was measured over 12-month period looking for survival hope, optimism, depression and anxiety.</p> | <p>Purpose to have conversations regarding goals of care to help patients cope with their diagnosis.</p> | <p>Not clearly defined</p>   | <p>Cancer makes patients feel uncertain about their quality of life.</p> <p>Many cancer patients viewed their care and fight during their disease as their most important goals.</p> <p>Patients who valued finding a cure for their cancer had more depression and less quality of life.</p> | <p>This article reviewed discussing end of life goals for cancer patients.</p> <p>It highlighted that when people feel that there is a cure, they experience more depression when they are told different. This affects their quality of life.</p> <p>This article supports my project in that having early end of life discussions can promote quality of life for cancer patients.</p> |
| <p><b>Siegel, R. L., M.P.H., Miller, K. D., M.P.H., &amp; Jemal, Ahmedin, D.V.M., PhD. (2017). Cancer statistics, 2017. <i>Ca : A Cancer Journal for Clinicians</i>, 67(1), 7. Retrieved from <a href="https://methodistlibrary.idm.oclc.org/login?url=https://search-proquest-com.methodistlib">https://methodistlibrary.idm.oclc.org/login?url=https://search-proquest-com.methodistlib</a></b></p> | <p>Descriptive study</p> <p>There are many different tables with cancer data for all</p>  | <p>Purpose to analyze and show the statistical facts of cancer. That cancer is a world - wide</p>        | <p>Search terms used statistical, data, cancer, inclusion data from 2016 to 2017. Exclusion data anything before 2016.</p> | <p>Cancer is the second leading cause of death in the United States but is a public health problem world- wide.</p> <p>In 2017 the projected new cancer diagnosis was 1,688,780 and 600,920 deaths to occur.</p>  | <p>This study has statistics from the year 2016 for cancer patients. This information will help support that cancer is a major world-wide health problem.</p>  |

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| <p><a href="http://ary.idm.oclc.org/docview/1861302821?accountid=58689">ary.idm.oclc.org/docview/1861302821?accountid=58689</a><br/> <b>Level VI</b></p>   | <p>50 states. Male and female and different types of cancers. There are also many different statistical data related to cancer.</p> | <p>problem.</p>  |   | <p>There is a decline in mortality from cancer due to decrease in smoking as well as early detection and better education.</p>  |  |
| <p>Tang, S. T., Liu, T., Liu, L. N., Chiu, C., Hsieh, R., &amp; Tsai, C. (2014). Physician-patient end-of-life care discussions: Correlates and associations with end-of-life care preferences of cancer patients--a cross-sectional survey study. <i>Palliative Medicine</i>, 28(10),</p> | <p>Evidence case-controlled study using a cross sectional survey .</p>  | <p>Purpose : To identify physician and patient end of life discussions. To identify patient's wishes for end</p> | <p>It was done in 23 hospitals throughout Taiwan from in person interviews. 2467cancer patients. It had an 89.3 % participant rate.<br/><br/>Key words: cancer, end of life discussions, palliative care.</p> | <p>Few cancer patients reported having been able to discuss their end of life care preferences with their physician.<br/><br/>Only 7.8 % respondents reported having end of</p> | <p>This case-controlled study showed that end of life discussions does not happen regularly due to physicians being uncomfortable with addressing these conversations.</p> |

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| <p>1222-30.<br/>doi:http://dx.doi.org<br/>.methodistlibrary.id<br/>m.oclc.org/10.1177/<br/>0269216314540974</p> <p>Level V</p>   |  | <p>of life<br/>to<br/>promot<br/>e<br/>quality<br/>of life<br/>for<br/>cancer<br/>patients<br/>.</p>  |   | <p>life<br/>discussions<br/>with their<br/>physician.</p> <p>Physician end<br/>of life<br/>conversations<br/>was positively<br/>correlated to<br/>preferring<br/>comfort care<br/>versus<br/>cardiopulmon<br/>ary<br/>resuscitation<br/>and invasive<br/>procedures.</p>   |   |
| <p>Victoria, K &amp; Patel, S<br/>(2016). The<br/>palliative care<br/>information act and<br/>access to palliative<br/>care in terminally ill<br/>patients: A<br/>retrospective<br/>study. <i>Indian Journal<br/>of Palliative Care</i> 22-<br/>4, 427-431.</p> <p>Level V</p> | <p>a<br/>retrospective<br/>study -a case-<br/>controlled<br/>study</p> | <p>To educate the<br/>public on asking<br/>questions<br/>before<br/>consenting to<br/>treatment and<br/>physicians on<br/>the importance<br/>of educating</p> | <p>Case controlled<br/>study focused on<br/>increasing<br/>knowledge about<br/>palliative care for<br/>terminally ill<br/>patients.</p> | <p>According to the<br/>Medical expenditure<br/>panel survey 64<br/>percent of the health<br/>care spending is<br/>concentrated on 10<br/>percent of the<br/>population with most<br/>of the money spent on<br/>end of life care.</p> <p>Patients are often<br/>under educated on the<br/>scope of treatments<br/>they are consenting<br/>too, and therefore<br/>may have unrealistic<br/>expectations of<br/>treatment.</p> | <p>This article has<br/>information<br/>regarding where<br/>some of the<br/>medical spending<br/>goes with end of<br/>life.<br/>It also has<br/>information<br/>supporting the<br/>need for<br/>education for<br/>physicians on the<br/>end of life care.</p> |

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| <p>White, P., Cobb, D., Vasilopoulos, T., Davies, L.E., Fahy, B. (2018). End of life discussions: Who's doing the talking? <i>Journal of Clinical Care</i> 43, 70-74. Doi:<a href="http://d.doi.org/10.1016/IJ.Jorc.2017.08.031">http://d.doi.org/10.1016/IJ.Jorc.2017.08.031</a></p> <p>Level V survey.</p> <p>Yucel, B., Akkas, E. A., Okur, Y., Eren, A. A., Eren, M. F., Karapinar, H., . . . Kiliçkap, S. (2014). The impact of radiotherapy on quality of life for cancer patients: A longitudinal study. <i>Supportive Care in Cancer</i>, 22(9), 2479-87. doi:<a href="http://dx.doi.org.methodistlibrary.idm.oclc.org/10.1007/s00520-014-2235-y">http://dx.doi.org.methodistlibrary.idm.oclc.org/10.1007/s00520-014-2235-y</a></p> <p>Qualitative level IV</p> | <p>Sample size was 367 patients who received curative radiation therapy between January 2010 and June 2012 at the Radiation Oncology Department of Cumhuriyet University School of Medicine.</p> | <p>To assess the influence that providers and nurse providers have on end of life discussions.</p> <p>The purpose is to determine if radiation treatments decrease or increase quality of life for cancer patients</p> | <p>chi-squares. Qualatrinics online survey in Provo UT</p> <p>The Departmental Ethics Committee of Cumhuriyet University's School of Medicine approved this study in accordance with the Declaration of Helsinki. There could be bias opinions based on personal beliefs.</p> <p>The problem is not clearly identified. The article does not state the issue with radiation and cancer patients.</p> <p>The sample size is large which could produce a variety of results. It may be hard to collect concrete data.</p> <p>Data collection was clearly defined. They used The</p> | <p>The studies revealed that radiation can affect life negatively in cancer patients and should be evaluated within the first six months of treatment. These are clearly identified.</p> | <p>This article supports my topic and will be used for background information in my research introduction and conclusion.</p> <p>This article will support my project in that radiation and chemotherapy can decrease a cancer patients' quality of life</p> |
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|  |  |  | <p>Core Quality of Life Questionnaire developed by the European Organization for Research and Treatment of Cancer (EORTC QLQ-C30) is an instrument for assessing health related QOL in cancer patients. This data collection tool has been validated and is used in many hospitals worldwide.</p> |  |  |
|--|--|--|---|--|--|

**Appendix D: Data Collection Tool for Cancer Patients**

| <b>Early End of Life Discussions to Promote Quality of Care for<br/>Cancer Patients<br/>Patient Questionnaire</b> |   |   |   |   |  |
|---|---|---|---|---|--|
| <b>1. Have you been diagnosed with cancer?</b>  |   |   |   |   |  |
| Please circle one: Yes No   |   |   |   |   |  |
| <b>Please answer the following questions with the appropriate response according to scale:</b>                    | 3 | 2 | 1 | 0 |  |
| 3 - High importance/well  |   |   |   |   |  |
| 2- Moderate importance/somewhat   |   |   |   |   |  |
| 1- Little Importance/not really   |   |   |   |   |  |
| 0- No Importance/didn't occur   |   |   |   |   |  |
| <b>2. How well do you feel your primary care provider discussed your treatment options?</b>                       |   |   |   |   |  |
| <b>3. Are there barriers to having early end- of -life discussions?</b>   |   |   |   |   |  |
| <b>4. How much impact did your beliefs guide your decisions about treatment?</b>                                  |   |   |   |   |  |
| <b>5. How much did your financial situation guide your decisions about treatment?</b>                             |   |   |   |   |  |
| <b>6. How important is it be aware of the community resources or support for cancer patients?</b>                 |   |   |   |   |  |
| <b>7. How important is it to know your treatment options and the outcomes?</b>                                    |   |   |   |   |  |



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| <p><b>8. Are there gaps in obtaining quality of care? Please circle one answer:    Yes    No</b></p> <p><b>Explain</b></p> |  |  |  |  |  |
| <p><b>9. What is your comfort level of having early end- of -life discussions? Explain barriers.</b></p>                   |  |  |  |  |  |
| <p><b>10. How important is it to receive open and honest communication from your providers? Please explain.</b></p>        |  |  |  |  |  |

**Appendix E: Data Collection Tool for Cancer Providers**

| <b>Early End of Life Discussions to Promote Quality of Care for Cancer Patients<br/>Providers Questionnaire</b> |   |   |   |   |  |
|---|---|---|---|---|--|
|   |   |   |   |   |  |
| <b>Please answer the following questions with the appropriate response according to scale:</b>                  | 3 | 2 | 1 | 0 |  |
| 3 - High importance/well  |   |   |   |   |  |
| 2- Moderate importance/somewhat   |   |   |   |   |  |
| 1- Little Importance/not really   |   |   |   |   |  |
| 0- No Importance/didn't occur   |   |   |   |   |  |
| <b>1. How important do you feel it is to discuss end-of-life decisions with cancer patients?</b>                |   |   |   |   |  |
| <b>2. How important do you feel it is too address a new cancer diagnosis with patients and families?</b>        |   |   |   |   |  |
| <b>3. How important do you feel it is to discuss treatment options with patients?</b>                           |   |   |   |   |  |
| <b>4 How important is it that health care providers receive training in having end-of-life discussions?</b>     |   |   |   |   |  |
| <b>5. How comfortable are you having early end-of-life discussions with cancer patients and families?</b>       |   |   |   |   |  |
| <b>6. Could education on having these end-of-life discussions be of benefit for providers?</b>                  |   |   |   |   |  |

|  |  |  |  |  |  |
|--|--|--|--|--|--|
| <p><b>Please circle one answer:    Yes   No</b></p>  |  |  |  |  |  |
| <p><b>7. Do you think educational tools on how to have early end- of- life discussions can help guide the best treatment options?</b></p> <p><b>Please circle one answer:    Yes   No</b></p>                  |  |  |  |  |  |
| <p><b>8. Are there gaps in providing quality of care to guide patient in treatment choices? Explain gaps if applicable.</b></p> <p><b>Please circle one answer:    Yes   No</b></p>                            |  |  |  |  |  |
| <p><b>9. What do you feel is important for providing quality of care? Explain.</b></p>   |  |  |  |  |  |
| <p><b>10. What suggestions do you have to increase comfort level of providers having early end-of-life discussions to guide treatment choices and promote quality of care for cancer patients? Explain</b></p> |  |  |  |  |  |

**Appendix F: Timeline**

| <b>Month</b>   | <b>Plan</b>   |
|----------------|---|
| <b>Month 1</b> | <b>Engage stakeholders, educate on project, and find site contacts</b>  |
| <b>Month 2</b> | <b>Screen and enroll eligible participants, obtain informed consent, distribute surveys</b>   |
| <b>Month 3</b> | <b>Clean data review common themes/barriers and develop a plan to distribute information to stakeholders. Make recommendations for future studies education and tool development.</b> |
|                |   |

**Appendix G: Informed Consent**  
**Nebraska Methodist College**

Title: **Quality of Care for Cancer Patients**

**Introduction**

You are asked to join (participate) in a research study led by Chanda Anderson, from the Doctorate Nurse Practitioner Program at Nebraska Methodist College. This study is for Doctorate Practitioner Nurse capstone project. Please read the details below and ask questions about anything you do not understand before deciding whether to join in the study.

It is your choice whether to join in the research or not. You may refuse to join the study, or you may stop the study at any time without loss of benefits to which you are otherwise due. Your choice whether to join the study will not affect your current or future relations with Nebraska Methodist College, Faith Regional Health Services, Faith Regional Physician's Services and Carson Cancer Center.

The researcher may also withdraw you from the study without your approval for one or more of the following reasons:

- The researcher decides that being a part of the study could be harmful to you.
- The study is cancelled.

You will be informed by the researcher(s) of any important new findings that develop during the study which may affect your decision to be a part of the study.

**What is the purpose of this study?**

The purpose of this project is to use surveys to identify potential barriers to early end of life discussions that may help guide treatment choices. It is anticipated that this information would be used in a future project to provide an evidence-based education program and develop tools to help health care providers feel comfortable having open and honest communication and early end of life discussions with cancer patients to promote quality of care and quality of life.

**How long will I be in the study?**

If you agree to take part in this study, you will be in the study for 4-5 months.

**What will happen during the study?**

Surveys will be distributed will be conducted with participants that have signed the informed consent including patients that have a cancer diagnosis, family members of cancer patients, providers and community members. The surveys will be distributed to the eligible participants during month two of the project. The data will be collected and analyzed into qualitative and quantitative data into tables. The barriers to having early end of life discussions will be identified. The subject is free to skip any questions that he/she would prefer not to answer. Participants will receive the appropriate survey questionnaire based on whether you are a provider and cancer patient.

**What are the risks of the study?**

This is a minimal risk research study. That means that the risks of being as part of this study are no more than those you have in everyday activities. There is a potential risk for emotional distress if questions being back memories or

bring tough decisions. There is always a risk for data breach even with all the hard locks, protection of private information, and safety guards that have been established.

**What are the benefits of this study?**

There are no anticipated benefits to subjects participating in this study. It is hoped that information obtained from this study will lead to educational tools to help providers and patients be more comfortable with having early end of life conversations.

**What are the alternatives to participating in this study?**

You do not have to participate in this study. There is no penalty to you if you choose not to participate in this study. Patients cancer treatment and care will be unaffected regardless if they participate in this study or not.

**Will my records be kept private (confidential)?**

Your information and the records associated with this study will be kept private. In any report about this study, you will not be identified. Your study record may be reviewed by Chanda Anderson, and the Nebraska Methodist College Institutional Review Board (IRB), mentor Dr. Kim Bland and Instructor Dr. Ann Oertwich. An IRB is a group of people who review the research to protect your rights. Because of the need to release information to these agencies, absolute privacy cannot be certain, but access to records will be limited to approved people as required by state or federal law.

**What if identifiable private information is collected as part of the study?**

Your information collected as part of the research will not be used or given to someone else for future research studies. Collective information obtained and analyzed may be used for future projects, but individual subjects will not be identified.

**Will it cost me anything to be in this study?**

Participating in this study will not add costs to your treatment. There will be no additional charges to you, or your insurance companies.

**Will I be paid for participating in this study?**

You will not be paid for being in this research study. There is no reimbursement for participation in this study.

**Who is funding this study?**

The Nebraska Methodist College and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research.

**Whom may I contact if I have questions?**

The researcher(s) conducting this study is/are:

Chanda Anderson

402-750-8904 during the day and at after hours.

You may call this numbers if you have questions, concerns, or complaints about the research.

You should also call this numbers if you have a research-related injury.

If you have questions regarding your rights as a research subject, you may contact a member of the Nebraska Methodist College Institutional Research Board at (402) 354-7116 (ask to speak with the IRB Chairperson). You may also call this number with problems, complaints, or concerns about the research. Please call this number if you

cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

General information about being a research subject can be found on the Office of Human Research Protections (OHRP) website: <http://www.hhs.gov/ohrp/index.html>.

**Statement of Consent**

Your signature says this research study has been explained to you, your questions have been answered, and you agree to take part in this study. You will receive a copy of this form.

|   |      |   |
|---|------|---|
| Date  | Time | Subject's Signature or<br>Signature of Subjects Personal Representative |
| Authority of Personal Representative if<br>signing on behalf of subject |      | Printed Name of Subject or<br>Subject's Personal Representative         |

**Statement of Person Who Obtained Consent**

I have discussed the above study with the subject or, when appropriate, with the subject's legally authorized representative. It is my opinion that the subject adequately understands the risks, benefits, and procedures involved with participation in this research study.

|      |      |  |
|------|------|--|
| Date | Time | Signature of Person Conducting Informed Consent<br>Discussion    |
|      |      | Printed Name of Person Conducting Informed Consent<br>Discussion |







