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The Knowledge and Attitudes Of Oncology Nurses On Advance Directives

Bailey Nettles

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THE KNOWLEDGE AND ATTITUDES OF ONCOLOGY NURSES
ON ADVANCE DIRECTIVES

by

Bailey Nettles

A Dissertation
Submitted to the Graduate School,
the College of Nursing and Health Professions
and the School of Leadership and Advanced Nursing Practice
at The University of Southern Mississippi
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Philosophy

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ABSTRACT

Advances in healthcare technology has changed how healthcare professionals care for patients, increasing the importance of Advance Directives (ADs). ADs are legal documents describing patient end-of-life care wishes. Despite the usefulness of ADs, particularly in oncology settings, most patients do not have one.

This qualitative content analysis study examined knowledge and attitudes of ADs among oncology nurses to obtain a better understanding of ADs. Literature on ADs and nurses is dominated by quantitative research. This study addresses knowledge gaps best filled by qualitative methods.

Ten experienced oncology nurses answered eleven open-ended questions using online video conference interviews. The eleven questions corresponded to five research questions. Content analysis met rigorous standards for trustworthiness, including data saturation.

Question 1 related to nurses' firm understanding of ADs found the category Legality and themes Written Document, Wishes for EOL Care, and Unable to Speak for Self. Question 2, related to AD barriers found the category Barriers and themes Lack of Education on AD, Convenience, and Families. Question 3, related to nurses' views of AD found the category Usefulness, with themes Prevention of Suffering and Unintended Consequences. Question 4, related to AD benefits found the category Benefits and themes Quality of Life and Peace. Question 5, related to AD discussions found the category Quality of Interactions with themes of Timing, Compassion, and Family Inclusion.

Oncology nurse participants understood the meaning, benefits, and barriers of ADs viewed ADs as useful and held AD discussions with families and patients. Results confirmed several findings from previous studies such as barriers to AD identified by Boddy et al. (2013). Results also confirmed aspects of Ruland and Moore's (1998) theory for a Peaceful End of Life.

Oncology nurse participants valued increased knowledge along with AD-focused discussions. Nurses estimated under 40% of their oncology patients had an AD at admission. Additionally, AD education is needed for patients, healthcare providers, and families to ease AD-related confusion, conflict, stress, and uncertainty. Further, increased AD knowledge and awareness empowers patients, families, and fellow nurses to achieve peaceful end-of-life outcomes.

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DEDICATION

I would like to thank myself and many others for this dissertation. I am so proud of myself for following through and completing this dissertation that has taken five years to complete. I would like to thank God for helping through the times I did not think I could do this. Thank you to my family for being there with words of encouragement and a listening ear. I would like to thank coffee and wine for helping through the long nights and edits. Lastly, I would like to thank my husband, Brandon. He has been there to hold me up through these last five years when I wanted to give up. Thank you all for helping me; I could not have done this without everyone.

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LIST OF ABBREVIATIONS

<i>AD</i>	Advance Directives
<i>ANA</i>	American Nursing Association
<i>BSN</i>	Bachelor of Science in Nursing
<i>CDC</i>	Center of Disease Control and Prevention
<i>CPR</i>	Cardiopulmonary Resuscitation
<i>DNI</i>	Do Not Intubate
<i>DNR</i>	Do Not Resuscitate
<i>EOL</i>	End of Life
<i>FGH</i>	Forrest General Hospital
<i>IRB</i>	Institutional Review Board
<i>KAESAD</i>	Knowledge Attitudinal Experimental Survey on Advance Directives
<i>MSN</i>	Master of Science in Nursing
<i>NAM</i>	National Academy of Medicine
<i>ONF</i>	Oncology Nursing Forum
<i>PEOL</i>	Peaceful End of Life
<i>PSDA</i>	Patient Self Determination Act of 1990
<i>QOL</i>	Quality of Life
<i>SDM</i>	Surrogate Decision Maker

CHAPTER I – INTRODUCTION

Statement of the Problem

Health care has experienced a technological and treatment boom in the last 50 years resulting in better survivability of trauma and disease. However, some people have recognized that they desire a limit to what sorts, types, and lengths of treatment they receive, particularly in circumstances in which recovery is not likely. Intensive technological treatments are often offered to severely ill and incapacitated individuals when technology and treatment will only prolong death and recovery. Balancing the ability to prolong life with the desire to not prolong death and suffering has placed patients, families, healthcare providers, and their agencies in difficult decision-making dilemmas.

A national response to patients', providers', and agencies' desires to address the problem of prolonging futile healthcare treatment was the enactment of the Patient Self Determination Act of 1990 (PSDA). The PSDA empowered patients by providing a way to delineate their healthcare treatment desires in the case of their incapacitation or mental incompetency through the use of Advance Directives (AD). An AD is a legal document that is written, signed, and witnessed when a patient is of sound mind. The AD instructs families and medical professionals on how and to what extent care should be provided to individuals at a time in the future when they are unable to make their own decisions.

Despite the PSDA (1990) requirement for healthcare agencies to ask and inform every patient about ADs, they remain highly underutilized. As a result, many patients are not using ADs to help medical professionals and families understand their final desires regarding future healthcare decisions (Butterworth, 2003). The literature reveals a

substantial number of patient barriers to AD completion, including lack of information and education, time, and readiness (Butterworth, 2003). Unfortunately, the literature is not as in-depth in exploring nurses' barriers and challenges in implementing ADs at the bedside.

Significance

The number of individuals, families, and healthcare providers expected to encounter decision-making about end of life (EOL) care is growing. One reason is that Covid-19 has significantly impacted the population's mortality and morbidity rates (Centers of Disease Control and Prevention [CDC], 2021). The CDC (2021) noted an increase in deaths, hospital stays, and ventilator usage related to Covid-19. Further, the population of the United States is aging, which is also associated with rises in chronic illness comorbidity and mortality (Mather, 2016). With the current Covid-19 crisis within healthcare and the aging population, nurses are increasingly involved in their patients' EOL discussions. The expectation that almost all these aging, acutely and chronically ill individuals will need intensive and/or complex treatments and measures to sustain their lives is why establishing an AD while the individual is of sound mind is useful and necessary. The use of ADs can ensure that families and healthcare providers will understand the level and extent of care individuals desire when they cannot make decisions for themselves in complex health situations. In turn, this improved understanding will help alleviate distress incurred by families and providers when facing difficult healthcare decisions.

As stated above, the PSDA of 1990 requires health care agencies to ask about and inform every patient about AD. In a study by Koss (2018), the researcher evaluated AD

completion under the PSDA. Koss (2018) found older adults were more likely to complete the AD, and if the patient did not have an AD in 2012, they had completed an AD in 2014. Koss also found patients were more likely to complete an AD if they were under the direct care of a provider covered by the PSDA (2018). In her study discussion, Koss (2018) raised a fair point, stating there was a lack of examination of efforts to raise awareness and facilitate AD completion in both patients and nurses.

Though healthcare agencies are required to discuss ADs with every patient, questions remain about the procedures used. Such as, are nurses asking the patient, how is asking taking place, are nurses helping with completion, and are nurses engaging the patients in a discussion about AD? The answers to these questions may range widely from state to state, from agency to agency, and from health provider to health provider. Regardless, nurses have a professional responsibility to ensure that patients understand their rights in the healthcare system (American Nurse Association [ANA], 2015), including facilitating patient autonomy. Educating and informing patients about ADs and their right to choose the type and level of care they desire at the EOL is an important nursing responsibility.

Often the lack of education and sharing of information is a recurring problem with implementing ADs (Butterworth, 2003; McDonald et al., 2017). The lack of education is a problem present in patients, families, and their healthcare providers. Nurses and other healthcare providers are not taking the time and may not be given the time needed to follow through with the PSDA, therefore voiding the act's intentions and hurting patients and their families (Butterworth, 2003).

Most nurses deal with dying patients in their practices in some way. Oncology nurses are a specialty group who deal with death more often than other nurses, with cancer being one of the three leading causes of death in the United States (Garcia et al., 2017). According to national statistics, cancer is the second leading cause of death in the United States (Heron, 2018). Cancer claimed 602,350 persons in 2020 in the United States and was even ranked above the death rates attributed to the new COVID-19 infection epidemic (CDC, 2021).

Patients with cancer can benefit greatly from EOL and AD discussions with their nurses. The cancer population often faces the thought and fear of premature death. Patients with cancer are one of the most ill and debilitated groups of patients, and one would expect the rate of AD completion and use to be moderately high. An AD helps alleviate the stress and uncertainty surrounding potential death, both for healthcare workers and patients (Garrido et al., 2015). Cancer in patients does not always follow a predictable progression, nor do patients have a set lifespan. There is no way to tell when or if death will occur. The variability of death expectations for cancer patients is why it is important that they have ADs in place to guide their families and healthcare providers. With an AD, a dying patient can experience a peaceful EOL (Garrido et al., 2015).

In a study of 191 cancer patients, only 55% (n=106) completed some form of AD (McDonald et al., 2017). Though over half of the patients studied had an AD, over half of the patients are still leaving many patients' families and healthcare providers without a document that legally indicates the patient's preferences for care should they be incapacitated. Patients who have made their decisions prior to incapacitation can alleviate some of their loved ones' stress around dying.

Optimistically, with an increased understanding of obtaining and using an AD, healthcare professionals can help address the problems associated with AD. Nurses' knowledge about ADs can affect how they ask patients and their confidence in providing AD education (Coffey et al., 2016). Coffey et al. (2016) studied AD knowledge and confidence of nurses in the United States versus other countries. They found United States nurses had more experience and confidence with AD because of PSDA legislation in place (1990). In addition, United States nurses felt adequately trained in EOL care and ADs (Coffey et al., 2016). Coffey et al. (2016) suggest nurses across the United States have the knowledge; they just need time and confidence to tell patients about ADs. The time may come when cancer patients become debilitated to the point that they will not have the capability to make their own decisions. Decisions that, if discussed earlier with family and providers, and included in a signed AD, would have provided assurance that their wishes for care would be followed.

During admission, healthcare agencies must bring up ADs according to the PSDA (Koss, 2018). Nurses who bear the responsibility of discussing the AD need to have the necessary information and time to share with patients (Coffey et al., 2016). The process which surrounds discussing ADs is fundamental, especially between oncology patients and their nurses.

The quantitative literature about AD is substantial; however, the qualitative research involving oncology nurses and AD is limited. The earliest studies on AD were quantitative and most were about nurses and cancer patients (McDonald et al., 2017; van Oorschot et al., 2012; Zheng et al., 2016). Other studies expanded on topics of ADs and included all critically ill patients (Hickman & Pinto, 2014).

The qualitative studies did not use regular staff nurses as participants but researched ADs in cancer patients, cultural differences, and nurse practitioners (Boot & Wilson, 2014; West & Hollis, 2012). These studies looked at the attitudes about AD from the patient's point of view, or, in one case, how a nurse practitioner used an AD as part of practice (Boot & Wilson, 2014).

One problem detected in reviewing previous studies is that the body of knowledge in ADs started with quantitative approaches and that a few qualitative studies came afterward. This approach to knowledge development has left a potential gap of needing a more in-depth understanding of ADs, confirming what is assumed to be true from the perspective of quantitative researchers, and perhaps uncovering new understandings. Among the studies found, no one researched oncology registered nurses' attitudes towards ADs qualitatively.

Purpose of the Study

The overall purpose of this study is to discover more about oncology nurses regarding AD knowledge and experiences with oncology patients. A qualitative, content analysis method was used. The study aims to build a basis for future research on the subject of ADs and lay a foundation for other researchers.

Implementing a qualitative study design using interviews and content analysis will help bridge the gap in knowledge related to oncology nurses and how they address ADs in their clinical practices. A content analysis, qualitative method will provide useful data on the existing phenomenon of obtaining ADs and helping nurses provide patients with a formal pathway toward peaceful deaths. The information gained through the study addresses the research gap which exists related to AD in the specialty area of oncology,

an area with an urgent need to get the AD experience right for patients, families, and nurses.

Research Question

The following five research questions were used to direct and guide this study. This study sought to discover and describe the experiences surrounding oncology nurses when talking to their patients about ADs. The questions include: How do oncology nurses discuss ADs with their patients, are they confident in engaging their patients in a discussion about AD, and what facilitates or hinders AD conversations? Specific research/interview questions include:

1. Do oncology nurses have a firm grasp and understanding of AD?
2. Do oncology nurses realize barriers with AD, both implementing and obtaining ADs?
3. How do oncology nurses view AD? Like/dislike; For/against
4. Do oncology nurses believe ADs benefit patients and quality of life?
5. How do oncology nurses begin the conversation with patients about ADs, or do they discuss them at all?

Theoretical Foundation Overview

Peace and acceptance are important aspects of the dying process for the patient and family. In response to this belief, Ruland and Moore (1998) created the theory for a Peaceful End of Life (PEOL). They aver that a dying patient needs the comfort of having a PEOL when leaving loved ones behind. The scope of the theory encompasses the relationship between the nurse and the dying patient. The theory defines a PEOL as being without pain, experiencing comfort, experiencing dignity, being at peace, and having a

closeness to significant others (Ruland & Moore, 1998). Ruland and Moore (1998) define an absence of pain as not having unpleasant emotional and/or physical experiences. Comfort is the freedom from discomfort, dignity is when the patient feels purpose and respect as a human, peace is the feeling of tranquility and fulfillment, and having significant others close is experiencing connectivity. These concepts define the PEOL theory and draw justification for using it as a theoretical framework for this AD research. The purpose behind the PEOL theory development was to promote a peaceful EOL for fatally ill patients, who assume death is nigh and welcome it.

A quick summary of the PEOL theory, outlined by Fawcett and DeSanto-Madeya (2005), illustrates the theory's validity according to several criteria, including significance to nursing, consistency, parsimony, clear language, and definitions. The PEOL theory is significant to nursing because of its connection to the nurse-patient relationship during the EOL period. The theory constantly uses the same five terms to define a PEOL, providing consistency. Ruland and Moore's (1998) theory has parsimony because of the clear, concise, and readable language used within the theory. An important aspect of the theory is Ruland and Moore's (1998) simple definitions of common language used within nursing, therefore increasing the readability among non-clinical personnel.

The PEOL theory frames this research through the five aspects found within a PEOL. The AD can provide that all five aspects of a PEOL are considered. The five aspects are 1) being pain-free, 2) having comfort, 3) having dignity and respect, 4) being at peace, and 5) being close to loved ones (Ruland & More, 1998). The third aspect is the experience of dignity and respect, and the fourth, being at peace fit within the importance

of having an AD. Nurses seek to assure patients are given dignity and respect while under nursing care. An AD can assist the patient in achieving an EOL experience that preserves dignity and respect. A patient can express their wishes to a proxy or power of attorney and through a living will the patient can be without pain, experience comfort, experience dignity, be at peace, and be close to loved ones. The intent of an AD and the PEOL theory fit together through all aspects of the theory.

The importance of the PEOL theory within the study is that it illustrates that having an AD is an avenue by which patients can achieve their PEOL. When one thinks of death, they want comfort and peace. As a family member, one wants their ailing loved one to have a peaceful death. Through talking about AD and having an AD everyone can achieve a PEOL experience. No one wants to think of their death as being painful or lengthened unnecessarily. A PEOL is an idea and a wish for every living soul, which reflects the PEOL theory is a notion that is so relatable to AD and can help improve the understanding of the importance of an AD for patients, families, and nurses.

A nurse's role within the EOL of a patient can have a large influence on patients' and families' final moments together. The nurse can facilitate conversations between themselves, the doctor, other health team members, patient, and family members (Croson et al., 2018). When a patient is near their EOL the nurse is aware of the plan of care and is usually at the bedside of the dying patient. Nurses can help a dying patient feel at ease with their presence, pain medication, as well as just listening to the patient's needs (Croson et al., 2018).

Limitations and Delimitations

The delimitations and limitations of this study are as follows.

1. Only oncology registered nurses currently practicing in the oncology specialty area with at least 6 months of current oncology experience were included in the study.
2. Participants were a convenience sample of volunteers.
3. Participants were recruited from multiple online oncology nursing forums.
4. Participants were at least 18 years old.
5. Participants were able to speak and respond to questions in English.
6. Participants had to be able to communicate over long distances with the researcher via electronic media.
7. Participants had to be able to grant and sign informed consent.
8. Participants could not electronically message their responses to questions.
9. All communication had to be verbal with a phone call or web camera.

Definitions

Advance directive (AD) - a tool used to speak for a patient about their medical treatment when they are not able to. An AD can consist of a living will, healthcare proxy, do-not-resuscitate orders, and durable power of attorney (National Academy of Medicine [NAM], 2015).

Closeness to significant others - connectedness to other human beings who care (Ruland & Moore, 1998).

Comfort - a relief from distress, peaceful, pleasurable (Kolcaba, 2010).

Dignity - having the respect of a human and their basic value, without harm to veracity and morals (Ruland & Moore, 1998).

Life - prolonging procedure-any medical procedure, treatment, or intervention. Including artificial nourishment and hydration, meaning it withstands, repairs, or replaces a spontaneous vital function, does not include comfort care medications, procedures, or to alleviate pain (Florida Senate, 765.101).

Living will - a witnessed document or statement willingly performed by a competent adult that communicates the person's guidelines involving end of life and procedures to extend life (Florida Senate, 765.101).

Pain - a feeling of sensory and/or emotion deemed undesirable; correlates with actual and impending tissue harm or described in terms of such (International Association for the Study of Pain [IASP], 2017)

Peace - tranquil, contentment, without worry, restlessness, and dread (Ruland & Moore, 1998).

Peaceful End of Life - being without pain, experiencing comfort, experiencing dignity/respect, being at peace, and being close to significant others (Ruland & Moore, 1998).

Proxy - a competent adult that has not been legally documented that makes medical decisions for the debilitated individual (Florida Senate, 765.101).

Resuscitation - a way to bring back someone who has stopped breathing or their heart is not beating; intubation, cardiopulmonary resuscitation (CPR), defibrillation (Martin, 2018).

Surrogate - a competent adult that is designated by an advance directive to make medical decisions and to receive health information (Florida Senate, 765.101).

Terminal condition - a medical condition where there is no reasonable treatment expected except death, i.e., injury, disease, illness (Florida Senate, 765.101)

Summary

Understanding more about the knowledge and attitudes among oncology nurses can help provide in-depth information about ADs that potentially is missing from the literature. ADs are a necessary part of health care; however, there are many problems surrounding ADs. These problems include finding time for ADs, and education. Nurses can help ameliorate these problems. If nurses can help inform and support patients on ADs, and barriers can be reduced or eliminated, hopefully, more ADs would be completed. ADs help nurses ensure patients have the EOL they desire; however, many patients and families do not discuss or complete ADs. Therefore, the EOL can be hectic and overwhelming for all involved. This study is meaningful because the results can help future researchers learn more about how to solve the problems associated with ADs.

CHAPTER II – LITERATURE REVIEW

The significance of a literature review is to demonstrate what has been said about topics, the context of topics within the discipline, what kind of questions are being asked, and to find gaps in knowledge that need to be addressed. Identifying gaps in knowledge helps illustrate why the study is needed in the discipline of nursing. In this chapter, a discussion of literature about registered nurses and their role in obtaining, implementing, and other issues related to ADs will be presented. The literature will also be summarized related to nurse attitudes towards and knowledge of ADs, the facilitators and barriers nurses experience with ADs, and where more knowledge is needed. The information learned through this chapter will provide an understanding of the current state of knowledge and why this study is necessary.

Nurses' Role in Advance Directives

Nurses belong to the most trusted profession in the United States in terms of honesty and ethical standards (Gaines, 2022). Therefore, if a nurse recommends to a patient to obtain or refrain from an AD, they may take the advice based on their general trust of nurses. Because of their trusted status, nurses are essential to the processes of AD creation, use, and maintenance. Also, according to a statement by the American Nurses Association (ANA), nurses should be eager for knowledge of ADs and know-how to aid and help accomplish ADs (ANA, 2016). The ANA also set the above statement as a standard of practice according to the Scope and Standards of Advocacy (ANA, 2016).

Jezewski et al. (2005a), in a foundational, descriptive, quantitative study examined the knowledge, attitudes, and experiences of AD within oncology nurses. Jezewski et al. (2005a) created, the Knowledge, Attitudinal, and Experiential Survey on

Advance Directives (KAESAD). Using a total of 794 oncology nurses, they found that 70% of oncology nurses were knowledgeable about AD and the oncology nurses scored a 58% on overall knowledge of AD, the PSDA, and state laws (New York) (Jezewski et al., 2005a). In addition, Jezewski and colleagues has performed many quantitative studies on ADs and nurses throughout the years (Jezewski & Finnell, 1998; Jezewski et al., 2003; Jezewski et al., 2005a; Jezewski et al., 2005b; Jezewski & Feng, 2007; Ryan & Jezewski, 2012; Scherer et al, 2006). For example, Ryan and Jezewski (2012) found 60% of the nurses they studied had a comprehensive understanding of ADs.

Coffey et al. (2016) performed a cross-sectional, descriptive, quantitative design studying nurses' knowledge regarding ADs across Hong Kong, Ireland, Israel, Italy, and the United States. Coffey et al. (2016) found 49% (n=77) in Hong Kong, 75% (n=139) in Ireland, 52% (n=72) in Israel, 62% (n=161) in Italy, 100% (n=344) in the United States, and 73% (n=793) of the whole sample had knowledge of ADs prior to the study. These results had a chi-square of 220.00 and a *P*-value of <0.01.

Oncology nurses' routine practice activities can also influence approaching patients about ADs. A quantitative study using a cross-sectional survey design found advanced practice oncology nurses (APRNs) (N=89) did not have a regular practice routine with advanced care planning but were knowledgeable about ADs (Zhou et al., 2010). The results of the study indicated that making the act of regularly approaching patients about AD a routine part of practice may aid nurses to more consistently help patients with advanced care planning. The present study will investigate oncology nurses' attitudes and knowledge when approaching patients about AD, which will further advance the body of knowledge about nurses and ADs.

Within hospice care agencies, an AD called a Do Not Resuscitate Order (DNR) can have specific instructions regarding aspects concerning cardiopulmonary resuscitation (CPR), and other heroic treatment measures (Martin, 2018). The DNR Order is also valid in inpatient oncology settings. The DNR can guide doctors and nurses in what type of care patients prefer, including whether cardiopulmonary resuscitation should be implemented if their health ultimately fails. The question remains, are nurses asking their patients about, and are they aware of their patients' AD wishes? The present study will find out more about oncology nurses' activities surrounding the utilization of ADs.

In a grounded theory qualitative study discussing AD within clinical nurse specialists, it was noted that most nurses need to know the patient's readiness, their ailment, and have a relationship with the patient and family before talking to them about ADs (Boot & Wilson, 2014). Notably, the authors called for the nursing profession to engage in future research to discover the specific factors that facilitate or serve as barriers when nurses to talk about advanced care planning with patients. The present study aims to discover more about facilitators and barriers oncology nurses encounter in the area of ADs, addressing that knowledge gap.

Oncology nursing is more suited than other nursing specialties for research of EOL planning because of the bond formed between the nurse and patient and the constant threat of dying (Yoo, 2021). Specialties like hospice, oncology, emergency room, and intensive care may see AD more often than other specialties; however, every specialty has some encounters with an AD. An essential aspect of nursing is advocacy for patients (ANA, 2016). Nurses are necessary to complete ADs, and the education of ADs is more suitable coming from a nurse (Hinders 2012). With AD, nurses help provide autonomy to

patients through advocacy (Croson et al., 2018). However, why is caring about AD from nurses essential, and why is there an importance for nurses to know about and carry out the processes surrounding ADs? Because through ADs, nurses are able to help patients have the EOL care they need and want and can fulfill their role to help provide a PEOL for their patients. By using and abiding by a patient's AD, nurses can provide a peaceful and dignified death for patients.

What Do Patients Believe About Advance Directives?

The patients' beliefs of and in ADs interact with how nurses fulfill their role in providing patients with a peaceful death on the patient's own terms. Nurses can inform, educate, and promote ADs at length and consistently. Ultimately, the patient's own knowledge, perceptions, and beliefs will dictate their initiation and use of an AD.

Boddy et al. (2013) researched hospital practitioners in Australia. Nurses, doctors, occupational therapists, dietitians, social workers, and other medical professionals were interviewed in this qualitative study. These practitioners identified several barriers for patients in obtaining ADs, including knowledge, convenience (getting and learning about AD), demographics, and emotional reactions (Boddy et al., 2013). The finding of the emotional reaction category was the most surprising. Practitioners believed patients had the added stress of pleasing families and not burdening families (Boddy et al., 2013). Boddy et al. (2013) suggested that patients need more knowledge about AD to understand ADs and understand that ADs are not about pleasing families but about one's own true wishes for EOL. Further, the knowledge gap for patients could be understood as patients not wanting to face their mortality (Boddy et al., 2013). In avoiding AD discussions,

patients should not assume death is a faraway event. Lee et al. (2013) found that only 20.6% of patients had a 3-month survival rate after CPR.

What Type of Patients Are Likely to Have an Advance Directive?

Researchers have found that while an AD is useful for most stages of life, most patients are not initiating an AD until after a serious or terminal diagnosis (van Oorschot et al. 2012). Also, van Oorschot et al. (2012) found that most patients with an AD had at least a high school diploma. According to the PSDA, an AD is necessary for all patients, as one can never be sure when they will need one (PSDA, 1990).

Xu et al. (2021) studied the completion rates of ADs in primary care settings in South Korea (N=158). The completion rate was 29.4% in the control group (usual care), 36.4% in the passive intervention group (pamphlet teaching), and the active intervention (pamphlet and physician teaching) group of 30.8% (Xu et al., 2021). The quantitative study found the participants who completed an AD did not want to die from or on life support and thought dying from the illness was better (Xu et al., 2021). The participants did not want to suffer while on life support and/or had accepted their incurable disease. Xu et al.'s (2021) study was important to see the difference among the younger and older population or healthy and chronic illness patients. Approximately 29.5% of participants who did not complete an AD thought they were too young, too healthy, or would not need one (Xu et al., 2021).

The PSDA (1990) requires all hospitals in the United States to provide information about patient AD creation and completion. This requirement serves as a stimulus for nurses to ask every patient whether they have an AD or understand what it is. Because patients have loved ones, families also should be informed about ADs. A

discussion between patients and their families about ADs and patients' desires regarding EOL care should occur whenever possible. Nurses can be instrumental in making sure the patient discusses the AD with the family.

Families, Culture, and Advance Directive

No discussion of ADs would be complete without addressing the role of family and culture in determining EOL care. Nurses recognize that family plays an influential role in most patients' care, especially within specific cultures. The family can either help or dismantle the care medical professionals bring to their loved ones. For example, among African-American cultures, EOL is not something widely spoken about and when the situation comes, they have trust in their families' decision for them (West & Hollis, 2012). For some cultures, patients do not bring up diagnoses or initiate discussions about death and have a hard time looking past stigmas of death within their culture (Boddy et al., 2013). In Korean families, for instance, knowing there may be a fear of lingering on life support (Xu et al., 2021) is relevant. For cultural reasons, the AD process may need to be modified by nurses to work within their patients' cultural norms (Alford, 2018).

Some family members from any culture may not agree with the patient's AD and refuse to let go of the patient and accept the terminal event. In this case, the family member is hindering the EOL the patient wants. The patient must have an AD in place to address this problem, and the family must know about the AD (Inoue et al., 2019). The essential part is to speak with one's family about EOL preferences. Unfortunately, some Surrogate Decision Makers (SDMs) do not have the advantage of knowing the patient's/loved one's preferences, thereby increasing the burden on the surrogate (Hickman & Pinto, 2014). The goal of an AD is to decrease the burden for loved ones,

and most patients believe this as well (McDonald et al., 2017; van Oorschot et al., 2012). Interestingly, West and Hollis (2012) found patients think their families have a good understanding of the EOL care the patient wants, even if they have not spoken to them about their plans for EOL.

Including families in EOL planning is vital because of the benefits it can bring for the patients. Families are most often at the bedside of the patients and may be engaged in their care at the hospital, as well as at home. Family members are often able to tell medical professionals the patient's cues of pain, discomfort, or need of immediate help (Croson, et al., 2018). Including families or having an SDM who is aware of one's preferences can benefit the patient at the EOL. Families can advocate for patients when they are unable to, which is important when there is no AD on file with the hospital. Nurses need to recognize that a family member or an SDM can play an important role with EOL care and the establishment of an AD for all patients.

Problems with Advance Directive

This review must mention the downfalls of AD as well as its merits. Most commonly, ADs that are not executed properly or are not completed correctly or completely are legally invalid (PSDA, 1990). Hinders (2012) found five patient barriers to completion; lack of information, the patient has never heard of an AD, had never discussed AD, thought providers would make the right call, and patients stating they just have not finished them yet.

Hinders (2012) also identified cultural barriers to completion. Among African American populations, families feel dignity and respect in caring for family members (Hinders, 2012). This need to provide for family members during times of illness may

prevent African American patients and families from discussing impending EOL issues. West and Hollis (2012) go into a deep discussion of African Americans and ADs resulting from their qualitative study. West and Hollis (2012) found three themes among African Americans and ADs: Proxy decision-making by family members, lack of education about ADs, and fear/denial of death. Many of the West and Hollis (2012) study participants assumed their families would already know how to take care of their EOL issues without explicitly discussing them with them.

Legal considerations are necessary to address as well. Hinders (2012) found five legal barriers to completion as well: Low reading levels among Americans, restrictions among same-sex and domestic partners being health care agents, lack of eligible witnesses due to state and notary guidelines, validity and execution of ADs across state lines, and lack of ability to express beliefs through AD forms.

Another problem with AD completion is patient demographics. Among most research about barriers, race, age, and culture were the most prevalent among them. Many people from the younger population believe they do not need an AD or will ever need one (Xu et al., 2021). Xu et al. (2021) found participants did not complete an AD because they felt they were too young, AD completion was inconvenient, and/or were unlikely to need one.

Gaps in the Literature

The problem within the literature is that AD studies tend to be descriptive quantitative studies that report frequencies of nurse qualities or AD activities. The literature is lacking in qualitative nurse-focused studies on AD. In addition, no studies were found that describe nurses' attitudes and knowledge within the context of the PSDA

requirements of implementing ADs in oncology settings. Also, there has not been a new study about oncology nurses' knowledge of ADs since 2005, meaning there is a need for current data. The present study utilizes a semi-structured interview to gather data related to each research question and uses content analysis to provide answers to each research question. With further information, insight into how oncology nurses address issues surrounding ADs may be achieved. The present study can also help spark conversations between nurses and others (not just patients) about AD.

The literature is primarily composed of quantitative data on the use and attitudes of AD but lacks a qualitative perspective of the process of informing and using AD. For example, cancer patients are more likely to have thought about their impending death and AD; which is why many AD researchers use cancer patients or nurses as subjects (Zheng et. al, 2016). The experiences of the oncology nurse and their patients are also why this researcher chose to study oncology nurses, as they likely have the most experience with ADs and were expected to be good informants. The information learned from this study of oncology nurses will add to the body of knowledge needed by nurses when caring for patients with cancer and helping each to choose the EOL care they desire.

Summary

According to the literature review, quantitative studies dominate the literature of AD. The knowledge gap exists in the area of qualitative nurse-focused studies on AD. As stated above, nursing is one of the most trusted professions (Gaines, 2022). If that is true, then nurses have the potential to exert great influence on the choices of their patients. Further understanding of nurses and the AD process will further the science, thus

improving EOL care for patients. Findings can also be used in the future to improve AD understanding and usage by other nurses.

The literature indicated that oncology patients were more likely to have an AD, yet that number was not as high as one would expect (McDonald et al., 2017). Nurses, as the health provider most likely to discuss ADs with oncology patients on admission, have an important role in informing patients about ADs. Through this study, there will be a better understanding of nurses' attitudes and knowledge to address the AD initiative.

CHAPTER III METHODOLOGY

The aim of this content analysis, a qualitative study was to examine the knowledge and attitudes of AD among oncology nurses. The qualitative design provided a way to obtain in-depth information about oncology nurses' knowledge and attitudes of ADs through the use of interviews and content analysis (Hsieh & Shannon, 2005). Research questions were constructed to address gaps in knowledge, and corresponding semi-structured open-ended interview questions related to each research question were devised to obtain data. Transcripts of interview data were produced, with the coding of the data to identify the standard concepts, or themes and categories, during analysis. Hsieh and Shannon (2005) also state there are different ways to process the data; this study used transcription and highlighting to obtain coding seen through the data. Through content analysis, this study will analyze the attitudes and knowledge of oncology nurses on ADs.

Sample

The participants of the study were limited to oncology nurses who were at least 18 years old. There were no limitations on the type of oncology nurse; however, participants had to be a nurse for more than six months. All participants were selected via a volunteer basis using snowball and convenience sampling, able to read English and sign their own consent. The nurses had to practice within the oncology nursing specialty at the time of the study and be a registered nurse (associates degree or higher). A total of 10 eligible nurses were interviewed. The importance of narrowing the participants is to focus the study and ensure they had shared a common situation.

Procedure

Recruitment

A complication was encountered during recruiting the sample due to the lack of participants enlisting in the study. First, the researcher asked permission from two sites, The Gypsy Nurse and The Oncology Nurse Forum. The IRB included both forums (Appendix A). The forum post stated “Hi, I need your help. I am a doctoral candidate at The University of Southern Mississippi. For my dissertation, I am trying to find out more about how oncology nurses approach patients about advance directives. If you are an oncology nurse and are interested in participating, please email me (xxxx.xxxx@usm.edu). You must be willing to have a 1-hour phone call or web camera interview. Thank you. This study has been approved through USM’s IRB (IRB-19-537).” The Oncology Nurse Forum (ONF) website could not technically support posting a forum for participants, therefore, the ONF could not support this study. After posting to The Gypsy Nurse, the admin in charge of The Gypsy Nurse rejected the post after previous approval. The IRB was modified to include seven other Facebook groups with nurses. The groups were Show Me Your Stethoscope, Travel Nurse Community, Nurses with Cards, Travel Nursing 101, Travel Nurse Network, The Academy of Oncology Nurse and Patient Navigators, and The Fun Nurse (Appendix A). Still, without many responses (1), the IRB was changed again to include Covid-19 Healthcare Professionals and Mississippi Nurse Association District 7 (Appendix A).

After still not recruiting enough participants, the researcher obtained an IRB through Forrest General Hospital (Appendix A). Then, the researcher modified the IRB again to include flyers (Appendix B) to get participants at FGH and pizza as an incentive

for participants (Appendix A). Lastly, the IRB was modified to include a \$10 Starbucks electronic gift card to reward participants (Appendix A). The post now read, “Hi, I need your help. I am a doctoral candidate at The University of Southern Mississippi. For my dissertation, I am trying to find out more about how oncology nurses approach patients about advance directives. If you are an oncology nurse and are interested in participating, please email me (xxxx.xxxx@usm.edu). You must be willing to have a 1-hour phone call or web camera interview. Thank you. This study has been approved through USM’s IRB (IRB-19-537). ****NOW OFFERING A \$10 VIRTUAL STARBUCKS GIFT CARD FOR PARTICIPANTS****” The researcher posted numerous times to all forums possible (Table 1 below). After finally getting ten applicants to participate in the study, the study reached saturation, and no more participants were required. The recruiting and data collection process took just over 1 year.

Table 1

List of Facebook Pages and Dates Posted

Forum	Date of Posts for Participants
Show Me Your Stethoscope	5/27 rejected 7/14 rejected 2/3 rejected 4/16 accepted
Travel Nurse Community	5/27 accepted 7/14 accepted 2/3 accepted 4/16 accepted
Nurses with Cards	5/27 accepted

	7/14 accepted 2/3 accepted 4/16 accepted
Travel Nursing 101	6/8 accepted 7/14 accepted 4/16 accepted
Travel Nurse Network	6/2 accepted 7/14 accepted 2/3 accepted 4/16 accepted
Travel Nurse Network-The Gypsy Nurse	5/27 rejected 7/14 rejected 2/3 accepted 4/16 accepted
The Fun Nurse	7/14 rejected 2/3 rejected 4/16 accepted
Academy of Oncology Nurse and Patient Navigators	2/3 accepted 4/16 accepted
Covid-19 Healthcare Professionals	8/27 rejected 2/3 rejected 4/16 rejected
Mississippi Nurses Association District 7	8/27 accepted 2/3 accepted 4/16 accepted

Questionnaire

The questionnaire used within the study consisted of 11 questions, each related to one of the research questions (Appendix C). The aim was to discover and describe

attitudes and knowledge of ADs among oncology nurses. The questions were open-ended and targeted questions per Hsieh and Shannon (2005). The questionnaire was crafted with assistance from a nurse researcher experienced in qualitative research and reviewed by the dissertation committee. The researcher found success using the interview questions. The researcher also asked for elaborations on answers to the questions. During those elaborations, participants often revealed data related to Ruland and Moore's (1998) PEOL theory, which will be examined in Chapter IV.

Data Collection

The researcher obtained interview data from the participants through video calls. The participants were asked inclusion screening questions via email to ensure they were eligible to participate in the study. The participants had to return the consent form (Appendix D) via email before the interviews began. With permission from participants, interviews were audio-recorded to be transcribed later using a word processing program. The researcher interviewed each participant for an average of 22 minutes. Interviews were conducted afterward as participants were recruited, which took just over a year. The interview had 11 set questions, and the researcher used open-ended questions and some follow-up questions. Memos taken during the interviews helped construct common themes and categories. The transcriptions were then analyzed using color-coding.

Data Analysis

Content analysis began with the detailed transcription of the recorded interviews (Hsieh & Shannon, 2005). Next, the researcher organized all the data by question and numbered each response one to ten, to reflect the participant's interview number. The data were printed and then coded for commonality and differences among the statements.

The researcher used highlighters and pens to underline/highlight the key concepts found or code the data. The researcher first picked common responses from the data, then proceeded to form codes for common responses, then gave new codes to any leftover data. As coding proceeded, existing codes and leftover codes were compared to the next piece of data until no new data codes were found.

Next, data were organized by code. Under each code, the response statement from the participants where the code emerged was put under the heading and number by question and interviewee (i.e., question one and interview one would be 1.1). Finally, the researcher reduced the coding to more straightforward and simpler terms. Hsieh and Shannon recommended a blind researcher audit the data and codes (2005). To achieve auditing, two separate Ph.D. prepared nurse content analysis experts, not involved in data analysis or coding, reviewed the data and analysis to see if the coding was reliable. After asking a few questions to the researcher, the auditors agreed the codes met standards of confirmability.

Ethical Considerations

Standardized ethical measures were taken during this study. The researcher obtained approval from The University of Southern Mississippi's IRB, as well as approval through the websites. The researcher required a signed, informed consent before participation within the study. The data obtained within the study did not require medical information. Personal identifiers were changed to maintain confidentiality. The researcher could not ensure anonymity because of multiple emails and a video correspondence took place. To protect confidentiality, data/recordings were kept within a locked computer, with the only password belonging to the researcher. The researcher kept

printed data in a locked cabinet with only one key kept by the researcher. The researcher will destroy the data after 5 years from the completion of the dissertation defense. The participants within the study were a volunteer convenience sample. The participants were introduced to the researcher by the researcher at the beginning of the interview and informed they were being recorded and the purpose of the study was explained before participating.

Informed Consent

Informed consent is the process of granting consent to treatment with knowledge of the consequences (Grove et al., 2013). Completion of informed consent is how the participants were made eligible to take part in the study. Without a signed informed consent, the potential participant could not engage in the study. The consent was emailed to them to sign and then emailed back to the researcher. The consent was a one-page document, and the researcher recommended the participant keep the original copy of the consent and email the researcher a copy. Participants were asked to complete the informed consent before the interview process. A copy of the informed consent used is in Appendix D.

Summary

The research design was qualitative design, using content analysis to produce answers to the research questions. The sample was comprised of 10 experienced oncology nurses using a snowball and convenience sampling to obtain participants. The researcher used online formats and flyers at one physical site to recruit participants. The participants agreed to an online consent to audio/video record the interviews before the interviews began. The interview questionnaire included 11 open-ended questions related

to the research questions. The interviews were conducted by online video calls and recorded for the researcher to transcribe afterward. The data analysis included transcription, coding, and followed Hsieh and Shannon's 2005 guidelines for content analysis. Ethical considerations were taken to ensure protection for both the researcher and participants.

CHAPTER IV RESULTS

Study results are organized by research questions, preceded by a description of the sample. Study trustworthiness is also discussed prior to results. Results were arrived at by using content analysis methods, as described by Kyngäs et al. (2020), and Hsieh and Shannon (2005). The data consisted of the transcripts and notes from ten participant interviews obtained over a year via video conferencing.

Sample Description

Demographics were obtained from participants during the interviews through direct questions. All nurses were currently employed in an oncology setting with at least 6 months in that area. The participants had 6 months-12+ years of experience in nursing, with a median of 6 years. There was one male participant and nine female participants in the study. Among the 10 participants, 2 were pregnant, 2 were getting their master's degree in nursing, 7 were BSN prepared nurses, 4 were clinic nurses, 3 were oncology nurse navigators, 3 were inpatient oncology nurses, and 1 was a Hispanic participant who spoke fluent English with Spanish being her first language. At least one clinic nurse had inpatient oncology nurse experience, and all three nurse navigators had inpatient and/or outpatient oncology experience. States represented by the sample include Mississippi, Louisiana, Florida, and Virginia.

Trustworthiness

Essential measures were taken in the present study to ensure trustworthiness. Kyngäs et al. (2020) delineate four steps to ensure the trustworthiness of a qualitative study: Credibility, dependability, confirmability, and authenticity. Kyngäs et al. (2020) use Lincoln and Guba's (1985) definition of trustworthiness. Lincoln and Guba define

trustworthiness as using the above criteria to encourage an audience to view the results found within a study as meaningful (1985).

Credibility

Three ways the researcher can ensure credibility is by recognizing self-bias, having the appropriate sample, and achieving data saturation (Kyngäs et al., 2020). Before this study, the researcher recognized sources of personal bias as the knowledge of PEOL theory, the potential key theoretical concepts the analysis might find due to previous studies, and previous first-hand clinical experiences with dying patients in oncological settings and ADs. The sample for the research was appropriate for the research questions asked because oncology nurses are often exposed to patients with, or needing ADs. Therefore, oncology nurses have adequate knowledge and experience of AD use. Further, questions were easily answered by participants. Saturation was achieved through repetition in answers and coding. By meeting credibility standards, the results of this study are strengthened.

Dependability

Dependability was ensured by ensuring the quality of the process of data collection, data analysis, and theory generation (Kyngäs, 2020; Lincoln & Guba, 1985). Dependability and reliability are interchangeable according to Lincoln and Guba (1985). Having outside researchers or experts review the data collection, analysis, and theory generation help provide reliability (Creswell, 2014). Two co-researchers reviewed and audited the raw data and concurred with the initial and subsequent coding and thematic categorizations. Thus, the researcher met dependability standards.

Confirmability

Confirmability is a part of qualitative analysis reliability, which can both help and hurt the trustworthiness of the research (Kyngäs et al., 2020). Confirmability was achieved in this research because the researcher included memos, quotes, and notes in the data results for the co-researchers as they audited the findings. However, Kyngäs et al. (2020) states creating memos can impair trustworthiness because the memos are intended for the researcher. An overwhelming amount of notes can hurt authenticity because the notes can root from bias from the familiarity of the subject whereas the readers may not have the overall knowledge the researcher does (Kyngäs et al., 2020).

Authenticity

A way to ensure and meet authenticity standards is to compare findings to quality and trusted citations from the literature to corroborate and support findings (Kyngäs et al., 2020). The results of this study support many literature findings, as well as extends current knowledge. Evidence of authenticity can be seen in Chapter VI. The results met authenticity requirements because this study upheld authenticity criteria.

Results

The coding of the data's categories and themes using content analysis as described by Kynäs et al. (2020) and Hsieh and Shannon (2005) was used to reduce the data and produce the findings for this study. Data were analyzed and results organized according to research questions, which corresponded to interview questions. Below are the research questions used in this study and the Coding Categories for Findings, Table 2.

1. Do oncology nurses have a firm grasp and understanding of AD?
2. Do oncology nurses realize barriers with AD, both implementing and obtaining ADs?
3. How do oncology nurses view AD? Like/dislike; For/against
4. Do oncology nurses believe ADs benefit patients and quality of life?
5. How do oncology nurses begin the conversation with patients about ADs, or do they discuss them at all?

Table 2

Coding Categories for Findings

Category	Themes
Legality	1) Written Document 2) Wishes for EOL Care 3) Unable to Speak for Self
Barriers	1) Lack of Education on AD 2) Convenience 3) Families
Usefulness	1) Prevention of Suffering 2) Unintended Consequences
Benefits	1) Quality of Life 2) Peace
Quality Interactions	1) Timing 2) Compassion 3) Family Inclusion

Research Question 1: Understanding of AD

To examine if the participants had a firm understanding of an AD, the first question of the interview asked participants to define ADs in their own words. The participants had a collective definition of an AD, which included the main category of Legality, and themes of, Written Document, Wishes for EOL Care, and Unable to Speak for Self. Participants' responses clearly recognized the AD as being a legal matter. For instance, participants 2, 4, 5, 6, and 10 stated an AD is a form of legal document. Other's responses captured the Legality Category stating "An advance directive is just a form a legal document stating their wishes after they are no longer able to decide for themselves for their care. It basically says what they want for end of life" (Participant 4). Participant 5 stated "The patient needs to be able to verbalize what they want and it's a legal document. So, it's not like someone can be like 'Oh no that's not really what you wanted'."

Participant #2's response encapsulated the themes of Wishes for EOL Care and Unable to Speak for Self: "An advance directive is what a patient wants if they are unable to speak for themselves... What they will want done if something happens... How hard they would want us to try to keep them alive... Who they would want to make decisions if the decision that needed to be made wasn't in advance directive?. So, basically, their wishes." In comparing participant responses to the PSDA, the participants seem to have a valid understanding of ADs and their intended uses.

Research Question 2: Barriers of AD

The present study's participants were able to clearly express the barriers they identified around obtaining ADs, resulting in the category of Barriers for this question.

Content analysis revealed themes of Lack of Education on AD, Convenience, and Families. A common theme in the data was Education; the nurses noted lack of education of patients, family, and other nurses as barriers to the AD process. Education had different points of perspective when expressed by participants. Some participants noted education from a nurse perspective, coined “nurse brain” by one participant. “You're the eyes and ears for the doctor; they're (patients) going to talk to you a lot more than them (the doctor)” (Participant 3). Further, participants explained that nurses can tell the doctor when the patients are tiring of treatments and indicate when the conversation about EOL is necessary. Also, education for nurses was described as “empowering,” saying, “It’s (the end of life/AD conversation) actually empowering to have such a discussion. I think nurses should have this (conversation) empowering nurses and educating them.” (Participant 8).

Others answered the question from a patient, family, or non-medical background perspective. Participants believed the education of patients and families is essential. Most of the participants understood this and spoke of how they educate patients and families on death and ADs.

Well, I think every patient should be questioned whether they have one and should be educated about what they are... I think there is that mentality of if I do that advance directive, you're giving up on me, nobody is going to treat me...I think there's not enough education... So, I think education and with compassion obviously is crucial.... You want to have that conversation. It's very important, especially in front of family. I think the idea is to explain to them that you're not giving up on them. (Participant 5)

I will talk to them on the phone pretty lengthy about it. They always have a lot of questions. I squeeze in that do you have an advanced directive. Do you know what that is if you don't you know let's talk about it? ... During that conversation, they'll make sure that they did finally do that (AD). (Participant 2)

Education among both patients and families was evident in the data. "... 'cause not many people know what the advanced healthcare directive even means," stated Participant 10 when asked how they discuss ADs with patients. A common misconception is once patients sign an AD, health care providers will not help them, but as Participant 2 succinctly stated, "We are not going to let you choke on your eggs."

Asking the participants, "About how many of your patients have an AD before treatment?" segued into a conversation about the theme, Convenience. The average of all the answers given from the participants estimated that 41.3% of oncology patients have ADs. The mode was 25%, 40%, and 50%, all having two answers each. The median was 40%. Two participants noted that the number increases after treatment has started. Participant 2 noted older patients were more likely to have them already when beginning cancer treatment. Participants indicated that patients, especially younger patients, do not see ADs as convenient, thinking that they do not or will not need them. Participant 5 talked about the convenience of getting an advance directive.

In Washington State, advance directives need to be on the refrigerator or need to be, or the fire department has to have like copies... I mean, that's a general lot more work... So, like in Washington, the POLST, which is signed by a physician it's not a lawyer... In Portland, I know my dad has one, and his is done by a

lawyer. But in Washington, it's done by a physician.... That's part of the problem too. (Participant 5)

Patients see doctors far more often than lawyers, and the price for a doctor's visit is a lot less than a lawyer because of insurance. The participants understood the convenience of obtaining ADs being a barrier. The convenience of a doctor's office visit and payment also ties into the obstacle of demographics. The participants did not go over the challenges due to racial demographics, but mentioned age demographics, stating that older populations were more likely to have them.

Interestingly, the most significant theme under Barriers was Families. Most participants noted that patients presumed family members would take over as proxy or as an AD instead of getting a legal AD. Many participants noted families were a barrier for medical professionals and patients, stating family members were more likely to extend care for patients when the outcome was not optimal from previous interventions. One participant said, "I think the legal proxy should never be a spouse or friend" (Participant 5) due to their tendency to overextend futile treatment. However, other participants noted the husband/wife/partner was more gracious to the patient (i.e., less unnecessary EOL interventions). Participant 9 stated, "I think more often than not it's the husband, the spouse that is more gracious to the patient." Graciousness appeared to be a merciful act performed by families in order to cease futile treatment.

Multiple participants stated a conversation with the families privately helped family members understand the outcomes and diagnosis, thus helpfully preventing strife and conflict. Unfortunately, family conflict occurs commonly throughout most end-of-life experiences (Ruland & Moore, 1998). However, Ruland and Moore (1998) state the

necessity of having loved ones at the bedside during EOL. Therefore, families are likely experiencing personal grief, which may create conflict within the family, and may reject the patient's EOL wishes. Participant 2 stated, "A lot of the patients that have a lot of turmoil in their family also have a lot of turmoil with death...That one person who's complaining about it is the problem person in the family." Multiple participants noted families would change or disregard ADs made by the patients.

At least two participants stated they had to have ethics committees meet with the families declaring the AD is legal, and the health care team will uphold the AD. Families fear loss, death, and not doing enough to help their sick loved ones. The guilt families feel is from not being near their dying loved one, or they have let them down. Grief is obvious because families are losing the ones they love. Participant 5 stated, "...at the time you know you're so in it, just save her. Do whatever you have to do. There's not really rational sense." Other participants (1 & 6) stated families feel guilty for giving up on their loved one more than feeling peaceful about their loved one's passing. The family's emotions are dictating their decisions. Participants noted the family's emotions were a large part of barriers to ADs.

Family discussion of ADs can also tie into the conversations about ADs nurses have. For example, participant 9 and many others had stories of past patients where the patient did not have an AD and assumed the family would take care of them, but instead, the families acted in the best way they thought.

I'll ask them if they have an advance directive.... Majority of the time they already have one... Some they'll say no, I'm not interested in that right now...

Some say they have their family like a husband or something and that'll husband

or wife will just take care of it... So, it's one or the other they either have one, or they'll take care of it.... I had a spouse who let her husband's fingers rot off... She just could not ever say no... He was like literally falling apart... So, that was that was not good. (Participant 9)

The conversation with families about the patient's AD or with one's own family about them can benefit patients and help improve quality of life.

Research Question 3: View of AD

The overall consensus among participants was that ADs were “very” useful. Thus, the Category of Usefulness. The theme that emerged from the content analysis was Prevention of Suffering, with pain being a part of suffering. Participants spoke about preventing unnecessary suffering and pain. They mentioned ADs sometimes helped prevent those situations. “...He decided didn't want any further treatment 'cause he had already been through enough. Then eventually, he was like a DNR, DNI, and then he passed throughout the night. It made a lot easier than, you know, having to code him.” (Participant, 7). Participant 5 mentioned how ADs can be useful or not useful, stating, “I think the non-useful part is the patients that don't do it and then we don't know their wishes. Then there ends up being a whole ethical, legal battle which I've seen, unfortunately. So, I think they are very useful. I just think it needs to be encouraged to be done. I think 100% of patients should have it... my oncology and even my non-oncology patients was encouraged them to get one done so that their wishes were written down and could be considered.”

A theme of Unintended Consequences also described what participants did not like about AD. One consequence was when the terms of the AD were aimed at doing

everything possible to treat and intervene during EOL. These AD situations can result in what participants viewed as unnecessary suffering and pain. “I just hate it when they're like full code... do this... do this... do this when the quality of life is not good.” (Participant 9).

Research Question 4: Benefits of AD and Quality of Life

Benefits were the category for this research question on what good can come of having an AD. Quality of Life was found to be an important theme because the patient can define their quality of life for themselves within the AD. Participant 9 stated, describing her viewpoint on ADs, “Don't do the dramatic interventions that you don't feel like the quality of life is gonna be great after.” Another participant said, “We're looking at letting her live her life the way she wants to for however much longer she has left” (Participant 3). The participants strongly believed in letting patients live the way patients want to live and not doing those “dramatic interventions” if the intervention is going to cause prolonged suffering.

The other theme identified in the data is Peace. Obtaining Peace includes maintaining dignity and avoidance of drama, avoidance of suffering, maintaining comfort, and acceptance of impending death. For instance, Participant 9 stated major interventions which prolonged life and possible suffering as “dramatic.” More than once, the mention of dying with “dramatic” interventions meant the family could not be by one's side at death due to the health care team's need to perform intensive interventions.

Lots of patients (were accepting of death, with an AD). I can remember a few that have just, I really admired with their strength of ... facing death with pride and you know seemed too not be afraid. You know, would feel like they were

probably scared, but they held their shoulders up, you know, chin up high. I'm ready and just go into it with dignity and grace really. Those deaths are usually very peaceful. (Participant 2)

Suffering is subjective to the one enduring the pain and suffering, but nurses know what to expect with EOL and how dying looks with “dramatic interventions.” Multiple participants stated these unnecessary interventions were prolonging misery in patients. However, participant 6 stated, “I can't say what is or is not ongoing suffering.” The decisions made by the family could prolong suffering and pain and are rooted in grief and emotion, not malice.

Decisions aren't made rationally (by family). They're made emotionally.....

There's obviously places where there's not an advance directive in place, the family's decisions are probably not in the best interest of the patients, and I can't say what is or is not ongoing suffering based off what the family decided.... I've been in where an advanced directive was not in place, and the family's decisions probably prolong their suffering. (Participant 6)

For one instance, we had a patient who, he was suffering. He failed the transplant process, and he did not want anything else to be done for him. He did not want to be intubated. He did not want to be a full code. He wanted a DNR, but his wife truly felt that he did not know what he was talking about. And so, he never put any of those wishes down. He never went forward with the advance directive. Even though the social worker met with him about it and so it ended up being the wife. He never was a DNR and its prolonged suffering. (Participant 10).

Suffering can look different for each patient. Participants stated feeding tubes, intubation/ventilation for an extended period, and coding the patients were indications of suffering/pain. In the end, everyone will die, but how their patients died was important to the participants. Participant 9 stated eloquently, “Their end result was the same, but the journey to get there was a lot more dramatic.”

Research Question 5: Conversations about AD

The category that emerged from the data for this question was Quality of Interactions. Quality of Interactions includes the characteristics of the conversations initiated with patients about ADs. One theme in this category was Timing. Every participant stated they speak to patients about ADs. Most participants stated their conversations were usually held during the admission process, whether admission to the cancer center or inpatient facility. Most noted discussing AD was part of the admission protocol. Though Participant 2 indicated they were not required to ask about ADs, they did so during admission, unsolicited from superiors.

Another theme is Compassion. Participants noted the conversations about ADs were not always easy conversations, making compassion an essential component in discussing the difficult and sensitive EOL issues surrounding ADs. Pehlivan and Güner, (2018) define compassion as a desire to act on behalf of others and is often seen as an important characteristic for nurses. Participant 5 stated, “I think education, and with compassion obviously is crucial.”

Family Inclusion was found to be an important theme that overlapped with the notion of conversations being potentially fraught with difficulty. Participants noted family conversations about ADs were important but could be difficult as well. Participant

4 stated the discussion with the family about the patient's AD was difficult when trying to support the patient's EOL decisions in discussions with the family.

“That's a very difficult situation...to talk to them about different things the patient would say to me. I wouldn't necessarily tell them my thoughts. You're trying to be an unbiased person. That's obviously their (the patient's) decision. I'm just telling them what the patient told me. That this is what they wanted, they wanted to be able to go home, not have to try and recover from different procedures. They just want rest. They want comfort. They want to be pain-free.” (Participant 4).

The data supported that conversations about ADs need to happen with families. Families may be there when the patient is unconscious; therefore, they can be actual actors on the ADs. As stated above, most patients assume their families will decide what happens in these instances; therefore, the family conversations with patients and/or health care providers are crucial. The participants noted they all spoke to patients about ADs, but the length of the discussion or thoroughness was differing. Inpatient participants reported they wished they had more time to go over what ADs are and how useful they were to patients. Participant 2 stated “They gotta get that patient quick because I got five more to take care...They don't have time to talk about.” Participant 9 stated, “I think we kind of sometimes and slide through that question... half the time they'll say yes.”

Summary

The results of this study were analyzed using rigorous qualitative standards, including data saturation, trustworthiness, and provided answers for each of the research questions. The data were saturated because many participants gave similar answers, data became repetitive, and shared the phenomenon throughout them. The study also fits

within Kyngäs et al.'s (2020) criteria for trustworthiness. The study met standards for credibility, dependability, confirmability, and authenticity.

Question One discussed the participant's general knowledge of ADs and gave a combined definition that aligned with the definition given in Chapter I. The themes found in Question One are Knowledge, Wishes for EOL Care, and Unable to Speak for Self, each fit under the Category of Legality. These themes help explain the information from the nurses' perspectives. Having a good foundation on the knowledge of ADs is important for nursing. Wishes for EOL Care and Unable to Speak for Self describe ADs in simple terms for patients.

Question Two spoke about the many barriers of ADs. The Category was determined to be Barriers. The themes found within Barriers of ADs are Lack of Education on AD, Convenience, and Families. The lack of education was not regarding healthcare workers but specifically towards patients and families. The convenience factor was shown in how inconvenient obtaining an AD is for most patients. And lastly, families are an important part of the EOL processes. They can hinder or help the process of having an EOL.

Participants regarded the usefulness of ADs as excellent. Question Three analysis revealed the Category of Usefulness, with themes of Prevention of Suffering, and Unintended Consequences. The participants found ADs to be practical and useful, therefore the Category of Usefulness. The theme Prevention of Suffering is a useful aspect of ADs because ADs can help healthcare workers know when to draw the line for dramatic interventions. However, the other side is the theme of Unintended

Consequences; meaning sometimes ADs are aimed to do everything possible for patients when interventions are likely futile.

Which leads to Question Four, the benefits of ADs. Analysis revealed the Category of Benefits and themes of Quality of Life, Peace, and Suffering. Quality of Life is important for AD benefits because ADs can help improve the quality of life at the EOL. Peace was also seen as a benefit of ADs because an AD can help eliminate the drama and conflict in EOL care. The last theme seen is Suffering. Suffering differs for every participant and patient, but the participants consistently viewed unnecessary interventions as suffering for patients and families.

Lastly, Question Five, conversations about ADs, lead to the Category of Quality of Interactions, with the themes of Time, Compassion, and Family Inclusion. The lack of time was discussed among participants. The participants wished they had more time in the day to discuss ADs at length and answer all questions surrounding them. This shortage of time also contributed towards feelings of a lack of Quality of Interactions between participants and patients. Compassion is also a necessary part of nursing care. The participants noted how patients and families are at a difficult point in life, therefore compassion is necessary when discussing ADs. Family Inclusion was a large part of discussing ADs. Families were often not included in the discussion of ADs; therefore, they did not know about the AD and were not able to uphold it.

Overall, participants revealed secure understandings of ADs, stating an AD is a legal, written document which expresses one's wishes for medical care and end-of-life care. The results confirmed participants' barriers to ADs, and participants viewed ADs overall as very useful for healthcare. The data also showed how nurses believe ADs can

both help and may unintentionally hurt patients. And lastly, all participants stated they discussed ADs, but the length of discussions differed among each participant.

CHAPTER V – DISCUSSION AND CONCLUSIONS

Introduction

In this final chapter, the results of this content analysis, qualitative study are discussed in relation to previous research findings, PEOL theory (Ruland & Moore, 1998), and implications for teaching, research, and practice. The study's purpose was to discover more about oncology nurses regarding AD experiences with oncology patients. The 10 participants were oncology nurses, over 18 years of age, with at least 6 months of recent oncology experience.

Eleven carefully crafted open-ended interview questions corresponded with the five research questions. Questions were generated from the researcher's own experiences, the literature, and identified gaps in the literature. Questions were readily answered by participants, indicating the questions were appropriate and applicable to the nurses' experiences and the topic. The data resulting from online video interviews were reviewed, transcribed, and analyzed using rigorous content analysis methods performed on data corresponding to each research question.

The results from the research question content analyses indicated the following Categories and corresponding Themes as follows. The first question is 'Do oncology nurses have a firm grasp and understanding of AD?' The category found in the first question is an Understanding of ADs and the themes are Knowledge, Wishes for EOL Care, and Unable to Speak for Self. The second research question asked if oncology nurses realize the barriers with ADs; the category being Barriers and the themes found were Lack of Education on AD, Convenience, and Family. The next question was how oncology nurses view AD. The category found was Usefulness and themes were

Prevention of Suffering and Unintended Consequences. The fourth question was do oncology nurses believe ADs benefit patients and QOL? The Benefits category encompassed themes of Quality of Life, Peace, and Suffering. And lastly, Question Five asked how oncology nurses begin the conversation of ADs with patients. Analysis revealed the category of Quality of Interactions, and themes of Time, Compassion, and Family Inclusion.

The interpretation of the findings, implications for nursing education, research, and practice are discussed below. Future research directions and limitations of the study are also discussed. Understanding these aspects of the study can help future researchers both fill in and identify new gaps in the literature, help direct nurse educators, and guide nursing practice on how to facilitate AD completion.

Interpretations of Findings

Overall Impressions of the Findings

Five major impressions resulted after reflection on the results. First is the importance participants placed on the increasing nurse, patient, and family knowledge of ADs. In this study, knowledge about ADs was an overarching theme that entered into many of the other analyses. Knowledge was empowering for all concerned. Knowledge of ADs was perceived to be the key to nurses being empowered to address what ADs are, the need for ADs, and supporting the patient through a PEOL experience. Likewise, the more AD information patients and families had, the better the chances that stress, uncertainty, and strife would be reduced, the AD completed, and a PEOL experience obtained. Second, the data supported the oncology nurses' belief that all their patients needed to have an AD. Oncology nurses viewed ADs as absolutely necessary to help

them fully understand the treatment or non-treatment goals of the patient. Even when the AD did not align with their personal opinions, the nurses still respected the patient's wishes and were committed to the terms of the AD, carrying the AD out fully. However, "Do no harm" is a thin ethical line. When an AD has stipulations for extreme measures in futile cases, are nurses really following the 'Do no harm' credit? In this study, oncology expressed personal angst when faced with following ADs that call for extreme measures in medically futile cases.

Third, the difficulty of obtaining an AD was described by the oncology nurses. The process for getting an AD is riddled with barriers and obstacles, particularly the lack of patient and family knowledge, patient inaction, different legal/institutional requirements, and nurses' time constraints. The lack of patient and family knowledge was described above and was viewed as a major barrier in obtaining, and executing an AD. Ultimately, securing ADs rely on patient action. Providers can bring up ADs, but if they are not truly discussing and helping patients follow through, then providers are failing the patient. The patient must take the initiative to finish an AD and discuss them with family and providers. The family's acceptance of the patient's EOL wishes may help prevent AD revocation due to grief and misunderstanding.

The laws surrounding ADs differ from state to state, and the process can also vary by institution. One participant suggested that the process could be simplified by making ADs a transaction between them and their physicians/providers. Having primary providers discuss the options and create the AD would be cost-effective and easiest for patients to access.

The time the process of obtaining and signing ADs was identified as another problematic area by the oncology nurses. Nurses said that they needed more time to talk about ADs with patients and families. The participants seemed eager to talk to patients about ADs; however, when nurses have 5-7 patients at a time, intimate lengthy discussions are almost impossible. This barrier could be addressed by making the AD initiation, procurement, and signature the physician's responsibility. However, some nurses saw ADs as an important aspect of their practice and enhanced their relationships with their patients, but rued the lack of time to do so consistently.

Fourth, the need for holding real discussions about AD with patients and families was identified as paramount. While ADs are a vital part of healthcare, the importance of the discussion of an AD is far greater. Discussion with patients, providers, and family helps the patient's wishes for healthcare be properly followed. If patients do not discuss their wishes with the right people, health care providers will not carry out their wishes in a way they would want.

Fifth, caring for patients near death is stressful for nurses and can lead to emotional burnout (Peterson et al., 2010). Oncology nurses expressed that they want what is best for their patients' EOL experience. Nurses who must help perform "dramatic interventions", which can cause extended suffering, hurt nurses emotionally. While the oncology nurses expressed how adamant they were to follow the patient's wishes, they also expressed how much following the patient's wishes hurt them when they had to perform futile and invasive treatments. Oncology is a specialty where the same patients are repeatedly readmitted for treatment. Thus, patients become close to nurses who are often also attached emotionally to the patients. When their patients die, nurses experience

emotional stress (Peterson et al., 2010). Nurses need to talk about their loss experiences and have time to heal after intense patient deaths to counteract burnout and allow for adequate processing of grief. The experiences of these deaths weigh on the nurses, much like they do on family members.

Comparison to Previous Literature

The literature discussed in Chapter II examines the nurse's role in ADs, the patient's belief of ADs, who is likely to have ADs, family and cultures, problems with ADs, and gaps in the literature. The nurses' role in AD was apparent in the literature and the present study's results. Knowledge of ADs among the oncology nurse participants were informed and perceptive. ANA (2016) stated the importance of knowledge of ADs and that oncology nurses were more likely to encounter ADs. Hinders (2012) states nurses were a sufficient way to educate patients about ADs, which correlates to the knowledge about ADs among nurses in the present study. The participants in the present study also agreed that the information should come from a nurse and not a doctor. Jezewski et al. (2005a) found 70% of oncology nurses were knowledgeable of ADs; whereas all of the participants in the present study were knowledgeable of ADs. The present study's participants corroborated these claims of knowledge with their perception and clarity of ADs.

Throughout the present study results and the literature review, a lack of education about ADs was evident. Boddy et al. (2013) stated knowledge, convenience, demographics, and emotional reactions were barriers to obtaining an AD. The present study's participants stated the importance of education among not only nurses but

patients and families as well. The present study's theme of Lack of Education was found to acknowledge the deficiency among patients and families but not among nurses.

The present study participants believed about 40% of their oncology patients had ADs on admission, though they estimate that percentage most likely increased after diagnosis and subsequent admissions. Participants also noted fewer younger patients were not likely to have ADs. These findings support the study conducted by Xu et al. (2021) and van Oorschot et al. (2012). These two studies noted patients were less likely to have an AD if they were younger, healthy, or without a terminal diagnosis.

Families were a common thread in the present study's results. The literature supports family inclusion because family inclusion can prevent them from hindering a patient's EOL wishes (Inoue et al., 2019). The present study's participants told numerous stories of families interfering with EOL wishes. Hickman and Pinto (2014) stated a lack of knowledge can burden family members and surrogates when they are not included on the EOL discussion. The nurses in the present study noted the importance of having the discussion of AD in front of the patient's family.

Boots and Wilson (2014) state nurses need to be aware of the barriers to ADs. The nurses in the present study identified barriers to ADs, forming the themes Lack of Education on AD, Convenience, and Family, which correlate to the barriers expressed by Henders (2012). Henders (2012) states the lack of information is a key barrier in AD completion.

Gaps in the literature are primarily due to a lack of qualitative nurse-focused studies that can describe and elaborate on how nurses can improve AD completion and EOL experiences for patients. The present study helped reduce the gap in the literature, as

it is a qualitative study focused on the knowledge and attitudes of oncology nurses who have responsibilities regarding the attainment of ADs. How nurses perceive the AD experience can help inform ways to achieve better AD completion rates. The present study shows nurses believe efforts toward improving education, increasing time spent on ADs, and improving convenience can help remove most of the barriers to completion rates.

Theoretical Consistency with PEOL

Ruland and Moore (1998) created the PEOL theory framing five aspects found within every PEOL. The five aspects are 1) being pain-free, 2) having comfort, 3) having dignity and respect, 4) being at peace, and 5) being close to loved ones (Ruland & More, 1998). Having peace and acceptance can help the death process for families and patients. The theory explains the relationship between nurse and dying patient. The purpose of PEOL theory is to help EOL become peaceful for ill patients.

Ruland and Moore (1998) describe PEOL thoroughly; having dignity, comfort, family without suffering or pain can achieve a PEOL. These concepts within PEOL are supported in the results of this study. The themes of Suffering, Prevention of Suffering, Lack of Education, Family, and Family Inclusion align with PEOL and ADs. Many participants in the present study noted peaceful deaths with family at their bedside and passing without pain or chaos. Ruland and Moore (1998) state the necessity of having loved ones at the bedside during the End of Life. Family members feel guilt, fear, and conflict (not only with themselves but with others). Ruland and Moore (1998) define dignity as “being respected and valued as a human being” (p. 172). Participants in the

present study did not mention the word dignity through the interviews; however, the researcher inferred dignity when participants mentioned peace and grace.

Comfort for patients is knowing that the nurse is “still here” (Participant 2). Comfort in the PEOL theory ties into the present study’s themes of Time and Compassion. Knowing nurses are supportive and involved in one’s health helps patients with comfort at End of Life. Suffering is subjective; many participants noted these “dramatic interventions” were unnecessary and could unintentionally cause the patient suffering and pain. Education of AD is also how patients can achieve PEOL. Ruland and Moore (1998) discuss inspiring trust and monitoring patients’ anxiety. There is no better way to inspire trust and diminish anxiety than education. One participant stated the importance of education for patients and families, “I think education, with compassion obviously is crucial” (Participant 5). The conversations and education of AD should include families and loved ones; moreover, Ruland and Moore (1998) require loved ones in decision making.

The results of the present study add to PEOL by adding ample information about how this theory is still relevant in today’s age. The PEOL theory does not contradict what was found in the study. The PEOL theory helped give a basic understanding of the mindset of EOL. The data can help PEOL because this study helps understand PEOL from a nurse’s perspective. PEOL is about how the patient feels, but this study shows how the nurse can help patients achieve a PEOL.

PEOL benefits this study and future research because the theory gives a preconceived idea of how EOL can look in the best situation. Knowing what to look for when studying EOL helps researchers find common ideas and common gaps in

knowledge. The PEOL theory can also give researchers ideas about what can go wrong in a dramatic EOL. The definitions given to a PEOL improve the accuracy of research. The clear and concise definitions used in PEOL theory help researchers exhibit the same phenomenon among multiple studies.

Implications for Nursing Education

Education for nurses needs to start as early as possible to ensure they are knowledgeable about ADs. The participants in the study were knowledgeable about ADs; however, education about how to discuss EOL decision-making is necessary education. In most nursing schools, there was not a course or an in-depth lesson about how to talk to patients and families about ADs. The discussion could be included in the introduction to nursing courses, in lessons on therapeutic communication, or when death and dying topics are addressed. Inclusion of content directly related to ADs could help future nurses learn how to have difficult but important conversations with families and patients. Such conversations will benefit patients, families, and ultimately the nurses themselves for years into the future. The End-of-Life Nursing Education Consortium (ELNEC) is a course/certification whose purpose is to improve the education of EOL care. This course is available for undergraduate nurses and graduate nurses; having this certification can improve nurses' knowledge on how to appropriately talk to patients about EOL care.

Educating not only nursing students but nurses, about ADs can help reduce the stigma related to of the perception of ADs being an unwelcome and morbid topic. Many states require continuing education credits to renew nurse registration or certification status. This finding of this study can be used to produce an educational presentation or article about ADs and how nurses may encourage other nurses as well as patients and

families to discuss ADs. Education for nurses should include how to discuss EOL wishes with families. Many participants in this study stated they had seen, heard of, or had had instances of, mediating AD issues between family and patients. Additionally, healthcare systems would benefit from requiring yearly updates and education on PSDA, EOL, and ADs.

Implication for Nursing Practice

Current nursing practice can benefit from the results of this study. Participant 8 suggested that a script and education tool for not only patients but for nurses in the clinical setting would help facilitate conversations about ADs. Having a prepared AD script can help nurses in busy clinical settings focus on ADs, and may ease the tension associated with difficult conversations about ADs. The script ideally should include a meeting with family, providers, and patients. The script should provide information to answer most common questions and issues related to having an AD. An associated clinical tool should include checklists on how to obtain and finish an AD. The tool should also include a checklist of all invasive life-sustaining procedures and interventions (i.e., total parental nutrition, gastrostomy tube, intubation, CPR, antibiotics, etc.) that may be used.

While a script would be beneficial to nurses who need help with EOL discussions with patients, system-wide change is necessary to overcome the barrier of time. A system-wide change of how patients are asked about ADs would help nursing practice. As well as, ensuring the nurses and other healthcare professionals have a specific amount of time to talk to patients about their ADs or EOL wishes. These tools can benefit nurses, but a system-wide change for EOL discussion would help lower barriers around ADs.

Nurses should also take time to prevent burnout. The National Academy of Medicine (NAM, 2019) provided six evidence-based practices to reduce burnout; they were to create an upbeat and helpful work atmosphere, including learning, lessen the consequences for administration encumbrance, help provide technological resolutions, support the staff, and adopt research findings. Using NAM's suggestions can improve burnout among nurses, but requires investment from healthcare institutions who value quality (Smith, 2014).

The last implication for future practice is expanding quality interaction time spent with patients. Time is necessary to adequately talk to patients and families about ADs. To assure the best context for securing ADs, nurses must be educated, have the proper tools, and have time to interact therapeutically with patients and their families. When all three are present we can assume nurses that the conditions are conducive to obtaining an AD. Nurses want what is best for their patients. Every participant in this study stated they always wanted to talk to patients and families about ADs, many stated that they were missing the time necessary.

Recommendations for Further Study

The concepts of, and relationships between, ADs nurses, patients, and families are burgeoning with ideas for future studies. For instance, a qualitative study exploring the dynamic between families and patients would provide more information about the AD experience from a needed perspective not found currently in the literature. This type of study could explore what may be inhibiting or conducive to patient-family discussions. Learning more about how and why patients do or do not discuss their wishes with families can help prevent future distress, pain, and suffering.

Another aspect of research that should be further pursued is creating a clinical script and an accompanying tool for AD completion. The study should incorporate current knowledge to create the script and tool. In creating the tool, it should be thoroughly vetted for validity using the expertise of clinical nurses as well as a panel of nurses with experience in tool development. A practical, valid and reliable tool that produced interval-level data for parametric statistical analyses would be useful to future researchers who would like to examine more about the relationship between ADs and patients.

Limitations of the Study

Limitations of this study should be considered. The primary limitation of this study was the difficulty of obtaining participants. Participants were hard to find, and the lack of participants were likely due to the COVID-19 pandemic. Nurse staffing is stretched to the limit because of the pandemic. Further, nurses report fatigue and exhaustion during this pandemic (Young, 2021) potentially inhibiting them from volunteering for a study. The limitations of this study did not impact the results of this qualitative study but did impact the time the study took to obtain data.

Conclusion

In conclusion, oncology nurse participants in this study indicated that ADs are useful, beneficial to patient EOL experiences, and nurses, patients, and families need more education. These findings support ADs as a vital part of health care. The overall consensus was more education for patients, healthcare providers, and patients about AD is necessary. Knowledge represents empowerment; when everyone is more knowledgeable, EOL experiences improve.

Oncology nurses revealed that they wanted what was best for the patients, wanted them to discuss their wishes through an AD, and grieve for the patients who die and suffer. The nurses also experienced suffering because of this grief. The participants supported the claim of lack of time to adequately discuss ADs with families and patients especially because the process to get a legal AD is difficult. And lastly, nurses want to “Do No Harm,” but can be forced to because patients do not have an AD or have an uneducated AD.

Nursing practice and education can benefit from this study by incorporating findings into education and practice surrounding ADs. Nursing education is essential for keeping nursing students and practicing nurses apprised of important research findings that can impact future practice. Educated nurses in practice areas can improve patient EOL outcomes and improve patient and family quests for a peaceful death. Through future research endeavors, an educational script and checklist can be developed, as well as a tool to measure concepts related to AD.

APPENDIX A – IRB Approval Letters

Office of Research Integrity



118 COLLEGE DRIVE #5125 • HATTIESBURG, MS | 601.266.6576 | USM.EDU/ORI

Modification Institutional Review Board Approval

The University of Southern Mississippi's Office of Research Integrity has received the notice of your modification for your submission Thoughts and Knowledge of Advance Directives Among Oncology Nurses (IRB #: IRB-19-537).

Your modification has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services regulations (45 CFR Part 46), and University Policy to ensure:

- The risks to subjects are minimized and reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered involving risks to subjects must be reported immediately. Problems should be reported to ORI via the incident template on Cayuse IRB.
- The period of approval is twelve months. An application for renewal must be submitted for projects exceeding twelve months.
- Face-to-Face data collection may not commence without prior approval from the Vice President for Research's Office.

PROTOCOL NUMBER: IRB-19-537

PROJECT TITLE: Thoughts and Knowledge of Advance Directives Among Oncology Nurses

SCHOOL/PROGRAM: School of LANP, Leadership & Advanced Nursing

RESEARCHER(S): Bailey Welsh ,Bonnie Harbaugh

IRB COMMITTEE ACTION: Approved

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

PERIOD OF APPROVAL: April 14, 2021

A handwritten signature in cursive script that reads "Donald Sacco".

Donald Sacco, Ph.D.
Institutional Review Board Chairperson

Office of Research Integrity



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PERIOD OF APPROVAL: December 18, 2020

Donald Sacco, Ph.D.
Institutional Review Board Chairperson

Modification Institutional Review Board Approval

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- Face-to-Face data collection may not commence without prior approval from the Vice President for Researches Office.

PROTOCOL NUMBER: IRB-19-537

PROJECT TITLE: Thoughts and Knowledge of Advance Directives Among Oncology Nurses

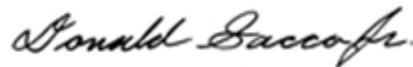
SCHOOL/PROGRAM: School of LANP, Leadership & Advanced Nursing

RESEARCHER(S): Bailey Welsh ,Bonnie Harbaugh

IRB COMMITTEE ACTION: Approved

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PERIOD OF APPROVAL: September 22, 2020



Donald Sacco, Ph.D.
Institutional Review Board Chairperson

Modification Institutional Review Board Approval

The University of Southern Mississippi's Office of Research Integrity has received the notice of your modification for your submission Thoughts and Knowledge of Advance Directives Among Oncology Nurses (IRB #: IRB-19-537).

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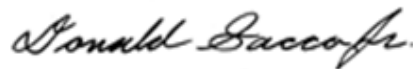
SCHOOL/PROGRAM: School of LANP, Leadership & Advanced Nursing

RESEARCHER(S): Bailey Welsh ,Bonnie Harbaugh

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PERIOD OF APPROVAL: August 26, 2020



Donald Sacco, Ph.D.
Institutional Review Board Chairperson

Modification Institutional Review Board Approval

The University of Southern Mississippi's Office of Research Integrity has received the notice of your modification for your submission Thoughts and Knowledge of Advance Directives Among Oncology Nurses (IRB #: IRB-19-537).

Your modification has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services regulations (45 CFR Part 46), and University Policy to ensure:

- The risks to subjects are minimized and reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered involving risks to subjects must be reported immediately. Problems should be reported to ORI via the Incident template on Cayuse IRB.
- The period of approval is twelve months. An application for renewal must be submitted for projects exceeding twelve months.
- FACE-TO-FACE DATA COLLECTION WILL NOT COMMENCE UNTIL USM'S IRB MODIFIES THE DIRECTIVE TO HALT NON-ESSENTIAL (NO DIRECT BENEFIT TO PARTICIPANTS) RESEARCH.

PROTOCOL NUMBER: IRB-19-537

PROJECT TITLE: Thoughts and Knowledge of Advance Directives Among Oncology Nurses

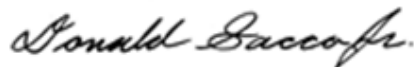
SCHOOL/PROGRAM: School of LANP, Leadership & Advanced Nursing

RESEARCHER(S): Bailey Welsh ,Bonnie Harbaugh

IRB COMMITTEE ACTION: Approved

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

PERIOD OF APPROVAL: May 20, 2020



Donald Sacco, Ph.D.
Institutional Review Board Chairperson

NOTICE OF INSTITUTIONAL REVIEW BOARD ACTION

The project below has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services regulations (45 CFR Part 46), and University Policy to ensure:

- The risks to subjects are minimized and reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
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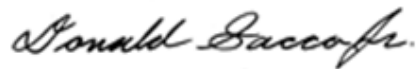
RESEARCHER(S): Bailey Welsh, Bonnie Harbaugh

IRB COMMITTEE ACTION: Approved

CATEGORY: Expedited

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

PERIOD OF APPROVAL: April 14, 2020





RESEARCH PARTICIPANTS NEEDED

Oncology nurses needed as research participants!
The research is about oncology nurses' knowledge and attitudes on advance directives.

I am a PhD candidate looking for oncology nurses for my dissertation. If you have been an oncology nurse for at least 6 months, hold an RN, and are interested in being a research participant please contact the email below.

The interviews are over zoom and should last anywhere from 30 minutes to 1 hour.

Please contact bailey.welsh@usm.edu for information.

NEW NOW OFFERING A \$10 GIFT CARD TO STARBUCKS FOR PARTICIPATING!!

Approved IRB through USM #IRB-19-537



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**Oncology nurses needed as research participants!
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Approved IRB through USM #IRB-19-537

APPENDIX C Questionnaire

1. Describe what you think an advance directive is.
2. About what percentage of your oncology patients have had advanced directives?
3. Describe how useful you think advance directives are.
4. Describe a time when you think a patient benefitted from an advance directive and why.
5. Describe a time when you have seen a patient who was more accepting of death. Was an advanced directive involved?
6. Describe a time when a proxy has helped with end-of-life; proxy meaning a power of attorney or family acting on the patient's behalf.
7. Describe a time when you mediated between a patient and their family about the end of life/patient's wishes.
8. Describe an experience you have had with a dying patient who had an advanced directive.
9. Describe an experience you have had with a dying patient who died without an advanced directive.
10. Tell me how you initiate talking about advanced directives with patients. Do you?
11. Describe how you think nurses can help or change problems with advanced directives.

APPENDIX D Informed Consent



INSTITUTIONAL REVIEW BOARD
STANDARD (SIGNED) INFORMED CONSENT

STANDARD (SIGNED) INFORMED CONSENT PROCEDURES	
<p>This completed document must be signed by each consenting research participant.</p> <ul style="list-style-type: none"> • The Project Information and Research Description sections of this form should be completed by the Principal Investigator before submitting this form for IRB approval. • Signed copies of the consent form should be provided to all participants. <p style="text-align: right;"><small>Last Edited February 9th, 2018</small></p>	

Today's date:		
PROJECT INFORMATION		
Project Title: Finding the Attitudes of Advance Directives among Cancer Patients and Oncology Nurses		
Principal Investigator: Bailey Welsh	Phone: 601-325-8373	Email: w639568@usm.edu
College: University of Southern Mississippi	Department: System Leadership and Health Outcomes	
RESEARCH DESCRIPTION		
<p>1. Purpose:</p> <p>The purpose of this study is to learn about oncology nurses and cancer patients and their relationship and attitudes with advance directives. The study will serve as a basis for future research. Hopefully with this research, medical professionals will begin to understand the attitudes of a dying patient on advance directives and how to discuss advance directives with them. The nurse's perspective will provide a better understanding of why patients do not understand or know about advance directives. There is a knowledge deficit among patients about advance directives.</p> <p>2. Description of Study:</p> <p>The study is a questionnaire based procedure by volunteer basis only. The questionnaire should take no more than 30 minutes. There are no invasive techniques used within this study.</p> <p>3. Benefits:</p> <p>The potential benefits to participating in this study is obtaining knowledge about advance directives. Also hopefully assisting in beginning to fill the gap in the literature on advance directive attitudes among patients and nurses.</p> <p>4. Risks:</p> <p>Participants might experience and inconvenience due to time. The questionnaire only takes about 30 minutes, however some participants may feel bothered by participating in a questionnaire while at work or receiving chemotherapy/radiation. There are no identified risks for the participants. The participant might experience discomfort when answering questions that the participant feels are invasive. The participants have and will be assured that he or she has the right to not answer any questions that make him or her uncomfortable in any way.</p> <p>5. Confidentiality:</p> <p>The data will not contain any participants or medical identifiers. The consents of the questionnaires will be</p>		

separated from the completed questionnaire to ensure no names are related to the number of the questionnaire. The researcher will have the only copy of the completed questionnaires. The data/questionnaires will be kept within a locked cabinet, with the only key belonging to the researcher. The researcher plans to throw away the data after 5 years.

6. Alternative Procedures:

None

7. Participant's Assurance:

This project has been reviewed by the Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations.

Any questions or concerns about rights as a research participant should be directed to the Chair of the IRB at 601-266-5997. Participation in this project is completely voluntary, and participants may withdraw from this study at any time without penalty, prejudice, or loss of benefits.

Any questions about the research should be directed to the Principal Investigator using the contact information provided in Project Information Section above.

CONSENT TO PARTICIPATE IN RESEARCH

Participant's Name: _____

I hereby consent to participate in this research project. All research procedures and their purpose were explained to me, and I had the opportunity to ask questions about both the procedures and their purpose. I received information about all expected benefits, risks, inconveniences, or discomforts, and I had the opportunity to ask questions about them. I understand my participation in the project is completely voluntary and that I may withdraw from the project at any time without penalty, prejudice, or loss of benefits. I understand the extent to which my personal information will be kept confidential. As the research proceeds, I understand that any new information that emerges and that might be relevant to my willingness to continue my participation will be provided to me.

Questions concerning the research, at any time during or after the project, should be directed to the Principal Investigator with the contact information provided above. This project and this consent form have been reviewed by USM's Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about rights as a research participant should be directed to the Chair of the Institutional Review Board, The University of Southern Mississippi, 118 College Drive #5116, Hattiesburg, MS 39406-0001, 601-266-5997.

Include the following information only if applicable. Otherwise delete this entire paragraph before submitting for IRB approval: The University of Southern Mississippi has no mechanism to provide compensation for participants who may incur injuries as a result of participation in research projects. However, efforts will be made to make available the facilities and professional skills at the University. Participants may incur charges as a result of treatment related to research injuries. Information regarding treatment or the absence of treatment has been given above.

Research Participant

Person Explaining the Study

Date

Date

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