YOUNG ADULTS
AND ADVANCE CARE PLANNING

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Abstract: Advance care planning (ACP) is often thought to be for the old or seriously ill, but young adults often experience unexpected accidents, leaving them unable to communicate their wishes for medical care. As the medical community strives toward person-centered care, not having an advance directive (AD) inhibits planning toward individual desires and places an unnecessary burden on next-of-kin to make choices for the patient. There is no comprehensive rule about when ACP should start. Ideally, it is an ongoing dialogue between individuals, their families, and their providers. This study explored young adults and advance care planning in the United States through the lens of Symbolic Interaction Theory and Systems Theory while examining the association of age and race/ethnicity on completing the tasks of ACP, the impact of having been exposed to ACP discussion with elders, the relationship of knowledge and health status, as well as the impact of experience with death on willingness to engage in those discussions. Recommendations for practitioners and future research are also addressed.

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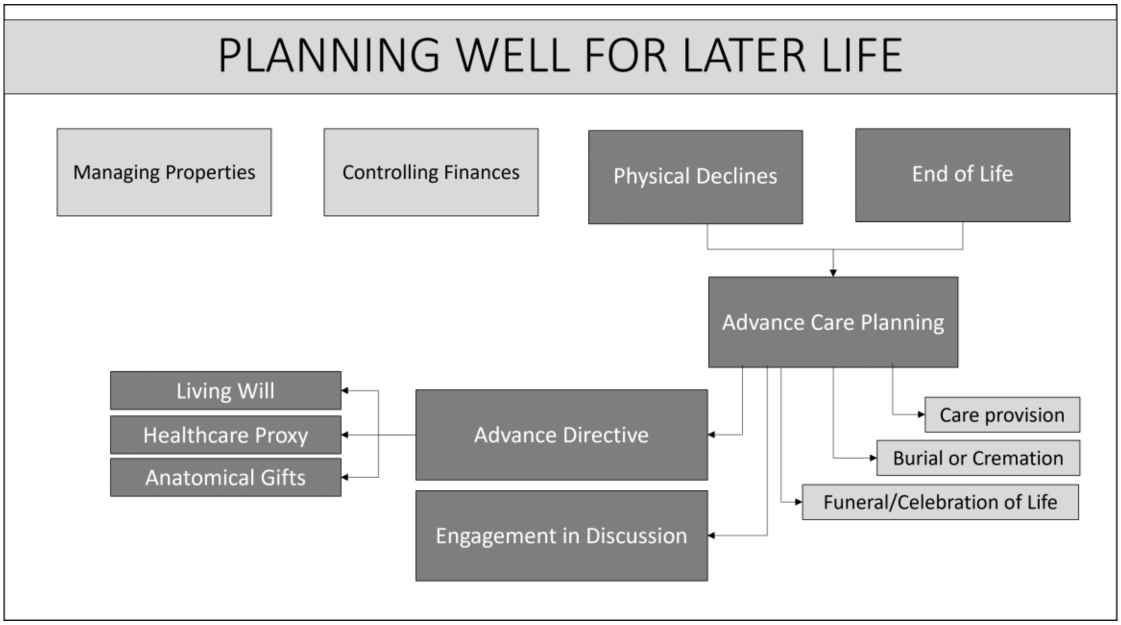
CHAPTER I

INTRODUCTION

Planning for later life involves many tasks; from the management of material properties and finances, to ensuring care is provided when physical abilities decline, and end-of-life nears. As can be seen in the Figure A below (developed by this author for the purpose of explaining what is involved in planning for later life), addressing physical declines and end-of-life ahead of time is the focus of Advance Care Planning (ACP). This involves processes of considering plans for care provision, deciding on burial or cremation, and working with loved ones to coordinate a funeral or celebration of life, as well as the completion of Advance Directives (AD) (which includes a living will, healthcare proxy, and anatomical gifts) and the Willingness to Engage in Discussion that facilitates that. The focus of this study was on Advance Care Planning (ACP) in the United States, which is reflected in Figure A by the dark gray boxes.

Figure A



Advance care planning (ACP) is an on-going process (Cheung et al., 2020; Hickman, Jr. & Pinto, 2013; Karel et al., 2004; McMahan et al., 2021; Periyakoil et al., 2017; Senteio & Callahan, 2020; Wiener et al., 2013) where individuals share with others about their own wishes for care and treatments, as well as their personal preferences that will enhance the individual's quality of life as they age (Baker & Marco, 2020, Emanuel & Emanuel, 1994; Otis-Green et al., 2019; Payne et al., 2009). Preferably, these discussions involve patients and their family (Bond et al., 2018; Kim et al., 2020; Senteio & Callahan, 2020), relieve anxiety (Bond et al., 2018; Nguyen et al., 2017) and encourage shared decisions (Allen et al., 2019; Bond et al., 2018; Bisognano & Goodman, 2013; Kim et al., 2020; Senteio & Callahan, 2020).

ACP is ideally completed prior to a medical crisis (Buiar & Goldim, 2019; Galambos et al., 2021; Karnik et al., 2002; Oriakhi et al., 2019; Wiener et al., 2013), while an individual is fully able to express desired cares (Karnik et al., 2002; Young et al., 2022). The discussion of ACP between family and medical providers focuses on end-of-life decisions (Billings & Bernacki, 2014) and quality of life, while also setting the expectation that future discussions are expected (Wiener et al., 2013). The overall process takes time and involves very individualized dialogues (Coats et al., 2019) that can be uncomfortable (Oriakhi et al., 2019). Still, it is through active engagement in ACP that individuals and their loved ones have the opportunity for clarification, which ideally results in less conflict when the need to implement ACP occurs (Karel et al., 2004).

As reflected in Figure A, there are several aspects of ACP, one of which is the completion of an Advance Directive (AD) (Gonzalez et al., 2021; Sumalinog et al., 2017). In the US, these documents are generally provided by the states in which individuals live, many times for free. As part of the on-going dialogue (Cheung et al., 2020; Ko et al., 2016; Mahon, 2011; Periyakoil et al., 2017) had with their loved ones and medical providers, individuals complete these documents to ensure their wishes are known. ADs are designed to provide patients a means of preventing treatments they would not choose for themselves (Baker & Marco, 2020: Payne et al., 2009; Pfirstinger et al., 2017) by directing their care themselves (Baker & Marco, 2020; Payne et al., 2009; Pfirstinger et al., 2017; Weaver, 2021). This equips their medical team and eases the stress of decision making on loved ones (de Caprariis et al., 2017).

Advance Directives

ADs are the best way to ensure autonomy (Bailoor et al., 2018; Bravo et al., 2008), allowing individuals to communicate not just their medical desires, but also their partialities for how they live to their proxy (Bailoor et al., 2018), thereby reducing their loved ones of the decision-making burden (Fifer, 2015; Kim et al., 2020; Hickman Jr. &

Pinto, 2013). The overarching goal of the items in any AD is to provide the individual with a dignified end of life (Buiar & Goldim, 2019). Some ADs include a preferred location for death (Karnik & Kanekar, 2016; Buiar & Goldim, 2019) and/or the medical provider's do-not-resuscitate (DNR) order (Billings & Bernacki, 2014). Most often, an AD includes two key documents: a living will and a healthcare proxy (Buiar & Goldim, 2019).

Living Wills

A living will declares individual preferences for treatments and care (Baker & Marco, 2020; Barker et al., 2021; Graw et al., 2021). This is a set of specific instructions (Kapp, 2000; Schubart et al., 2014) that allows individuals to elect, or decline, treatments such as antibiotics, cardiopulmonary resuscitation, ventilator, and artificial hydration or nutrition. The document itself declares what is required for it to go into effect (Salmond & David, 2005).

Healthcare Proxy

A healthcare proxy (sometimes called a healthcare power of attorney) provides the patient a way to identify someone to make decisions for them that are not covered in the AD when they are no longer able (Buiar & Goldim, 2019; de Caprariis et al., 2017; Gonzalez et al., 2021; Kapp, 2000; McMahan et al., 2013; Otis-Green et al., 2019; Portanova et al., 2017; Schubart et al., 2014; Starzee, 2017; Tamayo-Velazquez et al., 2010). Ideally the patient has been involved in on-going discussion with their proxy and the proxy is aware of the patient's treatment goals (Otis-Green et al., 2019). Since doctor's decisions for care can be impacted by both ADs and the proxy's input (Escher et al., 2014), it is important proxies are well-versed in the patient’s preferences (Hickman, Jr. & Pinto, 2013).

Anatomical Gifts

As part of an advance directive, anatomical gifts defines what, if any, donations are to be made of an individual’s body at the time of their death. This can be a sensitive issue (Periyakoil et al., 2017). In the USA, many states include donor options on individual drivers’ licenses (Otis-Green et al., 2019). Entire body, or specific organ, donation can be arranged prior to death.

Completion

Advance directive completion rates are low (de Caprariis et al., 2017; Graw et al., 2021) with less than one-third of Americans adults having completed one (Sorrell, 2018; Thoekle, 2018; Yadav et al., 2017), although 90% feel talking about end-of-life is important (Sorrell, 2018). The absence of an advance directive (AD) makes it difficult for medical providers to formulate plans and can cause an undue burden on family, affecting critical decisions about care (de Caprariis et al., 2017). Additionally, many adults develop informal supportive relationships with nonfamily members, and they could be whom the individual would choose as their decision maker (Thaggard & Montayre, 2019). But without an AD that appoints that person as a health care proxy, their role as the preferred person in the decision-making process is still unrecognized. Therefore, due to the nature of accidents and sudden illness, it is important to plan for later life care in advance (Barrison & Davidson, 2021; Kapp, 2000; Needle & Smith, 2016; Robinson et al., 2019).

To date, efforts toward advance planning have focused on elders (Kapp, 2000; Kavalieratos et al., 2015; Stone et al., 2023; Thoelke, 2018) and the bulk of the literature reports on those medically ill. Yet, medical crises can happen at any age, leaving someone incapacitated (Chan, 2019; de Caprariis et al., 2017) to the degree that an advance directive is needed to direct care. Young adults, specifically being at the highest risk of unintended injury or illness (Young et al., 2022) and in a season of changing support systems (Nelson 2008), are particularly in need of planning for their cares.

This study looks specifically at young adults, 18-29 years of age. Emerging adults have previously been declared as 21-29 years of age (Arnett & Schwabb, 2012) and young adults (included with adolescence) as those 12-24 (Fladeboe, et al., 2021). In the interest of including all young people who are old enough to make their own choices, this study included all 18–29-year-olds as Young Adults. This dissertation aimed to answer the following research questions: 1) What role do demographics play in Advance Care Planning (ACP) Status? 2) How is Life Experience related to Willingness to Engage in Discussion and ACP Status? 3) How are Knowledge and Willingness to Engage in Discussion associated with each other? 4) How are Life Experience, Knowledge, and Willingness to Engage in Discussion associated? 5) How are Health Status and Knowledge related?

CHAPTER II

LITERATURE REVIEW

As medical care has advanced, a multitude of life prolonging treatments have been developed to keep patients alive. Often, this is done without improving or providing significant quality of life (Karnik et al., 2002). In fact, patients can maintain living in a vegetative state for years (Ramsey, 2013). This can be emotional and expensive (Karnik et al., 2002). The U.S. medical system is geared toward aggressive treatment (Enguidanos & Ailshire, 2017) with interventions like ventilators and artificial hydration/nutrition prolonging life, but not curing any disease, relieving any pain, or improving a person's functioning (Weiss & Lupkin, 2010). Many individuals are receiving treatments they would not have chosen for themselves (Bisognano & Goodman, 2013; Omilion-Hodges et al., 2019).

Advance Care Planning

The process of ACP should emphasize preparation of family members to be prepared for communicating the patient's wishes when that is being done during an emotional time (Perkins, 2007). Identifying the proxy is important (Baker & Marco, 2020) but communicating with the proxy prior to crisis is essential to having wishes met when unable to communicate. When terminally ill most patients do not want aggressive treatments, but they tend to be initiated unless the proxy specifically instructs medical staff not to (Gabler et al., 2016). To be best prepared for decision making, proxies need to have on-going discussion to learn about their loved ones' values and everchanging goals for care, what they mean when they define their expected quality of life, and how their past experiences have shaped what they believe and desire to have happen (McMahan et al., 2013). It is not the template of the form or the nature of the proxy's relationship with the patient that matters most (Escher et al., 2014). Having an AD and a proxy who agrees with it is the best way for individuals to influence the decisions of medical providers (Escher et al., 2014).

It is important families recognize that with or without an AD, they will be asked to make choices (Cattagni Kleiner et al., 2019). And while there is not much to be found in the literature about ACP implementation (Chiu wu et al., 2020), what is known is that often proxies are making decisions that are good rather than what is specifically lined out by the patient (White & Arnold, 2011), not understanding they are supposed to be seeking what the patient would want rather than choosing what the proxy believes is best (Otis-Green et al., 2019).

Billings and Bernacki (2014) and Bailoor et al. (2018) both stress the value for communicating individual wishes as well as lifestyle options. Several studies have shown the discussion itself improves quality of life in later years (Baker & Marco, 2020, Emanuel & Emanuel, 1994; Otis-Green et al., 2019; Payne et al., 2009). It has even been suggested that just as activities like wellness checks and preventative screenings, advance directive discussions should be scheduled like vaccinations (Madrid & McGee, 2019).

Advance Directives

Bailoor et al. (2018) pointed out the use of ADs provides an avenue to identify decision makers to implement an individuals' desires. While McMahan et al (2013) stress the importance of choosing a proxy wisely to ensure they understand their role. Proxies are expected to spring into action when the patient can no longer make decisions for themselves (Baker & Marco, 2020) in a medical system that has yet to supply any systematic education about their role (Karel et al., 2004). Strides in family education have been made. Beginning in 2014, the Caregiver Advise, Record, and Enable (CARE) Act has been enacted in 40 states (AARP, 2023) and provides comprehensive education to family members and caregivers. Still, there is still much work to do to prepare proxies specifically.

Advance directive forms are available for free, are legally binding (Morhaim & Pollack, 2013), and remain the best tools to relieve the burden of decision making on loved ones (Hickman, Jr. & Pinto, 2013). Having an AD has the potential to ease the tension in families and reassures them they are making choices the individual would want, such as when to end life support (Ramsey, 2013). They also increase the likelihood of patients' wishes being followed (Nguyen et al., 2017). At minimum it should be offered to all adults (de Caprariis et al., 2017; West & Hollis, 2012) preferably prior to a medical crisis. After all, medical crises can happen at any age, leaving someone incapacitated and in need of a decision maker (de Caprariis et al., 2017). Because circumstances can change suddenly, it is important that ACP dialogues happen sooner (Barrison & Davidson, 2021). This should be a national priority (Yadav et al., 2017).

Policy and Practice

In 1990, the Patient Self-Determination Act was enacted requiring all facilities who are funded with federal dollars to ask every admitting patient whether they have an advance directive (AD) and if they do not, provide them with information about their right to do so (Inoue et al., 2018). The Act is aimed at equalizing access to advance directives (Koss & Baker, 2017) and intends to provide a guarantee that patients' wishes for care and treatment will be honored (Davis, 2013; de Caprariis et al., 2017; Inoue et al., 2018; Jezewski et al., 2007; Ramsey, 2013; Salmond & David, 2005). Policy makers as well as medical providers, have striven to encourage use of ADs (Ko et al., 2016) because they serve as a guide to medical providers and family members (Durbin et al., 2010) by detailing decisions the patient believes would improve their quality of life (Allen et al., 2019; Garrido et al., 2015).

Sadly, often proxies are named, and no discussion regarding their role or responsibilities has been had with them (Nicholas et al., 2014; Perkins, 2007). Proxies who do not know the patient's preferences are at higher risk of decisional burden (Hickman, Jr. & Pinto, 2013). They could choose to elongate someone's life in an avoidance of guilt or regret due to not knowing their wishes (Buiar & Goldim, 2019). ADs are comforting to proxies, as the proxy can know they are doing what the patient chose for themselves (Ramsey, 2013). In this way, they are a primary prevention strategy that works to alleviate the decisional burden (Hickman, Jr. & Pinto, 2013) that can confound circumstances (Nehra & Gupta, 2019) and have lasting impacts on proxies (Hickman, Jr. & Pinto, 2013).

Theory

Symbolic Interaction Theory

Human behavior is best understood by appreciating the meaning behind the behavior itself (Carter et al., 2018) and that symbolic meanings, developed through a process over time, are dependent on the interaction of individuals in social environments (Aksan et al., 2009; Olasina, 2014). The social reality is constructed in an evolving process of interpretation and action providing individuals with influence on one another and their environment (Aksan et al., 2009; Johnson, 2008). The individual is seen as both the giver and receiver of action (Stryker, 1972). There exists a reciprocal dynamic between meaning-making and behavior (Charmaz & Belgrave, 2013). And the interpretation of meaning is affected by environment and communicated through action (Johnson, 2008).

Symbolic interaction involves the meaning and values of actions (Aksan et al., 2009; Ballis, 1995; Charmaz & Belgrave, 2013; Folami & Olaiya, 2016; Fynbo, 2018; Olasina, 2014), objects (Ballis, 1995; Johnson, 2008; Olasina, 2014), symbols (Aksan et al., 2009; Ballis, 1995; Folami & Olaiya, 2016), and language (Charmaz & Belgrave, 2013; Fynbo, 2018; Stoner et al., 2019). Individuals create meanings (Ballis, 1995; Fynbo, 2018; Naidu & Benhura, 2016) and the broader society has an influence on them (Kuhn, 1964). Symbolic Interaction Theory takes into account the situation and the setting (Ballis, 1995; Johnson, 2008; Smith & Bugni, 2006), and poses that meaning is dependent on the individual’s viewpoint (Aksan et al., 2009; Ballis, 1995; Carter, et al., 2018; Kuhn, 1964; Naidu & Benhura, 2016) because things, even humans, do not have inherent meaning (Aksan et al., 2009). Even the development of self is a process that intertwines individuals’ experiences with how they perceive society’s view (Mead, 1934). Individuals draw boundaries and define relationships by naming things based on the meaning to the individual (Charmaz & Belgrave, 2013).

Humans assign meanings to symbols (Aksan et al., 2009; Charmaz & Belgrave, 2013; Johnson, 2008; Young, 1991), objects (Ballis, 1995), and gestures (Young, 1991). These meanings are dependent on the situation (Young, 1991) and hold power as perceived facts (Aksan et al., 2009). They use language as one of the ways to communicate these meanings (Aksan et al., 2009; Johnson, 2008; Stoner et al., 2019; Stryker, 1972). Whether spoken or unspoken, there is a reciprocal interpretation that enhances communication (Charmaz & Belgrave, 2013; Naidu & Benhura, 2016). Words may be essential to details of an event or object (Johnson, 2008). This is what separates humans from animals (Aksan et al., 2009). It is this communication, through socializing and educating, that individuals are able to glean from experiences in groups (Ballis, 1995; Mead, 1934). Through language, individuals develop different personalities (Stryker, 1972).

Objects often exist physically, like a couch or table. But can also be abstract, like emotions and motivations (Ballis, 1995; Johnson, 2008; Young, 1991). The meaning, or definition, is influenced by a multitude of things such as laws, societal norms, and roles (Aksan et al., 2009; Johnson, 2008) and then bolstered socially (Ballis, 1995; Johnson, 2008) through the interaction with, and action of, others (Johnson, 2008). The process of developing meaning for objects involves not just symbolization and social experiences, but also adjustments made through communication (Mead, 1934).

Meaning is always evolving (Charmaz & Belgrave, 2013; Folami & Olaiya, 2016; Fynbo, 2018; Naidu & Benhura, 2016), changing through interactions (Naidu & Benhura, 2016; Stoner et al., 2019), and intertwined with individuals' roles (Folami & Olaiya, 2016; Nazarinia Roy et al., 2014; Stryker, 1972; Young, 1991), which they transition in and out of over time and place (Young, 1991). Still, it is language that constructs social reality, and links every level of focus (micro through macro) as well as experiences across time (past to future) (Johnson, 2008). A simple, "How are you?" can be interpreted in a multitude of ways (Young, 1991).

Actions can have symbolic meaning assigned by the individual seeing them (Aksan et al., 2009; Ballis, 1995; Charmaz & Belgrave, 2013; Olasina, 2014) and can have different meaning for different people (Aksan et al., 2009; Folami & Olaiya, 2016; Olasina, 2014). Yet, it is through interaction with others that an individual develops how they interpret the actions of others (Ballis, 1995; Stoner et al., 2019) as well as where their limits are and what boundaries others hold (Olasina, 2014). Still, meanings are so dependent on setting, actors, and individual values, the sources of meaning are not clearly identified (Aksan et al., 2009). Individuals tend to act from their perceptions rather than what they know to be fact (Olasina, 2014). This could happen because in order to produce meaning, an event has to have occurred (Aksan et al., 2009) and meaning-making is done through their chosen actions (Charmaz & Belgrave, 2013). In fact, symbolic interaction has been referred to as a process of interpretating action (Aksan et al., 2009).

Systems Theory

The focus of Systems Theory is on the individual's relationship with the world around them (von Bertalanffy, 1972). As individuals interact with their worlds, they choose social actions to maintain balance (Cox et al., 2010). Individuals are free to make choices and decide their own actions, however those choices and actions are both influenced by and have influence on the broader system (e.g., family, community, and culture) (von Bertalanffy, 1972).

A system is a group of interacting parts (Anderson et al., 2013; Klein & White, 1996). Systems are dynamic, rather than static (von Bertalanffy, 1972), meaning a change in part of the system affects the system as a whole (Anderson et al., 2013; Henry, 2022; Whitchurch & Constantine, 1993). Therefore, it is impossible to understand an individual without understanding the systems in which they function (Klein & White, 1996).

Systems have multiple levels, all of which interact with the other levels (Anderson et al., 2013). As systems affect the environment around them, the environment also affects each system (Klein & White, 1996). For example, the system of the family in the community, which is another complex system. The community interacts with the system that makes up the culture. All of these interacting systems affect the family, as a whole, through feedback without redefining the system of the family. All systems have boundaries (Caws, 2015), that is what defines the beginning and end of each system (Anderson et al., 2013). Internal boundaries exist between family members and define autonomy while external boundaries define those in the family system from those outside the membership (Anderson et al., 2013). Likewise, the medical system has boundaries, to community access and information. There are community level barriers, a disconnect in the system, that prevents individuals from accessing care and assistance with advance care planning.

Intersection of Symbolic Interaction Theory and Systems Theory

Both theories recognize the bidirectional influence between individuals and social others. Systems Theory focuses on the relationship of individuals and the world around them (von Bertalanffy, 1972) and Symbolic Interaction Theory explores how individuals and social interactions are inseparable (Charmaz & Belgrave, 2013). Both theories identify culture as a major contributor to behavior in that Systems Theory suggests that culture plays a primary role in the construction of values (Rousseau, 2015) and interpretation of actions (Valentinov et al., 2019) and Symbolic Interaction Theory emphasizes an individual's culture (Nazarinia Roy et al., 2014), assuming society precedes the individual (Charmaz & Belgrave, 2013) and giving little emphasis to individual experiences outside the impact of community (Nazarinia Roy et al., 2014). In Systems Theory, individuals choose social actions based on what they believe and in Symbolic Interaction Theory, individuals process their experiences and formulate their responses from their perceptions. The intersection of these theories can help us understand young adults' and advance directives.

How Theory Explains Perceived Health and Knowledge/Awareness

Symbolic Interaction Theory explains that individuals interact in the domain of symbols (Aksan et al., 2009; Ballis, 1995; Folami & Olaiya, 2016; Stryker, 1972) and meanings (Aksan et al., 2009; Ballis, 1995; Johnson, 2008; Stoner et al., 2019; Stryker, 1972). Symbols represent something more than can be seen with the eye, while meaning is what that symbol says to the individual (Mead, 1934). This means there is more to human interaction than can be seen through observation. Individuals continually interpret and apply meaning to symbols they see in social interactions and construct their meaning according to their own reality. This, in turn, affects the way they choose to respond, in action or word, to the given circumstance. These symbols and perceived meanings affect the way the individual thinks and feels (Ballis, 1995; Olasina, 2014; Stryker, 1972). The meaning that is assigned to a symbol, influences how someone feels about the symbol. For example, if an individual sees an advance directive as a symbol inviting death to come, they are not likely to complete it. Their feelings related to the discussion of and preparation for end of life narrows their perceived options for response to situations involving that symbol.

Actions also have meaning and value in Symbolic Interaction Theory (Aksan et al., 2009; Ballis, 1995; Charmaz & Belgrave, 2013; Folami & Olaiya, 2016; Fynbo, 2018; Olasina, 2014). Social actions are seen, and they mean something. The behavior of exiting suddenly versus saying goodbyes and exiting casually has a different value and meaning to the individuals in the situation. Meanings are applied by individuals (Ballis, 1995; Fynbo, 2018; Naidu & Benhura, 2016) and are powerful due to being perceived as facts (Aksan et al., 2009). Using the advance directive symbol example, people believe their perception to be true. If an individual believes completing the advance directive is done out of genuine care and concern to relieve their loved one of the burden of making choices for their care, they are much more likely to engage in the process than those who view it as inviting death to come. Both would believe they are seeing the advance directive as the fact of the meaning they apply.

Meaning is always changing and developing (Charmaz & Belgrave, 2013; Folami & Olaiya, 2016; Fynbo, 2018; Naidu & Benhura, 2016). As individuals learn and grow, their understandings evolve and the meanings they assign to different objects, experiences, environments, and people change too. The institution of a bank means something different to a child being taught to save twenty-five cents a week (and get a sticker for giving their quarter to the clerk) than it does to the middle-aged single mom buying her first home and asking the bank for help with financing.

The way young adults perceive their own health may be associated with completion of an advance directives through the symbolic interaction of the meaning they apply to their own health as well as to document itself (because the AD means more to them than the ink on the paper). If they view ADs with an assigned meaning that it is something done by those in poor health, they may prolong their own completion because they feel they are in excellent, or even good, health themselves. There is also the consideration of culture. It is impossible to understand an individual without understanding the system in which they function (Klein & White, 1996). The meaning individuals assign to the act of completing an AD is formulated by their experience in their family or society, their experiences affect the options they see available.

How Theory Explains Advance Directive Completion

Through the lens of Symbolic Interaction Theory, actions can also have an assigned meaning (Aksan et al., 2009; Ballis, 1995; Charmaz & Belgrave, 2013; Olasina, 2014) which can vary from one person to the next (Aksan et al., 2009; Folami & Olaiya, 2016; Olasina, 2014) and people act based on what they perceive to be true (Olasina, 2014). From the Systems Theory lens, each part of a system affects other parts of the system (Klein & White, 1996). That means when a family system has developed an internal culture where the symbolic meaning related to completion of advance directives means they were inviting death to come, family members will likely not complete the document. Alternatively, a family emphasizing preparation for potential unexpected situations may be more likely to be open to completing an advanced directive. In both cases, what the family system and their members perceive to be true is likely to be the basis of the advanced directive decision, regardless of objective evidence (e.g., statistical facts). In the first example, a redefinition of the meaning of an advanced directive would be necessary for members to engage in this action.

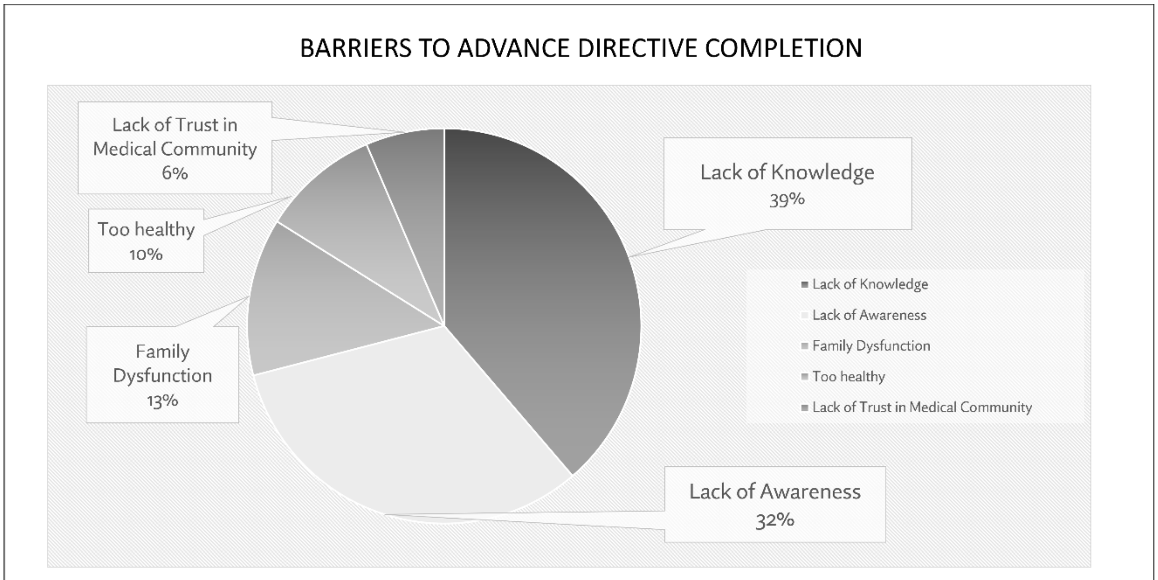
The words “advance directive” may hold a preconceived set of feelings and/or emotions based on an individual’s past experiences. An individual’s opinion and relationship with planning for later life can be greatly shaped by whether they have positive experiences, within their system, of others who planned ahead, exposed them to the implementation of an advance directive, and have a foundational understanding of the process. There is an internal process involved in considering later life or medical crisis. An individual can only see through the lens of their education and experience. If they have had exposure to illness or death, the impact they perceive will be influenced. They may be more willing to engage in thinking toward their own decline.

In summary, knowing an individual’s preferences for care guides treatment and reduces suffering, so that this life is ended well and that is reason enough to encourage ACP (Emanuel & Emanuel, 1994; Halpern & Emanuel, 2012). Understanding the driving forces for completing, or avoiding, the process of ACP and completion of ADs, through the lens of Systems and Symbolic Interaction will improve efforts to increase completion rates. Looking specifically at healthy young adults, as this population is woefully missing from the scholarship, and at substantial risk for unintentional accident or injury, will aid in empowering those individuals to direct their own care and equip their proxy to make decisions they would choose for themselves.

Barriers

As can be seen in Figure B, there are a number of barriers associated with ACP. Patients lack the knowledge necessary to complete their ACP (Cheung et al., 2020; de Caprariis et al., 2017; Kim et al., 2020; McDonald et al., 2017; Radhakrishnan et al., 2017; West & Hollis, 2012), or find the paperwork hard to understand (Scholten et al., 2018). A complete lack of awareness is often reported (Bernard et al., 2020; Cheung et al., 2020; Kavalieratos et al., 2015; Kim et al., 2019; Pollack et al., 2010; Rao et al., 2014; Thoekle, 2018). Some patients believe they are too healthy to need an AD (Bernard et al., 2020; Pollack et al., 2010; Radhakrishnan et al., 2017). Many believe ACP is for elders or those terminally ill (de Caprariis et al., 2017; Oriakhi et al., 2019).

Figure B



(Bailoor et al., 2018; Bernard et al., 2020; Billings & Bernacki, 2014; Buiar & Goldim, 2019; Cattagni Kleiner et al., 2019; Cheung et al., 2020; Coats et al., 2019; de Caprariis et al., 2017; Enguidanos & Ailshire, 2016; Genewick et al., 2018; Hart et al., 2018; Harvey et al., 2019; Hemsley et al., 2019; Howard et al., 2018; Kim et al., 2019; Kim et al., 2020; Ko et al., 2016; Koss & Baker, 2017; Macleod et al., 2020; McDonald et al., 2017; Miyashita et al., 2020; Nehra & Gupta, 2019; Oriakhi et al., 2019; Peck et al., 2018; Pfirstinger et al; 2017; Pollack et al; 2010; Poveda-Moral et al., 2021; Radhakrishnan et al, 2017; Rao et al., 2014; Risk et al., 2019; Sanders et al., 2019; Scholten et al., 2018; Senteio & Callahan, 2020; Thaggard & Montayre, 2019; West & Hollis, 2012; Wright, 2018; Yadav et al., 2017)

Lack of Knowledge

Dobbins (2019) identified six misconceptions that negatively impact completion of advance directives. They are believing an attorney is necessary; identifying a proxy forfeits a person's right to decision making; a living will is required to prevent unnecessary treatments; the state's form is the only one that works: and ADs are for older people (Bernard et al., 2020; de Caprariis et al., 2017; Dobbins, 2019; Oriakhi et al., 2019). An attorney is not required to completion an AD. The identification of a proxy does not lessen a person's control while they are able to communicate. A living will is not needed for families to discuss and decide on treatments with their medical providers. And ADs are not just for older people.

Having a negative attitude about ADs can keep someone from being willing to complete it (Ko et al., 2016). Attitude can be impacted by knowledge and understanding. The less a patient knows and understands about ACP, the more likely they are to prefer aggressive treatments (Kim et al., 2019; Senteio & Callahan, 2020). The more understanding a person has, the higher the likelihood of completion (Cattagni Kleiner et al., 2019; Ko et al., 2016; Scholten et al., 2018) as well as having a positive impact on the practitioner's relationship with the patient and relatives (Scholten et al., 2018).

Patients today gather information from their medical providers and make informed decisions for their own care (Pfirstinger et al.,2017). In fact, rarely does any individual entrust all their care to one general provider (Cheung et al., 2020). Many receive care from medical providers who are not medical doctors. So, it is increasingly important for all medical providers (Ko et al, 2016), including physician assistants, nurses, and social workers, to support patients viewing ACP as an ongoing process. They can do this by taking the initiative and starting the discussion (Karnik & Kanekar, 2016).

Family Dynamics

Family dynamics can be a barrier to completion (de Caprariis et al., 2017; Radhakrishnan et al., 2017). Fear of the discussion's impact on the relationship with loved ones keeps individuals from initiating (Bernard et al., 2020). Not having a family member to identify as a proxy (West & Hollis, 2012) or not trusting family members to make decisions for them (Radhakrishnan et al., 2017) are also barriers. Lacking time with family members to have detailed discussion (Radhakrishnan et al. 2017) and worrying family members may not agree which medical cares are to be included in the AD (Baker & Marco, 2020) are also concerns. In addition, individuals can be resistant to informing loved ones of their medical prognosis (Cheung et al., 2020) or worry about causing emotional pain (Bernard et al., 2020).

There have been public campaigns aimed at improving AD completion rates people find the process and the form difficult (Scholten et al., 2018). Some research points to health literacy as a barrier. According to the U.S. Department of Health and Human Services (2022) health literacy refers to "the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions." People from all demographics have low health literacy (Nahata et al., 2020). To reduce health status disparities, healthcare practitioners will have to do better at improving health literacy (Health and Human Services, 2022). This could be approached through overall reading and writing skills as well as, more specifically to ADs, providing reeducation at different time points (Nahata et al., 2020).

Access to health information written at an individual's reading level would also be beneficial (Health and Human Services, 2022).

Race and Ethnicity

While the specific data vary, the consistent trend in previous research (Bazargan et al., 2021; Gonzalez et al., 2021; Koss & Baker, 2017; Pollack et al., 2010; Portanova et al., 2017; Salmond & David, 2005) is that notable discrepancies exist in ACP among races. Overall African Americans have lower completion rates than European Americans (Koss & Baker, 2017; Salmond & David, 2005). Davis (2013) reported African Americans to have the lowest AD completion rates in the US. Bazargan et al. (2021) and Pollack et al. (2010) reported African Americans to be 50% less than European Americans to complete an advance directive and Portanova et al. (2017) reported African American to be 77% less likely than European Americans to have completed an advance directive. While completion rates have improved among both African Americans and European Americans, the discrepancy remains (Koss & Baker, 2017). Also in 2017, Hispanic Americans were reported to be half as likely as European Americans to have an AD (Gonzalez et al., 2021) and have 70% lower odds of AD completion than European Americans (Portanova et al., 2017).

While there was no differences in opinion on hospice, European Americans were significantly more positive about dying in the family home (Webb & Tucker, 2009) and African Americans were more likely to choose aggressive treatments (Karnik et al., 2002; Portanova et al., 2017) followed by Hispanics (Portanova et al., 2017). Also, diverse cultures address medical decision making and the end of life differently. In Chinese culture, for example, patients are not the primary decision maker, the family is, and they consider themselves best served by submitting to the education and experience of the medical provider (Cheung et al., 2020). The input of multiple decision makers (common in African American families) can be a barrier (Sanders et al., 2019). And in some Japanese and Taiwanese families, elders refuse to discuss end-of-life until faced with imminent death (Miyashita et al., 2020).

When it comes to a willingness to complete ADs, there are no significant differences among those willing to take part (Hart et al., 2018). Therefore, there must be underlying factors related to the discrepancies between races (Hart et al., 2018). Lack of trust in the medical community has been associated with African Americans' lower completion rates (Bazargan et al., 2021). For those who are not English speaking, a lack of materials they are able to read and understand can be a barrier (Radhakrishnan et al., 2017). This view is reinforced by the finding that English speaking Hispanic Americans are nearly twice as likely to have an AD then those who need an interpreter (Gonzalez et al., 2021).

Young Adults

The Health Insurance Portability and Accountability Act (HIPAA) became law in 1996 and calls for all protected health information (PHI) to be guarded from disclosure (Health and Human Services, 2022). Since then, permission to disclose PHI must be obtained from the patient (HIPAA Journal, 2022). This current law prohibits medical providers from communicating with anyone other than the patient, even with parents, once an individual reaches 18 years of age (Starzee, 2017).

Young adults are simply more likely to experience unintended injuries and accidents (Young et al., 2022). In fact, the leading cause of death in those 15-24 (12,044) and 25-34 (24,614) is unintentional injury (Centers for Disease Control and Prevention, 2018). Those who present to the emergency department with traumatic injuries, are typically younger than the general population (Graw et al., 2021), and many prefer not to receive life-sustaining treatments when recovery is no longer possible (Robinson et al., 2019). Leaving medical professionals without an identified family member to communicate with can prolong treatment.

Various Studies

The scholarship (Volhard et al., 2018) reveals studies done and articles written about advance care planning and advance directives focused on patients with dementia, in long term care facilities (Molloy et al., 2000), clinics (Barker et al., 2021; Lyon et al., 2004), and in hospitals (Cannone et al., 2019; Peck et al., 2018; Salmond & David, 2005; Wholihan & Pace, 2012). Specific interventions have been explored (Bisognano & Goodman, 2013; Chiu wu et al., 2020; Payne et al., 2009; Sorrell, 2018; Van Scoy et al., 2017) as well as alternative forms of ADs (Park et al., 2020; Periyakoil et al., 2017). Homeless populations have been targeted (Leung et al., 2015; Song et al., 2010). Studies have been done with medical providers and staff (Flowers & Howe, 2015; Galambos et al., 2021; Dexter et al., 1998) as well as through employers (Gonzalez et al., 2021; Heller, 2021).

There have been studies involving young adults with cancer (Fladeboe et al., 2021; Mack et al., 2016; Shay et al., 2017; Snaman et al., 2020), congenital heart defects (Farr et al., 2021), and those in need of psychiatric ADs (Scheyett & Rooks, 2012). The scholarship even offers insight into those younger than 18 (McAliley et al., 2000; Wiener et al., 2012), but healthy young adults have rarely been a target population. In the few studies focused on this population, the samples are taken from college campuses (Mahan & Bailey, 2022; Mroz et al., 2022; Robinson et al., 2019; Barrison & Davidson, 2021; Webb & Tucker, 2009).

Decision Making

Young adults are defining their self-identity (Nelson, 2008). The decisions young adults make depend on how they see the need for a decision and the role they play in it (Ofori-Ansah et al., 2020). This is a time of changing supports and could include disconnection from family (Nelson 2008). It is also crucial for developing effective health habits (Nelson, 2008). While young adults' decision making is complicated with personal and emotional concerns entangled with cultural aspects (Ofori-Ansah et al., 2020), all decisions about their treatment should be based on them as individuals (Mack et al., 2016). They have different informational needs affecting their view of the context of a decision and how it affects them (Ofori-Ansah et al., 2020). They may also want to identify a decision maker outside their biological family.

Young adults are not only comfortable thinking about dying (Mroz et al., 2022), 87% report they want to make their own choices for care (Young et al., 2022). Young people who are not chronically ill still think about end-of-life and have opinions about it (Lyon et al., 2004). In addition, while many believe completing an AD early would result in the maximum of aggressive treatments, this has not been found to be true (Enguidanos & Ailshire, 2017). In fact, those who complete their AD a decade prior to their death show the lowest rates of aggressive treatment (Enguidanos & Ailshire, 2017).

Medical Providers

Medical providers are not addressing the need for ACP with young adults (Farr et al., 2021). Understanding what matters to young adults will help medical providers have a positive impact (Ofori-Ansah et al., 2020). Since young adults have a distrust of establishments, and that may sway them from medical facilities (Gerard, 2017), understanding their parents' preferences is important as well. It could also work in reverse, by providing this information to young adults, their parents completion rates could be influenced (Genewick et al., 2018).

Preferences

Most young adults prefer all interventions to prolong their life (Young et al., 2022). In one study (Young et al., 2022), 87% chose to receive CPR if they had no pulse and were not breathing, while 96% would choose nutrition and hydration artificially should they have a pulse and respiration. Still others prefer fewer life sustaining treatments when recovery is not possible and only 36% want CPR performed (Robinson et al., 2019). With all the technology available, most will choose low-tech experiences in dying scenarios (Gerard, 2017), and with 40% of people dying in hospitals (Gerard, 2017), ADs become even more important.

Health Status

Even among those suffering with chronic conditions, young adult AD completion rates are low. Farr et al. (2021) looked at a sample of young adults suffering with congenital heart defects and in a study of 1541 participants found that only 7.3% had completed an AD. Farr (2021) went on to point out these patients could be the most at risk of dying, and yet, less than 1 in every 10 has named, legally, who will be their decision maker. Of those who have set up an AD, most did so in the hospital, which is an intimidating environment (Ramsey, 2013).

The literature shows addressing ACP is best while healthy (Buiar & Goldim, 2019; Hemsley et al., 2019; Kim et al., 2019). Most individuals will talk about ACP before they have a terminal diagnosis (Miyashita et al., 2020). Educating young adults now could help them in making decisions for their parents, before their own end-of-life choices are paramount (Kavalieratos et al., 2015). Understanding ACP early enables individuals to continue the discussion with both their loved ones and medical providers (Needle & Smith, 2016).

Knowledge

A common misconception about ADs is that they are for the old and the sick (de Caprariis et al., 2017; Oriakhi et al., 2019) but when patients of any age present to the hospital unable to communicate for themselves, without any documented AD, the medical staff cannot know what the patient would want for themselves (Allen et al., 2019).

The better someone understands ACP and ADs, the more likely it is to have a positive impact on their relationships with loved ones they include in the process (Scholten et al., 2018). Young adults report having little knowledge about ACP (Kavalieratos et al., 2015), but they are willing to learn and discuss the cares they want (Kavalieratos et al., 2015; Thoelke, 2018). Young adults want the information (Kavalieratos et al., 2015). Tripken & Elrod (2018) found young adults do not readily understand the terms and concepts in ACP. But AD knowledge increases confidence and equips individuals to discuss the topic with family and friends (Barrison & Davidson, 2021). Also, understanding the therapies or treatments available, along with the recovery possibilities, enables informed decisions about care (de Caprariis et al., 2017).

Life Experiences

The transition to adulthood is a move from dependence to autonomy (Balk, 2001; Davies et al., 2015; Needle & Smith, 2016). This rite of passage carries with it the right to direct one's own medical care (Kapp, 2000). Understanding ADs in early adulthood opens a mindfulness that helps individuals engage more fully in their care (Kapp, 2000). Additionally, recent research articles (Barrison & Davidson, 2021; Tripken & Elrod, 2018) have brought attention to young adults not being immune to becoming informal caregivers for loved ones who are suddenly unable to care for themselves. Having a working knowledge of ADs can aid them in being more involved in the care of their loved ones (Kapp, 2000) and having completed their own AD will equip them for conversations about their loved one's care. Robinson (2019) reported losing loved ones influences an individual's own wishes for their end of life. Experience informs, or impacts, decision making. Young adults with more death experiences or higher personal losses also report more reservations about ACP (Mroz et al., 2022) and may need added support (Wallace et al., 2019) in the process.

Willingness to Engage in Discussion

Since most people are motivated to complete an AD seeking to maintain their dignity (Genewick et al., 2018), have a comfortable death, and not be a burden to family (Kim et al., 2020), it makes sense that some would want to limit aggressive treatments (Enguidanos & Ailshire, 2017) and, with it, the overall expense (Bond et al., 2018). So, during the process, individuals may choose less aggressive treatments for themselves

(Weissman, 2020). In fact, those who complete their AD a decade prior to their death show the lowest rates of aggressive treatment (Enguidanos & Ailshire, 2017). ADs, therefore, relieve proxies and medical providers of guilt by offering permission to end life support (White & Arnold, 2011). Individuals can also specify when they would like a referral to palliative care and hospice (Tyacke et al., 2019).

There is no wide-ranging consensus on when to begin ACP discussions (Hughes et al., 2018). Completing too soon, or far from, death will mean choices are made that may not reflect real time desires in the wake of a crisis (Billings & Bernacki, 2014). Still, earlier studies have found today's young adults are willing to discuss end-of-life (Fladeboe et al., 2021; Gerard, 2017) and they want to be involved in decision making (Davies et al., 2015; Fladeboe et al., 2021; Needle et al., 2020). Sanders & Robinson (2017) found that ACP is a positive experience for young adults, as well as for their proxies. Several studies have found this population valuing the importance of ACP (Barrison & Davidson, 2021; Thoelke, 2018; Young et al., 2022). Young (2022) reported not only 73% of young adults feel it is important, but at their current age believe they should complete an AD and Gerard (2017) found more than half had already discussed end-of-life options with family (Gerard, 2017). Those who have not engaged in ACP may see it as something designed for withholding life-prolonging treatment (Sanders et al., 2019), however those who engage in the discussion, report it is an on-going process of shared decision-making (McMahan et al., 2021; Senteio & Callahan, 2020) designed to ensure high quality care (Emanuel & Emanuel, 1994; Otis-Green et al., 2019).

Current Study

While advance care planning (ACP) is often thought to be for the old or seriously ill, young adults often experience unexpected accidents, leaving them unable to communicate their wishes for medical care. As the medical community strives toward person-centered care (Pfirstinger et al.,2017), not having an advance directive (AD) inhibits planning toward individual desires and places an unnecessary burden on next-of-kin to make choices for the patient. Additionally, next-of-kin may not be the person an individual would want to make their choices.

While there is no comprehensive rule about when ACP should start, it is ideally done before a crisis and is an ongoing dialogue between individuals, their families, and their providers. This implies it is best to complete at the onset of adulthood (age 18 in the U.S.) Prior research has focused primarily on elders. Those who have looked at young adults have utilized samples who are seriously ill. This study will examine the following areas missing from the scholarship: young adults (across the diversity of health status), the association of knowledge and health status with willingness to engage in discussion around planning for later life, and the conditions that may motivate completion of advance directives. Prior research has also shown discrepancies in completion rates among diverse racial/ethnic groups.

The first goal of this study was to examine the differences in ACP Status between racial groups. It is hypothesized that ACP Status would significantly differ by race. The second goal was to look at the relationship of ACP Discussion with Elders and ACP Status. It was hypothesized that ACP Status could be predicted by ACP Discussion with Elders. The third goal was to explore the association between Willingness to Engage in

Discussion and Knowledge. It was hypothesized these would be positively and significantly correlated. The fourth goal was to look at the relationship between Experience with Death and Willingness to Engage in Discussion. It was hypothesized that Willingness to Engage in Discussion could be predicted by Experience with Death. And finally, the fifth goal was to examine the association between Health Status and Knowledge. It was hypothesized these will be positively and significantly correlated.

In summary, exploring the how and why of engagement in advance care planning and completion of advance directives, or the choice not to, through the lens of Symbolic Interaction and Systems Theories aids in understanding the internal process involved and grasping how that affects individuals. This can lead to improved educational efforts. Education and interventions could lead to increased completion rates, empowering individuals and protecting their loved ones from the grief of having to make choices in the wake of crisis.

CHAPTER III

METHODOLOGY

This dissertation contributes to the literature by addressing the gaps related to young adults and advance care planning, focusing on their willingness to engage in discussion around planning for later life, as well as the completion of advance care planning tasks. The following research questions were addressed: What role do demographics play in Advance Care Planning (ACP) Status? 2) How does ACP Discussion with Elders influence ACP Status? 3) How do Knowledge and Willingness to Engage in Discussion relate to one another? 4) What is the relationship between Experience with Death and Willingness to Engage in Discussion? 5) How are Health Status and Knowledge associated?

Participants and Procedure

This study was completed at Oklahoma State University. Adults (18 years old or older) were included in the study. The data were collected during the 2022-2023 academic year through online surveys (see Appendix A). Recruitment of participants was conducted at Oklahoma State University by online recruitment through the SONA system (College of Education & Human Sciences) as well as distribution of the survey link through snowball sampling via Facebook (see Appendix D) and chain referral emails (see

Appendix B and C.) SONA Participants received 1 research credit for completing the survey. Participants were not required to be actively enrolled students; however non-SONA participants did not receive compensation. An online consent was used and once signed, participants were redirected to the Qualtrics survey (https://okstateches.az1.qualtrics.com/jfe/form/SV_6fp7nXydDwXLrym). The instrument consisted of 72 questions (30 multiple choice, 24 yes/no, 6 Likert scales, 6 free text, and 6 True/False) and took approximately 30 minutes to complete. All surveys were conducted in English.

Measures: Advance Care Planning (ACP) Status

Three scales for ACP Status were developed for this study from survey questions (see Appendix A) to measure specific aspects of ACP: Tasks Completed, Knowing Plans, and Follow Up. The Tasks Completed Scale was created by summing the eight items (scored 0-8 with higher summed score indicating more tasks completed). Questions, responses, and scoring were as follows: Do you have a Do Not Resuscitate Order? Yes (1); No (0); I don’t know what that is (0); and I prefer to remain a full code (1). Do you have a living will? Yes (1); No (0); I don’t know what that is (0). Do you have life insurance? Yes (1) and No (0). Have you identified a healthcare proxy? Yes (1); No (0); and I don’t know what that is (0). Have you completed an advance directive? Yes (1); Started but not completed (0); and No (0). Have you made arrangements for your funeral/celebration of life? Yes (1); No (0). Have you made arrangements for your cremation or burial? Yes (1); No (0). And have you worked with an agency to plan for donating your body (or parts) at the time of your death? Yes (1); No (0); I do not want to donate my body (1); I don’t know how to do that (0).

If responding "No" to the previous questions, participants were directed to Knowing Plans questions. This scale was created by summing the five items (scored 0-5 with the higher summed score indicating more plans known.) Questions were as follows: Do you want a Do Not Resuscitate Order? Yes (1); No (0); I don't know what that is (0). Do you know what you want your living will to include? Yes (1); No (0). Do you know how much life insurance you want to have? Yes (1); No (0). Do you know who you would want your proxy to be? Yes (1); No (0). Do you know what you want your advance directive to include? Yes (1); No (0).

If responding "Yes" to Tasks Completed questions, participants were directed to Follow Up questions. The scale was created by summing the six items (scored 0-6 with higher summed score indicating more follow up completed.) Have you provided a copy to your doctor? Yes (1); No (0). Have you talked to anyone about your wishes? Yes (1); No (0). Have you discussed this (DNR) with your loved one? Yes (1); No (2). Have you discussed this (living will) with your loved one? Yes (1); No (0). Have you discussed this (life insurance) with your loved one? Yes (1); No (0). And have you discussed this (proxy) with that person? Yes (1); No (0).

Measures: Willingness to Engage in Discussion

The study builds on earlier work from Gerard (2017). The Willingness to Engage in Discussion Scale was created by summing the responses to five items (scored 0-21 with higher summed score indicating higher level of willingness to engage in discussion previously identified in Gerard (2017) as "Having the Conversation." Participants were asked: Have you had a conversation about end-of-life options? Yes (1); No (0). Would a discussion about death or planning around death be difficult to have in your family? With response options of:

5	4	3	2	1
Not at all difficult	Slightly difficult	Moderately difficult	Very difficult	Extremely difficult

Would a discussion about death or planning around death be considered disrespectful in your family? With response options of:

5	4	3	2	1
Not at all disrespectful	Slightly disrespectful	Moderately disrespectful	Very disrespectful	Extremely disrespectful

How willing would you be to have a conversation about end-of-life care options with a family member?” With response option of:

1	2	3	4	5
Very unwilling	Unwilling	Neutral	Willing	Very Willing

And compared to your parents or caregivers, are you more or less willing to have a conversation about end-of-life care options? With response options of:

1	2	3	4	5
Much less	Less	About the same	More	Much more

Measures: Health Status

This scale was created by summing the five items (scored 0-7 with higher summed score more severe health concerns.) The scale was constructed for this study using the following questions and response options: Do you have a health condition that requires routine medication and/or follow up with your health provider? Yes (1); No (0). Do you have a primary care physician? Yes (1); No (0). Have you been hospitalized in the last year? Yes (1); No (0). And how would you rate your overall physical health?

0	1	2	3	4
Excellent	Very Good	Good	Fair	Poor

Measures: Knowledge

The study made use of Dobbins (2019) work, using the six identified misconceptions as a foundation for measuring knowledge of advance directives. The scale was created by summing the six items (scored 0-6 with higher summed score indicating higher level of knowledge.) The True/False statements were as follows: Advance directives are designed primarily for older adults (False); A person does not need an attorney to prepare advance directive documents (True); Once a proxy is named, the patient gives up the right to make their own decisions (False); Only the state's advance directive form is valid (False); A living can prevent futile treatment at the end of life (True); and No medical care will be provided if the patient has an advance directive (False). Accurate responses scored 1, while inaccurate responses scored 0.

Measures: Life Experiences

Life Experiences were measured using seven specific questions: Have you ever been the caregiver to someone who was sick or in failing health? (Yes; No.) Did that experience prompt you to think about your own physical decline and needs later in life? (Yes; No.) Did your parents or caregivers discuss advance care planning with you? (Yes; No.) Have you experienced the death of a someone close to you? (Yes; No.) How long ago did they die? With the past year; Within 2 years; 3 years ago or more.) What role did their directive play? (Directed their medical care; Directed the distribution of their estate; They did not have an advance directive; and I do not know.) Which of the following decisions did you participate in? (Medical decisions; Funeral/Celebration of Life arrangements; Settling their financial/property estate; and I was not involved in decision making.) No composite was used for Life Experiences.

Measures: Willingness to Complete an Advance Directive

While this measure was not used in a hypothesis, the information is helpful in reflection for future steps. Participants were asked: Do you have an advance directive? (Yes; No.) Many doctors' offices have information about advance directives, would you be willing to discuss your own advance care planning with your primary care doctor? (Yes; No; I don't have a primary care doctor.) Would you be willing to attend an event at your university aimed at assisting students with completing their advance directives? (Yes; No; Depends on my schedule.) Sometimes places of worship have special events, would you be willing to attend an event at your place of worship aimed at advance directives? (Yes; No; I don't attend a place of worship.) What other resources would you be willing to go to for help with completing an advance directive? (Free text response.) If you knew help was available there, would you be more likely to seek help from the resources you identified? (Yes; No.)

Plan of Analysis

Data analysis was conducted using *IBM SPSS 26 Software* (2020). Descriptive statistics were computed and means and standard deviations (M ± SD) were used to describe variables, as well as frequencies and percentages for the nominal variables. A total of 12 analyses were conducted.

H1: ACP Status will differ by race.

One-way, within subjects ANOVAs explored the differences in ACP status (continuous DV) between all racial groups (categorical IV) and a t-Test compared ACP Status between racial groups as a dichotomous variable (Caucasian and Other).

H2: ACP Discussion with Elders will predict ACP Status.

Linear regressions tested the prediction of ACP Status (measured by Tasks Completed) (continuous DV) by ACP Discussion with Elders (dichotomous IV) in the Entire Sample, as well as specifically among Young Adults.

H3: Willingness to Engage in Discussion will be positively correlated with Knowledge.

Correlations explored the relationship between Willingness to Engage in Discussion (continuous DV) and Knowledge (continuous DV) in the Entire Sample, as well as specifically among Young Adults.

H4: Experience with Death will predict Willingness to Engage in Discussion.

Linear Regressions tested the prediction of Willingness to Engage in Discussion (continuous DV) by Experience with Death (dichotomous IV) in the Entire Sample, as well as specifically among Young Adults.

H5: Health Status will be positively correlated with Knowledge.

Correlations tested the relationship between Health Status (continuous IV) and Knowledge (continuous DV) in the Entire Sample, as well as among Young Adults.

This exploratory study is important because advance care planning is not just for the old or seriously ill. It expands the literature regarding young adults and advance care planning. It also explores the relationship between race and ACP, as well as the association of knowledge and health status with willingness to engage in discussion regarding ACP. Several exploratory analyses were also conducted to explore how young adults compare to those 30+. Findings are included. Based on the recent pandemic and its impact on both young adults and workers in medical fields, these discussions are timely and vital to autonomy (Mahan & Bailey, 2022).

CHAPTER IV

RESULTS

Between November 28th and December 12th, 2022, 532 adults (aged 18-82) participated in the current study. Table A reflects the demographics of the sample.

Table A

Demographics of the Sample

Age	Young Adults (<=29) 330 (62%) (*M* = 21.26) 30+ (30-82) 202 (38%) (*M* = 44.94)
Gender	Female 409 (76.9%) Male 113 (21.2%) Non-binary 9 (1.7%) Other 1 (.2%)
Race/Ethnicity	African American/Black 38 (7.1%) American Indian/Alaska Native 58 (10.9%) Asian 23 (4.3%) Caucasian 429 (80.6%) Hispanic/Latino 31 (5.8%) Pacific Islander 3 (.6%) Other 9 (1.7%)
Residency	Oklahoma 390 (73.6%) Texas 43 (8.1%) Kansas 34 (6.4%) Missouri 22 (4.2%) 22 additional states representing less than 4% each
Student Status	370 (69.7%) actively enrolled 161 (30.3%) not enrolled

Three hundred thirty were young adults (aged <=29) (with a mean age of 21.26), while 202 were 30+ (with a mean age of 44.94.) The mean age of the Entire Sample was 30.24 (median of 23). Sixty-two percent were in the young adult category, while 48% were in the 30+ category. Participants reported they identified as the following: 409 females (76.9%), 113 Males (21.2%), 9 Non-binary (1.7%), and 1 Other (.2%). The race/ethnicity of participants was reported as follows: 38 African American/Black (7.1%); 58 American Indian/Alaska Native (10.9%); 23 Asian (4.3%); 429 Caucasian (80.6%); 31 Hispanic/Latino (5.8%); 3 Pacific Islander (.6%); and 161 Other (1.7%). Overall, 26 states were represented with 390 (73.6%) residing in Oklahoma. 43 (8.1%) in Texas, 34 (6.4%) in Kansas, and 22 (4.2%) in Missouri. The other 22 states represented held less than 4% each. Three hundred seventy (69.7%) were actively enrolled students, while 161 (30.3%) were not currently enrolled.

As mentioned in Chapter 3, several scales were used in this study. Table B illustrates the alpha scores for those scales.

Table B

Scales and Alpha Scores

Scale	*a*
Tasks Completed	.775
Health Status	.356
Willingness to Engage in Discussion	.661
Knowledge	.437

The Tasks Completed Scale was created by summing (*a* = .775) the eight items (with higher summed score indicating more tasks completed). Knowing Plans, Follow Up, and an Overall composite, were not used as they yielded too few cases to create reliable scales. The Health Status Scale was created by summing (*a* = .356) the five items (with higher summed score indicating more severe health concerns) and standardized to ensure all measures contributed evenly to the scale. The Willingness to Engage in Discussion Scale was created by summing (*a* = .661) the responses to five items (higher score indicating more willingness to engage in discussions.) And the Knowledge Scale was created by summing (*a* = .437) the six items (higher summed score indicating higher level of knowledge.)

The Health Status Scale and Knowledge Scale have alphas under .70 (which is generally the acceptable level.) Since the scores are so low (under .50) the scales needed to be revised or replaced. In an attempt to improve reliability, the individual items were explored for removal. Removing any single item did not show an improvement in internal consistency. Interpretative caution must be applied as these results should be viewed as tentative.

Descriptive statistics revealed 78.35% of the Entire Sample had not completed, nor started an AD. And when looking specifically at Young Adults, that number becomes 92.5%. While for those 30+, 72.3% are without an AD. Yet, the sample had an overall knowledge mean of 4.2 (on a scale of 0-6) showing an average of 70% correct responses. Even looking at Young Adults specifically, the knowledge mean is 3.72, which is 62% correct responses. (Adults 30+ had a knowledge mean of 4.93.) These scores suggest some level of foundational knowledge about what advance directives are to do. Yet, that is not enough to prompt completion.

Research Question 1: What role do demographics play in Advance Care Planning (ACP) Status?

Hypothesis 1: ACP Status will differ by Race.

Table C

Results of One-way, Between Subjects ANOVAs Examining the Link Between ACP Status and Race in the Entire Sample

	n	ACP Status
African American / Black	25	1.64 (1.66)
American Indian / Alaska Native	29	1.41 (1.27)
Asian	12	1.17 (1.34)
Caucasian	345	1.80 (1.77)
Hispanic / Latino	15	1.67 (1.54)
Other	58	1.64 (1.63)
F		.618

One-way, between subjects ANOVAs were computed to examine the link between ACP Status and Race in the Entire Sample. The findings indicated that Race was not significantly related to ACP Status. The 25 participants in the African American / Black group had an average tasks completed of 1.64 (SD = 1.66); the 29 participants in the American Indian /Alaska Native group had an average tasks completed of 1.41 (SD = 1.27); the 12 participants in the Asian group had a mean of 1.17 (SD = 1.34); the 345 participants in the Caucasian group had a mean of 1.80 (SD = 1.77); the 15 participants in the Hispanic / Latino group had a mean of 1.67 (SD = 1.54); and the 58 participants in the Other group (which includes those who marked "Other" and those who marked more than one race/ethnicity) had a mean of 1.64 (SD = 1.63). The effect of Race, therefore, was not significant, *F*(5,478) = .618, *p* = .686.

Table D

Results of One-way, Between Subjects ANOVAs Examining the Link Between ACP Status and Race in Young Adults

	n	ACP Status
African American / Black	9	1.89 (1.66)
American Indian / Alaska Native	23	1.43 (1.38)
Asian	10	1.40 (1.35)
Caucasian	200	1.10 (1.03)
Hispanic / Latino	12	1.33 (1.50)
Other	38	1.08 (.85)
F		1.43

One-way, between subjects ANOVAs were computed to examine the link between ACP Status and Race in Young Adults. The findings indicated that Race was not significantly related to ACP Status. The 9 participants in the African American / Black group had an average tasks completed of 1.89 (SD = 1.66); the 23 participants in the American Indian /Alaska Native group had an average tasks completed of 1.43 (SD = 1.38); the 10 participants in the Asian group had a mean of 1.40 (SD = 1.35); the 200 participants in the Caucasian group had a mean of 1.10 (SD = 1.03); the 12 participants in the Hispanic / Latino group had a mean of 1.33 (SD = 1.50); and the 38 participants in the Other group (which includes those who marked "Other" and those who marked more than one race/ethnicity) had a mean of 1.08 (SD = .85). The effect of Race, therefore, was not significant, *F*(5,268) = 1.43, *p* = .214.

Table E

Results of One-way, Between Subjects ANOVAs Examining the Link Between ACP Status and Race in Adults 30+

	n	ACP Status
African American / Black	16	1.50 (1.83)
American Indian / Alaska Native	6	1.33 (.82)
Asian	2	0.00 (0.00)
Caucasian	145	2.76 (2.10)
Hispanic / Latino	3	3.00 (1.00)
Other	20	2.70 (2.18)
F		2.23

One-way, between subjects ANOVAs were computed to examine the link between ACP Status and Race in Adults 30+. The findings indicated that Race was not significantly related to ACP Status. The 16 participants in the African American / Black group had an average tasks completed of 1.50 (SD = 1.83); the 6 participants in the American Indian /Alaska Native group had an average tasks completed of 1.33 (SD = .82); the 2 participants in the Asian group had a mean of 0.00 (SD = 0.00); the 145 participants in the Caucasian group had a mean of 2.76 (SD = 2.10); the 3 participants in the Hispanic / Latino group had a mean of 3.00 (SD = 1.00); and the 20 participants in the Other group (which includes those who marked “Other” and those who marked more than one race/ethnicity) had a mean of 2.70 (SD = 2.18). The effect of Race, therefore, was not significant, *F*(5,186) = 2.23, *p* = .053.

Table F

Results of Independent Samples t-Test Examining the Link Between ACP Status and Race in the Entire Sample with Dichotomous Race Variable

	n	ACP Status
Caucasian	345	1.80 (1.77)
Other	139	1.55 (1.52)
t		1.42

To determine whether ACP Status differed by Race, an independent samples t-Test was conducted. Results revealed that the 345 participants in the Caucasian group (M = 1.80) reported insignificantly more tasks than those in the 139 participants in the Other group (M = 1.55). The effect of Race, therefore, was not significant, *t*(482) = 1.42, *p* = .156.

Research Question 2: How does ACP Discussion with Elders influence ACP Status?

Hypothesis 2: ACP Discussion with Elders will predict ACP Status.

To examine whether ACP Discussion with Elders is a significant predictor of ACP Status in the Entire Sample, a linear regression was computed. Results of the regression analysis indicated that ACP Discussion with Elders was significantly and negatively related to ACP Status (*Std.* $\beta = -.203$, $p < .001$: $R^2 = .041$, $p = .000$). ACP Discussion with Elders was a significant predictor of ACP Status, explaining 4% of the variance. (This negative correlation resulted from coding: yes (1); no (2).)

To examine whether ACP Discussion with Elders was a significant predictor of ACP Status when looking specifically at Young Adults, a linear regression was computed. Results of the regression analysis indicated that ACP Discussion with Elders was significantly and negatively related to ACP Status (*Std.* $\beta = -.274$, $p < .001$: $R^2 = .075$, $p = .000$. ACP Discussion with Elders was a significant predictor of ACP Status, explaining 7.5% of the variance. (This negative correlation resulted from coding: yes (1); no (2).)

To examine whether ACP Discussion with Elders was a significant predictor of ACP Status when looking specifically at Adults 30+, a linear regression was computed. Results of the regression analysis indicated that ACP Discussion with Elders was significantly and negatively related to ACP Status (*Std.* $\beta = -.066$, $p < .001$: $R^2 = .004$, $p = .369$.) ACP Discussion with Elders was a significant predictor of ACP Status, explaining .4% of the variance. (This negative correlation resulted from coding: yes (1); no (2).)

Research Question 3: How do Knowledge and Willingness to Engage in Discussion relate to one another?

Hypothesis 3: Willingness to Engage in Discussion will be positively correlated with Knowledge.

Table G

Results of Correlation Between Willingness to Engage in Discussion with Knowledge for the Entire Sample

Variable	*n*	*M*	*SD*	1	2
Willingness to Engage in Discussion	490	15.87	2.93	-	
Knowledge	468	4.20	1.36	.472*	-

Note: **p* < .01

A correlation was computed to assess the relationship between Willingness to Engage in Discussion and Knowledge in the Entire Sample. As indicated in Table 3, there was a significant positive correlation between the two variables, *r*(466) = .472, *p* = .001.

Table H

Results of Correlation Between Willingness to Engage in Discussion with Knowledge for Young Adults

Variable	*n*	*M*	*SD*	1	2
Willingness to Engage in Discussion	284	14.81	2.70	-	
Knowledge	296	3.72	1.29	.324*	-

Note: **p* < .01

A correlation was computed to assess the relationship between Willingness to Engage in Discussion and Knowledge in Young Adults. As indicated in Table H, there was a significant positive correlation between the two variables, $r(282) = .324$, $p = .001$.

Table I

Results of Correlation Between Willingness to Engage in Discussion with Knowledge for Adults 30+

Variable	*n*	*M*	*SD*	1	2
Willingness to Engage in Discussion	184	17.49	2.48	-	
Knowledge	194	4.93	1.11	.356*	-

Note: *$p < .01$

A correlation was computed to assess the relationship between Willingness to Engagement in Discussion and Knowledge in Adults 30+. As indicated in Table I, high levels of Engagement in Discussion were significantly positively related to high levels of Knowledge.

Research Question 4: What is the relationship between Experience with Death and Willingness to Engage in Discussion?

Hypothesis 4: Experience with Death will predict Willingness to Engage in Discussion.

To examine whether Experience with Death could predict Willingness to Engage in Discussion in the Entire Sample, a linear regression was computed. Results of the regression analysis indicated that Experience with Death was significantly and negatively related to Willingness to Engage in Discussion (*Std.* $\beta = -.147$, $p < .01$; $R^2 = .022$, $p = .002$). Experience with Death was a significant predictor of Willingness to Engage in

Discussion, explaining 2% of the variance. (This negative correlation resulted from coding: yes (1); no (2).)

To examine whether Experience with Death could predict Willingness to Engage in Discussion looking specifically at Young Adults, a linear regression was computed. Results of the regression analysis indicated that Experience with Death was not a significant predictor of Willingness to Engage in Discussion (*Std.* β = -.047; R^2= .002, p = .434).

To examine whether Experience with Death could predict Willingness to Engage in Discussion in Adults 30+, a linear regression was computed. Results of the regression analysis indicated that Experience with Death was significantly and negatively related to Willingness to Engage in Discussion (*Std.* β = -.116, p < .01; R^2= .013, p = .128). Experience with Death was a significant predictor of Willingness to Engage in Discussion, explaining 1.3% of the variance. (This negative correlation resulted from coding: yes (1); no (2).)

Research Question 5: How are Health Status and Knowledge associated?

Hypothesis 5: Health Status will Be Positively Correlated with Knowledge.

Table J

Results of Correlation Between Health Status and Knowledge for the Entire Sample

Variable	*n*	*M*	*SD*	1	2
Health Status	488	2.16	1.24	-	
Knowledge	490	4.20	1.36	.152***	-

Note: ****p* < .001

A correlation was computed to examine whether Health Status was related to Knowledge in the Entire Sample. As indicated in Table 7, there was a significant positive correlation between the two variables, *r*(486) = .152, *p* = .001.

Table K

Results of Correlation Between Health Status and Knowledge for Young Adults

Variable	*n*	*M*	*SD*	1	2
Health Status	294	1.95	1.25	-	
Knowledge	296	3.72	1.29	.178**	-

Note: ****p* < .01

A correlation was computed to examine whether Health Status was related to Knowledge. As indicated in Table 8, there was a significant positive correlation between the two variables, *r*(290) =.178, *p* = .002.

Table L

Results of Correlation Between Health Status and Knowledge for Adults 30+

Variable	*n*	*M*	*SD*	1	2
Health Status	194	2.49	1.14	-	
Knowledge	194	4.93	1.11	-.039	-

As indicated in Table L, Health Status (indicating high levels of health concerns) were not significantly related Knowledge.

Additional Exploratory Analyses

This study was designed to explore young adults and advance care planning. Findings revealed young adult autonomy is at risk. In the wake of a medical crisis, when unable to communicate but in a condition that is not likely to improve, 26.4% of young adults in this sample reported they wanted no life prolonging treatment, while 34% want all long prolonging treatments. If in a vegetative state, 42.7% want to be kept alive only to harvest organs, 23% do not want to be kept alive at all, and 2% would want to be kept alive indefinitely.

There is a need for education. In this sample, 52.7% of young adults believe ADs are for older adults, 45.5% believe an attorney is needed to complete the form and 28.2% believe naming a proxy forfeits their decision making. Also, 12% believe no medical care is provided once an AD is signed and 13.9% do not know what a “Do Not Resuscitate Order” is.

Healthcare is a prime point of connection, as 57.6% of young adults in this sample would be willing to discuss ACP with their PCP. While 13.9% do not have a PCP, only 13.9% said “no” to discussing with PCP. Also, 30.1% have a health condition requiring routine follow up. In this sample, 3 of the 14 young adults who were hospitalized in the last year were offered information about ADs and none of the three were offered assistance to complete the document.

Of the nine participants in the young adult group who had completed an advance directive, when asked for their motivation (with the option to mark all that apply), they reported their motivations as follows: 2 had prior experience with a loved one; 2 do so because a loved one asked them to; 2 wanted to avoid unnecessary treatments; 4 had a desire to control their own cares; 1 wanted to save loved ones money; and 1 wanted to avoid pain and suffering.

Exploratory analysis also revealed a significant difference in ACP Status when looking at the age groups shown in Table M.

Table M

Results of Independent Samples t-Test Examining the Link Between ACP Status and Age

	n	ACP Status
Group 1: Young Adults (<=29)	293	1.16 (1.09)
Group 2: 30+ Adults	192	2.58 (2.08)
t		-9.77

To determine whether young adults or 30+ adults are more likely to have advanced ACP Status, an independent samples t-Test was conducted. Results revealed that the 192 30+ Adults (M = 2.58) reported having completed significantly more tasks toward ACP than the 293 Younger Adults (M = 1.16), $t(483) = -9.77$, $p = .001$.

CHAPTER V

DISCUSSION

The purpose of this exploratory study was to examine advanced care planning amongst young adults. More specifically to gain understanding of young adults' knowledge related to advance directives, the association between knowledge and health status with willingness to engage in discussion around planning for later life care, and the conditions that may motivate engagement and completion of advance directives. Gaining insight in these areas can inform interventions that will improve completion rates, equipping individuals with autonomy to direct their own care while simultaneously relieving the burden of decision making from loved ones.

To best understand how young adults rate on these concepts, the current study examined each by looking at both the Entire Sample and specifically at Young Adults (those 18-29 years old.) This allowed for understanding how young adults scored, but also provided for understanding of how young adults compared (or contrasted) with the Entire Sample. Exploratory analyses were conducted to expand how young adults compared (or contrasted) to Adults 30+. Being equipped with the comparison to the Entire Sample, as well as to Adults 30+ provides insight into the functioning of Young

Adults, the Entire Sample, and Adults 30+ which can lead to recommendations for future directions.

Research Question 1: What role do demographics play in Advance Care Planning (ACP) Status?

Previous research has reported discrepancies among racial groups in completion rates for ADs ((Bazargan et al., 2021; Gonzalez et al., 2021; Koss & Baker, 2017; Pollack et al., 2010; Portanova et al., 2017; Salmond & David, 2005) However, in this sample no significant difference was found between racial groups. This was explored in all race/ethnicity categories in the Entire Sample, within Young Adults, within Adults 30+, and with race as a dichotomous variable across the Entire Sample. No significant differences were identified.

All Young Adults, in all racial groups, have completed less than two of the eight tasks included in ACP. Adults 30+ have completed less than three. They simply are not planning in advance for health emergencies or medical crises. Although completion rates are low across the board, we know that bias and discrimination likely play a role in access to advance care planning, both within the medical system and to the information in general.

Research Question 2: How does ACP Discussion with Elders influence ACP Status?

This study examined the association parents and caregivers had with their adult children's ACP through the education and discussion they provided. Young adults who had parents or caregivers who discussed ACP with them were more likely to have engaged in ACP for themselves. The same was reported for Adults 30+. There is a reciprocal dynamic between meaning-making and behavior (Charmaz & Belgrave, 2013) and individuals are affected by interaction with others (Naidu & Benhura, 2016; Stoner et al., 2019). An individual’s interpretation of meaning is affected by environment and communicated through action (Johnson, 2008). Learning about ACP is as natural as learning how to open an account or manage a budget. Taught by modeling and communication. Therefore, being involved in ACP with elders reinforces the value of the activity and encourages engagement for oneself.

In this study only 35% of Young Adults reported having had a conversation about end-of-life planning. That is far less than reported by Gerard (2017), where more than half had already discussed end-of-life options with family. The previous study included adults aged 18-34, while Young Adults in this study were aged 18-29, so there is the possibility that the conversation is occurring later, between 30-34. Having the conversation could be related to the natural progression of health decline in aging, however 30-34 is not the typical prime time of decline.

Research Question 3: How do Knowledge and Willingness to Engage in Discussion relate to one another?

Previous research has found the higher someone’s knowledge of ACP is, the higher their likelihood of completing an AD (Cattagni Kleiner et al., 2019; Ko et al., 2016; Scholten et al., 2018). This is supported by the current study. There is a significant positive correlation between basic knowledge about advance directives and the willingness to engage in discussion about end-of-life planning. This significant, positive correlation was revealed among the Entire Sample, Young Adults, and Adults 30+. Again, applying Symbolic Interaction Theory explains the connection as directly linked to the meaning an individual assigns to the AD document. Knowing human behavior is best understood by grasping the meaning attached to the behavior itself (Carter et al., 2018), we can better understand individuals within the context of their family or society when considering why completion rates remain so low in the United States. The meaning assigned to the act is formulated by experience and many have not been exposed to ADs or ACP at all. And if they have, the meaning they have assigned could come from misinformation. Changing the meaning individuals assign to the act of completing an AD is key to improving completion rates

This study reinforced previous findings about the link between knowledge and ACP engagement (Cattagni Kleiner et al., 2019; Ko et al., 2016; Scholten et al., 2018). While previous research looked at the relationship of knowledge and completion of the ADs and this study explored the relationship of knowledge on willingness to engage in discussion. Discussion leads to completion. This study found higher knowledge is related to higher willingness to engage in discussion. To understand how the dynamic of knowledge results in higher willingness to engage in discussion works, Symbolic Interaction Theory can be applied. The meaning attached to ACP and ADs is vital to completion. Many individuals have no exposure or hold misinformation related to the how the AD document works, what is required to complete one and/or how the process of advance care planning happens. Changing the meaning they have assigned the document and the process, through education, is key to improving completion rates.

Completion rates in this sample were low across the board. Less than 22% of participants had completed an AD. When looking specifically at Young Adults, the number decreases to 7.5%. That is to say, amongst the population with the highest likelihood of experiencing an unintended accident or injury that leads to their death, less than 1 in 10 have planned for their own care nor identified their desired decision maker. They may have chosen not to plan in advance because they lack knowledge of how to complete advance care planning or are unaware of what an AD actually is and what it can do to preserve their autonomy.

Young adults do have some understanding of ADs. Overall knowledge was good with mean scores of 70% across the Entire Sample, and 62% amongst Young Adults. They at least grasp some of what ADs are designed to do (or they are rather good at guessing.) These findings provide support to the idea that there is some symbolic interaction related to ACP and AD completion. If adults have a general knowledge of how to empower themselves with autonomy beyond the time when they are able to communicate for themselves, yet they choose not to complete the tasks required, there must be something more going on.

It could be that “advance directive” has a meaning to the individual (based on experience or misinformation) that is negative and therefore they are not willing to engage in the process. However, meanings are ever changing (Charmaz & Belgrave, 2013; Folami & Olaiya, 2016; Fynbo, 2018; Naidu & Benhura, 2016) through experiences with people and environments. Since people choose their actions based on what they know as the truth (Olasina, 2014), education is the key to improving engagement.

Educating individuals can also have a systemic impact on families. Changing the internal culture of a family to understand that ACP is a preventative measure in preparation for unexpected situations, has the potential to influence intergenerationally today and for generations to come..

It is also possible individuals do not know how or whom to identify as their decision maker. Not being equipped with confidence in whom to name may result in a lack of willingness to engage in discussion about all advance care planning. Individuals may also lack knowledge about treatment options or not understand the terminology in the document. Being aware of this lack of knowledge could also impede engagement.

Research Question 4: What is the relationship between Experience with Death and Willingness to Engage in Discussion?

Previous research showed experience with death resulted in having reservations about ACP among young adults (Mroz et al. (2022). That was supported in this study. When looking at the Entire Sample and Adults 30+, willingness to engage in discussion was predicted by having had experience with death. However, when looking at Young Adults specifically, no significant relationship was found.

It could also be that the Entire Sample (by nature of including 30+ adults) encompasses many who have had multiple exposures to death and that lends to their familiarity with the process of grieving and tasks involved in ending a life. Adults 30+ would undoubtedly include individuals with exposure to life experiences involving the loss of loved ones.

The lack of a significant relationship between Young Adults having had experience with death and their willingness in engage in discussion regarding their own end of life planning could be related to having never had any experience with death. It is possible those <=29 have yet to lose someone close to them. It could also be they had a negative experience with a loved one's death. The loss may have been recent, and the young adult may have been actively grieving at the time of this study.

Research Question 5: How are Health Status and Knowledge associated?

The literature reports that some patients believe they are too healthy to need an AD (Bernard et al., 2020; Pollack et al., 2010; Radhakrishnan et al., 2017). This aligns with the current findings, among Young Adults and across the Entire Sample, that those with more severe health concerns report higher levels of knowledge about ADs. However, it is not held for Adults 30+. There is no significant relationship between Health Status and Knowledge of Advance Directives in the Adults 30+ group.

Having more knowledge could occur due to the severe health concerns prompting exploration of ACP and completion of the AD at younger ages. It could also be that the natural progression of life and gathering of life experiences exposes individuals to knowledge unrelated to their health status. More research is needed to explore this.

Exploratory Analyses

This study’s exploratory analyses revealed many additional findings. The dramatic difference in young adults’ wishes for life-prolonging treatment reinforces the need to secure individual autonomy. In order for young adults to have their medical treatments provided in the ways they wish; no blanket policy can be applied. It is impossible to know which young adult wants no life prolonging treatment and which wants all treatments, in the absence of advance care planning and an AD. Young adults’ wish would vary too much for a universal protocol to meet their desires.

Their motivations to complete are also varied. While only nine participants in the Young Adult group had completed an advance directive, there was no general consensus about what moved them to engage in completing an advance directive.

This study also showed the need for young adults to be educated regarding ADs. There is a lack of understanding regarding what the components of an AD (i.e. do not resuscitate order) do functionally, as well as what is required legally (i.e. believing an attorney is needed) to have an advance directive in place as well as the power an AD gives individuals (i.e. believing they lose authority over their own care at identification of a proxy and receive no treatment with an AD.) Gaining these insights alone may improve completion rates among young adults.

The failure of the Patient Self Determination Act is apparent in this study's findings (since so few of those hospitalized were offered information about advance directives and none were offered any assistance to complete the form). The culture of death anxiety in the US, lends to discomfort around discussing topics of this nature. Those in healthcare settings who are charged with fulfilling the requirements of the Act may be without training on how to engage in the discussion themselves. They likely have not done their own advance care planning, nor completed their own advance directive. Having not experienced the process for oneself would make it difficult to come alongside someone else and assist them in doing the same thing. Still, healthcare appears to be a prime point of connection. With more than half of Young Adults reporting a willingness to have the conversation with their PCP and nearly a third returning to see their doctor for routine follow up care of a pre-existing condition, the doctor's office is opportune point for engagement.

Exploratory analyses also revealed a significant difference in tasks completed when looking at age. Adults in the 30+ group have completed significantly more tasks than Young Adults. (Yet even 30+ adults average under 3 of the 8 tasks completed.) The

30+ group's completion of more tasks could be related to living longer and therefore having had the experience of losing loved ones. It could also be related to health decline, and/or thinking about one's own mortality. It could also be happenstance due to exposure to the information.

Since there is not an established regulation defining the age when ACP should begin, it is logical to presume it is best to begin at the transition to adulthood, prior to crisis. Engaging at that turning point allows for the on-going discussion with loved ones and medical providers. If all adults began at 18 making plans for themselves, understanding ACP to be a continuing dialogue and ADs to be documents that can and should be updated, more tasks would be completed in both age groups.

Implications

Improving completion rates should be a public health priority if it is not an emergency. The culture of death anxiety in the US keeps individuals, and their loved ones, from planning for later life (Cheung et al., 2020). Death anxiety is so strong that even current policies fail to be implemented effectively. The Patient Self-Determination Act (1990) aims at equipping all patients with information about ADs, however it is implemented as a yes/no question at the time of hospital admission and follow up is rarely provided. Improving the way advance directive information is provided could improve completion rates substantially. Identifying, within facilities, whose role it is to share printed information and training all medical staff to have the conversation may improve completion rates.

Every adult has the right to define for themselves what they want for their medical care and lifestyle choices. Through ACP and the completion of an AD, autonomy extends beyond the individual’s ability to express their wishes. Yet there remains a disconnect where no specific regulation designates when this right is to be framed and most individuals are not even afforded the information to complete the tasks required. Efforts have been made at public education. A few examples include: The CDC (https://www.cdc.gov/aging/advancecareplanning/care-planning-course.html) offers an advance care planning course. The National Institute on Aging has developed an informational webpage (https://www.nia.nih.gov/health/advance-care-planning-advance-directives-health-care) discussing ACP and the completion of ADs. Five Wishes (https://www.fivewishes.org/) can be ordered in digital or paper format and is available for a small fee to anyone who visits their site. There are more resources online. Yet individuals are not engaging in the process. Potentially most concerning is that young people, while highest at risk for unintended accident or injury resulting in their death, are completely unaware of the right to maintain autonomy and communicate their own wishes for care now, to identify their own decision maker, and to finish their life in the ways they feel offer dignity and honor for themselves. They may not even be aware that they are at such high risk and need these preparations completed.

Limitations and Future Research

This study had many limitations. The researcher’s personal experience with loved ones dying in the absence of advance care planning and advance directives, as well as the researcher’s professional experience as a hospice social worker, provided a bias for action. There was an inherent sampling bias as participants were informed of the subject matter before beginning the survey questions and it could be that those who were willing to respond were also already equipped with some level of comfort about the subject matter and those who chose not to respond were uncomfortable discussing the subject but that went unrecorded. The cross-sectional nature of this study is also a limitation. While this study offers a snapshot in time and can be applied for understanding differences, it cannot assess changes over time. Future studies should focus on longitudinal designs using random sampling to explore the difference in engagement and completion over time.

The sample was inherently biased in that the college fields of study who were targeted through use of the College of Education SONA system were going into fields of study related to education and/or working with families. Being the students have already expressed a desire to work with this population, it is possible they have some experience that influences their willingness to engage in dialogue about advance care planning.

The scales used were developed for this study and not previously validated. They were utilized in an attempt to explore the subject matter in the absence of a validated scale. The low reliability of the Knowledge Scale and Health Status Scale demand further study. The items were explored to see if eliminating one (or more) may improve the reliability of the scale, however no significant difference would be made from the elimination(s). Interpretive caution must be applied to this study’s findings involving Knowledge and Health Status. At minimum, future research should conduct the same study again with the same scales, viewing these results as tentative. The results may aid in identifying items to exclude to improve the validity of these scales. Redesigning the scales would also be worth exploring.

The overwhelming majority of participants in the Young Adult group were actively enrolled college students. Future studies should expand on this age group by striving to include those who chose not to attend college. There was also compensation offered to students who participated through the SONA system, but no compensation to those who were not students. The compensation could have enhanced the engagement of the student population. Future studies should explore equal compensation, or a lack of compensation, for all participants.

The sample was disproportionately female. Several genders were underrepresented in the sample. To enhance the scientific quality and social relevance of findings, future studies should explore all genders and what influence gender may have on access to medical information and the meanings held with regard to the medical system as whole, ACP, and ADs. Future studies should also utilize random sampling to reflect the population of focus.

The sample was disproportionately Caucasian. Future studies should explore racial and ethnic minorities. Specifically, future research should look at the influence of bias and discrimination on access to medical services and information. Exploring the meaning that different cultures apply to ACP and AD, as well as to the medical system (since this is where ACP is currently set up to happen), could lead to insight that improves effectiveness in completion rates. Studies could evaluate the medical system as a factor, as well as the meaning applied to ADs and ACP in different groups and how bias and discrimination may impact access to information about ACP.

Studies should explore resources to engage young adults in these discussions outside of facilities, prior to crises. Outreach efforts could be at community centers, places of employment, places of worship, through voter registration, automobile registration, mailed with high school diplomas and/or when applying for a marriage license. Policy changes would have to happen however there are already several documents required to be completed in order to register a car, secure a diploma, or obtain a marriage license. It makes sense at each of these milestones to implement a practice of completing an advance directive.

Future studies should look at healthy individuals who have completed their ADs and what motivated them to do so. Exploring what motivates those who do complete an advance directive to engage in the task could led to the development of interventions and/or offer potential points of engagement. Further research should explore when those who are engaging in the conversation are doing it, as well as what motivates them at that specific time. Studies could also gather insight into those who refuse to engage and their reasoning for doing so. Work should be done to look at the impact of religion and political affiliation on willingness to engage in discussion. The intersection of held beliefs and engagement in advance care planning may offer insight into low completion rates.

Future studies should focus on the impact of elders modeling behavior for young adults and how to best implement ACP involvement at younger ages. Studies should also explore what other mentors could be utilized to improve completion rates. Education could begin in Family and Consumer Sciences classes in high school. It could start even sooner by normalizing conversations about death with children in elementary schools. Leadership in places of worship could also provide regular educational sessions.

Future studies should explore young adults' experience with death. As traditional family roles do not define how close someone feels to an individual, it is important to gain understanding of the relationships young adults have had with those they have lost.

Having been a caregiver may have a significantly different impact in times of loss than having been a neighbor or coworker. Grasping why having experienced the loss does not increase their willingness to engage in discussion will require understanding the relationships that were in place. Also, having had time elapsed since the loss may impact young adults' perception. They may be more or less willing to contemplate planning for their own end of life simply with the passage of time.

Having had, or not had, experience with death implies experience with ACP, or the absence of it. Future studies should also examine whether those who had engaged in ACP with their loved ones experience the same level of reservation about ACP as those whose loved ones did not discuss their wishes. Questions could be asked through online surveys focused on personal experience. One-on-one personal interviews would also be appropriate. Focus groups could be utilized as well. The aim would be to explore the emotional burden experienced by loved ones and whether that is impacted by having completed ACP and an AD.

Expanding understanding of the impact of being without an advance directive could be a powerful motivator for completion. Future studies should gather stories from family members and loved ones of those who died without having engaged in advance care planning or having an advance directive in place. Those family members could help aid in understanding the emotional burden it is to make decisions without the input of the person who is receiving the treatments and cares decided upon. These individuals could also help to understand the lasting effects of the experience. Knowing the impact of being unprepared to make decisions could be utilized to motivate healthy individuals to have conversations with those who would be their chosen decision makers. It could also motivate completion of advance directives.

The effect of educational interventions on healthy young people's willingness to engage in discussion and complete ADs should be the focus of follow up studies. Knowing that systems are dynamic, it follows that educating young people on ACP could lead to improved completion rates for not only their cohort, but their parents as well. By understanding the importance of planning ahead and communicating well, there could be a bearing on how the family, and its members, approach ACP. The on-going dialogue of young adults with their own parents could prompt elders to complete their own ADs, preparing young adults to support the wishes of their elders.

Recommendations for Policy and Practice

Medical providers, nurses, and social workers must assume that knowledge alone is not enough to motivate individuals to complete their ACP. Professionals should be leading by example and completing their own ACP and ADs as a way to assist them in normalizing the dialogue. They also should be educating on the importance of planning ahead, of parents and caregivers providing clear communication, and encouraging their discussion of ACP early and often with young adults. Service professionals should be having those discussions with young adults themselves and advocating for programming that equips them to complete ACP. Professional organizations (i.e., state regulatory boards, medical associations, and attorney generals) should be provided education and reinforcing the value of ACP and ADs.

Primary care providers should be completing advance directives with their patients at a minimum as part of the annual wellness visit. Hospitals and medical offices should have social workers assigned as Advance Care Planners, with the defined role of assisting patients and their families in engaging in the necessary dialogue and completing their advance directives.

Programs should be developed and aimed at educating practitioners, as well as the general public, on advance care planning and completing advance directives as a preventative medicine measure that prepares them for unforeseen emergencies. To date, there has not been an identified population who is doing this well and/or in great numbers. There is a desperate need to educate all adults, across the country, on the implications of not having advance care planning in place and the power that completing an advance directive provides, but especially among young adults. This could be done one-on-one at college enrollment, as part of employment onboarding, during an annual wellness examination or when renewing a driver's license (just as is done with organ donor registration.) County extensions could provide community education events on college campuses aimed specifically at educating young adults on advance care planning and the role and responsibilities of being a healthcare proxy.

There should be training for those who have been identified to serve as healthcare proxies. To be the designated decision maker for another human being is a serious responsibility. Healthcare proxies should have a minimum baseline knowledge of the documents that name them, what the expectations are of them going forward, and when their responsibility is activated. They need an on-going dialogue with the individual they are expected to make decisions for. They need a clear understanding of the individual's desires for care and preferences for treatment and lifestyle options. After all, they are being asked to make choices for the individual who identified them. Choices the individual would have made for themselves rather than choices the healthcare proxies would want to make for the individual or themselves. Training courses should be developed to equip individuals to fully understand the dynamic of decision making “as someone would” rather than decision making “for someone else,” in order to fulfill this role effectively.

Policy changes need to happen that will allow employers to include advance directives as part of the onboarding process at the start of employment and continue annual reviews throughout the life of employment with the agency. Colleges and universities should require advance directive documents of students and employees as a condition of enrollment and/or employment. Student services and/or human resources could be trained to offer support and assist with completion. Regular reviews need to occur when “qualifying events” occur (i.e., marriage, childbirth, moving employment.) The United States Armed Forces should put protocols in place to require advance directive completion at enlistment and reenlistment. Family team building classes should include advance care planning and advance directives for family members as well.

Further research should focus on the effectiveness of the current policy within facilities (asking at admission if patients have an advanced directive) and what follow up is being provided. The effect of offering one-on-one assistance should be evaluated as well as which medical providers could best facilitate the process. A three-hospital study should be completed with one doing business as usual, the second clearly defining whose role it is to provide AD education (and training them to do so), and the third educating all staff to lead by example, completing their own ADs and normalizing the conversation with patients. This would provide insight into the impact of having a clearly defined protocol for implementing the Patient Self Determination Act as well as reveal how powerful normalizing the conversation is.

This study makes great strides toward understanding young adults and advance care planning. There remains a great deal of work to be done. Future studies should be planned with the overarching goal of continuing to gain understanding that will inform interventions. Testing interventions and finding ones that are effective will improve completion rates. It is important that anyone doing this work is aware knowledge alone is not a sufficient motivator toward task completion. Knowing what needs to be done, and how to do it, is not even enough to prompt individuals to action. Exploring the disconnect between knowledge and behavior will provide insight into what will move individuals to protect their own wishes and shield their loved ones from the burden of uninformed decision making. Learning how to overcome the disconnect between knowledge and behavior will equip professionals and families to empower individuals to engage in their own advance care planning. Through that process, they will be best equipped to complete an advance directive, affording them the autonomy to direct their own care and relieving their loved ones of the burden of making choices for them without their input.

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APPENDICES

APPENDIX A

SURVEY QUESTIONS

Informed Consent

The purpose of this study is to examine the experiences of young adults with regard to advance care planning and the completion of advance directives.

Advance care planning *is an ongoing dialogue between patients, their families, and their providers that prepares everyone involved for meeting the patient's wishes when they decline physically and/or are not able to communicate.*

Advance directives *are documents that enable patients to express their wishes for future medical care, preparing their families and providers to make decisions, in the event the patient is not able to communicate.*

Your participation is voluntary, there is no compensation, and you are free to skip any question and/or withdraw at any time with penalty. This survey will take approximately 30 minutes to complete, and your responses will be anonymous. The data collected will be used in my dissertation and may be published.

If you agree to participate in this research, please choose "Yes" below:

a. Yes
b. No

The survey begins on the next page.

First, we would like to gather some basic information.

1. What is your age? ___

2. What gender do you identify with?
    a. Male
    b. Female
    c. Nonbinary
    d. Other: __________________

3. What is your relationship status?
    a. Single without children
    b. Single with children
    c. Living with partner
    d. Married without children
    e. Married with children
    f. Divorced
    g. Widowed
    h. Other ______

4. What ethnicity do you identify with?
    a. African American/Black
    b. American Indian/Alaskan Native
    c. Asian
    d. Caucasian
    e. Hispanic/Latino
    f. Pacific Islander
    g. Other

5. Are you currently enrolled as a student?
    a. Yes
    b. No

6. In what state do you currently reside? __________

For the next 6 questions, please choose True or False.

7. __ Advance directives are designed primarily for older adults.
8. __ A person does not need an attorney to prepare advance directive documents
9. __ Once a proxy is named, the patient gives up the right to make their own decisions.
10. __ Only the state's advance directive form is valid
11. __ A living will can prevent futile treatment at the end of life.

12. __ No medical care is provided if a patient has an advance directive

Next, we'd like to ask you some questions regarding your recent health.

13. Do you have a primary care physician?
    a. Yes
    b. No

14. Do you have a health condition that requires routine medication and/or follow up with your health provider?
    a. Yes (skips to Q#15)
    b. No (skips to Q#16)

15. If yes, what is the condition? ______________________

16. How would you rate your overall physical health?

Excellent	Very Good	Good	Fair	Poor

17. Have you been hospitalized in the last year?
    a. Yes (skips to Q#18)
    b. No (skips to Q#20)

18. If yes, did you receive written information about advance directives during your stay?
    a. Yes
    b. No

19. If yes, did anyone offer to assist you in completing an advance directive during your stay?
    a. Yes
    b. No

20. Who is your legal next-of-kin? (In Oklahoma, the legal hierarchy goes: Guardian, Health Care Proxy, Durable Power of Attorney (documented BEFORE 11/1/21), Spouse, Adult Children, Mother/Father, Adult Brother/Sister, Other Adult Relative, Close Friend.)
    a. Guardian
    b. Healthcare Proxy
    c. Durable Power of Attorney
    d. Spouse
    e. Adult Child

f. Mother
g. Father
h. Adult Brother
i. Adult Sister
j. Other Adult Relative
k. Close Friend
l. I do not know.

The following questions relate directly to advance directives and advance care planning.

21. How do you feel when you hear the words “advance directive”?
  a. Overjoyed
  b. Comforted
  c. Anxious
  d. Confused
  e. No identifiable feeling
  f. Other: ___________________

22. Have you completed an advance directive?
  a. Yes (skips to Q#21)
  b. Started but not completed (skips to Q#25)
  c. No (skips to Q#23)

23. If yes, what motivated you to complete your AD?
  a. Prior experience with a loved one
  b. Loved one asked me to
  c. Avoiding unnecessary treatments
  d. Controlling my own cares
  e. Avoiding pain/suffering
  f. Saving my loved one(s) money that would have been spent on unnecessary treatments
  g. Other: ____________________

24. If yes, have you: (Mark all you have completed)?
  a. Provided a copy to your doctor
  b. Discussed your wishes with your proxy
  c. Discussed your wishes with other family/loved ones

25. If no, do you know what you want your advance directive to include?
  a. Yes
  b. No

26. If no, which of the following reasons relates to why you have not completed an advance directive? (Mark all that apply.)
    a. Before today, I did not know what an advance directive was.
    b. I do not know how to access an advance directive.
    c. I do not want to think about death.
    d. I do not want to talk about death.
    e. I am too healthy.
    f. I am too young.
    g. I do not have anyone I trust to be my proxy.
    h. I would not know which treatments were right for me.

27. If started but not completed, which of the following reasons relate to why you have not completed an advance directive? (Mark all that apply.)
    a. Before today I did not know what an advance directive was.
    b. I do not know how to access an advance directive.
    c. I do not want to think about death.
    d. I do not want to talk about death
    e. I am too healthy.
    f. I am too young.
    g. I do not have anyone I trust to be my proxy.
    h. I would not know which treatments were right for me.

28. If no or started but not completed, have you talked to anyone about your wishes?
    a. Yes
    b. No

29. Many doctors' offices have information about advance directives, would you be willing to discuss your own advance care planning with your primary care doctor?
    a. Yes
    b. No
    c. I don't have a primary care doctor.

30. If you are a student, would you be willing to attend an event at your university aimed at assisting students with completing their advance directives?
    a. Yes
    b. No
    c. Depends on my schedule.
    d. I am not currently enrolled as a student.

31. Sometimes churches have special events, would you be willing to attend an event at your church aimed at advance directives?

   a. Yes
   b. No
   c. I don't attend church.
   d. Depends on my schedule.

32. What other resources would you be willing to go to for help with completing an advance directive? (Mark all that apply.)
    a. My parent/caregiver
    b. Community Center
    c. Other: ________________

33. If you knew help was available there, would you be more likely to seek help from the resources you identified?
    a. Yes
    b. No

34. Have you provided care and support to someone who was sick?
    a. Yes (skips to Q#33)
    b. No (skips to Q#34)

35. If yes, did that experience prompt you to think about your own physical decline and needs later in life?
    a. Yes
    b. No

36. Have your parents or caregivers discussed advance care planning with you?
    a. Yes
    b. No

37. Do you think discussing advance care plans has a positive or negative impact on family relationships?

Very Positive	Positive	Neutral	Negative	Very Negative

The following 5 questions relate to your engagement with those you are close to.

38. Have you had a conversation about end-of-life care options?
    a. Yes
    b. No

39. Would a discussion about death or planning for death be difficult to have?

Not at all difficult	Slightly difficult	Moderately difficult	Very difficult	Extremely difficult

40. Why or why not? ______________________

41. Would a discussion about death or planning for death be considered disrespectful?

Not at all disrespectful	Slightly disrespectful	Moderately disrespectful	Very disrespectful	Extremely disrespectful

42. Why or why not? _____________________

43. How willing would you be to have a conversation about end-of-life care?

Very unwilling	Unwilling	Neutral	Willing	Very Willing

44. What would increase your willingness? ______________________________

45. Compared to your elders, are you more or less willing to have a conversation about end-of-life care?

Much less	Less	About the same	More	Much more

46. Who are you most willing to discuss your wishes for care with?
    a. Mother
    b. Father
    c. Brother
    d. Sister
    e. Other relative
    f. Romantic partner
    g. Friend
    h. I do not know.
    i. I will not discuss with anyone.

47. Who is the person you would choose to make medical decisions for you if you were not able to?
    a. Mother
    b. Father
    c. Brother

    d. Sister
    e. Other relative
    f. Romantic Partner
    g. Friend
    h. I do not know.

48. Have you discussed your wishes with the person you identified?
    a. Yes
    b. No
    c. I did not identify anyone.

49. If you were to have an unexpected accident/health issue and were unable to communicate, not knowing if your condition is **temporary**, what would you definitely want them to give you? (Mark all that apply.)
    a. Antibiotics
    b. CPR (Cardiopulmonary Resuscitation involves chest compressions and rescuing breathing when a person's heart or breathing stops.)
    c. Ventilator (An appliance that is used to breathe for someone who is not able to do so for themselves.)
    d. Artificial hydration/nutrition
    e. All life-prolonging treatments
    f. I would not want them to give me anything.

50. If you were to have an unexpected accident/health issue and were unable to communicate, knowing your condition was **not likely to improve**, what would you definitely want them to give you? (Mark all that apply.)
    a. Antibiotics
    b. CPR (Cardiopulmonary Resuscitation involves chest compressions and rescuing breathing when a person's heart or breathing stops.)
    c. Ventilator (An appliance that is used to breathe for someone who is not able to do so for themselves.)
    d. Artificial hydration/nutrition
    e. All life-prolonging treatments
    f. I would not want them to give me anything.

51. If you were to have an unexpected accident/health issue and **left in a vegetative state with a ventilator breathing for you and no recordable brain activity**, would you want to be kept alive? (Mark all that apply.)
    a. Yes
    b. Only long enough to harvest my organs
    c. No

    d. I do not know

52. Are you an organ donor?
    a. Yes
    b. Some organs
    c. No

53. Have you experienced the death of someone close to you?
    a. Yes
    b. No

54. If yes, how long ago did they die?
    a. Within the last year.
    b. Within 2 years.
    c. 3 years or more

55. If yes, what role did their advance directive play?
    a. Directed their medical care
    b. Directed the distribution of their estate.
    c. They did not have an advance directive.
    d. I do not know.

56. If yes, which of the following decisions did you participate in:
    a. Medical care
    b. Funeral/Celebration of Life arrangements
    c. Settling their financial/property estate
    d. I was not involved in decision making

57. If yes, did your loved one's death increase your understanding of advance directives and/or advanced care planning?
    a. Yes
    b. No

58. Do you have a Do Not Resuscitate Order?
    a. Yes (skips to Q#58)
    b. No (skips to Q#57)
    c. I do not know what that is.
    d. I prefer to remain a full code.

59. If no, do you want a Do Not Resuscitate Order?
    a. Yes

b. No
c. I do not know what that is.

60. If yes, have you discussed this with your loved one?
    a. Yes
    b. No

61. Do you have a living will?
    a. Yes (skips to Q61)
    b. No (skips to Q#60)
    c. I do not know what that is.

62. If no, do you know what you want your living will to include?
    a. Yes
    b. No

63. If yes, have you discussed this with your loved one?
    a. Yes
    b. No

64. Do you have life insurance?
    a. Yes (skips to Q#63)
    b. No (skips to Q#64)

65. If yes, is your life insurance provided through your employment?
    a. Yes
    b. No

66. If no, do you know how much life insurance you would like to have?
    a. Yes
    b. No

67. If yes, have you discussed this with your loved one?
    a. Yes
    b. No

68. Have you identified your healthcare proxy?
    a. Yes (skips to Q#68)
    b. No (skips to Q#67)

    c. I do not know what that is.

69. If no, do you know who you want your proxy to be?
    a. Yes
    b. No

70. If yes, have you discussed this with that person?
    a. Yes
    b. No

71. Have you made arrangements for your personal and medical care when you are no longer able to care for yourself?
    a. Yes
    b. No
    c. I don’t know how to do that.

72. Have you made arrangements for your funeral/celebration of life?
    a. Yes
    b. No
    c. I don’t know how to do that.

73. Have you made arrangements for your cremation or burial?
    a. Yes
    b. No
    c. I don’t know how to do that.

74. Have you worked with an agency to plan for donating your body (or parts) at the time of your death?
    a. Yes
    b. No
    c. I don’t want to donate my body.
    d. I don’t know how to do that.

75. If you were to complete your advance care planning today, what would motivate you?
    ____

Thank you for participating in this study! Each state has published an advance directive form. Oklahoma resources are available below.

The Oklahoma Advance Direct Act can be found at:
https://govt.westlaw.com/okjc/Browse/Home/Oklahoma/OfficialOklahomaStatutes?guid=N8CA65030C75C11DB8F04FB3E68C8F4C5&transitionType=Default&contextData=%28sc.Default%29

The Oklahoma Advance Directive form:
http://www.okdhs.org/OKDHS%20Publication%20Library/87-07W.pdf

The Oklahoma Bar offers the following information regarding wills:
https://www.okbar.org/freelegalinfo/will/

APPENDIX B

RECRUITMENT EMAIL FOR OSU STUDENTS

Subject:

Request for Participation in Dissertation Survey

Body:

Hello! I am contacting you today to ask for your participation in my dissertation research study. I am a doctoral candidate at OSU-Tulsa in Human Development and Family Science. My dissertation topic is Young Adults and Advance Directives. I am looking to gather information about the experience of young adults related to advance care planning and the completion of advance directives. You must be between 18-29 years old to participate.

Your email address has been provided to me by OSU as part of their student directory information.

The survey is expected to take you no longer than 20 minutes to complete, and your responses will be anonymous. If you would like to participate in the survey, please click on the link provided below.

(https://okstateches.az1.qualtrics.com/jfe/form/SV_6fp7nXydDwXLrym)

Thank you in advance! I appreciate your help. Pass it on to your friends, near and far!

APPENDIX C

RECRUITMENT EMAIL FOR NON-OSU PARTICIPANTS

Subject:

Request for Participation in Dissertation Survey

Body:

Hello! I am contacting you today to ask for your participation in my dissertation research study. I am a doctoral candidate at OSU-Tulsa in Human Development and Family Science. My dissertation topic is Young Adults and Advance Directives. I am looking to gather information about the experience of young adults related to advance care planning and the completion of advance directives. You must be between 18-29 years old to participate.

Your email address has been provided to me by a mutual friend who thought you would be ideal to provide feedback!

The survey is expected to take you no longer than 20 minutes to complete, and your responses will be anonymous. If you would like to participate in the survey, please click on the link provided below.

(https://okstateches.az1.qualtrics.com/jfe/form/SV_6fp7nXydDwXLrym)

Thank you in advance! I appreciate your help. Pass it on to your friends, near and far!

APPENDIX D

SURVEY RECRUITMENT FACEBOOK POST

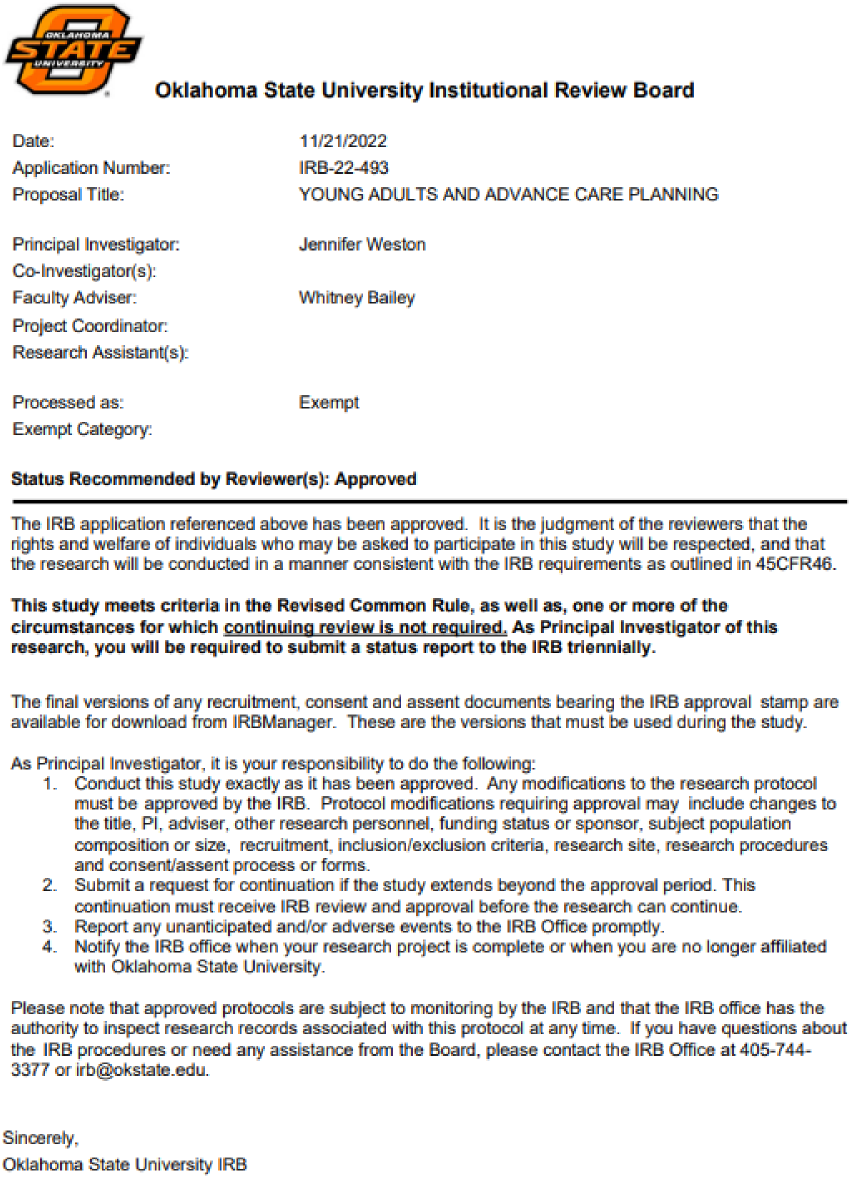
Hello, Friends! As many of you know, I am a doctoral candidate at OSU-Tulsa in Human Development and Family Science. My dissertation topic is Young Adults and Advance Directives. I am recruiting participants (between 18-29 years old) to follow the link below and participate in my research survey.

(https://okstateches.az1.qualtrics.com/jfe/form/SV_6fp7nXydDwXLrym)

It takes about 20 minutes to complete, and responses are anonymous. Thank you in advance! I appreciate your help. Please pass it on to your friends, near and far!

APPENDIX E

IRB APPROVAL LETTER



Oklahoma State University Institutional Review Board

Date: 11/21/2022
Application Number: IRB-22-493
Proposal Title: YOUNG ADULTS AND ADVANCE CARE PLANNING

Principal Investigator: Jennifer Weston
Co-Investigator(s):
Faculty Adviser: Whitney Bailey
Project Coordinator:
Research Assistant(s):

Processed as: Exempt
Exempt Category:

Status Recommended by Reviewer(s): Approved

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in 45CFR46.

This study meets criteria in the Revised Common Rule, as well as, one or more of the circumstances for which continuing review is not required. As Principal Investigator of this research, you will be required to submit a status report to the IRB triennially.

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp are available for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be approved by the IRB. Protocol modifications requiring approval may include changes to the title, PI, adviser, other research personnel, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2. Submit a request for continuation if the study extends beyond the approval period. This continuation must receive IRB review and approval before the research can continue.
3. Report any unanticipated and/or adverse events to the IRB Office promptly.
4. Notify the IRB office when your research project is complete or when you are no longer affiliated with Oklahoma State University.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact the IRB Office at 405-744-3377 or irb@okstate.edu.

Sincerely,
Oklahoma State University IRB

VITA

Jennifer D. Weston
Candidate for the Degree of
Doctor of Philosophy

Dissertation: YOUNG ADULTS AND ADVANCE CARE PLANNING

Major Field: Human Development and Family Science

Biographical:

Education:

Will complete the requirements for the Doctor of Philosophy at Oklahoma State University, Tulsa, Oklahoma in May 2023.

Completed the requirements for the Master of Social Work at University of Kansas, Lawrence, Kansas in May 2013.

Completed the requirements for the Bachelor of Science in Social Work at Pittsburg State University in Pittsburg, Kansas in May 2012.

Experience:

2019-2023	Graduate Research Assistant, Oklahoma State University
2021-2023	Instructor of Record
2019-2020	Graduate Teaching Assistant, Oklahoma State University
2015-2017	Adjunct Professor, Pittsburg State University
2017-2020	Therapist, Community Mental Health and Private Practice
2015-2019	Hospice Social Worker/Bereavement Coordinator
2014-2015	School Social Worker/Outpatient Therapist
2011-2014	Adult Case Manager, Community Mental Health

Professional Memberships:

2019-current	Licensed Clinical Social Worker, Oklahoma
2017-current	Licensed Clinical Social Worker, Missouri
2020-current	Association of Geriatrics, Healthcare Professional Member