

PROVIDERS' KNOWLEDGE, ATTITUDES AND WILLINGNESS TO USE  
AN END-OF-LIFE PROTOCOL ON AN INPATIENT ONCOLOGY UNIT

by

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As members of the DNP Project Committee, we certify that we have read the DNP project prepared by Renee Sakalauski entitled "Providers' Knowledge, Attitudes and Willingness to Use an End-of-Life Protocol on an Inpatient Oncology Unit" and recommend that it be accepted as fulfilling the DNP project requirement for the Degree of Doctor of Nursing Practice.

  
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Final approval and acceptance of this DNP project is contingent upon the candidate's submission of the final copies of the DNP project to the Graduate College.

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Date: December 22, 2017

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SIGNED: Renee Sakalauski

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## DEDICATION

This project is dedicated to all of the oncology patients, who I cared for over the years, who fought tremendously and tenaciously for their lives, but ultimately lost their battle to cancer. May you look down from heaven and know that I still think of you. Your smiles and gracious hearts continue to fuel my soul to fight for patient-centered end-of-life care.

Know, that I will always hold your heart more tenderly than my own

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## ABSTRACT

**Objective:** The purpose of this Doctor of Nursing (DNP) project was to examine providers' knowledge, attitude, and willingness to use an end-of-life care protocol on an inpatient unit.

**Background:** Cancer is second leading cause of mortality in the United States and despite increases in hospice and palliative care services, many cancer patients at end-of-life are dying in the hospital setting. Research shows the use of an end-of-life care protocol set increases patient care outcomes and increases provider satisfaction with end-of-life care, however; they are not being utilized in many hospitals. The National Consensus Project (NCP) for quality palliative care published evidence based clinical practice guidelines as a set of standards for improving the quality of patient care specifically at end-of-life. There is very little research that examines determinants related to providers' knowledge, attitudes, and willingness to use an end-of-life care protocol based on the clinical practice guidelines established by the NCP.

**Methods:** Qualitative descriptive research study consisting of a electronic survey questionnaire.

**Setting:** Large cancer facility in Goodyear, Arizona.

**Participants:** Sample of 21 out of 35 providers that included hospitalists, physicians, oncologists, nurse practitioners, and physician assistants.

**Conclusions:** Providers were not knowledgeable regarding the NCP's clinical practice guidelines for end-of-life care, but their attitudes strongly favor the six suggested practice guidelines for actively dying patients, and they were somewhat willing to adopt these practices. There was also a moderate correlation between the number of years worked with end-of-life patients and the providers' willingness to learn more about and to use end-of-life care protocols in their practice.

## **CHAPTER I: STATEMENT OF THE PROBLEM**

Patients who are approaching end-of-life in the acute care setting are shown to have significant unmet physical and emotional needs specifically with pain management, dyspnea, anxiety, and spiritual needs (Teno, Freedman, Kasper, Gozalo, & Mor, 2015). Poorly controlled symptom management for dying patients has been attributed the lack of standardized order sets, however; the use of standardized end-of-life care order sets have significantly shown to improve patient comfort and nurse and provider satisfaction (Treece, 2007). The willingness to adopt or accept the use of an end-of-life protocol by providers in an inpatient setting is unknown. The focus of this study is to examine providers' knowledge, attitudes and willingness to use a standardized end-of-life care protocol in an inpatient oncology setting.

### **Background and Significance**

Cancer is the second leading cause of death in the United States, with nearly 1,600 oncology patients dying every day (American Cancer Society, 2013). Providing quality care to actively dying oncology patients in the hospital setting presents unique challenges for nurses and providers. Inpatient oncology patients at end-of-life require careful symptom management to ensure patient comfort and quality of care. Despite significant growth in hospice and palliative care services, there is an increased trend in utilization of hospitals in the last 90 days of life (Teno et al., 2013). There are several factors that contribute to the lack of hospice enrollment for cancer patients, which leads to this population becoming increasingly critical at end of life (Obermeyer, et al., 2014). Patients are reluctant to transition to hospice care in fear of not being able to seek second, third, and even fourth opinions. Due to this dynamic, patients are arriving to hospitals in critical conditions and are immediately admitted to inpatient units. They are often

too critical to transition to an outpatient hospice facility and they die in the hospital with inadequate symptom management, and lack of resources for family members (Carey, et al., 2017).

When evaluating the impact of end-of-life order sets for providers, a 2008 study reported an increase in provider's comfort levels with palliative care and were shown to improve symptom management for patients (Jarabek, Cha, Ruegg, Moynihan, & McDonald, 2008). Walling, Brown-Saltzman, Barry and Quan (2008) found that of the 89 providers interviewed regarding the implementation of an order protocol for end-of-life symptom management, nearly all of the providers found the use of the protocol to be valuable with regards to end-of-life care.

Research indicates a correlation between positive nursing attitudes and end-of-life care practices and the use of specific guidelines or protocols (Abarshi, Papavasiliou, Preston, Brown, & Payne, 2014), (Jarabek, Cha, Ruegg, Moynihan, & McDonald, 2008; Bakitas, Bishop, Caron, & Stephens, 2010; Treece 2007). A 2014 systematic review of nurses' attitudes and practice at end-of-life concluded that reported burdens could be supported by operational guidelines or protocols (Abarshi, Papavasiliou, Preston, Brown, & Payne, 2014). Velarde-Garcia et al. (2017) assessed difficulties perceived by nurses providing end-of-life care in the hospital setting and concluded that nurses need the use of guidelines or protocols specific to critically ill patients in order to provide quality of care.

Although there is a definite correlation between provider and nurse satisfaction with the use of an end-of-life care protocol, there is little evidence to suggest that providers are willing to adopt and utilize an end-of-life care protocol in the inpatient setting. Research exploring

providers' attitudes towards an evidence based end-of-life care protocol and their willingness to use such a protocol is also lacking.

### **Local Problem**

End of life care protocols at a cancer facility in Goodyear, Arizona are not currently being utilized by providers to standardize care for actively dying patients on an inpatient unit. The cancer facility is structured as an outpatient cancer facility for ongoing oncology treatment related to chemotherapy, radiation, surgery, physical therapy, rehabilitation, mind and body, nutrition, palliative care, and many other services. The facility is unique in that it also has an integrated inpatient unit designed to care for established patients after surgery and for oncologic emergencies related to treatment. The inpatient unit is designed to care for oncology patients at any acuity level from medical/surgical to ICU as well as patient's requiring hospitalization for chemotherapy administration.

Through a telephone interview and request for service, patients from all over the country are scheduled in advance for an intake appointment for the outpatient facility. However, there are several occasions where the patient is actively dying, but still arrives to the facility seeking treatment, and they are immediately admitted to the inpatient unit based on the assessment of the provider during their outpatient intake appointment. The patients are deemed too critically ill to pursue outpatient treatment and within days of being admitted to the hospital, they die on the inpatient unit. The cancer facility is not credentialed to offer an inpatient hospice option and palliative care consults are specific to outpatient services only. During the actively dying phase of these patients, hospitalists/providers write patient specific orders based on their own

preferences which are inconsistent from patient to patient and subsequently may not meet the patient's needs.

The directors and executives of the cancer facility have recognized the need for an evidence-based end-of-life care protocol or provider order set for providers to utilize for patients who are actively dying on the inpatient oncology unit. While there is a recognized need for such protocol, there has not been an assessment conducted among physicians, hospitalists, oncologists, nurse practitioners, and physician's assistants regarding their knowledge, attitudes, and willingness to use an end-of-life care protocol.

### **Purpose of the Project**

The purpose of this DNP project is to study providers' knowledge, attitudes and willingness to use an end-of-life care protocol for oncology patients actively dying on an inpatient unit at a cancer facility in Goodyear, Arizona.

The method of this project will involve administering a survey questionnaire to providers to ascertain their perceptions of an end-of-life care protocol. Key stakeholders include physicians, hospitalists, oncologists, nurse practitioners, and physician assistants who provide care to oncology patients in the facility. This project was an initial step in a quality improvement effort to standardize patient care, improve quality of patient care, and facilitate provider satisfaction with end-of-life care. Prior to implementing an end-of-life care protocol, an evaluation of providers' knowledge, attitudes and willingness to use a protocol is needed to assess their readiness to adopt this evidence-based practice.

### **Conceptual Framework**

In a scholarly doctorate of nursing practice (DNP) project, the purpose of utilizing theories, models, frameworks, and concepts is to provide a base or structure to guide care, understand phenomenon related to health care, achieve congruence between processes, evaluate effectiveness of interventions and improve efficient continuity of care (Zaccagnini & White, 2014). The use of a conceptual framework approach, specifically the Eight Domains of the NCP Guidelines for Quality Palliative Care, will guide and support the purpose of this proposed DNP project.

Further, it is proposed that provider knowledge, attitudes, and expressed willingness to use practice protocols are important areas to better understand in order to promote certain practices among providers. In general, the psychological literature related to the theory of planned behavior indicates that knowledge and attitudes can be predictors of actual behavior (Steinmetz, Knappstein, Ajzen, Schmidt, & Kabst, 2016).

A desired goal is that it is the subjective norm for providers within the cancer center in Goodyear, AZ that actively dying patients will receive provider specific orders at their end-of-life. This project is based upon the overall assumption is that the use of such protocol would positively impact the inpatient unit from a nursing and patient standpoint. It is important to determine provider knowledge, attitudes and willingness to use a protocol. Therefore, this DNP project would study providers' knowledge, attitudes and willingness to use of an end-of-life protocol for actively dying oncology patients on an inpatient unit. These findings may then help guide the implementation of an end-of-life care protocol and establish a subjective norm for providers focused on overall higher quality of care for their patients.

## **Eight Domains of the NCP Guidelines for Quality Palliative Care**

The National Consensus Project (NCP) for quality palliative care published clinical practice guidelines as a set of standards for improving quality of patient care at end-of-life (2013). This conceptual framework proposes that these eight domains set an evidence based standard for actively dying patients (NCPQPC, 2013). The domains are as follows: 1. Structure and Processes of Care, 2. Physical Aspects of Care, 3. Psychosocial and Psychiatric Aspects of Care, 4. Social Aspects of Care, 5. Spiritual, Religious, and Existential Aspects of Care, 6. Cultural Aspects of Care, 7. Care of the Patient at End of Life, and 8. Ethical and Legal Aspects of Care. The use of this framework will incorporate the eight domains for quality palliative care, specifically the seventh domain related to the care of the patient at end-of-life. The preferred practice guidelines of the seventh domain will provide the appropriate information and structure to design the survey for this DNP project.

### **Domain 7: Care of the Patient at End of Life**

The seventh domain has four guidelines that focus of the care of the patient at end-of-life. There are also six preferred practice guidelines described as preferred practice 26-31. The following are the four guidelines described in the NCPQPC 2013 publication.

Guideline 7.1 – The interdisciplinary team identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of patients and families.

Guideline 7.2 – The interdisciplinary team assesses and in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential symptoms, patient and

family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures.

Guideline 7.3 – Respectful post-death care is delivered in a respectful manner that honors the patient and family culture and religious practices.

Guideline 7.4 – An immediate bereavement plan is activated post-death.

These guidelines were established to ensure that the interdisciplinary team attends to the patient's and family's values, preferences, beliefs, culture, and religion to promote a peaceful, dignified and respectful death (NCPQPC, 2013).

Under Domain 7, there are six preferred practice guidelines for care of patients at end-of-life. The six preferred practice guidelines are as follows in the NCPQPC 2013 publication:

- Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.
- The family is educated on a timely basis regarding signs and symptoms of imminent death in a developmentally, age-, and culturally appropriate manner.
- As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for site of death, and fulfill patient and family preferences when possible.
- Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns and fears about using narcotics and of analgesics hastening death.
- Treat the body post-death with respect according to the cultural and religious practices of the family and in accordance with local law.

- Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death when the family remains the focus of care.

### **Research Questions**

The aim of this project is to describe healthcare providers' self-reported knowledge of an end-of-life care protocol, attitudes towards standardization of care based on clinical practice guidelines, and willingness to use an end-of-life care protocol.

Three research questions of this study are as follows:

1. What is health care providers' knowledge about an end-of-life care protocol?
2. What are health care providers' attitudes towards an end-of-life care protocol?
3. What is health care providers' willingness to use an end-of-life care protocol?

Three research questions were developed to describe the cognitive dimensions of practice: knowledge about a particular practice, attitudes about the value of a practice, and willingness to engage in a certain form of practice, in this case, an end-of-life care protocol. The seventh domain of the Eight Domains for quality palliative care conceptual framework provided the content for the targeted practice protocol. These questions will be evaluated based upon the health care providers' survey responses regarding their knowledge, attitudes, and willingness to use an end-of-life care protocol in practice.

## **CHAPTER II: LITERATURE REVIEW**

### **Synthesis of Evidence**

The National Consensus Project (NCP) for quality palliative care published clinical practice guidelines as a set of standards for improving quality of patient care at end-of-life (2013). Due to the uncertainty of outcomes for patients with cancer, these guidelines are imperative among oncology patients at end of life. Research indicates the importance of having guidelines, order sets, or protocols for actively dying patients (Lynch, 2014), (Bakitas, Bishop, Caron, & Stephens, 2010), (Treece P. , 2007).

Research shows strong evidence to support palliative care models and/or end-of-life care protocols for patients actively dying in the hospital setting. Research shows positive patient outcomes related to symptom management and nurse and provider satisfaction with the use of an end-of-life care protocol for patients dying in acute care settings. To synthesize research related to this phenomenon, several literature searches were conducted using CINAHL, PubMed, Cochrane and Embase. The following key words or Boolean phrases were utilized for the searches: palliative care, inpatient, end-of-life, and protocol. other related terms that were used to search included: dying, hospital, order sets, guidelines, hospice, and symptom management. The inclusion criteria for the search included: human studies, published within the last fifteen years, and English language. The search yielded a total of 123 articles. Articles were excluded based on duplication, setting, and patient's acuity. Articles were included based on relevancy to an inpatient acute care setting and end-of-life.

There is significant evidence to support the use of palliative care models for oncology patients at end-of-life (Lynch, 2014). A literature review regarding palliative care delivery

models showed that nursing should utilize a model for optimal impact on patient care outcomes (Wiencek & Coyne, 2014). Another literature review on the use of palliative care models designed with the NCP framework showed positive outcomes for consensus of guidelines that support palliative care (Bakitas, Bishop, Caron, & Stephens, 2010).

There is also evidence to support nursing and provider satisfaction with the use of a standardized end-of-life care protocol for actively dying patients. Literature and quantitative studies show that implementation of a withdrawal of life support order form was associated with high levels of physician and nurse satisfaction (Treece, et al., 2004). A qualitative study conducted at The Mayo Clinic, found a 10% increase in resident's comfort levels regarding palliative care after the implementation of a standardized order set (Jarabek, Cha, Ruegg, Moynihan, & McDonald, 2008). Another qualitative study conducted at UCLA Health Systems found that providers found the use of end-of-life symptom management order (ESMO) protocols to be favorable and valuable (Walling, Brown-Saltzman, Barry, Quan, & Wenger, 2008).

Research also indicates a correlation between positive nursing attitudes and practice at end-of-life with the use of specific guidelines or protocols. A systematic review of nurses' attitudes and practice at end-of-life concluded that reported burdens could be supported by operational guidelines or protocols (Abarshi, Papavasiliou, Preston, Brown, & Payne, 2014). A qualitative study concluded that nurses need the use of guidelines or protocols specific to critically ill patients in order to provide quality of care (Velarde-Garcia, Pulido-Mendoza, Moro-Tejedor, Cachon-Perez, & Palacios-Cena, 2016). Although research shows that nurses favor the use of an end-of-life care protocol, there is still reluctance from inpatient units to utilize such protocols. A retrospective study evaluating the consistency of use of an end-of-life symptom

management protocol indicated that provider characteristics suggest inadequate attention to comfort at the end of life (Walling, Barry, Yamamoto, & Wenger, 2011). These findings suggest that providers may actually impact or affect the use or consistency to use an end-of-life care protocol based on their own preferences despite evidence-based research which supports the use of such protocols at end-of-life.

A quantitative study that examined which domains or elements of the NCP palliative care guidelines were considered important at end-of-life found that parents and clinician highly value the majority of palliative care domain outlined in the NCP framework (Kassam, Skiadaresis, Habib, Alexander, & Wolfe, 2013). An extensive systematic review evaluating the Liverpool Care Pathway revealed that breathlessness or dyspnea was better controlled for patients on the care pathway compared to patients not on the pathway (Chan, Webster, & Bowers, 2016).

The biggest gap in the research findings is the lack of strong literature regarding inpatient providers perceptions towards the use of an end-of-life care protocol in an inpatient oncology hospital setting. End-of-life care protocols in an inpatient setting is known among the palliative care community providers and evidence-based practice has already been research to support implementation. The NCP established clinical practice guidelines to support this phenomenon. However, there is very little literature regarding providers' knowledge, attitudes and willingness to use an end-of-life care protocol.

### **CHAPTER III: METHODS**

As part of the development for this DNP project, the methodology behind the structure of the actual project is outlined here in the method sections of this project proposal. The methodology includes descriptions of the design, sample, setting, data analysis, resources, and budget. Each of these components of the methodology are thoroughly described to accurately illustrate the entire project.

#### **Design**

The design of this DNP project is a quantitative descriptive research study. The aim of the study is to examine providers' knowledge, attitudes, and willingness to use an end-of-life care protocol for oncology patients actively dying on an inpatient unit in order to identify their acceptance and willingness to utilize an evidence-based protocol in the future. The results from this study will elicit pertinent information for future quality improvement projects related to end-of-life care protocols for inpatient oncology units.

#### **Sample Criteria**

The targeted participants of this study included oncology providers which encompassed physicians, hospitalists, oncologists, nurse practitioners and physician's assistants. There are thirty-five providers who provide direct patient care to oncology patient in the facility. The target number of participants was a maximum of 35 and a minimum of 10 participants. Criteria for participation were the following characteristics: currently employed with Cancer Treatment Centers of America, and provider direct patient care to oncology patients.

### **Setting**

This DNP project occurred at a large cancer center in Goodyear, Arizona. The cancer center provides services that include outpatient clinics, chemotherapy infusion, radiation, research, surgery, imaging, physical therapy, naturopathic medicine, mental health, rehabilitation, internal medicine, pain management, and an inpatient hospital unit. This project took place throughout the cancer center as patients often transition from the outpatient setting to the inpatient setting. The patient population for this inpatient setting includes oncology, chemotherapy, medical, surgical, telemetry, progressive care, and ICU.

### **Questionnaire**

The online survey was composed of five demographic questions, and 16 items regarding use of an end-of-life care protocol: four dichotomous Knowledge items, seven Attitude items measured on a 4-point Likert-type scale, and five Willingness items measured on a 4-point Likert-type scale (Appendix E). The survey questions were created based on the preferred practices of Domain 7 of the Eight Domains of NCP for Quality Palliative Care and the specific oncology inpatient setting. The investigator's advising committee reviewed and provided evaluation of the face validity and content validity of the items.

### **Data Collection Procedure**

Approval was obtained from the Director of Professional Practice, Jaclyn Figueras, from Cancer Treatment Centers of America (Appendix A), and from the University of Arizona IRB (Appendix B). Data collection for this project occurred through the use of an emailed electronic survey based upon the investigator-designed questionnaire. The survey platform application Surveygizmo was used for distribution of electronic survey, informed consent, data collection,

and data analysis. Surveygizmo is a survey platform that allows for construction, customization, distribution, and analysis of survey data in a confidential and anonymous manner (Surveygizmo, 2017). Instructions, purpose of the study, informed consent, and deadline to complete the survey along with the survey items were included in the email correspondence.

The online survey was distributed to 35 providers using an anonymous and confidential survey platform called Surveygizmo. Every individual identified as a physician, hospitalist, oncologist, nurse practitioner, or physician assistant who provides direct care to oncology patients was invited to participate in the study.

In order to preserve the integrity of the study and the participants, each individual received a recruitment email requesting their participation in completing the survey, but also explained that their participation was voluntary, anonymous, and confidential. The recruitment email stated that they were specifically selected because they provided direct patient care to oncology patients (Appendix C). The online survey was distributed to each of the 35 providers, and was available for one week, from November 27, 2017 through December 4, 2017.

### **Data Analysis**

The quantitative data from the 21 completed surveys were transferred from Surveygizmo to a Microsoft Excel datasheet. The data were analyzed using descriptive statistics, including measures of central tendency (mean, median, mode) and dispersion (range and standard deviation) on the demographic questionnaire (to describe the sample) and provider survey (to describe participant responses) on each scale: knowledge, attitudes, and willingness (Polit & Beck, 2012). The data were also analyzed using Pearson's  $r$  statistic to test correlations between number of years as an oncology provider with each of the 16 questions as well as number of

years providing end-of-life care with each of the 16 questions. The resources used to analyze and report the data from the surveys included a spreadsheet from Surveygizmo which was transferred to Microsoft Office Excel.

## **Ethical Considerations**

### **Informed Consent**

Participants in any study should always be respected as individuals who are capable of making their own decisions (Polit & Beck, 2012). This DNP project respects human dignity by asking participants for their willing participation in the electronic survey with full disclosure and informed consent of their responses (Appendix D).

### **Beneficence**

It is the duty of the investigator to ensure that human research is done to benefit a specific population and that harm is minimized during a research study (Polit & Beck, 2012). There was no known or foreseen immediate, long-term or detrimental harm to the participants completing the online survey for this quantitative descriptive project.

### **Justice**

Study participants have the right to fair treatment and right to privacy and should be selected based off the study requirements (Polit & Beck, 2012). All individual selected to participate in this project were selected based on the direct patient care they provide on the oncology unit. Each participant will remain anonymous and their privacy will be ensured and respected.

**Institutional Review Board (IRB)**

This project was reviewed by the Institutional Review Board (IRB) through the University of Arizona to ensure that the project followed the ethical requirements appropriate for research. On November 22, 2017, the IRB determined that this project did not require the oversight of IRB (Appendix B).

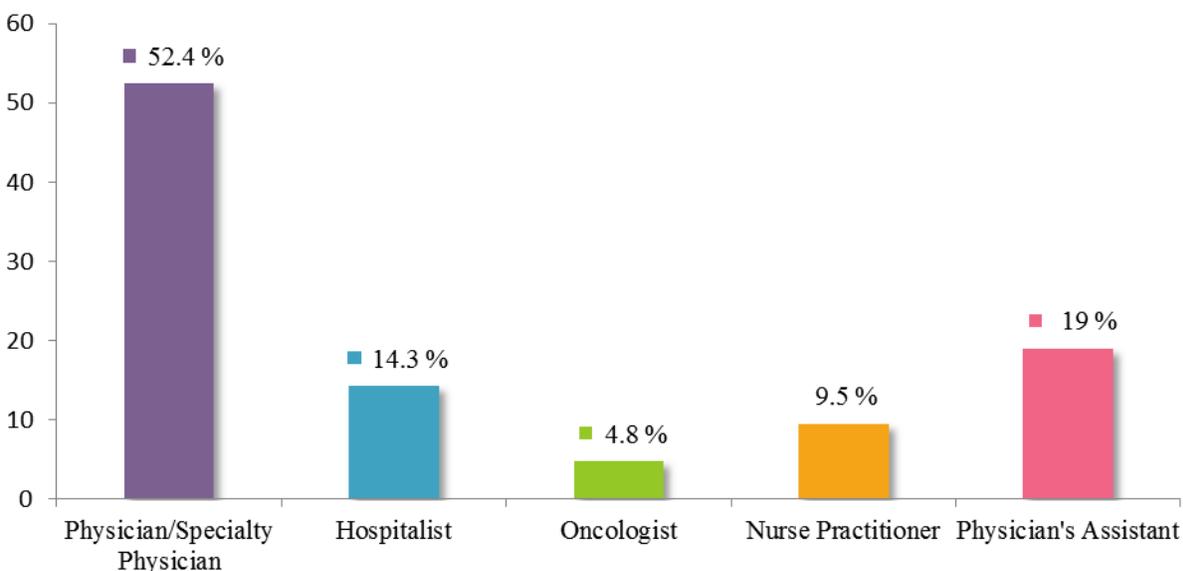
## CHAPTER IV: RESULTS AND DISCUSSION

This section presents the findings for each goal of the study along with a description of the sample and reliability estimate of the questionnaire based upon the current sample. The data obtained from the online survey were analyzed using descriptive statistics, including measures of central tendency (mean, median, mode) and dispersion (range and standard deviation) and Pearson's  $r$  correlation tests on each item in the survey to assess knowledge, attitudes, and willingness to use an end-of-life care protocol (Polit & Beck, 2012).

### Description of Sample

A sample of 21 participants (a 60% response rate) responded and completed all questions on the survey. Shown in Table 1, of the sample size (N=21), 11 (52.4%) were specialty physicians, three (14.3%) were hospitalists, one (4.8%) was an oncologist, two (9.5%) were nurse practitioners, and four (19%) were physician's assistants.

TABLE 1. *Participant Sample (N=21) Distributed Across Specialty Type/Profession*



### **Sample Demographic**

All 21 participants responded that they do provide direct patient care for oncology patients. Each participant then indicated how many years they were employed as a clinician, how many years they worked in an oncology setting, and how many years they provided end-of-life care to patients. Table 2 lists the participant demographic and total number of years for each category. All three hospitalists (14.3%) reported the same number of years for each category, which totaled 10 years for the three hospitalists. This also indicates that all three hospitalists have worked in oncology and with end-of-life care since becoming physicians. The one oncologist (4.8%) reported working as a clinician for 40 years with 39 of those years in oncology and end-of-life care. The two nurse practitioners (9.5%) reported working as clinicians for a combined total of 24 years with 27 combined years in oncology, and 38 combined years with end-of-life patients. This indicates that the nurse practitioners included the number of years they worked as registered nurses before they became nurse practitioners. The 11 specialty physicians (52.4%) reported a combined total of 142.5 years employed as clinicians with only 66.5 of those years in an oncology setting, and 52 years with end-of-life care. This indicates that only 33% of the total combined years employed as physicians was related to end-of-life. The four physician's assistants (19%) reported a combined total of 46 years employed as clinicians with 16.5 of those years in oncology, and 12 years with end-of-life care.

TABLE 2. *Participants' Mean Number of Years Worked as a Clinician, in an Oncology Setting, and with End-of-Life Care*

<b>PARTICIPANT DEMOGRAPHIC TABLE</b>			
	<b>How many years have you been employed as a clinician?</b>	<b>How many years have you worked in an oncology setting?</b>	<b>How many years have you provided end-of-life care to patients?</b>
<b>Hospitalist</b>	3.33	3.33	3.33
<b>Nurse Practitioner</b>	12	13.5	19
<b>Oncologist</b>	40	39	39
<b>Physician/Specialty Physician</b>	12.95	6.05	4.73
<b>Physician's Assistant</b>	11.5	4.16	3

### **Survey Questions**

Table 3 illustrates descriptive statistics as well as correlation coefficient statistics for each survey question. This correlation analysis was an additional analysis done to explore how provider specialty might relate to their responses on the survey. Each of the questions and results will be discussed individually under each research question.

TABLE 3. Results on Selected Items Across Participants (N = 21)

<b>Knowledge, Attitudes, and Willingness to Use an End-of-Life Care Protocol Survey</b>					
<b>Knowledge</b>	<b>Mean</b>	<b>Mode</b>	<b>SD</b>	<b>Pearson's r # of years in oncology</b>	<b>Pearson's r # of years with EOL</b>
Question 1	1.9	2	0.3	0.07	0.08
Question 2	1.95	2	0.22	0.14	0.15
Question 3	1.95	2	0.22	0.14	0.15
Question 4	1.38	1	0.5	-0.08	<b>-0.34*</b>
<b>Attitudes</b>	<b>Mean</b>	<b>Mode</b>	<b>SD</b>	<b>Pearson's r # of years in oncology</b>	<b>Pearson's r # of years with EOL</b>
Question 5	1	1	0	Void	Void
Question 6	1.05	1	0.22	-0.15	-0.15
Question 7	1.05	1	0.22	-0.12	<b>0.44*</b>
Question 8	1	1	0	Void	Void
Question 9	1.05	1	0.22	-0.12	<b>0.44*</b>
Question 10	1.05	1	0.22	-0.12	<b>0.44*</b>
Question 11	1.67	1	0.73	-0.09	0.06
<b>Willingness</b>	<b>Mean</b>	<b>Mode</b>	<b>SD</b>	<b>Pearson's r # of years in oncology</b>	<b>Pearson's r # of years with EOL</b>
Question 12	1.29	1	0.56	-0.17	0.17
Question 13	1.52	1	0.68	-0.01	<b>0.41*</b>
Question 14	1.76	2	0.7	0.22	0.11
Question 15	1.81	2	0.75	0.27	0.21
Question 16	1.43	1	0.6	<b>0.30*</b>	<b>0.36*</b>
4-point Likert Scale: 1 = Strongly Agree, 2 = Agree, 3 = Disagree, 4 = Strongly Disagree					
Dichotomous Scaling for Questions 1-4					
* = < .05					

## Results of Each Research Question

### Knowledge

**Research question 1: What are health care providers' knowledge about an end-of-life care protocol?** For this research question, participants responded to four questions regarding providers' knowledge base using a dichotomous scale with answer options of either "Yes" or "No." These questions sought to understand each provider's knowledge base regarding the Eight Domains of the National Consensus Project (NCP) for Quality Palliative Care, the Seventh Domain of the NCP for Quality Palliative Care, the six practice guideless for end-of-life care, and each providers' perceived knowledge of end-of-life care (Table 4).

TABLE 4. *Participants' (N=21) Results on Each Knowledge Question*

Knowledge Question	Responded YES
Are you familiar with the Eight Domains of the National Consensus Project (NCP) for Quality Palliative Care?	0.095%
Did you know that the Seventh Domain of the NCP for Quality Palliative Care is specifically for end-of-life care?	0.048%
Are you aware that there are six preferred practice guidelines from the NCP for Quality Palliative Care for care of the patient at end-of-life?	0.048%
Are you knowledgeable regarding end-of-life care for oncology patients?	0.619%

Of the total participants (N=21), 19 providers (90.5%) were not familiar with the Eight Domains of NCP for Quality Palliative Care. Two providers (9.5%), one nurse practitioner and one specialty physician, indicated they were familiar with the Eight Domains of NCP for Quality Palliative Care.

One provider (4.8%), a specialty physician, knew that the Seventh Domain of the NCP for Quality Palliative Care was specifically for end-of-life care. Twenty providers (95.2%) did not know that the Seventh Domain of the NCP for Quality Palliative Care was specifically for end-of-life care.

One provider (4.8%), a specialty physician, was aware that there are six preferred practice guidelines from the NCP for Quality Palliative Care for care of the patient at end-of-life. Twenty (95.2%) were not aware that there are six preferred practice guidelines from the NCP for Quality Palliative Care for care of the patient at end-of-life care.

Thirteen providers (61.9%), (one oncologist, one physician's assistant, two nurse practitioners, three hospitalists, and six specialty physicians) reported being knowledgeable regarding end-of-life care for oncology patients. Eight providers (38.1%) reported not being knowledgeable regarding end-of-life care for oncology patients.

## **Attitudes**

**Research question 2: What are health care providers' attitudes towards an end-of-life care protocol?** A set of seven questions (Questions 5-11) on the survey were used to examine providers' attitudes regarding an end-of-life care protocol. The first six questions were developed based on the six preferred clinical practices guidelines established by the NCP for Quality Palliative Care specifically for actively dying patients. The seventh question addressed the providers' perceived attitude regarding an end-of-life care protocol. These questions were designed using a 4-point Likert scale with response categories of *Strongly Agree*, *Agree*, *Disagree*, and *Strongly Disagree* (Table 5). Descriptive statistical analysis of these questions is illustrated on Table 3.

TABLE 5. *Participants' (N = 21) Attitude Toward NCP EOL Care Guidelines*

Question	Strongly Agree	Agree	Disagree	Strongly Disagree
5	21	0	0	0
6	20	1	0	0
7	20	1	0	0
8	21	0	0	0
9	20	1	0	0
10	20	1	0	0
11	10	8	3	0

For question 5, every participant (N=21) “strongly agreed” that recognizing and documenting the transition of a patient to the active dying phase or end-of-life phase and communicating to the patient, family, and staff the expectation of imminent death is important for an inpatient unit.

For question 6, 20 participants “strongly agreed” and one participant (a specialty physician) “agreed” that it is important for the patient and family to be educated on a timely basis regarding signs and symptoms of imminent death in a developmentally, age appropriate, and culturally appropriate manner.

For question 7, 20 participants “strongly agreed” and one participant (a specialty physician) “agreed” that it is important to routinely ascertain and document patient and family wishes about the care setting for site of death, and to fulfill patient and family preferences when possible.

For question 8, all 21 participants “strongly agreed” that it is important to provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and to address concerns and fears about the use of narcotics.

For question 9, 20 participants “strongly agreed” and one participant (a specialty physician) “agreed” that it is important to treat the body post-death with respect according to the cultural and religious practices of the family and in accordance with local law.

For question 10, 20 participants “strongly agreed” and one participant (a specialty physician) “agreed” that it is important to facilitate effective grieving by implementing a bereavement care plan in a timely manner after the patient's death when the family remains the focus of care.

For question 11, ten participants “strongly agreed,” eight participants, “agreed,” and three participants “disagreed” that it is important for their practice to use a standardized end-of-life care protocol for actively dying patients. The 10 participants who “strongly agreed” included one hospitalist, two physician’s assistants, two nurse practitioners, and five specialty physicians. The eight participants who “agreed” included one oncologist, one physician’s assistant, two hospitalists, and four specialty physicians. The three participants who “disagreed” included one physician’s assistant and two specialty physicians.

## **Willingness**

**Research question 3: What are health care providers’ willingness to use an end-of-life care protocol?** Questions 12 through 16 sought to examine providers’ willingness to use an end-of-life care protocol, willingness to learn about the NCP clinical practice guidelines, willingness to provide input regarding an end-of-life protocol for the inpatient unit, willingness

to create an evidence-based end-of-life care protocol, and willingness to learn more about end-of-life care protocols. These five questions were designed to assess willingness to adopt a new concept, willingness to learn, and willingness of involvement for practice change. These questions were designed using a 4-point Likert scale with response categories of *Strongly Agree*, *Agree*, *Disagree*, and *Strongly Disagree* (Table 6). Descriptive statistical analysis of these questions is illustrated on Table 3.

TABLE 6. *Participants' (N=21) Willingness to Use an EOL Care Protocol*

<b>Question</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
<b>12</b>	16	4	1	0
<b>13</b>	12	7	2	0
<b>14</b>	8	10	3	0
<b>15</b>	8	9	4	0
<b>16</b>	13	7	1	0

For question 12, 16 participants “strongly agreed,” four participants, “agreed,” and one participant “disagreed” that they were willing to learn about the Eight Domains of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care. The 16 participants who “strongly agreed” included eight specialty physicians, four physician’s assistants, two hospitalists, one oncologist, and one nurse practitioner. The four participants who “agreed” included one hospitalist, one nurse practitioner, and two specialty physicians. The one participant who “disagreed” is a specialty physician.

For question 13, 12 participants “strongly agreed,” seven participants “agreed,” and two participants “disagreed” that they were willing to use a standardized evidenced-based end-of-life care protocol in their practice. The 12 participants who “strongly agreed” included one nurse practitioner, one hospitalist, seven specialty physicians, and three physician’s assistants. The seven participants who “agreed” included one nurse practitioner, one oncologist, one physician’s assistants, two hospitalists, and two specialty physicians. The two participants who “disagreed” included two specialty physicians.

For question 14, eight participants “strongly agreed,” 10 participants “agreed,” and three participants “disagreed” that they are willing to provide input regarding an end-of-life care protocol for the inpatient unit. The eight participants that “strongly agreed” include four physician’s assistants, three specialty physicians, and one hospitalist. The 10 participants who “agreed” included one nurse practitioner, one oncologist, two hospitalists, and six specialty physicians. The three participants who “disagreed” included one nurse practitioner and two specialty physicians.

For question 15, eight participants “strongly agreed,” nine participants “agreed,” and four participants “disagreed” that they are willing to be part of a team that creates an evidence-based end-of-life care protocol for actively dying patients on the inpatient unit. The eight participants who “strongly agreed” included two hospitalists, three specialty physicians, and three physician’s assistants. The nine participants who “agreed” include one oncologist, one hospitalist, one physician’s assistant, and six specialty physicians. The four participants who “disagreed” included two nurse practitioners and two specialty physicians.

For question 16, 13 participants “strongly agree,” seven participants “agreed,” and one participant “disagreed” that they are willing to learn more about end-of-life care protocols. The 13 participants who “strongly agreed” included seven specialty physicians, four physician’s assistants, and two hospitalists. The seven participants who “agreed” included one oncologist, one hospitalist, two nurse practitioners, and three specialty physicians. The one participant who “disagreed” included a specialty physician.

### **Additional Analyses**

In addition to analyzing descriptive statistics, including measures of central tendency and dispersion on the provider survey, the data were also analyzed using Pearson’s  $r$  statistic to test correlations between number of years as an oncology provider with each of the 16 questions as well as number of years providing end-of-life care with each of the 16 questions. As illustrated on Table 3, there were seven significant correlations between certain items and years worked in oncology and/or years worked with patients at end-of-life. One significant correlation found was that the fewer years worked with patients at end-of-life correlated with being more knowledgeable about end-of-life care in oncology.

Another significant correlation found was that the greater years of experience with patients at end-of-life correlated with the providers’ strongly favoring the importance to routinely ascertain and document patient and family wishes about the care setting for site of death. In addition, fulfilling patient and family preferences when possible, the importance to treat the body post-death with respect according to the cultural and religious practices of the family and in accordance with local law. And the importance to facilitate effective grieving by implementing a

bereavement care plan in a timely manner after the patient's death when the family remains the focus of care, and the importance.

Another significant correlation found was that the greater years of experience with patients at end-of-life correlated with the providers' willingness to use a standardized evidenced-based end-of-life care protocol in their practice. These findings seem to illustrate a correlation with the number of years experienced with end-of-life care and their positive attitudes towards the NCP end-of-life guidelines and their willingness to use a protocol in their practice.

### **Discussion of Results**

With regard to providers' knowledge about an end-of-life care protocol, less than 10% of providers were knowledgeable about the Eight Domains of NCP for Quality Palliative Care. In 2004, The NCP identified and published eight important domains of quality palliative care and since its inception, the NCP has published several evidenced-based clinical practice guidelines specifically for end-of-life (NCPQPC, 2013). Unless these providers have intentionally incorporated palliative care or end-of-life clinical guidelines into their practice, then it is not surprising that their knowledge base is lacking with regard to these guidelines and protocols. However, despite their lack of knowledge of the NCP preferred clinical practice guidelines, 61% of the providers felt they were knowledgeable about end-of-life care for oncology patients. A possible reason for not exploring or adopting an end-of-life care protocol is that the providers already feel that they are knowledgeable about end-of-life care. Another reason for not adopting an end-of-life care protocol may be related to the providers' role in making the decision that the patient is actually at end-of-life. A large qualitative study in two Los Angeles hospitals explored providers' defined roles of end-of-life care their perceptions of their specific tasks for initiating

end-of-life care found that providers were more comfortable with a multidisciplinary approach to that decision (Nedjat-Haiem, et al., 2017).

With regard to providers' attitudes towards an end-of-life care protocol, every provider either "strongly agreed" or "agreed," with the six suggested practice guidelines for end-of-life care. In fact, 100% of providers responded with "strongly agree" for two of the questions and 95% of providers responded with "strongly agree" for four of the questions. While the majority of providers strongly agreed with the six evidence-based practiced guidelines, only 47.6% of providers "strongly agreed," only 38.1% "agreed," and 14.3% "disagreed" that it is important for their practice to use a standardized end-of-life care protocol for actively dying patients. This drastic attitude shift could be related to the descriptive word "standardized." More research is needed to identify reasons why the providers do not feel that it is important for their practice to use an end-of-life care protocol.

With regard to providers' willingness to use an end-of-life care protocol, the majority of providers "strongly agreed" or "agreed" that they were willing to learn more about the Eight Domains of the NCP for Quality Palliative Care and willing to learn about end-of-life care protocols. The majority of providers also either "strongly agreed" or "agreed" that they were willing to use an end-of-life care protocol. Additionally, most providers either "strongly agreed" or "agreed" to be willing to provide input and/or be part of team that creates an evidence-based end-of-life care protocol for the unit. While providers were not knowledgeable regarding the NCP's clinical practice guidelines for end-of-life care, their attitudes strongly favor the six suggested practice guidelines for actively dying patients and the majority of providers were willing to adopt these practices.

Providers were not knowledgeable regarding the NCP's clinical practice guidelines for end-of-life care, but their attitudes strongly favor the six suggested practice guidelines for actively dying patients, and they were somewhat willing to adopt these practices. There was also a moderate correlation between the number of years worked with end-of-life patients and the providers' willingness to use a standardized evidenced-based end-of-life care protocol in their practice. These findings seem to illustrate a correlation with the number of years experienced with end-of-life care and their positive attitudes towards the NCP end-of-life guidelines and their willingness to use a protocol in their practice.

### **Limitations and Strengths**

A limitation of this project is the generalizability of survey findings into other inpatient oncology units. Since the purpose of this quantitative descriptive project was to assess providers' knowledge, attitudes, and willingness to use an end-of-life care protocol for future implementation, the findings of this project are specific to this cancer facility. The survey tool used for this project did not undergo formal validity testing as it was created by the investigator to assess possible determinates to future implementation of policy change. However, the responses suggested that there was internal consistency across items, and that respondents understood the items. There were no incomplete survey responses.

### **Implications for Future Practice**

Results from this quantitative research project were anticipated to be used for improved implementation and adoption strategies for a quality improvement effort to standardize patient care, improve quality of patient care, and facilitate provider satisfaction with end-of-life care. Prior to implementing an end-of-life care protocol, an evaluation of providers' knowledge,

attitudes and willingness to use a protocol was needed to assess their readiness and willingness to adopt this evidence-based practice.

### **Implications for Future Inquiry**

It is unknown whether the specific culture, philosophy, and mission of the facility may have influenced recruitment and responses from the participants. An implication for future inquiry would be to explore how characteristics of the setting may influence provider's knowledge, attitudes and willingness to use an end-of-life care protocol for actively dying patients on an inpatient oncology unit.

APPENDIX A:

APPROVAL FROM CANCER TREATMENT CENTERS OF AMERICA



14200 W. Celebrate Life Way  
Goodyear, AZ 85338

tel 623-207-3000  
fax 623-207-3003  
web [cancercenter.com](http://cancercenter.com)

To whom it may concern,

Renee Sakalauski has permission to conduct her U of A DNP quantitative research study at Cancer Treatment Centers of America, Western Regional Medical Center (WRMC). Renee has permission to access the WRMC physician email data base and work addresses to submit her questionnaire. The organization is happy to partner with Renee and her research study.

If you have any questions, I can be reached at [Jackie.Figueas@ctca-hope.com](mailto:Jackie.Figueas@ctca-hope.com) or at 623-207-3741.

Thank you,

Jaclyn Figueras, MSN, RN OCN  
Director of Professional Practice

APPENDIX B:  
THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD APPROVAL  
LETTER



**Research**  
Office for Research & Discovery

Human Subjects  
Protection Program

1618 E. Helen St.  
P.O.Box 245137  
Tucson, AZ 85724-5137  
Tel: (520) 626-6721  
<http://rgw.arizona.edu/compliance/home>

<b>Date:</b>	November 22, 2017
<b>Principal Investigator:</b>	Renee Sakalauski
<b>Protocol Number:</b>	1711050860
<b>Protocol Title:</b>	PROVIDERS' KNOWLEDGE, ATTITUDES AND WILLINGNESS TO USE AN END-OF-LIFE CARE PROTOCOL ON AN INPATIENT ONCOLOGY UNIT
<b>Determination:</b>	Human Subjects Review not Required

The project listed above does not require oversight by the University of Arizona because the project does not meet the definition of 'research' and/or 'human subject'.

- **Not Research as defined by 45 CFR 46.102(d):** As presented, the activities described above do not meet the definition of research as cited in the regulations issued by the U.S. Department of Health and Human Services which state that "research means a systematic investigation, including research development, testing and evaluation, designed to contribute to generalizable knowledge".
- **Not Human Subjects Research as defined by 45 CFR 46.102(f):** As presented, the activities described above do not meet the definition of research involving human subjects as cited in the regulations issued by the U.S. Department of Health and Human Services which state that "human subject means a living individual about whom an investigator (whether professional or student) conducting research obtains data through intervention *or* interaction with the individual, or identifiable private information".

Note: Modifications to projects not requiring human subjects review that change the nature of the project should be submitted to the Human Subjects Protection Program (HSPP) for a new determination (e.g. addition of research with children, specimen collection, participant observation, prospective collection of data when the study was previously retrospective in nature, and broadening the scope or nature of the research question). Please contact the HSPP to consult on whether the proposed changes need further review.

The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).

APPENDIX C:  
SURVEY RECRUITMENT LETTER

Dear provider,

In the next few days you will receive an email requesting your participation in an online survey for a quality improvement project.

The purpose of this quality improvement project is to assess providers' knowledge, attitudes and willingness to use an end-of-life care protocol for actively dying patients on the inpatient unit at Cancer Treatment Centers of American (CTCA), Western. This is a quality improvement project being conducted by Renee Sakalauski, Adult Gerontology Acute Care Nurse Practitioner student at The University of Arizona.

You are invited to participate in this quality improvement project because you are a specialty physician, hospitalist, oncologist, nurse practitioner or physician's assistant.

Your participation in this quality improvement project is completely voluntary and confidential. You may choose not to participate. The project involves completing an online survey that will take approximately 5-10 minutes. The results of this project will be used for scholarly purposes only and may be shared with representatives from The University of Arizona and Cancer Treatment Centers of America.

Best regards,

Renee Sakalauski, BA, RN, BSN, OCN

APPENDIX D:  
INFORMED CONSENT

## End-of-Life Care Protocol Study

The purpose of this quality improvement project is to assess providers' knowledge, attitudes and willingness to use an end-of-life care protocol for actively dying patients on the inpatient unit at Cancer Treatment Centers of America (CTCA), Western. This is a quality improvement project being conducted by Renee Sakalauski, Adult Gerontology Acute Care Nurse Practitioner student at The University of Arizona. You have been invited to participate in this quality improvement project because you are a specialty physician, hospitalist, oncologist, nurse practitioner or physician's assistant.

Your participation in this quality improvement project is voluntary. You may choose not to participate. If you decide to participate in this quality improvement project, you may withdraw at any time. If you decide not to participate in this project or if you withdraw from participating at any time, you will not be penalized in any way.

The procedure involves completing an online survey that will take approximately 5-10 minutes. Your responses are anonymous and confidential. All data is stored in a password protected electronic format. To help protect your confidentiality, the survey will not contain information that will personally identify you. The results of this project will be used for scholarly purposes only and may be shared with representatives from The University of Arizona and Cancer Treatment Centers of America.

**ELECTRONIC INFORMED CONSENT: Please select your choice below.**

Clicking on the "Yes" button below in question 1 indicates that:

- you have read the above information
- you voluntarily agree to participate
- you are at least 18 years of age

If you do not wish to participate in the research study, please decline participation by clicking on the "No" button and exit the survey.

1. By clicking "Yes", I am giving informed consent to participate in this study. \*

- Yes
- No
-

APPENDIX E:  
ONLINE SURVEY

**Demographic Questions:**

#	Question	Answer
1	Do you provide direct patient care for oncology patients?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2	How many years have you been employed as a clinician?	_____ years
3	How many years have you worked in an oncology setting?	_____ years
4	Indicate whether you are a specialty physician, hospitalist, oncologist, nurse practitioner, or physician's assistant?	<input type="checkbox"/> Specialty Physician <input type="checkbox"/> Hospitalist <input type="checkbox"/> Oncologist <input type="checkbox"/> Nurse practitioner <input type="checkbox"/> Physician's assistant
5	How many years have you provided end-of-life care to patients?	_____ years

**Knowledge questions:**

#	Question	Answer
1	Are you familiar with the Eight Domains of the National Consensus Project (NCP) for Quality Palliative Care?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2	Did you know that the Seventh Domain of the NCP for Quality Palliative Care is specifically for end-of-life care?	<input type="checkbox"/> Yes <input type="checkbox"/> No
3	Are you aware that there are six preferred practice guidelines from the NCP for Quality Palliative Care for care of the patient at end-of-life?	<input type="checkbox"/> Yes <input type="checkbox"/> No
4	Are you knowledgeable regarding end-of-life care for oncology patients?	<input type="checkbox"/> Yes <input type="checkbox"/> No

**Attitudes related to end-of-life care:**

<b>5</b>	Recognizing and documenting the transition of a patient to the actively dying phase or end-of-life phase and communicating to the patient, family, and staff the expectation of imminent death is important for an inpatient unit	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>6</b>	It is important for the patient and family to be educated on a timely basis regarding signs and symptoms of imminent death in a developmentally, age appropriate, and culturally appropriate manner	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>7</b>	As part of the ongoing care planning process, it is important to routinely ascertain and document patient and family wishes about the care setting for site of death, and to fulfill patient and family preferences when possible	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>8</b>	It is important to provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and to address concerns and fears about the use of narcotics	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>9</b>	It is important to treat the body post-death with respect according to the cultural and religious practices of the family and in accordance with local law	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>10</b>	It is important to facilitate effective grieving by implementing a bereavement care plan in a timely manner after the patient's death when the family remains the focus of care	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>11</b>	It is important for my practice to use a standardized end-of-life care protocol for actively dying patients	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree

**Willingness to use an end-of-life care protocol:**

<b>12</b>	I am willing to learn about the Eight Domains of the NCP for Quality of Palliative Care.	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>13</b>	I am willing to use a standardized evidenced-based end-of-life care protocol in my practice.	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>14</b>	I am willing to provide input regarding an end-of-life care protocol for the inpatient unit.	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>15</b>	I am willing to be part of a team that creates an end-of-life care protocol for actively dying patients on the inpatient unit.	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
<b>16</b>	I am willing to learn more about end-of-life care protocols.	<input type="checkbox"/> Strongly Agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree

## REFERENCES

- Abarshi, E., Papavasiliou, E., Preston, N., Brown, J., & Payne, S. (2014). The complexity of nurses' attitudes and practice of sedation at the end of life: a systematic literature review. *Journal of Pain Symptom Management, 47*(5), 915-925.
- American Cancer Society. (2013). Cancer facts & figures 2013. *American Cancer Society*, 1-64.
- Bakitas, M., Bishop, M., Caron, P., & Stephens, L. (2010). Developing successful models of cancer palliative care services. *Seminars in Oncology Nursing, 26*(4), 266-284.
- Carey, E. C., Dose, A. M., Humeniuk, K. M., Kuan, Y. C., Hicks, A. D., Ottenberg, A. L., Tilburt, J. C., & Koenig, B. (2017). The experience of hospital death. *The American Journal of Hospice and Palliative Care*, 1-9. doi:10.1177/1049909116689547
- Chan, R., Webster, J., & Bowers, A. (2016). End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Database of Systematic Reviews*, 1-31.
- Glickman, S., Baggett, K., Krubert, C., Peterson, E., & Schulman. (2007). Promoting quality: the health-care organization from a management perspective. *International Journal for Quality in Health Care, 19*(6), 341-348.
- Jarabek, B. R., Cha, S. S., Ruegg, S. R., Moynihan, T. J., & McDonald, F. S. (2008). Use of a palliative care order set to improve resident comfort with symptom management in palliative care. *Palliative Medicine, 22*, 343-349.
- Kassam, A., Skiadaresis, J., Habib, S., Alexander, S., & Wolfe, J. (2013). Moving toward quality palliative cancer care: parent and clinician perspectives on gaps between what matters and what is accessible. *Journal of Clinical Oncology, 31*(7), 910-915.
- Lynch, M. (2014). Palliative care at the end of life. *Seminars in Oncology Nursing, 30*(4), 268-279.
- NCPQPC. (2013). *Clinical practice guidelines for quality palliative care* (3rd ed.). Pittsburgh, PA: National Consensus Project for Quality Palliative Care.
- Nedjat-Haiem, F. R., Carrion, I. V., Gonzales, K., Ell, K., Thompson, B., & Mishra, S. I. (2017). Exploring health care providers' views about initiating end-of-life care communication. *American Journal of Hospice & Palliative Medicine, 34*(4), 308-317.
- Obermeyer, Z., Maker, M., Abujaber, S., Dominici, F., Block, S., & Cutler, D. (2014). Association between the medicare hospice benefit and health care utilization and costs for patients with poor-prognosis cancer. *Journal American Medical Association, 312*(18), 1888-1896.

- Polit, D. & Beck, C. (2012). *Nursing research: generating and assessing evidence for nursing practice*. New York: Wolters Kluwer Health.
- Steinmetz, H., Knappstein, M., Ajzen, I., Schmidt, P., & Kabst, R. (2016). How effective are behavior change interventions based on the theory of planned behavior? A three-level meta-analysis. *Journal of Psychology*, 224(3), 216-233. Retrieved from <https://doi.org/10.1027/2151-2604/a000255>
- Surveygizmo. (2017). Retrieved from survey platform. <https://www.surveygizmo.com/>
- Teno, J. M., Freedman, V. A., Kasper, J. D., Gozalo, P., & Mor, V. (2015). Is care for the dying improving in the United States? *Journal of Palliative Medicine*, 18(8), 662-666.
- Teno, J. M., Gozalo, P. L., Bynum, J. P., Leland, N. E., Miller, S. C., Morden, N. E., Scupp, T., Goodman, D. C., & Mor, V. (2013). Change in end-of-life care for medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*, 309(5), 470-477.
- Treece, P. (2007). Standardized order sets for end of life care. *Journal of Hospice and Palliative Nursing*, 9(2), 70-71.
- Treece, P. E., Crowley, L., Chan, J., Rubenfeld, G., Steinberg, K., & Curtis, R. (2004). Evaluation of a standardized order form for the withdrawal of life support in the intensive care unit. *Critical Care Medicine*, 32(5), 1141-1148.
- Velarde-Garcia, J., Pulido-Mendoza, R., Moro-Tejedor, M., Cachon-Perez, J., & Palacios-Cena, D. (2016). Nursing and end-of-life care in the intensive care unit. *Journal of Hospice & Palliative Nursing*, 18(2), 1-6.
- Walling, A. E., Barry, T., Yamamoto, M., & Wenger, N. (2011). Missed opportunities: use of an end-of-life symptom management order protocol among inpatients dying expected deaths. *Journal of Palliative Medicine*, 14, 407-412.
- Walling, A., Brown-Saltzman, K., Barry, T., Quan, R., & Wenger, N. (2008). Assessment of implementation of an order protocol for end-of-life symptom management. *Journal of Palliative Medicine*, 11(6), 857-865.
- Wienczek, C. & Coyne, P. (2014). Palliative care delivery models. *Seminars in Oncology Nursing*, 30(4), 227-233.
- Zaccagnini, M. & White, K. (2014). *The doctor of nursing practice essentials: a new model for advanced practice nursing* (2nd ed.). Burlington, MA: Jones & Bartlett Learning.