A Descriptive Study of Oncology Providers' Attitudes, Subjective Norms, and Perceived Behavioral Control Regarding Discussion of Palliative Goals of Care for Individuals with Advanced Cancer

Item Type	text; Electronic Dissertation
Authors	Wong, Sarah
Publisher	The University of Arizona.
Rights	
Download date	
Link to Item	http://hdl.handle.net/10150/626618

A DESCRIPTIVE STUDY OF ONCOLOGY PROVIDERS' ATTITUDES, SUBJECTIVE NORMS, AND PERCEIVED BEHAVIORAL CONTROL REGARDING DISCUSSION OF PALLIATIVE GOALS OF CARE FOR INDIVIDUALS WITH ADVANCED CANCER

by

Sarah Wong

A DNP Project Submitted to the Faculty of the
COLLEGE OF NURSING
In Partial Fulfillment of the Requirements
For the Degree of
DOCTOR OF NURSING PRACTICE
In the Graduate College
THE UNIVERSITY OF ARIZONA

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THE UNIVERSITY OF ARIZONA
GRADUATE COLLEGE

As members of the DNP Project Committee, we certify that we have read the DNP project prepared by Sarah Wong entitled "A Descriptive Study of Oncology Providers' Attitudes, Subjective Norms, and Perceived Behavioral Control Regarding Discussion of Palliative Goals of Care for Individuals with Advanced Cancer" 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.

I hereby certify that I have read this DNP project prepared under my direction and recommend that it be accepted as fulfilling the DNP project requirement.

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STATEMENT BY AUTHOR

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SIGNED: __Sarah Wong___________________

ACKNOWLEDGMENTS

I would like to express my gratitude and appreciation to my committee members, Drs. Pamela Reed, Heather Carlisle and Laura McRee. Without their support and patience, I could not of have been more of an advocate for palliative care and for completing my doctoral project.

To my family and friends, thank you for all your love and support through my academic journey.

DEDICATION

To my loving family and friends who supported me along the way being the amazing supporters that they are.

TABLE OF CONTENTS

TABLE OF CONTENTS – *Continued*

LIST OF FIGURES

LIST OF TABLES

ABSTRACT

Background: Palliative care means improving quality of life along a spectrum of illnesses including cancer. Cancer is one of the leading causes of death. Having the discussion of goals of care including palliative care is important to have with individuals who have advanced cancer. There were limited studies that identify the providers' attitudes, subjective norms, and perceived behavioral control on discussion of goals of care including palliative care.

Purpose/Aim: This Doctoral Project consisted of identifying factors (i.e., attitudes, behaviors and subjective norms) in discussion of goals of care with their terminal cancer patients in the outpatient oncology clinic. Multiple studies have demonstrated the lack of knowledge providers have about palliative care. Through this study, the attitudes, subjective norms, and behaviors of providers were evaluated regarding goals of care for palliative care.

Methods: An investigator developed questionnaire with six-point Likert-type scaling was used to measure each dimension (attitudes, subjective norms, and perceived behavioral control) regarding discussion of goals regarding care. These questionnaires were sent electronically to the oncology providers at Arizona Center for Cancer Care in Phoenix, Arizona. The data were collected through Qualtrics.

Outcomes: Six providers participated in the survey. Results on the Attitude subscale indicated that the providers regarded discussing goals of care including palliative as very important and beneficial to patients. In comparison to this subscale score, the results on the Subjective Norms and Perceived Behavioral Control subscales were somewhat lower, though still above the mean, indicating that providers regarded the norm and level of resources available for discussing goals of care as somewhat lacking in their work setting. Further research is needed in this area of

inquiry, including a quality improvement project to promote quality care in discussing goals of care including palliative care with patients who are diagnosed with advanced cancer.

CHAPTER I: INTRODUCTION

Palliative care, according to the World Health Organization (WHO), means improving the quality of life (with symptom and pain management) for patients and their families who are dealing with a life-threatening disease/illness including terminal cancer. It includes emotional and spiritual support along with assisting families coping with the loved ones' illness or death (WHO, n.d.). Palliative care was perceived as caring for people who are actively dying. Now it is recognized as the process of improving quality of care for individuals with chronic and terminal illness at any age (Parikh, Kirch, Smith, & Temel, 2013). The best time to initiate palliative care discussion is when the individual is diagnosed with a poor prognosis of a disease by the primary care provider that can be further evaluated at the oncology specialty level. A poor prognosis would be defined as a condition that is unable to be treated or cured. An early referral to palliative care improves the quality at the end of life care (Barton, 2014).

A guideline by the National Consensus Project for Quality Palliative Care provided suggestions for best practice in palliative care (Dahlin, 2013). One of the best practices is to have thoughtful life discussions regarding their goals of care, to honor individuals' life decisions regardless of their state of wellness in an established a patient-provider relationship. However, evidence indicated that palliative care referrals are underutilized in the outpatient setting. Referral rates are seemingly low in the outpatient setting, despite evidence from multiple studies that indicate the importance and improvement in end of life care when referrals to palliative care are introduced early in the disease process.

Among multiple research studies on palliative care and programs in initiating palliative care, there is limited knowledge about this specialty (Brickner, Scannell, Marquet, & Ackerson, 2004; Stein, 2008). Research is needed to better understand the dynamics behind the approach to discuss goals of care in their cancer care. Therefore, the focus of this study is to describe the provider attitudes, subjective norms and perceived behavioral control regarding goals of care in the oncology setting.

Background and Significance

National Consensus Project on Quality Palliative Care

One guideline that is crucial in developing a baseline or core of information of palliative care is through the National Consensus Project on Quality Palliative Care (NCP, 2013). This project produced a guideline necessary to provide the best care in the palliative healthcare field. Based on this guideline, there are eight domains in which quality palliative care guidelines list as different aspects of care – (*i.e,. social, ethical, and physical for example*). These serve a purpose to improve (to name a few): patient and family centered palliative care; comprehensive palliative care through all different health settings; early introduction of palliative care at diagnosis (NCP, 2013).

The guidelines describe how all these domains are used in affecting the quality of palliative care; in turn, providers have a set standard of care in approaching palliative care. The domains addressed this study are domain 8 regarding ethical and legal aspects of care in addition to domain 3 that entails the psychological and psychiatric aspects. There is still some confusion in when and what goals of care are addressed with the oncology specialists.

According to the American Society of Clinical Oncology (ASCO), earlier intervention of palliative care provided should be integrated earlier in the diagnosis of terminal cancer or illness (Smith et al., 2012). The earlier the intervention is to disease-modifying treatments, the lower the risk for increased costs in hospital visits and hospitalizations. The focus of the early discussion about goals of care in palliation

The National Comprehensive Cancer Care Network advised that in their guidelines palliative care screening should be initiated at the initial oncology visit along with subsequent visits. (NCCN, n.d.). Among multiple research studies and programs initiating palliative care, there is a lack of knowledge of how goals of care are addressed in palliative care (Brickner, Scannell, Marquet, & Ackerson, 2004; Fox, 2007; Stein, 2008). Palliative care can be misconstrued as only managing pain from cancer, but palliative care is appropriate for managing pain and symptoms of other illnesses as well as cancer.

Palliative care not only involves an interdisciplinary team in the medical field and the patient but with loved ones of the individual. With most palliative care interventions/programs available in the hospital and inpatient settings, oncology specialists can be the stepping-stone in introducing goals of care of palliative care in the outpatient setting (Meier, 2010). Timely and effective communication between the provider and patient about the end- of life-including palliative care improves the quality of life (Slort, Blankenstein, Deliens, & Van der Horst, 2011; Walczak et al., 2014).

Studies that show early referral and discussion of goals of care in the outpatient setting improve the end-of-life care more than in inpatient hospital settings (Hui, Kim, Roquemore, Dev, Chisholm, & Bruera, 2014; Barton, 2014; Hui, Park, Liu, Reddy, Dalal, & Bruera, 2015). There has been satisfaction in patient scores based on early referrals to palliative care. In these studies, the authors discussed an important point that early referrals improve the quality of life especially in terminal cancer patients (Gibson, 2016). There are studies that goals of care discussed early assist in satisfaction of family at least in dementia (van Soest-Poortvliet, van der Steen, de Vet, Hertogh, Deliens, & Onwuteaka-Philipsen, 2015). Although goals of care for different illnesses are present, there are limited studies in the best practices of goals of care discussion with terminal cancer patients. Through a study by Docherty, Lester, and O'Reilly (2016), patients' attitudes were examined which revealed a desire for discussion of goals of care that consists particularly about symptom management and comfort level were addressed.

Local Problem

Although cancer patients are the not the only individuals that can receive palliative care, it is one of the most prevalent in referrals (Hui et al., 2016). Cancer is the leading cause of death in the past five years in all of Arizona (Arizona Department of Health Services, n.d.). Cancer incidence rates and costs are projected to rise by the year 2020 to $173 billion dollars, a 39% increase from 2010. With the growing aging population, cancer costs are expected to rise with advances in diagnostic technology and in up and coming treatments (Balboni et al., 2011). Providing all available options including referrals and communication of the goals of care from oncology specialist when the initial diagnosis is made alleviates costs in unnecessary hospital stays (Dahlin, 2010). Assessing patients' goals of care provides patients the opportunity to have a voice – the central voice in their decisions about their own health. Early intervention of palliative care can reduce hospitalization rates and costs for individuals.

Purpose/Aim

The purpose of this project is to describe provider attitudes, subjective norms, and perceived resources/behavioral control about the goals of care in patients diagnosed with stage 4 advanced cancer in the oncology clinic. Providers have the knowledge to understand what cancer and other illnesses are and how they affect their patients. The problem being studied may be related to provider attitudes and available resources regarding this discussion. Minimal discussions about referral practices and goals of care between providers and patients regarding terminal cancer diagnosis and treatments have been observed (Hui et al., 2016). Studying potential underlying reasons may provide insight to help providers find the ease in discussing healthcare goals and palliative care.

Theoretical Framework

The purpose for this project is identifying healthcare provider attitudes, subjective (perceived) norms, and perceived behavioral control regarding discussing patient goals of care in the oncology outpatient setting. A better understanding of this may be used to help providers engage in discussions of patient goals for palliative care and improve quality of care by increasing rates for palliative care (Slort, Blankenstein, Deliens, & van der Horst, 2011; Walczak et al., 2014). The Theory of Planned Behavior (TPB) provides a framework for the focus of this project.

The TPB proposes three determinants of a behavior: attitudes, subjective norms, and perceived behavioral control (Ajzen, 1991; Godin & Kok, 1996). This theory provides a framework for understanding, and ultimately changing and predicting human behavior (Ajzen, 2011). For purposes of this current study, the theory was used in this study to guide areas of questions about attitudes, perceived subjective norms, and perceived behavioral control concerning palliative care practices, including when and what the goals of palliative care are discussed. Providers' experiences with the subjective norms of their clinical setting and in communicating with patients with terminal cancer may influence their views on these determinants. The intention to “perform” or communicate to their patients about palliative care is theorized to be increased if the attitudes and subjective norms are favorable and there is a high-perceived behavioral control (Ajzen, 1991). Therefore, a first step in a long-term goal to promote discussion of early goals of care in palliative care is to describe the existing attitudes and perceptions related to when and what goals of care should be discussed among healthcare providers. Knowing and understanding resources available in palliative care promotes ease into referring patients with terminal illness.

The three components or concepts in the Theory of Planned Behavior, attitudes, perceived subjective norms, and perceptions about ease or difficulty of the behavior are applicable to this study focus in that they identify concepts that may influence specific behaviors, which in this case are behaviors regarding discussion of healthcare goals in advanced cancer care. The attitude of the behavior means the degree to which the individual favors the behavior (Azjen, 1991). The *attitude* in this study referred to the degree to which the primary care provider favors discussion of goals of care with patients facing a serious diagnosis~~.~~ Subjective norms refer to the social pressure to perform or not to perform a certain behavior (Azjen, 1991). In this study, *subjective norms* refer to the primary care providers’ perception of (possibly negative) attitudes towards norms about palliative care referral practices and whether the environment (i.e., practice) prefers or supports referrals for palliative care. If the environment is not suitable for referrals, providers are more likely to decrease the provider’s discussion of care goals. The last determinant of planned behavior, perceived behavioral control, consists of the perceived ease/difficulty of performing a behavior. This concept is defined in this study in terms of available resources may help shape the *perception of the ease or difficulty* in palliative care practices and referrals. The survey addressed these three components of theory, which are relevant to long-term goal of increasing the likelihood of a certain behavior, discussion of goals regarding palliative care.

Research Questions

The theory of planned behavior provided the framework for the following three basic research questions of this descriptive study.

1. How favorable are providers' attitudes about palliative care discussions to goals of care?
2. To what extent do providers perceive discussion of healthcare goals with advanced cancer patients and to do so as early as possible as an accepted are the norm at their work environment?
3. To what extent do providers perceive that they have adequate resources (work environment and knowledge-based) for discussing care goals and for making palliative care referrals as appropriate?

CHAPTER II: LITERATURE REVIEW

The purpose of this project was to assess the providers' perception, attitudes and subjective norms on discussion of goals of care with their patients who have advanced cancer at the time of diagnosis. The search strategy imposed was from PubMed, Google Scholar and CINAHL. Through PubMed, MeSh terms were used including palliative care, goals of care, communication, and providers through various combinations. Other terms included were terminal cancer and advanced cancer (as these terms were used interchangeably in some articles). Through CINAHL, there were also a combination of searches through the terms palliative care, communication, providers, and terminal cancer. Among all these terms, the term, "goals of care," was the focus in the search through all three search databases.

The levels of evidence presented in the research studies pertaining to the field of interest ranged from Level I, random control trials to Level IV, cohort studies and Level V, qualitative studies. Most studies consist of descriptive studies from the literature review.

The literature findings were reviewed with the theory in mind. However, no published studies were found that directly addressed subjective norms for discussing care goals for terminal cancer patients in the oncology setting. The studies that follow addressed attitudes, behaviors, and resources related to this discussion.

Attitudes and Behaviors

Based on literature review, discussion of goals of care occur most often late with terminal cancer patients (Pfeil, Laryionava, Reiter, Hiddemann, & Winkler, 2015). In this study, Pfeil, Laryionava, Reiter, Hiddemann and Winkler (2015) studied factors in how physicians and nurses in oncology perceive their roles when discussing with their patients about the end-of-life. The providers and nurses had seen and discussed end-of-life care with patients of “incurable cancer.” The patients are classified as advanced cancer individuals, but the study did not specify the types of cancer. Results indicate after thorough interviews with physicians and nurses, that patients had unrealistic expectations about the goals of care, the need for more understanding in the nurses’ role to discuss goals of care and the physicians’ balance of their own biases and subjective emotional commitment to their patients. This study also indicated the uncertainty of when the discussion for goals of care are appropriate (i.e., stage of caner).

LeBlanc et al. (2015) formed a mixed methods study that examined perceptions of palliative care in oncologists who see patients who have a hematologic and solid tumor cancer. This study mostly focused on the referral patterns relating to patients with either a hematologic or solid tumor cancer. There were 66 respondents (oncologists). Of those 66, some 23 respondents were treating hematologic cancers while the other 23 respondents were treating patients with solid tumors. Oncologists who were specialized in hematology would only view palliative care and discussion of goals as an end-of life care while oncologist who specialize in solid tumors prefer to apply palliative care as an adjunct especially to their complex cases (LeBlanc, et al., 2015). In conclusion, this study showed that the goals of care are varied among individuals with different treatment goals, and among providers regarding their preferences in managing palliative care on their own as compared to utilizing resources.

The literature revealed that providers reported that their views on goals of care discussions are not affected by their knowledge and skills. The providers’ perception of how the goals of care are addressed were mostly focused on their experience and how complicated the disease course is for the patient. The more complicated is the disease course of the patient’s cancer, the more hesitant and confusing it is for the provider to address the goals of care to the patient (Pfeil, Laryionava, Reiter, Hiddemann, & Winkler, 2015). Multiple findings from literature indicate providers prefer not to discuss goals of care to individuals with terminal cancer whether it may be on a personal level or the patient's lack of support on the recommendations.

Snyder, Hazelett, Allen, and Radwany (2013) evaluated primary care physicians' experience and knowledge with advance care planning and palliative care. As a result, out of 372 surveys sent, 158 providers replied. From the results, it was made apparent the providers believe the goals of care should be discussed at the end-of life. The patients are chronically ill and have no specific disease course noted in the study. It is critical to point out that the providers lack the knowledge of resources and what is the difference between palliative care and hospice care. The study also notes that those providers who have a higher comfort level about discussing palliative care the more likely to initiate the discussion of goals of care (Snyder, Hazelett, Allen, & Radwany, 2013).

Resources to Support Discussion of Palliative Care Goals

Resources need to be available in palliative care to specifically provide better outcomes for the patients with advanced cancer. The goals of care, as addressed in one article, emphasized the need to prioritize the patients' considerations rather than the providers' recommendations and interventions near the end of life (Bernacki & Block, 2014). In the study regarding communication about goals of care, Bernacki and Block (2014) addressed that conversations about goals of care and the need for better resources and education for providers to feel comfortable addressing this topic. This article examined the best practices and interventions in improving goals of care discussion. As a result, resources are needed in the providers' education to having guided structured formats to help guide the support for palliative care goals (Bernack & Block, 2014).

In addition, the perceived idea from oncology and other providers is that some of the barriers tend to lie in both the providers' hands but also the patient's as well.

In a study by Salins Ramanjulu, Patra, Deodhar, and Muckaden (2016), a literature review was completed to determine any evidence for and against early palliative care. Thirty-one articles were reviewed and revealed that a significant amount of studies showed early palliative care improves quality of life and patient satisfaction. From this literature review, it demonstrated the need to study what and when goals of care should be addressed especially in advanced cancer patients (Salins Ramanjulu, Patra, Deodhar, & Muckaden, 2016). It also revealed the need for additional resources in palliative care that are made more apparent for providers to readily use them.

Conclusions from Review of the Literature

Of all the studies in the literature review, there were limited research that specifically addressed the behaviors, attitudes and perceptions of the goals of care from oncologists who treated advanced cancer patients. Each study had its own limitations. There was a study that provided a plan to discuss goals of care discussion with dying patients, but not necessarily to examine the *what* and *when* the goals of care discussion are most effective with oncology providers and advanced cancer patients (Balaban, 2000). One of the most relatable studies was from Zhou, Stoltzfus, Houldin, Parks, and Swan (2010), who evaluated knowledge, attitudes, and practice behaviors among oncology advanced practice nurses. Through this study, the researchers use the term advanced care planning versus discussion of goals of care. They labeled advanced care planning as discussion of goals of care especially at the end of life care (Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010). From the literature review, there were multiple studies that indicate the need for early discussion of palliative care discussion and referrals. From much of the literature review, most studies explained the need for structured formats to successfully integrate into the patient care process (Balaban, 2000; Bernacki & Block, 2014). Overall, further studies needed to be examined and to understand the providers' perception, attitudes, and behavior on what and when the goals of care necessary. There was an insufficient amount of literature that focuses on the provider's attitudes and behavior in initiating goals of care at the time of diagnosis of advanced cancer patients.

CHAPTER III: METHODS

In this chapter, the study sample inclusion criteria, setting, instrument, procedure and human subjects' protocol, and plans for data analysis are presented. Ethical issues that may affect the survey and study are also presented. Also, there is an in-depth description of the instrument to be used to obtain participant responses.

Design

The design of this study was a descriptive study about providers' perceptions regarding the discussion of goals of care regarding palliative care. A quantitative questionnaire along with a demographic form was used to obtain the data. Some open-ended questions were also used to allow for brief responses that participants wanted to provide in reference to the areas addressed in the questionnaire.

Sample and Setting

The sample consisted of oncology specialists, Nurse practitioners and physicians in the Phoenix area. The setting was through multiple locations of oncology providers through the Arizona Center for Cancer Care throughout Phoenix, Arizona. These locations are in the oncology specialty. In these practices, the providers that care for individuals age ranging from 20s to death. The providers care for individuals with oncology disorders. These practices increase the likelihood that providers are familiar with palliative/hospice care.

Inclusion criteria consisted of the following items to participate in the study:

1. Providers working at an oncology practice, full time.
2. The oncology providers must be currently caring for patients who have advanced cancer.

3. Over one-year experience.

The sample size was projected to be a minimum of 20 participants, from five locations of the oncology practice. This number is based on the number of oncology specialists in each practice. I estimated an attrition rate to be 10 to 20%, from the initial pool of possible 20 respondents (Moran, 2014).

Human Subjects Considerations

Respect for autonomy of persons is involved with individuals having the right for their own thoughts, beliefs and values as well as decisions and choices (Entwistle, Carter, Cribb, & McCaffery, 2010). I have respected their answers and practices that the provider has. Along with respect of autonomy are considerations for honesty, confidentiality, and fidelity are all included. Explaining and making a commitment to the individuals of what is expected in the study (Entwistle, Carter, Cribb, & McCaffery, 2010). This study does give privacy to the providers; the responses are used in my research and the participants are kept anonymous.

The research involved surveying oncology providers' attitudes regarding goals of care of palliative care. A description will be presented of what the study was about and the intentions for the study and findings. In beneficence, medical personnel including physicians/providers seek to do "good" and do no harm (Longest, 2010). Rating their answers on the survey would be viewed as providing important and necessary information to help others in this population rather than helping one self. (Beauchamp, 2010). There was not much risk when having surveys completed by practices since their identity was kept in private. Justice refers to fairness (Longest, 2010). It simply asks if it would be fair and beneficial to the subjects being asked to participate in the study (Longest, 2010). Institutional Review Board (IRB) approval was obtained since the study involves human beings and their perspectives (i.e., providers) in the study (Arizona Office for the Responsible Conduct of Research, 2015).

Instrument: Oncology Provider Survey on Goals of Care in Advanced Cancer

Participants completed the “Oncology Provider Survey.” This questionnaire was developed by the investigator based upon the theory of planned behavior concepts. It consisted of 10 items that focus on attitudes, subjective norms, and perceived behavioral control of oncology providers who care for individuals with advanced cancer (Appendix D). The content validity was determined to be adequate based upon the DNP Project committee reviewing the items for relevance. Three respondents were also asked to evaluate the questionnaire based on the study’s focus.

Participants responded to each item using a six-point Liker-type scale, rating from completely disagreeing to completely agreeing with the statements listed in the questionnaire. The responses were related to their practices regarding discussions of goals for palliative care.

Scoring the Questionnaire

The items were rated on a six-point Likert-type scale. Responses are summed across items within each of the three Subscales representing each of the three components of the Theory of Planned Behavior. Subscale scores range from 1.0 to 6.0 for each Subscale. The Subscale scores were obtained by summing across items and dividing by the number of items, which generated a range that was comparable across all Subscales. Items 1 to 3 measure Component 1. Attitude. Items 4 to 6 measure Component 2. Subjective norms. Items 7 to 10 measure Perceived Behavioral control.

In addition, responses also were summed across all 10 items to obtain a general score that ranges from 10 to 60. This score indicated the degree of intention that the oncology provider will discuss goals of care and possibly palliative care goals in their work environment. An open-ended question was provided at the end for providers' input on goals of care in palliative care.

Procedure

After obtaining IRB approval, initially, an email was sent out to oncology specialists by the practice manager at Arizona Center for Cancer Care in Phoenix, Arizona. Potential participants were sent an email by the practice manager that contains a welcoming letter and instructions on how to complete the survey. The completion of the questionnaire indicated their consent to participate in the study. Participants received instructions electronically through Qualtrics on how to complete the survey.

The data were collected through an online survey using through the University of Arizona Qualtrics. Using the online survey method had its benefits as well as its risks. Some of the strengths in having an online survey are of convenience, good sample size, low cost, controlled samples and fast results. Some of the weaknesses that may arise from having an online survey would be a lower response rate if providers are uninterested or considering the survey as junk mail (Evans & Mathur, 2005).

Data Analysis

Quantitative data were analyzed using descriptive statistics, including measures of central tendency (mean) and dispersion (standard deviation) on the demographic questionnaire (to describe the sample) and provider survey (to describe participant responses on the subscales and total scale (Polit & Beck, 2012). Qualitative data from the open-ended questions were collected with no personal identifiers. The data collected were analyzed through Qualtrics as well as manual calculations.

CHAPTER IV: RESULTS

Outcomes

Data Collection

The survey was active from October 5, 2017 to October 20, 2017. There was a recruitment letter with the survey link was sent and distributed to the oncology providers of the Arizona Center for Cancer Care listserv by the practice manager. On October 12, 2017, a second remind email was sent out to increase recruitment. Although there was a low response rate, the survey was closed on October 20, 2017 because of a time constrain and it was unlikely that many providers would respond with additional reminders or requests.

Sample

Overall, there were six providers participated in the survey. All six providers were eligible in the survey since they were working full time, work in an oncology practice, and care for patients with advanced cancer. The sample (N=6) consisted of three (50%) nurse practitioners and three (50%) physicians. All participants have at least one year of experience as a provider (100%) with a range of 1.25 to 35 years. Of these years as a provider, participants reported an average of about eight years in the oncology field with a range of 3 to 15 years. Five participants have received no formal training (83%), while the one participant received training on the job (17%). About half of the participants have at least five years of experience in the oncology field. Table 1 list all the demographics of the participants in this study.

TABLE 1. *Oncology Providers' Demographics* (n=6)

Demographics		**n (%)**	**Mean Score (±SD)**	**Range**
Type of Provider	Nurse Practitioner	3 (50%)		
	Physician (MD, DO)	3 (50 %)		
Years as a Provider	0-5 years	3 (50%)		
	6-10 years	1 (17%)		1- 35 yrs
	11-15 years	0 (0 %)	12.08yrs	
	16-20 years	1 (17%)	(13.31)	
	20+ years	1 (17%)		
Any Formal Training in Palliative Care	No	5 (83%)		
	Yes	1 (17%)		
Years in Oncology Field	0-5 years	3 (50%)		
	6-10 years	1 (17%)	8.17 yrs	3- 15yrs
	11-15 years	2 (33%)	(4.58)	

Note: Participants responded in an open-text format.

Oncology Providers' Scores on Total Scale

All 10 items were calculated for each respondent to evaluate the degree of intention of discussion of goals of care. The scores can range from 10 to 60. Of all the respondents, the range for the total score was from 40 to 57. The higher the score, the more likely the intention to discussing goals of care including palliative care in the provider's work environment.

Oncology Providers' Scores on Attitudes Towards Discussion of Goals of Palliative Care

The participants were asked to rate statements regarding attitude towards discussion of goals of palliative care based on a Likert Scale with 1 for strongly disagree to 6 for strongly agree. The *Attitude* subscale score was 5.50 (SD 1.97). In reference to the individual items, the mean score of oncology providers' attitudes on discussion of goals of palliative care was 5.83 indicating that discussing goals of care including palliative care is beneficial to the patients. The average score the providers rated on how comfortable they are discussing goals of care with palliative care is 4.83 (SD of 1.60) with a wide range from 2 to 6 (Table 2). There is less of a range when participants rate that discussing goals of care is important especially with the patients diagnosed with advanced cancer.

TABLE 2. *Providers' Attitude on Discussion of Goals of Care for Palliative Care* (n=6)

Statements	**Mean Score (SD)**	**Range (Max-Min)**
Discussing goals of care that include palliative care is beneficial for patients at the end of life.	5.83 (0.41)	5 to 6
I am comfortable discussing goals of care that include palliative care at the time of diagnosis for patients who have advanced cancer in my work setting.	4.83 (1.60)	2 to 6
It is important to discuss goals of care for palliative care for patients who are diagnosed with advanced cancer.	5.83 (0.41)	5 to 6
Subscale Score	5.50 (1.04)	4.67- 6

Note: Participants rated the statements on a Likert Scale 1 (Strongly Disagree) – 6 (Strongly Agree)

Oncology Providers' Subjective Norms on Discussion of Goals of Palliative Care

The mean score on the overall *Subjective Norms* subscale score was 4.88 (SD=1.28). In terms of individual items on this subscale, there was a mean score of 5.33 (agree) when providers were asked to rate if their work environment is supportive of discussing goals of care including palliative care with a range of 4 to 6 (Table 3). The providers had a mean score of 5.17 with a standard deviation of 0.75 and range of 4 to 6 when asked to rate the statement on their colleagues typically discussing goals of care, including palliative care, with their patients of advanced cancer. The scores for mean and range were calculated with the results of 4.17 and 2 to 6, respectively, when the participants were asked to rate on the statement that discussing goals of care including palliative care at the initial diagnosis is the norm at the practice.

TABLE 3. *Providers' Subjective Norms on the Goals of Care for Palliative Care* (n=6)

Statements	**Mean Score (±SD)**	**Range (Max-Min)**
My work environment is supportive of discussing goals of care that include palliative care with patients who have advanced cancer.	5.33 (1.03)	4 to 6
My work colleagues typically will discuss goals of care, including palliative care, with their patients who have advanced cancer.	5.17 (0.75)	4 to 6
Discussing goals of care that include palliative care with the patient at the initial diagnosis of cancer is the norm in my work environment.	4.17 (1.72)	2 to 6
Subscale Score	4.88 (1.28)	3.33– 5.67

Note: Participants rated the statements on a Likert Scale 1 (Strongly Disagree) – 6 (Strongly Agree)

Oncology Providers' Perceived Behavioral Control

The overall mean score on the *Perceived Behavioral Control* subscale score was 5.04 (SD=0.81). In terms of individual item scores, the mean score of 4.50 with a standard deviation of 0.84 were calculated when participants rated on the statement of the work environment having the resources to be able to discuss the goals of care across the trajectory (Table 4). The range for this statement was from 3 to 5. There was a mean score of 5.50 with a range of 5 to 6 when the providers were asked to rate on work environment being comfortable to discuss goals of care including palliative care with patients being treatment for cancer. Providers rated with mean score of 5.17 with a range of 5 to 6 if they have adequate knowledge about palliative care with patients who are diagnosed with advanced cancer. When the providers were asked about their knowledge on how to discuss goals of care, the mean score was 5.00 with a standard deviation of 0.85 and range of 4 to 6.

TABLE 4. *Providers' Perceived Behavioral Control on the Goals of Care for Palliative Care* (n=6)

Statements	**Mean Score (±SD)**	**Range (Max-Min)**
My work environment has the resources I need to discuss goals of care with patients across the trajectory of their illness as their goals may change for palliative care.	4.50 (0.84)	3 to 5
My work environment makes it comfortable for me to discuss goals of care that include palliative care with patients during their treatment for cancer.	5.50 (0.55)	5 to 6
I have adequate knowledge about palliative care to discuss this with patients at their initial diagnosis of advanced cancer.	5.17 (0.76)	4 to 6
I have adequate knowledge about *how to* discuss goals of care that include palliative care with patients who have advanced cancer.	5.00 (0.85)	4 to 6
Subscale Score	5.04 (0.81)	4- 5.75

Note: Participants rated the statements on a Likert Scale 1 (Strongly Disagree) – 6 (Strongly Agree)

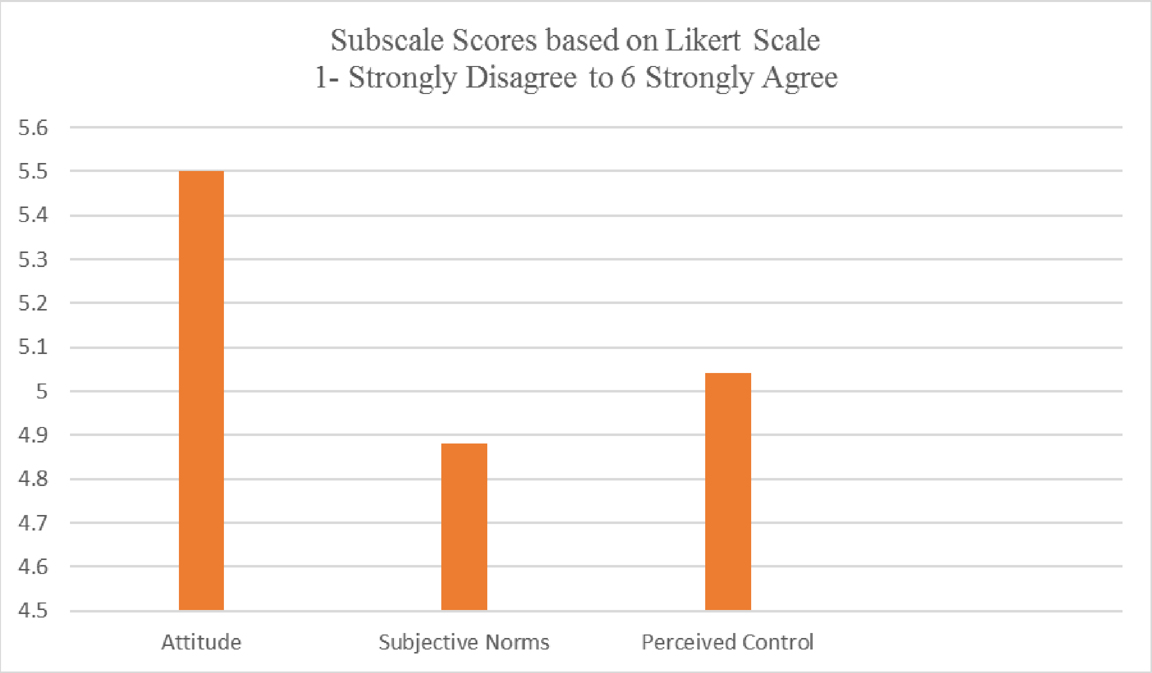


FIGURE 1. Subscale Scores of Attitude, Subjective Norms and Perceived Behavioral Control

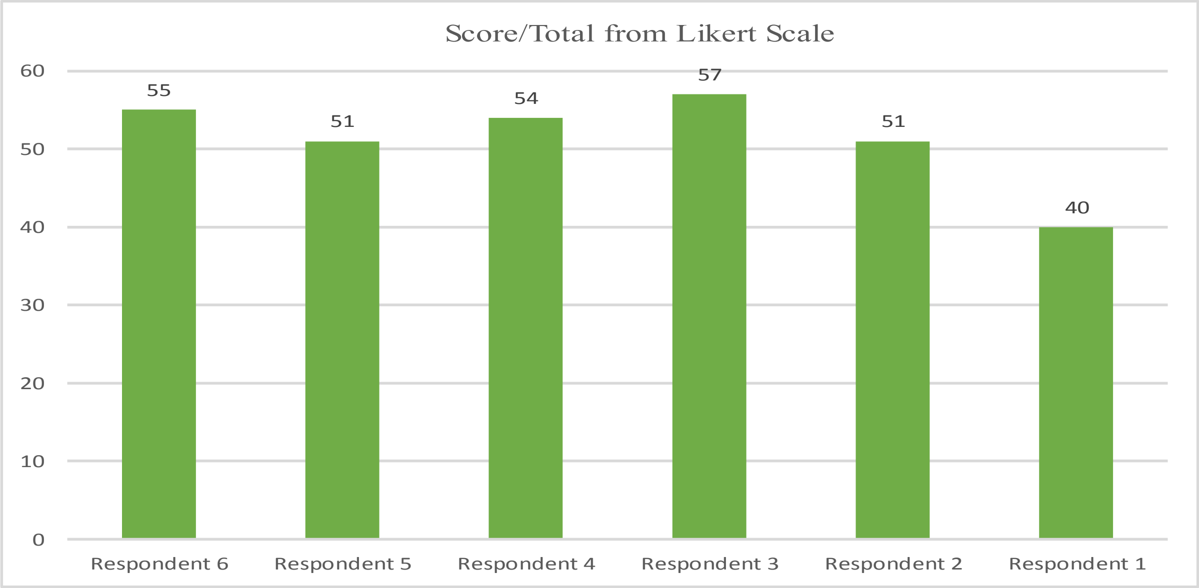


FIGURE 2. Oncology Providers' Total Score for Likert Scale per Respondent

Responses from Open-Ended Questions

There were two open-ended questions at the end of the end to provide the oncology providers' input on the goals of care. A few of the key themes included providers discussing who is the patient's support system and what their wishes and goals throughout the whole process of treatment. One of the questions, "How would you go about initiating discussion on goals of care in palliative care?" the participants responded with:

- Talk about what is important to the patient
- Talk about how things are at home and who is their support system
- Discuss what the patient wants their overall goals of care are. Discussing expectations would be, and what the patients' goals are for their treatment
- Discussing cure versus palliative and asking their first goals, wishes, and realistic expectations
- Meet with patient and family first
- Ask open-ended questions about fears, what their wishes are in regards of treatment, what is important to them, and which family members are influential in their life.

The second open-ended question asked about description of what is palliative care compared to end-of-life care. Their responses were:

- Palliative care can be referred to chronic condition which may alter life expectancy. End-of-life care is within six months of life expectancy.
- Palliative care is help at home with activities of daily living (ADL)
- Palliative care is more symptom management and comfort care. End-of-life care is care provided at the end of life which involves palliative care and other types of care depending on patient's plan of care.
- Palliative care can be over many years with illnesses that may kill the patient. End of life care is more symptom based.
- Palliative care is supportive care.
- Palliative care is more focused on multi-disciplinary approach to the patient's needs with some short-term changes which allows to begin the end of life discussion. End-of-life care refers to more comfort and relief of symptoms with a much shorter time course.

The participants described palliative care more as an extensive long-term care that can be more of comfort care with multiple chronic illnesses and disease processes. The providers viewed the end-of-life care to be symptom relief at the end of life with a short-term life expectancy of less than six months. Palliative care and end-of-life care related to symptom management, but palliative care occurs potentially at various stages of the disease and progression of the patient's illness, and end-of life care occurs at the final phases of the patient's life.

There were various responses when providers were asked how they would go about initiating goals of care including palliative care. The oncology providers explained they focus on what the patient's needs are and what is important in their lives. They would start off discussing goals and what their expectations are with treatment and wishes along the way with management of their advanced cancer.

CHAPTER V: DISCUSSION

Summary

Through this DNP study, the evidence clearly reveals there is no formal training among the participants to discuss the goals of care in palliative care. Among the evidence to date, there is no study that evaluates oncology providers' attitudes, subjective norms, and perceived behavioral control on goals of care including palliative care. However, there are studies that evaluate certain aspects of goals of care. National Consensus Project on Quality Palliative Care gives recommendations and best practices on palliative care; however, this does not reflect the providers' attitudes, subjective norms, and perceived behavioral control.

Attitudes

The mean score of oncology providers' attitudes on discussion of goals of palliative care were mostly positive. All respondents replied to the statements agreeing with the importance to have discussion of goals of care as well as the providers seeing that discussing goals of care including palliative care is beneficial. Of all the statements regarding attitudes towards discussion of palliative care, providers are only somewhat comfortable discussing goals of care with patients who have advanced cancer. There was a range of responses for how comfortable the providers were in discussing goals of care including palliative care with patients. In the study Zhou, Stoltzfus, Houldin, Parks, and Swan (2010), advanced practice nurses who had advance care planning discussions with patients, scored positivity on their attitudes including comfort level of discussing advance care planning. This study also yielded a positive result with some degree of variability in responses of comfortability in discussing goals of care including palliative care with a patient who is diagnosed with advanced cancer.

Subjective Norms

Based on the results, the participants agreed to having their work environment being supportive for discussing goals of care including palliative care (Table 3). Oncology providers' responses on perceived subjective norms revealed mostly a positive response. The responses were like the statement of having work colleagues discussing goals of care with patients who have advanced cancer. Of the statements for perceived subjective norms, there was some disagreement of having a norm in discussing goals of care at the initial diagnosis of cancer. The subscale score of the responses for this category revealed the participants have the least positive responses overall (Figure 2). According to the National Consensus Project on Quality Palliative Care (NCPQPC), the environment is an important aspect when providing palliative care as well as good support of education and training for the providers to give quality palliative care (NCP, 2013). These findings reflected the need for professional training and education leading to a more comfortable environment in discussing goals of care including palliative care.

Perceived Behavioral Control

From the study's findings, most respondents highly agreed with the work environment being comfortable to discuss goals of care including palliative of care (Table 4). The response was closely similar regarding the providers having adequate knowledge about palliative care when discussing goals of care. Some providers agreed while others disagreed with the work environment of having the resources to discuss the goals of care with the patient across the trajectory of their illness. These findings were consistent with a study completed by Zhou, Stoltzfus, Houldin, Parks, and Swan (2010) which revealed a positive response on providers having adequate knowledge about goals of care but with some variance of agreeability. From this study as well, there were some variation of agreeability to which the providers feel they have the knowledge on how to address goals of care and on palliative care. Based on the responses, the participants fairly agreed on most statements in the perceived behavior control (i.e., environment).

Open-Ended Responses

First and foremost, conversations with patients regarding their wishes can allow them to gain more knowledge about their treatment options as well as have better outcomes of palliative care (Peereboom & Coyle, 2012). One of the questions addressed *how the provider would go about initiating goals of care including palliative care*. Two key themes were that providers would discuss who is the patient's support system and what their wishes and goals throughout the whole process of treatment. These two themes related to the NCPQPC guidelines. Domain 3 and Domain 4 addressed the psychological and social aspects of care, respectively. Domain 3 referred to the family understanding and discussing expectations and goals throughout treatment. Domain 4 explained what needs are with the patient and their families. (NCP, 2013).

Addressing the patient's wishes and goals applied to Domain 8 of ethical and legal aspects of care in the NCPQPC guidelines. Respecting the patient's wishes in collaboration with family and provider supported one of the key themes (NCP, 2013). According to an article from Lo, Quill, and Tulsky (1999), open-ended questions would produce more of a positive response when initiating palliative care. Although the authors provided examples of questions for end-of-life, these can be used for goals of care discussion. One of the examples provided was, "what concerns you the most?" is a common question that elicits conversation about palliative care and symptom management.

The second open-ended question addressed the provider's *definition of palliative care compared to end-of life care.* Of the responses, a few key themes were noted. From the open-ended questions that were asked with the survey, there were a few common themes. One of them was that providers defined palliative care to be symptom management throughout a course of illness while end-of life-care refers to the last six months of the individual's life. Another key theme was that palliative care is a broad spectrum of managing symptoms and helping with activities of daily living while end-of life care is focused on comfort at the end of life. According to the NCPQPC guidelines, symptom management is an important factor in providing quality palliative care from the physical aspects of care (NCP, 2013). End-of life care refers to close to impending death and NCPQPC guidelines support the discussion of addressing symptoms to the patient and family (NCP, 2013). There are multiple definitions on what palliative care is compared to end-of life care. One of definitions that was consistent with the participants' responses is that palliative care is available at any stage of any serious illness and the patient's needs change overtime (Wheeler, 2016).

Subscale and Overall Scores

Of the three subscales, the *Attitude* Subscale revealed the most positive response from the participants (Figure 2). The subscale the participants were least in agreement was the subjective norms. All respondents were more likely to discuss goals of care including palliative care with patients who have advanced cancer.

In this study, oncology providers (i.e., nurse practitioners or physicians) rated on a Likert scale on statements regarding attitude, subjective norms, and perceived behavioral control. Most of the providers responses were positive and intention of discussion of goals of care were likely.

However, there were some inconsistencies among the responses. Providers indicated their work environment is suitable to discuss goals of care including palliative care, but did not strongly agree there were resources available in the work setting to discuss the goals. Among the three categories- perceived behavioral control, attitude, and subjective norms, the participants' attitude about discussing goals of care were well accepted. In addition, while every participant has at least one year of oncology experience, most did not receive any formal training to discuss goals of care including palliative care with patients of advanced cancer. With no formal training on discussion of goals of care including palliative care, there was some lack of what proper discussions and topics to address with the patient with advanced cancer. The participants' responses were influenced on their experiences, what they perceived as palliative care and environment versus formal training on goals of care.

In this study, the participants were from one oncology practice. Half of the participants (n=3, 50%) were nurse practitioners, while the other half (n=3, 50%) were physicians (DO or MD). There were some distinctions among the scores of the providers and nurse practitioners. In the *Attitude* subscale, nurse practitioners had a slight overall lower average score of responses in that the nurse practitioners had a slightly less positive attitude about discussing goals of care with patients. By looking at the survey, there were no significant difference in the *Subjective norms* subscale in the average scores between physicians and nurse practitioners. For *Perceived Behavioral control* subscale, the results showed no difference as well. Among these participants, there were a few providers who had over 10 years of oncology experience (n=2, 33%). A discrepancy was noted on the responses for subjective norms. The participants viewed that discussion of the goals of care including palliative care may not be the norm in the practice.

In Figure 1, the overall subscale among all the respondents indicated that the lowest score was in the subjective norms subscale; while providers had highly positive attitudes about the importance of discussing goals of care, their views on the norm of doing this in their work setting indicated that this was less of a norm in their work setting. Their perceived behavioral control regarding discussion of goals of care fell in between the Attitude and Norm subscales. Further, in comparing nurse practitioners and physician ratings on Attitude subscale, the physicians rated slightly higher. The nurse practitioners who also reported less experience in the oncology field, felt less comfortable in discussing goals of care with patients with advanced cancer.

Limitations

There are some limitations to this study as this was conducted in one oncology practice. The response rate was low resulting to only six respondents. The low response rate may be a result of one oncology practice with the survey being open for 15 days. The whole participant pool was reached through the listserv as it was solely relied on the practice manager who distributed the invitation and reminder emails. The study was stopped even through there was a low response rate with a low response after a reminder email was sent out. Since this is one of the first studies and a small study to evaluate the oncology providers' attitudes, subjective norms, and perceived behavioral control of discussion of goals of care including palliative care, the findings cannot be generalized.

Implications for Practice and Research

Any implications for practice are very tentative, given the small sample. Based upon this specific sample, the following inferences were made, although additional research is needed to determine if they have validity. Discussing goals of care in palliative care can help the oncology provider establish a better rapport with patients. Although there is no formal training for the oncology providers to discuss the goals of care with patients, the environment was supportive and suitable to start the conversation with the patient. Most of the oncology providers agreed that discussion of goals of care including palliative of care is important and beneficial, but there is not much resources were available to have this discussion. Having the discussion of goals of care including palliative care can help the individual understand their trajectory of their illness (Ahia & Blais, 2014). This doctor of nursing practice study provided some insight how oncology providers view what palliative care is and how this would lead to discussion of the goals of care with a patient. It may be useful for providers to have a reminder or some formal education to guide the discussion of care at all stages of the patient's diagnosis. The discussion does not have to start at the advanced cancer diagnosis.

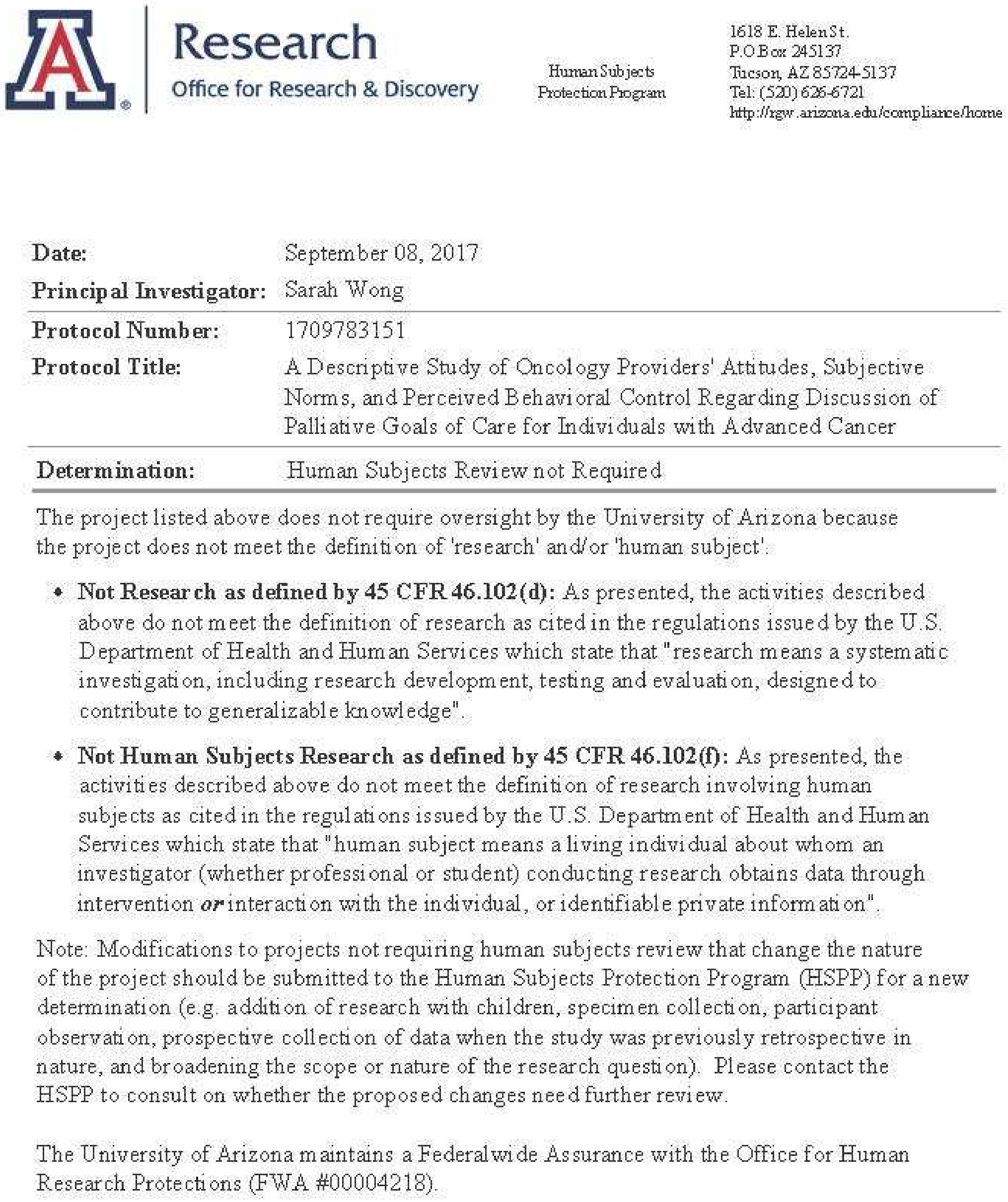
This study provides insight for further evaluating the providers' attitudes, subjective norms, and perceived behavioral control in discussion of goals of care. This study can be a stepping stone for a quality improvement (QI) project in providers incorporating goals of care including palliative care in their practices. In implementing a QI project, it would be important to first assess and facilitate interest in instituting a change in practice in the setting. The providers should be involved in planning the information and protocol for engaging in discussions with the patients regarding goals of care. The providers could also develop strategies and options to improve practice in this area and to facilitate adoption of the new protocol, and to evaluate its effectiveness after instituting the new practice to discuss goals of care including palliative care with patients.

Conclusions

Cancer is one of the leading diagnoses in the United States. As this become more prevalent, providers would benefit from training and education to discuss goals of care including palliative care with patients. This doctor of nursing project gives this a slight insight and perspective from the oncology provider's view. The findings of this initial study provide data to stimulate further research and interventions on improving discussion of goals of care with patients.

APPENDIX A:

THE UNIVERSITY OF ARIZONA INTERNAL REVIEW BOARD (IRB) APPROVAL



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

Date: September 08, 2017

Principal Investigator: Sarah Wong

Protocol Number: 1709783151

Protocol Title: A Descriptive Study of Oncology Providers' Attitudes, Subjective Norms, and Perceived Behavioral Control Regarding Discussion of Palliative Goals of Care for Individuals with Advanced Cancer

Determination: 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 B:

INVITATION LETTER

Dear Provider:

My name is Sarah Wong and I am a graduate student at the University of Arizona's Doctorate of Nursing Practice (DNP) Program- Family Nurse Practitioner track (FNP). I am interested in assessing and identifying the Oncology providers' perceptions, behaviors and attitudes about the goals of care in palliative care with individuals who have advanced cancer.

If you are a nurse practitioner or physician, are currently working at Arizona Center for Cancer Care with one year of experience that cares for individuals with advanced cancer, I would like your input on this topic.

The survey will take about 10 to 15 minutes to complete. There is no risk in answering these questions on the survey.

Please click on the link below to access the survey, and complete it by ##/##/####. I will send a reminder email one week before it closes.
[LINK]

The questionnaire will consist of questions regarding palliative care, your perception and attitudes about what the discussion of goals care are in palliative care. This study is voluntary but will be essential in identifying behaviors and attitudes on the goals of care in palliative care.

Thank you for taking the time to read this hoping you will consider this study. I sincerely appreciate your participation in this survey understanding that you are busy. If you have any questions, feel free to email me.

Sincerely,

Sarah Wong, MSN, FNP-BC
Doctor of Nursing Practice Student
University of Arizona College of Nursing
sarahw@email.arizona.edu

APPENDIX C:

REMINDER LETTER

Dear Provider:

My name is Sarah Wong. I am a Family Nurse Practitioner and I am a graduate student at the University of Arizona's Doctorate of Nursing Practice (DNP) Program- Family Nurse Practitioner track (FNP). This is a reminder to complete the survey if you have not had the chance to complete this yet. I sincerely appreciate your participation in this survey understanding that you are busy. I am interested in assessing and identifying the Oncology providers' perceptions, behaviors and attitudes about the goals of care in palliative care with individuals who have advanced cancer.

If you are a nurse practitioner or physician, are currently working at Arizona Center for Cancer Care with one year of experience that cares for individuals with advanced cancer, I would like your input on this topic.

The survey will take about 10 to 15 minutes to complete. There is no risk in answering these questions on the survey.

Please click on the link below to access the survey, and complete it by ##/##/####. I will send a reminder email one week before it closes.
[LINK]

The questionnaire will consist of questions regarding palliative care, your perception and attitudes about what the discussion of goals care are in palliative care. This study is voluntary but will be essential in identifying behaviors and attitudes on the goals of care in palliative care. Thank you for taking the time to read this hoping you will consider this study. I look forward to your participation in the survey. If you have any questions, feel free to email me.

Sincerely,

Sarah Wong, MSN, FNP-BC
Doctor of Nursing Practice Student
University of Arizona College of Nursing
sarahw@email.arizona.edu

APPENDIX D:

ONCOLOGY PROVIDER SURVEY

Instructions: Please complete the Oncology Provider Survey by "clicking" in the box to indicate your level of agreement (on the 6-point scale) with each item below. Please only rate based on the focus on palliative care of patients who have advanced cancer when responding to each item.

	Strongly Disagree 1	**Disagree 2**	**Slightly Disagree 3**	**Slightly Agree 4**	**Agree 5**	**Strongly Agree 6**
1. Discussing goals of care that include palliative care is beneficial for patients at the end of life.	○	○	○	○	○	○
2. I am comfortable discussing goals of care that include palliative care at the time of diagnosis for patients who have advanced cancer in my work setting.	○	○	○	○	○	○
3. It is important to discuss goals of care for palliative care for patients who are diagnosed with advanced cancer.	○	○	○	○	○	○
4. My work environment is supportive of discussing goals of care that include palliative care with patients who have advanced cancer.	○	○	○	○	○	○
5. My work colleagues typically will discuss goals of care, including palliative care, with their patients who have advanced cancer.	○	○	○	○	○	○
6. Discussing goals of care that include palliative care with the patient at the initial diagnosis of cancer is the norm in my work environment.	○	○	○	○	○	○
7. My work environment has the resources I need to discuss goals of care with patients across the trajectory of their illness as their goals may change for palliative care.	○	○	○	○	○	○

ONCOLOGY PROVIDER SURVEY (CONT’D)

Instructions: Please complete the Oncology Provider Survey by “clicking” in the box to indicate your level of agreement (on the 6-point scale) with each item below. Please only rate based on the focus on palliative care of patients who have advanced cancer when responding to each item.

	Strongly Disagree 1	**Disagree 2**	**Slightly Disagree 3**	**Slightly Agree 4**	**Agree 5**	**Strongly Agree 6**
8. My work environment makes it comfortable for me to discuss goals of care that include palliative care with patients during their treatment for cancer.	○	○	○	○	○	○
9. I have adequate knowledge about palliative care to discuss this with patients at their initial diagnosis of advanced cancer.	○	○	○	○	○	○
10. I have adequate knowledge about *how to* discuss goals of care that include palliative care with patients who have advanced cancer.	○	○	○	○	○	○

1. How would you describe palliative care compare to end-of-life care?

____

2. How would you go about initiating discussion on goals of care in palliative care?

____

APPENDIX E:

DEMOGRAPHICS FORM

DEMOGRAPHICS FORM

1. What type of provider are you? (MD, DO, NP, PA)? ______________________

2. How long have you been a provider? __________ years/months

3. What area are you currently practicing in?

4. How long have you been in this area of practice? ___________ years/months

REFERENCES

Ahia, C. L. & Blais, C. M. (2014). Primary palliative care for the general internist: integrating goals of care discussions into the outpatient setting. *The Ochsner Journal*, *14*(4), 704-711.

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, *50*(2), 179-211.

Ajzen, I. (2011). Theory of planned behavior. *Handbook of Theories of Social Psychologies Volume One*, *1*, 438.

Amano, K., Morita, T., Tatara, R., Katayama, H., Uno, T., & Takagi, I. (2015). Association between early palliative care referrals, inpatient hospice utilization, and aggressiveness of care at the end of life. *Journal of Palliative Medicine*, *18*(3), 270-273. doi:10.1089/jpm.2014.0132.

Arizona Department of Health Services. (n.d.). *Population health and vital statistics: Arizona health Status and vital statistics 2013 annual report.* Retrieved from http://www.azdhs.gov/plan/report/ahs/ahs2013/index.php?pg=state

Arizona Office for the Responsible Conduct of Research. (2015). Determination of human research. Retrieved from http://orcr.arizona.edu/sites/orcr.arizona.edu/files/Determination%20of%20Human%20Research%20v2015-04.doc

Balaban, R. B. (2000). A physician's guide to talking about end-of-life care. *Journal of General Internal Medicine*, *15*(3), 195-200.

Balboni, T., Balboni, M., Paulk, M. E., Phelps, A., Wright, A., Peteet, J., ... & Prigerson, H. (2011). Support of cancer patients' spiritual needs and associations with medical care costs at the end of life. *Cancer*, *117*(23), 5383-5391.

Barton, M. K. (2014). Early outpatient referral to palliative care services improves end-of-life care. *CA: A Cancer Journal for Clinicians*, *64*(4), 223-224.

Brickner, L., Scannell, K., Marquet, S., & Ackerson, L. (2004). Barriers to hospice care and referrals: survey of physicians' knowledge, attitudes, and perceptions in a health maintenance organization. *Journal of Palliative Medicine*, *7*(3), 411-418.

Dahlin, C.M. (2010). Communication in palliative care: an essential competency for nurses. In B. R. Ferrell & N. Coyle (Eds.), *Oxford textbook of palliative nursing*, 3rd edition (Chapter 5, pp. 107-133). New York, NY: Oxford University Press.

Dahlin, C. M. (2014). National consensus project for quality palliative care. *Oxford Textbook of Palliative Nursing*, 11.

Docherty, C., Lester, L., & O'Reilly, S. (2016). Attitudes toward palliative care and end-of-life issues: a prospective survey in patients with metastatic cancer. *Irish Medical Journal*.

Evans, J. R. & Mathur, A. (2005). The value of online surveys. *Internet Research*, *15*(2), 195-219.

Fine, E., Reid, M. C., Shengelia, R., & Adelman, R. D. (2010). Directly observed patient physician discussions in palliative and end-of-life care:a systematic review of the literature. *Journal of Palliative Medicine*, *13*(5), 595-603.

Fox, C. R. (2007). What health care providers know (and need to know) about palliative care. *Journal of Allied Health*, *36*(4), 209-215.

Godin, G., & Kok, G. (1996). The theory of planned behavior: a review of its applications to health-related behaviors. *American Journal of Health Promotion*, *11*(2), 87- 98.

Greer, J. A., Jackson, V. A., Meier, D. E., & Temel, J. S. (2013). Early integration of palliative care services with standard oncology care for patients with advanced cancer. *CA: A Cancer Journal for Clinicians*, *63*(5), 349-363.

Hui, D., Kim, S. H., Roquemore, J., Dev, R., Chisholm, G., & Bruera, E. (2014). Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer*, *120*(11), 1743-1749.

Hui, D., Yee-Choon, M., Bruera, S., Yimin, G., Hutchins, R., Masanori, M., & ... Bruera, E. E. (2016). Referral criteria for outpatient palliative cancer care: a systematic review. *Oncologist*, *21*(7), 895-901. doi:10.1634/theoncologist.2016-0006

Hui, D., Park, M., Liu, D., Reddy, A., Dalal, S., & Bruera, E. (2015). Attitudes and beliefs toward supportive and palliative care referral among hematologic and solid tumor oncology specialists. *The Oncologist*, *20*(11), 1326-1332.

Keating, N. L., Landrum, M. B., Rogers, S. O., Baum, S. K., Virnig, B. A., Huskamp, H. A., ...& Kahn, K. L. (2010). Physician factors associated with discussions about end-of-life care. *Cancer*, *116*(4), 998-1006.

Kloeppel, E. M., Hanaya, H., Seilacher, E., Schroth, S., Liebl, P., Keinki, C., ... & Huebner, J. (2016). Utility of a referral letter to improve comprehensibility of cancer patients in palliative care: a single-center study. *Journal of Cancer Education*, 1-6.

LeBlanc, T. W., O'Donnell, J. D., Crowley-Matoka, M., Rabow, M. W., Smith, C. B., White, D. B., ... & Schenker, Y. (2015). Perceptions of palliative care among hematologic malignancy specialists: a mixed-methods study. *Journal of Oncology Practice*, *11*(2), e230-e238.

Lo, B., Quill, T., & Tulsky, J. (1999). Discussing palliative care with patients. *Annals of Internal Medicine*, *130*(9), 744-749.

Mason, M. (2010, August). Sample size and saturation in PhD studies using qualitative interviews. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* (Vol. 11, No. 3).

Meier, D. E. (2011). Increased access to palliative care and hospice services: opportunities to improve value in health care. *Milbank Quarterly*, *89*(3), 343- 380.

Moran, K. (2014). The Proposal. In K. Moran, R. Burson, & D. Conrad (Eds.), *The doctor of nursing practice scholarly project: a Framework for success*, (Chapter 11, pp. 239-275). Burlington, MA: Jones & Bartlett Learning.

National Consensus Project on Palliative Care. (2013). Clinical practice guidelines for quality palliative care. Retrieved February 13, 2015 from http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd Edition.pdf

Parikh, R. B., Kirch, R. A., Smith, T. J., & Temel, J. S. (2013). Early specialty palliative care translating data in oncology into practice.

Peereboom, K., & Coyle, N. (2012). Facilitating goals-of-care discussions for patients with life-limiting disease-communication strategies for nurses. *Journal of Hospice & Palliative Nursing*, *14*(4), 251-258.

Pfeil, T. A., Laryionava, K., Reiter-Theil, S., Hiddemann, W., & Winkler, E. C. (2015). What keeps oncologists from addressing palliative care early on with incurable cancer patients? An active stance seems key. *The Oncologist*, *20*(1), 56-61.

Polit, D. F., & Beck, C. T. (2012). *Resource manual for nursing research*. Wolters Kluwer Health/Lippincott Williams & Wilkins.

Sasahara, T., Watakabe, A., Aruga, E., Fujimoto, K., Higashi, K., Hisahara, K., ... & Kinoshita, H. (2014). Assessment of reasons for referral and activities of hospital palliative care teams using a standard format: a multicenter 1000 case description. *Journal of Pain and Symptom Management*, *47*(3), 579-587.

Salins, N., Ramanjulu, R., Patra, L., Deodhar, J., & Muckaden, M. A. (2016). Integration of early specialist palliative care in cancer care and patient related outcomes: a critical review of evidence. *Indian Journal of Palliative Care*, *22*(3), 252-257. doi:10.4103/0973-1075.185028

Slort, W., Blankenstein, A. H., Deliens, L., & Van der Horst, H. E. (2011). Facilitators and barriers for GP–patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *British Journal of General Practice*, *61*(585), e167-e172.

Smith, T. J., Temin, S., Alesi, E. R., Abernethy, A. P., Balboni, T. A., Basch, E. M., ... & Von Roenn, J. H. (2012). American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. *Journal of Clinical Oncology*, *30*(8), 880-887.

Snyder, S., Hazelett, S., Allen, K., & Radwany, S. (2013). Physician knowledge, attitude, and experience with advance care planning, palliative care, and hospice: results of a primary care survey. *American Journal of Hospice and Palliative Medicine*, *30*(5), 419-424.

Stein, G. L. (2008). Providing palliative care to people with intellectual disabilities: services, staff knowledge, and challenges. *Journal of Palliative Medicine*, *11*(9), 1241-1248.

van Soest-Poortvliet, M. C., van der Steen, J. T., de Vet, H. C., Hertogh, C. M., Deliens, L., & Onwuteaka-Philipsen, B. D. (2015). Comfort goal of care and end-of-life outcomes in dementia: a prospective study. *Palliative Medicine*, *29*(6), 538-546.

Walczak, A., Butow, P. N., Clayton, J. M., Tattersall, M. H., Davidson, P. M., Young, J., & Epstein, R. M. (2014). Discussing prognosis and end-of-life care in the final year of life: a randomised controlled trial of a nurse-led communication support programme for patients and caregivers. *BMJ Open*, *4*(6), e005745.

Williams, C. (2011). Research methods. *Journal of Business & Economics Research (JBER)*, *5*(3).

World Health Organization. (n.d.). *WHO definition of palliative care*. Retrieved from http://www.who.int/cancer/palliative/definition/en/

Yamagishi, A., Morita, T., Kawagoe, S., Shimizu, M., Ozawa, T., An, E., ... & Miyashita, M. (2015). Length of home hospice care, family-perceived timing of referrals, perceived quality of care, and quality of death and dying in terminally ill cancer patients who died at home. *Supportive Care in Cancer*, *23*(2), 491-499.

You, J. J., Downar, J., Fowler, R. A., Lamontagne, F., Ma, I. W., Jayaraman, D., ... & Neary, J. (2015). Barriers to goals of care discussions with seriously ill hospitalized patients and their families: a multicenter survey of clinicians. *JAMA Internal Medicine*, *175*(4), 549-556.

Zhou, D. N. P., Jill, C., Parks, M. D., & Susan, M. (2010). Knowledge, attitudes, and practice behaviors of oncology advanced practice nurses regarding advanced care planning for patients with cancer.