How Older Adults Perceive the Terminology “Allow Natural Death”: A Qualitative Dissertation

A Dissertation Presented to the
Faculty of the M. Louise Fitzpatrick
College of Nursing
Villanova University

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy in Nursing
By Jodi Erickson, BA, MSN, RN, CNL

Dissertation Committee:
Chair: Dr. Mary Ann Cantrell, PhD, RN, CNE, ANEF FAAN
Co-Chair: Dr. Meredith MacKenzie Greenle, PhD, RN, CRNP, CNE

Dedication

This work is dedicated to older adults who have lived full lives, shared their wisdom, and deserve to die comfortably. It is also dedicated to the nurses who work tirelessly to ensure that older adults die in a way that is congruent with their end-of-life wishes. This work is not easy, but it is worth it. Thank you for the difference you make in the lives of others.

This work is also dedicated to my dad, Robert E. Gustavson, who encouraged me with his final words to me to pursue nursing, and to my mom, Susan Harvey Manger, who loved me endlessly even when she thought I was “doing too much”.

Finally, I dedicate this work to my husband, Alden, and my child, Mel, whose support and kindness picked me up and kept me moving forward oh-so-many times. I love you.

Acknowledgments

I would like to take this moment in time to thank my committee, Dr. Mary Ann Cantrell and Dr. Meredith MacKenzie Greenle, for their time and support during the dissertation process. Their kind guidance and thoughtful insight impacted my work and this research in so many poignant ways. Under their watchful eye, a relatively new nurse with a passion for end-of-life and older adults became a nurse scientist. I am forever grateful to you both.

Where would a student be without the support of their friends and family? I would like to tell my family how deeply grateful I am to you and for your love. When I had no faith in myself, you reminded me of the important work I was doing and will continue to do. Alden and Mel, you use your words for good and I so appreciate the eternal love you give. Lauren and Brian, thanks for being amazing step-kids who consistently support me with encouragement. Eric there are no words. 333, BB, 333. Davey James, Kirsten, and Douggie, you love and you share your energy and time so generously. Cole, Steve, Julie, Karen, you have been such amazing support people during this process. Kristen, our over forty years of friendship has meant more to me than you will ever know. I appreciate the laughter and the tears that we have shared, and I hope that I make you proud. You make me proud every day.

To Dr. Patsy Maloney, thanks for your mentorship and your encouragement. You saw the teacher in me and your faith in me stuns me to this day. To my Pacific Lutheran University family, thank you for cheering me on through every step of the PhD educational process. I look forward to being part of the PLU SoN team for a long time. To my Annie Wright Schools family, it amazes me how you always show up right when I need you most. I am so grateful for growing up in a place that values the individual, values community, and teaches its students to think, to

dream, and to work hard. Thank you also to MultiCare Celebrate Seniority for your support of this project.

Who knew when this program started how important my PhD cohort would become to me! Together we discussed all things research and philosophy and nursing. We prepped for the qualifying exam, attended each other’s proposals and defenses, watched each other’s families grow and change, all while staying focused on the goal of becoming nurse scientists. I appreciate each of you.

There are so many more people that I would like to acknowledge but know that I would invariably leave people out. Please know that each of you has made a difference in my life and in my work. You listened and encouraged and believed in me. I will forever appreciate the love, the constructive feedback, and the unwavering support.

Thank you, thank you, thank you.

Abstract

In the older adult population, people do not consistently die where or in a manner they envision, and the words used when discussing end-of-life (EOL) preferences can influence how one dies. One of the terms most used to indicate a person's wishes for no heroic measures during EOL decision making is Do Not Resuscitate (DNR). Another term in the EOL literature is Allow Natural Death (AND); however, AND is underexamined and not utilized consistently in the healthcare industry. The purpose of this study was to explore the perceptions of adults ages 65 and older who are not terminally ill regarding the meaning of the term DNR as compared to the term AND. To do this, 24 individual semi-structured interviews were conducted via Zoom. Participants were interviewed to 1) determine how older adults describe their understanding of the terms AND and DNR, and 2) identify preference for AND or DNR among older adults. The data from this qualitative descriptive study generated four themes: 1) Control; 2) Emergency versus Calm; 3) Communication is Key; and 4) Quality of Life. The results of this study inform patients, loved ones, and healthcare professionals about how older adults understand DNR and AND to be similar and different, and provide insight into which term may be preferred in which EOL settings. Future research is indicated, including introducing EOL discussions into high school curriculums, and to conduct a similar study focused on people of color as well as people from different faith perspectives.

Keywords: allow natural death, do not resuscitate, older adults, end-of-life decision making

Table of Contents

Chapter One

Introduction

Communication impacts care at the end of a person's life, and effective communication can help ensure people experience a peaceful death (Rafferty et al., 2016). More specifically, while people typically envision dying in a calm and quiet manner, foregoing heroic interventions (Ko et al., 2013; Lindqvist & Tishelman, 2015), this wish is often not communicated or understood by healthcare providers or family. Given that older adults (65 years and older) accounted for 73% of deaths in the United States in 2016, of which the majority were due to chronic illness (CDC, 2017), this population may be influenced the most by language used in EOL decision-making conversations. In order to act in concordance with the wishes of older people who are dying, the healthcare system must empower patients and healthcare professionals to communicate effectively and in a way that minimizes distress for all involved (Hinderer, 2012; Lief et al., 2018; Rafferty et al., 2016; Wright et al., 2010). There has been little research done on how people perceive the meanings of end-of-life (EOL) terminology. Exploring these perceptions may ultimately lead to more effective EOL communication among patients, their families, and healthcare providers.

The language currently used to communicate a desire for no heroic measures utilizes the words "do not" and therefore, does not focus on what *will* be done. More specifically, the use of negation in the term "Do Not Resuscitate" (DNR) in EOL decision-making conversations may contribute to the confusion regarding the meaning of the terms in actual clinical practice (Baumrucker, 2001; Gibson et al., 2018; Knox & Vereb, 2005; Levin & Coyle, 2015; Mack et al., 2010; Stecher, 2008). The terminology of DNR is primarily utilized in the hospital but is also incorporated into the majority of Physician Orders for Life-Sustaining Treatment (POLST) forms which are a community-based EOL communication tool (Chen & Azueta, 2017).

In order to proactively address challenges such as these, the Institute of Medicine (IOM) released a brief in September 2014, followed by a full report in 2015, entitled “Dying in America: Improving Quality and Honoring Preferences Near the End of Life.” The IOM called for the healthcare system to be person-centered in its delivery of care, with increased accessibility to resources at the end of life and for more communication between the provider and the patient, including the more consistent use of advance care planning tools. Specifically, the report noted “ways to improve shared decision making” as an area for further research (Institute of Medicine [IOM], 2015).

In order to enhance shared decision-making, this dissertation focused on how the meanings of differing EOL terminologies were perceived by older adults. Establishing this understanding may enhance conversations between patients and their providers and/or family members regarding EOL decisions, which may facilitate improved shared decision-making. In this chapter, the background and significance of this dissertation study will be discussed. Additionally, the purpose of this study, research questions, definitions, and a pertinent theoretical framework will be described.

Background

When people discuss the dying process before death is imminent, dying is frequently envisioned as quiet, calm, and peaceful (Ko et al., 2013; Lindqvist & Tishelman, 2015). People often visualize simply not waking up (Callahan, 1993; Lindqvist & Tishelman, 2015). This pleasant picture differs dramatically from the reality in many cases especially in acute care settings where medical interventions, including heroic measures, are often taken to maintain life

(Fischer et al., 2013). The majority of people indicate prior to hospitalization that they would prefer not to experience any life-sustaining measures, such as ventilator support or cardiopulmonary resuscitation (CPR) (Silveira et al., 2010). Likewise, 56% of people wish to die at home (Higginson et al., 2017), while only 30.5% of people actually died at home in 2016 (CDC, 2017). Though literature has indicated that place of death preferences change depending on the disease trajectory (Dassel et al., 2018), the hospital setting continues to be the least preferred place of death (Higginson et al., 2017). Having an EOL discussion increases the likelihood of a person receiving care consistent with their wishes when dying (Mack et al., 2010).

By convention, the terminology indicating no heroic measures be provided to a patient, allowing them to die naturally, is DNR. If a patient has a standing DNR order documented by a healthcare provider, no CPR will occur in the event the patient stops breathing or their heart stops beating (medlineplus.gov, 2018; Stecher, 2008). If a person wishes to have full interventions should they stop breathing or should their heart stop beating, the doctor will order "Full Code" (Stecher, 2008). Many experts have indicated that the terminology of DNR may be ineffective or concerning because it is negative and is focused on what should not be done (Baumrucker, 2001; Knox & Vereb, 2005; Meyer, n.d.; Stecher, 2008). Language has been shown to affect how people respond to communication (White, 2003). In the framework of EOL decision-making, patients and families may be hesitant to agree to DNR because it focuses on what will not be done (Baumrucker, 2001; Knox & Vereb, 2005; Levin & Coyle, 2015; Meyer, n.d.; Stecher, 2008), whereas AND focuses on what will be done for a patient at the end of life.

The term AND was originally proposed by Reverend Chuck Meyer in the 1990s (www.hospicepatients.org/and.html). An AND order indicates that, if a patient were to stop breathing or their heart to stop beating, the patient would be allowed to die naturally and the care providers would focus on keeping the patient comfortable (Stecher, 2008). A research-based understanding of the concept of AND, particularly as perceived by older adult individuals has not been established, nor has a pervasive adoption of this verbiage in current clinical practice occurred (Baumrucker, 2001; Stecher, 2008). There is a lack of studies in the literature focusing on the meaning of AND from the perspective of the individual patient.

Despite the lack of research focused on the use of AND in clinical settings or on the understanding of the meaning of AND, the terminology has been utilized by some states in EOL paperwork. In the United States, 43 states use “Physician Orders for Life-Sustaining Treatment” (POLST) forms as a way to communicate patient wishes at the end of life (POLST.org, 2018) and AND terminology has been incorporated into many of these forms. This form, which may have different names in different states, is completed by a provider and a patient, and is ideally initiated when a patient is diagnosed with a chronic or serious illness (POLST.org, 2018). It acts as a provider’s order for EOL interventions and can transfer between facilities and settings. While 28 states in the United States use AND terminology that is contained in some way on the POLST form, only four of those states use AND solely in their version of the POLST form (Chen & Azueta, 2017). Twenty-four states use AND alongside DNR in the POLST form. The remaining 22 states either do not use AND in their POLST form, or have no POLST program (Chen & Azueta, 2017). A lack of uniformity in how AND is defined has led to confusion on the part of healthcare providers and has contributed to inconsistent usage of the term (Chen & Azueta, 2017).

Significance

When a person does not die in the manner in which they would prefer, distress for the person, the person's family, and healthcare professionals often increases (Hinderer, 2012; Rafferty et al., 2016; Wright et al., 2010). While research has shown that healthcare providers find conversations surrounding death awkward and, as a result, often avoid these (e.g. McCarthy et al, 2008; Wright et al., 2010), there is evidence to suggest that providers prefer to use AND over DNR when they do engage in EOL discussions with patients and family members (Jones et al., 2008; Venneman et al., 2008; Wittmann-Price & Celia, 2010).

To address the dissonance between where and how people wish to die and where and how they actually experience death, using the terminology "Allow Natural Death" (AND) instead of the current standard terminology of "Do Not Resuscitate" (DNR) may make the decision-making process much less stressful (Baumrucker, 2001; Gibson et al., 2018; Knox & Vereb, 2005; Levin & Coyle, 2015; Meyer, n.d.; Stecher, 2008; Taft, 2010). Exploring the perceptions of older adults about their understanding of the meaning of the term AND versus DNR may not only provide a more thorough understanding of individuals' preferences for EOL decision-making terminology but may also serve to inform healthcare professionals about the most beneficial verbiage to employ with patients and families during EOL decision-making conversations. To date, there has been little research conducted to explore the meaning of AND versus DNR from the patients' perspectives. As a first step to addressing this gap in the literature, this dissertation study sought to understand patients' viewpoint on EOL terminology which may in turn facilitate decreased distress for all involved at end of life (Hinderer, 2012; Lief et al., 2018; Rafferty et al., 2016; Wright et al., 2010).

When a person does not die at home or in a way consistent with their wishes, research has shown that patients experience a lesser quality of life at EOL (Hales et al., 2014; Khandelwal et al., 2017; Wright et al., 2010). While not all people wish to die at home, patients often are reported to experience increased pain and decreased comfort when dying in the hospital setting as compared to the information reported by loved ones of people who die in a non-hospital setting (Khandelwal et al., 2017; Wright et al., 2010). In the hospital setting, managing EOL symptoms, for example pain and dyspnea, may not be adequate (Toscani et al., 2005).

In addition to distress, this disconnect between where people would like to die and where they do die has shown to increase the cost of healthcare. The cost of inpatient care more than doubles between ages 66 and 89 before it starts to decline again (Neuman et al., 2015). This leads to an increased financial burden on American society (Joynt et al., 2017). As the United States strives to decrease expenditures in healthcare, a change in EOL decision-making may provide a natural opportunity to increase quality of life for dying people while reducing costs (Baily, 2011; Jennings & Morrisey, 2011; May et al., 2016).

Statement of Problem

There is often ineffective and inconsistent communication surrounding EOL decision-making among patients and their care providers and family members (Carr & Khodyakov, 2007; Gawande, 2014; Long-Sutehall et al., 2011). Current clinical practice has been shown to cause distress in all three parties—patients, families, and healthcare providers (Hinderer, 2010; Rafferty et al., 2016; Wright et al., 2010). Approaches or strategies to decrease the distress in these discussions are needed to allow these conversations to happen more regularly (Callahan, 1993; Gawande, 2014; IOM, 2015). It is currently unknown if older adults (ages 65 and older) understand the meanings of the terms AND and DNR separately, nor is it known whether they understand the similarities and differences between the two terms.

Purpose of Study

The purpose of this study was to explore the perceptions of older adults (ages 65 and older) regarding the meaning of the terms AND and DNR. Gaining these insights may foster patients', families', and medical professionals' ability to determine the most appropriate verbiage to use when discussing EOL decisions with elderly patients.

Research Questions

The two research questions posed by this study are:

1. How do older adults (ages 65 and older) who have not been diagnosed as terminally ill describe their understanding of the terms AND and DNR?
2. Do older adults (ages 65 and older) who have not been diagnosed as terminally ill indicate a preference for AND or DNR?

Assumptions

This study operated on the assumption that participants would be willing to discuss their perceptions of AND and DNR, and that they would propound those views openly in the Zoom interview setting. It was also assumed that participants would be willing to use a computer or device to participate in research remotely.

Definitions

In this dissertation, the following six operational definitions were employed.

End-of-life Decision-making: Making decisions that will affect end-of-life. This process can occur well in advance of actual death or closer to actual end-of-life (Thelen, 2005).

Older Adult: In this study, an older adult is person who is 65 years old or older.

Allow Natural Death (AND): Death will be allowed to occur naturally, with interventions that will be comforting and without any life extending interventions (Stecher, 2008).

Do Not Resuscitate (DNR): A person will not be resuscitated if a life ending event occurs. A person will not receive Cardiopulmonary Resuscitation (CPR) or intubation (Stecher, 2008).

Chronic Illness: A medical diagnosis for a condition which the patient will have to manage for the remainder of life. This illness has no cure, is not immediately life ending but is potentially life altering.

Terminal Illness: A medical diagnosis for an illness that will most likely cause death within six months and for which there is no cure.

Advance Care Planning: The process of addressing end-of-life decision-making prior to actual end-of-life or diagnosis with a terminal illness (Carr, 2012).

Theoretical Framework

The Communication Accommodation Theory (CAT) is a biolinguistic and sociopsychological theory developed by Giles and Coupland (1988). The theory describes the interaction between two individuals within a context. It was designed to help increase understanding of how people alter their speech in order to communicate with others, as well as how others perceive those alterations. The authors consider their theory a “basis for sociolinguistic explanation” (Giles et al., 1991). The qualitative descriptive study utilized the labeling strategies component of CAT to guide the analysis of collected data in part, because these labels have been shown to be helpful in categorizing healthcare messages (Ahmed & Bates, 2016; Hehl & McDonald, 2014; Jones et al., 2007; Scott & Caughlin, 2015). Additionally, CAT has been used in empirical studies with the older adult, cognitively intact population (Hehl & McDonald, 2014; Lagacé et al., 2012).

The goal of CAT was initially to characterize the interaction between speakers during spoken communication and it was called “Speech Accommodation Theory”. As the theory developed, it became focused on overall communication, not only spoken communication, and was renamed CAT. All communication according to the theory is set within a context that is shared between two individuals, whether that is the language being used or the situation in which the communication occurs. CAT has been used to guide a number of research studies throughout the last three decades and features prominently in healthcare communication as well as within other fields, such as psychology and linguistics (Giles et al., 1991; Hehl & McDonald, 2014; Jones et al., 2007; Scott & Caughlin, 2015).

According to CAT, within a context the speaker will make a statement that may be communicated in ways that are convergent or divergent. (Coupland & Giles, 1988). When a statement is made in a convergent manner, it is intended to bring the speaker figuratively closer to the receiver. Divergent communication on the other hand, creates space between the speaker and the receiver. The speaker has objectives for the communication, called “interactional goals”, which may be to “promote social approval, promote communication efficiency, or promote distinctiveness” (p. 177, Coupland & Giles, 1988). The speaker may use convergent or divergent messaging in order to communicate a desired meaning. The message is encoded biolinguistically by the speaker through accommodation strategies, for example changing tone of voice or varying the formality of the language used. Once the speaker has communicated, the receiver then decodes the speaker’s message by evaluating it through their personal understanding of the context. Next, the receiver labels the message as accommodative, over-accommodative, or under-accommodative. The receiver then attributes intent to the speaker’s message and evaluates the message as positive or negative.

The dissertation study utilized qualitative descriptive methodology for data collection and Sort & Sift analysis (Maietta et al., 2017). The researcher anticipated employing tenets of CAT when identifying themes within the data. In the study, the primary category of CAT utilized influenced the labeling strategies. In labeling, the recipient of a communication subconsciously labels the information received into one of three categories: accommodative, over-accommodative, or under-accommodative (Coupland & Giles, 1988). If a message is accommodative, the perceiver interprets the message as having been given in a way that is understandable and that accommodates the receiver's understanding effectively. In the setting of this study, a participant may have expressed that the terminology conveyed the message of no heroic interventions in a way they could understand and that was supportive in nature. When a message is interpreted as over-accommodative, the receiver may assume the speaker oversimplified the communication and made it overly descriptive which may be perceived negatively. In this study, the participant may have perceived that the terminology is oversimplifying a concept. The participant may have felt that the terminology implied they are not capable of understanding the concept in its original form, leaving them to feel insulted and ultimately disconnected from the communication. Finally, if the speaker is perceived as under-accommodative, the receiver may feel as if the speaker is speaking over the receiver. For example, a study participant may have shared that the terminology presented is not something they comprehend. The participant may have felt vulnerable to being perceived as incompetent if they are unable to understand the information being presented. Therefore, under-accommodative communication may also have a negative impact on the relationship as well as the communication itself.

Summary

Communication impacts care at the end of life (Rafferty et al., 2016). When death preferences are not honored, patients, families, and healthcare providers may experience emotional upset and healthcare costs for unwanted or futile interventions may soar (IOM, 2014; Callahan, 1993; Gawande, 2014). In the qualitative descriptive study, using CAT offered the opportunity to examine how older adult participants understand, receive, and interpret the meaning of DNR and AND in terms of Coupland and Giles' (1988) accommodative, over-accommodative (too simple), or under-accommodative (too complex) communication categories. This study explored the perceptions of older adults regarding their understanding of the meaning of AND and DNR, as well as how the terms are perceived to be different by using labeling strategies of CAT to analyze data collected individual interviews via Zoom.

Chapter 2: Review of the Literature

Introduction

The purpose of this chapter is to review the literature investigating the use of “Allow Natural Death” (AND) and “Do Not Resuscitate” (DNR). Currently, there is a paucity of research focusing on the perceived meaning of AND across healthcare populations, whereas the term DNR and its perceived meaning have received relatively greater attention in the research literature. While the use of AND is considered policy in some states (POLST.org, 2018), it is not commonly used terminology in the United States in general; consequently, there has been minimal research conducted that has focused on this terminology. Because communication impacts care at end of life (Rafferty et al., 2016) and because of emotional upset when EOL preferences are not understood or honored (IOM, 2014; Callahan, 1993; Gawande, 2014), literature regarding both AND and DNR will be explored. This chapter will offer a synthesis and analysis of 20 empirical studies in the areas of AND and DNR.

Review of the literature

Searches were completed in three databases, specifically ProQuest PsycINFO, CINAHL, and Pubmed, using the key search term *allow natural death*. While no date range was specified in each search, the earliest empirical study was published in 2008. The dates of the AND articles range from 2008 to 2018. The search in Pubmed yielded one article, the CINAHL search yielded 21 articles, and ProQuest PsychInfo resulted in four articles. The articles were reviewed to determine if they were empirically based and relevant to the problem, purpose, and research questions of this dissertation study. Duplicate studies were eliminated. Based on this analysis, seven published studies and one dissertation study focused on AND were included for review (Barnato & Arnold, 2013; Fairlie, 2015; Fan et al., 2018; Jones et al., 2008; Miljkovic et al., 2015; Patel et al., 2016; Venneman et al., 2008; Wittmann-Price & Celia, 2010). Of the eight AND studies, seven were conducted in the USA and one was conducted in Taiwan (Fan et al., 2018).

Additional searches using the same three databases were completed using the key search terms of *do not resuscitate* and *meaning*. Articles reviewed were limited to those dated 1994 and later because the older literature was minimal and challenging to obtain. The dates of the DNR articles range from 1994 to 2018. The search in ProQuest resulted in 11 articles, the search in PubMed resulted in 26 articles, and the CINAHL search resulted in 19 articles. Duplicates were eliminated as were articles that were not in English, not empirically based, and/or not relevant to the study, for example not focused on the meaning of DNR. Based on these criteria, a total of 12 empirical articles focusing on the meaning of DNR were found to be appropriate for review (Abu-Ghori et al., 2016; Alrimawi et al., 2018; Bellini & Damaro, 2009; Henneman et al., 1994; Eliott & Olver, 2003; Jezewski, 1994; Jezewski & Finnell, 1998; Mirarchi et al., 2017; Robinson et al., 2012; Rohrer et al., 2006; Sanderson et al., 2013; Sullivan et al., 2004). Of these 12 studies, nine were conducted in the USA, one in Canada (Robinson et al., 2012), one in Palestine (Alrimawi et al., 2018), one in Saudi Arabia (Abu-Ghori et al., 2016) and one in Australia (Eliott & Olver, 2003).

Of the entire body of literature reviewed, a total of eight empirical studies comparing the use of the term AND versus DNR and 12 empirical studies solely focusing on the meaning of DNR specifically will be discussed. Within the AND and DNR literature, four similar groupings of participants were identified: healthcare providers, surrogate decision makers, patients, and “healthy adults”. The “healthy adults” grouping consisted of participants who did not report illness and who did not report working in healthcare. These participants were college students or adults recruited from the community in which the study was conducted. In the next section, the AND literature will be reviewed, followed by the DNR literature.

Allow Natural Death Literature

For AND research investigations, a total number of 2,316 study participants across the eight studies were included. These studies will be presented by types of study participants: healthcare providers, surrogate decision makers, ill adults, and healthy adults. The first three studies addressed here focused on medical professionals and their preferences regarding the use of AND as compared to DNR (Jones et al., 2008; Venneman et al., 2008; Wittmann-Price & Celia, 2010).

Healthcare providers. A study by Jones et al. (2008) used a qualitative approach to explore providers' beliefs regarding the terminology of AND and DNR. The study included four open-ended written prompts to healthcare providers (Jones et al., 2008). There were 118 study participants who responded to the open-ended prompts, including 53 physicians, 45 nurses, and 20 healthcare providers in other fields, such as social work, speech therapy, and child life (Jones et al., 2008). Based on the participant responses, two primary themes were identified: Ambiguity and Family-Centered Communication. Despite participant concerns that the term AND itself may be ambiguous, the participating providers indicated that the use of AND enhanced communication with patients and their families, and provided families a feeling of doing, for example, providing comfort, as opposed to withholding, for example, not doing chest compressions. Within the theme of Family-Centered Communication, five sub-themes were identified: "change of focus", "increased ease of approaching family", "discussion-promoting communication", "being proactive", and "family healing" (Jones et al., 2008). Overall, providers recognized the term AND as being potentially helpful in EOL discussions which could lead to less traumatic deaths and better healing for the families.

Venneman et al. (2008) also focused on healthcare providers as did Wittmann-Price and Celia's (2010) research, which was a replication of the Venneman et al. (2008) study. Both studies aimed to determine if changing the title of the DNR order to AND would increase support of an end-of-life order among healthcare providers. Venneman et al. (2008) chose to embed the terms AND and DNR in order sets that were identical, except for their titles, given that physicians communicate actions that they deem best for patients' outcomes through orders in the medical setting. Responses from three groups, nurses, nursing students, and non-nursing students, were analyzed. Each participant read an end-of-life scenario focused on a loved one. Participants were then asked how likely they were to choose an EOL order option after reading the scenario, either AND or DNR. Participants were presented with one EOL order option, AND or DNR, not both. The results of the Venneman et al. (2008) study showed those participants offered the AND order were more likely to endorse the order after reading the EOL scenario (77.19%) versus those offered the DNR order (69.15%) based on the findings from a one-way ANOVA, *F*(685, 1)   12.43, *p*   0.000.

The study by Wittmann-Price and Celia (2010) did not compare the likelihood of healthcare providers endorsing order sets using AND versus DNR; instead, all participants were asked to rate the likelihood of endorsing order sets that used AND after reading the short vignette about a hypothetical loved one that was used in Venneman et al., 2008. Of the 187 study participants, 87 were physicians, 13 were medical students, 72 were employed as nurses and 15 were nursing students (Wittmann-Price & Celia, 2010). Within the physician population, 50% of the participants were female and 50% were male whereas the nurses were 78% female. Another marked difference between the physicians and the nurses was age. Seventy-eight percent of the physicians fell into the age group of 26-40 while only 3% of nurses were in this age group. The results revealed that 83% of the nurses and 78% of physicians surveyed provided responses that they were 75% or greater more likely than not to consent to an AND order for their loved one.

In all three studies (Jones et al., 2008; Venneman et al., 2008; Wittmann-Price & Celia, 2010) which included 870 participants in total, healthcare providers appeared to support the use of AND during EOL discussions. Each study utilized surveys to collect the data. Of these studies, Jones et al., 2008, was the only qualitative study and also was the only study that addressed the perceived meaning of the terms AND and DNR, finding the term AND ambiguous but family-centered. Two studies were conducted in Texas (Jones et al., 2008; Venneman et al., 2008) which may limit generalizability however the large overall sample size may be a strength of these studies (Jones et al., 2008; Venneman et al., 2008; Wittmann-Price & Celia, 2010).

Surrogate decision makers. The second group of study participants represented in the AND literature was people who reported being surrogate decision makers, which totaled 829 participants across four studies (Barnato & Arnold, 2013; Fairlie, 2015; Patel et al., 2016; Venneman et al., 2008). In order to assess the effect of surrogate decision makers' emotional state on EOL decision-making after discussions with a physician, Barnato and Arnold (2013) and Patel et al. (2016) both conducted quantitative simulation-based studies using 5x2 between subject randomized factorial designs. The samples included a total of 472 individuals (n 252 and n 220 respectively) who were older than 35 and who reported having been in the role of healthcare decision maker for a spouse or parent.

In these studies (Barnato & Arnold, 2013; Patel et al., 2016), the participants, who were in the role of surrogate decision makers, were randomized for emotional arousal by either being shown the picture they had provided of their loved one and going through two 30-second visualization sequences focused on the loved one, or being shown a picture of a park and going through two 30-second visualization sequences that were not focused on a loved one. Study participants were also randomized for physician communication behavior; the physician actor either responded to the participant using scripted phrases that showed personal caring and involvement or did not use the scripted phrases. Additionally, each study participant was randomly assigned decision options that were “framed” in three different ways, meaning that the scenario was manipulated in such a way that one of two messages was conveyed for each of the three variables. Specifically, each study participant was presented with the same scenario however there were three possible variations: 1) the alternative to cardiopulmonary resuscitation (CPR) as being a) AND, or b) DNR; 2) the decision being a) the patient’s, or b) the surrogate’s; and 3) a) CPR being presented as the social norm, or b) no CPR being presented as the social norm.

The results of both studies showed that emotional arousal or lack thereof did not have a significant effect on the choice for CPR, nor did the physician use of a script for attending to emotions (Barnato & Arnold, 2013; Patel et al., 2016). Framing the alternative to CPR as AND did however influence more study participants to choose AND for their loved one in the scenario; DNR as the alternative resulted in 61% choosing CPR as compared to 49% for those offered AND as the alternative to CPR (OR, 0.58 [95% CI, 0.35 0.96]) (Barnato & Arnold, 2013). According to the Barnato and Arnold (2013), their study provided the first empirical data showing that the use of the terminology of AND influences decision-making in hypothetical scenarios.

Patel et al. (2016) explored the influence of the terms AND and DNR on optimism bias which is defined by the authors as the subject's perception of how likely the hypothetical terminally ill patient was to live after having the EOL discussion with the physician. The population and structure of this study was identical to Barnato and Arnold (2013) with the exception of the outcomes measured. If the participant predicted the likelihood of survival as higher than the likelihood stated by the doctor, optimism bias was considered to be present (Patel et al., 2016). Findings indicated that using AND instead of DNR significantly decreased optimism bias (24% vs 37%, p .035). The results of Patel et al. (2016) supported the results of Barnato and Arnold (2013) in that they showed the use of AND does influence EOL decision-making in hypothetical scenarios.

To determine if changing the title of a DNR order to AND would increase support of the order by people with no healthcare background, 123 non-nursing students who represented the population with *no healthcare background* and who were asked to consider a scenario from the perspective of a surrogate decision makers were included in the Venneman et al. (2008) study. The majority of this group (56%) were under the age of 26, suggesting that the study participants who represented the surrogate decision makers were not reflective of those typically involved in EOL decision-making conversations (Venneman et al., 2008). That being said, this group of non-nursing students preferred the use of AND (60.69%).

Fairlie (2015) conducted a quantitative study for her dissertation work to investigate the relationship between EOL terminologies and decisional conflict in surrogate decision makers. The study focused on the terminology of AND as compared to DNR. In the study, Fairlie utilized the Decisional Conflict Scale (DCS) to measure the degree of internal conflict the study participants experienced in decision making with the two terms of AND and DNR. Study participants were asked to identify an adult family member who was not their child, and then asked to read a short EOL scenario created by Fairlie, inserting their loved one's name as the subject of the discussion, and were offered the choice of having the patient receive full interventions or either AND or DNR. Study participants were randomized to receive either AND or DNR; study participants were not offered both of these EOL options.

Study participants were also provided a Patient Decision Aid (PtDA) tool that explained CPR and its effects on a patient, some statistics on how effective CPR was, and some questions to ask oneself while making the decision (Fairlie, 2015). These PtDA tools, created by Fairlie, used either AND or DNR in the explanation so that they were consistent with each subject's questionnaire and scenario. After reading the scenario and reviewing the PtDA tool, study participants were asked if they would agree to signing an AND or DNR form (Fairlie, 2015). The study participants also completed the DCS to determine if they experienced decisional conflict upon making their decision in the hypothetical scenario.

The findings generated by Fairlie's dissertation research (2015) indicated no significant difference in the DCS scores between the terms of DNR and AND. In contrast, study participants who were given the AND option were eight times more likely to sign a document than those who were offered DNR as the EOL option ($p < 0.001$). In addition, AND study participants were more likely to be satisfied with their decision. Participants who were offered the DNR version of the order expressed less certainty in their decision ($p < 0.0001$).

Fairlie (2015) concluded that the terminology of AND positively impacts the comfort level of surrogate decision makers when they choose that end-of-life option. In addition, the results showed that people offered AND after reading the vignette were more likely to choose the AND option, and therefore the terminology itself impacted decision making in hypothetical scenarios. Fairlie (2015) attributed some of the comfort level when choosing both AND or DNR to the use of a PtDA in the study.

Within the surrogate decision maker grouping, Barnato and Arnold (2013) and Patel et al. (2016) found that using the terminology of AND instead of DNR significantly impacted the EOL decision making in hypothetical scenarios. Study participants in both were much more likely to endorse the AND orders than orders using DNR terminology. The surrogate decision maker population in Venneman et al. (2008) consisted of college students similar in demographics to nursing students involved in the study and may not have been representative of the population typically involved with EOL decision making. Of these studies, only Fairlie (2015) focused specifically on older adults. Fairlie (2015) also showed that decision to endorse an EOL order was significantly impacted by use of AND terminology. It is important to note that all of these studies were conducted using hypothetical situations and provide no evidence that the terminology would impact actual EOL decision-making (Barnato & Arnold, 2013; Fairlie, 2015; Patel et al., 2016; Venneman, 2008). The lack of data on how terminology impacts decision-making in real situations remains a significant gap in the literature. Additionally, while these three quantitative studies provide evidence that use of AND may be beneficial during EOL decision making, the studies do not explore the meaning of the terminology itself.

Patients. Of the AND literature, only one study was conducted focusing on patients and 93 terminally ill oncology patients participated (Miljkovic et al., 2015). Miljkovic et al. (2015) examined how patients with advanced cancer, who were identified by their physicians as being terminally ill, perceived their prognosis and end-of-life (EOL) care, and if they would choose AND versus full code or DNR versus full code in three hypothetical scenarios. Study participants were randomly assigned to different groups; one group was offered the choices of “AND” or “full code” (n 46), and the other group was offered “DNR” and “full code” (n 47). Three hypothetical scenarios were presented to each participant, and participants indicated if they would choose to be full code or the presented alternative (AND or DNR) in each scenario. The scenarios predicted life expectancy as being one year, six months, and one month.

According to Miljkovic et al. (2015), statistical analyses showed no significant difference between participants choosing either AND or DNR ($p > 0.54$), depending on which alternative they were offered. Another outcome of this quantitative descriptive study showed that only 39% of the participants considered themselves to be terminally ill despite all of them fitting this description. In other words, 61% of the participants did not consider themselves within at least one year of death even though their doctor did. Although not a stated aim of the study, the contradiction between physician and patient understanding of the same illness may carry importance for future research because it may indicate that there may be some inadequacies in healthcare providers and patient communication. Despite being terminally ill, these study participants were making decisions for hypothetical situations and not for their own actual care. There is a lack of real-world testing as to the impact of EOL terminology in actual EOL decision making situations and the resulting outcomes of care.

Healthy adults. The final subgroup identified in the AND studies was healthy adults. There were 524 healthy adults surveyed by Fan, Wang, and Lin (2018). The purpose of the study by Fan et al. (2018) was to explore the effects of a DNR order title that included AND terminology. Additionally, the study explored the barriers to communication and the information needed by the participants to make a decision. This quantitative study was a cross-sectional survey of healthy adults who were between the ages of 20 and 88 with a mean age of 39.19, and who were recruited in the community and from a family practice clinic in East Taiwan. Using a paper survey, participants were provided a scenario in which an 80-year-old male with lung cancer scenarios was now found to have metastases to the bones and brain. The relationship of the hypothetical patient to the study participants was not specified in the study. This scenario was followed by a series of questions asked to determine preference for AND versus DNR and to determine the types of information study participants wanted in order to make the EOL decision**.** Participants were significantly more likely to agree to end-of-life orders when AND was presented instead of DNR (t -4.51, $p < 0.001$). Additionally, it was found that participants wanted information regarding remaining life expectancy and the hypothetical patient's prognosis when making EOL decisions.

This quantitative study (Fan et al, 2018) indicates that healthy adults may prefer the use of AND instead of DNR when having EOL decision making discussions. A strength of Fan et al. (2018) was the large number of study participants which represented a wide age range. This study did not focus specifically on older adults nor did it explore the meaning of AND. Fan et al. (2018) did explore what information healthy adults may want to assist in decision making, for example prognosis and life expectancy, using quantitative methodology.

Summary. In summary, four themes emerged from the AND research: 1) AND appears to be considered a more acceptable option by healthcare providers, surrogate decision makers, and healthy adults than DNR in all studies including these populations (Barnato & Arnold, 2013; Fan et al., 2018; Jones et al., 2008; Patel et al., 2016; Fairlie, 2015; Venneman et al., 2008; Wittmann-Price & Celia, 2010). However, Miljkovic et al. (2015) found that the use of AND and DNR did not influence decision making for terminally ill cancer patients. 2) AND terminology was considered a clearer way to communicate regarding end-of-life decision making to patients and families than DNR by healthcare professionals (Jones et al., 2008; Venneman et al., 2008;

Wittmann-Price & Celia, 2010). Only Jones et al., 2008, discussed meaning and concluded that the meaning of AND terminology may be ambiguous. It is unknown how patients, family members, and healthcare providers may define AND. 3) All of the studies utilized hypothetical situations for decision making. The only study that was most similar to a non-hypothetical context was Miljkovic et al. (2015) because the patients were terminally ill, and this study found that the difference in terminology did not affect the outcomes. 4) There may be a relationship between context and meaning. According to Patel et al. (2016), the use of AND decreased optimism bias which may indicate that the study participants interpret information provided to them differently when presented through the lens of AND being the EOL option. Fan et al. (2018) identified that study participants wanted information regarding life expectancy and prognosis before making a decision in a hypothetical scenario. This may suggest that a person's decisions are impacted by the actual information and not solely the verbiage used in the discussion, for example AND. However, Miljkovic and colleagues (2015) found that varying life expectancies from 1 month to 1 year did not change participants' choices. This indicates that the context of a situation matters when EOL decisions are made and that those decisions may be impacted both by perceived meaning of the terminology as well as the context in which the decision occurs. These themes support the need for research focusing on the understanding of the meaning of EOL terminology and how that may change with context. Next, the DNR literature will be considered.

Do Not Resuscitate Literature

In the DNR literature reviewed, a total of 1,636 participants were queried as to their understanding of the meaning of DNR. Similar to the AND literature, the DNR literature can be grouped by population: healthcare professionals, patients, and healthy adults. Surrogate decision makers were not identified as a population within the reviewed DNR literature however there was one DNR study that included caregivers (Rohrer et al., 2006). A separate category was not created for this population and findings regarding caregivers will be included within the healthy adult section.

Healthcare professionals. A total of 606 healthcare professionals participated across seven studies focused on the meaning of DNR (Abu-Ghori et al., 2016; Bellini & Damaro, 2009; Henneman et al., 1994; Jezewski, 1994; Jezewski & Finnell, 1998; Mirarchi et al., 2017; Sanderson et al., 2013). Bellini and Damaro (2009) and Mirarchi et al. (2017) reported a lack of consistent understanding of DNR by healthcare providers. Mirarchi et al. (2017) surveyed 137 emergency medical services (EMS) providers in order to assess which form of communication would best ensure a patient's wishes would be honored: POLST forms and/or living wills, *or* those items in combination with a video message. The study participants were presented with nine scenarios and asked to determine whether the hypothetical patient was a DNR or full code for each scenario. Of the 137 study participants, 70 received only the documents with the scenarios and 67 received the documents and the video message. The results suggested that while the video messaging helped support the patient wishes identified in the POLST forms and living wills, there was very little clarity or standardization in the meaning of the forms as reported by the EMS providers.

Bellini and Damaro (2009) found wide variation in the understanding of DNR among 68 NICU nurses who were surveyed. In this comparative descriptive study which measured knowledge, attitudes, and the practice of study participants, only 24% of NICU RNs identified DNR as meaning no CPR. When nurses were more experienced, an enhanced understanding of DNR was identified, for example in practice, knowledge, and beliefs. More education did not have the same positive impact on the understanding of DNR as experience did. These two studies elucidate the inconsistencies of the understandings of DNR within the healthcare population itself.

While the meaning of DNR in practice may be inconsistent across healthcare providers, those who participated in the research reviewed for this dissertation study indicated that provider priorities shift with the placement of a DNR order. More specifically, according to the results of two quantitative studies of healthcare providers (Henneman et al., 1994; Sanderson et al., 2013), the course of care typically changes after the placement of a DNR order, meaning that interventions other than CPR or intubation may not be provided.

To compare the attitudes of nurses regarding care provided for critically ill patients when a DNR order is present as compared to when it is not present, Henneman et al. (1994) surveyed 80 critical care RNs using two nearly identical scenarios. The only difference between the two scenarios was that one no code status included for the hypothetical patient and the other specified a DNR order being in place. The participants were then asked to rate how likely they were to provide 20 different nursing interventions for that patient using a Likert scale. When the DNR order was in place, nurses were much less likely to report changes to the doctor or to do regular physiological monitoring. When a DNR order was in place, nurses were more likely to conduct spiritual assessments and similar psychosocial work.

Sanderson et al. (2013) surveyed 107 physicians and 159 nurses who practiced in an acute care pediatric setting with the goal of determining clinicians' understanding of DNR. The potential study participants received an email invitation to participate in the 148-item web-based survey. The items on the survey focused on attitudes and behaviors surrounding EOL discussions and resuscitation orders. Most of these pediatric healthcare professionals (66.9%) defined DNR to mean not providing resuscitation in the event of a cardiac or pulmonary arrest. The remaining 33.1% of study participants understood DNR to be the point at which treatments are limited, not only in resuscitation efforts. More broadly, 85% believed that overall care changed after the placement of a DNR order. These participants indicated that the focus of care transitioned to keeping the patient comfortable, possibly including the limitation of care or withdrawal of life support. The vast majority of healthcare providers who participated (97.1%) did not believe that a DNR order indicated giving up on or abandoning the patient.

Multiple studies indicated the amount of care provided by healthcare professionals was consistent after a DNR was placed but that the type of care provided shifted (Abu-Ghori et al., 2016; Jezewski, 1994; Jezewski & Finnell, 1998). Abu-Ghori et al. (2016) conducted a qualitative descriptive study in Saudi Arabia using reflective journaling to describe the workflow of RNs after the placement of a DNR order. Study participants were trained in journaling methods and then asked to reflectively journal for four to six weeks. The participants were allowed to journal in a private location of their choosing in order to ensure they felt safe. Once journaling was complete, the researchers systematically analyzed the data in order to identify themes within the data. Three themes were identified in this study: “exhausted medical treatment”; “continuity of nursing care”; and “cultural considerations in nursing care” (Abu-Ghori et al., 2016). Within the second theme of this study, 26 RNs reported that their workload remained consistent after a DNR order was placed, but that the work following this order was more focused on emotional support.

In a grounded theory study, Jezewski (1994) conducted semi-structured one-on-one interviews in order to better understand the discomfort that occurs in consenting a patient for the DNR orders as well as how nurses manage these situations. Twenty-two critical care nurses from a variety of settings were interviewed. Results showed that nurses consider themselves “culture brokers” because they help bridge the medical and non-medical cultures. In other words, nurses assist families and patients in understanding the meaning of DNR and what care looks like once a DNR order is placed.

Similarly, Jezewski and Finnell (1998) conducted a grounded theory study to identify the experiences of oncology nurses during the DNR consent process. Twenty-one oncology RNs were interviewed in semi-structured one-on-one interviews. From the data, two themes were identified: a) patients, families, and care providers had different understandings of the DNR terminology, and b) the most tension occurred when the different players did not agree on the meaning of DNR. The researchers concluded that the lack of shared meaning contributed immensely to conflict within the DNR consenting process.

Of these seven studies, four were conducted using quantitative methodology (Bellini & Damaro, 2009; Henneman et al., 1994; Mirarchi et al., 2017; Sanderson et al., 2013) and three were conducted utilizing qualitative methodology (Abu-Ghori et al., 2016; Jezewski, 1994; Jezewski & Finnell, 1998). Six studies were conducted in the United States (Bellini & Damaro, 2009; Henneman et al., 1994; Jezewski, 1994; Jezewski & Finnell, 1998; Mirarchi et al., 2017; Sanderson et al., 2013) and one was conducted in Saudi Arabia (Abu-Ghori et al., 2016). Five of the studies focused on nurses as study participants (Abu-Ghori et al., 2016; Bellini & Damaro, 2009; Henneman et al., 1994; Jezewski, 1994; Jezewski & Finnell, 1998) while only two focused on healthcare providers other than nurses, for example doctors and EMS workers (Mirarchi et al., 2017; Sanderson et al., 2013). Nurses reported that nursing work becomes more focused on providing emotional support and addressing psychosocial aspects of caring, for example spiritual assessments, when a DNR was in place (Abu-Ghori et al., 2016; Henneman et al., 1994;

Jezewski, 1994; Jezewski & Finnell, 1998). While these studies did not directly address the meaning of DNR, they all demonstrated that nurses were involved with care for these patients regardless of code status and that patients who were transitioned to DNR continued to receive care similar to the amount they received prior to the code status change.

Patients. Three studies focused on the perceived meaning of DNR from the perspective of oncology patients (n 345), (Eliott & Olver, 2003; Rohrer et al., 2006; Sullivan et al., 2004). Two of the studies utilized quantitative methodology (Rohrer et al., 2006; Sullivan et al., 2004) and one leveraged a qualitative approach (Eliott & Olver, 2003).

Rohrer et al. (2006) conducted research to determine the preferences of family members and patients with regards to DNR orders as well as to assess their understanding of DNR orders. In this study, 193 people who had experienced or were experiencing a cancer diagnosis received a survey in which they were asked what their understanding of DNR was and were provided two definitions: a) “Do not pump on my chest if my hearts stops and put me on the ventilator just to keep me alive” and b) “Do not do anything to me if my hearts stops even if the cause is due to a treatable condition.” (p872-873). Of these two definitions, Rohrer et al. (2006) identified the second option as the *correct* definition of DNR. This was followed by two scenarios for which they were asked to choose DNR or full code. The results showed that 34% of participants shared the same understanding of DNR as the researchers. When asked if they would want to be DNR status if they were expected to be deceased within six months, study participants understanding of DNR was not correlated to their preferences. Study participants were then asked if they would want to be resuscitated if they had 30% chance of being cured and living longer than six months. Of those who responded positively, 70% did not have the same understanding of the meaning of DNR as defined by the researchers. The researchers concluded that, due to a lack of understanding regarding the meaning of DNR, a large number of cancer patients may be at risk of choosing the code status which was actually the opposite of their EOL wishes.

Sullivan et al. (2004) conducted a quantitative study to better understand study participants beliefs about DNR and how that is impacted by religiosity. This survey was conducted with 48 adult oncology patients in New York. After signing the consent form, study participants completed the survey. The results showed that, while 75% of cancer patients believed they understood the meaning of DNR (Sullivan et al., 2004), only 32% actually understood the meaning of DNR as defined by Sullivan et al. (2004). No significant differences were found related to different religious backgrounds.

Eliott and Olver (2003) supported these findings in their qualitative study which revealed that people have varying understanding of what DNR means. There were 23 study participants who were diagnosed with cancer but who were not actively dying. A female clinical psychologist interviewed the study participants in a one-to-one setting using open ended questions. According to Eliott and Olver (2003), while participants' definitions of DNR varied, they were able to identify common themes. For example, the one theme that emerged was "that medical attempts to ensure continuation of life are undesirable and the patient's subsequent death is desirable" (Eliott & Olver, 2003, p. 102). Other themes that emerged from this research included that DNR means that life will not be prolonged, that a patient will not be "brought back", and that DNR is instrumental in preventing vain resuscitation attempts.

Of the patient-focused studies, in which all study participants were cancer patients, two used quantitative methodology and were conducted in the United States (Rohrer et al., 2006; Sullivan et al., 2004). Only one study utilized qualitative methodology, which was conducted in Australia (Eliott & Olver, 2003). There were no studies found that focused specifically on patients who had conditions other than cancer. Overall, these three studies consistently demonstrated that there was no single shared understanding of the meaning of DNR among cancer patients (Eliott & Olver, 2003; Rohrer et al., 2006; Sullivan et al., 2004).

Healthy adults. In three studies, 610 adults with a variety of backgrounds, who did not report having an illness, were queried as to their understanding of the meaning of DNR (Alrimawi et al., 2018; Robinson et al., 2012; Rohrer et al., 2006). Of those who participated in these studies, the majority identified themselves as being familiar with the term DNR or aware of its meaning.

Alrimawi et al. (2018) conducted a qualitative descriptive study set in Palestine to explore Palestinian understanding of the DNR concept. Fifty adult participants over the age of 25 were invited to participate in one-to-one semi-structured interviews which were conducted in study participants' homes. Of the 30 who responded, 24 were interviewed at which point data saturation was achieved. Similar to study participants in Rohrer et al. (2006), participants were identified as having a lack of understanding regarding the meaning of DNR. A majority of the study participants believed that DNR was the same concept as removal of life-sustaining devices. Additionally, many participants felt that the Muslim religion would consider DNR the equivalent of murder. While the study set in Palestine may represent a culture quite different to that of the United States, the study supports that people may lack an understanding of the meaning of DNR similar to that of the researchers and this could impact the outcomes of EOL care.

Similarly, Robinson et al. (2012) surveyed 386 people over 40 years old who were visiting their primary care provider (PCP) for routine services in order to better understand outpatient experiences with DNR and their preferences regarding DNR discussions. Front desk employees offered the survey to outpatients as they checked in for an appointment. After completing the demographic section, study participants were asked to identify if they were familiar with the term DNR or not. Based on their answer of yes or no, they were referred to different pages within the survey. Those who had indicated not being familiar with the term were provided with a definition of DNR which was “A do-not-resuscitate order means that a person would prefer to die a natural death; i.e., if their heart stops beating, they do not wish for medical personnel to try and save them using CPR (cardiopulmonary resuscitation)” (p.231). The survey then went on to ask when, where and with whom all participants would want to discuss DNR. Results showed that 86% of these participants identified being familiar with the term DNR and 86% said they would like to have code status conversations with a PCP. In stark contrast, only 8% reported actually having EOL discussions with a provider.

While Robinson et al. (2012) identified that participants did not report discussing EOL decisions with a provider, Rohrer et al. (2006) found that only 34% of people understood the meaning of DNR to be consistent with the researchers’ understanding of DNR in a group of 84 participants who had never had a cancer diagnosis and 75 participants who are caregivers for cancer patients. In a study designed to determine the preferences of family members and patients with regards to DNR orders as well as to assess their understanding of DNR orders, these participants were provided a survey in which they were asked which of two DNR definitions was correct followed by two scenarios for which they were asked to choose DNR or full code. Researchers concluded that these caregivers and healthy adults were at risk for choosing DNR instead of full code when they had actually intended to choose full code, or vice versa, if they were in a decision-making situation. The lack of consistent shared understanding of the DNR terminology may lead to unwanted outcomes.

Of these three studies, two were conducted using quantitative methodology (Robinson et al., 2012; Rohrer et al., 2006) and one utilized qualitative methodology (Alrimawi et al., 2018). One study was set in Palestine (Alrimawi et al., 2018), one was set in Canada (Robinson et al., 2012), and one was conducted in the United States (Rohrer et al., 2006). While most study participants reported being familiar with the term DNR and thought the topic should be discussed with their PCP, a very low percentage actually had discussed it with their PCP (Robinson et al., 2012). The Palestinian population did not have a clear understanding of the meaning of DNR or thought that DNR was the same as terminal extubation (Alrimawi et al., 2018). The lack of consistency in understanding of DNR as well as the inconsistency of discussing DNR status with a PCP may indicate that a better understanding of the EOL terminology would benefit the greater population.

Summary. In summary, three themes emerged from the DNR literature: 1) The data from the patient and healthy adult populations indicated that this population reports being familiar with DNR terminology yet demonstrated differing interpretations of said terminology (Eliott & Olver, 2003; Robinson et al., 2012; Rohrer et al., 2006; Sullivan et al., 2004). 2) These populations indicated wanting to discuss EOL decisions with their PCP yet a very small proportion reported actually having discussed EOL decisions with their provider (Robinson et al., 2012). 3) Healthcare providers generally held an understanding of the meaning of DNR to indicate that CPR was not appropriate, yet differed in their practical interpretation or implementation of the DNR order (Bellini & Damaro, 2009; Jezewski, 1994; Mirarchi et al., 2017; Sanderson et al., 2013). Widespread inconsistencies in the populations studied regarding the meaning of DNR may indicate that additional research needs to be done in order to gain clarity and thereby enhance EOL conversations.

When comparing the themes identified in the AND literature to those identified in the DNR literature, similarities and differences were identified. Both AND and DNR may be interpreted differently by providers, patients, surrogate decision makers, and healthy adults. The understanding of the meanings of AND and DNR appears to impact the practices of healthcare providers differently. Additionally, the understanding of the meaning of either AND or DNR by patients, surrogate decision makers, and healthy adults as well as the context of the discussion may impact EOL decision making. A difference in the AND and DNR literature is that healthcare providers, surrogate decision makers, and healthy adults appear to consider AND a more acceptable form of terminology than DNR. This was not explored in the DNR literature because the term of AND did not exist prior to the early 2000s. As with the AND literature, many of the DNR studies were conducted using hypothetical contexts. There were three other DNR studies which focused on oncology patients, but they utilized hypothetical contexts when identifying outcomes (Eliott & Olver, 2003; Rohrer et al., 2006; Sullivan et al., 2004).

Gaps in the Literature

There is a paucity of research focused on the use of AND as compared to DNR. Presently, there are only eight empirical articles focused on the term AND, with the two earliest being published in 2008. The majority of these articles focus on study participants who are healthcare providers (Jones et al., 2008; Venneman et al., 2008; Wittmann-Price & Celia, 2010). Two articles recruited study participants who had reported being a surrogate caregiver for a family member (Barnato & Arnold, 2013; Patel et al., 2016) and one study recruited terminally ill cancer patients (Miljkovic et al., 2015). Additionally, one dissertation study (Fairlie, 2015) and one additional study (Fan et al., 2018) were conducted regarding the use of AND as compared to DNR with study participants representing older adults from senior living facilities, senior centers, the greater community and a health care center.

A search of the peer-reviewed literature yielded nearly twice as many DNR articles as the AND-related articles. Of these studies, seven focused on healthcare providers (Abu-Ghori et al., 2016; Bellini & Damaro, 2009; Henneman et al., 1994; Jezewski, 1994; Jezewski & Finnell, 1998; Mirarchi et al., 2017; Sanderson et al., 2013). Three studies focused on healthy adults and their understanding of the meaning of DNR (Alrimawi et al., 2018; Robinson et al., 2012; Rohrer et al., 2006). Another three empirical studies focused on the cancer population to determine how these patients may understand DNR (Eliott & Olver, 2003; Rohrer et al., 2006; Sullivan et al., 2004).

While all of the studies reviewed focused on the use of AND or on the meaning of DNR, only two studies address the actual perception of older adults regarding the term DNR and none addressed the perception of older adults regarding the term AND. A number of studies defined the terms for the study participants (Fairlie, 2015; Venneman et al., 2008; Wittmann-Price & Celia, 2010). Given that there have been eight studies focused on AND since the creation of the term and that the meaning of this terminology to older adults has not been fully studied, additional rigorous research is warranted in order to better understand how the non-healthcare population perceive the meaning of AND. Additionally, there has been minimal research conducted comparing non-healthcare providers' understanding of AND with that of DNR. Of the studies that have compared AND to DNR, none focus on older adults with chronic conditions specifically. Studying this population may facilitate insight into how older adults understand the meaning of the terms AND and DNR during a stage in life when death, while not imminent, is a relevant topic and area of potential concern.

Limitations in the literature may include selection bias in studies focused on healthy adults and reporting bias in the studies focused on the patient population. For example, utilizing college students to represent the general public when researching EOL decision making preferences may not be representative of the adult population who typically makes EOL decisions (Venneman et al., 2008). In the patient population, all of the study participants were diagnosed with cancer. Responses from these participants may have had swayed because the stage of their cancer, for example terminal cancer, may influence their answers (Eliott & Olver, 2003; Miljkovic et al., 2015; Rohrer et al., 2006; Sullivan et al., 2004). Additionally, this may limit the generalizability of the data to other patient populations, for example people with common chronic conditions such as heart failure, arthritis, or respiratory conditions.

A gap in the literature is created by the nature of the AND literature when compared to the DNR literature. Research focused on AND and research focused on the meaning of DNR are remarkedly different in that the majority of the AND research compares the AND terminology to DNR while the DNR literature focused on meaning, description, and outcomes. This may be because much of the DNR literature pre-dates the AND literature. Additionally, because DNR is well known EOL terminology, perhaps the researchers did not identify a need to compare it to other options.

Another evident gap identified in the research literature pertains to the absence of an exploration of the understanding by older, chronically ill adults of the meaning of the terms AND and DNR. None of the AND studies reviewed identified healthy older adults as the study population. While Fairlie's work (2015) revealed that the terms do impact study participants differently, there were no data giving specific insight into how participants perceived meanings of these EOL terms. Many studies addressed preference for AND as compared to DNR, but the researchers did not delve into participants' perceptions of the meaning of these EOL terms themselves (Barnato & Arnold, 2013; Fairlie, 2015; Fan et al., 2018; Miljkovic et al., 2015; Patel et al., 2016; Venneman et al., 2008; Wittmann-Price & Celia, 2010). Having an understanding of older adults' perceptions of the meanings of AND and DNR is an important first step before being able to identify preference for either term in the context of EOL decision-making. An additional gap in the existing literature revealed by this review is the relative imbalance in the use of qualitative versus quantitative methodologies to study the AND and DNR terms. More specifically, of the 22 studies, 16 were quantitative and six were conducted using a qualitative methodology. Conducting AND versus DNR research using a qualitative approach may begin to address the disparity in methodology type and may also allow for a deeper and richer understanding of how the terms are comprehended.

Summary

This review of the extant literature provides a basis on which to build future research. Fairlie (2015) recommended continued research about AND terminology. Jones et al. (2008) recommended further research on the perspectives of patients and families regarding the terminology of AND. The empirical literature focused on AND consistently explored the meaning of AND among healthcare providers and surrogate decision makers (Barnato & Arnold, 2013; Jones et al., 2008; Patel et al., 2016; Venneman et al., 2008; Wittmann-Price & Celia, 2010) rather than patients.

Overall, the research studies have indicated that study participants' decisions regarding EOL scenarios are positively influenced by the use of AND (Barnato & Arnold, 2013; Fairlie, 2015; Jones et al., 2008; Patel et al., 2016; Venneman et al., 2008; Wittmann-Price & Celia, 2010). For example, the findings of previous research studies indicate that study participants, including health care providers as well as participants who identified as a surrogate decision maker for a family member, were more confident in EOL decisions made when AND was offered as an option or when AND was framed as the alternative to CPR (Jones et al., 2008; Barnato & Arnold, 2013; Patel et al., 2016: Venneman et al., 2008; Wittmann-Price & Celia, 2010; Fairlie, 2015). Patients and healthy adults may not understand the difference between DNR and *comfort care* (Sanderson et al., 2013). The one AND study focused on patients rather than surrogate decision makers or healthcare providers showed no difference in preference between AND and DNR (Miljkovic et al., 2015). The literature concerning the meaning of DNR indicates that there may not be a consistent understanding of the meaning of DNR for both providers *and* patients or families/caregivers (Bellini & Damaro, 2009; Eliott & Olver, 2003; Mirarchi et al., 2017; Rohrer et al., 2006). This current study may help healthcare professionals gain insight into how EOL terms are perceived by older adults which may lead to changes in how EOL decisions are discussed with patients and families.

Chapter 3: Methodology

Introduction

This study explored the perception of older adults regarding the terminology of Allow Natural Death (AND) and Do Not Resuscitate (DNR) using a qualitative descriptive approach with individual interviews conducted via Zoom. This chapter provides an in-depth discussion of the theoretical conceptualization and the appropriateness and rationale of the selection of a qualitative approach for the research study. A detailed description of the research design, inclusive of study setting, recruitment processes, data analysis, data collection procedures, and data management strategies will be described. In addition, ethical considerations for study participants as well as the known limitations of the study are identified.

Overview of Qualitative Description

The research method and design used in this study was a qualitative descriptive design. Qualitative descriptive designs are a common approach taken in qualitative research studies to portray the experience of the participants in its most authentic way (Sandelowski 2000; 2010). The data are not overly manipulated during the reporting out, also known as re-presentation, phase of research (Jiggins Colorafi & Evans, 2016; Sandelowski, 2000). Re-presentation is "a straight descriptive summary of the informational contents of data organized in a way that best fits the data" (Sandelowski, 2000, p. 339). A qualitative descriptive design is suitable when the researcher is striving to describe phenomenon or to summarize the shared understanding of a specific experience or words (Sandelowski, 2000).

In qualitative descriptive studies, many researchers choose to conduct individual interviews using semi-structured questioning techniques as the data collection tool. Using this technique, the researcher records both the observed and spoken responses to questions using field notes and recordings (Yin, 2011). Individual interviews allowed the researcher to engage directly with the participant which lead to thicker description because the style is more naturalistic. This means that the structure of the process itself may not be perceived as prescribed as other qualitative methodologies. (Jiggins Colorafi & Evans, 2016; Kim et al., 2017).

Once data collection was complete, the researcher utilized content analysis to analyze and re-present the data (Maietta, 2017; Sandelowski, 2000). This allowed the researcher to remain data-near, or closer to the surface meaning of the data collected, when analyzing and reporting thick, rich findings (Jiggins Colorafi & Evans, 2016; Sandelowski, 2000; 2010). Content analysis is a form of data analysis focused on summarizing the information provided from data collection (Kim et al., 2017). Sandelowski (2000) states that qualitative descriptive research and re-presentation produces an understanding of an occurrence in language that is relevant to the situation which leads to authentic data.

Design

Theoretical Framework

The Communication Adaptation Theory (CAT) by Giles and Coupland (1988) was utilized in this dissertation study, as discussed in Chapter One. Specifically, the labeling strategies of accommodative, over-accommodative, or under-accommodative (Coupland & Giles, 1988) influenced the researcher's categorization of the data collected during the semi-structured one-on-one interviews. These labeling strategies have been utilized in empirical studies and have been helpful in categorizing healthcare messages (Ahmed & Bates, 2016; Hehl & McDonald, 2014; Jones et al., 2007; Lagacé et al., 2012; Scott & Caughlin, 2015).

In this biolinguistic and sociolinguistic theory, Giles and Coupland (1988) posit that receivers of a message decode the message by evaluating it through their own personal understanding of the context. The receiver labels the message as accommodative, over-accommodative, or under-accommodative, and then evaluates the message as positive or negative. These three receiver labels were used to direct the analytical process. This led to a better understanding of how the terms AND and DNR are understood by older adults and if they were perceived as positive or negative in nature.

Context and Setting

The target population for the study was people aged 65 and older from Pierce County, in Western Washington State. Pierce County is home to approximately 876,764 people. Approximately 117,847 of those residents, or 13.4%, are the age of 65 years old or above. In the United States, 16.0% of residents are age 65 years old or above. Within the county, 66.7% of the population is white (not Hispanic), 10.9 % Hispanic, 7.19% two or more races, 6.65% black or African American, 5.92% Asian, 1.51% Hawaiian or Pacific Islander, 0.867% American Indian or Alaska Native, and 0.255% other races (Data USA, 2019). These numbers can be compared to the averages of the Unites States which are 60.4% white (not Hispanic), 18.3% Hispanic, 2.7% two or more races, 13.4% black or African American, 5.9% Asian, 0.2% Hawaiian or Pacific Islander, and 1.3% American Indian or Alaska Native (United States Census Bureau, 2019). In Pierce County, approximately 91.2% of the population over 25 years old are high school graduates, as compared to 87.7% nationwide, and approximately 26% have earned a Bachelor's degree or higher, as compared to 31.5% nationwide (United States Census Bureau, 2019). Being aware of the racial differences and educational differences within Pierce County, the principal investigator (PI) aimed to recruit participants who were racially representative of the county while still focusing on the study's inclusion criteria (Krueger & Casey, 2015). The study participants were recruited primarily through a community-based membership program for people ages 55 and older called Celebrate Seniority located in Pierce County.

The Celebrate Seniority program is sponsored by a larger healthcare organization called MultiCare Health Systems (MHS) and is not housed in one of the MHS hospitals. The Celebrate Seniority program offers educational and social opportunities to its members as well as opportunities to volunteer in the community. Established in 1988, the program volunteers engage the greater Pierce County area in Western Washington State through a variety of outreach programs. Examples of roles in which members who volunteer may work are: staff and operate a thrift shop, tutor children in the school system, provide blood pressure screenings at local senior centers, and conduct mailings for various departments of the parent organization, to name a few. For all members, the program provides a variety of educational programs, exercise classes, and social events throughout the year. While it shares some similarities to a traditional senior center, Celebrate Seniority is different in that the primary focus of the program is to support successful aging by engaging older adults in community service as well as social events.

This setting was chosen because its focus is older adults, many of whom volunteer within the program. According to Krueger and Casey (2015), engaging potential study participants where they work or volunteer can be an effective way to recruit since the potential study participants already feel a connection to the organization and/or location. Celebrate Seniority attracts members from all over the county and is free of charge. Because of the easy membership application and the cost-free opportunities offered by the program, there are minimal barriers for membership, which allows for diversity among the study participants.

Sample

Once institutional review board (IRB) approval was obtained from MultiCare Health System, the parent organization of Celebrate Seniority, and Villanova University, study participants were recruited through the volunteer and membership program. Inclusion criteria were: 1) being age 65 or older, 2) having no terminal illness, 3) be able to speak and understand English, and 4) being able to attend the interview online. As discussed in Chapter 1, *terminal illness* was defined as a medical diagnosis for an illness that will most likely cause death within six months (U.S. Federal Code, 2019) and for which there is no cure, and *chronic illness* was defined as a medical diagnosis for a condition which the patient will have to manage for the remainder of life (World Health Organization, 2018). A chronic illness has no cure, is not immediately life ending but is potentially life altering. For this research project, study participants were asked to self-report the existence of terminal illness.

The literature reviewed identified that study participants close to death may not be impacted by AND and DNR (Miljkovic et al., 2015). The literature also suggested that it is currently unknown if older adults understand the meaning of AND and DNR separately (Barnato & Arnold, 2013; Fairlie, 2015; Fan et al., 2018; Jones et al., 2008; Miljkovic et al., 2015; Patel et al., 2016; Venneman et al., 2008; Wittmann-Price & Celia, 2010). Studying the perceptions of older adults who are not close to death allowed for a clearer understanding of how the terms are perceived.

Recruitment of Participants

An invitation to participate in the study was mailed to 300 Celebrate Seniority members by Celebrate Seniority (see Appendix A). While Celebrate Seniority has approximately 6000 members throughout Pierce County, Washington State, the program supervisor offered to send letters specifically to 300 members. The program supervisor felt that including the article in the newsletter would generate too much interest and that many members would be denied participation because of the relatively small number of anticipated participants, possibly causing upset members. Additionally, the plan had been to distribute flyers to be posted at Grannies' Attic, the Celebrate Seniority thrift shop, which is next door to the Celebrate Seniority offices, and in the various meeting rooms (see Appendix B). Because of the Covid-19 pandemic at the time of recruitment and interviews, this did not happen as both Grannies' Attic and Celebrate Seniority were closed to volunteers and the public. The program supervisor acted as a gatekeeper for the study. According to Creswell (1998), a gatekeeper is someone within a site who can act as a trusted liaison between the researcher and the potential participants because they have rapport already established with the potential participants. Recruitment efforts through Celebrate Seniority resulted in 12 study participants. Potential participants were directed by the gatekeeper, as well as the recruiting materials, to email or call the researcher for additional information. The researcher utilized an original Gmail account, EricksonNursingResearch@gmail.com, and a dedicated cellular phone number for recruitment purposes.

Additionally, the PI incorporated snowball recruitment techniques. Snowball recruitment occurs when a researcher requests leads or referrals from people who either 1) have agreed to be in the study, or 2) are familiar with the researcher (Krueger & Casey, 2015; Yin, 2011). This included posting a recruitment message on the PI's personal Facebook account and requesting that the post is shared. The PI also asked participants to share the research opportunity with people who would also be interested and who met the inclusion criteria. Snowball recruitment resulted in an addition 12 participants. Once data saturation occurred, recruitment efforts were ended.

The recruitment letters and the social media posts invited interested potential study participants to contact the researcher by email or phone. If an email was received expressing interest, the PI would call the potential participant back. During the phone call, the PI described the study and its potential benefit to society, explain the study protocol, and shared that a $20 Fred Meyer gift card would be offered for participating in the study. Fred Meyer is a local grocery store. If the person continued to be interested in participating, the PI would ask the potential participant the recruitment questions. If they qualified to participate, the PI set up an interview time for the participant. Immediately after solidifying a date and time for the interview, the PI emailed the study participant a confirmation email, including the date and time of the interview and a Zoom link, and a copy of the consent form (Appendix C) to read prior to the interview. One day prior to each scheduled interview, the PI called the study participant to confirm the upcoming interview and to ensure that the participant was comfortable accessing Zoom. Because of the PI’s familiarity with this program, some study participants were acquaintances of the researcher.

Data Collection Procedure

The individual interviews occurred on Zoom. Once the study participant had signed on to the designated Zoom link, the PI introduced the participant to the Research Assistant and “locked” the Zoom room so that no one else could enter the virtual space. The participant was asked for permission to record the Zoom interview and, upon receiving permission, the PI recorded the interview using the Zoom recording feature. Study participants were mailed a $20 gift card to a local grocery store after their participation. If the study participant did not live in an area where the store chain was located, the PI mailed them a $20 gift card to the store of their choosing.

As detailed in the Data Collection Manual Plan and Script (Appendix E) once study participants are recruited, an interview date was established. Spouses or significant others will be discouraged from attending an individual interview together in order to prevent one person deferring to the other when sharing thoughts (Krueger & Casey, 2015). A brief verbal demographic survey was conducted to collect data on gender, age, race, level of education, and if the study participant is living alone or with someone. Collection of demographic data was completed in order to provide general background information regarding the participants. While the demographic data was not considered during the analysis of the focus group interviews, these data may influence possible future areas of study because knowing the demographic data may influence how researchers plan future studies. A list of standardized questions (see Appendix F) was used by the researcher to initiate and guide the discussion during each semi-structured individual interview.

Each individual interview was conducted using the list of standardized interview questions (see Appendix F). Each individual interview lasted 30 to 45 minutes (Loeb et al., 2006; Twiss, 2010). A research assistant was present during each interview to taking field notes. The PI trained the research assistant to take field notes using Phillippi and Lauderdale's (2018) field note guidelines. The assistant was a Bachelor of Science in Nursing (BSN) student from a local university who expressed interest in research. The assistant was trained on taking field notes as well as appropriate demeanor in the individual interview setting. The research assistant was considered adequately trained when they identified two purposes for field notes, two keys to interaction with a participant, and three items to record in the field notes.

During the individual interviews, the dialog was recorded using Zoom's record feature. At the start of the interview, the Zoom room was "locked" which meant that no additional people would be able to sign into the Zoom call. This ensured privacy was maintained during the interview. Names were be redacted in the transcription, and each participant was assigned a pseudonym in the transcription and any subsequent documentation to maintain anonymity (Lin, 2009; Richards & Morse, 2013). In addition to the recordings, the research assistant took field notes that were used in data analysis as well.

Field notes were used in conjunction with the voice recordings and transcripts during data collection (Phillippi & Lauderdale, 2018). The field notes focused on documenting the visualized physical environment of the participant, interactions between the study participant, PI, and research assistant, the participant's behaviors during the interview such as body language, facial expressions, and/or signs of discomfort, any of the recorder's personal thoughts, and any questions that may arise (see Appendix G). This information led to richer and thicker data. Similar to the recording of the research assistant's personal thoughts, the researcher employed journaling throughout the study.

The researcher recorded personal thoughts by journaling before and after the recruitment interactions, before and after the interviews, and intermittently during the analysis process. Any researcher bias identified in the journaling was addressed during analysis. Journaling by the researcher is also a helpful tool in ensuring rigor and trustworthiness as will be discussed later in this chapter (Amankwaa, 2016).

All recordings were transcribed by Same Day Transcriptions, Inc., a professional transcription service which meets HIPAA compliance standards. The data were electronically sent to and from the transcription company utilizing their secure and encrypted web-based services. Upon returning the transcriptions, data was deidentified and pseudonyms were assigned by the researcher. All transcripts were saved to an external hard drive which was stored in the researcher’s locked office (Richards & Morse, 2013). Additionally, any hard copies of the transcripts were locked in a cabinet in the researcher’s locked office.

Data Management Procedure

Data management, according to Lin (2009), is managing data with regards to “human subject’s protection, confidentiality, data storage and record keeping, data ownership, and data sharing” (p. 132). Protection of human subjects will be discussed in a later section. In this section, confidentiality, data storage, ownership, and sharing will be discussed.

According to Lin (2009), confidentiality entails keeping data containing personal information of the study participants private. This can be done by removing study participant names from all notes and transcripts (Lin, 2009). The researcher addressed study participants by name during the interviews and names were redacted from the transcript to protect the privacy of the study participants (Lin, 2009). Each participant was assigned a pseudonym in the transcription and any subsequent dialog to maintain anonymity. A master list of the study participants’ names and contact information as well as their interview date was maintained for the purpose of following up for member checking (Krueger & Casey, 2015). All other data was de-identified by utilizing the study participants’ pseudonyms on all records except the master list.

For data storage, all study materials were stored in a locked cabinet in the researcher’s locked office (Lin, 2009). Digital information was stored on the researcher’s password-protected personal computer and password-protected backup drive which was either with the researcher or in a locked environment at all times, for example in the researcher’s office or at the researcher’s home. All non-digital study materials will be shredded or destroyed five years after the study has been completed (Lin, 2009). Digital data will be erased permanently from the researcher’s computer and backup drive. Raw data will not be shared, and the researcher will own the data until it is destroyed.

Data Analysis

Once transcribing was complete, the data was analyzed and transformed into emergent patterns using In Vivo coding by means of Atlas.ti software (Saldaña, 2016). The approach used was the Sort and Sift method (Maietta, 2017). Sort and Sift is an iterative approach to qualitative data analysis during which there are two main cycles: “diving in” and “stepping back”. During the initial phase, one dives into reading and reviewing the data as well as recognizing similarities and recording these findings. The second part of the cycle is to step back from the data and to reflect on it. “Stepping back” allows the researcher to re-strategize and re-orient to the data. It is during the “stepping back” phase that the researcher identifies connections within the data and reflects using memo writing techniques and diagramming. These two phases occured iteratively until the researcher determined that the evidence was present to identify and support themes from the data.

In Vivo coding was used during the “diving in” phase of analysis. In Vivo coding utilizes the actual words of the study participants in order to capture the essence of the data (Saldaña, 2016). In Vivo coding may be confused with NVivo which is the name of a software product marketed towards qualitative researchers; NVivo, the software, was not utilized in this study. In Vivo coding uses the actual words of the study participants in the analysis which endorses authenticity of the analysis. Utilizing the verbatim words of the study participants also ensures that the analysis remains data-near. In addition to In Vivo coding, provisional coding was utilized.

In the provisional coding, predetermined codes are used during data analysis (Saldaña, 2016). For this study, the CAT labeling strategies of accommodative, over-accommodative, or under-accommodative (Coupland & Giles, 1988) were the predetermined codes. The In Vivo codes were considered through the lens of the CAT labeling strategies during the data analysis. Once In Vivo codes were identified and provisional coding was considered, trustworthiness was established.

Rigor and Trustworthiness

Trustworthiness

Trustworthiness in qualitative research is the level to which the research is considered to represent the truth (Amankwaa, 2016). Trustworthiness consists of four elements: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). In qualitative research, procedures may be developed in order to establish trustworthiness (Amankwaa, 2016). The four elements of trustworthiness will be discussed here.

Credibility

Credibility is the confidence that a study has been conducted in a manner consistent with traditional qualitative studies in a way that was well documented and reliably collected (Cope, 2014). There are multiple ways to confirm credibility, including member checks and journaling plans (Amankwaa, 2016). For this study, the researcher utilized member checking by emailing two participants, the research assistant, and a PhD prepared nurse scientist an excel spreadsheet containing the main themes identified, the labeling strategies of CAT, and an abbreviated initial analysis. The researcher followed up the email with either and email or a phone discussion regarding the themes and outcomes. During these interactions, the researcher asked the participants and resources if the analysis represents the words used during the interviews they attended. The researcher also inquired as to whether the study participants had any questions regarding the process of the study. Responses were recorded in a Word document by the researcher. The researcher also independently journaled, such as journaling after every interview as well as after discussions with the research assistant and with the dissertation committee.

In addition to member checking and journaling, the researcher ensured prolonged engagement and persistent observation as described by Lincoln and Guba (1985). Prolonged engagement is achieved when the research spends adequate time learning about the participants and building a rapport with them. This was achieved through multiple interactions with study participants via phone and email. Persistent observation is taking notice of the various forms of data, including the spoken words but also body language and interactions. By being a persistent observer, the researcher used the data to identify what is of consequence to the participants and therefore the study.

Transferability

The second aspect of trustworthiness is transferability. Transferability is being able to apply the information learned to other contexts (Amankwaa, 2016). According to Amankwaa (2016), transferability can be evidenced by providing thick description as well as journaling. Thick description can be achieved by designing a study with open ended questions in order to stimulate comprehensive responses, as well as by re-presenting the data collected in a way that portrays the data as thick and rich. Journaling by the researcher assisted in providing thick description because the researcher recorded the date of the interview as well as any biases presented or other information that would enhance analysis.

Dependability

The third aspect of trustworthiness is dependability. Dependability is evidenced when the data collected are consistent and stable (Amankwaa, 2016). In qualitative research, results are very dependent on the environment and therefore may vary because of that, however results may also overlap (Connelly, 2016). If the data generated from the research are in alignment with the CAT labeling strategies, this too supports dependability because CAT is an established communication theory (Coupland & Giles, 1988). To ensure dependability, the researcher audited field notes, interview transcripts, and journaling in order to creating audit trails. Audit trails allowed the researcher to ensure authenticity of the data as well as stability of the data (Amankwaa, 2016).

Confirmability

The fourth aspect of trustworthiness is confirmability. Confirmability demonstrates consistency in the data, its neutrality, and the repeatability of the data (Connelly, 2016). Using triangulation of sources may support confirmability in addition to ensuring the existence of thick, rich data (Amankwaa, 2016; Lincoln & Guba, 1985). The researcher triangulated data from the participants to determine consistency of the data. Journaling is another way to determine confirmability, especially after interviews and any perceived significant experience (Amankwaa, 2016). The researcher maintained a journal as discussed previously.

Protection of Human Subjects

Study participation was completely voluntary and informed consent was requested via an email consent form sent to the participant prior to the scheduled interview. At the start of each interview, the full consent form was reviewed and verbal consent was obtained as per the IRB approval. The emailed consent form was 14-point font which is ideal for older adults for reading

(Bernard et al., 2001). Participants could choose to withdraw from the study at any point without fear of retribution or untoward consequences. The study posed little physical risk to participants, but the topic could evoke emotional discomfort for study participants and individuals who do not qualify for the study. If an individual did not qualify for the study and had concerns regarding the disqualification, the PI would have encouraged the individual to contact their primary care provider to discuss the experience and would also have provided information regarding counseling services. This did not occur. Additionally, at the end of each interview, the researcher would have provided information regarding counseling services for the participants if the topic of EOL decision-making results in emotional discomfort. If a participant appeared to be or voiced experiencing emotional distress during the interview, the researcher offered that they take a break from the interview. Had a break occurred, Zoom recording would have been paused and the researcher would have asked the participant to return to the camera in approximately ten minutes. At that point, the researcher would have asked the participant if they would prefer to continue or to halt the interview. Two participants were tearful during the interviews, and both declined to take a break.

Potential Limitations

Three limitations of this study have been identified. These are: 1) the results are not generalizable; and 2) there may have been possible bias introduced by the PI messaging. First of all, this study recruitment was conducted in a city in the Pacific Northwest Region of the United States through an educational and volunteer program focused on older adults named Celebrate Seniority. Because of the specificity of the location and the population, the results themselves may not be considered generalizable to other older adult populations (Atieno, 2009). The results may be used in the future as building blocks for further research but may not directly be applied to other populations or settings. In addition to not being generalizable, the PI may have inadvertently introduced bias into the study.

Secondly, the PI may have introduced unintentional bias into the study through messaging used in asking the interview questions. Researchers often unknowingly introduce bias into qualitative studies (Buetow, 2019). This may have influenced the answers generated by study participants inadvertently. Steps were be taken to prevent unintentionally biased communication with study participants, such as journaling as discussed in the trustworthiness section (Amankwaa, 2016). These two potential limitations were expected however did not detract from the use of qualitative descriptive research methodology to answer the research question of this study.

Summary

This chapter provided information regarding the methodology of the study which was conducted with study participants ages 65 and older who were not terminally ill, who spoke and understood English, and who were able to attend an online one-on-one interview via Zoom. The participants were recruited utilizing a letter mailed to potential participants and snowball recruitment techniques, including word of mouth referrals and utilizing social media. The study explored the perception of older adults regarding the meanings of AND and DNR. One-on-one semi-structured interviews were conducted through Zoom and results were member-checked for accuracy. The collected data was analyzed using the “Sort and Sift” method utilizing In Vivo coding as well as provisional coding considering the labeling strategies of CAT. The research design, sample, recruitment, data analysis, and trustworthiness described in this chapter support the purpose of this study.

Chapter 4: Findings

Introduction

The purpose of this study was to contribute to the body of scientific knowledge by exploring the perceptions of older adults regarding their perceptions of the end-of-life terminology Do Not Resuscitate (DNR) as compared to Allow Natural Death (AND). The research questions posed were:

1) How do older adults (ages 65 and older) who have not been diagnosed as terminally ill describe their understanding of the terms AND and DNR?

2) Do older adults (ages 65 and older) who have not been diagnosed as terminally ill indicate a preference for AND or DNR?

Four themes were identified from the data which provide greater insight into how older adults understand the terms AND and DNR. The four themes are: 1) Control; 2) Emergency vs. Calm; 3) Communication is Key; and 4) Quality of Life. Additionally, the data provided a variety of opinions on which term is preferred by the participants with no clear overall preference identified.

Description of the Sample

For this study, semi-structured interviews were conducted via Zoom with 24 participants. Of the 24 participants, 91.7% (n 22) were from the Pacific Northwest, with 75% (n 18) residing specifically in Pierce County, Washington State, and 8.3% (n 2) residing on the East Coast. The sample was a very highly educated group of people. Of the 24 participants, 95.8% (n 23) had attended some college, with 50% (n 12) holding a master’s degree or higher. Of the 24 participants, 79.2% (n 19) identified as female, 20.8% (n 5) as male, 50% (n 12) were married, 20.8% (n 5) divorced, 16.7% (n 4) widowed, and 8.3% (n 2) single; 25% (N 6) lived alone and 75% (N 18) lived with someone, including a friend, child, or spouse. Additionally, the sample was not ethnically diverse, consisting of 87.5% (n 21) Caucasian Americans, 4.2% (n 1) African Americans, 4.2% (n 1) Jewish Americans, and 4.2% (n 1) Hispanic Americans. Ages of the participants ranged from age 65 to 89, with 25% (n 6) ages 65 to 69, 50% (n 12) ages 70-74, 12.5% (n 3) ages 75 through 79, 0% in the 80 to 85 range, and 12.5% (n 3) in the 86 to 89 age range (Appendix H).

Analysis of the Data

Once data were collected, the voice recordings were sent to Same Day Transcriptions through their secure portal. Once the typed transcript was received, the PI reviewed it for accuracy and also removed all participant names. Using Maietta's Sift and Sort method (Maietta et al., 2017), the PI reviewed the data, including the transcripts and the field notes generated by the RA, using Atlas.ti and identified In Vivo codes. In Vivo codes are derived from the words of the participants (Saldaña, 2016). Once all of the transcripts were reviewed in the initial diving in phase, the PI then entered the stepping back phase in which she reflected on the codes identified and did cursory diagramming of the codes and their quotations (Appendix I).

A second diving in this phase occurred during which the transcripts and field notes were again reviewed and codes were reconsidered. During this phase the PI condensed some codes, for example "a more gentle way" and "not as threatening" were merged into the code "a more peaceful way", as these codes meant similar things and, for simplicity, it was decided to combine them into one code. The next step was again to "step back" for more reflection. During this phase, the four themes were identified. An Excel spreadsheet was created and utilized during this process as well. The purpose of the Excel spreadsheet was group like things together in a way that was simple to navigate. When the themes were identified, the PI emailed the Excel spreadsheet to the research assistant, a PhD prepared qualitative researcher in nursing, and to two study participants to ensure credibility of the data. Finally, when preparing to report the data, all participants were assigned a pseudonym created by the PI.

Research Question One

Four themes emerged that address Research Question One which was “How do older adults (ages 65 and older) who have not been diagnosed as terminally ill describe their understanding of the terms AND and DNR?” The four themes are: 1) Control; 2) Emergency vs. Calm; 3) Communication is Key; and 4) Quality of Life.

Theme One: Control.

Control was overwhelmingly the consistent message from all of the participants regardless of how they perceived the two terms. According to Ione, age 72, “The fact that you are making the decision for your end of life is the most important thing you can do.” Participants understood both terms to be something that would communicate their EOL wishes thereby allowing them some control over how they would die. Participants shared stories and perceptions that demonstrated the importance of control, explained the value of planning, expressed the wish to help their families, and what can happen when a person's wishes are not honored.

Many participants discussed the importance of an individual having control with regards to how they die. Sharleen, a 65-year-old retired RN, sums up control by stating, “And it’s really not your story, it’s the patient’s story. It’s my story, I want to tell my story my way.” Margot, age 74, echoed this sentiment by stating:

> I’m saying I have the right to say I don't want to suffer, I don't want to keep trying when it may gain me a few days, but those days may not be a quality of life that I would like to have.

Losing a loved one is hard, according to Emilie, age 70, but a death may be more peaceful if the person dying makes that choice. Emilie stated:

> I've had some friends with cancer and to allow them to go in their own time, that was hard on all of the friends. But that was definitely his choice. And we sat around and cried and those kinds of things, but it was a peaceful passing… I think that that's, sometimes it makes me sad. Because I would want the person to continue to be in my life because I love them. But I also think that it is the individual's, the right to choose how much they want to suffer or endure. And if they have come to the point where there is the end of wanting to endure, I think that that's good. They need to have that control.

Control appeared to be the core focus of all participants when queried about their understanding of AND and DNR or how the terms made them feel.

Many of these answers were in response to either: “How does the term DNR make you feel?” or “How does the term AND make you feel?” For example, 89-year-old Olive stated, “[DNR] makes me feel that maybe I have some control over my end of life and that no one else is going to intercede in my wishes.” In response to the questions about how the two EOL terms made her feel, Esther, age 88, exhibited a need for control when she stated, “I don’t have any problem with the words themselves, but I would like to be resuscitated. Do not resuscitate, I kind of place on someone else that wants that, but I don’t.” This want for control led many participants to discuss wanting to plan ahead for their future.

Many participants approached the idea of control from a planning perspective. For example, Abe, age 67, shared “And then, I have just a little bit of a control over… my end-of-life type of occurrences” and also stated:

> But I know everything's being taken care of. So, I'm not going to come back and haunt anybody to make sure it happens. Although I may do it just to piss people off. (laughter) But no, I just think being open and honest with yourself about what death is and being prepared for it just shows you, "What am I prepared for college?" "Am I prepared to have children?" And I guess sometimes we just don't get choices in all these matters. And same way with death too, but, you know, being as prepared as you could possibly be…

Monica, age 71, also expressed the important of being prepared:

> But, you know, time marches on and I have my form on my refrigerator should an EMT or somebody be called to let them know what my decisions are, you know. I don't want it left to, you know, a friend, neighbor, or my brother to decide for me. So, I don't think it's any truer. Life is a rollercoaster where you don't know what it's going to bring you today or the next day. So, you know, you might as well be prepared for it.

May, age 73, too reflected on control at EOL being reflected through planning stating, "People who are very fact oriented would need to have their finances, their medical stuff, everything in order. And they'd have to know all the ins and outs." She states that the planning may also benefit others because the organized and data-oriented person does not "want anybody else having to deal with it and just a whole number of other things."

Eve, age 73, shared that AND made her feel "empowered", and that the planning component brings her comfort. She reflected on the importance of planning by saying, "I've gone through preplanning for this. So, it's comforting to know that, but you know, there's a lot of legalities involved. And so, it's very important that things are in place."

Margot's spouse decided to stop pursuing life-extending measures and the result of his decision was time to plan his services. According to Margo, age 74, "[spouse said] 'I've had it; I can't do this anymore.’ But then he was--he planned his own funeral and he was very straightforward with my [child] about what he wanted and very open about what he said.” Margot expressed that their family benefited from her spouse having the time and control to plan as it allowed for closure and connection for them all.

Participants also shared wanting control of the situation in order to prevent discomfort for their families. Adele, age 71, wanted make her wishes clear so that her children would not need to fight with the healthcare system, stating “I don’t want to get into a push me/pull me with my doctors or my caregivers for [child] and [child]. They know what I want and I want it. And I want what I want especially if it’s we’re near the end, you know.” Eve, age 73, expressed similar sentiment when she stated, “It wouldn't put my family in a quandary because if you don't have anything in place, they would be more likely to have the person or have me, resuscitated, and that could be very, very costly and unnecessary.” Monica, age 71, understood that she may not be able to control the situation when she is dying and she summed up her ideas about control by saying “So, you know, we joke about that. And so, for that again, after I’m gone who cares? I’m not going to make the decision. But I would like to steer them in that direction. And that’s how come I’m trying to get things all lined up, so it just makes it easier.” A desire to prevent distress for their families by making EOL plans was evident in the data. Also in the data, some participants offered information about what happens then those wishes are not honored.

When a person’s EOL wishes are not respected, participants shared that they felt a lack of control. Olive, age 89, had experienced an illness during which her family decided to allow artificial ventilation. She shared this conversation:

> ‘Why didn't you let me go? Just step on the tube or something like this,’ because I was under the ventilator and all. And [child] says, ‘Mum, we couldn't; you had too much life

> in you. We just couldn't let you go.' So, at that point in time, I felt that I had lost my power to ask for a natural death.

Olive's family did finally allow for extubation and Olive was able to breath on her own, but this is not often the case.

Another participant, 71-year-old Alex, shared that he initiated CPR for his spouse despite knowing there was a DNR order in place. "I personally knew that; I knew [spouse] had a DNR order, but I couldn't help myself. I jumped on top of the bed, and on top of her, and I started doing CPR. And of course, the people crowded around, and the nurses came from the nurse's station, and were trying to pull me off." While sharing this experience, Alex appeared to have anguish over his actions despite his spouse having died well prior to this interview.

The theme of control was central to how participants perceived the meaning of the two terms, and was evident throughout the data, regardless of if a participant preferred AND, DNR, or wanted to be resuscitated. Participants wanted to exercise control at end of life by planning ahead which some felt would alleviate unwanted stress for their loved ones. In addition to wanting control, the data also showed that participants perceived the terms DNR and AND as being appropriate for different situations, in particular that DNR is a term used in emergent situations while AND is reserved for expected deaths.

Theme Two: Emergency versus Calm.

When discussing perceptions of the two terms, participants consistently identified that DNR was a term used during emergent situations, such as visits to the emergency room, when there was a "flurry" of activity (Ione, age 72). Rebecca, age 68, stated, "Do Not Resuscitate to me seems so emergency." AND was consistently envisioned as "peaceful" (Ione, age 72; Vivian, age 66; Mervyn, age 68; Rebecca, age 68), being used in the home setting, and very rarely associated with care provided in the hospital setting. Marcus, age 77, summed this up, saying:

> I have different pictures in my head of those things, you know. I'm a science guy. So, "do not resuscitate" means there's a lot of control there for me. So, if I'm put in a situation I have a lot of control where the "natural" aspect seems to put it in a different picture where you're at home and you're dying. And you're going to die in an easy, natural way. "Do not resuscitate" usually has a picture of me being in a hospital in a particular situation where there's lots of things that could happen to me. And I don't want them to happen.

For a number of participants, the two terms share the same meaning but belong in the different settings.

Multiple participants expressed that the term DNR was accompanied by visions of situations in which there was a lot of activity and tension. Monica, age 71, stated, "I would assume that most cases DNR refers to hospitalization or maybe, you know, emergency whatever." Bev, age 78, stated simply, "DNR kind of has more urgency to it." According to Ione, age 72, "Do Not Resuscitate to me feels like there's some sort of violence going on. Not violence but flurry, not peaceful. I think that's a nice term allow natural death. I like it." Alex, age 71, shared that "[DNR] always brings up a hospital situation where there's some emergency of life, risk of death of, like, death. And if you did something, it would save their life, or stop their dying, prevent them from dying." Daphne, age 68, shared this image:

> To me, when I hear, "Do not resuscitate," what I envision is someone is walking down the street, they see me collapsed in a pile, my heart is stopped or whatever, or something

> has happened drastically. When they get me to the hospital, tear open my shirt or whatever, if I'm dead, do not try to kickstart me back to life. Does that make sense?

Abe, age 67, summarized, "… Do Not Resuscitate is for me more of like a medical term, a directive for the medical industry."

For many participants, AND and DNR held similar meanings but were applied in different settings. For example, Alex, age 71, stated, "So, they're very similar. To me they're very similar. I mean, they're different because one is an emergency, an emergent situation. And the other, it may not be may be, it may be very long-term." Mervyn, age 68, shared, "I think they're similar in the end, but I think they're different in probably the setting. That would be my observations, most likely a setting difference, but not so much an end result." Similarly, Monica, age 71, stated, "Do Not Resuscitate … is more of an emergency thing as opposed to Allow Natural Death. Either way I think the outcome's roughly the same." She explained:

> Okay, "allow natural death". I think that's used more in an in-home nursing care situation whereas the "do not resuscitate" might be more of a medical thing like nursing home, hospitalization. I think that's the difference, you know, in terms of the context.

Marcus, age 77, said:

> But I see one as a situation that Do Not Resuscitate is really, you've got an ambulance. You've got people there the doctors and stuff. And you're saying, "Don't mess with me." And the other one, it's, you know, I'm at home. I'm going to die.

Alex, age 71, shared that the setting and intensity of the situations surrounding the usage of AND and DNR are simply different when he stated, "[With AND] it could be days, weeks, or months before they actually succumb to their illness. Whereas [DNR] usually means they're gonna succumb to their emergency quickly, seven minutes at the most." Jaclyn, age 74, shared, "[with

DNR] I think of something horrific, like a horrific surgery that went bad or a car accident or something like that. And [AND] is like a person has lived a long life, … it's just a natural progress for life." May, age 73, stated:

> I mean natural death, you just see someone passing away. When you say do not resuscitate, you see them in a critical situation with people around them trying to decide whether to do something, not to do something, what to do, you know. So, it's maybe a little more agitated. And the decision process could be a little bit tougher. Natural death I might see a family member sitting holding a hand. Everybody having said goodbye. And letting them pass easily.

The data clearly demonstrated that AND and DNR are understood to belong in different settings by the study participants. Participants also expounded on the feeling associated with the two terms.

Not only do the terms hold similar meaning but in different contexts for participants, they also hold similar meanings but different feelings. Mervyn, age 68, shared, "[DNR is] usually more stressful I would think and [AND is] a little more natural or a little more relaxed." Rebecca, age 68, reflects:

> Do Not Resuscitate makes me feel like we've been here before and we've had some real emergencies, and, kind of, a hypercritical, intense emotional feeling. Allow a natural death seems to be where it can be, not orchestrated, but allowed to have a more peaceful [death].

Vivian, age 66, shared that "It seems like when you say, "do not resuscitate," that seems so much more final, but when you say just to allow naturally, to me that's more calming, more peaceful, not as threatening, not as life ending I think." Mervyn, age 68, also shared that the two terms, while similar, elicit different feelings:

> I think if you allow natural death would be more calming I guess, I'll use that word again. It's more I guess both of them of are kind of matter of fact. I mean you know what the ultimate end would be. But I think if you allow natural death, it lets you think it lets you feel like or think that you have more control over the situation. Whereas do not a DNR is just okay, here we go, you know, this is what we're going to do because I've done this DNR then here we go. And allow natural death, it would probably be more of a discussion. I think… about this is what we need to do, this is what we're going to do so [AND] would probably be more of a discussion versus a "okay, here you go."

Overall, AND was found to be a more peaceful, gentler term whereas DNR was associated with emergencies and the flurry and stress that accompanies those situations.

The data showed that participants perceived AND and DNR as being terms with similar meanings that are used in very different situations. DNR was envisioned as occurring in an emergency setting where there is a lot of bustling activity and the outcome of DNR is certain death. AND is envisioned as being utilized in a calmer, gentler, typically home setting where the dying person may be surrounded by family. Regardless of the term that is used, "communication is extremely key" (Sharleen, age 65) in order to ensure all players, whether that be family members, lawyers, or medical professionals, are aware of one's wishes. Communication is the next theme identified in this study.

Theme Three: Communication is Key.

The importance of communication resonated in the data. Participants perceived AND and DNR to be terms used to communicate EOL wishes, and discussed the importance of discussing their wishes with family members as well as healthcare professionals. Some participants also shared situations that occurred as the result of poor communication. Opinions varied as to which party is responsible to ensure good communication occurs. Most participants felt it was the responsibility of the individual whose wishes were in question; others felt that doctors, lawyers, or a person's children should initiate end-of-life discussions. Only one person expressed not realizing the importance of discussing wishes with anyone other than a medical professional. Participants often also perceived DNR as more direct than AND. This appealed to some. It was also identified that DNR is negative in nature which may not allow for open dialogue.

Many participants identified that communication was of utmost importance when making EOL decisions. That communication could be with family or friends; it could also be with medical professionals or lawyers. The important thing was that the communication happened to make one’s wishes known and to ensure the wishes are honored. Jeri, age 73, shared her experience of a dear friend who was at the end of life:

> The doctors stated, “Here's where you as a family have decisions to make and here are some of the possible outcomes. And we will respect whatever decision you make.” This positively impacted the experience, And I found that very, very helpful for the wife, for the children, for us as friends. And it was the need to communicate, not dictate.

For May, age 73, the discussion should occur with family prior to when the decision needs to be implemented, “because generally when you get to the point of having to make that decision, you’re not in the best place to be doing it.” Ione, age 72, agreed, stating that EOL wishes should be:

> Communicated very forcefully, especially with older people. Because in the moment, a son or a daughter, they’re not going to want to let go. They’re not going to want to let go.

> And I think you have to make it very clear to them that this is what you want. This is your decision, not their decision.

Mervyn, age 68, explained the importance of discussing wishes early in life because of the stress associated with last minute decisions. He stated:

> I think that's a little challenging for you to start to think about then if you haven't ever even talked about it, or even really thought about… Rather [than] waiting clear till like 20 minutes before it happens, …and all of a sudden somebody says, "oh, have you ever thought about what you want to do?" If you never have, it would be harder to make that decision.

Esther, age 88, explained that loved ones typically want to abide by a person's wishes, stating:

> I think everybody that's closer to end of life should let those that are closest relatives know what their desire is so that that can be done, because I'm sure most people I know would like to fulfil the wishes of the person that is making the transition.

May, age 73, also felt that wishes should be discussed but encouraged that discussion to happen for all adults, especially those with children:

> And having that EOL discussion or that do not resuscitate discussion isn't age related necessarily but we tend to compartmentalize it that way. But anybody who has a family member who has children needs to have gotten wills into place. They need to have had somebody who's going to take over for them. And that person or persons needs to know what they would want, regardless of age.

End-of-life discussions may not be easy. Sharleen, age 65, explained, "I do have this conversation with my husband, my family. And they don't like it. They're like, 'why do you always talk about death?' I'm like, 'because I don't want to have anyone wondering what I want.'" Daphne, age 68, discussed the feelings she had related to specific words, stating "Do Not Resuscitate is a negative term; you start out with the two terms 'do not', so right away, it kind of puts you on guard like, 'Okay, there's a *do not do this*.'" Daphne explained that these negative feelings make it more difficult to have EOL discussions.

Rebecca, age 68, shared that EOL discussions are important because surrogate decision makers will need to be able to support the dying person's wishes despite EOL paperwork being done. She stated, "I think that there needs to be a discussion with whoever you have chosen to make your decision [so they] understand that they will be, even though you have an [advanced directive], they will be required to… reiterate [it]." With good communication, Sharleen, age 65, described that death can be meaningful, stating:

> And death could be something that, as people, we come together at the bedside… and we just talk about what a great life someone's had. Or what memories you'd like them to remember of you. I don't know I think it's just about having those open-ended conversations.

One participant expressed surprise at the idea of discussing one's EOL wishes with anyone other than healthcare professionals. Nia, age 86, stated, "Well, to be honest, I don't know if I've had any end-of-life discussions. I probably ought to at my age." She also stated, "Well, because I thought these were discussed only with your medical [professionals], and not necessarily with family." This statement was an anomaly in the data however reflects the need for a focus on communication at the end of life.

While most participants discussed the importance of communicating EOL wishes, some participants shared experiences when those wishes were not honored. For example, Kirk, age 74, discussed an experience during which the opposite of his spouse's wishes occurred. Kirk and his spouse had worked with an attorney to draw up advance directives. On the way home from the appointment with the attorney, they stopped at their preferred hospital, dropped of the documents, and requested the documents be included in their medical records. When Kirk's spouse did near the end of their life and was taken to the hospital, there was a flurry of activity, and his spouse was intubated without his understanding. Kirk shared:

> As it later turned out, they had installed the ventilator into my wife at that time. We're up in our room, my wife is unconscious, I'm in shock. And things started to happen. And there were things I would have expected to happen. But I also expected the hospital to have looked at my wife's records and found out that none of this stuff was supposed to have ever been done. So as a result, she ended up probably being in a lot of pain and confused and just lingered for six days before she died. That's the problem I have with DNRs.

Bev, age 78, also discussed that healthcare providers may not respect a person's EOL documents. She stated, "people don't bother to read what you have made a point of putting at your doctor's office… they just don't read them, and they just go ahead and do whatever; and that's where I find that a frustrating thing." These participants shared that they experienced distress as a result of their wishes not being honored. For healthcare providers, there is also distress experienced when working with patients nearing the end of their lives.

Sharleen, age 65, and Alex, age 71, both retired healthcare professionals, discussed EOL decision making from the perspective of the providers. Sharleen, a retired nurse, stated, "I don't know that those two terms would have made the conversation different. I think the reality is that we never spoke to patients in the sense of things aren't necessarily going to be better." Sharleen also stated, “I think dying patients, nurses tend to avoid them too because it’s uncomfortable.” Alex, a retired doctor, explained the discomfort experienced by healthcare professionals:

> I mean doctors tend to use big words, and fancy words, and they sometimes don't get down to the level of their patient, and the person, the people they're talking to. I mean, they're trying to remove themselves from it, so they don't have the emotional connectivity, so they can remain objective. And many times, when people try to stay objective, they use defensive words that don't allow touch or feeling, and don't allow a real clear understanding to the common man.

Sharleen expressed frustration with EOL discussions from the healthcare perspective. She stated:

> … I see people that have months, years, and I watch families crumble and decay in the process and get completely absurd in their thought processes. “Let’s get them a computer like they have for those people that have cerebral palsy that they can just hit buttons to communicate with us.” Like they’re 20 liters positive of fluid, they're in renal failure, heart failure, and no, that computer’s not going to do a whole lot. But we don’t have those conversations. We actually listen to them.

Sharleen also shared that providers may associate death of a patient with failure. She stated,

> Doctors… take it as some kind of failure. I failed you because you died. But if I can make you live three months longer with chemo I’m going for it because that’s my success story. And it’s really not your story, it’s the patient’s story. It’s my story, I want to tell my story my way. So, I think we have to have the conversations with folks.

Healthcare providers may perceive death differently than their patients, creating discomfort or distress when working with patient nearing death. Participants shared that there was often uneasiness when discussing EOL wishes with loved ones.

Many participants also discussed the discomfort or push back that can be experienced when attempting to have EOL decision making discussions with family members. Eve, age 73, reflected, “how do you really talk to your family about death, especially if they don't want to hear it?” Bev, age 78, suggested that, “people are trying to shelter children--and I don't know where I would even say the age break would be--but I think people try to shelter children from something that's not good, that's bad.” Similarly, Kate, age 73, shared:

> So, I think it's best to have the conversations, but do the right paperwork, too. Because you know how ugly that can get … when people don't do it. And I have friends my age who still won't do that. And I think, "You're not doing your kids any favor, and you're not, maybe gonna get what you want."

In order to ensure EOL wishes are respected, Maura, age 70, stated “…I would say the [most important thing discussed is the] conversation about letting other people know what my wishes are.”

Many participants discussed ideas that can help better EOL communication. Ideas included utilizing social media, simply discussing the topic of EOL with friends and loved ones, and incorporating the discussions into the annual Medicare wellness check with a provider.

Adele, age 71, found that social media can be utilized as an instrument of communication, stating:

> But I’m a big fan of Facebook. I like finding articles that resonate with me. I have a number that are printed out in our EOL files to remind the [children] that we saw this, or talked about this, or what all. And so, I do think social media is a great tool.

Participants also suggested that people could have regular discussions with friends and loved ones in order to raise awareness of EOL topics as well as their specific wishes. Ione, age 72, stated:

> I think actually it should be a topic of discussion with everybody. With friends. If something comes up, I mean I know I've said to my friends, "do you have [an advanced directive]?" You know I think that the more natural the discussion is, the easier I think people deal with it. More easily people deal with it. Yeah.

Margot, age 74, discussed the importance of honesty by saying, "I think being honest about how people feel; not just agreeing because you think the person wants you to agree, but being quite honest about how you feel." Ione, age 72, suggested that one begins discussed EOL wishes early in life, stating:

> Because you never [know], I mean this is not just an EOL thing, this is a, I mean it's a lifelong thing. Anything you can walk out the door today and be faced with that decision. It's not just for old people. And I think if that was brought up more to younger people at a younger age that it was necessary to make wills and necessary to make healthcare directives, that everybody would just have them. And I think EOL would be more easily accepted.

Ione also shared that wishes may change, necessitating regular review of wishes:

> But it might not be a bad thing to bring up annually because sometimes the person that you have chosen to make your decisions, that may not be appropriate anymore. They have moved, you may not like them anymore and want them to make the decision.

Mervyn, age 68, stated:

> I think allowing or learning to use the words that make people feel better I think is important, or the way that we say things I think is important, versus just saying them I guess. I think there needs to be some compassion I guess. And it makes you feel more compassionate in those situations.

When asked when the best time would be to begin addressing EOL decision making, Adele, age 71, reflected:

> I think for most of us of an aging population, it probably does not occur until you begin to deal with your own aging parent. And then, you begin to have those questions about yourself and, "What is it I want? What do I want to be different? What do I not want to put my friends and family through?" And I think that's at that point when I began having those conversations with the [children] and kind of paying attention to what people are doing, so. But I think it's a really good question, [researcher], that perhaps we should even be talking with our adult children what that looks like [for them].

In addition to discussing one's wishes with loved ones and family members, multiple participants suggested the discussion be part of a person's annual medical checkup. Ione, age 72, stated:

> I don't think it would be a bad thing as part of an annual, they now do this Medicare annual wellness check. And I think it wouldn't be a bad idea to just [say] do you have one? And are your choices up to date and still valid? Probably wouldn't be a bad idea.

Eve, age 73, said:

> I could see that on a list of things that as a patient ages or even before they age, where they're getting close to that, like I said, 60 years old possibly. That it be part of the talk

> that the doctor and the patient has when they do their Medicare evaluation or physical to bring that up.

Kate, age 73, also shared that a person’s primary provider could be part of the discussion, stating:

> I think at a certain age if the patient doesn't bring it up, the provider should do it… should ask, "Have you thought about what you want," especially if they know you, and they see you falling apart piece by piece. And they can guess what the options might look like. I would, I would hope that they would bring it up.

Marcus, age 77, suggested that providers bring up the topic earlier, stating, “… in a doctor’s office it should be definitely an educating situation especially Geriatrics, but even before Geriatrics… I think that by the time you’re 40 you should’ve talked about it, you know. It’s something you should have a discussion about.” Sharleen, a 65-year-old retired nurse, discussed the responsibility of healthcare professionals to encourage EOL discussions, stating, “I think we’re responsible to help people transcend that death doesn’t have to be scary and we can talk about it, we can be open, we can express our feelings, our fears, our concerns and all that.” She stated, “I’m not sure I’m expressing myself right, but I know when I was at the bedside, I don’t think families always understood do not resuscitate. They thought we were giving up on patients.”

To help people understand EOL discussions, Alex, age 71, suggested, “I think common terms should be used. I think as simple and common of a term without being crass, and without being obtuse, but without being insensitive.” Kate, age 73, reflected a similar thought, stating, “I think being honest about whatever condition a person might have as that factors into the discussion, to talk about, not in a gruesome way. But let's talk about what this might look like as the disease advances." The data reflected the importance of communication as well as what happens when communication is not effective at the end of life. The perception of both AND and DNR was that they are tools that, when used effectively, can enhance EOL communication. Participants wanted good communication in order to ensure they experience a good quality of life throughout their lives.

Theme Four: Quality of Life.

The data showed that participants consider quality of life when they are determining their EOL wishes. For many people, a good quality of life (QOL) is being able to think, communicate, and maintain control of their lives. For others, being able to connect with people defines a good QOL. For one participant, QOL was being able to breathe and take nutrition. Regardless of a participant's preference for AND or DNR, QOL was a topic about which participants perceived as being related to both terms.

Multiple participants shared experiences when a person they knew extended their life through disease treatment which caused a decline in their perceived QOL. For example, Kate, age 73, shared, "And in his case, it would have, he would have had a better last two years if he had stopped his chemo and gotten involved in palliative care. That would have been much better for him." Margot, age 74, shared her spouse's decision to stop medical interventions, thereby providing their family time to plan and communicate. Margot's spouse said, "I've had it; I can't do this anymore." Margot continued:

> But then… he planned his own funeral, and he was very straightforward with my son about what he wanted and very open about what he said. So, I think, in our family, we try to be really honest about how we feel about things.

Margot summarized by stating:

> I’m saying I have the right to say I don't want to suffer, I don't want to keep trying when it may gain me a few days, but those days may not be a quality of life that I would like to have.

Olive’s friend had a different experience which, per Olive, age 89, the friend later regretted, feeling as if she had “put [her spouse] through misery and pain.” Olive shared:

> [friend said] “Well, let them keep him living, keep him living.” After he was gone, she said “[Olive], I made a horrible mistake.” She said, "I put him through misery and pain that he didn't need to go through knowing that there was very little slim chance that he would survive for my own wanting to keep him with me." And those types of things, I think the heroics of the medical profession are at fault.

Daphne, age 68 and the primary caregiver for her mother, stated “a good quality of life for me is a certain amount of independence, that's pretty important.” Having experienced end of life from the perspective of a caregiver, Daphne shared candidly:

> And it's more of quality as opposed to life itself. As I said, my mother is 94.7 and I don't- and that's what's hard is because I don't want to be her; I don't want to be the person who's kind of batty and sitting there in her diapers.

For many participants, a good QOL was one in which decision-making ability was still present. According to Margot, age 74, “if I have mental clarity and I can interact with people still, that's a quality of life.” Emilie, age 70, said, “So for me, and this is my big thing, is that my mind be able to work.” Olive, age 89, stated, “… quality of life is to be able to reflect, to recognize, and to make a decision, and act upon it.” Jeri agreed, age 73, stating:

> For me, personally, mental acuity, and part of my stress on that is my father had Alzheimer's. He died of Alzheimer's. And probably being somewhat, have a little control

> over myself. Okay. It wouldn't have to be total, but some is what I would personally want… the point at which somebody has to make a decision for me, then quality of life is gone.

Bev, age 78, had similar thoughts, stating:

> I guess, to me, it's more mental. As long as my mind works, I'm able to speak, I'm able to communicate to people; if I was stuck in a wheelchair, I probably wouldn't be happy about it, but if I could still do a lot of the things that I like to do--reading, crocheting--that'd be fine.

A number of participants shared that they would value relationship at end of life. For example, Jeri, age 73, described a good quality of life as, "one where mentally you are connected with reality… I mean I can answer it for me, personally, but on a larger sense, most of it has to do with mental ability, not necessarily physical." For Daphne, age 68, "still [having] the community of friends... I think that friends and family, being able to be a part of and knowing that you're a part of that" held great importance. Olive, age 89, agreed, "Quality of life, to me, would be able to enjoy your surroundings, able to enjoy personal relationships, and able to find some aspect of life which you feel you're still contributing."

For some participants, QOL was explained as both physical and mental wellness. Marcus, age 77, shared:

> I'd like to say that we're just pragmatic, but I'm not sure that's the right word. I'd like to survive as long as I can on my own. And when end of life comes, I'd like it to be in my own home and we have enough money to deal with it.

Nia, age 86, voiced:

> Well, to have a good quality of life, you would have to be mentally alert, physically well and able to navigate on your own, able to take care of your own business, … just being able to take care of you and yours.

Jaclyn, age 74, echoed this definition, stating:

> I'd say [QOL] would be do things for myself. I don't want to have to put that on anybody… which is exactly basically how I live now. So basically, I want what I have now. I want to be able to care for myself, able to keep my space clean whatever. Be able to cook for myself.

Abe, age 67 stated that QOL is:

> Not needing many outside resources in order to live my life meaning being hooked up to a machine to be able to breathe. I would be able to pretty much function on my own and that would define my quality of life without needing constant assistance…

Maura, age 70, discussed advanced directives and the unavoidability of death, stating:

> They don't make me feel great but on the other hand I've already actually signed one. So for me there's no point in having life if I'm just going to be not be able to function or anything else or to be a burden. So for me you know it's inevitable, for all of us at some point.

For these participants, quality of life was explained as maintaining the ability to make decisions.

Quality of life varied from individual to individual. For Adele, age 71, QOL is balance. She explained:

> It sounds really woo-woo when I say it, but I look at a lot of things from an energetic perspective. If I'm working so hard to heal myself that I'm falling apart in another place,

> then the energy's off, you know. Finding those ways of being that makes you feel inside like you're centered, and you have your balance, and the energy is right.

On the other hand, 88-year-old Esther's definition of QOL was perhaps the most rudimentary: "You're breathing and able to take nutrition…and…let's see…those two, for sure." The data surrounding QOL demonstrated that different people truly have differing ideas of what they value at the end of their lives.

Research Question Two

Research question two was, "Do older adults (ages 65 and older) who have not been diagnoses as terminally ill indicate a preference for AND or DNR?" The participant responses were varied and did not overwhelmingly show a preference as a whole, but many participants did indicate a preference. Some participants shared that the words were so similar that the use of one over the other would not impact their decision. Those who did indicate a preference either preferred the calm, peaceful, collaborative nature of AND or, on the other hand, preferred the commanding tone of DNR.

For those who felt that use of the different terms would not impact them one way or the other, it was felt that the terms held similar meaning. Sharleen, age 65, stated, "I don't know that those two terms would have made the conversation different." Maura, age 70, was matter of fact and stated, "I don't know that they make me feel all that different, one from the other." Eve, age 73, expressed similar feelings and stated, "As far as the person who is dying goes, either sentence is perfectly fine with me, I don't have any qualms about it whatsoever." For Adele, age 71, the two terms spoke to different sides of her personality. She shared:

> The DNR speaks to my scientific medically inclined side and the 'allow natural death' appeals to my woo-woo side. So, you know, for me, it speaks to two sides of that personality and they're both saying the same thing, you know. Just let me go.

May, age 73, indicated that for her there was no difference, but she also realized that people are individual by stating, "So for me it's not that different. But for some people it would be very different." Abe, age 67, reflected on the two terms from the perspective of how they may be perceived by healthcare professionals and realized they were both instructions. He marveled:

> Wow! Boy, that's a really good question. Well, the impact is for the doctor… on "do not resuscitate". The impact on "natural death"? Well, I guess that would be the same too for the doctor because that's also a directive in some sort of a way… But wow! They're both directive, so I never would've thought of that. Yeah. Wow. Huh.

For these participants, there was no preference indicated for AND or for DNR. For others, the term AND was preferred because of its calm, peaceful sense of acceptance.

As indicated in the discussion of theme two, many people indicated that AND had more of a sense of calm and peace. Daphne, age 68, even used the term "umbrella of acceptance" when describing the feeling around the term AND. Daphne's preference was, "Allow natural death. That is more of an allowance, it's more of spreading your arms to allow as opposed to 'do not.'" Bev, age 78, shared, "I think it would make me calmer, I think it would just let me be at peace--I think, personally." Eve, age 73, indicated, "[AND] would be a nicer way, I think, of saying 'Do Not Resuscitate.' Just let the person pass away peacefully." Adele, age 71, viewed the terms through the lens of relationship, stating, "So, I think in terms of developing a relationship, the all-natural talking about natural death would resonate for me." Mervyn, age 68, indicated that the term could allow for connection, stating, “And allow natural death, it would probably be more of a discussion I think…” Vivian, age 66, expounded:

> Well, I think if you use the terminology to die naturally, it just seems a lot nicer than, okay, I don’t want to be resuscitated. I don’t want somebody pounding on me, or using paddles, or that kind of stuff. I mean I think that’s important. It’s a hard process and hard to go through and you don’t want somebody just throwing those words [DNR] out at you. I mean if the doctors want to use them I think that’s fine and dandy, but as a patient you really don’t want to hear that. I think it does make a difference.

These participants preferred the use of AND over DNR in EOL discussions while other participants wanted the firmer tones associated with DNR.

Some participants preferred the use of DNR because they felt it was a term that would decisively communicate their wishes. Marcus, age 77, said, “Allow natural death. See, that wouldn’t be my preference.” For Jeri, age 73, DNR was more of a concrete statement. She stated, “[with DNR] I would say, ‘Okay, what we're talking about is resuscitation.’ We're keeping the basic elements going or not. I guess I want the data, and [AND] doesn't give me any data.” Kirk, age 74, viewed DNR as a commandment, stating:

> If I would have had both of those options and check a box, I would have still checked DNR. I think that request requires some degree of forcefulness. Do not I mean, you’re commanded, “do not”. The other one “allow”, I think the DNR is a better way to say it.

These participants indicated that DNR had more authoritative qualities than AND. Overall, preferences for terms were varied and there was not one term that was clearly preferred by this population in this study.

Summary

Twenty-four participants aged 65 to 89 participated in one-on-one semi-structured interviews via Zoom, an online meeting platform. These participants shared their understanding of the meanings of DNR and AND as well as how the two terms made them feel. The discussions were honest, open, and at times tearful. Data collected for this study resulted in identifying four themes, including 1) Control; 2) Emergency vs. Calm; 3) Communication is Key; and 4) Quality of Life. Participants shared that, regardless of wanting to be resuscitated or not, they all valued being able to control or influence how they die. Many participants clearly envisioned DNR being utilized in an emergent setting while they envisioned AND being employed in a calm, home-like setting. Participants expressed the importance of open communication with loved ones and medical providers. And finally, participants shared their personal thoughts on quality of life. The data provided a better understanding of how older adults who have not been diagnosed with a terminal illness describe their understanding of the terms AND and DNR as well as a glimpse into their preferences for the terms.

Chapter 5: Conclusions and Implications

Introduction

When older adults think about death, they often envision a calm setting in which they drift off to sleep surrounded by their loved ones (Ko et al., 2013; Lindqvist & Tishelman, 2015). For our aging population, often these end-of-life (EOL) wishes are not communicated with the people who will make that decision when the person can no longer speak for themselves (Carr & Khodyakov, 2007; Gawande, 2014; Long-Sutehall et al., 2011). Communication may be key to ensuring that older adults die in a manner that they wish, and the use of language plays a role in that process (Callahan, 1993; Gawande, 2014; Institute of Medicine [IOM], 2015). In the 2014 IOM brief entitled Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, it was identified that the public be engaged to identify ways to promote ongoing and substantive communication about end-of-life (EOL) wishes. The purpose of this study was to explore the perceptions of older adults regarding the terms of Allow Natural Death (AND) and Do Not Resuscitate (DNR). Chapter Five provides a discussion regarding the outcomes of the study, their relationship to the research questions and the review of the literature, limitations of the study, implications for nursing practice, education, and policy, and finally, recommendations for future research.

Relationship of Study Findings to the Review of the Literature.

Theme One: Control

The theme of control identified in this study is consistent with the findings of Fan et al. (2018) in which participants indicated they preferred having more information and knowing the prognosis for their disease when making EOL decisions. While none of the studies reviewed specifically called out a need for control, Fan et al. (2018) did query participants regarding a desire for more information during EOL scenarios, and the preference for having more information may indicate a desire for control. In this current study, participants clearly perceived that having some amount of control over their EOL experience would help them feel more at peace. Several participants also expressed wanting to make EOL decisions to make the process of their death less stressful for their loved ones. They perceived that communicating their wishes could allow for their loved ones to advocate for their wishes with fewer feelings of guilt. Fan et al. (2018) findings differ from this current study's because Fan and colleagues found that participants were significantly more likely to choose AND instead of DNR in response to a hypothetical EOL scenario whereas participants in this current study indicated that the two terms have a place in different settings.

This current study's findings are consistent with recent research focused on advance care planning (ACP). In a study that explored the perceptions of older adults regarding the ACP process, Miller et al. (2019) found that participants would like to be actively involved with the decision-making process to prevent burdening their loved ones and to make their wishes known. Interestingly, while participants appreciated the information shared during the ACP process by specially trained healthcare professionals, they were hesitant to actively involve their loved ones in those conversations despite wanting to spare them from eventual burden at end-of-life.

This current study builds on what is currently known about AND and DNR by further emphasizing the importance of control during EOL situations for older adults. The participants consistently expressed a desire to have decision made that were in alignment with their wishes. In this qualitative dissertation study, participants also expressed that the context of the situation, whether it be an emergency or an expected death, impacted their understanding of the use of the EOL terms which resulted in *Theme Two: Emergency versus Calm*.

Theme Two: Emergency versus Calm

Theme Two: Emergency versus Calm emphasizes the concept of meaning in context. Context is the setting in which an event or experience occurs (Merriam-Webster, n.d.). Overwhelmingly, the study participants identified that AND and DNR elicited thoughts of different EOL contexts. DNR conjured up images of emergencies and flurries of activity while AND prompted descriptions of calm, peaceful death. The review of the literature revealed that there may be a relationship between context and meaning (Fan et al., 2018; Miljkovic et al., 2015; Patel et al., 2016). For example, in Miljovic et al. (2015) participants were diagnosed with a terminal illness and did not have a statistically significant preference for either AND or DNR, whereas Fan et al. (2018) studied health adults and participants were significantly more likely to agree to end-of-life orders when AND was presented instead of DNR. The ACP literature also supports the idea of context. In a study that explored how context influenced ACP across four different outpatient clinic settings, Shaw et al. (2020) found that the disease itself did not influence a participant's perception of the ACP process but that a driver for EOL decision making could be disease burden, or how far a disease has progressed. Results of Shaw et al. (2020) appear to indicate that being sicker changes how ACP is perceived by patients. These findings indicate that people's perceptions of EOL terms may be impacted by the context, or the setting, of their situation.

The results of this current study are truly striking in how clearly the participants imagined the words used in different settings. In a review of the AND literature, all but one study (Miljkovic et al., 2015) utilized hypothetical situations in their studies. In this current study, no hypothetical situations were introduced and participants were asked: 1) how they perceived the meaning of the terms, and 2) how the two terms made them feel. The answers captured how clearly the two terms were envisioned being used in different environments. This differed from the extant literature in that the AND literature reviewed provided EOL scenarios but did not ask the participants their perceptions of the verbiage. Not providing a scenario, as was the methodology in this current qualitative study, allowed the participants to share their perceptions of how the terms are used independent of a suggested context. Jones et al. (2008) offered the perspectives of the healthcare providers who indicated that they preferred AND because it enhanced EOL communications by changing the focus of the conversation to what can be done for a dying patient and promoted discussion. The themes resulting from Jones et al. (2008) did not discuss the two terms being associated with different environments.

Theme Three: Communication is Key

In the previous studies that examined the construct of AND and preference for AND versus DNR, AND was generally considered to be a clearer form of communication than DNR (Barnato & Arnold, 2013; Fan et al., 2018; Jones et al., 2008; Patel et al., 2016; Fairlie, 2015; Venneman et al., 2008; Wittmann-Price & Celia, 2010). This varied somewhat from what this perception-focused study's data revealed. For the participants who preferred use of DNR, they perceived the language as being more direct. For those who expressed preference for AND, they perceived the language to be calmer and more peaceful. Regardless of the terminology preferred, participants agreed that engaging in communication itself was of great importance. These findings differ from previous research findings because many of the studies (Barnato & Arnold, 2013; Fairlie, 2015; Fan et al., 2018; Patel et al., 2016; Venneman et al., 2008; Wittmann-Price & Celia, 2010) utilized scenarios to elicit responses regarding AND and DNR and those scenarios may have driven the participant responses. This current study asked for participants to share their perceptions of the terms without assuming a scenario. This is important because there was a dearth of information in the extant literature about how older adults perceive EOL terminology. Without being directly asked about the importance of communication, participants consistently discussed it. Because of this, the theme of *Communication is Key* resulted.

While many participants did give indications as to their terminology preference, the open-ended questions focused more on perception than preference. Many participants in this current study expressed that people may avoid discussing death and EOL wishes from fear or discomfort. However, the ACP literature indicates that effective communication can decrease stress at EOL for patients and their loved ones (Rasmussen et al., 2018). In a communication-focused study that explored how ACP prior to an intensive care unit (ICU) admission impacted the experience of patients and their families, Rasmussen et al. (2018) concluded that increased focus on discussing a person's care preferences prior to needing hospitalization can improve patient and family experience in the ICU. Rasmussen et al. (2018) suggested that early communication decreased stress for patients and loved ones. To decrease fear of death and to increase conversations regarding EOL, the participants in this current study encouraged engaging in ways to normalize the discussion of death in society This theme aligns with the recommendations of the IOM (2014) brief report entitled *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* which calls for measures to increase the awareness of people regarding EOL options and of the needs of dying people and their support systems.

Theme Four: Quality of Life

While the construct of quality of life (QoL) was not a focus of this study, nor was the extant literature used to support this study, QoL was a clear theme in this study's findings. When study participants were asked how they perceived the terms of AND and DNR, QoL was often discussed in relation to their perceptions. Participants explained QoL differently, implying that the EOL terminology does not exist in a vacuum, or without context. QoL was explained as everything from “breathing and able to take nutrition” to “balance” to “basically, I want what I have now”. This, too, supports the theme identified in the AND literature indicating there is a relationship between context and meaning (Fan et al., 2018; Miljkovic et al., 2015; Patel et al., 2016) because different people explain QoL differently and thereby have different ideas of how they would like to die. According to some QoL literature focused on older adults and EOL, QoL cannot be defined as the same thing for all people and that the measurement of QoL will be higher if a person’s priorities are considered and honored (Bowling, 2008; Stewart et al., 1999). The findings of this current study emphasize the importance of the perception of the individual, how it differs from person to person, and that context influences how a person perceives the meanings of EOL terms.

Limitations of the Study

There were several limitations in this study, which may have impacted the data quality. One limitation of this study is that it did not attract a diverse group of people, both educationally and ethnically. Of the 24 participants, only one did not have any college education. Additionally, all but three participants identified as Caucasian, with one identifying as African American, one as Hispanic American, and one as Jewish American. The principal investigator (PI) intentionally aimed to create a diverse participant pool by asking for referrals of people of color who might be interested through social media. This request yielded zero participants despite the post being shared by multiple social media contacts. A subsequent post inviting potential participants to contact me elicited many contacts. This post was identical to the initial post but only identified a need for participants to be age 65 or older, not the specific request for people of color to participate. A more ethnically and educationally diverse sample may have provided richer data. This may have been beneficial in that different themes may have been identified. It may also have generated additional ideas for future research.

Another limitation was that the study may not have drawn participants who were apprehensive about discussing EOL topics. In the case of this study, the most participants freely discussed their perceptions of EOL decision making which implies they were not overly hesitant to participate. The majority shared having previously engaged in conversations about death and dying. Results of the study may have been different had the participants been reticent to share their perceptions of AND and DNR. The literature indicates that EOL topics cause distress for patients, surrogate decision makers, and healthcare professionals (Hinderer, 2012; Rafferty et al., 2016; Wright et al., 2010). If the participants were averse to discussing EOL concepts, perhaps the insight gained would help identify why the topic is particularly challenging for so many people. This data could lead to the generation of new ideas that could impact future interventions and research. The eventual results of such research could be decreased distress for those involved with EOL decision.

A third limitation may have been conducting the interviews over Zoom instead of in a face-to-face setting. Had the interviews been conducted in a common location, such as the Celebrate Seniority offices, study participants who were not technologically savvy may have been more willing to participate. While older adults have expressed liking the idea of video conferencing, many are uncomfortable with computers or express concerns regarding the privacy and safety of such devices (Moyle et al., 2020; Outila & Kiuru, 2021). Because the interviews were conducted distantly, the social aspect of meeting in person and promise of coffee and refreshments were not viable options, and this may have acted as a deterrent for participation

(Yuan et al., 2016). Additionally, participants were sent gift cards to a local grocery store for participating. The majority of the study participants did not seem driven by that reward and two participants requested that their gift cards be given to the Research Assistant. This incentive may have been more effective if interviews had been done in person.

Implications for Practice

This study presents significant implications for practice for healthcare providers. The literature tells us that all involved, including nurses and other healthcare professionals, experience distress during EOL situations (Hinderer, 2012; Rafferty et al., 2016; Wright et al., 2010). The data in this study shed light on what is important to older adults during EOL discussions, including control, defining QoL, and good communication. These finding are consistent with work done in advance care planning as well (Miller et al., 2020; Shaw et al., 2019). The topic of death may be more normalized in healthcare if openly discussing EOL thoughts with work peers and other resources in the healthcare setting, perhaps chaplains or therapists who are on staff to support the bedside staff, is encouraged. Nursing staff may benefit from participating in educational programs, such as End-of-Life Nursing Education Consortium (ELNEC) curricula, to increase their comfort in EOL discussions (ELNEC, 2021). These may decrease the distress experienced by healthcare professionals in EOL situations.

Another implication for practice would be to provide healthcare professionals with a proficient working knowledge of the terms AND and DNR. Currently, AND is incorporated into Physician Orders for Life-Sustaining Treatment (POLST) forms in approximately 28 states (Chen & Azueta, 2017). The data suggest that the two terms are envisioned by older adults as occurring in different settings. If healthcare professionals are familiar with both terms and how they are often perceived, they can choose which term to utilize in which setting. The two terms could be considered tools in the proverbial toolbox of nurses, doctors, and other providers. Since both terms are on the POLST in 24 states (Chen & Azueta, 2017), the POLST form could be utilized by healthcare professionals in both ways, either focusing on AND or DNR depending on the situation.

According to the American Nurses Association (n.d.), nurses in particular focus on the human response to health conditions and, because of this, nurses encounter many unique EOL situations. Having a working understanding of how AND and DNR are perceived by older adults may enhance nurse-client communications. For example, if a nurse is working with a family who is very concrete, perhaps they would utilize DNR during EOL discussions. If a nurse is working with a family that is more emotionally and conversationally driven, the nurse may elicit engaged discussion from the family by employing the term AND. This family may benefit from using AND as older adults may perceive it as more peaceful.

Implications for Policy

When considering EOL decision-making policy, it may be beneficial to approach the topic from the perspectives of control and context. Finding words that can be used in EOL scenarios, whether it be an emergent or a calm situation, may decrease distress for patients, surrogate decision makers, and healthcare providers while providing patients more control over how they die. One way to do this may be to incorporate AND into the POLST forms of more states. This aligns with the 2014 IOM recommendations to ensure that care delivery is both person-centered and family-oriented and is enhanced by frequent healthcare professional and client communication which may ensure that people have control over their dying by supporting the desired QoL.

According to the IOM (2014), policy changes are indicated in the payment systems that contribute the disconnect between people's needs and the services they are provided. The data from this current study provides support for that call for policy change. The IOM calls for incentivizing coordination of care, advance care planning, and shared decision making (IOM, 2014). The data from this current study indicates that older adults would appreciate better communication and a personalized approach to their needs and wants, including discussion about what the individual considered good QoL. As more research provides additional information about EOL decision-making, policy changes may benefit patients, surrogate decision makers, and healthcare professionals by changing how death is addressed in our society.

Implications for Healthcare Education

The IOM recommended that healthcare education take steps to broaden the knowledge of all healthcare professionals regarding EOL (2014). The data present some implications for healthcare education despite not being the topic of the study. The themes of the study inform the science of how older adults perceive the terms AND and DNR and also provide insight into preferences regarding EOL decision making language. In healthcare education, students may benefit from learning that older adults value control when discussing the topic of death, that individuals have different perceptions of what good QoL is, and that words may carry different meaning in varied contexts. Similar to the implications for practice, teaching both terms, AND and DNR, in the classroom setting may provide students with strategies to successfully engage in EOL discussion with patients, families, and healthcare professionals. Additionally, the data suggest the importance of shifting societal views of death from "bad" to "natural." Healthcare education can impact this by openly and honestly discussing death in the classroom setting and how the healthcare professionals are impacted by death. Broaching the topic of death from this perspective may better prepare new providers for the emotional impact of death in the clinical setting. The increased awareness may contribute to lessening distress felt by healthcare professionals in the clinical setting.

Currently, death and dying are taught in a variety of ways in nursing schools. Some schools integrate it into the curriculum by offering a class on the topic or integrate ELNEC Undergraduate into their coursework. Other schools are not as deliberate at integrating EOL content into the nursing classroom setting (Lippe et al., 2018). AND is not being consistently taught in nursing education. A more consistent approach to EOL nursing education, including the terminology of AND, may be indicated.

Recommendations for Further Research

As discussed in Chapters One and Two, there is a dearth of empirical evidence focused on the use of AND in EOL decision making. This current study provides direction for future research in the area. Further research could include establishing a study to determine how willing high school educators, parents, and students would be to allow EOL discussions to be part of the high school curriculum. Many study participants suggested that an increase in education at the K-12 level related to EOL decision making could lead to a societal shift. Beginning the discussion of death and EOL decision making at the high school level was recommended. To do this, study participants recommended integrating EOL content in the curriculum in K-12 education, specifically high school content. Research is needed to gain greater understanding of how this may be done.

The construct of transition was identified by several study participants and may have been an emerging theme. Further research could be done to explore how older adults interpret the word *transition* when related to death and EOL decision making. The participants suggested that transition could be used instead of or in conjunction with AND or DNR. To do this, researchers may choose to query study participants regarding their perceptions of a variety of EOL terms, including transition, AND, and DNR, using the Communication Accommodation Theory (CAT) labeling strategies of accommodative, over-accommodative, and under-accommodative which informed the analysis of this current study (Coupland & Giles, 1988). The conceptual framework of CAT was developed by Giles and Coupland (1988) as biolinguistic and psychosocial theory. CAT may help people understand how communication is altered by the communicator to relay a certain message and how that message may be understood by the receiver (Giles et al., 1991). For this study, CAT was taken into consideration during the analysis phase. While the data from this descriptive qualitative study were not categorized specifically into those categories, CAT informed the resulting themes. Specifically, participants shared their perceptions of the two EOL terms presented, and those perceptions informed participants' indicated preference. For example, a participant who self-identified as a data-focused person may have perceived AND to be under-accommodative and DNR as accommodative, and a different participant may have found DNR over-accommodative because of its direct nature, preferring AND. Additionally, CAT indicates that all communication happens within a context. The data in this study indicated that AND and DNR prompt thoughts of different EOL contexts for the participants, one being an emergent setting and one being a calmer environment. Continued use of CAT concepts in EOL research may be beneficial to better understanding of how EOL terms are perceived.

Next, research on AND terminology continues to be lacking in the literature. Additional qualitative and quantitative studies focused on perception of the term AND may develop a richer and deeper understanding as to how the terms are understood by participants. Replication of this current study in different geographical locations and with ethnically and educationally diverse older adults, as well as healthcare providers, can contribute to the state of the knowledge, as could reexamining the data or replicating this study focused on how faith influences one's perception of AND and DNR.

Finally, while this study exhibited that participants envision AND and DNR being used in different contexts, more research is indicated to determine if use of AND in emergent settings, regardless of if the patient has an advanced directive or not, may result in calmer experiences for patients, loved ones, and healthcare providers. The review of the literature indicated that AND may be perceived as clearer by patients, surrogates, and providers (Barnato & Arnold, 2013; Fan et al., 2018; Jones et al., 2008; Patel et al., 2016; Fairlie, 2015; Venneman et al., 2008; Wittmann-Price & Celia, 2010). Utilizing AND terminology during actual EOL scenarios in the emergency department setting may provide evidence that AND could result in reduced stress for all involved with the process. These research topics paired with a focus on increasing diversity of participants, both in ethnicity and educational level, may bring to light information that will further impact nursing practice, nursing education, and policy.

Summary

This qualitative descriptive study explored the perceptions of older adults regarding the terms Allow Natural Death and Do Not Resuscitate. The data provided rich description about how older adults understand these two terms and if they prefer one term over the other. In practice, healthcare professionals may be better prepared to have EOL conversations if they are familiar with both terms, AND and DNR, because they could choose which terms would be most appropriate for specific situations. To support this, healthcare education can incorporate both terms into curricula to increase awareness of the terms. When considering policy implications of this research, approaching EOL conversations from the perspective of control may help healthcare professionals to empower patients and family members to make informed EOL decisions. The data also produced ideas for future research, including introducing EOL discussions into high school curriculums, and exploring the use of the word “transition” in EOL discussions. Conducting this research should include a focus on eliciting data from a wide variety of people, ethnically and educationally, to better understand the impact of the topic on a wider array of people. Because the topic of AND remains underexamined in the literature, further studies may provide greater insight into how to best communicate with older adults during EOL decision making situations.

References

Abu-Ghori, I. K., Bodrick, M. M. E., Hussain, R., & Rassool, G. H. (2016). Nurses' involvement in end-of-life care of patients after a do not resuscitate decision on general medical units in Saudi Arabia. *Intensive and Critical Care Nursing (2106)*33, 21-29.

Ahmed, R., & Bates, B. R. (2016). To accommodate, or not to accommodate: Exploring patient satisfaction with doctors' accommodative behavior during the clinical encounter. *Journal of Communication in Healthcare, 9*(1), 22-32.

Allan, B. A., Bott, E. M., & Suh, H. (2015). Connecting mindfulness and meaning in life: Exploring the role of authenticity. *Mindfulness, 6*(5), 996-1003.

Alrimawi, I., Saifan, A. R., Abdelkader, R., & Batiha, A. (2018). Palestinian community perceptions of do-not-resuscitate order for terminally ill patients: A qualitative study. *Journal of Clinical Nursing, 2018*(27), 2719-2728.

Amankwaa, L. (2016). Creating protocols for trustworthiness in qualitative research. *Journal of Cultural Diversity, 23*(3), 121-127.

American Nurses Association. (n.d.). *Scope of practice*. Retrieved August 24, 2021, from https://www.nursingworld.org/practice-policy/scope-of-practice/

American Nurses Association. (n.d.). Short definitions of ethical principles and theories. Retrieved from http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Resources/Ethics-Definitions.pdf

Angell, M. (2015). A better way out. *The New York Review of Books*. Retrieved from https://www.nybooks.com/articles/2015/01/08/better-way-out

Atieno, O. P. (2009). An analysis of the strengths and limitation of qualitative and quantitative research paradigms. *Problems of Education in the 21st Century, 13*(2009), 13-18.

Baily, M. A. (2011). Futility, Autonomy, and Cost in End-of-Life Care. *Journal of Law, Medicine & Ethics*, *39*(2), 172-182. doi:10.1111/j.1748-720X.2011.00586.x

Barnato, A. E., & Arnold, R. M. (2013). The effect of emotion and physician communication behaviors on surrogates' life-sustaining treatment decisions: a randomized simulation experiment. *Critical Care Medicine, 41*(7), 1686-1691.

Baumrucker, S. J. (2001). Sounding board: AND versus DNR. *American Journal of Hospice & Palliative Care,* 18(6), 370-371.

Bellini, S., & Damaro, E. G. (2009). Nurses' knowledge, attitudes/beliefs, and care practices concerning do not resuscitate status for hospitalized neonates. *Journal of Obstetric, Gynecological, & Neonatal Nursing, 28*(2), 195-205.

Bernard, M., Liao, C. H., & Mills, M. (2001). The effects of font type and size on the legibility and reading time of online text by older adults. Presented at CHI 2001. Seattle, WA: Association for Computing Machinery.

Bowling, A. (2008). Enhancing later life: How older people perceive active ageing? *Aging & Mental Health, 12*(3), 293-301.

Buetow, S. (2019). Apophenia, unconscious bias and reflexivity in nursing qualitative research. *International Journal of Nursing Studies, 89*(2019), 8-13.

Callahan, D. (1993). Pursuing a peaceful death. *The Hastings Center Report*, *23*(4), 33 38.

Carr, D., & Khodyakov, D. (2007). End-of-life health care planning among young-old adults: an assessment of psychosocial influences. *Journal of Gerontology*, *62B*(2), S135 S141.

Carr, D. (2012). “I don’t want to die like that…”: the impact of significant others’ death quality in advance care planning. *Gerontologist, 52*(6), 770-781.

Centers for Disease Control and Prevention (2017). *Underlying cause of death, 1999-2016 results.* Retrieved from https://wonder.cdc.gov/controller/datarequest/D76;jsessionid 33B8BFE0E3F3D49609C9EC73D8E17546 on Oct 30, 2018

Chen, D., & Azueta, D. (2017). Clarity or confusion? Variability in uses of “Allow Natural Death” in state POLST forms. *Journal of Palliative Medicine, 20*(7), 695-696.

Chun, D. M. (2012). Review article: Replication studies in CALL research. *CALICO Journal, 29*(4), 591-600.

Connelly, L. M. (2016). Trustworthiness in qualitative research. *MedSurg Nursing, 25*(6), 435-436.

Cope, D. G. (2014). Methods and meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum, 41*(1), 89-91.

Coupland, N., & Giles, H. (1988). Introduction: The communicative contexts of accommodation. *Language & Communication, 8*(3/4), 175-182

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: SAGE Publications, Inc.

Dassel, K. B., Utz, R., Supiano, K., McGee, N., & Latimer, S. (2018). The influence of hypothetical death scenarios on multidimensional end-of-life care preferences. *American Journal of Hospice and Palliative Medicine, 35*(1), 52-59.

Data USA (2019). Data USA: Explore, map, compare and download U.S. data. Retrieved from https://datausa.io/profile/geo/pierce-county-wa

Do-not-resuscitate order (2018). In MedlinePlus. Retrieved from https://medlineplus.gov/ency/patientinstructions/000473.htm

Durable Power of Attorney (n.d). Retrieved December 1, 2014 from http://www.wsma.org/doc_library/ForPatients/EndOfLifeResources/AdvanceDirectives/advance-directive-forms.pdf

Eliott, J. A., & Olver, I. N. (2003). Legitimating do-not-resuscitate orders: A discursive study of cancer patients' speech. *Journal of Palliative Care, 19*(2), 100-106.

End-of-life Nursing Education Consortium (ELNEC), (2021). *End-of-life Nursing Education Consortium (ELNEC) FACT SHEET*. Retrieved from https://www.aacnnursing.org/Portals/42/ELNEC/PDF/ELNEC-Fact-Sheet.pdf

Fairlie, D. (2015). *Does end of life terminology influence decisional conflict in surrogate decision makers?* (Doctoral Dissertation). Retrieved from ProQuest PsychInfo. (Accession No. 2015-99060-021)

Fairlie, D. E. (2018). Specific words and experience matter to surrogates when making end of life decisions. *Health Communication, 33*(5), 537-543.

Fan, S., Wang, Y., & Lin, I. (2018). Allow natural death versus do-not-resuscitate: Titles, information contents, outcomes, and the considerations related to do-not-resuscitate decision. *BMC Palliative Care, 17*(114), 1-7.

Fischer, S., Min, S.-J., Cervantes, L., & Kutner, J. (2013). Where do you want to spend your last days of life? Low concordance between preferred and actual site of death among hospitalized adults. *Journal of Hospital Medicine*, *8*(4), 178 183.

Gawande, A. (2014). *Being mortal: Medicine and what matters most at the end.* Metropolitan Books.

Gibson, A., VanRiel, Y. M., & Kautz, D. D. (2018). Encourage early conversations about palliative care. *Nursing 2018, 48*(5), 11-12.

Giles, H., Coupland, N., & Coupland, J. (1991). Accommodation theory: Communication, context, and consequence. In H. Giles, J. Coupland, & N. Coupland (Eds.), *Contexts of accommodation: Developments in applied sociolinguistics* (pp 1-52). Cambridge, England: Cambridge University Press.

Gillan, P., van der Riet, P., & Jeong, S. (2014). End of life care education, past and present: A review of the literature. *Nurse Education Today*, *34*(3).

Hales, S., Chiu, A., Husain, A., Braun, M., Rydall, A., Gagliese, L., Zimmermann, C., & Rodin, G. (2014). The quality of dying and death in cancer and its relationship to palliative care and place of death. *Journal of Pain and Symptom Management, 48*(5), 839-851.

Hall, M. J., Levant, S., & DeFrances, C. J. (2013). Trends in inpatient hospital deaths; National hospital discharge survey, 2000-2010. *National Center for Health Statistics Data Brief Number 118*. Retrieved from http://www.cdc.gov/nchs/products/databriefs/db118.htm.

Hehl, J., & McDonald, D. D. (2014). Older Adults' Pain Communication During Ambulatory Medical Visits: An Exploration of Communication Accommodation Theory. *Pain Management Nursing*, *15*(2), 466 473.

Hendry, M., Pasterfield, D., Lewis, R., Carter, B., Hodgson, D., & Wilkinson, C. (2013). Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying. *Palliative Medicine*, *27*(1), 13 26. doi:10.1177/0269216312463623

Henneman, E. A., Baird, B., Bellamy, P. E., Faber, L. L., & Oye, R. K. (1994). Effect of do-not-resuscitate orders on the nursing care of critically ill patients. *American Journal of*

Critical Care, 3(6), 467-472.

Higginson, I. J., Daveson, B. A., Morrison, R. S., Yi, D., Meier, D., Smith, M., Ryan, K., McQuillan, R., Johnston, B. M., & Normand, C. (2017). Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. *BMC Geriatrics*, *17*, 1 14.

Hinderer, K. A. (2012). Reactions to patient death: the lived experience of critical care nurses. *Dimensions of Critical Care Nursing*, *31*(4), 252 259.

Hoyert, D. L., & Xu, J. (2012). Deaths; preliminary data for 2011. *National Vital Statistics Reports*, *61*(6).

Institute of Medicine (US). Committee on Approaching Death: Addressing Key End-of-Life Issues (2014). *Report Brief - Dying in America: Improving quality and honoring individual preferences near the end of life.* Retrieved from http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf

Institute of Medicine (US). Committee on Approaching Death: Addressing Key End-of-Life Issues (2015). *Dying in American; Improving quality and honoring individual preferences near the end of life.* National Academies Press.

Ishikawa, Y., Sakiko, F., Saito, T., Fujita, J., Watanabe, M., & Yoshiuchi, K. (2013). Family preference for place of death mediates relationship between patient preference and actual place of death: a nationwide retrospective cross-sectional study. *PLOS One*, *8*(3).

Jennings, B., & Morrissey, M. B. (2011). Health care costs in end-of-life and palliative care: The quest for ethical reform. *Journal of Social Work in End-Of-Life & Palliative Care, 7*(4), 300-317.

Jezewski, M. A. (1994). Do-not-resuscitate status: Conflict and culture brokering in critical care units. *Heart & Lung, 23*(6), 458-465.

Jezewski, M. A., & Finnell, D. S. (1998). The meaning of DNR status: Oncology nurses' experiences with patients and families. *Cancer Nursing, 21*(3), 212-221.

Jiggins Colorafi, J., & Evans, B. (2016). Qualitative descriptive methods in health science research. *Health Environments Research & Design Journal, 9*(4), 16-25

Jones, B. L., Parker-Raley, J., Higgerson, R., Christie, L. M., Legett, S., & Greathouse, J. (2008). Finding the right words: Using the terms Allow Natural Death (AND) and Do Not Resuscitate (DNR) in pediatric palliative care. *Journal of Healthcare Quality, 30*(5), 55-63.

Jones, L., Woodhouse, D., & Rowe, J. (2007). Effective nurse parent communication: A study of parents' perceptions in the NICU environment. *Patient Education & Counseling*, *69*(2007), 206 212.

Joynt, K. E., Figueroa, J. F., Beaulieu, N., Wild, R. C., Orav, E. J., & Jha, A. K. (2017). Segmenting high-cost Medicare patients into potentially actionable cohorts. *Healthcare, 5*(1-2), 62-67.

Khandelwal, N., Curtis, J. R., Freedman, V. A., Kasper, J. D., Gozalo, P., Engelberg, R. A., & Teno, J. M. (2017). How often is end-of-life care in the United States inconsistent with patients' goals of care? *Journal of Palliative Medicine, 20*(12), 1400-1404.

Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. *Research in Nursing & Health, 2017*(40), 23-42

Knox, C., & Vereb, J. A. (2005). Allow Natural Death: A more humane approach to end-of-life directives. *Journal of Emergency Nursing, 31*(6), 560-561.

Ko, E., Cho, S., Perez, R. L., Yeo, Y., & Palomino, H. (2013). Good and bad death: Exploring the perspectives of older Mexican Americans. *Journal of Gerontological Social Work*, *56*(1), 6 25.

Krueger, R. A., & Casey, M. A. (2015). *Focus groups: A practical guide for applied research* (5th ed.). Los Angeles, CA: SAGE Publications, Inc.

Lagacé, M., Tanguay, A., Lavallée, M., Laplante, J., & Robichaud, S. (2012). The silent impact of ageist communication in long term care facilities: Elders' perspectives on quality of life and coping strategies. *Journal of Aging Studies, 26*(2102), 335-342.

Lambert, S. D., & Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing, 62*(2), 228-237.

Levin, T. T., & Coyle, N. (2015). A communication training perspective on AND versus DNR directives. *Palliative and Support Care, 2015*(13), 385-387.

Lief, L., Berlin, D. A., Maciejewski, R. C., Westman, L., Su, A., Cooper, Z. R., Ouyang, D. J., Epping, G., Derry, H., Russell, D., Gentzler, E., Maciejewski, P. K., & Prigerson, H. G. (2018). Dying patient and family contributions to nurse distress in the ICU. *Annals of American Thoracic Society, 15*(12), 1459-1464.

Limerick, M. (2002). Communicating with surrogate decision-makers in end-of-life situations: Substitutive descriptive language for the healthcare provider. *American Journal of Hospice and Palliative Care*, *19*(6), 376 380.

Lin, L. (2009). Data management and security in qualitative research. *Dimensions of Critical Care Nursing, 28*(3), 132-137.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: SAGE Publications, Inc.

Lindqvist, O., & Tishelman, C. (2015). Room for Death International museum-visitors' preferences regarding the end of their life. *Social Science & Medicine, 139*(2015), 1-8.

Lippe, M., Johnson, B., Barger Mohr, S., & Rhoads Kraemer, K. (2018). Palliative care educational interventions for prelicensure health-care students: An integrative review. *American Journal of Hospice & Palliative Medicine, 35*(9), 1235-1244.

Loeb, S., Penrod, J,. & Hupcey, J. (2006). Focus groups and older adults: tactics for success. *Journal of Gerontological Nursing*, *32*(3), 32 38.

Long-Sutehall, T., Willis, H., Palmer, R., Ugboma, D., Addington-Hall, J., & Coombs, M. (2011). Negotiated dying: A grounded theory of how nurses shape withdrawal of treatment in hospital critical care units. *International Journal of Nursing Studies, 48*(2011), 1466-1474.

Mack, J. W., Cronin, A., Keating, N. L., Taback, N., Huskamp, H. A., Malin, J. L., Earle, C. C., & Weeks, J. C. (2012). Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. *Journal of Clinical Oncology, 30*(35), 4387-4395.

Mack, J. W., Weeks, J. C., Wright, A. W., Block, S. D., & Prigerson, H. G. (2010). End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology, 28*(7), 1203-1208.

Maietta, R. C., Hamilton, A., Swartout, K., Mihas, P., & Petruzzelli, J. (July, 2017). Sort & Sift, Think and Shift: Let the data be your guide. In The Odum Institute's 14th Annual Qualitative Research Summer Intensive, Chapel Hill, North Carolina.

May, P., Garrido, M. M., Cassel, J. B., Kelley, A. S., Meier, D. E., Normand, C., Stefanis, L., Smith, T. J., & Morrison, R. S. (2016). Palliative care teams' cost-saving effect is larger for cancer patients with higher numbers of comorbidities. *Health Affairs, 35*(1), 44-53,1-17.

McCarthy, E. P., Pencina, M. J., Kelly-Hayes, M., Evans, J. C., Oberacker, E. J., D'Agostino, Sr., R. B., Burns, R. B., & Murabito, J. M. (2008). Advance care planning and health care preferences of community-dwelling elders: The Framingham Heart Study. *Journal of Gerontology, 63A*(9), 951-959.

Merriam-Webster. (n.d.). Context. In *Merriam-Webster.com dictionary*. Retrieved August 15, 2021, from https://www.merriam-webster.com/dictionary/context

Meyer, C. (n.d.) New designation for allowing a natural death ("A.N.D.") would eliminate confusion and suffering when patients are resuscitated against their wishes. *Retrieved from http://www.hospicepatients.org/and.html*

Miljkovic, M. D., Emuron, D., Rhodes, L., Abraham, J., & Miller, K. (2015). "Allow Natural Death" versus "Do Not Resuscitate": What do patients with advanced cancer choose? *Journal of Palliative Medicine, 18*(5), 457-460.

Miller, H., Tan, J., Clayton, J. M., Meller, A., Hermiz, O., Zwar, N., & Rhee, J. (2019). Patient experiences of nurse-facilitated advance care planning in a general practice setting: A qualitative study. *BMC Palliative Care, 18*(25).

Miquelon, P., & Vallerand, R. J. (2008). Goal motives, well-being, and physical health: An integrative model. *Canadian Psychology, 49*(3), 241-249.

Mirarchi, F., Cammarata, C., Cooney, T. E., Juhasz, K., & Terman, S. A. (2017). TRIAD IX: Can a patient testimonial safely help ensure prehospital appropriate critical versus end-of-life care? *Journal of Patient Safety, 00*(00), 2017, 1-9.

Moyle, W., Jones, C., Murfield, J., & Liu, F. (2020). 'For me at 90, it's going to be difficult': Feasibility of using iPad video-conferencing with older adults in tong-term aged care. *Aging & Mental Health, 24*(2), 349-352.

National POLST Paradigm Program Designation (2018). In National POLST Paradigm. Retrieved from http://polst.org/programs-in-your-state/

Nauck, F., Becker, M., King, C., Radbruch, L., Voltz, R., & Jaspers, B. (2014). To what extent are the wishes of a signatory reflected in their advance directive: a qualitative analysis. *BMC Medical Ethics*, *15*(52).

Neuman, T., Cubanski, J., Huang, J., & Damico, A. (2015). *The rising cost of living longer: Analysis of Medicare spending by age for beneficiaries in traditional Medicare* (Henry J. Kaiser Family Foundation Report January 2015). Retrieved from https://www.kff.org/medicare/report/the-rising-cost-of-living-longer-analysis-of-medicare-spending-by-age-for-beneficiaries-in-traditional-medicare/

Outila, M., & Kiuru, H. (2021). "Picturephone in my home": Actor-Network Theory and Foucauldian Discourse Analysis on northern Finnish older adults starting to use a video conferencing service. *Journal of Technology in Human Services, 39*(2), 163-192.

Patel, D., Cohen, E. D., & Barnato, A. E. (2016). The effect of framing on surrogate optimism bias: A simulation study. *Journal of Critical Care, 32*(2016), 85-88.

Phillippi, J., & Lauderdale, J. (2018). A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research, 28*(3), 381-388

Rafferty, K. A., Cramer, E. M., & Priddis, D. (2016). Managing end-of-life uncertainty: Applying problematic integration theory to spousal communication about death and dying. *American Journal of Hospice & Palliative Medicine, 33*(1), 69-76.

Rasmussen, K., Raffin-Bouchal, S., Redlich, M., & Simon, J. (2018). Duty to defend: Patient and family experiences of advance care planning conversations held prior to intensive care unit admission. *Canadian Journal of Critical Care Nursing, 29*(3), 19-25.

Richards, L., & Morse, J. M. (2013). *Readme first for a user's guide to qualitative methods* (3rd ed.). Thousand Oaks, CA: SAGE Publications, Inc.

Robinson, C., Kolesar, S., Boyko, M., Berkowitz, J., Calam, B., & Collins, M. (2012). Awareness of do-not-resuscitate orders: What do patients know and want? *Canadian Family Physician, 2012*(58), 229-233.

Rohrer, J. E., Esler, W. V., Saeed, Q., Saeed, S., Periman, P., Beggs, D., Hancock, P., & Lim, S. H. (2006). Risk of mistaken DNR orders. *Support Cancer Care, 14*(8), 871-873.

Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). Los Angeles, CA: SAGE Publications, Inc.

Sandelowski, M, (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 2000*(23), 334-340

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 2010*(33), 77-84

Sanderson, A., Zurakowski, D., & Wolfe, J. (2013). Clinical perspectives regarding do-not-resuscitate order. *JAMA Pediatrics (167)*10, 954-958.

Scott, A. M., & Caughlin, J. P. (2015). Communication nonaccommodation in family conversations about end-of-life health decisions. *Health Communication, 30*, 144-153.

Shaw, M., Bouchal, S. R., Hutchinson, L., Booker, R., Holroyd-Leduc, J., White, D., Grant, A., & Simon, J. (2020). Influence of clinical context on interpretation and use of an advance care planning policy: A qualitative study. *CMAJ Open, 8*(1), E9-E15.

Silveira, M. J., Kim, S. Y. H., & Langa, K. M. (2010). Advance directives and outcomes of surrogate decision making before death. *The New England Journal of Medicine, 362*(13), 1211-1218.

Stecher, J. (2008). 'Allow natural death' vs. 'do not resuscitate'. *American Journal Of Nursing*, *108*(7), 11.

Stewart, A. L., Teno, J., Patrick, D. L., & Lynn, J. (1999). The concept of quality of life of dying persons in the context of health care. *Journal of Pain and Symptom Management, 17*(2), 93-108.

Sullivan, M. A., Muskin, P. R., Feldman, S. J., & Haase, E. (2004). Effects of religiosity on patients' perceptions of do-not-resuscitate status. *Psychosomatics, 45*(2), 119-128.

Taft, R. (2010). The origins of 'allow natural death". *Retrieved from http://allowingnaturaldeath.org/2010/08/the-origins-of-allow-natural-death/*

Thelen, M. (2005). End-of-life decision making in intensive care. *Critical Care Nurse*, *25*(6), 28.

Toscani, F., Di Guilio, P., Brunelli, C., Miccinesi, G., & Laquintana, D. (2005). How people die in hospital general wards: A descriptive study. *Journal of Pain and Symptom Management, 30*(1), 33-40.

Twiss, J. (2010). Conducting aging well focus groups. Aging well in communities: A toolkit for planning, engagement & action. Retrieved from http://www.phi.org/uploads/application/files/u94h5c9gfy1lrlznic9cjrs8q9a5x4zwlqnjrcbtis6knwbzju.pdf

United States Census Bureau (2019). QuickFacts. Retrieved from https://www.census.gov/quickfacts/fact/table/US/PST045218

U.S. Federal Code (2019). 42 USC 1935x; Title 42: The public health and welfare/Chapter 7: Social Security/Subchapter XVIII: Health insurance for aged and disabled/Part E: Miscellaneous provision. Retrieved from https://uscode.house.gov/view.xhtml?req_terminally+ill&f_treesort&fq_true&num_13&hl_true&edition_prelim&granuleId_USC-prelim-title42-section1395xVenneman, S. S., Narnor-Harris, P., Perish, M., & Hamilton, M. (2008). “Allow natural death” versus “do not resuscitate”: three words that can change a life. *Journal of Medical Ethics*, *24*, 2 6. doi:10.1136/jme.2006.018317

Venneman, S. S., Narnor-Harris, P., Perish, M., & Hamilton, M. (2008). “Allow natural death” versus “do not resuscitate”: three words that can change a life. *Journal of Medical Ethics*, *24*, 2 6. doi:10.1136/jme.2006.018317

Whitcomb, J. J., Esing, N. (2012) A closing word: Do not resuscitate versus allow natural death and should we change our approach. *Dimensions of Critical Care Nursing, 31 (4), 265-266.*

White, P. (2003) Effects of wording and stimulus format on the use of contingency information in causal judgment. *Memory & Cognition, 31* (2), 231-242.

Wittmann-Price, R., & Celia, L. (2010). Exploring perceptions of “do not resuscitate” and “allowing natural death” among physicians and nurses. *Holistic Nursing Practice*, *24*(6), 333 337.

World Health Organization (2018). Noncommunicable diseases. Retrieved from https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases

Wright, A. A., Keating, N. L., Balboni, T. A., Matulonis, U. A., Block, S. D., & Prigerson, H. G. (2010). Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *Journal of Clinical Oncology 28*(29), 4457-4464.

Yin, R. K. (2011). *Qualitative research from start to finish.* The Guilford Press.

Yuan, S., Hussain, S. A., Hales, K. D., & Cotten, S. R. (2016). What do they like? Communication preferences and patterns of older adults in the United States: The role of technology. *Educational Gerontology, 42*(3), 163-174.

Appendix A: Recruitment Article

Research Participation Opportunity!

By Jodi Erickson, MSN RN

Do you have something you would like to say about how people die? Have you ever wanted to participate in research but have not had a local opportunity to do so? Well, this may be your opportunity. Jodi Erickson, a nurse at MultiCare Good Samaritan Hospital and faculty at the Pacific Lutheran University School of Nursing, is conducting a qualitative research study this spring as part of the requirements for her PhD through Villanova University. The purpose of the study is to explore the perceptions of older adults regarding terms used during end-of-life decision making conversations. There is no risk to you in participating yet your involvement may influence how end-of-life decision making is discussed in the future. Additionally, all participants will receive a $20 gift card for Fred Meyer as a thank you for their time and insight.

If you are interested in participating and if you meet the following criteria:

1) being age 65 or older,
2) having no terminal illness,

3) being able to speak and understand English, and

4) being able to attend an interview online,

please email Jodi at EricksonNursingResearch@gmail.com or call her at

If you qualify, you will be scheduled to participate in a one-to-one interview online with Jodi. The interview will last approximately 60-90 minutes.

If you have any questions, please do not hesitate to contact Jodi. Thank you in advance for participating in this important research!

Appendix B: Recruitment Flyer

Research Participation Opportunity!

Topic: End-of-Life Decision Making Terminology

When: Fall 2020

Where: An online Zoom interview

What: One-on-one interview exploring the perceptions of older adults regarding end-of-life decision making terminology

If you are interested in participating and if you meet the following criteria:

1) being age 65 or older,

2) having no terminal illness,

3) being able to speak and understand English, and

3) being able to attend the interview online,

please email the researcher at EricksonNursingResearch@gmail.com

or call her at .

MultiCare

VILLANOVA UNIVERSITY

CELEBRATE SENIORITY

PACIFIC LUTHERAN UNIVERSITY

Appendix C: Informed Consent

MultiCare
Institutional Review Board
Approved: 06/09/2020
Expires: No Expiration Date

Consent for Participation in a Human Research Study

Title of research study:	How Older Adults Perceive the Meaning of "Allow Natural Death"
Investigator:	Jodi Erickson, MSN RN CNL Doctoral (PhD) Student Villanova University M. Louise Fitzpatrick College of Nursing Phone: e-mail: jerick02@villanova.edu or EricksonNursingResearch@gmail.com
Supervising Professor:	Mary Ann Cantrell, PhD, RN, CNE, ANEF FAAN Professor, Director PhD Program Villanova University M. Louise Fitzpatrick College of Nursing Phone: (610) 519-6829 e-mail: mary.ann.cantrell@villanova.edu

Key Information:

This is a study about how older adults understand end-of-life decision making terminology. Individual interviews will happen over the internet and you will be asked to take part in an interview. The interview will last about 60-90 minutes. You will be asked questions about yourself prior to the start of the interview. No major risks have been identified relating to this study.

Why am I being invited to take part in a research study?

You are invited to take part in this study because you are: 1) age 65 or older, 2) have no terminal illness, 3) able to speak and understand English, and 4) able to attend the interview online.

What should I know about a research study?

- The researcher will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.
- You can know that we are committed to best practices for safety and the well-being of all participants.

Who can I talk to?

If you have questions, concerns, or think the research has hurt you, contact the researcher at or jerick02@villanova.edu, or the supervising professor at (610) 519-6829 or mary.ann.cantrell@villanova.edu.

This research is approved by an Institutional Review Board (IRB). You can contact the IRB office at (253) 403-3877 or IRB@MultiCare.org if:

- Your questions or concerns are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.
- You feel you have been injured or harmed while participating in this research.

Why is this research being done?

The goal of this research is to better understand how end-of-life decision making words are understood by older adults. By gaining a better understanding of these thoughts, better ways of communicating regarding death may be identified.

How long will the research last?

The interview will last about 60-90 minutes.

How many people will be studied?

About twenty people will take in this research.

What happens if I say yes, I want to be in this research?

If you take part in this research, the researcher will contact you to set up a time for a one-on-one interview. The interview will take place online during Summer 2020. You will receive a link to an online video meeting program. The interview will last about 60-90 minutes. It will consist of you, the researcher, and a research assistant who will help with taking notes and recording. The interview will be recorded and then written up. Your private information will be removed from the recording and transcription. At the beginning of the meeting, the researcher will ask you simple questions about yourself, including your gender, age, ethnicity, level of education, marital status, and if the you are living alone or with someone. At the end of the interview, you will be sent a $20 gift card to Fred Meyer.

What happens if I do not want to be in this research?

Participation in research is completely voluntary. You can decide to take part or not to take part.

What happens if I say yes, but I change my mind later?

You can leave the study at any time. It will not be held against you. Because any data collected up to leaving the study will be recorded, you will be asked if it is okay to use the information collected. If you give verbal permission on the recording for it to be used, data will be included in the study results, including any demographic data collected prior to the interview. You will still receive the $20 Fred Meyer gift card for partial participation in the interview.

Is there any way being in this study could be bad for me?

No physical, legal, social or financial risks are identified with this study. It is possible to have uncomfortable feelings related to the topic of death. There is a list of resources provided if these uncomfortable feelings occur.

It is also possible that there are risks to you we cannot predict.

Will being in this study help me in any way?

There are no promised benefits to you from taking part in this research. A possible benefit is feeling good about sharing your thoughts and ideas. Possible future benefits include changing how end-of-life decision making terms are used in the medical field and discussions about death.

What happens to the information collected for the research?

Your personal information will be removed from any recordings to limit the use and disclosure of your personal information. The information collected may be inspected by the IRB as well as some nursing faculty at Villanova University.

What else do I need to know?

If you take part in this research, you will get a $20 gift card to Fred Meyer after the interview for your time and effort.

There is no cost to you to participate other than the cost of internet, your computer/phone, and your time.

Your private information will be removed from anything you provide. After this, the information could be used for future studies without additional informed consent. Results of the study may be shared in nursing journals or at nursing conferences. However, your identity will not be disclosed.

We will provide you a copy of this form for your records.

RESEARCH SUBJECT'S BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a research study. You have the right:

1. To be told what the study is trying to find out;

2. To be told what will happen to you and whether any of the procedures, drugs, or devices are different from what would be used in standard practice;
3. To be told about any risks, side effects or discomforts associated with the research and with what frequency they will occur;
4. To be told if you can expect any benefit from participating and, if so, what the benefit might be;
5. To be told about other choices and how those alternatives may be better or worse than being in the study;
6. To be allowed and encouraged to ask any questions concerning the study before agreeing and during the course of the study;
7. To be told what sort of medical treatment is available should complications arise during the study and whether there will be payment for such complications or medical treatment;
8. To refuse to take part at all or to change your mind about participating even after the study has begun and to know that a decision not to take care will not affect the care they would otherwise receive;
9. To receive a copy of the consent form;
10. To be free of pressure when considering whether you wish to agree to be in a study;
11. To be assured that their confidentiality will be maintained;

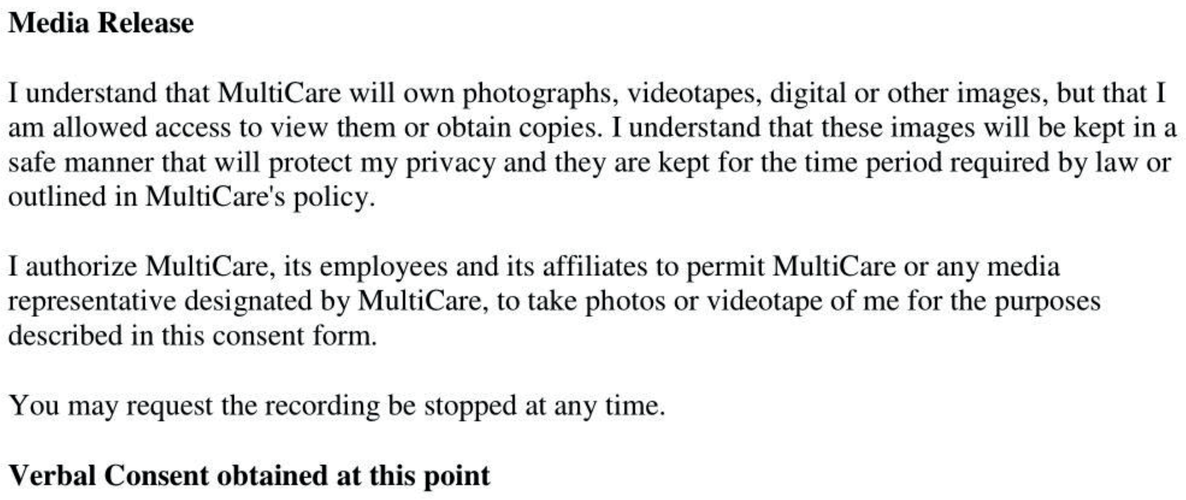
If you are considering participating in a research study and have questions about your rights as a subject may contact the MultiCare Health System IRB by calling the MHS IRB Office (253) 403-3877.

SUBJECT'S STATEMENT

My decision to be in this research study is voluntary. A decision not to take part or to quit the study at any time will have no effect on the care to which I am entitled. I have read this consent form. The purpose of this study, its potential risks, and any possible benefits have been explained to me.

My questions were answered, and I am free to ask questions at any time during the research. I have read all seven pages of the consent form, and I have decided to take part in this research study.

Verbal Consent obtained at this point



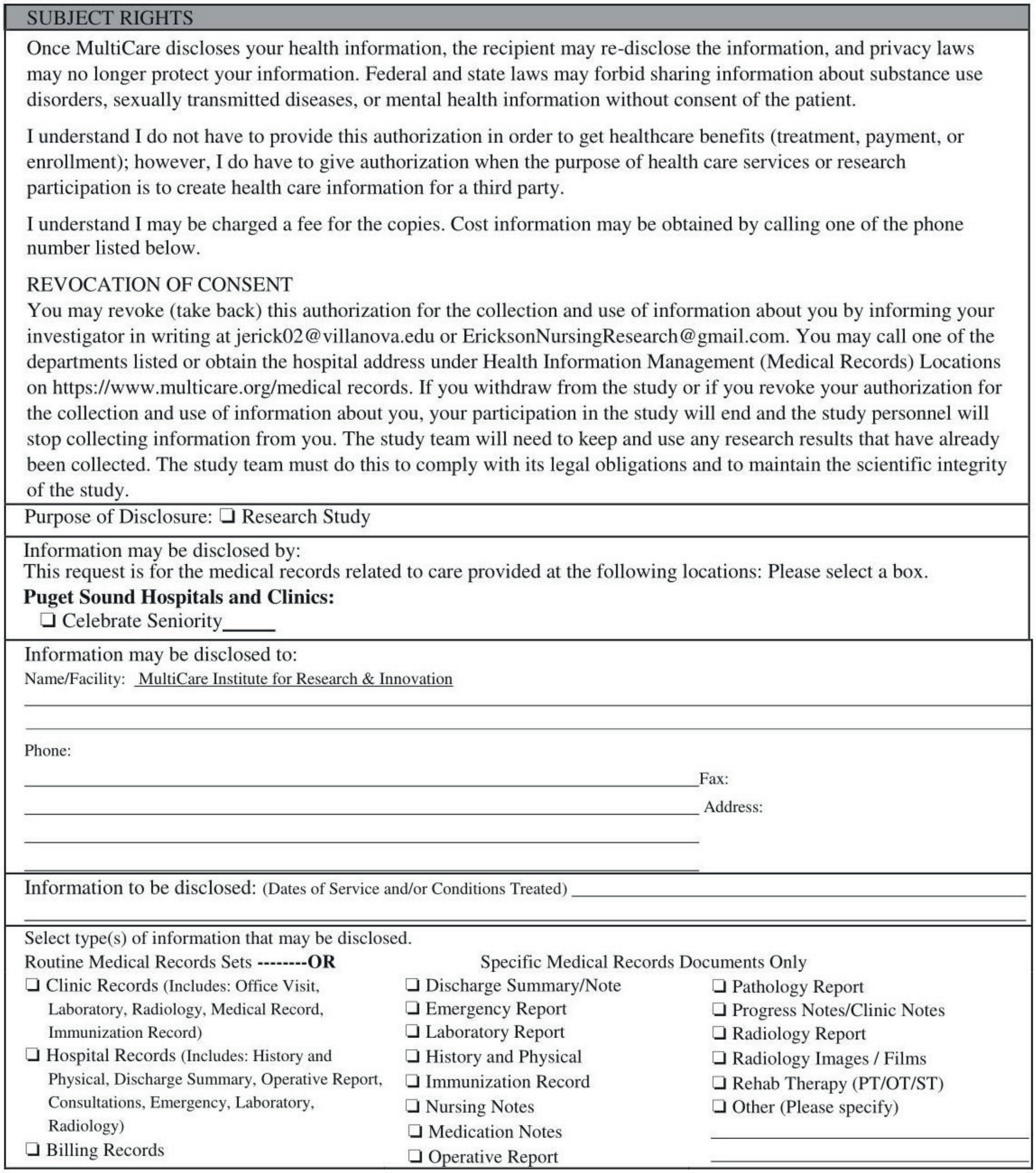
Media Release

I understand that MultiCare will own photographs, videotapes, digital or other images, but that I am allowed access to view them or obtain copies. I understand that these images will be kept in a safe manner that will protect my privacy and they are kept for the time period required by law or outlined in MultiCare's policy.

I authorize MultiCare, its employees and its affiliates to permit MultiCare or any media representative designated by MultiCare, to take photos or videotape of me for the purposes described in this consent form.

You may request the recording be stopped at any time.

Verbal Consent obtained at this point



SUBJECT RIGHTS

Once MultiCare discloses your health information, the recipient may re-disclose the information, and privacy laws may no longer protect your information. Federal and state laws may forbid sharing information about substance use disorders, sexually transmitted diseases, or mental health information without consent of the patient.

I understand I do not have to provide this authorization in order to get healthcare benefits (treatment, payment, or enrollment); however, I do have to give authorization when the purpose of health care services or research participation is to create health care information for a third party.

I understand I may be charged a fee for the copies. Cost information may be obtained by calling one of the phone number listed below.

REVOCATION OF CONSENT

You may revoke (take back) this authorization for the collection and use of information about you by informing your investigator in writing at jerick02@villanova.edu or EricksonNursingResearch@gmail.com. You may call one of the departments listed or obtain the hospital address under Health Information Management (Medical Records) Locations on https://www.multicare.org/medical records. If you withdraw from the study or if you revoke your authorization for the collection and use of information about you, your participation in the study will end and the study personnel will stop collecting information from you. The study team will need to keep and use any research results that have already been collected. The study team must do this to comply with its legal obligations and to maintain the scientific integrity of the study.

Purpose of Disclosure: ☐ Research Study

Information may be disclosed by:
This request is for the medical records related to care provided at the following locations: Please select a box.

Puget Sound Hospitals and Clinics:

☐ Celebrate Seniority_____

Information may be disclosed to:

Name/Facility: MultiCare Institute for Research & Innovation

Phone:

Fax:

Address:

Information to be disclosed: (Dates of Service and/or Conditions Treated) ____________________

Select type(s) of information that may be disclosed.

Routine Medical Records Sets **--------OR**

- ☐ Clinic Records (Includes: Office Visit, Laboratory, Radiology, Medical Record, Immunization Record)
- ☐ Hospital Records (Includes: History and Physical, Discharge Summary, Operative Report, Consultations, Emergency, Laboratory, Radiology)
- ☐ Billing Records

Specific Medical Records Documents Only

- ☐ Discharge Summary/Note
- ☐ Emergency Report
- ☐ Laboratory Report
- ☐ History and Physical
- ☐ Immunization Record
- ☐ Nursing Notes
- ☐ Medication Notes
- ☐ Operative Report
- ☐ Pathology Report
- ☐ Progress Notes/Clinic Notes
- ☐ Radiology Report
- ☐ Radiology Images / Films
- ☐ Rehab Therapy (PT/OT/ST)
- ☐ Other (Please specify)

I authorize the release of the below information: (Initial all that apply) See reverse side for details

____ HIV (AIDS virus)
____Sexually transmitted diseases
____Genetic information and indicators
____ Psychiatric diagnosis or mental health
____Substance use disorder

* * * NOTE: If this section is not completed, records of this type (if they exist), will not be released. * * *

***If the records requested above will result in any charges, I understand I will be contacted with an estimate of those charges before the records are produced. MultiCare's charges for release of information vary depending upon the nature and extent of the records requested. For more information, please go to https://www.multicare.org/medical-records*

This Authorization will expire in six years after you sign this authorization document.

STATEMENT OF AUTHORIZATION

I have read this form and its contents were explained. My questions have been answered. I voluntarily agree to allow study staff to collect, use and share my data as specified in this form. I will receive a copy of this form for my records. I am not giving up any of my legal rights by agreeing to participate.

Verbal Consent will be obtained at this point

Appendix D: Data Collection Manual: Script and Plan

Data Collection Manual:

Script and Plan

Principal Researcher: Jodi Erickson, BA MSN RN CNL

Contact Information:

Study Name: ***How Older Adults Understand the Meaning of Allow Natural Death***

Study Purpose: ***The purpose of this research is to gain a better understanding of how end-of-life decision making terminology is perceived by older adults. By gaining a better understanding of these perceptions, more effective ways of communicating regarding end-of-life decision making may be identified through further research.***

Inclusion Criteria: 1) age 65 or older, 2) having no terminal illness, 3) being able to speak and understand English, and 4) being able to attend the interview online.

Data Collection Procedure

1. A recruitment letter will be sent to 300 potential participants by MultiCare Celebrate Seniority. A social media post will be made as well. The letter and post will include general information regarding the study, including:
    a. Purpose of Study
    b. Inclusion Criteria
    c. How to Participate
    d. PI Contact Information
2. When potential participants contact the PI via email or telephone, the PI will conduct a screening to ensure the participants meet the inclusion criteria.
3. Screening Tool Script:

   a. "Thank you for your interest in this study. Is it okay if I ask you some questions regarding your health?"
   b. Proceed with screening questionnaire if answer is yes. If answer is no, ask if one can answer any questions in order to proceed. If answer continues to be no, thank the person for their time and provide contact info of PI.
   c. Complete screening tool.
   d. If answers to questions 1-3 are YES, the answer to question 4 is NO, state "You meet the criteria to participate in this study and we would really appreciate your participation. Participation is purely voluntary and you may change your mind at any time." Continue to step 3e.
   e. If a potential participant meets the criteria, a mutually agreed upon time will be identified. The consent form will be emailed to the participant immediately after the screening call. The form will be reviewed during the interview and verbal approval will be obtained.
   f. Provide participant with PI's contact information and state "Thank you so much for your time (name). We look forward to seeing you again at the interview on (date and time). You will receive a reminder call a day or two prior to your focus group interview date. If you have any questions or concerns prior to that, feel free to contact Jodi by phone or email. Thanks again!"

4. One to two days prior to each interview, the PI will call the participant scheduled for that interview and state, "This is Jodi Erickson, the nurse researcher who will conducting the interview for which you are signed up. I just wanted to remind you that you will be participating on (date) at (time). Can we expect to see you there?... Thank you so much

for your time!" If there is no answer, the PI will leave a message stating, "This is Jodi Erickson, the nurse researcher who will conducting the interview for which you are signed up. I just wanted to remind you that you will be participating on (date) at (time) via Zoom. If you have any questions, please feel free to contact me at (cell number). Thank you so much for your time. I look forward to speaking with you on (day of the week)!"

5. On the day of each one-on-one interview, the PI and RA will log on the Zoom meeting approximately ten minutes prior to the scheduled interview. Attire for PI and RA will be business casual, for example black slacks and a modest blouse. The PI and RA will discuss specifics about the interview and ready themselves for the interview.
6. At scheduled time, PI will invite the participant into the Zoom meeting from the virtual waiting room. The PI will then "lock" the Zoom meeting. Lock is a security option through Zoom which prevents additional people from entering the Zoom meeting. PI will state:
    a. "Thank you all for coming and participating in this interview."
    b. "My name is Jodi Erickson and I am the nurse researcher conducting this interview as part of my dissertation work at Villanova University. This is [RA's name] and they are a nursing student at Pacific Lutheran University."
    c. "I'll be conducting the interview and [RA's name] will be assisting me by taking notes and helping with any other needs that arise."
    d. "Is it okay if I begin recording using the Zoom recording feature now?"
    e. "When you signed up for this, you were emailed a consent form. Is it okay if we review the consent form at this time?" Once consent is reviewed and the

participant gives recorded verbal consent, state, “Just as a reminder, your participation is completely voluntary. If at any time you are feeling uncomfortable or would like to end your participation, please just let me know. If that happens, we’ll take a small break.”

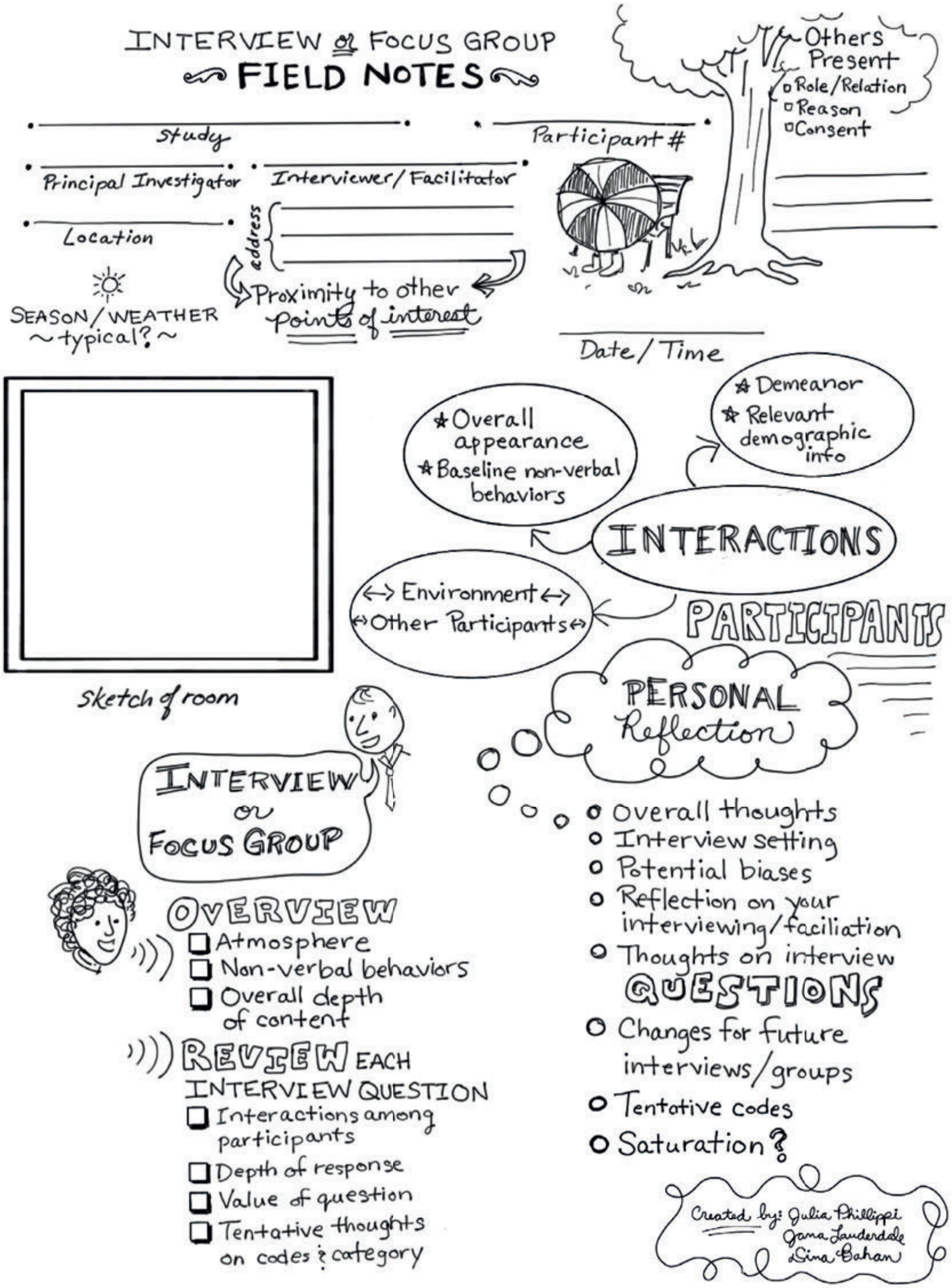
   f. “Additionally, I want to assure you that although we’ll use your name in this interview, your name will be removed from the transcripts to ensure your privacy. Any documents or recordings related to this study will be kept in a locked cabinet in my locked office until five years after the study is complete at which time they will be destroyed.”
   g. “Today’s interview will last approximately 45 to 60 minutes. Does you have any questions?”

7. PI will commence with interview questions (Appendix F). The RA will take field notes.
8. At end of the interview, PI will thank the participant for their participation, will field any questions, and will inform the participant that a Fred Meyer gift card will be mailed to them within a week. The Zoom recording will be stopped.

Appendix E: Semi-Structured Interview Questions

Semi-structure questions	Rationale
“In the context of end-of-life decision-making, when you hear the term ‘Do Not Resuscitate’, what do the words mean to you?”	Explore the meaning of DNR
“In the context of end-of-life decision-making, when you hear the term ‘Do Not Resuscitate’, how does this make you feel?”	Explore the emotions related to DNR
“In the context of end-of-life decision-making, when you hear the term ‘Allow Natural Death’, what do the words mean to you?”	Explore the meaning of AND
“In the context of end-of-life decision-making, when you hear the term ‘Allow Natural Death’, how does this make you feel?”	Explore the emotions related to AND
Wrap up question: What do you consider to be the most important question discussed?	Allows for closure and help the researcher know “where participants place importance.” (Krueger & Casey, 2015, p. 146)

Appendix F: Field Notes



INTERVIEW or FOCUS GROUP

FIELD NOTES

Study

Participant #

Principal Investigator

Interviewer/Facilitator

Location

address

Proximity to other points of interest

SEASON/WEATHER

~typical?~

Date/Time

Others Present

- ☐ Role/Relation
- ☐ Reason
- ☐ Consent

sketch of room

INTERACTIONS

- ✱ Overall appearance
- ✱ Baseline non-verbal behaviors

- ✱ Demeanor
- ✱ Relevant demographic info

- ↔ Environment ↔
- ↔ Other Participants ↔

PARTICIPANTS

PERSONAL Reflection

- ○ Overall thoughts
- ○ Interview setting
- ○ Potential biases
- ○ Reflection on your interviewing/faciliation
- ○ Thoughts on interview QUESTIONS
- ○ Changes for future interviews/groups
- ○ Tentative codes
- ○ Saturation?

INTERVIEW or FOCUS GROUP

OVERVIEW

- ☐ Atmosphere
- ☐ Non-verbal behaviors
- ☐ Overall depth of content

REVIEW EACH INTERVIEW QUESTION

- ☐ Interactions among participants
- ☐ Depth of response
- ☐ Value of question
- ☐ Tentative thoughts on codes & category

Created by: Julia Phillippi
Jana Lauderdale
Sina Bahan

Template by Phillippi & Lauderdale (2018)

Appendix G: Demographic Information of Study Participants

Table 1

Variable	**Categories**	**n**	**%**
Gender	Female	19	79.2%
	Male	5	20.8%
Age	65-69	6	25%
	70-74	12	50%
	75-79	3	12.5%
	80-84	0	0%
	85-89	3	12.5%
Ethnicity	Caucasian	21	87.5%
	African American	1	4.2%
	Hispanic American	1	4.2%
	Jewish American	1	4.2%
Education	High School Diploma	1	4.2%
	Some College	4	16.7%
	Two Year Degree	1	4.2%

	Bachelor’s Degree	6	25%
	Master’s Degree	9	37.5%
	Doctoral Degree	3	12.5%
Marital Status	Married	12	50%
	Divorced	5	20.8%
	Widowed	4	16.7%
	Single	2	8.3%
Living Situation	Alone	6	25%
	With Someone	18	75%
Region	Pacific Northwest	22	91.7%
	East Coast	2	8.3%

Appendix G: Diagram of Participant 19 Quotations and Codes