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The Role of Advanced Practice Nurses in Advanced Care Planning for Cancer Patients

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College of Health Sciences

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Sincere McMillan

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2019

Abstract

The Role of Advanced Practice Nurses in Advanced Care Planning for Cancer Patients

by

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MS, New York University, 2009

BS, Adelphi University, 2006

Project Submitted in Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice

Walden University

February 2019

Abstract

In the United States, more than 75% of people will spend their last months of life in a health care facility. A key role for clinicians is to discuss care goals with the patients as part of a process called advanced care planning (ACP). As part of the oncology care team, advanced practice nurses (APNs) could help to increase the frequency of ACP discussions. The purpose of this project was to assess the knowledge and practice experiences of APNs regarding ACP at a National Cancer Institute designated cancer care hospital. Carper's patterns of knowing was the theoretical framework of this project. Data from an institutional survey of APN conducted in 2017 was analyzed for this project. The survey used a standardized, validated tool designed to assess knowledge and experiences related to advanced directives and ACP among the APN staff. Survey participants included 131 APNs. Demographics and descriptive analysis of the frequency of responses was performed. Key findings were positive regarding the importance of the APN in promoting a structured communication process to discuss the patient's wishes (92%), and that an effective ACP discussion could help patients identify a trusted individual as their health care proxy (88.6%). Additionally, the data indicated that the staff APNs had a perceived lack of knowledge regarding how to conduct ACP discussions. The implications of these findings support social change by informing advanced nursing practice of the importance of ACP for patients with cancer.

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Dedication

I dedicate this project to God, without Him this work could not have been done. My family, who have stood by my side and supported me from the very beginning. I especially want my daughter to know how much she inspires me every day to be a better person.

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Section 1: Nature of the Project

Introduction

Advance practice nurses (APN) deliver care to patients, families, and caregivers. As a part of the healthcare team, APNs diagnose, treat, and provide preventative health services. Research suggests that a component of comprehensive care includes discussions concerning advanced care planning (ACP). This project is designed as an attempt to better understand the role of the APN in ACP with cancer patients from the perspective of practicing clinicians at a National Cancer Institute (NCI)-designated acute care cancer hospital. Opening this dialogue may have the potential to impact APN practice and drive discussion for incorporating ACP principles early in patients' disease course, which may positively impact quality of life and patient satisfaction.

Problem Statement

In the United States, more than 75% of people will spend their last months of life in a health care facility where they may receive aggressive therapies and invasive care (Wilson, Kottke, & Schettle, 2014). While efforts are underway to improve patient and family experiences throughout the trajectory of illness, patients may still experience multiple transitions between home and various health care settings, including hospitals and postacute care facilities. A retrospective study by Bekelman et al. (2016) comparing the site of death, health care utilization, and hospital expenditures for patients dying with cancer in seven developed countries found that despite having the second lowest hospitalization rate 40.3% of U.S. decedents had an intensive care unit admission in the last 180 days of life compared with less than 18% in other reporting nations (Bekelman et al., 2016). Patients and their families have a right to advocate for the care

that they want; however, an important role for a clinician is to assess the patient's care wishes as part of an ongoing process referred to as advance care planning (ACP). When a patient's care goals are known it may be possible to minimize or eliminate treatments that a patient does not want. There has been a shift occurring in health care with the greater acceptance of palliative medicine and supportive care over the past several decades. Palliative care is interdisciplinary and focuses on improving a patients' quality of life by addressing their physical, emotional, and spiritual needs (Bickel et al., 2016). In a 2014 report, the Institute of Medicine suggested that the palliative care approach offered an opportunity for patients and families to receive care that brings medical, social, emotional, and spiritual dimensions together (Tulsky, 2015). Palliative care is not hospice care, which is, by contrast, a predominantly community-based program that provides multidimensional care for patients with terminal illness and their families. Typically, patients who are hospice eligible have an expected shortened life expectancy (Bickel et al., 2016). Working in conjunction with volunteers, hospice agencies often provide services ranging from symptom management to bereavement care. Hospice care is sometimes considered within the spectrum of palliative or supportive care; however, the two terms are not synonymous. Clinicians, as well as patients and families, may have misconceptions about what constitutes palliative and/or supportive care. Despite the increase in supportive care programs, patient referrals to these programs often come after aggressive treatments have been exhausted and can occur when patients are within their last days to weeks of life, limiting their effectiveness. This suggests that the increasing availability of such services has not shifted the focus of care in this country from one that is aggressive and curative focused (Wilson et al., 2014).

The term ACP has come to indicate the process involved in learning about the types of care decisions that patients might need to make, the consideration of those decisions ahead of time, and the discussion about their preferences, often by putting them into an advance directive (AD; U.S. Department of Health and Human Services National Institute on Aging, 2015). The usefulness of ADs in ACP has been documented in the literature. First emerging in the 1960s, ADs are a legal guide for the use of potentially life-prolonging medical treatment (Lovell & Yates, 2014). ACP builds upon the autonomy of patients by extending their care wishes to the stage in life where they either have advanced disease or have become cognitively incompetent to make complex medical decisions. Included in ACP is the completion of AD such as health care proxies and living wills that specify care goals (Lovell & Yates, 2014).

Attempts have been made legislatively to increase the number of Americans who participate in ACP. The Patient Self Determination Act of 1990 required hospitals and nursing homes receiving federal funds to inform patients of their right to refuse life-sustaining care and to have the patient's wishes recorded in the medical record (Appel, 2010). In 1993, the Uniform Health Care Decisions Act, adopted by six states, sought to increase the use of ADs by easing requirements for their creation (Appel, 2010). Yet large segments of the U.S. population still do not participate in ACP with their providers or complete an AD signifying their wishes (Lovell & Yates, 2014). If this is true for the general population, I questioned if there was any difference in participation in ACP among patients with cancer, a patient population with which I currently work.

Although cancer is now viewed as a chronic disease due to the growing number of cancer survivors, cancer remains the second most common cause of death in the U.S. In 2017, it was

estimated that 600,920 Americans would die from the disease (Siegel, Miller, & Jemal, 2017). This suggests that even as persons with cancer can expect to live longer, addressing care goals remains a high priority. AD completion rates in the United States among cancer patients varies but is thought to be relatively low. According to Zhou, Jill, Parks, & Susan (2010), only 31% of patients with advanced cancer reported having baseline discussions about supportive care issues with their oncology clinicians (Zhou et al., 2010). In this project I sought to explore how APNs, who are often a vital part of the health care team for cancer patients, understand, feel, and practice ACP at an NCI-designated cancer care hospital.

Local Context for Gap-in-Practice

According to the New York Palliative Care Information Act of 2011 clinicians, including APNs, who are treating patients diagnosed with a terminal illness or conditions should offer the patient information and counseling on the available options for palliative care (Astrow & Popp, 2011). However, at the time of enactment, APNs could not provide certification for these services. Additionally, the law in New York State prohibited ANPs from signing do not resuscitate and other orders pertaining to life sustaining treatments. This was as a barrier for patients seeking such services, especially in rural or medically underserved areas. An addendum to the law passed in 2017 which took effect in 2018 that allows APNs in New York State to sign do not resuscitate orders and Medical Orders for Life-Sustaining Treatment (New York State Department of Health, 2018). As the numbers of APNs increase, it is likely that more patients will have these clinicians as their primary providers of choice or as part of their healthcare team. As a result, I believe that APN practice should routinely include discussions concerning the

wishes of patients regarding life sustaining treatment(s), and patients should be able to contemplate such personal decisions with their preferred provider.

Significance and Implications for Nursing Practice

Supportive care issues may raise uncertainties for the APN for several reasons. First, because the advance practice role can differ from state to state, APNs may question if initiating ACP discussions is within their scope of practice. Secondly, ACP is in part an ethical issue, which represents a “grey area” that some practitioners may feel uncomfortable navigating. A third reason may be the practitioner’s own beliefs or morals regarding issues of health and wellness, which may lead to difficulty in initiating conversations with patients. Finally, not many APNs receive standardized training on how to have ACP discussions with patients and families, and there is a lack of information regarding ACP in nursing curricula and job orientations (Cohen & Nirenberg, 2011). The lack of educational preparation regarding ADs and a perceived lack of authority in decisions about supportive care for their patients can be a significant practice barrier for APNs (Cohen & Nirenberg, 2011). The national decline in primary care physicians may lead to a need to strengthen the APN workforce to develop the skills to have ACP conversations with patients. This is in line with the Institute of Medicine 2011 report, *The Future of Nursing: Leading Change Advancing Health*, which encourages advanced practice registered nurses to practice to the fullest extent of their education and training (Fairman, Rowe, Hassmiller, & Shalala, 2011).

Purpose Statement

The purpose of this project was to assess the knowledge and practice experiences of APNs regarding the role of AD and ACP at an NCI-designated acute care cancer hospital. This

project assessed how APNs view their role in ACP with cancer patients. This project is unique in that its focus is specific to APNs working with cancer patients.

Gap-in-Practice Defined

As a patient transitions through the stages of disease, APNs may need to address a myriad of concerns surrounding quality of life, pain control, nutrition, and symptom management. Patients and families often want to know what to expect during the process of cancer treatment and may experience a range of emotions that require skilled navigation by clinicians. Primary palliative care consists of the palliative care competencies required of all care clinicians including APNs. These competencies include the ability to assist patients and their families in establishing appropriate goals of care as well as facilitating care decisions that are consistent with the patient's wishes. APNs can be central in helping patients articulate these goals and documenting them in the medical record. The literature identifies that lack of clinician expertise and mastery of empathetic communication can be barriers to addressing ACP (Derksen, Olde Hartman, Bensing, & Lagro-Janssen, 2016). In addition, the healthcare environment in the United States continues to reinforce the use of high technology, critical care, and curative intent (Wilson et al., 2014). Death is often considered to be the worst possible outcome of illness instead of a culmination of the cycle of life. The identification of these gaps in practice suggests that assessing the role of the APN in ACP is critically important. This doctoral project has the potential to address the gap-in-practice by identifying what APNs understand about ACP with cancer patients and how they put these tools into practice when managing oncology patients.

Nature of the Doctoral Project

Project Sources of Evidence

An initial literature review demonstrated a lack of conceptual or operational definitions for the proposed project using APNs as a population focus. Specifically addressing ACP in the oncology setting, Barakat et al. (2013) looked at ACP knowledge and documentation by oncologists in hospitalized cancer patients. What the researchers found was that on many occasions, ACP discussions were deferred by oncologists in favor of discussions about curative measures, symptom prevention, and efforts to prolong life (Barakat et al., 2013). It is possible that ACP discussions seem counterintuitive to some cancer care clinicians and initially distressing for patients and families. This may mean that an important opportunity to introduce the concept of ACP may be missed. Even though oncology patients are living longer, many still face morbidity and mortality from the disease or its sequel. Some surveys of physicians caring for cancer patients showed that they did not engage in supportive care discussions with patients until very late in the disease trajectory or when all treatment options were exhausted (Barakat et al., 2013).

Project Method

This project was conducted by analyzing the results of a 2017 web-based survey conducted at my collaborating institution. The survey was an adapted model of the "Oncology APN's Knowledge, Attitudes, and Practice Behaviors Regarding Advanced Care Planning" tool created by Zhou et al. (2010). This is a standardized, validated tool that was identified as the most applicable and reliable to assess the concepts of knowledge and experiences related to AD and ACP in the nursing population.

Project Question

The question that this project attempted to answer is “what are the knowledge and practice experiences of APNs regarding AD and ACP?” As the researcher, I wanted to determine how knowledgeable APNs are concerning AD and ACP. Secondly, I wanted to identify how APNs perceive their role in ACP. Over a 1 month period in 2017 at a 473 bed NCI-designated cancer hospital, a standardized validated survey was sent to all advanced practice nurses with direct patient care responsibilities to assess this information. A total of 479 practicing APNs received this electronic survey with 131 responses (27% response rate). Through this doctoral project I analyzed this data in an attempt to better understand the knowledge and experiences of APNs regarding ACP among cancer patients. Current literature suggests that oncology patients, especially those with advanced disease, may be poorly informed regarding the nature of their disease, prognosis, and intent of treatment (Ghandourh, 2016). By discovering potential barriers to AD and ACP use, it is hypothesized that APNs can more effectively provide comprehensive care for their cancer patients.

Significance to Practice

APNs view patients in terms of their comorbidities, function, social supports, cognition, and overall fitness. This approach can provide a holistic view of the patient and help determine the treatment plan that best meets the patients’ needs. For example, an 80-year-old patient newly diagnosed with colon cancer who has a high level of functional and cognitive fitness may be able to clinically tolerate different treatment options that an 80-year-old patient with similar comorbidities who is functionally frail and/or cognitively impaired. This is not to suggest that patients and families do not have the right to determine the best treatment plans for themselves,

and the purpose of this paper is not to suggest that this right be taken from any patient. However, it is important for patients and families to make informed, individualized decisions based on the best clinical evidence available. While cancer is not the “death sentence” it was once thought to be, the disease still carries a high morbidity and mortality rate. When patients opt for cancer treatment, the role of the clinician is to support and guide the patient through the many stages of the treatment plan. This includes addressing the physical, emotional, spiritual, and mental toll that treatment can take on patients. In my opinion, this should also include addressing the patient’s overall goals of treatment during the early stages of the disease and providing clear and accurate information on anticipated symptoms, impacts to quality of life, and prognostication to the clinician’s best ability.

There are times when, even in spite of treatment, a patient’s disease progresses or does not respond to best available care. While patients should be encouraged to make the best decision for themselves regarding further lines of treatment or other more invasive therapies, in my opinion it is important that all options are presented to the patient, including developing a long-term plan in the event that more treatment is not in their best interest or is not available. In the United States, \$80 billion per year is spent on end-of-life care, almost half of which goes towards interventions for cancer patients (Tan & Jatoi, 2011). Some of these costs, which can include covering expensive antineoplastic agents, implementing interventions such as cardiopulmonary resuscitation, and intensive care unit monitoring within days or weeks of death may not lead to better outcomes (Tan & Jatoi, 2011). Their usage may be decreased if a patient’s plan of care is discussed in advance. What I have seen in my practice is that discussions concerning ACP often come within days or weeks of the patient’s death, which can lead to poorer symptom control,

more frequent hospitalizations, and a perceived decrease in quality of life. Healthcare programs that integrate long-term care planning may help reduce anxiety, disease burden, frequent hospitalizations, and health care costs while improving patients' quality of life (Meghani & Hinds, 2015). Clinicians who engage with patients and their families throughout their cancer journey regarding the patient's goals of treatment may have a better understanding of the patient's long-term plan, which can be documented in the medical record in advance. This may lead to less crisis-oriented decision making for the family and help the patient, family, and care team address the needs of the patient throughout their disease course (Shay & Lafata, 2015). It is important to state that ACP is not a one-time conversation, but an evolving process. In my opinion, it should be within the APN's scope of practice to initiate a conversation about care goals and continue to reassess goals with the patient at key biopsychosocial transition points including before treatment or before initiating new lines of therapy, if there is a change in clinical status or at any point directed by the patient. What I have found in practice is that difficulty can arise when the goals of the patient and family are not known or if they are unclear. To minimize this as much as possible, open dialogue should be encouraged.

Stakeholder Analysis

Stakeholders include the informal networks of individuals who could potentially be impacted by research activities and have a vested interest in a particular initiative. For this project stakeholders include APNs, oncologists, patients and their caregivers, payers such as Medicare and private insurance, and employers. Studies have demonstrated the beneficial effects on patients and families when supportive care is introduced into routine cancer care, including improvements in pain, reduced hospital costs and readmissions, increased hospice use, and

enhanced survival (Finn, Green, & Malhotra, 2017). For stakeholders, this means that incorporating ACP and AD is not only best practice but can significantly impact patient care quality.

Contributions to Nursing Practice

A study by May et al. (2016) demonstrated that only 25% of patients with an advanced cancer diagnosis and multimorbidity (the presence of more than one chronic condition) admitted to hospitals with palliative care programs received a consultation within 2 days of admission (May et al., 2016). Although palliative care is recommended, it may not be feasible to provide this specialty service to all patients with cancer due to significant workforce shortages and limited access to specialty palliative care (Becker et al., 2017). This suggests that there is a continued need for clinicians to understand primary palliative care, which is defined as basic palliative care—including basic symptom management, psychosocial support, and discussions about prognosis and goals of care—provided by clinicians, including APNs, who are not palliative care specialists (Hui & Bruera, 2016). This project could potentially inform the practice of APNs and uncover their utilization of primary palliative care techniques among cancer patients.

Summary

APNs work closely with oncologists to provide care to patients and their families. Given the increase in APNs and research that supports the early introduction of ACP for many cancer patients, identifying where APN providers struggle with the concepts of AD and ACP can help patients and their families get the care they need.

Section 2: Background and Context

Introduction

The purpose of this scholarly project was to assess the knowledge and practice experiences of APNs regarding the role of AD and ACP at a cancer specialty hospital. In this section of the project paper, I examine the themes of the literature review and analysis of available evidence.

Concepts, Models, and Theories

The theoretical framework for this project was Carper's patterns of knowing. The use of this theoretical framework helped identify four key areas from which nursing knowledge is produced. This theory not only addresses how a practitioner uses evidence-based knowledge but how nurses identify their moral self and reconcile their obligation to protect and respect human dignity and choice (Zander, 2007). Evidence-based practice integrates clinical expertise with patient values and current best evidence (Young, Rohwer, Volmink, & Clarke, 2014). Clinical and research evidence is constantly changing, and APNs need to be aware of the latest guidelines to be able to offer interventions that are most effective (Young et al., 2014). Providing evidence-based care typically involves five steps: (a) converting information needs into answerable questions, (b) finding the best evidence with which to answer the questions, (c) critically appraising the evidence for its validity and usefulness, (d) applying the results of the appraisal into clinical practice, and (e) evaluating performance (Young et al., 2014). In the profession of nursing, evidence-based practice has evolved to incorporate a patient-centered approach that reflects the entirety of nursing research and clinical practice (Mackey & Bassendowski, 2017).

According to the International Council of Nurses, evidence-based practice in nursing is defined as:

A problem-solving approach to clinical decision making that incorporates a search for the best and latest evidence, clinical expertise and assessment, and patient preference values within a context of caring (International Council of Nurses, 2012, Fig. 1, p. 6).

Although the process of caring is not unique to nursing, its inclusion in the definition of evidence-based nursing highlights the importance of understanding patient preferences and values as Carper's theory suggests. The patterns of knowing are empirical, personal, ethical, and aesthetic (Cody, 2006). The major emphasis here as it relates to the problem presented by this project is the ability to recognize patterns of learning associated with nursing and ACP. In addition, the different ways of knowing can be used to generate a clearer understanding of the advance practice experience and a broader integration of ACP knowledge. The design of this theory makes it an ideal theoretical framework for the evaluation of the knowledge and practice experiences of APNs in regard to ACP. Overall the use of this theory as a framework underscores the nursing metaparadigm and highlights the art and science of the profession.

Definitions

The following terms are defined for the purpose of this project:

Advance directive (AD): Competent adults have the ethical and legal right to make decisions regarding their health care including appointing a surrogate to make decisions on their behalf should they become incapacitated. An AD is a tool championed as a way to communicate a patient's preferences including guiding options for life sustaining treatments. Research suggests that many individuals do not complete these forms even in the face of life-threatening

illness (Green et al., 2015). Patients with advance directives are more likely to receive care in line with their wishes, which may lead to higher quality of life, especially at the end of life, as well as less caregiver stress and depression (McDonald, du Manoir, Kevork, Le, & Zimmermann, 2017). Conversely, patients without AD are more likely to receive aggressive treatments including intensive care admissions.

Advance care planning: Advance care planning (ACP) is seen as a process of communication between patients, clinicians, and caregivers that may include, but is not limited to, completing written documents regarding future treatments and advance directives (Brinkman-Stoppelenburg, Ritetjens & van der Heide, 2014). ACP can encompass relational, emotional, and social factors. Clinicians should recognize that patient decisions are often the result of a complex and dynamic interplay between all parties involved. While there are concerns that ACP may provoke fear, distress, anxiety, or other emotions in patients, a systematic review by Brinkman-Stoppelenburg et al. (2014) found that patients or families who participated in ACP at end-of-life did not report more stress, anxiety, or depression compared to patients or families who did not participate in ACP. It is therefore important for clinicians to individually gauge the readiness of patients and families to participate in ACP and provide appropriate supportive care as needed.

Relevance to Nursing Practice

The role of nursing in ACP has been documented in the literature. A randomized control trial looking at patient outcomes in early versus delayed initiation of concurrent palliative oncology care used structured telehealth advance practice nurse coaching sessions and follow up calls as part of an integrated oncology and palliative care model (Bakitas et al., 2015). The researchers assessed patient quality of life, 1-year and overall survival, resource use, and location

of death. Although the researcher found no statistical differences in patient-reported outcomes there was a statistically significant difference at 1 year as a 15% survival advantage was noted in the early-entry group (Bakitas et al., 2015).

In another study, Szekendi et al. (2018) conducted a field trial of an intervention designed to promote the integration of early palliative care by identifying seriously ill patients appropriate for a discussion of their goals of care and to advance the role of nonpalliative care clinicians by increasing their knowledge of and comfort with primary palliative care skills (Szekendi et al., 2018). The researchers embedded a palliative care physician or nurse clinician within a nonpalliative care service or unit for up to 6 months. What they found was that at the sites where this program was initiated, there was an increase in the presence of palliative care within the selected service or unit and the nonpalliative care clinicians reported increased comfort and skill at conducting goals of care conversations (Szekendi et al., 2018). Research such as this show that nurses have a role in promoting palliative care and can be utilized to advance ACP.

To my knowledge, this project is one of the first to explore the role of the APNs in the use of AD and ACP among cancer patients. What is unique about this project is that participants are APNs who work with cancers of varying types, across age ranges and disease states. Understanding how this group of clinicians view AD and ACP and how they utilize these tools may provide better insight into APN practice and perhaps identify gaps in knowledge or provider comfort level with ACP that were not previously explored among this population.

Local Background and Context

The importance of ACP in cancer patients has been well documented; however, patients may be poorly informed regarding the nature of their disease, prognosis, and intent of treatment.

An article by Raskin, Harle, Hopman, & Booth, (2016) suggested that targeting oncology clinicians is an important strategy for increasing rates of ACP among cancer patients. The researchers described the extent to which medical oncologists document discussions regarding prognosis, treatment benefit, and goals of care with a cohort of outpatients with advanced pancreatic and lung cancer. Their results found that only 4% of patients had goals of care documented by medical oncologists, but in 64% of cases, medical oncology notes described their disease as incurable (Raskin et al., 2016). Other discussions such as identifying an alternate decision maker, designating a power of attorney, writing an advance directive, and choosing a preferred place to receive end-of-life care were only documented in a minority of cases (Raskin et al., 2016).

The reasons why more patients with cancer do not have discussions with their oncology team regarding their care trajectory are likely multifactorial. The literature suggests that both clinicians and patients report barriers to communication about ACP. For clinicians, these barriers include lack of time, discomfort with emotions from the patient, and concerns about the potential to destroy hope (Houben, Spruit, Groenen, Wouters, & Janssen, 2014). Patients on the other hand may not be aware of the relevance of ACP and AD and may have the assumption that the clinician will initiate such discussions when they are needed (Houben et al, 2014). This communication stalemate can lead to situations where decisions about life-sustaining treatments become crisis-oriented or fail to occur at all.

For this project, data was collected in a 473-bed NCI-designated cancer hospital in an urban center. This facility has a diverse patient population and large number of APNs. At the collaborating institution, there were 479 APNs employed as nurse practitioners caring for both

hospitalized and community dwelling patients with cancer. While the role of the APN at this institution varied depending on setting and service (medical or surgical), the foundation of the role was to collaboratively work with an interdisciplinary team to provide medical care, educate patients and their family caregivers, and participate in research/ practice improvement.

Role of the Doctor of Nursing Practice Student

I currently practice as a nurse practitioner at my collaborating institution treating geriatric patients with cancer. This project holds significance to me as an advance practice provider because I often care for patients who would benefit from ACP, and I am aware of how difficult these conversations can be for all parties involved. In my clinical practice, I discuss patient cases and collaborate with other APN colleagues. I am surprised by how often my colleagues recognize when patients need ACP but do not initiate supportive care or ACP discussions themselves. This is what led to the development of this project.

My role as principle investigator was to conduct the literature search that provided the background for this project as well as identify a tool that could be converted into electronic format for the online survey. This foundational work was completed during my practicum experience under the supervision of my mentor. Once a tool was identified, I worked closely with the nursing research department at my collaborating institution to assess the validity of the tool and its appropriateness for use in the intended study population. Finally, working with the information technology department at the institution, I was responsible for creating the electronic version of the survey that was sent to all APNs throughout the institution. For this doctoral paper, I obtained permission to access the archived survey data and worked directly with a

biostatistician to analyze the previously collected data. I have no financial, personal, or commercial biases that may impact the nature of this project.

Summary

This section of the project reviewed the literature, the literature search strategies, and the theoretical framework that guided this project. This section also highlights how ACP can increase the likelihood that patients have their wishes honored throughout their disease course. Carper's patterns of knowing was discussed in this section as an avenue of inquiry into the role of the APN in ACP.

Section 3: Collection and Analysis of Evidence

Introduction

APNs such as nurse practitioners can be an important ally for cancer patients facing important decisions about care planning. One suggested way APNs can assist these patients is by initiating and facilitating ongoing discussions about patient's care goals. While the numbers of advance practice nurses continue to grow in the United States, research on how these providers view their role in ACP is limited.

The goal of this project was to explore the knowledge and practice experiences of APNs regarding ACP. This project explored APN knowledge of ADs and practice experiences with ACP and AD. Although the number of cancer survivors continues to increase as treatment options become more available, cancer is a contributing factor in many deaths in the United States. Therefore, engaging with patients concerning their wishes for care can be an integral part of the patient-centered experience (Carr & Luth, 2017). It should be noted that these care discussions are encouraged as part of an ongoing dialogue between patients and their clinical team, which often includes an APN. When these discussions are exploratory, conversational, and longitudinal, it can minimize or eliminate the need for families and caregivers to make "crisis decisions," which often occur in the face of a life-threatening injury or insult (LeBlanc & Tulskey, 2018).

Thus far in this paper I have discussed the rationale for the project, provided a theoretical framework that guides the project, and discussed the local background and context. In this section I will discuss the practice-focused question, explore sources of evidence, provide details on literature review, analysis, and synthesis, and conclude with a summary.

Practice-Focused Question

The gap-in-practice section identified that APNs are treating patients with chronic comorbid conditions, some which may be terminal, but there are no mandatory guidelines regarding discussions of ACP for APNs. Potentially, this may serve as a barrier for patients to receive such services, especially in medically underserved areas. The purpose of advance care planning is to help patients prepare for current and future decisions about their medical treatment. ACP is meant to be an ongoing process where a patient's current condition and prognosis are reviewed, preferences for information regarding their illness are elicited, and likely medical dilemmas are presented with options for care discussed (Sudore & Fried, 2010). In this way, ACP is meant to be an active process that includes the patient, their caregivers, and their clinicians. As more APNs step into the role of primary care provider and as more of these clinicians lead multidisciplinary teams treating complex clinical cases, they may be tasked with undertaking discussions regarding ACP with patients.

Addressing the role of APN in ACP is an important one, especially as the numbers of APNs continues to expand. According to the American Association of Nurse Practitioners (2017), there are more than 234,000 APNs who practice as nurse practitioners in the United States. Their exposure to principles of palliative and supportive care can vary widely. As discussed previously, APNs may be unclear about their role in ACP partly because there is no recommended standardized training on how to have these discussions embedded into APN education, and there is a lack of uniform information regarding ACP in nursing curricula and job orientations (Cohen & Nirenberg, 2011).

The question that I attempted to answer with this project was, “What are the knowledge and experiences of APNs regarding AD and ACP among cancer patients?” To answer this question, a survey was sent in 2017 to all practicing APNs at an acute care cancer hospital. This previously collected data at the collaborating institution was analyzed as the main data source for this project. The goal of this project was to explore what APNs understand about ACP, including ADs, and to understand their practice experiences regarding ACP in the hope that this knowledge could lead to a clearer understanding of the role of the APN in this process.

Literature Search Strategy

The ability to integrate and synthesize literature is a requirement for doctorally prepared nurses. The search strategy used to identify the literature for this project involved accessing the following databases: Walden University Library, New York University Library, PubMed, Embase, PsycINFO, CINAHL Plus with Full Text, MEDLINE, and EBSCO. The key words used during the search, both singularly and in multiple combinations, included *advance practice nurses, nurse practitioner, advance directives, advance care planning, knowledge, attitudes, behaviors, experiences, oncology, and cancer*. The search was limited to the English language, with articles published between 2010 to 2017. To ensure that applicable evidence-based literature was reviewed and summarized for this project, it became necessary to include articles published before 2010 because these seminal articles continue to support current practice. All searches were limited to adult patients as the issues and research surrounding childhood cancer and ACP were thought to differ from the adult population. Ten articles were used to create the literature review for this project.

Literature Review

Overall the literature review demonstrated a lack of information regarding the proposed research topic using APNs as the population of focus. Even though APNs increasingly are caring for patients with cancer, their perceived role in ACP and advance directive completion rates among cancer patients is suspected to be low.

Sources of Evidence

To answer the research question, I retrospectively retrieved and reviewed the results of a web-based survey assessing the knowledge and practice experiences of advanced practice nurses regarding ADs and ACP conducted at the collaborating institution. This survey was conducted using a web-based survey tool. The survey was an adapted model of the "Oncology APN's Knowledge, Attitudes, and Practice Behaviors Regarding Advanced Care Planning" tool created by Zhou et al. (2010). A review of nursing, medical, and health related literature was conducted regarding APN knowledge and experiences in relation to AD and ACP among adult patients with cancer. After reviewing the literature, the Zhou et al. (2010) tool was identified as the most applicable and reliable to assess the concepts of knowledge and practice experiences related to these concepts in the nursing population. The lead author of the instrument was contacted by this author via e-mail and permission was granted to use the tool for this project. Two expert content reviewers at the collaborating institution assessed the appropriateness of the tool for use at the project site. One content reviewer was a leader in palliative care nursing and the head of the nurse practitioner led division of the supportive care service at the institution and the other content reviewer was the head of nursing research at the institution.

The original survey tool consisted of 52 questions; however, the survey used for this project consisted of 50 questions. The two omitted questions from the original survey were “In my practice, I estimate that approximately % of advanced cancer patients utilize hospice services” and “In my practice setting, I estimate that the following percentages of patients who receive hospice care die (please write your estimated percentages in the appropriate box)” were deemed by the content experts to address issues (hospice and end-of-life care) outside the scope of this project. The following section outlines the nature of the tool; the full version can be found in Appendix A.

Section 1 of the survey, the demographic section, consisted of 11 questions including participant age, gender, highest level of education, and current practice setting. All questions in this section were modified from the original version to be more applicable to the collaborating institution. The age question was originally a blank fill-in; however, it was modified to include age ranges to minimize the possibility of participant identification and to ease data collection. The gender question was modified to include an “other” category to be more gender inclusive. The religion question was expanded to include major recognized religions in the United States, Christian, Muslim, Jewish, Buddhist, Hindu, and none. The highest level of education question was expanded to include all levels of advance practice nursing from master’s through postdoctorate. The current practice setting question was altered to be specific to the collaborating institution and include inpatient hospital/acute care and outpatient care both in urban and regional/ suburban settings.

Section 2 of the survey titled “Knowledge About Advance Care Planning” consisted of 12 questions, seven true or false questions and five multiple choice questions. These questions

were not modified from their original version. Section 3 titled “Attitudes Toward Advance Care Planning” was broken down into three subsections “Beliefs About Advance Care Planning,” which had a total of eight questions, “Subjective Norms About Advance Care Planning,” which had a total of six questions, and “Perceived Control About Advance Care Planning,” which had a total of four questions. All questions of this section were Likert-scale type questions where 1 was strongly agree and 5 was strongly disagree. No questions in this section were modified from their original version. Section 4, “Practice Behaviors in Advance Care Planning Discussion” consisted of 4 Likert-scale type questions where 1 was strongly agree and 5 was strongly disagree. No questions in this section were modified from the original. The final section of the survey, “Other Practice Information,” originally consisted of seven questions, four multiple choice questions and three fill-in questions. The survey was modified to include two open-ended questions with free text response options to obtain additional data regarding ACP in respondents’ clinical practice and their perceived barriers to ACP. All these modifications and additions were reviewed by the expert content reviewers at the collaborating institution and determined to have no impact on the tool's validity or reliability. The survey was distributed to individual practitioners by secure e-mail. Each participant was provided an anonymous link to the survey and could only take the survey once.

This survey data is highly relevant to the practice problem addressed by this project. The chosen survey tool was a standardized and validated tool that addresses the specific concepts under investigation. The tool does have limitations. The Cronbach alpha for the attitudes and practice behavior question sets ($r = 0.76$ and $r = 0.83$ respectively) represented good reliability. Other question sets such as the assessment of the experiences of APNs had a lower Cronbach

alpha score ($r = 0.56$). After reviewing the tool with content experts at the collaborating institution, this tool was deemed to be the best available and was used with the knowledge of its limitations. Access to the raw data from this project was provided after a written request was submitted to the nursing research and the research & technology management departments at the collaborating institution. The data had all personal information removed so that participants could not be identified.

Study Population

I chose APNs as the study population for two main reasons, availability and scope of practice. Data was collected in a 473-bed NCI-designated cancer hospital in an urban center. This facility has a diverse patient population and large number of APNs. The APN workforce continues to grow, and an estimated 23,000 new providers completed their academic programs in 2015-2016 (Fang, Li, Kennedy, & Trautman, 2017). APNs complete didactic and clinical training to provide comprehensive, evidence-based care to patients and have greater autonomy in their practice than registered nurses. At the collaborating institution, there were 479 APNs employed as nurse practitioners caring for both hospitalized and community dwelling patients with cancer.

Analysis and Synthesis

The data collection for this project started with approval from Walden University institutional review board (IRB), approval number 09-13-18-0593784. Approval from the collaborating institution IRB was also obtained. After receiving approval, I accessed data from the 2017 web-based survey assessing the knowledge and practice experiences of advanced practice nurses regarding advance directives and advance care planning conducted at the

collaborating institution. The data measures included participant demographics, an assessment of knowledge regarding advance directives, and practice behaviors such as frequency of participation in advance care planning discussions. All participant data was de-identified.

Data Analysis

This doctoral project is a secondary analysis of the survey data. A secondary data analysis is an analysis of previously collected data (Johnston, 2017). The utilization of this existing data provided a viable option for this capstone project. Answers to web-based survey questions of APNs were retrieved. The data collected for this project was entered directly into and managed via a secure database called REDCap. REDCap (Research Electronic Data Capture) is a data management software system supported by the collaborating institution. REDCap is a tool for the creation of customized, secure data management systems including web-based data entry forms, reporting tools, and a full audit trail of data manipulation.

Upon obtaining the data, participant demographics were assessed including total number of participants and survey response rate, age of participants, highest level of education, and details on their practice settings. The nature of the data that had been collected was both quantitative and qualitative; however, this project focused on the reporting of quantitative data. In regard to APN knowledge, I analyzed survey responses to determine how knowledgeable APNs at the collaborating institution were in regard to ADs. Regarding practice behaviors, the goal was to understand how APNs at the collaborating institution used ACP in their practice. I thought this to be an understudied area but one that I felt had the potential to impact care for many patients. Even though there is a growing body of literature concerning palliative care

nursing and advance care planning, this study provides a unique focus on the perspectives of practicing APNs.

Summary

Care that APNs provide has a meaningful impact on patients and families. Understanding the role of the APN in ACP is essential to promoting quality care. In the next section, I discuss the population, sample size, data collection, instrument, and the data analysis. This project has implications for patient care, provider empowerment, and improved ACP among cancer patients.

Section 4: Findings and Recommendations

Introduction

While the numbers of internal medicine physicians in the United States declines for various reasons, as previously stated the numbers of APNs is expanding. APNs may have a unique opportunity to address the access to health care challenges that may face many Americans. The U.S. population is aging, which presents a unique challenge. As more people are living longer, health care providers trained in the management of chronic comorbid conditions, including cancer, will be needed to help patients maintain quality of life and reduce morbidity. According to an article by Fried, Zenoni, Iannone, O'Leary, & Fenton (2017), part of providing comprehensive care includes facilitating ACP discussions with patients and families. These discussions are meant to be a part of ongoing care, ideally not as a one-time crisis-oriented event. While ACP is important across any disease spectrum, this project focused specifically on the role of APNs in ACP with oncology patients. While the literature highlights the importance of ACP, little data is available regarding the knowledge, attitudes, and practice behaviors of APNs in respect to ACP among cancer patients. This is what I sought to address in this project. This project does not address the APN's role in caring for patients who may be at end-of-life or enrolled in hospice care. Among cancer patients, despite the known benefits of palliative care and ACP, the literature suggests that these types of discussions may not be happening.

To answer the project question—What are the knowledge and experiences of APNs regarding AD and ACP among cancer patients?—I retrospectively retrieved and reviewed the results of a web-based survey assessing the knowledge and practice experiences of APNs regarding AD and ACP that was conducted at the collaborating institution. As previously stated,

this data set was highly relevant to the practice problem addressed by this project. The survey was based on a validated and established questionnaire entitled “Oncology APN’s Knowledge, Attitudes, and Practice Behaviors Regarding Advanced Care Planning” created by Zhou et al. (2010). At the time of project development, I deemed the use of a web-based survey the most appropriate method of data collection due to potential cost savings, potential improved response rates, and the ability to streamline data analysis. The chosen questionnaire was used as a survey tool because it was standardized and validated to address the specific concepts under investigation in this project. The collaborating institution provided access to the raw data from this survey after I obtained institutional and Walden University IRB approval.

Findings and Implications

A total of 479 APNs employed at the collaborating institution were invited to participate in the electronic survey. Of 479 potential participants, 131 responses were received (response rate 27%). The following analyses were conducted using the data from the survey responses.

Participant Demographics

Ninety-five percent of respondents were female with ages ranging from 25 years to 50 years of age and older. Most respondents identified as Christian (74.8%, $N = 98$) although there was representation from many major religious groups (see Table 1).

Table 1

Participant Demographics

Age	18-24	0.0%	
	25-30	7.6%	(<i>N</i> = 10)
	31-39	38.9%	(<i>N</i> = 51)
	40-49	30.0%	(<i>N</i> = 39)
	50 and over	23.5%	(<i>N</i> = 31)
Gender	Male	3.8%	(<i>N</i> = 5)
	Female	95.4%	(<i>N</i> = 125)
	Other	0.8%	(<i>N</i> = 1)
Religion	Christian	74.8%	(<i>N</i> = 98)
	Muslim	3.0%	(<i>N</i> = 4)
	Jewish	7.6%	(<i>N</i> = 10)
	Buddhist	1.5%	(<i>N</i> = 2)
	Hindu	0%	
	None	12.9%	(<i>N</i> = 17)

The majority of respondents held a master's degree (84%, *n* = 110), and most were certified in adult (25.6%, *n* = 34) or family health (25.6%, *n* = 34).

The collaborating institution offers oncologic care in a variety of settings. Acute care represents the care provided to patients who are hospitalized while clinicians in ambulatory and regional care settings provide community-based care. Respondents represented all care settings with 46% practicing in acute care inpatient settings and 42% and 12% practicing in the ambulatory outpatient and regional settings respectively (see Figure 1).

Current Practice Setting

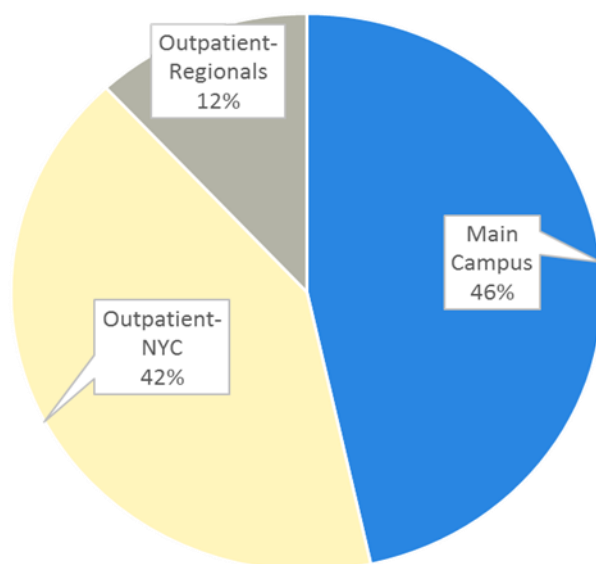


Figure 1. Demographics regarding participants' practice setting.

Most respondents worked full-time day shifts. Within these care settings, respondents represented a variety of practice specialties. Thirty-three percent worked in medical oncology, 27% worked within a consultation service, and 11% worked in surgical oncology. The remaining respondents represented critical care (11%), pediatrics (10%), supportive care and pain management (6%), and radiation oncology (2%; see Figure 2).

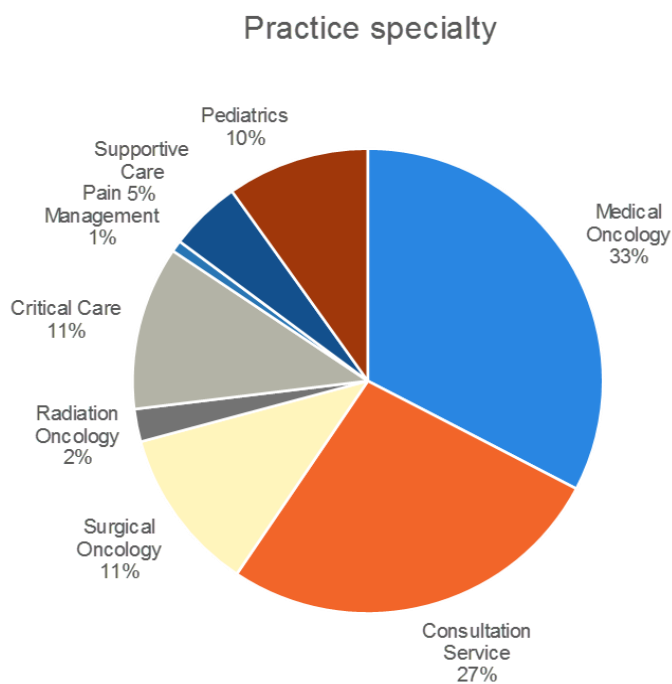


Figure 2. Demographics regarding participants' practice specialty.

In addition to varied work settings and practice specialties, respondents also had a range of years of experience as APNs and in the field of oncology. Most respondents had been working as an advance practice provider for 0-5 years (37%) but there were providers who responded to the survey who had more advance practice experience. 26% of respondents had worked as an advance practice provider for 6-10 years, 18.3% for 11-15 years, 11.4% for 16-20 years, and 7.6% had worked as an advance practice provider for 21 years or more. In terms of total years working in oncology nursing, most respondents had worked in oncology for 6-10 years (28.2%) but the range of oncology experience of participants was broad, with 24.4% of respondents having worked in oncology 21 years or more, 10% for 16-20 years, 21% for 11-15 years, and 17% for 0-5 years. For this survey, years of oncology experience also included years working as a registered nurse in oncology care if applicable.

The demographic data suggests that the survey had acceptable representation across ages, level of education, practice settings and specialties, and years of experience both as an APN and in oncology nursing. While the smaller sample size may impact generalizability in other settings, the sample was representative of the collaborating institution's APN population.

Participant Knowledge about Advance Care Planning

One hundred twenty-seven participants completed this section in its entirety representing a response rate of 26.5%. To assess participant's knowledge about ACP, the survey included 12 multiple choice questions (see Appendix B). These questions addressed AD, the patient self-determination act (PSDA), the five wishes, the physician order for life sustaining treatment (POLST), and the role of the oncology nurse in ACP.

Advance Directives

Central to the role of participating in ACP with patients is the ability to understand what ADs are and how they are used in healthcare. As previously defined in this paper, ADs are a legal guide for the use of potentially life-prolonging medical treatment and are used to communicate a patient's preferences (Lovell & Yates, 2014). Examples of AD include living wills, durable power of attorney for health care, and health care proxies. An analysis of the responses showed that 80.3% of respondents could correctly identify an example of an AD. 85% of respondents believed that among Americans there is a lack of AD usage. The lack of AD use in the United States is supported by the literature. In 2017 researchers reviewed 150 studies published between 2011 and 2016 that looked at the proportion of U.S. adults who completed ADs. Of nearly 800,000 people, approximately 37% completed some kind of AD. Of those, 29% completed living wills, 33% health care proxies, and 32% remained "undefined," meaning the

type of AD wasn't specified or was combined (Yadav et al., 2017). The literature suggests there are likely many reasons for this overall lack of AD usage including time constraints, provider and/or practitioner fear, provider lack of knowledge regarding how to conduct ACP conversations, and institutional culture.

Ninety seven percent of respondents believed that AD documents can be revoked at any time, which is true if the patient is cognitively capable of making such changes. Interestingly, respondents were split on one question regarding the applicability of AD. The question asked if a notarized AD from one state is legal in all other states. 33.9% of respondents said this was true, 35.4% said this was false, and 30.7% did not know (see Figure 3). A review of the literature found that while some states do honor AD from another state, others will honor out-of-state AD so long as they are like the state's own law. Further complicating this matter, some states do not have an answer to this question, meaning patients and their families may be unaware of potential gaps in protections. Currently there is no “universal” AD that would be applicable in all states. A way providers can address this situation should they have a patient who spends a significant amount of time in more than one state would be to have the patient complete an AD for all the applicable states they spend any significant amount of time in.

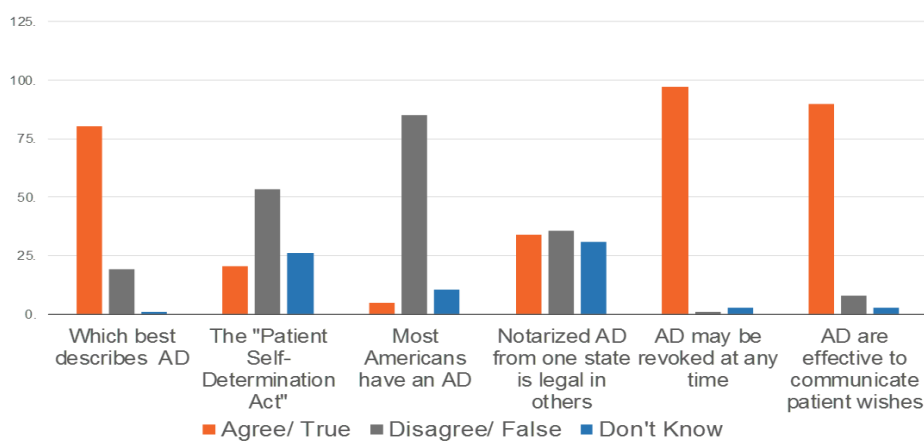


Figure 3. Advanced practice nurse knowledge concerning advance directives. $N = 127$. Overall, the data showed that the cohort of respondents who completed this section were knowledgeable in what AD are and 89.8% of participants responded that they believe AD are effective tools for communicating patient wishes.

The Patient Self-Determination Act

About 47% of respondents were not knowledgeable about the PSDA. The PSDA is a federal law that requires that most hospitals, nursing homes, home health agencies, and HMOs routinely provide information on AD to patients. Under the PSDA, institutions are required at the time of admission to give patients a written summary of their health care decision-making rights and the facility's policies with respect to recognizing ADs. In addition, the PSDA also requires facilities to ask patients if they have an AD and document that fact in their medical record, educate their staff about AD, and prevent discrimination based on a patient's AD status.

The Physician Order for Life Sustaining Treatment

Sixty nine percent of respondents were not knowledgeable about the POLST. A POLST form does not replace an advance directive but they work together. A POLST is a medical order that outlines the specific medical treatments a patient would want during a medical emergency if the patient cannot speak for themselves. POLST forms can be appropriate for individuals with a serious illness or advanced frailty and they often address issues such as cardiopulmonary resuscitation, artificial feeding, antibiotic use, and comfort measures. In New York State, the POLST form is called the MOLST or medical orders for life sustaining treatment. MOLST forms can be used in a variety of healthcare settings by both physicians and APNs. These forms are typically completed after a discussion between patients or surrogates and health care providers in a non-emergent setting. According to the New York State Department of Health, when using a MOLST, a licensed physician or APN must always, at a minimum: confer with the patient and/or

the patient's health care agent or surrogate about the patient's diagnosis, prognosis, goals for care, treatment preferences, and consent by the appropriate decision-maker and sign the orders derived from that discussion. Under New York State law, the MOLST form is the only authorized form in the state for documenting both nonhospital do not resuscitate and do not intubate orders (health.ny.gov, 2017).

Although data concerning how many APNs complete MOLST forms with their patients in New York State still needs to be reported, a study in the Journal of Palliative Medicine looking at Oregon found from 2010 to 2015 85.3% of POLST forms were signed by a physician, 10.9% of forms were signed by an APN, and 3.8% of forms were signed by a physician assistant. According to the article, from 2010 to 2015, the overall percentage of POLST forms signed by an APN increased from 9.0% in 2010 to 11.9% in 2015 (Hayes, Zive, Ferrell, & Tolle, 2017). This increase in POLST completion by APNs may represent the start of a shift among healthcare providers who conduct ACP with patients.

Overall, respondents lacked knowledge concerning the PSDA and POLST. This represents an area where more education may be needed. It should be noted that APNs should receive such education in accordance with the laws of the state in which they practice.

The Role of the Oncology Nurse

Ninety two percent of participants responded that the role of the oncology nurse in ACP is to promote a structured clinician-patient communication process to discuss the patient's wishes. 96.7% of participants did not agree that the best time to discuss ACP with patients is when they are seriously ill. This is in line with the views of many national organizations such as the American Society of Clinical Oncology, the American Nurses Association, and the Hospice

and Palliative Nurses Association which all have position statements supporting the early integration of palliative care and ACP. 88.6% of respondents felt that part of an effective ACP discussion was to help patients identify a trusted individual as his/her health care proxy while 8.1% thought that having the patient bring or sign an AD was important. 3.3% of respondents reported they did not know which option made up part of an effective ACP discussion. The literature suggests that provider knowledge concerning ACP can be a motivator or barrier to conducting such conversations. In a systematic review of perceptions and experiences of patients, families, and health care providers with ACP among cancer patients, researchers found that health professionals' knowledge of and attitudes towards ACP were consistently found to be an important factor in their willingness to initiate or participate in ACP (Johnson, Butow, Kerridge, & Tattersall, 2016). Finally, during ACP discussions 65.9% of respondents thought it was most important to involve the patient's health care proxy while 29.3% of respondents thought the disclosure of the diagnosis and prognosis of the patient was most important to discuss. Ideally an ACP discussion should include both parameters. In a 2015 study, researchers attempted to develop quality indicators related to end-of-life communication and decision making. One of the highest rated indicators was "since admission, a member of the health care team has talked to the patient and/or substitute decision maker about a poor prognosis or indicated in some way that the patient has a limited time left to live". In addition, the study pointed to the fact that an important indicator of quality ACP is that it occurs before hospitalization, when the patient can discuss his/her preferences for using or not using life-sustaining treatments with their substitute decision maker (Sinuff et al., 2015).

The data suggests that overall APNs are knowledgeable regarding AD, however there are areas where APNs knowledge may be lacking. Understanding the components of an ACP discussion is an important skill for any clinician and this may be an area where more education and real-world ACP exposure may be beneficial to APNs.

Attitudes Towards Advance Care Planning

The data set explored APNs attitudes toward ACP by assessing participant's beliefs about ACP, subjective norms about ACP, and perceived control regarding ACP. 121 respondents completed this section in full representing a response rate of 25.2%.

Beliefs About Advance Care Planning

A common belief among members of the public as well as some clinicians is that ACP has the potential to lead to psychological distress among patients. A 2015 study by Green and colleagues suggested that such conversations do not adversely affect hope or anxiety among advance cancer patients (Green et al., 2015). The study further suggests that patients with advanced illness may appreciate the value of ACP and are "more satisfied" when provided an opportunity to extensively consider end-of-life conditions and life-sustaining treatments. It should be noted that while the needs of a patient with advanced cancer may differ from patients with a newly diagnosed cancer, it is important for clinicians to assess a patient's readiness for participation in ACP on an individual basis. While delaying ACP during the early diagnosis or treatment phases may be deemed appropriate, the literature suggests that patients tend to follow the lead of their clinicians with many believing that physicians are responsible for initiating discussions regarding ACP (Johnson et al., 2016). With this in mind, it is important that clinicians not ignore their role in initiating ACP discussions, especially at major clinical

transition points such as when treatment stops working, when disease progresses, or in the face of organ failure.

Among survey respondents, 82.7% disagreed or strongly disagreed that ACP can destroy a patient's sense of hope. 93.4% disagreed or strongly disagreed that ACP will speed up the dying process in many patients. 95.9% of participants believed that ACP should be discussed with every patient regardless of diagnosis. 96.7% of respondents believed ACP discussions are very important for patients with life-threatening illness, 91.7% believe ACP can reduce the end-of-life care decisional crisis, and 93.7% believe ACP can improve patients and family's satisfaction about end-of-life care.

Given survey participants overwhelmingly positive beliefs regarding the benefits of ACP, it may be important to integrate supportive care into oncology practice. There is continued discussion regarding the best methods for such integration but characteristics such as the health-care system, hospital setting, and local resource availability should be taken into consideration (Hui & Bruera, 2016).

Subjective Norms About Advance Care Planning

Knowledge of APN practice around ACP is limited as few studies exist involving APNs and ACP (Dube, McCarron, & Nannini, 2015). Eighty-nine percent of respondents reported the belief that ACP is a professional responsibility for nurse practitioners, but 76.5% believe it is a *personal* responsibility to discuss ACP with patients and families. This discrepancy may point to an unclear understanding of the APN role in ACP discussions including who should initiate such discussions. This discrepancy may also be attributed to the varied roles of APNs, lack of clinical time to conduct these types of conversations, communication difficulties, personal anxiety, and

lack of provider training (Dube et al., 2015). Interestingly, 68.9% of respondents felt supported by colleagues in discussing ACP with patients and families. Although this percentage represented most respondents, it is important to note that a perceived lack of support among APN colleagues concerning ACP may represent an important opportunity for increased mentorship which may require support from administration. Research does suggest that having the support of leadership is a facilitator to participating in ACP (Dube et al., 2015). Making these discussions a part of routine care may improve APN participation.

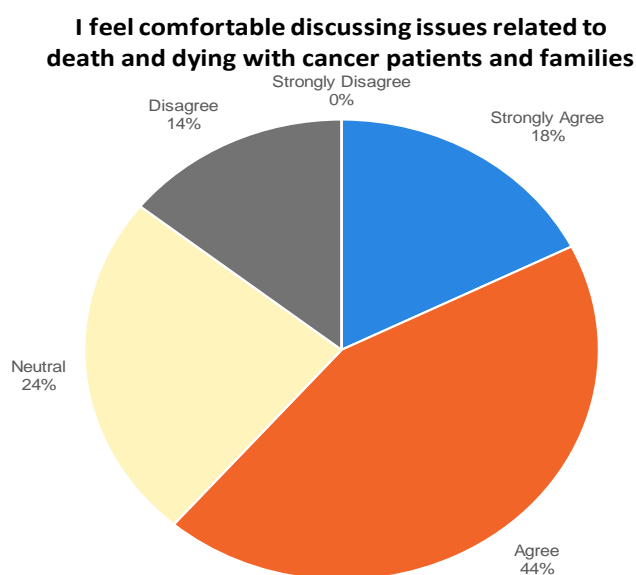


Figure 4. Assessment of comfort discussing death and dying with patients and families.

Perceived Control about Advance Care Planning

To assess APNs perceived control about ACP, the survey included 4 questions that were aimed at assessing the comfort level of APN with discussing ACP with cancer patients. When asked if they as clinicians felt comfortable discussing issues related to death and dying with

cancer patients and families, 44% of respondents agreed and 18% strongly agreed that they felt comfortable with these discussions (See Figure 4). Results were similar when APNs were asked if they felt comfortable discussing ACP with cancer patients. 49.6% agreed while 16% strongly agreed they felt comfortable discussing ACP with cancer patients. However, only 39.5% of respondents agreed and 11.8% strongly agreed with the statement that they feel confident in their ability to communicate “bad news”. Finally, when asked about their knowledge concerning how to conduct ACP conversations with patients and their families, only 34% of APNs agreed and 10% strongly agreed that they felt they had sufficient knowledge to conduct such conversations (See Figure 5).

From these survey responses, the importance of preparation and training in the art and skill of ACP is highlighted. Education and training focused on conducting ACP discussion may enhance the formal preparation of APNs to participate in ACP and should be considered a priority for institutions and providers who want to increase the use of ACP discussions among patients (Dube et al., 2015). In addition, education and training focused on conducting ACP discussion may enhance the formal preparation of APNs to participate in ACP. The pivotal role of education was further confirmed by Dube and colleagues (2015) as researchers found that nurse practitioners who had taken continuing education courses in supportive care were more than twice as likely to have had ACP discussions with patients compared with nurse practitioners who had not taken such classes (Dube et al., 2015). Thus, the role of education in ACP may have a long-term effect on provider knowledge and comfort in participating in ACP with patients.

**I have sufficient knowledge about how to conduct
ACP conversations**

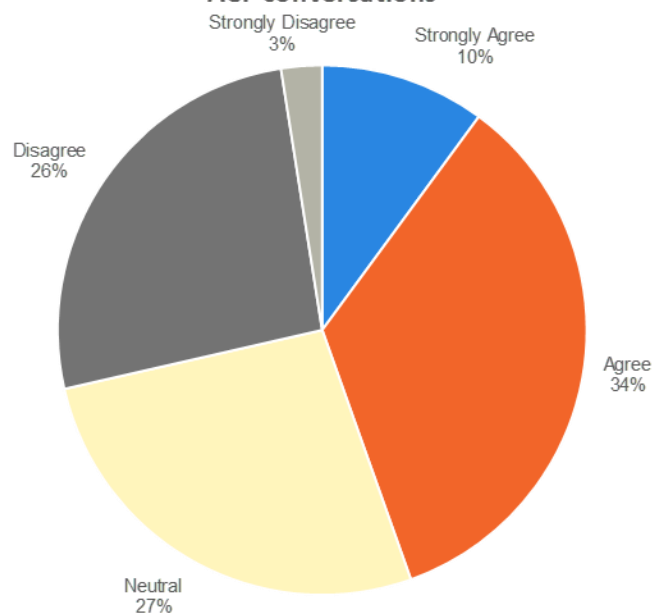


Figure 5. Assessment of knowledge regarding how to conduct ACP conversations.

Practice Behaviors in Advanced Care Planning Discussion

The last series of questions looked specifically at how APNs are currently using ACP in their own practice at the collaborating institution. Only 25.4% of respondents at the collaborating institution reported routinely initiating ACP discussions with cancer patients. Although studies on APN use of ACP among cancer patients is limited, the relatively low percentage of APN initiating ACP discussions at the collaborating institution may point to an opportunity for further research regarding APN perceptions on barriers to initiating ACP. In the Dube study (2015) APNs identified the following as barriers to ACP: lack of time, staff shortage, and appointment type. System barriers included lack of education, lack of standardized forms, lack of electronic

medical record to support documentation and retrieval of information, and lack of leadership support (Dube et al., 2015).

Among respondents, 64.4% had not had ACP discussions with more than 50% of their cancer patients. In exploring the reasons for this discrepancy among APN at the collaborating institution, the following was considered. 40.8% of respondents of this survey work in a consultative, surgical oncology, or radiation oncology service. In the collaborating institution, these services are generally called upon to follow alongside the primary medical oncology team and may not encounter opportunities to discuss ACP with patients as their interaction with the patients are often brief and focused on a specific problem. Of those consult services that do follow patients for a longer term, APNs may prefer to default to the primary oncologic team to discuss ACP. Among respondents, 50.9% stated they routinely follow up with ACP discussion with cancer patients when appropriate. This may suggest that once an ACP discussion is initiated, an APN may feel more favorable towards readdressing the patient's treatment goals. In terms of practice behaviors. 33.1% of respondents' states that the oncologist sometimes initiates the discussion of ACP, whereas 32.2% of respondents stated the oncologist often or always does.

Summary

The discussion of the role of APN in ACP is an important one, especially among patients with chronic medical conditions such as cancer. The data shows that APNs have an overwhelmingly positive view of the benefits of AD and ACP, however there is a perceived lack of knowledge regarding how to conduct such discussions. In practice, APNs are often following up on ACP discussions but not necessarily initiating these conversations which may represent a

unique opportunity for more educational or supportive collaborations among clinical care team members.

Section 5: Dissemination Plan

The purpose of this project was to assess the knowledge and practice experiences of APNs regarding AD and ACP among cancer patients at my collaborating institution and to highlight provider attitudes and practice behaviors concerning AD and ACP. The full implementation of the recommendations of this project is beyond the scope of this paper. However, the results of this project add to the body of evidence that supports the importance of addressing ACP among cancer patients and empowering APNs to do so. APNs are a growing population of clinical providers in the United States, and as more APNs care for patients with varying levels of multimorbidity, a standardized realistic approach to educating advanced practice providers concerning ACP may be beneficial. Such an educational initiative may advance nursing practice and build confidence among providers to use the important skill of effective communication. Ideally, such an educational initiative would be introduced when nursing students are pursuing their advanced degree as part of their didactic education prior to entering the workforce; however, this does not negate the importance of addressing ACP in job orientations and perhaps as a mandatory component throughout a provider's clinical experience. This project will be presented at the collaborating institution to APNs and nursing administration at an upcoming grand rounds session to disseminate the findings and elicit suggestions regarding possible educational initiatives. It is my hope to discuss integrating the recommendations from this project into the current APN orientation process at the institution.

Analysis of Self

As an advanced practice provider and a DNP student, I believe my role is to improve patient care and impact practice change. In practice, I suspected a lack of APN utilization of ACP, and through this project I now have data that supports this. In oncology, APN practice encounters many disease types. While the initiation of ACP discussions should be individualized for each patient depending on patient preference and disease state, I realize that for a master's prepared nurse, conducting ACP discussions is within the scope of practice. This project has motivated me to continue to seek ways to empower APNs to practice at the highest level of their skill set. My collaborating institution is NCI and Magnet designated. This means that the center has been deemed a center of excellence in cancer care as well as in nursing. While I consider myself extremely fortunate to practice at an institution with a strong vision and patient-centered values, this project has emphasized to me the importance of developing an institution-wide care model that integrates principles, processes, and practices of supportive care as part of routine comprehensive cancer care from the time of diagnosis.

Summary

Many national organizations such as the American Society of Clinical Oncology, the American Nurses Association, and the Hospice and Palliative Nurses Association have position statements supporting the early integration of palliative care and ACP in clinical practice. It is important that all care providers, including APNs, are empowered to use ACP techniques with patients. While this project focused on the cancer population, it may be beneficial to study ACP usage and APN practice with other chronic disease states as well. Overall, ACP is not meant to be a "death sentence" but rather a way to extend the autonomy of patients past the point where

they are able to speak for themselves. Providers who appropriately participate in ACP may assist their patients to get the care that is most consistent with their overall wishes.

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Appendix A: Survey Questionnaire, Oncology Nurses Knowledge, Attitudes, and Practice

Behaviors Regarding Advanced Care Planning

I. Demographics

1. Age:

 18-24 25-30 31-39 40-49 50 and above

2. Gender

 Male Female Other

3. Religion

 Christian Muslim Jewish Buddhist Hindu None

4. Highest level of education

 Masters degree Post Master's degree/ certification Ph.D. Doctor of Nursing Practice (DNP) Doctor of Nursing Science (DNS) Post doctorate

5. Current practice setting

 Inpatient- Main Campus Outpatient- New York City Outpatient- Regional (Commack, Basking Ridge, Rockville Center, Westchester, etc.)

6. As of today, how many years have you been working as an advance practice provider?

 0-5 6-10 11-15 16-20 21 years or more

7. Total years working in oncology nursing

- 0-5
- 6-10
- 11-15
- 16-20
- 21 years or more

8. Advance practice nursing specialty certification (check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> AOCN® or AOCNP® or AOCNS® | <input type="checkbox"/> Family Nurse Practitioner |
| <input type="checkbox"/> Adult Nurse Practitioner | <input type="checkbox"/> Pediatric Nurse Practitioner |
| <input type="checkbox"/> Adult/Geriatric Nurse Practitioner | <input type="checkbox"/> Psychiatric-Mental Health Nurse Practitioner |
| <input type="checkbox"/> Palliative Care Certification | <input type="checkbox"/> Gerontological Nurse Practitioner |
| <input type="checkbox"/> Acute Care Nurse Practitioner | <input type="checkbox"/> No APN certification |

9. Practice specialty

- Medical oncology
- Consultation service
- Surgical oncology
- Radiation oncology
- Critical Care (UCC, ICU, OR, PACU)
- Pain Management
- Palliative and hospice care
- Pediatrics

10. Are you:

- Full time
- Part time
- Per Diem

11. What shift do you work?

- Days
- Evenings/ Swing-shift
- Nights

II. Knowledge about Advance Care Planning (ACP)

12. Which of following best describes Advance Directives?

- A. Living Will
- B. Durable Power of Attorney for Health Care or Health Care Proxy
- C. Both A and B
- D. Don't know

13. The "*Patient Self-Determination Act*" mandates that all competent individuals must sign an "Advance Directive."

- A. True
- B. False
- C. Don't know

14. Most Americans have implemented an “Advanced Directive”.
- A. True
 - B. False
 - C. Don’t know
15. A notarized Advance Directive from one state is legal in all other states.
- A. True
 - B. False
 - C. Don’t know
16. A patient may revoke his/her Advance Directive at any time.
- A. True
 - B. False
 - C. Don’t know
17. Advance Directives are effective to communicate the patient’s wishes for the end-of-life care.
- A. True
 - B. False
 - C. Don’t know
18. To my knowledge, the role of the oncology nurse in Advance Care Planning (ACP) is_____
- A. Skillfully asking patients to sign an Advance Directive.
 - B. Promoting a structured clinician-patient communication process to discuss the patient’s wishes for end-of-life care.
 - C. Don’t know
19. The best time to discuss ACP is when patients are seriously ill.
- A. True
 - B. False
 - C. Don’t know
20. For an effective ACP discussion, it is important to ask the patient_____
- A. To bring or sign an advance directive
 - B. To identify a trusted individual as his/her Health Care Proxy
 - C. Don’t know
21. During the ACP discussion, it is important to _____
- A. Involve patient’s Health Care Proxy.
 - B. Disclose the diagnosis and prognosis to the patient.
 - C. Don’t know.
22. Which of the following description is true about “*Five Wishes*”?
- A. Contains five wish statements to direct medical treatments when seriously ill.
 - B. A living will that outlines patient’s personal, emotional, spiritual, and medical wishes.
 - C. Don’t know.

*23. I am knowledgeable about the “*Physician Order for Life Sustaining Treatment (POLST)*”.

- A. True
- B. False
- C. Don’t know

III. Attitudes toward Advance Care Planning (ACP)

<u>Beliefs about Advance Care Planning (ACP)</u>	Strongly agree	Strongly disagree
24. ACP will speed up the dying process in many patients.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
25. ACP should be discussed with every patient regardless of diagnosis.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
26. ACP discussion is very important for patients with life-threatening illness	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
27. ACP can reduce the end-of-life care decisional crisis.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
*28. ACP discussion can destroy patients’ senses of hope.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
29. ACP can improve patients’/families’ satisfaction about end-of-life care.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
*30. ACP reduces the likelihood of non-beneficial treatment at the end-of-life.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
*31. ACP discussion is the physician’s responsibility.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
<u>Subjective Norms about Advance Care Planning (ACP)</u>		
*32. ACP is a professional responsibility for nurse practitioners	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
33. The practice of ACP is consistent with Patient-Centered Care Standards.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
*34. I believe it is my responsibility to discuss ACP with patients and families.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
35. Most cancer patients want to know about their diagnosis, prognosis, and available care options.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>	
*36. Most cancer patients, if asked, want to discuss their wishes for end-of-life care with clinicians.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>	
*37. My colleagues support me in discussing ACP with patients and families.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>	
<u>Perceived Control about Advance Care Planning (ACP)</u>		
38. I feel comfortable discussing issues related to death and dying with cancer patients and families.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>	
39. I feel comfortable discussing ACP with cancer patients.	1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>	

*40. I have sufficient knowledge about how to conduct ACP conversations with cancer patients and their families. 1 2 3 4 5

41. I feel confident in my ability to communicate the “bad news”. 1 2 3 4 5

IV. Practice Behaviors in ACP Discussion

*42. In my practice, I routinely **initiate** ACP discussions with cancer patients. 1 2 3 4 5

43. In my practice, I routinely **follow up** ACP discussions with cancer patients when appropriate. 1 2 3 4 5

*44. In my practice, I **have had ACP discussions** with more than 50% of cancer patients. 1 2 3 4 5

*45. In my practice, I routinely talk with patients/families about palliative and hospice care options when appropriate. 1 2 3 4 5

V. Other Practice Information

* 46. In my practice, the oncologist (s) _____initiates the discussion of ACP.

- A. Never
- B. Rarely
- C. Sometimes
- D. Often
- E. Always
- F. Don't know

*47. In my practice, I estimate that approximately _____% of advanced cancer patients have had an ACP discussion with a clinician (i.e. an advanced practice nurse or a physician).

- A. < 25%
- B. 25-50%
- C. 51-75%
- D. 76-100%
- E. Don't know

48. I estimate that approximately _____% of advanced cancer patients receive chemotherapy during the last month of life.

- A. < 25%
- B. 26-50%
- C. 51-75%
- D. 76-100%
- E. Don't know

49. Based on your experience, please list 3-5 major barriers to ACP discussion.

50. In your practice, what events, situations or circumstances prompt you to discuss ACP with cancer patients and their families.

Thank you for completing this survey!

Appendix B: Knowledge of Advance Care Planning Survey

1. Which of following best describes Advance Directives?
A. Living Will; B. Durable Power of Attorney for Health Care or Health Care Proxy; C. Both A and B;
D. Don't know
2. The "*Patient Self-Determination Act*" mandates that all competent individuals must sign an "Advance Directive." A. True; B. False; C. Don't know
3. Most Americans have implemented an "Advanced Directive." A. True; B. False; C. Don't know
4. A notarized Advance Directive from one state is legal in all other states. A. True; B. False; C. Don't know
5. A patient may revoke his/her Advance Directive at any time. A. True; B. False; C. Don't know
6. Advance Directives are effective to communicate the patient's wishes for the end-of-life care.
A. True; B. False; C. Don't know
7. To my knowledge, the role of the oncology nurse in Advance Care Planning (ACP) is_____
A. Skillfully asking patients to sign an Advance Directive; B. Promoting a structured clinician-patient communication process to discuss the patient's wishes for end-of-life care; C. Don't know.
8. The best time to discuss ACP is when patients are seriously ill. A. True; B. False; C. Don't know
9. For an effective ACP discussion, it is important to ask the patient_____
A. To bring or sign an advance directive; B. To identify a trusted individual as his/her Health Care Proxy;
C. Don't know
10. During the ACP discussion, it is important to _____
A. Involve patient's Health Care Proxy; B. Disclose the diagnosis and prognosis to the patient; C. Don't know.
11. Which of the following description is true about "*Five Wishes*"? A. Contains five wish statements to direct medical treatments when seriously ill; B. A living will that outlines patient's personal, emotional, spiritual, and medical wishes; C. Don't know
12. I am knowledgeable about the "*Physician Order for Life Sustaining Treatment (POLST)*". A. True; B. False; C. Don't know

Appendix C: Primary Author's Permission

From: Guiyun Zhou
Sent: Monday, May 23, 2016 12:22 PM
To: McMillan, Sincere S
Subject: Re: Knowledge, attitudes, and practice behaviors of oncology APN Survey

sure.

best luck.

Guiyun Zhou

From: McMillan, Sincere
Sent: Monday, May 23, 2016 12:11 PM
To: guiyunzhou; bethannswan
Subject: Knowledge, attitudes, and practice behaviors of oncology APN Survey

Good day to you Dr. Zhou and Dr. Swan,

My name is Sincere McMillan and I am an advanced practice nurse at Memorial Sloan Kettering Cancer Center in New York, NY. It is indeed my distinct pleasure to write to you. I am currently pursuing my DNP at Walden University and my final project will be directly related to how advance practice nurses at my institution view and use advance care planning in their clinical practice. As part of this project, I will be developing a questionnaire which will be sent to all practicing nurse practitioners at Memorial Sloan Kettering via email.

I had the pleasure of reading your 2010 article "Knowledge, attitudes, and practice behaviors of oncology advanced practice nurses regarding advanced care planning for patients with cancer" and the survey questions you and your colleagues developed. I would like to model the questionnaire I am building off of your team's research. In the article, there is mention that to ensure content validity, your survey was reviewed by a panel of experts in the field of palliative care and academic research. Is it possible to obtain the results of this review? If not, could you perhaps share with me the psychometrics of your survey tool?

I appreciate any help that you can provide and thank you in advance for your consideration.

Regards,

Sincere McMillan
Nurse Practitioner
Geriatric Medicine
