

OLDER ADULTS CONCEPTION  
OF A 'GOOD DEATH'

by

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## ABSTRACT

Advances in medical care have led to an increasing number of older adults living with at least one chronic illness over a longer period of time. Correspondingly the disease trajectory and dying process may be prolonged, providing individuals with more time to plan for what they consider a ‘good death.’ A ‘good death’ is described through research primarily according to medical and biological aspects. While the psychosocial and spiritual elements are also part of a ‘good death,’ it is difficult to delineate the individual aspects important to individuals near the end of life.

This study used descriptive qualitative research methods to describe older adults’ conceptions of a ‘good death,’ specifically the psychosocial and spiritual factors. Data were collected from 12 community-dwelling older adults in central Alabama, utilizing a semi-structured interview guide. Qualitative content analysis guided the data analysis procedures. Corr’s (1992) task-based approach to coping with dying framed the study and served to categorize participant statements.

The findings suggested that a number of physical, psychological, social, and spiritual components contributed to the conception of a ‘good death,’ and that these were often interrelated. For example, the type of medical treatment desired at the end of life was influenced by the potential effect on members of the participants’ social network, such as necessity for the participants’ family members to care for them when they were no longer independent and had a poor quality of life. Participants’ motivations and values guided what these individuals believed could help them achieve a ‘good death.’ Conceptions were highly personal with the realization

that preparation would allow them to control their situation, although unpredictable, near the end of life.

Health social work practice may be strengthened by these findings as it confirms the holistic nature of helping older adults prepare in advance for the end of life. Efforts to maximize quality of life throughout serious illness and near the end of life are essential so that older adults may die a ‘good death.’

## DEDICATION

This dissertation is dedicated to my wife, Mallory La'Shae Maynard, my parents, Cecil and Kelli Maynard, and my brother Connor Maynard. I would not be where I am today without your love and support.

## LIST OF ABBREVIATIONS AND SYMBOLS

*IOM* Institute of Medicine

*BCSI* Brief Screen for Cognitive Impairment

*NASW* National Association of Social Workers

*ACP* Advance Care Planning

*GDI* Good Death Inventory

*GDS* Good Death Scale

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## CHAPTER 1 - INTRODUCTION

Expectedly, with the increase in population, the number of people who have died each year in the United States increased steadily between 1935 and 2010. However, mortality rates have declined (Hoyert, 2012) and life expectancies have increased overall. These changed statistics over time are attributable to the introduction and success of general antibiotics, vaccines, and other medical advances, including effective chemo- and radiotherapies for cancer and organ transplantation for diseases previously experienced as terminal upon diagnosis (Hoyert, 2012; Zhavoronkov, Debonneuil, Mirza, & Artyuhov, 2012). In 2016, compared to deaths caused by external factors (e.g. homicide, accidents), chronic illnesses were the most prevalent cause of death for adults aged 65 and older in the United States (Heron, 2018). Further, almost two-thirds of adults aged 65 and older manage two or more chronic illnesses (Ward, Schiller, & Goodman, 2014). The dying process is often more prolonged for individuals with chronic illnesses when compared to those with acute illnesses. Physicians and the general public may believe in the ability to ‘stave off’ death indefinitely, thus contributing to the delay of adequate planning for the end of life. This may, in turn, result in unwanted or futile treatment.

One consequence of older adults being diagnosed with multiple chronic illnesses is that the ability to predict prognosis accurately becomes more difficult (Institute of Medicine [IOM], 2014). Because of the prognostic complexity caused by the interaction of multiple chronic illnesses, end-of-life planning that focuses on the needs and wishes of patients as individuals must occur earlier in the disease process. Early planning allows patients to voice their preferences for end-of-life care and to avoid unwanted treatment.

## **Elements of a ‘Good Death’**

The IOM (1997) broadly defined a good death as being “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards” (p.24). This definition suggests that a ‘good death’ is highly personal and dependent on the perspective, experiences, and culture of the individual within their social network.

Meier et al. (2016) reported that preferences for treatment during the dying process were the most commonly mentioned components of a good death and included preferences for ‘how’ one would die and the perceived factors that constituted ‘readiness’ to die a ‘good death.’ How one wished to die implied that medical components were important to people when they were near the end of life but also indicated that psychosocial and spiritual components play a significant role in the dying process. For example, some older adults reported that having close family and friends who visit is important to a ‘good death’ because they can interact socially or pray together (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Gelo, O'Brien, & O'Connor, 1997; Ko, Cho, Perez, Yeo, & Palomino, 2013), while others wish to die alone because they do not want their family to experience discomfort in the process (Gelo et al., 1997). Although the individual components of a good death identified by patients, families, and health care providers may vary in level of importance, the main factors of a good death, such as a manageable dying process, pain control, and emotional well-being, were all believed to be essential to consider (Meier et al., 2016).

Cultural elements were also considered by many as important (Meier et al., 2016; Raisio, Vartiainen, & Jekunen, 2015). For example, older Japanese Americans consider reducing familial burden as one of the most important components for achieving a good death (Hattori &

Ishida, 2012). Also, preferences for care at the end of life are likely influenced by the culture and social network of each individual (Caralis, Davis, Wright, & Marcial, 1993; Duffy, Jackson, Schim, Ronis, & Fowler, 2006; Wallace, 2015). Planning with providers should include opportunities to explore the factors individuals believe important for a ‘good death,’ while respecting patient diversity. For example, black and Hispanic individuals prefer life-sustaining treatments more often than do their white counterparts (Caralis et al., 1993). Health care providers may be able to better facilitate end-of-life care planning discussions, and thus a ‘good death,’ by engaging in culturally-relevant discussions. However, while culture should be considered when discussing treatment options at the end of life and what constitutes a ‘good death,’ healthcare providers should also address individual differences that are guided by individuals’ unique experiences (Duffy et al., 2006). This is due to the unique and nuanced expectations individuals experience in regards to culture.

Much of the literature medicalizes the concept of a ‘good death’ and thus it seems like an event that can be attained by all if there is access to the ‘right’ medical treatment (Meier et al., 2016). However, older adults may worry about being able to define and express their views of a ‘good death,’ knowing that progression of chronic/serious illness is inevitable. The ideal ‘good death’ is one that is good for all parties involved. However, Raisio et al. (2015) suggested that often an individual’s death, in reality, may not reflect her or his wishes as their preferences and needs, and indeed end up being more ‘medical’ than holistic. The study attempts to examine a more holistic view of a ‘good death,’ as perceived by older adults, emphasizing the psychosocial and spiritual components considered important.

## **Statement of Problem, Purpose, and Research Questions**

Despite the broad nature of the IOM's (1997) definition of a good death, much of the literature focuses on physical aspects of a good death. The biopsychosocial model allows for the holistic exploration of disease and illness by considering the psychosocial and spiritual determinants of health, in addition to the medical components (Engel, 1977). Little is known, specifically, about the psychosocial and spiritual aspects that may influence the experience of a 'good death.' These factors likely affect quality of life at all stages of illness and arguably are more important to consider toward the end of life when physical components are the main concern of health care providers.

The purpose of the current study was to examine older adults' perceptions of a 'good death' through an in-depth exploration of the psychosocial and spiritual factors that may contribute to being able to experience a death they would call 'good.' It was not to determine the ability to achieve a 'good death,' but rather to understand the components that older adults consider to be important contributors to the experience of a 'good death.' Gathering data from community-dwelling older adults who are not immediately facing the end of life allowed for a thoughtful, 'future' perspective not as likely to be based on the potential fear or apprehension that may occur as the end of life approaches.

Research questions addressed were:

1. How do older adults conceptualize a 'good death'?
2. What specific psychosocial and spiritual factors are essential to consider in achieving a 'good death'?
3. What do older adults perceive as the facilitators and challenges to being able to achieve a 'good death'?

## Methodology

The current study used descriptive qualitative research methods to describe components that older adults perceive as important to a good death. For each of 12 older adults living in central Alabama, two in-depth interviews were conducted about their perceptions of a ‘good death.’ The strategy of the two in-depth individual interviews with each participant was adapted from Seidman’s (2013) multiple interview model. The multiple interview model allowed the researcher to build greater rapport and thus likely increased comfort of the participants in sharing their views on a potentially difficult topic. It also allowed for direct clarification that would not have been possible with only a single interview. Participants were recruited using a snowball sampling procedure beginning within the researcher’s acquaintance network. Participants were included if aged 65 or older, lived in central Alabama, and were cognitively able to participate in the research process as determined by the *Brief Screen for Cognitive Impairment (BSCI)* (Hill et al., 2005).

The storage and formatting of the data followed standard qualitative techniques. The data were audio recorded, transcribed verbatim, and stored using an encrypted cloud-based storage system. The qualitative data analysis software used during analysis was NVivo 12. Qualitative content analysis was the data analysis strategy used to categorize and describe the data. This data analysis strategy provided a framework for summarization and description of the data in a systematic way (Forman & Damschroder, 2008). Participants (via member checking) were encouraged to review the transcripts and initial codebook to ensure that factors perceived as contributing to a good death were accurately categorized and described.

## **The Researcher**

I prepared to conduct a dissertation using qualitative research methods by taking qualitative research courses and participating in several research projects that used qualitative research methods. Examining the literature and other key works on end-of-life and qualitative research methods provided an understanding of the skills required to conduct sound research on the topic. Additionally, I consulted with more experienced researchers and community members to formulate recruitment strategies as I understand that they know the best techniques to engage the population served.

My interest in this topic began during the first year of my doctoral program when a family member attempted suicide and life support kept him alive for a period of time. When discussing the situation with my family, one person said they thought that they should remove life-sustaining measures because “he wanted to die and who are we to go against his wishes.” When I heard that statement, I became fascinated with the idea of a ‘good death’ and allowing one to choose how and when they die. While this situation differs from the experiences of the participants interviewed for this study, I wanted to know more about whether there were some commonalities between this situation and that of older adults with serious illness and how a good death is defined by older adults.

### **Researcher Assumptions**

The assumptions of this study come from my understanding of the available literature and discussions with experts in the field. I assumed that the participants had thought about death to the extent that they are able to provide a description of their conception of a good death because of their age and the likelihood that they have experienced death of someone within their social network. As people age, they are more likely to experience the deaths of family members and

friends, giving them the opportunity to consider what they perceive as important as they near the end of life.

I assumed that the majority of participants would discuss pain and symptom management as a primary component of a ‘good death.’ This assumption is based on the fact that much of the good death research literature focuses on pain and symptom management. While the interviews allowed for participants to discuss these physical components of a ‘good death,’ questions in the interview guide used prompts to engage participants further in discussion about psychosocial and spiritual concerns.

The third assumption was that psychosocial and spiritual components are considered as important as the physical components of a good death when asked to perceive that pain and symptoms are adequately controlled. Additionally, it was assumed to be likely that psychosocial and spiritual components would be intertwined with participants’ discussions of a desire for pain and symptom management.

### **Significance of Study for Social Work Practice**

The ethical principle of dignity and worth of the person in the National Association of Social Workers (NASW, 2017) code of ethics states that social workers “treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity” and “promote clients’ socially responsible self-determination.” The IOM (1997) definition of a good death is congruent with the ethical principle of dignity and worth of the person in that it should reflect patient wishes and cultural standards. The ethical principles and standards of the NASW Code of Ethics are congruent with the IOM’s definition of a good death and provide a foundational mandate for social workers to take a leadership role in ensuring quality of life for older adults.

This study's findings may have significance for the field of social work and other allied health care professions. The findings may help guide care planning discussions between individuals, their families, and health care providers. A better understanding of what older adults consider important to a 'good death' will enable social work practitioners to assess and intervene in accordance with the individuals' wishes. Health social workers are trained to address individuals'/families' psychosocial and spiritual needs, while the medically-trained members of the healthcare team can work to address the physical aspects of death and dying. Social workers in all types of health care settings may use the findings from this study to address psychosocial and spiritual concerns related to a 'good death' earlier in and throughout the disease process. Additionally, social workers in hospice and palliative care settings can incorporate older adults' perceptions of important components leading to a good death into the interdisciplinary care plans and work with health care team members to ensure psychosocial and spiritual well-being and quality of life toward the end of life.

## CHAPTER 2 - LITERATURE REVIEW

Understanding what constitutes a ‘good death’ can enhance social workers’ and other health care providers’ ability to improve the death and dying experiences among older adults. Advance care planning (ACP) is one manner in which older adults can voice their preferences for dying; however, much of the information requested in ACP documents focuses on the medical aspects of dying (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). This medicalized worldview of someone’s wishes near and at the end of life may limit the realization of a good death because it fails to consider psychosocial and spiritual aspects of dying (Castillo et al., 2011). Defining older adult’s conceptions of a good death may help to provide a framework that healthcare providers can use in discussion and formulation of ACP documents with older adults.

### **Attempts to Define a Good Death**

Understandably, there is considerable variability in the definition and components of a good death. This variability is a result of whom (e.g. the individual, the family, or healthcare providers) is asked to define it and the context that is provided in research to date (Meier et al., 2016). For example, pre-bereaved or bereaved family members indicated that quality of life is a more important consideration of a ‘good death’ when compared to the preferences of patients and health care providers. The relative weight of various factors perceived to constitute a good death is contextual and is often defined according to the health status of the individual (Vig, Davenport, & Pearlman, 2002). This suggests that providers must continuously re-evaluate

preferences to gain an accurate understanding of individuals' preferences throughout the disease process.

In 1997, the Institute of Medicine (IOM) defined a 'good death' as one that is "free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (1997, p.4). This suggested that dying is more than an individual experience and that attempts to understand how each person defines it should recognize the contribution of their families, friends, and communities to the extent desired by the individual. Distress and suffering, though subjective in nature, are often defined medically (e.g. pain, physical symptoms, and futile medical treatments). However, psychological, social, and spiritual distress and suffering may also prevent the experience of a 'good death' (T. Hughes, Schumacher, Jacobs-Lawson, & Arnold, 2008). Social workers may intervene with individuals' psychological, social, and spiritual needs near the end of life to further enhance the likelihood of a good death among older adults.

According to Byock (1997), there are several tasks that can facilitate a 'good death,' or what he calls 'dying well.' He framed these tasks as: asking for forgiveness, offering forgiveness, and saying 'I love you' and goodbye. Acknowledging and confronting the tasks provides opportunities for continued growth at the end of life and is also a stage in life that should be embraced rather than avoided.

Schneidman (2007) asserted that death is highly personal and should reflect the individual's preferences. "It is a death that one might choose if it were realistically possible for one to choose one's own death" (2007, p. 245). He presented 10 items to consider when determining whether or not a death is good: whether it was, natural, mature, expected, honorable,

prepared, accepted, civilized, generative, rueful, and peaceful. These criteria recognized that death is more than a medical experience and included the importance of relationships and preparation of and for the individual and those within their social network for the end of life.

There is a dearth of literature that focuses solely on the psychosocial and spiritual components of a ‘good death’ (Maynard & Csikai, 2017). Differentiating between the psychological, social, and spiritual components is often difficult because there is overlap between the concepts. Meier and colleagues (2016) identified that preferences for dying, pain-free status, emotional well-being, and religiosity/spirituality were among the most common themes among patients in a systematic review of literature. Specific themes regarding preferences for dying included the death scene, death during sleep, and preparation. The death scene, including where, when, and how the individual wished to die, was the most frequent component of a good death identified among patients. These common themes when taken together incorporate the physical, psychological, social, and spiritual components of dying. This suggests the need for providers to attend to each of these areas when working with individuals as they prepare for and near the end of life.

### **Components of a ‘Good Death’ among Older Adults**

Delineating the factors of a good death is difficult since the concept of a ‘good death’ lacks consensus within the literature (Meier et al., 2016; Raisio et al., 2015). In a sample of community-dwelling older adults, several components of a ‘good death’ (e.g. without pain, in sleep, quickly) are reported more frequently than others, however, none of the components considered important were reported by more than 50% of the sample (Vig et al., 2002). This suggests a lack of consensus regarding what contributes to a ‘good death’ among older adults. Further complicating this is the notion that death is a highly personal experience and is likely

guided by a variety of factors, including culture, and other life factors, and desires, as well as prognosis (Steinhauser, Christakis, et al., 2000). In addition, when the physical components of a ‘good death’ are adequately addressed, psychological, social, and spiritual concerns will emerge. Using the biopsychosocial spiritual model to organize the components of a ‘good death’ will allow for an in-depth exploration of the factors considered important as individuals near the end of life.

### **Physical Components**

As stated above, the physical aspects of death and dying are among the primary concerns that compose conceptions of a ‘good death’ (T. Hughes et al., 2008; Ko et al., 2013; Tong et al., 2003; Vig & Pearlman, 2004). These physical aspects include pain management and symptom control, consideration of medical treatments desired, and medical conditions considered acceptable near the end-of-life. While older adults may be able to continue to manage many of these concerns at home on their own (with primary care physician), hospice and palliative care can supplement care when they meet certain criteria. However, often adequate pain management may not occur due to delays in referral to hospice or palliative care (Bakanic, Singleton, & Dickinson, 2016; Teno et al., 2007). This delay may result from prognostic uncertainty (Fine, 2018); the individual or their family’s unwillingness to accept the diagnosis or prognosis (Sanders, Burkett, Dickinson, & Tournier, 2004); or physician and health care providers’ lack of comfort when discussing death or the end of life (Bakanic et al., 2016; Bernacki & Block, 2014).

Pain management and symptom control are most frequently referred to within the physical dimension of a ‘good death’ among older adults and are a primary concern (Ko et al., 2013; Pierson, Curtis, & Patrick, 2002; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000; Vig et al., 2002). However, the concern may be alleviated through conversations

with the health care team regarding how comfort can be maximized (Steinhauser, Clipp, et al., 2000). The level of pain that may be experienced is most often associated with a good versus a bad death; a high level of perceived pain being associated with a worse death (Pierson et al., 2002). Older adults who perceived they may have a painful death may also anticipate a difficult dying process overall. Managing this pain may make the achievement of a ‘good death’ more likely.

### **Psychological Components**

The IOM (1997) definition of a good death states that it is one in which individuals’ deaths reflect and respect their wishes. This suggests that one’s autonomy should be fostered during the dying process. Asserting autonomy allows individuals to retain ‘control’ over their dying process and death (Pierson et al., 2002). ACP documents are intended to allow individuals’ own wishes regarding health care decisions to be known in advance, thus enabling them to retain autonomy after losing capacity to speak for themselves. Because the ideal model includes discussion with family or other individuals active in the decision-making process and naming of a health care proxy, individuals may be reassured that their autonomy will prevail. Participation in the medical decision-making process through use of ACPs is often comforting to older adults because they perceive there will be less burden of decision-making for family members (Hattori & Ishida, 2012). Also, family members are often relieved by the presence of an advance directive, as then they are carrying out/ensuring the wishes of the individual who is dying and not being the individuals asked to decide about care and treatment for them.

Autonomy is more than retaining control with regards to medical decision-making; it also may reflect wishes in a general sense to continue living life ‘to the fullest’ (Goldsteen et al., 2006), also called richness in life (Corr, 1992). Many older adults wish to remain independent as

long as possible by continuing engagement in activities that they find enjoyable and not relying on others for care. The perceived burden on caregivers contributes to a less than ideal death for some and can be anxiety provoking (Vig & Pearlman, 2004). Thus, the social effect of losing autonomy has psychological implications for older adults as the end of life nears.

Beyond autonomy, emotional well-being is also identified as a key component of a good death among patients in previous research (Maynard & Csikai, 2017, February; Meier et al., 2016). Emotional well-being may mean reducing negative emotions (e.g. anger, spite) and being free from anxiety or fear (Steinhauser, Christakis, et al., 2000; Tong et al., 2003). Fostering emotional health can help older adults experience a death they would consider as ‘good.’

A sense of life completion may contribute to psychological well-being at the end of life (Pierson et al., 2002; Steinhauser, Clipp, et al., 2000; Tong et al., 2003; Winland-Brown, 2001). In order to feel at peace with their lives and have a sense of life completion, some older adults may attempt to resolve personal conflicts. This may include conflicts with individuals within their families or coming to terms with previous life decisions. In addition to repairing and enhancing relationships, older adults may wish to complete any ‘unfinished business’ or goals (Steinhauser, Clipp, et al., 2000; Winland-Brown, 2001). The realization of a ‘good death’ may be more likely when older adults perceive their life as complete because all tasks perceived as important will be completed.

### **Social Components**

Corr (1992) defined the social dimension of dying as including interpersonal relationships with individuals within their social network. The term social network refers to the relationship between social units (e.g. individuals, families, communities) (Faust & Wasserman, 1994). Several social components of a good death are present in the literature, such as family

presence during the dying process and not dying alone (Bakanic et al., 2016; Ko, Kwak, & Nelson-Becker, 2015; Vig et al., 2002); maintenance of social connections and communication with those in the social network (Ko et al., 2015; Winland-Brown, 2001); and ensuring the death is considered ‘good’ by all involved (Raisio et al., 2015).

The presence of family appears to be a major component of a good death (Gibson et al., 2008; T. Hughes et al., 2008). When discussing the end of life, some older adults and health care providers regard the presence of family as positive because they can share in the end-of-life experience by providing support (Bakanic et al., 2016; Vig et al., 2002). While many older adults wish to have family close when end of life is near, others may prefer no or limited family presence at the time of death in order to minimize perceived burden during what may be a difficult time (Vig et al., 2002). This discrepancy in the desire for family presence suggests that the care team for the individual closely assess the social needs of the individuals throughout the dying process. In addition, continuous evaluation of preferences throughout the disease trajectory and dying process provides opportunities for the individual to ‘change their mind’ about who they want to be present at the time of their death.

Specifically, social connections at or near the end of life appear to contribute to a good death (De Jong & Clarke, 2009; Ko et al., 2015; Pierson et al., 2002). The presence of family, friends, or others at or near the end of life contributes to perceptions of social connectedness and may increase the likelihood of experiencing a good death (Pierson et al., 2002). Among homeless older adults, the fear of dying alone, and the perceived social isolation, are related to the perceived experience of a bad death (Ko et al., 2015). Social relationships can be understood as making the death and dying experience ‘bearable’ (Pierson et al., 2002) and feeling supported at

that time (Ko et al., 2015). Facilitating social connections to the magnitude important to the individual is key to the experience of a good death.

Communication with those in the social network is often complex when someone is near the end of life. It may involve the ability to speak to and spend time just ‘being’ with others (Ko et al., 2013; Ko et al., 2015; Nelson, Schrader, & Eidsness, 2009; Pierson et al., 2002), as well as spending time with family to plan future care and funeral and financial arrangements (Goldsteen et al., 2006). Having time to make amends and resolve conflicts as needed with individuals in their social network with whom there may be estrangement may allow for ‘closure’ for both the individual and the other person (Hattori & Ishida, 2012). Preparation in all aspects can reduce the burden felt by those in the social network (Goldsteen et al., 2006; Hattori & Ishida, 2012; Steinhauser et al., 2001). For example, in a study of older Japanese Americans, Hattori and Ishida (2012) suggested that preparation reduces burden on family by helping to reduce the financial needs and decision-making responsibilities of family members prior to and following death.

Another social factor of a good death is for whom the death is ‘good.’ The IOM (1997) stated that family wishes, in addition to the individual’s preferences, are also important factors in achieving a good death. Preparation for funeral arrangements or caregiving responsibilities contributes to the good death of the individual and those in their social network (Hattori & Ishida, 2012). This type of preparation implies that a focus on others can contribute to a good death and dying experience for individuals and their family/friends.

It is evident that many of these social components have significant overlap; however, it is important to recognize them as distinct factors within a ‘good death.’ For example, individuals who wish to have family present as death approaches, may prefer the presence for support or for

opportunity to make amends (exhibiting a psychological aspect of a ‘good death’), thus contributing to social connectedness.

### **Spiritual Components**

A ‘good death’ was often conceptualized in a spiritual or religious context prior to modern medical advances (Walters, 2004). In this context, a death was considered ‘good’ if the individual had a relationship with a ‘higher power.’ For such individuals, following religious traditions in preparation for death, such as receiving sacraments such as the ‘anointing of the sick’ in the Catholic tradition or having time for prayer or spiritual counseling with a clergy person may be important. With the advances in medical science, the conceptualization of a ‘good death’ has changed to be more medicalized, but religious and spiritual components remain an essential part of preparation for death (Bratcher, 2010; Braun & Zir, 2001; Pierson et al., 2002; Tong et al., 2003). The presence of religious or spiritual leaders to offer support at the time of death can contribute to a ‘good death’ (Braun & Zir, 2001) and is seen as important so that the dying person’s spiritual needs may be met (Vig et al., 2002). Because the aging population is diverse and may have equally diverse spiritual needs or desires at the end of life (Bratcher, 2010; Pierson et al., 2002), assessing and providing services based on those preferences is critical to the experience of a ‘good death.’

Also, older adults use spirituality to frame their expectations for the end of life (Ko et al., 2013; Ko et al., 2015). Faith in a higher power can provide the belief that death is predetermined, that it provides an opportunity to meet their higher power, and that the afterlife they will experience is contingent on the way that life was lived. For example, reflecting on how one lives one’s life may allow for comfort when considering what comes after death, in religious/spiritual terms the afterlife, if the individual is content with their spirituality.

## **Attempts to Measure a ‘Good Death’**

Beyond using qualitative or anecdotal statements to conceptualize a ‘good death,’ attempts have been made to quantify the concept in an effort to determine whether an individual experienced a ‘good death.’ Researchers have developed standardized instruments to measure a good death, including the Good Death (GDI) Inventory (Miyashita et al., 2008) and the Good Death Scale (GDS) (Tsai, Wu, Chiu, Hu, & Chen, 2005). Both the GDI and GDS were initially developed in Asian countries (i.e. Japan and Taiwan); further, the majority of research using these instruments is based in Asian countries (Hales, Zimmermann, & Rodin, 2010). Since these were developed and used in Asian countries, additional psychometric testing is needed to understand the application to and appropriateness of these measures in western countries. The GDI was initially developed to evaluate the perception of a ‘good death’ with bereaved family members (Miyashita et al., 2008). The GDI includes 18 independent domains with three to four statements associated with each domain and has since been applied to terminally ill older adults, the general population, and healthcare providers (Miyashita et al., 2015; Morita et al., 2014). The GDS is a five-item assessment tool that has been used with terminally ill adults (Cheng et al., 2008; Tsai et al., 2005). In addition to using previously existing instruments, other measures for a ‘good death’ were developed by researchers for specific use in their own studies (Steinhauser, Christakis, et al., 2000). Results of these studies again revealed a primary focus on physical aspects of the dying process, rather than the psychosocial components, because of the content measured in the instruments and the responses from the participants. Further, while there are several instruments designed to measure a ‘good death,’ no agreed upon measure exists (Meier et al., 2016).

While some research that reported results of quantitative measures of a ‘good death’ did include psychosocial and spiritual statements (Miyashita et al., 2008; Tsai et al., 2005), few studies provided opportunity for elaboration on these concepts by study participants (Hales et al., 2010; Meier et al., 2016; Vig et al., 2002). As noted, the measurement of a ‘good death’ is often done after death (with bereaved caregivers or health care providers) to determine whether an individual experienced a ‘good death,’ and there is limited literature that provides application of these measures in practice.

### **Theoretical Framework**

While there are multiple theories available to help understand death and dying experiences (Copp, 1998), Corr’s (1992) *Task-Based Approach to Coping with Dying* was used to frame the present study. Corr’s approach follows a biopsychosocial and spiritual model for coping with the end of life and may provide guidance for social work intervention with older adults at or near the end of life. The tasks that Corr believed necessary to address within this framework are categorized into four primary dimensions: physical, psychological, social, and spiritual. According to this framework, individuals nearing the end of life may move back and forth between tasks as they face concerns or problems that need to be addressed. Therefore, framework is not linear and does not prescribe an order of accomplishing tasks. This approach is flexible also in that the completion of all of the framework’s tasks is not necessary and the successful coping with dying is individualized (Corr, 1992). This is unlike traditional stage theories of death and dying, such as the Kübler-Ross (1973) model, that imply prior stages must be complete before advancing towards acceptance of death.

The physical dimension of coping with dying focuses on addressing the physical needs of the individual (Corr, 1992). At the most basic level, this requires that adequate nutrition and

hydration are met, as well as the control of pain and other physical symptoms arising from the disease process. This is essential because when these basic needs are met, it allows dying individuals, caregivers, and health care providers to then recognize and attend to individuals' psychological, social, and spiritual concerns. For example, after pain and related symptoms are adequately controlled, assuming this is important to the individual, providers may notice that the individual has unresolved issues with family members that he/she would like to address, a concern of some individuals as they near the end of life (Ko et al., 2015).

Corr (1992) suggested that security, autonomy, and 'richness' are the main components of the psychological dimension of coping with dying. Each of these components is influenced by the individual's specific circumstances. For example, richness in life, or life satisfaction, for one individual may include participating in activities that make them feel as if their life is continuing on as normal (e.g. knitting, coloring, shopping), while others may wish a list of items to complete before they die (travel, learning to play an instrument, etc.). Autonomy is the ability of the individual to retain control of various aspects of their life, including medical decision making. Psychological security is described as the experience of feeling safe and secure throughout the dying process.

The social dimension focuses on relationships that the individual has as resources to help them cope with impending death. This task recognizes that the individual ascribes a certain value to relationships with others and society at large. For example, the individual may consider their relationship with family more important than the relationships with others in their social network, and that difference should be recognized. This approach to coping with dying stresses the importance that one places on specific relationships and that these relationships may change as an individual approaches the end of life.

Spiritual components of coping with dying include the individual's personal morals and values. Corr (1992) stated that hope is a major factor of the spiritual dimension and may also, like the other dimensions, change as the individual's disease progresses and the end of life is imminent. For example, when the individual is early in the disease process, they may 'hope' for curative treatments to be successful so their status within the community remains unchanged, while later in the disease process they may hope for their life to be a positive influence on others. Religion is encompassed within the spiritual domain, however, it is important to note that this may not be important to all individuals as they near the end of life. Participation in formal religious practices may allow the person the opportunity to explore the meaning of their life within a specific religious tradition. For example, one may reflect on their life to determine if they lived in such a way that reflects the teachings of their religion. If they determine that they are 'uncomfortable' spiritually, individuals may be able to address their concerns within the context of their religion, possibly receiving guidance from leaders of their religious denomination.

### **Gaps in the Current Literature**

A 'good death' is a key concept in the study and provision of end-of-life care. However, a lack of consensus exists regarding the definition and key components of a good death. Not only does a large portion of the literature focus on physical aspects, but perspectives studied are primarily those of proxy informants (family, caregivers) and healthcare providers (Bakanic et al., 2016; Bosek, Lowry, Lindeman, Burck, & Gwyther, 2003; Nelson et al., 2009; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000). Following their systematic review of literature, Meier et al. (2016) stated that more research was needed from patients' perspectives,

partly due to the discrepancies between patients, families, and providers on the components of a ‘good death.’

Much of the literature uses proxy informants and healthcare providers to describe the components of a ‘good death’ (Bakanic et al., 2016; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000) or to determine if an individual experienced a good death (Bosek et al., 2003; Miyashita et al., 2015; Miyashita et al., 2008; Nelson et al., 2009). Understanding the perception of the experience of a ‘good death’ from the perspectives of proxy informants and healthcare providers, while useful in certain areas of inquiry, neglects the individuals’ experiences and perspectives by design. In addition, quantitative research on a ‘good death’ offers limited opportunities for participants to provide context for their perception of a good death.

Research attempting to define a ‘good death’ with the general population (e.g. facility- and community-dwelling older adults, caregivers, bereaved family members) in the United States uses qualitative research traditions more often than mixed methods or quantitative research (Maynard & Csikai, 2017; Meier et al., 2016). These studies often identify the factors considered important to a ‘good death’ but a discussion of the motivations and value placed on the factors is minimal. Many of the psychosocial and spiritual components of a ‘good death’ are often embedded within medical/physical concerns. Distinguishing between the psychological, social, and spiritual components can be difficult, particularly when older adults ascribe multiple meanings to various components of a ‘good death.’ Certain factors, including support from religious leaders or having family and friends pray for the individual, cross multiple domains, suggesting the need for a more in-depth exploration of what specifically makes spirituality important to individuals as they near the end of life.

## **Statement of Problem/Summary of Gaps to be Addressed**

Despite the comprehensive nature of the IOM's (1997) definition of a 'good death,' much of the literature focuses on physical aspects of a 'good death.' A biopsychosocial model, such as Corr's (1992) framework, allows for the holistic exploration of disease and illness by considering the psychosocial and spiritual determinants of health, in addition to the medical components (Engel, 1977). Little is known, explicitly, about the psychosocial and spiritual aspects that may influence the experience of a 'good death.' These factors likely affect quality of life at all stages of illness and arguably become more important toward the end of life, when physical aspects may dominate concerns of most health care providers.

## **Research Questions**

The purpose of this study was to explore older adults' perceptions of a 'good death' through an in-depth examination of psychosocial and spiritual factors that may contribute to being able to experience a death they would call 'good.' This study's aim was not to define the concept of a 'good death' but rather to understand the components that older adults consider contributors important to them. This also fills a critical gap in the literature by adding the voices of older adults to previous literature on the topic. Gathering data from community-dwelling older adults who are not immediately facing the end of life allowed for a thoughtful, 'future' perspective and was not as likely to be based on the potential fear or apprehension that may occur as the end of life approaches. In this present qualitative study, participants were asked to discuss their conception of a 'good death' in depth, with an attempt made to separate the various components as specified in Corr's (1992) framework. It also allowed for clarification about the meaning of the various components of a good death that they described.

Participants were interviewed following a semi-structured interview guide that addressed the following research questions.

1. How do older adults conceptualize a 'good death'?
2. What specific psychosocial and spiritual factors are essential to consider in achieving a 'good death'?
3. What do older adults perceive as the facilitators and challenges to being able to achieve a 'good death'?

## CHAPTER 3 - METHODOLOGY

This chapter details the methodology utilized in this study, including research design, sample selection/procedures, and recruitment strategy. Development of the data collection measures and data analysis are described as well.

### **Research Design**

Significant overlap exists among physical, psychosocial, and spiritual components of a ‘good death’ and further complicates understanding this concept from the perspectives of older adults. Little research that delineates the various psychosocial and spiritual components of a ‘good death’ is available in the literature. Much of the literature attempts to identify whether individuals had a good death based on samples of bereaved family caregivers and/or health care professionals. Such research on the topic of a ‘good death’ used primarily quantitative research methods (Miyashita et al., 2015; Miyashita et al., 2008; Steinhauser, Christakis, et al., 2000) with no agreed upon measure of a good death (Meier et al., 2016).

This study utilized a descriptive qualitative research approach (Merriam, 1998; Sandelowski, 2000) to describe the components that older adults perceive as important to a good death. The specific qualitative method used in this study is descriptive, also called pragmatic or generic, qualitative research (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000; Savin-Baden & Major, 2013). Pragmatic qualitative research methods “seek(s) to discover and understand phenomenon, a process, or the perspectives and worldviews of the people involved” (Merriam, 1998, p. 11). A continuum exists within pragmatic qualitative research,

ranging from an objective, descriptive perspective (Merriam, 1998; Sandelowski, 2000) to a subjective, interpretive perspective (Thorne, Kirkham, & MacDonald-Emes, 1997).

Because the purpose of this study was to examine and describe the conception of a ‘good death’ from the perspective of older adults living in central Alabama, this type of exploration indicated a descriptive qualitative research approach. An objective description of data was most appropriate to address the research questions, as it allowed for identification of factors contributing to the participants’ perceptions of a ‘good death’; understanding the thoughts/motivations for these perceptions was desired rather than an interpretation of the participants’ conceptualization of a ‘good death.’ Description of the participants’ perceptions of psychosocial and spiritual components contributing to a ‘good death’ using the language presented by the participants was thus possible. These qualitative methods added depth to attempts to define the meaning of a ‘good death.’

### **Researcher Subjectivity Statement**

At the time of the study, I had completed all required coursework to engage in a dissertation study. I prepared to conduct a dissertation using qualitative research methods by taking qualitative research courses and participating in several research projects that used qualitative research methods. An appreciation of the skills necessary to engage in quality qualitative research on the end of life resulted from examining the current literature and other key works on end-of-life and qualitative research methods. Additionally, I consulted with community partners to refine recruitment strategies and language used during recruitment and in the interview guide. The director of a local community center for older adults shared that, for example, using the words death, die, and dying may be ‘off-putting’ to some, so I used the euphemism ‘passed or passing away’ when speaking with participants.

My experience with the death of my cousin made me question my preconceived notions of a good death and pushed me towards the path of respect for self-determination at the end of life. I am, generally, comfortable with the topic of death and I am able to engage in conversations related to the end of life. However, when framing the study, I recognized that spirituality and religiosity would likely be an important factor to the conception of a ‘good death’ among these study participants (particularly due to the geographical context). This is an area that I was uncomfortable with discussing, yet I understood that this was an unavoidable topic of conversation. Being that the aim of the study was to explore the conception of a ‘good death’ from the perspectives of older adults, it was necessary for me to acknowledge and reflect on my lack of comfort with the topic of religiosity and spirituality. I worked to understand and be conscious of my comfort with this topic during the study by memoing and discussing concerns with other researchers.

### **Epistemological Framework**

Pragmatism is the epistemological framework that guided the present study. Pragmatism is defined as a research paradigm that focuses on outcomes or consequences rather than antecedents (Cherryholmes, 1992; Creswell, 2013; Savin-Baden & Major, 2013). This approach assumes that there is no best way to understand reality and that methods used to understand experiences should acknowledge and concentrate on the outcomes, suggesting a ‘use what works’ approach to research.

Using the pragmatic framework, I selected methods that would provide the most practical data when addressing the research questions. Cherryholmes (1992) asserted that a pragmatic epistemological stance “seeks to clarify meanings and looks to consequences” (p.13). Descriptive qualitative research allowed for the analysis and presentation of study findings in a

manner that reflects the perceptions of study participants. Further, I recognized my own personal biases to ensure that these biases did not influence the data analysis and presentation. This recognition and consciousness allowed for the opportunity that the findings accurately reflected participants' perceptions. Memoing and member checking was also used to ensure trustworthiness of the findings (discussed in detail later in this chapter).

## **Sample and Procedures**

### **Sampling Strategy and Recruitment**

A snowball sampling strategy was used to access older adults living in central Alabama. Study aim, sample specificity, the use of an established theory, quality of dialogue, and data analysis strategy are used to determine information power (Malterud, Siersma, & Guassora, 2016). Larger samples are required when the study aim is broad, the specificity of the sample is sparse, there is limited theoretical support for the study, the quality of dialogue is weak, and the analysis strategy is cross-case. A sample of at least 10 participants, with the option to recruit additional participants, was desired to achieve sufficient information power. This decision was related to the relatively broad study aim, a moderately dense sample (older adults in central Alabama), the use of Corr's (1992) framework for coping with death and dying, and cross-case data analysis strategy. Further, the option to recruit additional participants was due to the inexperience of the researcher in conducting individual interviews for the purpose of research (may result in weak dialogue during the research interviews). Eligibility requirements for the study were age 65 or older and cognitively able to participate in the interview process as determined by a score below the established threshold on the *Brief Screen for Cognitive Impairment* (BSCI) (Hill et al., 2005) (Appendix 1).

The snowball sampling procedures began within the researcher's acquaintance network, with the initial contact starting with individuals from varied occupational backgrounds and contact with or access to older adults living in a rural community. Initial participants from a variety of backgrounds and settings was desired to enhance the likelihood of a heterogeneous sample. Sandelowski (2000) suggested that a maximum variation sample is ideal for qualitative description research studies. Because more than 80% of people aged 65 or older have been diagnosed with multiple chronic health conditions, it is likely that most of the participants would have been managing treatment for at least one chronic illness. This notion allowed for the assumption that participants have some familiarity with the progression of and future care needs for managing long-term illness until death. Thus, this allowed for examination of the participants' perceptions of a good death, as they may have thought about it given their experience with illness while not being so close to the end stage of their own chronic illness to be potentially distressed by the study's discussion.

Participant recruitment began after the University of Alabama Institutional Review Board approval on September 19, 2018 (Appendix 2). A research recruitment flyer (Appendix 3) described the purpose of the study and other details about how the study was to be conducted, as well as the researcher's contact information. The flyers were given to individuals in the researcher's social network to pass out to individuals whom they encountered who they believed met the study eligibility criteria. Potential participants contacted the researcher directly to express interest in the study. By phone, the researcher again described the purpose of the study and what participation would involve and affirmed continued interest in the study. At that time, participants were asked to complete the BSCI (Hill et al., 2005), a phone-based screening tool for cognitive impairment.

In several cases, prospective participants gave permission, to the individual who first described the study to them and/or provided the recruitment flyer, to have their contact information forwarded to the researcher. The researcher received this contact information and then called these potential participants and followed the procedures as previously described. No individuals who expressed interest in the study were screened to have BSCI scores indicating cognitive impairment, thus all 12 individuals that were recruited were eligible to participate.

During the screening phone call, the researcher ascertained the participant's choice of location for the interview. This varied and included the participant's home, a private office on the University of Alabama campus, and at a local church. At the end of each interview, participants were given several copies of the study recruitment flyer and were asked to provide the recruitment flyer to individuals in their social network that they thought may be interested in the study.

Participant recruitment and data collection continued until sufficient information power was achieved (Malterud et al., 2016) and the participant pool reached a minimum of 10 participants. The number of participants needed to achieve information power was unable to be accurately predicted prior to data collection and preliminary analysis because the main consideration for this determination was the quality of dialogue. Eight (8) participants were recruited within the initially planned two-month time period for completion of recruitment. The recruitment period was then extended because the minimum desired participant number did not reach the minimum (10). After preliminary review of the interview dialogue, the researcher determined that the quality of dialogue was such that additional participants, beyond the minimum of 10, were needed to establish sufficient information power. A total of 8 participants were initially recruited and after extending the recruitment period, 12 participants were enrolled

in the study. After reviewing the data from the 12 participants, the data was determined to have sufficient information power, as evidenced by ‘weak’ quality of participants’ dialogue. For example, one participant stated that they did not think about death and that they are comfortable with the topic and therefore expanded little on the topic. While this is useful information, the data was determined to lack richness in regards to their conception of a ‘good death.’

Additionally, codes continued to emerge during the preliminary data analysis suggesting that additional data was needed to fully grasp the conception of a ‘good death’ among older adults in central Alabama.

### Sample Characteristics

A total of 12 participants enrolled in and completed the study. Participant characteristics are presented in Table 1.

Table 1

<i>Participant Characteristics</i>						
Participant Pseudonym	Age	Gender	Race	Marital Status	Religious Affiliation	Medical Diagnosis
James	70	Male	White	Married	Baptist	Cataracts
Robert	75	Male	White	Married	Episcopal	Depression
Mary	65	Female	White	Married	Episcopal	None
Linda	69	Female	White	Married	Episcopal	High Blood Pressure / Arthritis / Sleep Apnea
Patricia	69	Female	White	Married	Episcopal	Osteoporosis / Hypothyroid
John	77	Male	White	Married	Episcopal / Buddhist / Sufism	None
Sandra	72	Female	White	Married	Baptist	High Cholesterol
Barbara	69	Female	White	Single	Lutheran	Arthritis
William	78	Male	White	Single	Episcopal	High Blood Pressure / High Cholesterol
Dorothy	93	Female	White	Widow	Baptist	None
Susan	66	Female	White	Single	Baptist	High Blood Pressure / Hernia
Carol	76	Female	White	Widow	Christian	High Blood Pressure

Pseudonyms are used in place of the participant's names. To protect confidentiality, pseudonyms were selected by the most popular name during the participant's birth year as determined by the participants age. Participant age, gender, race, marital status, religious affiliation, and medical diagnoses are presented. Data on the participants' demographics were gathered directly from the participants prior to beginning the main part of the first interview (see background data sheet Appendix 4).

All participants were age 65 or older, with participant age ranging from 65 to 93. The majority of participants identify as female, while 4 identified as male. All participants interviewed for the study were white and reported being members of the Protestant religions; with Episcopal and Baptist most common. The most common diagnoses reported by the participants were: two with arthritis, two with high cholesterol, and four with high blood pressure. Additionally, three reported no current medical diagnoses and four participants reported two or more current chronic medical conditions.

### **Data Collection Procedures**

Data for the study was collected using two face-to-face individual interviews with each participant. This was an adaptation from Seidman's (2013) three-interview model. The three-interview model was developed for use in phenomenological studies to allow for an in-depth understanding of a specific phenomenon's essence. In this model, each interview had specific goals: (a) focused life history, (b) the details of the experience, and (c) reflection on the meaning (Seidman, 2013). The first two interviews were combined for the present study because the depth needed for a 'focused life history' was not necessary; however, participants were asked to discuss a recent experience with death during the first interview (first question in interview guide) in order to orient them to the topic. Further, the time commitment required for individuals

to participate in three interviews was perceived to place an unnecessary burden on potential participants, thus the three-interview model was adapted to two.

In order to participate in the study, participants consented to the use of an audio-recording device. Prior to beginning the initial interview, the consent form (Appendix 5), explaining the purpose of the study and the participants' involvement was reviewed with the potential participants (questions answered, if any) and signature obtained. After participants engaged with the consent process at the time of the initial interview, the researcher presented participants with a one-time \$20 universal gift card as a 'thank you' for their time. Participants completed a re-consent form (Appendix 6) prior to beginning the second interview. The interviews lasted between 25 minutes to 75 minutes each. Initial interviews were generally completed in a shorter period of time than the follow-up interviews, possibly due to the development of rapport with the participants and the likelihood that they thought about the topic in the time between interviews.

## **Measures**

Each participant completed a short questionnaire to gather background data including basic demographic and health information before open-ended research questions were offered. The data sheet explained the purpose of obtaining this data and knowing participants' demographics. After completing the data sheets, an interview guide (Appendix 7 and 8), with the principal questions to be asked, was used in order to be consistent with all participants to obtain, at a minimum, the type of data targeted by the research questions.

The first interview combined the first two interviews proposed in Seidman's (2013) model and included a focused history of the participants experience with death and the details of the participant's conception of a 'good death.' The second interview allowed participants to

reflect on their conceptions of a ‘good death’ identified through the first interview and discussed the perceived barriers and facilitators of a ‘good death.’ A semi-structured interview guide was used in each interview. These contain several questions regarding participants’ conceptions of a ‘good death’ that were asked of all participants. During the first interview (see Appendix 7 for first interview guide), the initial questions were general in nature in order to build rapport with the participant and to orient them to the topic. For example, the participant was asked to share an experience about someone they knew who died. This also allowed participants to share a brief history about their experience with death. This was followed by questions that elicited participants’ perceptions of psychosocial and spiritual components considered important in their conceptions of a ‘good death.’ These questions may have been more sensitive requiring more personal reflection and additional ‘inward’ exploration by the participants. For example, they were asked to describe what specific factors they consider important, assuming that pain and other symptoms are well managed. In the beginning of the second interview (see Appendix 8 for second interview guide), the researcher summarized the main points participants discussed during the initial interview. Participants were asked if they wanted to supplement the previous statements made to provide clarification regarding their previous statements. This was followed by questions about facilitators and barriers of a ‘good death’ and led to further exploration of the degree to which participants believed they would be able to die in the manner that they consider a ‘good death’ given their life circumstances.

All participants completed the *Patient Health Questionnaire* (PHQ-9) (Appendix 9) following each interview. This was done to ensure that participating in the interview did not activate thoughts of suicide or self-harm. The researcher was able to provide initial support to the participants as needed and had a referral list of mental health professionals (Appendix 10) who

could provide individual counseling to participants if concerns were identified. None of the participants met PHQ-9 criteria for referral (i.e. “Consider Other Depressive Disorder” or “Consider Depressive Disorder”). The data gathered from the PHQ-9 was not used for any other reason in the study.

### **Data Analysis**

Several techniques were utilized during data analysis in order to enhance trustworthiness and the description of the data. Data analysis began during the interviews with participants; participants’ statements were initially categorized while writing the field notes during the interviews. Using these field notes, the researcher began preliminary analysis of the data, while still receiving feedback from the participants regarding initial ‘codes.’ Further, the field notes provided initial insights into the data and helped in the development of the codebook. Each interview was listened to in its entirety two times prior to the beginning of transcription. This allowed for initial data immersion by the researcher. The audio-recorded data was transcribed verbatim. Transcription was completed by the researcher to allow for continued immersion in the data. Transcripts included all statements made by both the participants and the researcher. Additionally, each transcription was checked for accuracy by listening to the audio file while following along with the transcript to allow for further immersion of the researcher into the data. The transcribed files were uploaded individually into NVivo 12 and stored in UA Box (a secure cloud-based data storage and sharing website). Handwritten field notes were taken during the interview on a sheet of paper with no identifying information included, scanned into a pdf document, and uploaded into the UA Box folder for the study immediately following the interview. All handwritten notes were destroyed after being uploaded to the UA Box folder.

## Qualitative Content Analysis

The data analysis strategy used in this study was qualitative content analysis, which is a “dynamic form of analysis of verbal and visual data that is oriented toward summarizing the informational contents of that data” (Sandelowski, 2000, p. 338). Sandelowski (2000) stated that qualitative content analysis is the most appropriate method when engaging in descriptive qualitative research. Qualitative content analysis was appropriate because it allowed for a summarization and objective description of the data (Forman & Damschroder, 2008). Additionally, the procedures involved in qualitative content analysis require that researchers categorize data in a systematic way. This process allowed for the researcher to understand participant’s perceptions and experiences with the phenomenon by noting which categories and subcategories are most mentioned. The categorization and description of the phenomenon using the participants own language allowed for the understanding of how individuals conceptualized the phenomenon, a ‘good death,’ in the present study. The steps for qualitative content analysis outlined by Schreier (2014) were followed, including development of a coding frame, segmenting the data, pilot coding, main data analysis, and presenting and describing the findings. The following (Table 2) provides an outline for the data analysis strategy used in this study.

Table 2.

### *Steps in Qualitative Content Analysis*

- 
1. Deciding on a research question.
  2. Selecting material.
  3. Building a coding frame.
  4. Segmenting.
  5. Trial coding.
  6. Evaluating and modifying the coding frame.
  7. Main analysis.
  8. Presenting and interpreting the findings.
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*Note:* Reprinted from “Qualitative Content Analysis,” by M. Schreier, 2013, *The SAGE Handbook of Qualitative Data Analysis*, p.7. Copyright 2014 by SAGE Publications

According to Schreier (2014), a coding frame, also called a codebook, is composed of the categories and subcategories that will be used to code the data. The coding frame development followed several steps to ensure that it met the following criteria: unidimensional main categories, mutually exclusive subcategories, and an exhaustive coding frame. The first step was selecting material to help develop the main categories and subcategories. During data collection, transcription, and data immersion, the researcher developed the initial coding frame. Memoing helped facilitate this process and common themes and statements were extracted from the data. The second step in developing a coding frame is structuring and generating the main categories and subcategories (codes). A concept- and data-driven method guided the development of the main categories. The concept-driven method for main category development emanated from the research questions. These a priori categories, including a good death for self, barriers to a good death, and facilitators of a good death, were derived initially from the semi-structured interview guide. Additionally, main a priori codes for a good death were identified, guided by Corr's (1992) task-based approach to coping with dying: physical, psychological, social, and spiritual factors. The development of additional codes and categories continued until no new codes or categories were seen in the data. Every dimension was not necessarily discussed by each of the participants because of individually specific nuances in how they conceptualized a 'good death.' After the final coding frame was developed, codes and categories were defined. This process required designating names for the categories and codes that reflected a description of the concept. Since codes were mutually exclusive, the codes and categories were specific enough to differentiate between codes that shared similarities. For example, 'financial' resources were discussed in the context of both barriers and facilitators of a good death. These were differentiated based on the context of the statement and described in the code definitions. After

codes and categories were adequately defined, the coding frame was reviewed to ensure that the codes and categories met the aforementioned criteria.

Segmenting the data refers to when the data is broken down into units of analysis (Schreier, 2014). Formal and thematic segmentation are two options for dividing the data into units of analysis (Schreier, 2014). Formal segmentation is when the data is divided using the natural structure of the data (e.g. words, sentences). Often, formal segmentation results in data division that is less meaningful than thematic segmentation, dividing the data based on changes in a topic or thought (Schreier, 2014). For this study, thematic segmentation was used; data was divided based on topical changes in participant statements. For example, one participant said, “it would be good to be free of pain. And I think that you know, if I did have to have cancer like them [participant’s parents] to have the inpatient hospice” (Patricia). In this excerpt, the data was separated as follows: 1. “it would be good to be free of pain” and 2. “if I did have to have cancer like them to have the inpatient hospice.” These are two distinct thoughts and were coded separately as 1. ‘minimize physical distress’ and 2. ‘location of death.’ If formal segmentation based on the entire participant statement was used in this example, the entire paragraph would have required a singular code, thus neglecting the changes in the participant’s thoughts about the conception of a ‘good death.’ Further, participants often discussed multiple factors of a good death within a stream of thought and formal segmentation, which would not have allowed for codes to be mutually exclusive, a requirement of the coding frame according to qualitative content analysis.

After the initial coding frame was developed, pilot coding occurred. During this phase, the coding frame was used to code a portion of the data to ensure that the coding frame was exhaustive. A second researcher independently coded the interviews of two randomly selected

participant transcripts to establish a Kappa for inter-coder reliability. A kappa score between 0.81 and 1.00 suggests nearly perfect or excellent agreement; 0.60 and 0.80 is satisfactory or substantial agreement; and 0.40 and 0.60 suggests moderate or fair agreement (Burla et al., 2008; Hruschka et al., 2004). For the first interview, both coders only coded at the category level (i.e. Good death for self, Barriers to a good death, and Facilitators for a good death). This was done to ensure that the definitions were adequate and to improve trustworthiness in the codebook. A Kappa score of (0.53) for the main categories was determined using the coding comparison tool in NVivo 12, suggesting moderate agreement between the coders. The second round of testing for inter-coder reliability was done on a separate interview, using only the codes in the data. This established a Kappa score of 0.66, suggesting satisfactory inter-coder reliability. While the Kappa score was lower than 0.80, agreement between coders was 95% and 98% for the parent and child coding respectively. The coders also had a consensus meeting to discuss coding differences. During the consensus meeting, for example, the primary researcher coded “smells just bring back memories like that” as “good death,” while the second coder did not. Upon discussion, both agreed that this should be coded as a “good death” because of the context statements around the statement. After the pilot coding phase, the coding frame was no longer changed and was considered the final coding frame. Using the final coding frame, this researcher coded all of the data collected during the study. Analytic memos written throughout the coding process allowed for a critical analysis of coding procedures and initial findings to be presented.

A variety of strategies were used to describe the data, including using the participants own words and figures describing the relationships between the components of a ‘good death’ (see Chapter 4 Findings). While the codes were mutually exclusive, double coding occurred during data analysis. Data that were double coded were not coded within the same category. For

example, statements that were coded as ‘treatment’ were not also coded as ‘type of death or illness,’ both within the physical domain. Statements were, however, coded as both ‘treatment’ and ‘social effect on other’ when participants stated that they wanted (or did not want) treatment because of the potential effect that the treatment could have on the experience of their families and friends. Double coding provided context to participant statements regarding their conception of a ‘good death.’ An unanticipated consequence of double coding was that it allowed for the emergence of the interconnected nature of the factors considered important to the conception of a ‘good death.’ The use of the participants own words is essential to the accurate description of their ‘good death.’ This helped ensure that introduction of the researcher’s biases and interpretations was limited. Additionally, a concept map was developed to provide a visual presentation of a ‘good death.’

### **Reflection and Memo Writing**

Memoing is an important component of qualitative research (Birks, Chapman, & Francis, 2008; Charmaz, 2006). Charmaz (2006) suggested that writing memos serve a variety of purposes and the researcher should write memos in a style that they prefer. There is no specific manner in which the memo should be organized. The memos for this study were free flowing, allowing for the documentation of thoughts throughout the process. Memoing occurred throughout this study and had different ‘goals’ at the various stages. Birks and colleagues (2008) described three types of memos beneficial when engaging in descriptive research studies: operational, coding, and analytical. Operational memos were used to outline the decision making throughout the entire research process. For example, during the participant recruitment stage, operational memos were used to describe recruitment procedures, including the decision to recruit additional participants to increase information power. In addition, the researcher took

field notes during the interviews and added additional thoughts immediately after the interviews, when appropriate. These field note memos were useful in the codebook development and data analysis phases to reorient the researcher to initial thoughts regarding the data. Memoing during the coding phase of the study allowed for an audit trail of the researcher's thoughts during the coding process and helped in describing these coding procedures. Additionally, the coding phase memos allow for an opportunity to confront assumptions and the exploration of the relationship of the codes with the research questions. For example, 'preparation' seemed to have psychological, social, and spiritual motivations. These memos helped to gain a better understanding of thoughts in order to allow for more credibility in statements made regarding this idea. Analytical memos were used to help in the in-depth exploration. These were documented during the data analysis phase. Analytic memos provided an opportunity to think critically about the data and how the findings relate to the research questions. Additionally, analytic memos allowed the researcher to document biases and how these biases were acknowledged throughout the research process. It is essential that qualitative research reflects the data, thus, memoing allowed for the reflexivity within this process (Birks et al., 2008). The memos written throughout this study were reviewed periodically and allowed the researcher to gain insight into the data and the analysis process that may otherwise have been ignored or missed.

### **Establishing Trustworthiness**

Member checking and use of an audit trail (Savin-Baden & Major, 2013) were the two strategies employed to ensure the trustworthiness of the data. Member checking occurred at multiple points during the study. Participants were asked during the informed consent process if they would agree to be contacted to participate in member checking. Due to the initial

conceptualization of the study, the researcher did not have strategies in place to retain participant contact information for the participants who called the researcher directly. This resulted in the inability to contact several participants for member checking. However, the phone numbers for four participants that were initially provided to the researcher by the informants through email were called and asked to participate in member checking. These four participants engaged in the initial member checking stage, where they were encouraged to review their own transcriptions for agreement or corrections as they recall. After reviewing the edited transcripts and participant feedback, the researcher accepted participants' suggested changes and began codebook development. For the second round of member checking, three participants were contacted to assist in code refinement after the coding frame was developed. The researcher spoke with these participants about the coding frame and one participant stated that an additional code was likely needed (Spiritual Barriers). This and other feedback was incorporated into the final coding frame used to code the data. Since the goal of the current study was to describe the conceptions of a good death among older adults, as they described it, all participant changes or comments were incorporated.

An audit trail is a description of the entire research process (Savin-Baden & Major, 2013). Documentation of the research process and the rationale for decisions made was kept and is summarized in the audit trail. The audit trail, in conjunction with memos, helped verify that the research process was systematic. Additionally, the audit trail allowed clarification for each step and process throughout the research study.

### **Ethical Considerations**

The study protocol was approved by the University of Alabama IRB on September 19, 2018. The IRB protocol (see approval letter, Appendix 2) included a description of the purpose

of the study, participant recruitment, data collection, data protection/management processes, and strategies to ensure that participants were protected from unnecessary harm.

To protect participants' confidentiality, all information, including transcript and audio files, were stored using an encrypted web-based storage system (UA Box). Pseudonyms were used rather than the participants' actual names. In this final document, participant quotations are presented using these pseudonyms.

Death is often a difficult topic to discuss and it was possible that some participants may have experienced discomfort discussing conceptions of a good death. To address this potential discomfort, the researcher 'checked in' with participants periodically and asked if a break was needed. Participation in the project was voluntary and this was explained during the consent process as well. Participants were told they could complete as much or as little of the interview as they wanted without affecting receipt of the 'thank you' gift card. Participants understood in the consent process that they could request to discontinue the interviews. No participants made such a request. Immediately following the completion of the interview, the participants were given an opportunity to discuss questions regarding the interview and concerns about the interview topic.

Transcription of the recordings occurred in the School of Social Work's doctoral student office, a private room in the library, and at the researcher's home office. Noise canceling headphones and privacy screens (on computers in public areas) were used to protect the confidentiality of the participants. This ensured that only the researcher could hear the audio when it was being played for transcription and see the transcription document.

## **Benefits and Risks**

The study did not likely directly benefit the participants of the study. However, they may have felt good about participation in a study that may help other older adults in the future. Also, these participants potentially benefited by being encouraged to think in greater depth about their wishes at or near the end of life. Further, participants may have been prompted to engage in conversations about the end of life, particularly about their wishes with their friends, families, and healthcare providers. As a potential benefit, participants, with available contact information, will be provided with a summary of the findings for personal use following the study.

There was minimal anticipated risk to the individuals who participated in this study. Several participants experienced some discomfort when discussing the topic; however, these participants did not withdraw from the study. Participants were able to refuse to answer any questions or end the interview if they became uncomfortable. After each interview, participants completed the PHQ-9, which was scored prior to the researcher leaving the interview site. In the event that participants became extremely upset during the interviews, the researcher was able to provide initial support and a referral to a crisis hotline or local agency. The researcher is a licensed graduate social worker (LGSW) who was engaging in ongoing supervision towards clinical licensure and was trained to offer initial support during the interview when the participant needed or requested support. However, this support was not intended to be therapeutic in nature and a referral to a mental health professional would have been made if discomfort continued and/or at the individual's request. No participant met criteria for referral based on PHQ-9 scores or requested a referral, thus no referral was made to the crisis hotline or a local professional agency.

## **Data Safety and Management**

All interviews were audio-recorded on two separate devices. Multiple devices were necessary to ensure that data was captured in the event that one device failed during the interview. Audio data were uploaded to a secure web-based cloud storage system (UA Box), reviewed for audibility, and afterwards deleted from the recording device. All audio recordings were transferred to the UA Box account and permanently removed from the digital recording devices.

All files related to the current study were de-identified and stored in a UA Box folder designated for the study. Separate folders were used for completed BSCI forms, completed PHQ-9 forms, completed informed consent forms, interview audio, transcription of the audio, scanned copies of handwritten interview notes, data analysis using NVivo 12, and memos. Access to the UA Box folder that contains participant information was limited to the researcher and dissertation chair. All files were uploaded to UA Box and all other copies were destroyed.

Identifying information was not included in written reports and/or manuscripts resulting from the study so that confidentiality was protected. Participants were assigned a participant identification number (and later a pseudonym). This number was not linked to the individual and was only used to link the participant information sheet to the transcribed data. To provide context to the quotations, the participants were identified using pseudonyms and only as much information from the participant data sheet as necessary.

## CHAPTER 4 - FINDINGS

The purpose of this study was to describe older adults' perceptions of a 'good death,' specifically the psychosocial and spiritual factors that the participants considered important. Data to address the three primary research questions was gathered from twelve participants using a multiple interview model and a semi-structured interview guide for both interviews (Appendix 7 and 8). Participant age, race, gender, religious affiliation, and brief medical history were described to provide context to the findings. Direct participant quotes illustrate findings and reveal the participants' conceptions of a 'good death' in their own words.

### **Components of a 'Good Death'**

Since the purpose of the present study was to describe the psychosocial and spiritual aspects of a good death and the interview guide focused on these concepts, the data does as well. The concept map (Figure 1) shows the how the codes and categories relate to the concept of a 'good death.' The major categories of a 'good death' were physical, psychological, social, and spiritual. Each of these major categories had child codes that contributed to the participants' conception of each of the components of a 'good death.' For example, the child codes of the physical category included minimizing physical distress, type of death or illness, and treatment. Expectedly, psychological and social components were discussed more frequently than the physical components. When participants did tend to speak more about physical aspects, they were guided back to a focus on psychosocial and spiritual aspects of a good death. A brief description of each of the major categories and codes are presented in Appendix 11.

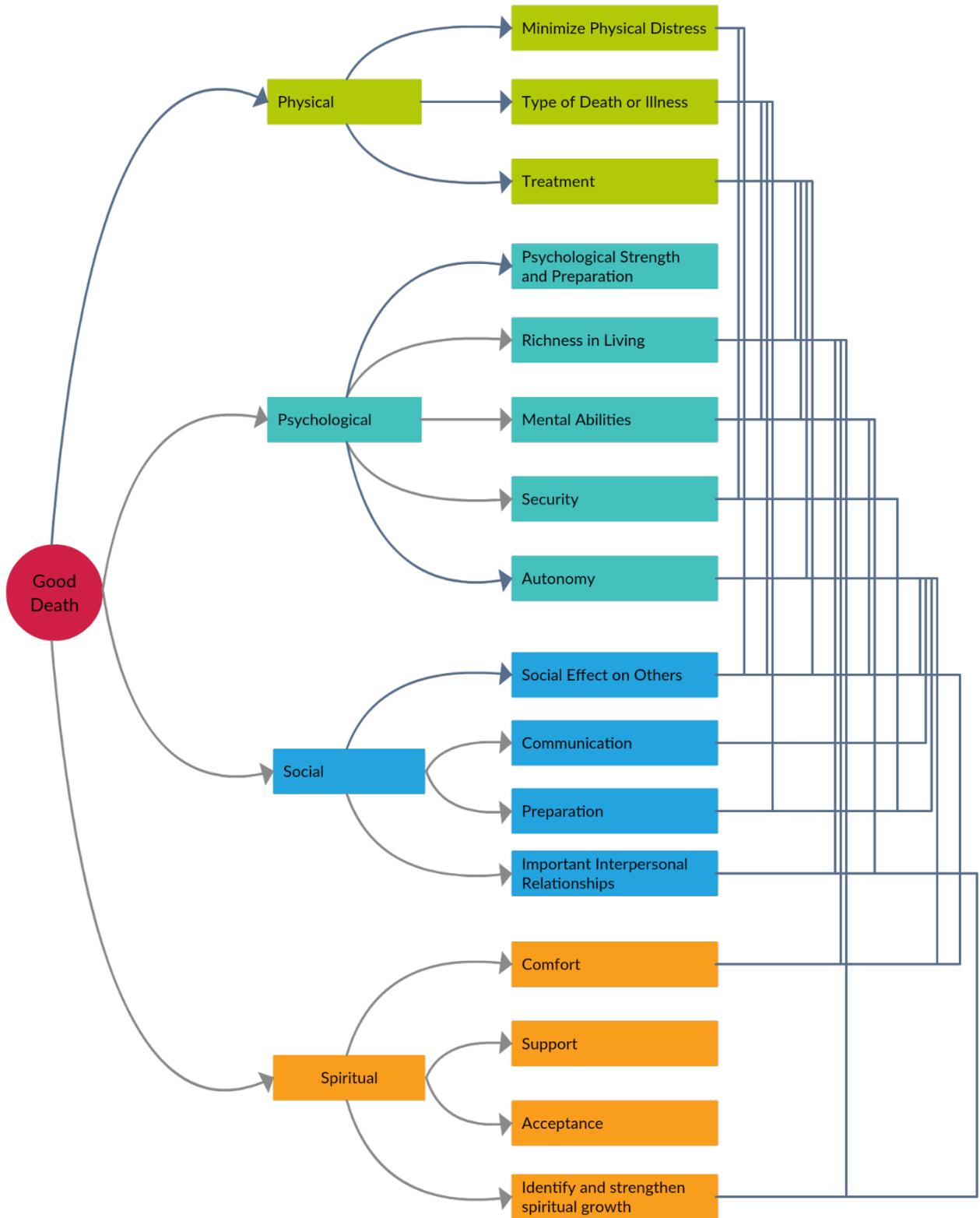


Figure 1. Concept map of a 'good death.'

Participants were asked which aspects of a ‘good death’ were important and the reasons, allowing for the exploration of the concepts in a deeper manner. The depth with which participants discussed the components of a ‘good death’ required, at times, double coding of the data. This allowed for the emergence of interconnectedness of several components of a ‘good death’ considered important to the study participants. Double coding was particularly useful when discussing the physical components of a ‘good death.’ For example, when defining a good death one participant stated “Truly, I think the most peaceful way to go would be to die in your sleep,” and continued to say that “you’re not putting your family through a long, drawn-out illness or death” (Susan) when asked to explain what made that peaceful for her. This suggests a social aspect of a seemingly physical contribution of a ‘good death.’ Similar connections or overlapping concepts are seen throughout the data and are presented on the right side of the concept map (Figure 1).

## **Physical**

All participants mentioned physical components of dying when asked to define a ‘good death.’ In many cases, participants discussed these factors prior to presenting other aspects of a ‘good death.’ The main physical components of a ‘good death’ that participants mentioned pertained to the type of death or illness, minimizing physical distress (e.g. pain management or symptom control), and the type of medical treatment desired. While the focus of this section is on the physical aspects of a ‘good death,’ the participants’ reasons for their statements are not to be overlooked. Throughout the interviews, participants provided justification for physical components they considered important, often integrating psychological, social, or spiritual aspects of a ‘good death.’ In addition, participants typically connected these physical aspects to

experiences with the deaths of others in their social circles, including friends and family members. When asked to describe a good death, one participant (Sandra) said:

I'm hoping that when it comes time for me to die that I don't have anything like cancer because that's what my mother had and my grandfather had and I watched these treatments that they had to take and chemo is pretty ugly.

This account illustrates the interconnectedness of the physical aspects and psychological and social components of a 'good death.'

**Type of death or illness.** Participants perceived that the type of death or illness influenced the experience of a 'good death.' This was coded as 'type of death or illness' if it specifically reported how the experience of a 'good death' was influenced by the type of death or illness. Many participants reported that death should not be prolonged, regardless of the type of illness. A shorter dying process is considered ideal for several reasons. The idea of "liv[ing] years hooked up to machines that I don't even know I'm in the world" was considered "terrible" (William) and the antithesis of a 'good death.' This was seen as a source of distress and reported as something that should be avoided. Another participant stated that an extended dying process could be difficult because of the potential for complications. "One system sort of starts to fail and then another one starts to fail and another one starts to fail and it goes on" (Robert). Conversely, others discussed that a longer dying process is preferred at times to allow individuals the opportunity to "say goodbye" or have time to get their affairs in order.

Beyond discussing the length of the dying experience, many participants stated that they wanted to die in their sleep. Among the reasons that dying during sleep was important, participants often focused on how certain illnesses or injuries can be "traumatic" or "debilitative" to the individual or those close to them. For example, Mary said, "It's not traumatic for the

individual because you don't fall or hurt yourself. There's no blood or that kind of thing," when explaining the perceived benefit of dying during sleep. Another described it as "a gentle passing as opposed to something that is traumatic." This view of a peaceful death, during sleep, was echoed by many study participants.

Not having Alzheimer's or dementia were also described as important to a good death. Participants reported that Alzheimer's and dementia would limit their desire to remain independent and engaged with their environment. One participant described dying with Alzheimer's as "sort of losing yourself" (Barbara), while another stated that complications from Alzheimer's limited the ability to engage in everyday activities.

**Minimize physical distress.** The minimization of physical distress was seen as a main contributor to a 'good death.' Statements about 'minimizing physical distress' addressed issues of general physical concerns, including pain and symptom management. The management of pain was particularly important to the participants and was mentioned often throughout the interviews. Pain was to be limited because "pain is no fun for anybody" (Patricia). Another participant (John) deemed it as unacceptable by saying, "It's completely uncivilized to let people suffer." He later defined suffering as "pain, agony, pain and agony." Participants stated that pain medication and hospice were options for managing pain. For example, Carol said, "there's so much medicine and different that they can do, that's why hospice is so good...they are going to keep you comfortable, they're not going to let you suffer in pain." This showed an understanding of the potential benefits of pain management and hospice care.

Another contributor to minimizing physical distress was the idea of maximizing comfort. As one participant explained, "I don't think it's realistic that you'll always be pain-free...it's more like that you're able to reach an acceptable level of comfort" (Patricia). Further, Robert

discussed pain within this context by saying, “sharp pain that’s so uncomfortable that you can’t relax. I guess that’s the key. Can I relax?”

**Treatment.** Discussion of minimizing physical distress and the type of death or illness often led the participants to identify the types of treatment preferred at the end of life.

‘Treatment’ was defined as any statement about the level or type of treatment that an individual wants or does not want at the end of life. The type of treatment desired was “contextual” and based on potential outcomes of the treatment. However, the participants generally preferred comfort care over curative care or ‘heroic measures.’ For example, one participant said “I’ve asked [for] no life support. If there’s no hope, no life support” (Susan). Another participant stated: “If there was a hope for improvement that outweighed the pain and suffering, I would want that. But mostly I think the general answer is comfort care” (Linda). This was a consistent sentiment among many participants; continued curative treatment was only desired if it would improve quality of life.

### **Psychological**

The psychological factors of a ‘good death’ are personally idiosyncratic in nature and describe what individuals consider important to their mental and emotional well-being. The aspects described by the participants included: richness in living, autonomy, security, mental abilities, and psychological preparation and strength.

**Richness in living.** Statements connected to ‘richness in living’ focused on the participant’s quality of life, including factors that are important or provide satisfaction to the individual. Participants discussed that retaining quality of life was important to their conception of a ‘good death.’ For example, when discussing a friend’s current health status (i.e. advanced Parkinson’s Disease) one participant said “He doesn’t have much else in his life that’s, you

know, enjoyable. So, I would hate to live like that myself” (William). The participant considered the inability to take care of his basic needs as contributing to a low quality of life. Several participants stated that quality of life was more important than quantity of life. One participant described living on life-support for a significant period of time as having a low quality of life by saying “I mean, what am I doing except taking up space...If I can’t recognize the people I love, then why?” (Susan). She saw this as being a ‘shell’ of herself and did not consider it as a good way to die. Enjoying life as long as possible seems to be a hallmark of richness of living.

In addition to quality of life, participants described what provided satisfaction in their lives. For example, when talking about his love for music, one participant said, “Music is an extremely important part of my life...[I] definitely want to be able to listen to music as long as I possibly can and have it be part of my life” (William). Another participant described his current travel plans and stated that he would like to continue doing that as long as possible, “just keep on keeping on” (Robert). Participants also discussed spending time outside and observing nature, “If we have a screened-in porch, I could imagine wanting to spend time outside” (Linda). Study participants indicated that they wanted to continue participating in activities that they found enjoyable.

**Autonomy.** Autonomy was another psychological aspect contributing to a ‘good death.’ Statements about the ability to retain control or independence at the end of life were coded as ‘autonomy.’ Participants reported a desire to remain independent or in control of their lives. Study participants described that independence is important to their conception of a ‘good death,’ specifically not having to rely on family or caretakers to provide basic needs. One example of this is seen when Dorothy described her idea of independence, “take care of myself and do what I wanted to do and not have to depend on someone else bathing me and taking care of me.”

Several study participants report taking steps to retain control through the end of life. For example, Carol said,

I want to be in control of my life or death. And the way you do that is to put it in writing, what I want. And I have already told them verbally, but you know, sometimes kids don't listen that well.

This exchange came after the participant discussed her desire to remain independent and steps she had taken to ensure that her wishes would be followed. This preparation is a way in which study participants believed that they could retain some sense of control at the end of life. In addition, one participant discussed funeral planning as a way to maintain control. This participant said that he organized his funeral in a way that followed Episcopal traditions because they were “comforting” and “celebratory.”

**Security.** Participants also discussed that the perceived ability to manage their ‘situation’ at the end of life and be free from anxiety or fear will contribute to a ‘good death,’ coded as ‘security’ in the data. Carol described a good death as being at peace; she defined this as “being free of anxiety and worry and strife, you know, stress.” In addition, the care that the participants wished to receive related to the way that potential providers or family may treat them. One participant who discussed his willingness to receive inpatient hospice services said “they treat you with dignity and treat you as though you’re a human being” (William). Another participant stated that receiving care in a facility is, at times, easier because you are “never completely alone with a stranger” (Patricia). Being in an environment where you feel safe and comfortable, “in familiar surroundings” (James), was reported as important to several participants. However, according to participants, this can be influenced by the level of trust you have in the caregivers to respect your wishes.

**Mental abilities.** Study participants considered retaining their mental abilities as important. Participants' statements that described being "aware," "mental acuity," and the ability to engage with others were coded as 'mental abilities.' One participant described this as being "in control of your tongue" (Patricia). She stated that this is important because you will not disclose anything that may be hurtful to others. This statement was embedded within a conversation of being a burden to others and that losing your mental abilities will be a burden to herself and to others. Another participant described mental acuity as "being able to think and respond to stimulus" (James). This was mirrored by other participants, in that they wanted to be aware enough to engage with others and "know what is going on in the world" (Barbara).

**Psychological preparation and strength.** Participants discussed psychological preparation and strength for the end of life. Statements about the individual preparation and strength needed to 'get through' the physical and psychological concerns at the end of life were coded as 'psychological preparation and strength.' Participants' statements about psychological preparation often reflected a notion of accepting their mortality. One participant reflected on watching others be angry as they near the end of life. During this discussion, James stated, "If you come to accept that we're all mortal and there is a time and place for death, then maybe you won't experience that kind of reaction to an impending death." Psychological preparation also influences one's ability to engage in legal or other types of preparation. For example, one participant spoke about her desire to write her own obituary but she doesn't "have enough courage to do that yet" (Dorothy). This suggested that participants know what is needed to ensure a 'good death,' yet they may lack the ability to do that currently. Participants spoke about their desire to have psychological strength to get through the physical and psychological issues that may present at the end of life. Barbara described Ruth Bader Ginsburg's recent experience

with lung cancer, “She is definitely a trooper, she’s got strength. I don’t have anywhere near that strength, would be nice to have that kind of strength.”

## **Social**

Participants discussed social components that contribute to a good death frequently during the interviews. Many of the social aspects that contribute to a good death relate to the participant’s perceptions of how their dying and death would affect others, important interpersonal relationships, preparation as a social experience, communication with those in their social network, and social support.

**Social effect on others.** Minimizing the negative and maximizing the positive effect of the death and dying on others was the most noted social component of a ‘good death.’ Participant statements were coded as ‘social effect on others’ when participants discussed how the death and dying process affects others before, during, or after death. One participant (Linda) stated, “I would hope that I would be able to model for them a good death. So that they wouldn’t be frightened.” While another (Mary) addressed this by saying “I don’t want to scare my grandchildren.” She further discussed that she remembered how a family member smelled when they were dying and “smells just bring back memories like that.” These accounts demonstrated the participants’ awareness of the influence that death has on others. Being aware of what might influence others’ perceptions of death and experience after death is what brought participants to their conclusions. For example, Barbara discussed how difficult and stressful her experience with caring for her mother was as she neared the end of life and stated that she would be willing to receive care in an assisted living facility rather than have family care for her. Her justification for this was that her child is an only child and “I don’t want to put the burden on him...that I had.” This illustrated the desire to model a ‘good death’ for family members.

**Important interpersonal relationships.** Study participants also discussed maintaining and enhancing interpersonal relationships, coded as ‘important interpersonal relationships.’ These discussions often addressed spending time with important people because these relationships are meaningful to the participants. Patricia stated that a good death would be “if you could die with your relationships intact and that you can have enough control that you can choose how you treat other people.” Another participant stated “to try to be someone who is a joy to be around and not someone who is always emotionally that we call them emotional vampires” (James). The idea of maintaining relationships with others when end of life is near contributed to the conception of a ‘good death’ because they are able to spend time together, visiting and reminiscing about positive shared experiences.

In addition, making amends and not “having a lot of regrets” with people they consider important was presented by the participants. For example, Carol stated:

Make sure that your relationships with others, you have taken care of anything that needs to be taken care of. If you if you have somebody you need to ask forgiveness for something you've done or said or whatever then take care of it on a daily basis because we don't know when we're going to have tomorrow.

Having time for closure with important interpersonal relationships allows for those involved to ‘come to terms’ with the end of life and is seen as contributing to a good death. Further, the type of death (i.e. acute or chronic) may affect this closure. Dying due to an act of violence limits the ability for closure and makes the experience of a ‘good death’ less likely for the participants and their family.

**Preparation.** Preparation was discussed as something that can be done to increase autonomy at the end of life, however, many participants perceived this as a social contributor to a

‘good death.’ Statements were coded as ‘preparation’ if they addressed how preparation was related to social aspects of the participant’s life, as well as if the motivation to prepare was social in nature. Advance preparation was a way to reduce the burden on their family during the dying process and after death occurs. These participants stated that to experience a ‘good death’ was as important for their families as it was for themselves. When discussing the importance of advance care planning, one participant said, “It’s a comfort to your family. It shows that you love them and that you want your death to not be a burden to them” (Carol). In addition, this participant discussed that by preparing in advance, the family was able to be present during the death and dying process while not having to worry about the “business” side of dying. Having family and friends present was important to the participants, and planning allowed for that to occur. Preparation also allowed participants to address financial concerns as they near the end of life. For example, several participants discussed that preparing documents with insurance plans, financial account information, and funeral and burial plans demonstrates that you thought about your family and care about their well-being. Sandra made the following comment about her preparation:

So we sat there and looked at a book and picked out our caskets and did the whole thing. And then we just started paying for it making monthly payments. And we have wills, we have power of attorneys, I have a living will. We’ve just taken care of pretty much all of that and I have a lot of information at home written down with the will. Like, you know, you can find this in this place and that in that place. I’ve done that, you know for family.

This and other types of preparation makes the death easier on family members and is seen as a gesture to demonstrate your care for others.

**Communication.** Communication with those in your social network was also considered as a social aspect of a ‘good death.’ Statements that addressed communicating with members of the participant’s social network about various aspects of life and death were coded as ‘communication.’ The purpose for the communication varied between participants. One participant discussed telling family members “that I love them, that I was proud of them, that I could see good things in the future for them” (Linda). She stated that this communication was about talking about important topics and things that they should remember. Another topic in these conversations is the treatment choices that one desires. For example, “I want both my kids on the same page about what I want” (Susan). These conversations could help the individual retain a sense of autonomy, while minimizing the conflict around treatment decisions that may present as they near the end of life.

**Social support.** Few participants mentioned a desire for social support. The support from family was seen as a way to provide comfort to the individual. Statements about social relationships that provide support to the participant at the end of life were coded as ‘social support.’ One participant spoke of having her son present “especially at the very end, you know, my son, comfort. Just so I’m not totally alone” (Barbara). Social support can be interpersonal, as well as support from social groups or agencies “just being part of a community, having support of a community, not being alone, because at the time people become demented then the family is suffering a lot. And so supporting them” (Patricia). Support from providers is seen in tangible items (e.g. meal preparation or transportation assistance) or guidance about what to expect as death approaches. For example, “maybe people, like, that would help ease me into a situation, you know. It’s help, guide, guidance, guide me. Sort of like Yoda, Obi-Wan” (Barbara). Further,

this participant gave the example that hospice workers have training to help support individuals as they near the end of life.

## **Spiritual**

The majority of participants disclosed spiritual components of a ‘good death.’ The comfort that spirituality provided was particularly important to many of the participants. Further, participants often framed their spirituality through a religious lens.

**Comfort.** Participant statements that relate to the use of spirituality to find comfort at the end of life were coded as ‘comfort.’ Comfort gained from the study participants’ spirituality often related to what happens after death, “we all know, as Christians, that we’ve got a better life ahead of us” (Dorothy). Another participant said, “I have the promise of an afterlife so I don’t have to worry” (James). Among the study participants, their spirituality made them express comfort with what comes after death, thus the experience of death is less frightening. Additionally, several participants were comfortable with their perceived ability to handle the end of life because “I know nothing’s going to happen to me that He doesn’t know about and that He doesn’t take care of” (Susan). Participants seemed confident in their spirituality and the comfort that spirituality provides them, particularly as they approach the end of life.

**Identify and strengthen spiritual growth.** The end of life, according to the participants, is a time where you can, and should, identify or strengthen your spirituality. Statements were coded as ‘identify and strengthen spiritual growth’ if the participant reported that identifying or fostering spirituality when approaching the end of life was important to the conception of a ‘good death.’ The participants framed this in the context of staying involved with church and participating in religious ceremonies. For example, taking communion (a religious sacrament) would be preferred when possible. One participant stated that “to know the Lord Jesus Christ as

your savior and to die in your sleep would be best” (Sandra). She further discussed that she hasn’t “given the end of life a lot of thought” due to her faith and spirituality. In addition, one participant suggested that in order not to fear death, you should “get involved in the church and serve the Lord” (Dorothy). Participants discussed these as opportunities to continue and solidify spiritual growth.

**Acceptance.** Being comfortable with death when approaching the end of life, through a spiritual lens, was important, among several study participants. Statements that related to the use of spirituality to foster acceptance of death and the afterlife were coded as ‘acceptance.’ Many participants believed that their acceptance of death was influenced by their spirituality. For example, one participant stated, “We don’t get to pick. We have to take it as it comes and I believe that God will be with me when it’s my turn. And I’ll have to just take life as it comes” (Patricia). Conversely, another participant discussed potentially talking to a religious or spiritual leader to “try to get my head straight” (Barbara). For the participants, spiritual acceptance would make a ‘good death’ more achievable. Additionally, participants reported that spirituality may foster hope, “a reassurance about everything’s going to be all right” (William). The study participants used their spirituality to find acceptance in the fact that they will die, while allowing them to remain hopeful about death, dying, and the afterlife.

**Support.** A spiritual support system may also foster a ‘good death’ for older adults as they near the end of life. Participant statements regarding the spiritual support systems that contribute to a ‘good death’ were coded as ‘support.’ Members of the support system may “pray” for the individual or can provide comfort or guidance. One participant stated, “I’m very comfortable with where I am spirituality. So I don’t know that I would need anything more. I’m very fond of our priest here and I want to have him around some of the time” (Linda). Despite

their current spiritual state, participants noted that support would be helpful in achieving a good death.

### **Location of Death**

Participants frequently mentioned the location of death as contributing to a ‘good death.’ While several participants preferred to die at home, many would rather receive care in a facility (e.g. inpatient hospice or assisted living facility). The location of care was discussed as an option to reduce burden on the caregivers and to allow family members to be emotionally and physically present. This is seen when Barbara discussed being the caregiver for her mother:

I don’t think I’d be one that would insist on staying at home or anything like that because I think my [son]’s the only one to take care of me and I don’t want to put the burden on him, that I had [with my mother].

Another participant said of dying in hospice, “They control your pain and take care of, really good care of you. And, you know, it’s a really easy death” (William). Several participants stated that dying in a hospital likely receiving unwanted treatment would not be desirable and preferred other locations. Much of the discussion regarding location of death focused on the treatment that you receive at that location. “They take such good care of you and it’s such a beautiful facility [inpatient hospice] and the people are so caring. You know, I don’t see how you could have a better death than that” (William). While one participant discussed dying at home as an option, she noted that you should be able to trust the in home caregiver, “if you’re going to be alone in your home with another person who’s not a family member or known friend, then there’s a possibility of feeling afraid of that person” (Patricia). While this was only mentioned by this participant, however, the possibility exists that individuals who are dying may be concerned

about their trust in the caregiver and the quality of care received, which may influence the preferred location of death.

### **Facilitators for a ‘Good Death’**

Participants were asked to talk about what would increase the likelihood of achieving their conception of a ‘good death.’ These facilitators of a ‘good death’ identified from the participants’ responses, were preparation, social aspects, spirituality, and physical aspects of death and dying. While, participants are, at times, able to influence the facilitators of a ‘good death,’ some aspects of death and dying were also seen as out of their control. According to the study participants, certain illnesses are considered as a barrier to a ‘good death.’ While the type of illness that you will have at the end of life cannot be predicted, there are ways older adults can attempt to mitigate the likelihood or severity of the illness. For example, one participant stated that you can “try to be physically active, take care of your body” (Patricia).

Preparation, described as advance planning, can facilitate a good death. Participants prepared in many different ways, including discussion of treatment preferences with family members, completing legal documents, and giving away personal items. Legal preparation was most frequently discussed. Participants reported that advance care planning would allow them to retain control at the end of life. The legal preparation often focused on the desired treatments for the end of life and naming an individual to be a health care proxy. Many participants saw value in completing written advance directives, in addition to having conversations with family members and proxy decision-makers. For example, one participant reported having conversations with her daughter about end-of-life preferences saying, “verbally she knows what I want, but I think it’s probably better that I get it in writing” (Susan). Preparation may also facilitate a ‘good death’ by providing comfort to self and other by having ‘affairs’ in order.

“We’ve already decided on our resting places and things; we’ve taken care of all of our business” (Sandra). Further, this participant attributed her comfort with death and dying to her advance planning. Other documents that older adults could prepare include insurance plans, usernames and passwords, and financial information. This planning facilitates a good death because it allows others to be present, both physically and emotionally, when an individual dies.

Participants disclosed creative planning options for the end of life to ensure that they would be able to die a death they consider ‘good.’ One participant discussed assisted death throughout the interview. He provided preparation strategies (e.g. collection pain medication) that would enable him to die his ‘good death’ due to the fact that assisted death was not legal where he lived. For example, he reported, “I’ve often thought of getting hold of some drugs that I could take at the last minute” (John). However, he would prefer to speak with his healthcare team for support, “I’d rather be civilized about it and talk to people about it and let them know what I’m doing.” Another participant discussed the construction of his house and how it was built to accommodate him and his partner as they aged and should they experience mobility issues, “our house is designed so that we can live on one floor without any issues.” These participants illustrated resourcefulness and determination when preparing for the end of life.

Addressing funeral and burial concerns may also increase the likelihood of a ‘good death.’ Some participants stated that planning allows you to design your funeral in a manner that is comforting to you. Another aspect of planning is that participants could write their own eulogy or obituary. This allows older adults to reduce the burden on family, by choosing what they want rather than having the family guess what they would prefer.

Social facilitators of a ‘good death’ include communication with and support of others and the trust that wishes will be respected. John stated,

All I can do is to make sure my wife knows, and I know, and my brother and sister know, and my two children know, that's, and my granddaughter who is probably the most level-headed person in the family know.

This illustrates that communication with family can support the realization of a 'good death,' particularly when wishes were conveyed to multiple family members so "they can expect it and won't fight me over it." In addition, participants reported having family that support their decisions will help ensure a 'good death.' For example, when responding if she thought she would experience a 'good death,' Linda said, "if there's preparation and my husband survives me, about a hundred percent sure." When asked why she thought that, she laughed while saying, "because he'll do whatever I want." Other participants shared the viewpoint that their family will respect their wishes at the end of life. Confidence in their family's willingness to follow the participants wishes often results from previous discussions and experiences (e.g. children supporting the decision to move into a retirement community) with family members.

Participants often described spirituality in the context of being a facilitator of a good death. Spirituality provided the participants with comfort about the death and dying experience and allowed for the belief that their death will be 'good.' One participant said that there is nothing that can be done to increase the likelihood of a 'good death' because "I just leave that in the Lords hands" (Carol). Spirituality may provide a framework for managing their expectations for death. For example, several participants stated that they do not "fear" or "dread" death because of their expectations of an afterlife. It's possible that the spirituality of the participants will help them come to acceptance if they are unable to experience their conception of a 'good death.' For example, a participant who perceives dying with cancer "one of the worst things" also stated "but I just got faith in God that whatever happens is going to be okay" (Dorothy).

This illustrates that even though one may initially experience a death that is incompatible with their conception of a ‘good death,’ they may be able to experience a ‘good death’ because of their faith.

Pain management and length of death are physical facilitators of a good death.

Participants perceived pain management as a facilitator for a ‘good death’ because it reduces suffering and makes people comfortable as they die, “if they [healthcare providers] know I am in a terrible lot of pain then ease my pain, who cares if I die a drug addict” (James). Additionally, a quick, rather than prolonged, dying process was seen as preferable “because it’s just death, nobody suffers.” This notion was echoed by several participants and indicates that the type or length of death may facilitate the experience of a ‘good death’ among older adults.

### **Barriers to a ‘Good Death’**

Anything that would make achieving a ‘good death’ less likely, as perceived by the study participants, was coded as a barrier to a ‘good death.’ Most barriers of a ‘good death’ were physical or social concerns. Physical barriers included types of death or illness that would prevent a ‘good death’ from occurring. For example, participants reported that Alzheimer’s or dementia would reduce the likelihood of a ‘good death’ because the “loss of mental faculties” (James) and “it’s a living death, your body is living but your brain is not living” (Carol). Additionally, another participant stated that even though Alzheimer’s or dementia is not ideal, “I wouldn’t know I wasn’t achieving my ‘good death’ at the end.” This illustrated that participants preferred not having Alzheimer’s or dementia but acknowledge that they will likely not realize it is occurring. Alzheimer’s and dementia were also seen as difficult for families. Reflecting this social aspect, one participant stated that “you don’t want your family to walk in and find your body or to see you out of your mind and saying things that are frightening to them” (Patricia).

Other medical conditions that could reduce the likelihood of a ‘good death’ included cancer, heart attack, stroke, and other disabilities (e.g. losing vision).

In addition to physical illness, participants stated that the type of death could be a barrier to a ‘good death.’ Many participants voiced that dying from an accidental death would prevent them from having a ‘good death.’ For example, when responding to a question about what might prevent her from achieving a ‘good death,’ Dorothy stated, “an auto accident or a tornado.” In addition, participants reported that being murdered would prevent their conception of a ‘good death.’ As Patricia put it, “I think it would be terrible to die violently, to be murdered, that would be terrible to have your last relationship with another human being be that.” Linda also described the effect that certain deaths would have on family members by saying, “if they didn’t have a chance to do any leave-taking or if they saw my body mangled or murdered, those kinds of things would not be good for them.” These cases illustrate that the type of death can influence the participant’s conception of a ‘good death,’ particularly the social aspects that are considered important. Some noted that the dying process itself is not something that is predictable but rather something that they will need to manage when it presents itself. Further, Sandra reported that she will likely not die the way she prefers, “it would be great to die in your sleep, but I don’t know many people that do die in their sleep.”

Conflict within the family regarding the care of the participant was seen as a barrier to achieving a good death. This conflict is often associated with the various end-of-life treatment decisions. According to Sandra,

I think that a lot of the times health care people are afraid of being sued. So, if there’s one family member that pitches a hissy fit about, then they don’t want to go along with your

wishes. They want to please the person that is going to sue them, because they know you can't sue.

Another participant stated that while it is unlikely, "disagreement that might arise with my children" (Sandra) and prevent a good death. Conflict within the family can also relate to what happens after death. For example, Susan described a disagreement with a family member about her desire to be cremated, which was a distressing experience, "he said he would fight it all the way to the end." Participants reported that they attempted to voice their preferences in advance to family members to reduce this conflict.

Beyond conflict within the family about treatment decisions, the openness to communication about end-of-life preferences is another social barrier to a 'good death.' James reported that he tried to have conversations about his end-of-life preferences with one of his children, who responded by saying "I don't want to hear this." During this conversation, James disclosed that the topic was discussed in close proximity to the death of another family member and asserted that this situation may have influenced his daughter's reaction. However, other participants had similar concerns about family members, their children specifically, not listening or grasping the content of these discussions. For example, Susan said, "I have already told them verbally but, you know, kids don't listen that well." The perception that family members lack a willingness or ability to engage with the participant's end-of-life conversations seems to limit the ability or achieve a 'good death' related to the participant's desire to remain independent and to retain a sense of autonomy.

Family medical status, including family health issues or a family member predeceasing the participant, can also act as a barrier for a 'good death.' For example, Mary was confident that she would be able to experience a 'good death' because her husband would ensure that her

wishes were followed. She followed that with saying, “If he dies first, I’m probably in a pickle. Yeah, because my two sisters are a little more emotional.” Sandra reported that one of her main concerns is dying before her husband because she worries that he will not have the necessary support. These participants illustrate the concern that the health status of people in their social network may act as a barrier to a ‘good death.’ Further, participants report concern that these issues may shift the burden of care onto others who are less willing to follow the participant’s directives.

Several participants stated that it is necessary to plan for the end of life; however, it is likely for these wishes to change. For example, Dorothy discussed a book she received related to planning for the end of life and her hesitation to fill it out because of a friend’s experience with it. “She said she had erased and changed hers so much that she is going to get a new one. So I just haven’t started on mine.” James reported a similar barrier to completing written advanced directives, “once you commit to writing about it, it becomes something that’s committed to.” These participants perceived providing a written document as a statement that their mind is made up and should not be changed.

## CHAPTER 5 - DISCUSSION

The purpose of this study was to examine and describe the psychosocial and spiritual factors that contribute to the experience of a ‘good death’ from the perspective of older adults. The major findings from the study are discussed in this chapter. The most notable findings include the interrelatedness of the physical, psychological, and social components of a ‘good death’, spirituality as an independent construct, preparation, and the manner in which participants describe quality of life. Implications for social work will be presented, as well as study strengths and limitations, following the discussion of the major findings.

### **Discussion of Findings**

As expected, the psychological and social components perceived as important by the participants were mentioned more frequently than physical aspects. Spiritual components were not discussed to the same extent as the physical, psychological, or social aspects. Even though the spiritual aspects of a ‘good death’ were discussed less often than the biopsychosocial components, the participants expressed that their spirituality and faith were very important to experiencing a ‘good death.’

The physical aspects of a ‘good death’ included minimizing physical distress, the type of treatment that the participant would prefer at the end of life, and the type of death or illness. Minimizing physical distress and the type of treatment desired is often seen in the literature on a ‘good death’ (Ko et al., 2013; Vig et al., 2002); this may relate to the presence of options to address these concerns as individuals approach the end of life. The concept map (Figure 1) demonstrates that the physical components of a good death are often related to the other

dimensions; this interrelationship of the components of a ‘good death’ will be discussed in detail later. In addition, the type of death is seen as important to the participants. Participants overwhelmingly preferred not to have a prolonged dying process. However, this is conditional, because having time to prepare themselves and those close to them was also thought to contribute to a ‘good death.’

A number of psychological components of a ‘good death’ were discussed by the participants. Quality of life and engaging in activities that provide satisfaction were among the most common psychological factors of a ‘good death.’ Participants discussed the activities that they enjoyed and stated that being able to engage in these activities as long as possible are important to the experience of a ‘good death.’ There is a connection between these activities and the participants’ desire for independence or control over their life. For example, living in a community that supports older adults as they age and driving when possible are several ways that the participants retain control. They report a desire remain independent through the end of life. In addition, being in a comfortable environment and free from anxiety and fear was important to the participants. Study participants stated that they would be willing to receive care in various facilities because of the dignified and caring treatment they provide to older adults as they near the end of life.

Participants acknowledge that their death will likely affect others and report a desire to maximize the positive effect of their death on others (Vig & Pearlman, 2004). They recognized that experiencing death is difficult but that there are opportunities to reduce the fear or anxiety that others may have regarding death and dying. The expectations about death and potential death anxiety can be influenced by experiences with death (Barrett, 2013; Carmack & DeGroot, 2016), supporting the participants’ concerns with of the social effect of their death on others.

This is also seen in the desire to maintain and enhance important interpersonal relationships. Additionally, participants perceived preparation as a social experience (Singer et al., 1998). Preparation may be done by older adults to retain autonomy (Hattori & Ishida, 2012; Pierson et al., 2002), however, the participants report that it is done for social reasons. Preparation may reduce the perceived burden on family and allow the family to be present, physically and emotionally, throughout the death and dying process. Social support was minimally discussed by the participants but was desired in the form of individuals being present, as well as services from agencies. A ‘good death’ is often conceptualized as one where the family is present (Gibson et al., 2008; T. Hughes et al., 2008), however, some participants believed that the presence of family may not be ideal due to the potential for the family to perceive the death as negative or not good.

Spiritual aspects of a ‘good death’ included comfort gained through spirituality, identifying or developing spirituality, acceptance of death through a spiritual lens, and a spiritual support system. Spirituality, often religiosity with the study participants, provided a comfort that they may not otherwise receive (Gelo et al., 1997). For example, the participants were able to find death less frightening because of their faith and the afterlife ‘promised’ by their religion. Participants also stated that the end of life was not a time to ignore their spirituality, but rather a time to embrace it and continue their spiritual growth. Using spirituality to come to acceptance of death was another way to experience a ‘good death’ (LeBaron et al., 2015). Study participants suggested that their spirituality provided a framework for understanding that life will end and certain things will be out of their control. In addition, developing relationships with spiritual leaders can help individuals come to acceptance about the end of life. Participants stated that these, and other spiritual relationships, can provide support to the individual as they approach the

end of life. Individuals and spiritual communities can provide unique support that the participants desire at or as they approach the end of life.

Participants also described the location of death as contributing to the experience of a good death. The location of death was considered important because of the care provided to the individual. For example, dying in a facility was, at times, ideal because the ability to receive pain management and symptom control in a timely manner. This reflects prior research with bereaved family members where the provision of hospice services is associated with the perception of a 'good death' (Cagle, Pek, Clifford, Guralnik, & Zimmerman, 2015). Dying at home is often preferred because it is a comfortable and familiar environment, however, there are concerns that non-kinship care may be anxiety or fear provoking for the dying person. The expectation of being able to experience a 'good death' seems related to the location of death and the services available, according to the participants and within the literature (Cagle et al., 2015)

Expectedly, the barriers presented by the study participants were often the opposite of facilitators, consistent with previous research on 'good' and 'bad' deaths (Vig et al., 2002; Vig & Pearlman, 2004). For example, type of death or illness could be seen as both a barrier and facilitator for a 'good death.' Similar to Vig and colleagues (2002), participants often preferred a quick and painless death, while having a prolonged death was considered a barrier to a 'good death,' or a 'bad death.' A prolonged death was a barrier because it would be difficult for family members, which is in stark contrast with the desire to model a 'good death' for their families. In addition, preparation may facilitate a good death by providing a mechanism for older adults to show their family that they are important and cared for because they will not have to worry about the 'business side' of death and dying (Nelson et al., 2009).

## **A ‘Good Death’ Defined**

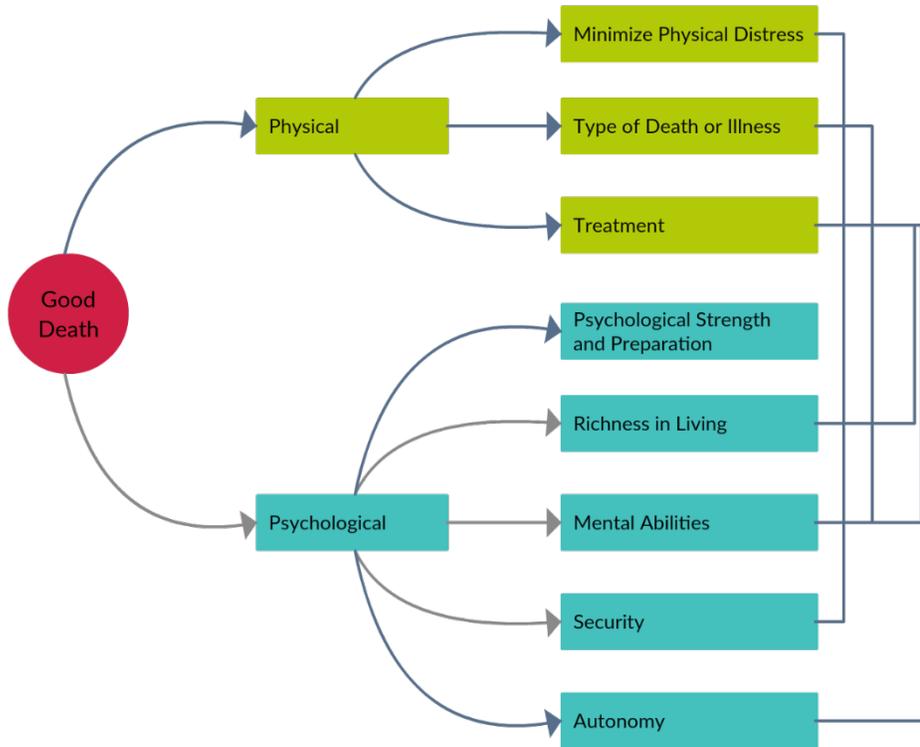
The primary purpose of this study was to describe psychosocial and spiritual components of a ‘good death’ according to older adults. In recognition of the likelihood that physical aspects of serious illness and the dying process would dominate conversation, the following specific question was used with the participants to target the psychological, social, and spiritual components of a ‘good death.’ “If pain and other physical symptoms are well-controlled, what other factors would be most important to you near the end of life?” Participants were then prompted to identify and discuss psychological, social, and spiritual components. The concept map (Figure 1) shows that often psychosocial and spiritual components of a ‘good death’ were interrelated with the physical components. Even though the study design attempted to ‘control’ for a dominating of focus on physical components, it was still discussed to a great extent by the participants. This outcome suggests an inability to view the components of a ‘good death,’ as identified by Corr (1992), independently. This also confirms findings of a systematic review (Maynard & Csikai, 2017) on the psychosocial and spiritual components of a ‘good death.’ In this review, few research studies were identified that exclusively focused on only psychosocial factors contributing to conceptions of a good death among adults and family members/caregivers.

### **Inter-connectedness of Components**

#### **Physical and Psychological**

This study revealed a relationship between the physical and psychological components of a good death and is shown in Figure 2. Pain and symptom management, type of death or illness ‘desired,’ and type of treatment preferred were often influenced by what participants considered psychologically important for a good death. As the participants discussed the physical

components of a ‘good death,’ they justified these by presenting the psychological components that influenced their physical preferences.



*Figure 2.* Relationships between physical and psychological components.

Minimizing physical distress (e.g. pain and symptom management) is often a primary concern as older adults near the end of life (Ko et al., 2013; Pierson et al., 2002; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000; Vig et al., 2002). Also suggested is that pain and symptom management may act as a mechanism to increase security (i.e. free from fear or anxiety, in a situation perceived as safe, or belief that they can manage the end of life) as older adults near the end of life. Although the relationship between increased pain and the perception of a worse dying process has been previously discussed (De Jong & Clarke, 2009; Pierson et al., 2002), these findings suggest that this may occur because older adults are more comfortable with the prospect of their own death when pain and symptoms are adequately managed.

The treatment options that participants perceived as contributors to a ‘good death’ often influenced the discussion of the resultant quality of life, mental abilities, and autonomy of an individual as they approach the end of life. Participants stated that they would prefer medical treatments that increase quality of life and allow for the retention of their mental abilities. One participant discussed the possibility of hastening death, through voluntary stopping eating and drinking, and how he would “get a doctor who would go along with me and give me some pills to relieve the pain” (John). A desire to retain a sense of autonomy may present itself in the type of treatment that one wants at the end of life. ACP is one option for presenting treatment preferences to family and health care providers (Black & Csikai, 2015; Luth, 2016; Singer et al., 1998). Providing opportunities for older adults to discuss the reason that certain treatment options contribute to a ‘good death’ may allow for more in-depth conversations about goals of care at the end of life.

### **Physical and Social**

A relationship between physical and social components is also seen in the data (see Figure 3). Many participants believed that the physical components of a ‘good death’ were influenced by the perceived effect on others. Having family present at the end of life has been discussed as a potential contributor to a ‘good death’ (Gibson et al., 2008; T. Hughes et al., 2008). However, the perception that others may have to watch as older adults experience a prolonged death, unmanaged pain/physical symptoms, or unnecessary or burdensome treatments may limit the opportunity to experience a ‘good death.’ Again, while the physical components were important, they were often framed in a manner that revealed the importance of lessening a potential negative effect on those in their social network. A separate discussion of preparation is presented later.

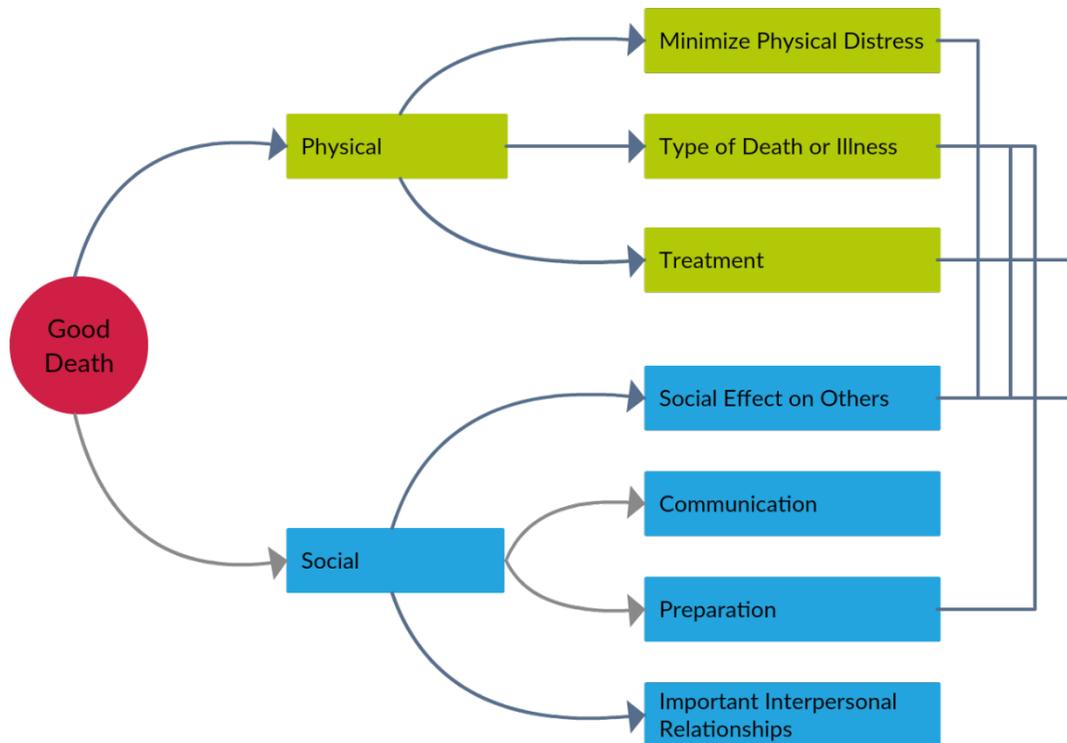
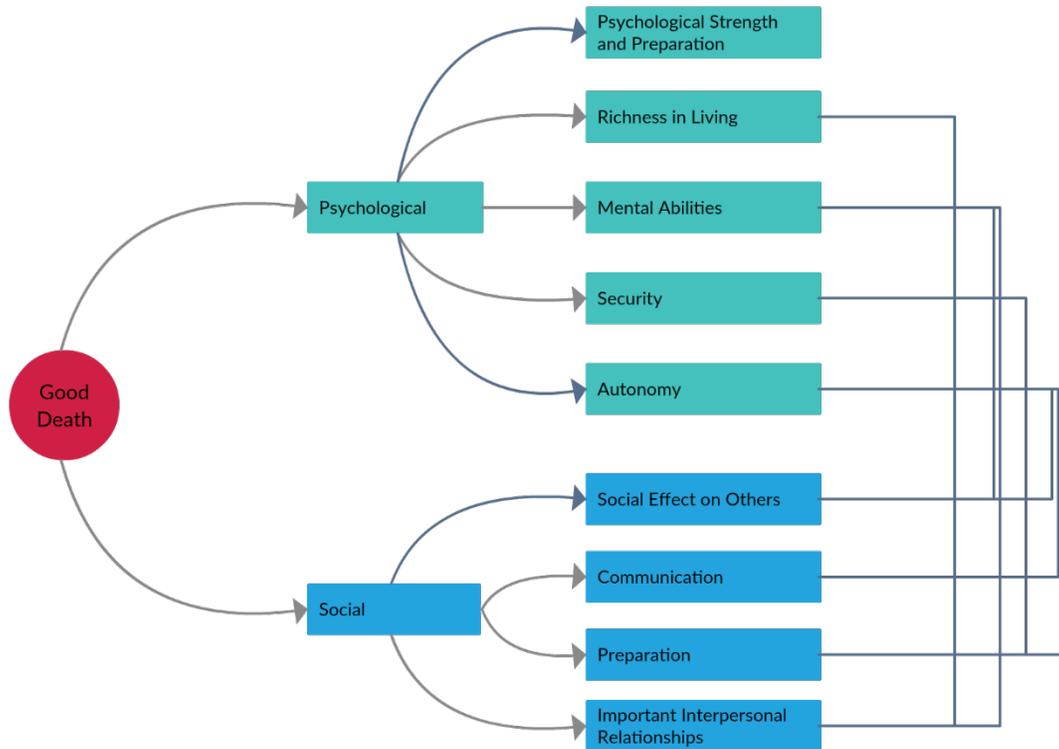


Figure 3. Relationship between physical and social components.

### Psychological and Social

Participants disclosed that psychological components of a ‘good death’ often related to the social components (see Figure 4). The data showed that the relationships can be inter-dependent, meaning that social aspects influence the psychological and the psychological aspects influence the social. This is also supported in the literature (Maynard & Csikai, 2017; Meier et al. 2016).



*Figure 4.* Relationships between psychological and social components.

According to the study participants, the desire to enhance and maintain important interpersonal relationships is influenced by perceived richness in living (i.e. what is important to the individuals, what makes life worth living, and quality of life) and mental abilities. In addition, perceived richness in living may also be influenced by the interpersonal relationships in the lives of older adults. Participants perceived their social connections as valuable and they wanted to see those relationships flourish as they contribute to their richness in living. According to Patricia, “that’s what gives meaning to your life, is your relationship with other people.” If older adults have limited quality of life, the desire or ability to engage with others may be absent. Conversely, opportunities such as support to engage in activities that they enjoy, may enhance interpersonal relationships among older adults with limited quality of life, thus adding to the potential for improved richness in living. Several participants reported that they enjoyed reading and described situations where family members can read to them in the event that they were

unable to read themselves, due to disabilities or other limits to their mental abilities. This suggested a need for a social system that is both willing and able to support the individual and their needs through the end of life.

The participants considered remaining autonomous or independent as important for several reasons. Participants wanted to retain a sense of control in their lives. They did this through preparation for the end of life through communication with the family about their preferences and completing advance care documents to get their ‘affairs in order.’ This was discussed as a way to reduce the burden on family regarding medical decision-making and financial matters, including funeral planning (Goldsteen et al., 2006; Singer, Martin, & Kelner, 1999). This connection between autonomy and the social components of a ‘good death’ is such that it can increase psychological well-being as the end of life approaches and foster/deepen social relationships.

### **Spiritual**

The spiritual components of a ‘good death’ were generally distinct from the discussion of physical, psychological, and social components for these participants. Participants reported that spirituality provides comfort about the end of life that is unique from the comfort gained through minimizing physical distress, richness in living, autonomy, important interpersonal relationships, and preparation, among others. This may result from the ability to find acceptance of death through faith.

Distinct from the physical and psychosocial components of a good death, participants believed spirituality was important in framing their conception of a good death. Their own religiosity and/or spirituality was seen as a strength. Fostering and utilizing this type of strength at the end of life may contribute to a hoped for ‘peaceful’ death. Understanding the importance

of religiosity and spirituality for older adults near the end of life may allow family members to feel ‘comfort’ in knowing that the older adult will be safe and comfortable after death occurs.

### **Location of Death**

Older adults, in general, prefer to die at home when diagnosed with a terminal illness (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Black & Csikai, 2015), and this preference is relatively stable as illness progresses (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). The study findings are consistent with the previous literature, as these participants reported a preference for dying at home because it is comfortable and ‘familiar.’ However, participants were comfortable with, and some even preferred, dying with the care of hospice, specifically inpatient services. Further, where participants prefer to die is related to the type of treatment they desire and the ability to receive pain and symptom management. Preference for not dying in a hospital was influenced by the potential utilization of life-sustaining medical treatments (e.g. intubation, life support, “hooked up to all kinds of machines,” etc.) that could be frightening to family members. William stated that, while “you may get good treatment [in the ICU/hospital], it’s not a good way to go.” Hospice care was preferred due to the quality of care. In addition, the ability to receive pain management was a driving force behind participants’ preference for dying in facilities, specifically inpatient hospice. This suggested a common misconception about hospice as the majority of hospice care is provided in the location the individual considers as ‘home’ (National Hospice and Palliative Care Organization, 2018). Therefore, pain and symptom management can be, and is often, provided in the home through hospice services; however, a potential delay in care during a crisis made inpatient a preferred setting for some participants. Beyond the preferences for treatment and desired pain and symptom management, the social effect of dying on others influenced the location preferences of

older adults in the study. Thus, location of death has the potential to reduce the burden of care on family members. Gott, Seymour, Bellamy, Clark, and Ahmedzai (2004) reported that while older adults preferred dying at home, there are concerns about home care services versus care in medical facilities (e.g. quality of care received, potential burden on family, lack of informal caregivers in the home).

### **Preparation**

Throughout the literature, preparation is discussed as a way in which older adults can retain autonomy when approaching the end of life (Bernacki & Block, 2014; Ditto et al., 2001; Hattori & Ishida, 2012; Pierson et al., 2002). The participants also reported similar motivations for their engagement in preparation, but additionally reported social motivations. For example, engaging in preparation was done to show family and friends that you care about or ‘love’ them. Additionally, consistent with previous literature (Goldsteen et al., 2006; Hattori & Ishida, 2012; Steinhauser et al., 2001), the desire to reduce burden on family members was described as another motivator for preparation. Preparation may allow the families of older adults to be present, physically and emotionally, at the time of death rather than being consumed by end-of-life treatment decisions.

Many participants reported previous engagement with some form of preparation, either through completing advance care documents or through communication with family members about their wishes for care/treatment at or near the end of life. Communication with family is often the most common form of advance planning. There are, however, situations where preparation and type of death or illness interact with the ability to prepare. Certain deaths (e.g. car accident, a debilitating stroke) eliminate the ability to prepare for the end of life due to the immediacy of the death or the limitations caused by the illness. Therefore, formal or informal

advance planning is essential. In addition, previous advance preparation may not consider the complications that are associated with certain illnesses such as these. Naming a health care proxy and discussing end-of-life preferences with them may help mitigate this issue; however, prior research has revealed that proxy decision-makers incorrectly predicted the preferences for medical care nearly 1/3 of the time (Ditto et al., 2001; Marks & Arkes, 2008; Shalowitz, Garrett-Mayer, & Wendler, 2006). While most participants preferred a ‘quick’ or ‘short’ dying process, having time to plan and attend to affairs was also seen as beneficial. Thus, a longer dying process may be desirable if the older adult perceives that their prior planning was inadequate. Preparation also influences the security that older adults perceive as important at the end of life. For example, participants trusted that, through planning, their wishes will be honored. One participant discussed that he believed that he will experience the good death that he planned because he trusts his healthcare proxy “implicitly.”

For these reasons, preparation is often considered as a facilitator for a good death, in that the other psychosocial and spiritual factors of a ‘good death’ are more likely to present when adequate preparation has occurred. For example, older adults’ concerns about potential family conflict about the division of the estate after death can be limited by completing legal documents. Additionally, naming a healthcare proxy may facilitate a ‘good death’ because older adults may feel comfortable knowing that their wishes will be respected (i.e. security and autonomy).

### **Quality of Life**

The manner in which quality of life was discussed was notable with the participants. Quality of life was often discussed as what would limit quality of life rather than what would enhance it. This is evidenced when participants discussed the type of death or illness preferred at the end of life. Participants stated that they did not want the cause of death to be one that limited

quality of life, especially if the illness trajectory was long. Treatment preferences may also be influenced by this and treatments would be considered if they increased quality of life. Thus, treatment decisions were conditional on the potential outcomes, in relation to quality of life.

The relationship between mental abilities and type of illness was such that illnesses that have negative effects on mental abilities, and consequently quality of life, were not preferred. While it is not possible to predict the type of illness that will cause older adults to die, how those illnesses might influence mental abilities was paramount.

Continuing doing what they ‘were currently doing’ was also important to the perception of quality of life (Corr, 1992; Goldstein et al., 2006). Several participants stated that they wanted to travel or continue traveling as the end of life approaches, suggesting that retaining independence contributes to greater perceived quality of life among study participants. In addition, preparation can increase quality of life for older adults. For example, one participant discussed the construction of his house (e.g. wide doors to accommodate wheelchairs, designed to allow all people to live on a single floor, etc.) as a way to prepare for the end of life and that it will allow for him and his partner to receive medical care in the home.

Further, the manner in which older participants discussed quality of life suggested that limited quality of life acts as a barrier to the realization of a ‘good death.’ Type of death or illness, for example, may prevent older adults from being able to engage in activities considered important (i.e. richness in living), thus preventing the individual from dying a death they would consider ‘good.’

### **Social Work Implications**

The present study has implications for social workers and health care providers working with older adults and their families. The findings suggest that the physical, psychological, social,

and spiritual components are interrelated. These connections warrant further exploration during advance planning conversations. Social workers should be involved in the advance planning conversations early in the disease process to address a holistic management of serious illness. This can be done by inquiring about the motivation for the specific choices and eliciting details about other conditions that are important to the experience of a ‘good death.’ The Person-Centered Oncologic Care and Choices is a values-based advance care planning model that elicits patient care in the context of their values and motivations (Epstein et al., 2017; Epstein et al., 2018). While advance care planning models that assess and integrate values are available, a recent review of the literature found that opportunities to clarify values were not consistently available in written advance care planning documents (Bridges et al., 2018). When older adults are engaging in advance care planning, social workers should supplement previously established tools with discussions about values to further understand individuals’ preferences and motivations for certain choices.

Beyond facilitating conversations between and among older adults, their families and health care providers, the interrelatedness of the components of a ‘good death’ present opportunities for social workers to address underlying concerns of older adults as they near the end of life. It is not sufficient to only manage pain and other physical symptoms as the end of life approaches. The findings call for a more in-depth exploration of what older adults consider a ‘good death’ so that those conditions are all met. For example, pain and other distressing symptoms may be the main concern voiced by the individual but, after further assessment, it may be discovered that they wish to model a ‘good death’ through not experiencing what may seem undesirable to others. Understanding the interrelatedness of a ‘good death’ is necessary and will allow social workers to use their professional skills to facilitate meeting these needs as well.

The location of death, while separate from the framework used to guide the study conceptualization, contributed to older adults' conceptualization of a 'good death.' Location of death was framed within physical, psychosocial, and spiritual contexts; thus social workers should assess to uncover the value ascribed to and motivation for the preferred location of death by older adults. This information could guide future discussions between older adults and their health care team. Discussions should address the factors considered important within the context of preferred location of death. Additionally, social workers need to explore and assess the social support and community resources that can help to ensure that death occurs according to the older adults' preference.

Study participants often framed their conceptions of a 'good death' within the context of their previous experiences with death. Understanding how they perceived the deaths of others has multiple implications. Observing the death of others may be related to the experience of death anxiety by forcing the individual to confront their mortality (Barrett, 2013; Carmack & DeGroot, 2016). Death anxiety is defined as the 'fear and anxiety' associated with the notion that humans are mortal (Lehto & Stein, 2009). Increasing 'good death' experiences among family members and friends may increase the likelihood that individuals themselves believe that they will experience a 'good death' when approaching the end of life, reducing anxiety that one will experience a death they would not consider as 'good.' This further emphasizes the idea that death is a social experience and has implications beyond the individual who is approaching death. Health care providers have opportunities to educate those present near the death about expectations as one approached the end of life, potentially further reducing the death anxiety experienced.

Even though the participants discussed spirituality in the context of religion in this study, specifically Christianity, the findings are relevant to people with a variety of religious and spiritual backgrounds. For example, older adults may value engaging in religious or spiritual ceremonies, regardless of the denomination. Assessing for what is important to older adults spiritually, as the end of life approaches, could increase social workers' abilities to connect older adults with community resources that can help foster spiritual growth if this seems important. In addition, social workers on hospice teams may partner with pastoral care representatives to help assess spiritual concerns of older adults as they near the end of life. The findings call for increasing the partnership between social workers and religious and spiritual leaders to address the specific spiritual needs of older adults. This partnership could be in the form of fostering spirituality particularly near the end of life, for example, providing access to religious sacraments or traditions and addressing spiritual concerns. Due to the relative importance of religious and spiritual components of a 'good death,' as described by these participants, social workers and spiritual leaders can assess for spiritual concerns or provide access to religious or spiritual care throughout the illness trajectory.

The findings from this study can guide clinical discussions with older adults and their families. Social workers could help facilitate understanding and support from the family by using the framework of interconnectedness of the factors of a 'good death.' For example, they can specifically ask about values and motivations that older adults consider important to their conception of a 'good death.' Further, social workers can provide foundational information regarding the death and dying process to individuals and their families, particularly for those experiencing death anxiety. Providing psychoeducation regarding the interconnectedness of the components of a 'good death' may help others recognize that certain decisions regarding type of

treatment, such as who should be present at the time of death and the desired location of death, may have underlying motivations. These clinical discussions can occur from initial diagnosis of a serious or life-limiting illness, during curative treatment, palliative care, or hospice referrals near death and after death. The post-death conversations with caregivers, family, and friends who are experiencing complicated grief may be beneficial. Social workers can share information about the individual that may have been unknown to these persons about possible motivations for the individual's end-of-life decisions.

### **Strengths and Limitations**

This study had several strengths. The study strengths include the focus on psychosocial and spiritual components of a 'good death' from the perspective of community-dwelling older adults. Previous studies were predominately quantitative with mixed samples of adults (of all ages), family members/caregivers, and health care providers. Also earlier studies examined the concept of a 'good death,' primarily focusing on medical aspects/treatment preferences, and paid little attention to psychosocial and spiritual factors. Another strength of this study is the data analysis and data presentation strategies (e.g. direct participant quotes and concept maps), which allowed for an objective description of the findings. Participant statements were not interpreted and were coded as they were presented to the researcher, thus the presentation of the study findings reflect the conception of a 'good death' from the perspectives of older adults.

The study's two interview design is another strength. This provided the participants additional time to consider and discuss their conception of a 'good death.' At the beginning of the second interview, the researcher summarized the participants' statements regarding a 'good death' and asked if there was anything the participant wanted to add. Several study participants mentioned that they had thought about the topic since the initial interview and provided

additional information and clarification, thus allowing for more ‘rich’ data. For example, the first interview with James lasted 20 minutes, while the second was closer to 45 minutes. At the end of the second interview, he said, “The questions you’ve asked, you know, kind of made me think about them in the last week or so” (James). Had the more ‘traditional’ single interview model been used, it is likely that additional participants would have been needed to achieve the same richness of the data. The multiple interview model also allowed for deeper rapport to be developed between the researcher and participants.

The present study is not without limitations. The major limitation is that, while there was some variability in the participants’ demographics, they were relatively homogeneous (e.g. white, Christian religion). It is possible that the conception of a ‘good death’ is different for other racial and ethnic populations or among older adults with different spiritual or religious backgrounds. Further, it is possible that people residing in rural areas or urban clusters may have different expectations for the end of life than people from urban areas.

The goal of qualitative research is not to produce generalizable findings and this study is no different. The number of participants in the present study, while adequate for qualitative description, is small. The small sample size and relative homogeneity of the participant pool limits transferability to older adults with different demographic characteristics. Caution should be taken when applying the findings to other population subgroups. However, the present study provided insight into the inter-connectedness of the physical, psychological, social, and spiritual components of a good death that can help frame end-of-life planning discussions with older adults within other population settings.

Recruitment followed a snowball sampling procedure described in detail in Chapter 3. Several individuals in the acquaintance network were given recruitment flyers to distribute to

potential participants. However, fewer than anticipated flyers may have been distributed because they were ‘screening’ the individuals first, even though the researcher asked that they not do so. Anecdotally, one individual disclosed to the researcher that they did not distribute the flyers because they did not think anyone in their social network would likely participate in the study. However, the extent that this happened, in general, is unknown.

Additionally, the interview guide was not pilot tested with older adults to ensure that the questions were clear, while gathering the information necessary for this study. During the interviews, one question (“Please share a recent experience about someone you know who has died”) seemed particularly difficult for the participants to understand. Recent is a relative term and several participants asked “how long back are you talking.” While the purpose of this question was to orient the participants to the topic, pilot testing may have shown that the question should have been refined to increase clarity. Many participants likely framed their conception of a ‘good death’ around their experiences with the death of others within their social network. The researcher did, however, consult with the director of a community agency and two community-dwelling older adults about the study protocol and interview guide and received feedback about the language used. The feedback from the community members was considered and incorporated into the recruitment materials and interview guides.

Member checking was one strategy to ensure trustworthiness of the data during the study. However, the researcher did not have a consistent strategy to retain participant contact information during the study. Consequently, the contact information for several participants was not retained after initial phone contact with the researcher. It is possible that the participants without contact information would have wanted to edit the content of their transcripts or the codebook and suggested additional codes or clarified code definitions.

## **Future Research**

Because the sample was largely homogeneous, future research must include a diversity of older adults to understand the nuances between and among other population subgroups (i.e. different religions/spiritual backgrounds, people of color, etc.). This can inform not only social work practice but also other members of the interdisciplinary health care team in working with older adults from diverse demographic backgrounds.

During the interviews, participants often disclosed that it was difficult to describe their conception of a ‘good death’ because it depended upon the type of death that they would experience (and is unknown). To address this issue, future research could use case vignettes describing the most common causes of death for adults aged 65 or older, including the symptoms, prognosis, and course of treatment. Case vignettes is a research strategy that can desensitize and orient study participants to topics (R. Hughes & Huby, 2002). Similar designs have been used in research on the treatment preferences for the end of life (Clarke et al., 2017; Michael, O’Callaghan, & Clayton, 2016; Ramos et al., 2019). Diseases of heart and malignant neoplasms are the most common causes of death among older adults and are associated with more than 46% of all U.S. deaths (Heron, 2018). Providing these vignettes could help orient study participants to the most likely causes of death, while allowing for more consistent discussions of their conception of a ‘good death.’

## **Conclusions**

The purpose of the study was to identify and delineate the physical, psychological, social, and spiritual components of a good death in order to better define the concept of a ‘good death.’ While it is possible to view the concepts as independent, the motivations for certain preferences expressed by these participants suggested that what older adults consider important to a ‘good

death' are interrelated. The findings from this study provide a framework for social workers to understand the factors considered important to the conception of a 'good death' as interrelated.

Participants described numerous physical, psychological, social, and spiritual factors that contribute to a good death. The description of a good death was further nuanced based on the motivations and value placed on specific factors. This makes the definition of a 'good death' unique to each person. However, based on the findings from the present study, a good death may be defined as 'a highly personal, yet complex interaction of physical, psychological, social, and spiritual preferences influenced by the motivations for and values ascribed to the factors. It is dependent on the situation that the individual is experiencing and includes the time period leading to death, death itself, and the time following death.'

Social workers have the skills and resources to facilitate a 'good death' for older adults. Particularly, in order to increase the likelihood of a good death, social workers should assess the motivations for and value ascribed to factors older adults consider important to the experience of a 'good death' as well as preferences for treatment and care.

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APPENDIX 1 – Brief Screen for Cognitive Impairment

**Brief Screen for Cognitive Impairment**

**Question 1.** Delayed recall

Number of words <i>not</i> correctly remembered after delay	Score
0	0
1	2
2	4
3	6

**Question 1 Score** \_\_\_\_\_

**Question 2.** How frequently do you need help with planning a trip for errands?

<u>Response</u>	Score
Never	0
Rarely	1
Sometimes	2
Frequently	3
Always	4

**Question 2 Score** \_\_\_\_\_

**Question 3.** How frequently do you need help with remembering your medications?

<u>Response</u>	Score
Never	0
Rarely	2
Sometimes	4
Frequently	6
Always	8

**Question 3 Score** \_\_\_\_\_

***Sum of questions score*** \_\_\_\_\_

**Interpretation**

For patients using at least 1 medication, a score of greater than or equal to 12 indicates a higher likelihood of cognitive impairment.

For patients not taking any medications medication, a score of greater than or equal to 8 indicates a higher likelihood of cognitive impairment.

APPENDIX 2 – IRB Approval



Office of the Vice President for  
Research & Economic Development  
Office for Research Compliance

September 19, 2018

Quentin R. Maynard  
School of Social Work  
Box 870314

Re: IRB#: 18-OR-343 "Older Adults' Conceptions of a 'Good Death' "

Dear Quentin Maynard:

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your application has been given expedited approval according to 45 CFR part 46. Approval has been given under expedited review category 7 as outlined below:

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

Your application will expire on September 18, 2019. If your research will continue beyond this date, complete the relevant portions of the IRB Renewal Application. If you wish to modify the application, complete the Modification of an Approved Protocol Form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate a apparent immediate hazards to participants. When the study closes, complete the appropriate portions of the IRB Request for Study Closure Form.

Please use reproductions of the IRB approved stamped consent/assent forms to provide to your participants.

Should you need to submit any further correspondence regarding this proposal, please include the above application number.

Good luck with your research.

Sincerely,

  
Carpaneto T. Myles, MSW, CIM, CIP  
Director & Research Compliance Officer

358 Rose Administration Building | Box 870127 | Tuscaloosa, AL 35487-0127  
205-348-8461 | Fax 205-348-7189 | Toll Free 1-877-820-3066

**Research Recruitment Flyer**

**Title:**

Older Adults and the Treatment of Medical Illness

**Researcher Contact Information**

Quentin R. Maynard

(XXX)-XXX-XXXX

qrmaynard@crimson.ua.edu

**Sponsor**

The University of Alabama School of Social Work, Tuscaloosa,  
Alabama

**Who is Eligible?**

Adults (65 and older) who are cognitively able to participate in a research study.

**Study purpose and procedures:**

This study will examine older adults' preferences for the treatment of medical illness as they near the end of life.

**What exactly is being asked of you?**

You will be asked to participate in two individual face-to-face interviews with the possibility of follow-up conversations to make sure the information discussed during the interviews was understood well. Each interview will be conducted at a pre-arranged location of your choosing (such as in your home or another location) that is private and familiar to you. Each interview may last about 30-60 minutes and will be audio recorded. The interview will be guided by several questions designed to help us understand your preferences for the treatment of medical illness as you near the end of life.

**Are there any risks to me?**

There is minimal anticipated risk to you if you participate in this study. You may experience some discomfort when discussing the topic. Your participation is completely voluntary and you may withdraw participation at any time without penalty or loss of any benefits you would otherwise receive.

**What are the benefits to me?**

You will benefit from knowing that you made a contribution to the understanding of the preferences for treatment of medical illness that may possibly help other older adults. You will receive a \$10 gift card as a ‘thank you’ for your time in the interview process after each interview.

**When and where will the interview take place?**

The interview will be arranged between you and the researcher directly and may take place in your home or another location according to your preference.

**How do I express interest in participation?**

You may call Mr. Quentin R. Maynard (researcher) at (XXX)-XXX-XXX or email Mr. Maynard at qrmaynard@crimson.ua.edu. The researcher will discuss the purpose of the study and an interview arranged if you wish to participate.

APPENDIX 4 – Background Data Sheet

**Participant Background Data Sheet**

**Demographics**

<b>Participant #</b>	
<b>Age</b>	
<b>Gender</b>	
<b>Race</b>	
<b>Religious affiliation</b>	
<b>Attend religious services? How often?</b>	
<b>Marital Status</b>	<input type="checkbox"/> Married <input type="checkbox"/> Single <input type="checkbox"/> Widow/widower
<b>How long have you been attending the senior center?</b>	

**Brief Medical History**

<b>Diagnosis</b>	
<b>When diagnosed</b>	
<b>Currently receiving treatment?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>What type?</b>	
<b>How often?</b>	

APPENDIX 5 – Consent Form

**Consent Form**  
UNIVERSITY OF ALABAMA

Individual's Consent to be in a Research Study

**Study Title:** Older Adults and the Treatment of Medical Illness

**Investigator Name:** Mr. Quentin R. Maynard, LGSW, MSW, Doctoral Candidate

You are being asked to be in a research study. This study is called “Older Adults’ and the Treatment of Medical Illness”. This study is being done by Mr. Quentin R. Maynard, a doctoral candidate in the School of Social Work at the University of Alabama. Mr. Maynard is being supervised by Dr. Ellen L. Csikai who is a professor of Social Work at the University of Alabama.

**What is this study about?**

This study is being done to find out what type of treatments older adults want for medical illnesses as they near the end of life. Specifically, the researcher would like to learn more about what medical, psychological, social, and spiritual factors older adults consider as important. You will be asked to describe what you want your end of life to look like and what could be done to make that better. I will also you for information to help me describe you and the other participants, including age, race, gender, diagnosis, etc.

**Why is this study important—What good will the results do?**

The findings will help health care providers understand older adults’ preferences for the treatment of medical illnesses. This will help them provide the type of care that reflects older adults wishes.

**Why have I been asked to take part in this study?**

You responded to an invitation to participate that was presented by someone you know. You told me that you are at least 65 years old and were willing to schedule an initial interview.

**How many other people will be in this study?**

The investigator hopes to interview at least 10 older adults within the next two months.

**What will I be asked to do in this study?**

If you agree to be in this study, Mr. Maynard will interview you twice in your home or a place of your own choosing about your preferences for the treatment of medical illness at the end of life. Both interviews will be tape (audio) recorded to be sure that all your words are captured accurately. Allowing the interview to be tape recorded is necessary for the participation in the study.

I may contact you two to three times to ask you to check my work. I would like to make sure that I understand what you tell me correctly. You do **not** need to participate in the follow-up discussions.

**How much time will I spend being in this study?**

There will be two interviews. Each interview should last about 30-60 minutes, depending on how much information about your preferences you choose to share.

The follow-up discussions will be brief and should take around 30 minutes.

**Will being in this study cost me anything?**

The only cost to you from this study is your time.

**Will I be compensated for being in this study?**

In appreciation of your time, you will receive a universal \$10 gift card.

**What are the risks (problems or dangers) from being in this study?**

The chief risk to you is that you may find the discussion of your experiences and preferences to be sad or stressful. You may get upset by thinking about your death or the death of others. You can control this possibility by not being in the study, by refusing to answer a particular question, or by not telling us things you find to be sad or stressful. I am a licensed graduate social worker and can provide initial support and can recommend a counselor to you if you seem to be upset or depressed. Seeing the counselor would be at your own expense.

**What are the benefits (good things) of being in this study?**

There are no direct benefits to you. Although you may not benefit personally from being in the study, you may feel good about knowing you have helped us gain a better understanding of preferences for medical treatment at the end of life.

### **How will my privacy be protected?**

You are free to decide where we will visit you so we can talk without being overheard.

We will visit you in the privacy of your home, in a private room at the senior center, or in another place that is convenient for you. I will use headphones when listening to the interview recording, so no one else can hear what you said.

### **How will my confidentiality be protected?**

For your protection, your confidentiality cannot be maintained if you disclose self-harm during our conversation.

The only place where your name appears in connection with this study is on this informed consent. The consent forms will be scanned and stored on a password protected web-based file service. Mr. Maynard will assign you a participant number which will link your data sheet to the interview. When the interview is recorded, we will not use your name, so no one will know who you are on the tape. Once I return to my office, I will listen to the tape and type out what was said. After the interviews are typed, I will destroy the audio files. Typing the interview and destroying the audio files should occur within 30 days of the interview.

I will write research articles on this study but participants will be identified only as “persons from living in West Alabama”. I may use what you say but will identify you as an “older adult” or another general descriptor. No one will be able to recognize you.

### **What are the alternatives to being in this study?**

The only alternative is not to participate.

### **What are my rights as a participant?**

Being in this study is totally voluntary. It is your free choice. You may choose not to be in it at all. If you start the study, you can stop at any time. If you decide to stop the interview, you will still receive the gift card. Not

participating or stopping participation will have no effect on your relationships with the University of Alabama.

The University of Alabama Institutional Review Board is the committee that protects the rights of people in research studies. The IRB may review study records from time to time to be sure that people in research studies are being treated fairly and that the study is being carried out as planned.

**Who do I call if I have questions or problems?**

If you have questions about this study right now, please ask them. If you have questions later on, please call Mr. Maynard at 205-523-5502. If you have questions or complaints about your rights as a research participant, call Ms. Tanta Myles, the Research Compliance Officer of the University at 205-348-8461 or toll-free at 1-877-820-3066.

You may also ask questions, make a suggestion, or file complaints and concerns through the IRB Outreach Website at <http://ovpred.ua.edu/research-compliance/prco/>. After you participate, you are encouraged to complete the survey for research participants that is online there, or you may ask Mr. Maynard for a copy of it. You may also e-mail us at [rscompliance@research.ua.edu](mailto:rscompliance@research.ua.edu).

I have read this consent form. I have had a chance to ask questions. I **agree** to be audio recorded.

---

Signature of Research Participant Date

---

Signature of Investigator Date

**Can the researcher contact me for follow up discussions?**

I would like to talk to you during the research process. During these discussions you may be asked to review the typed up interview and check if I understood what you said. Participating in the follow-up discussions is voluntary and you may change your mind at any time.

I **agree** to allow the researcher to contact me for follow-up discussions.

---

Signature of Research Participant Date

---

Signature of Investigator Date

I **do not agree** to allow the researcher to contact me for follow-up discussions.

---

Signature of Research Participant Date

---

Signature of Investigator Date

APPENDIX 6 – Re-consent Form

**Consent Form**

UNIVERSITY OF ALABAMA

Individual's Consent to be in a Research Study

**Study Title:** Older Adults and the Treatment of Medical Illness

**Investigator Name:** Mr. Quentin R. Maynard, LGSW, MSW, Doctoral Candidate

You are being asked to be in a research study. This study is called “Older Adults’ and the Treatment of Medical Illness”. This study is being done by Mr. Quentin R. Maynard, a doctoral candidate in the School of Social Work at the University of Alabama. Mr. Maynard is being supervised by Dr. Ellen L. Csikai who is a professor of Social Work at the University of Alabama.

**What is this study about?**

This study is being done to find out what type of treatments older adults want for medical illnesses as they near the end of life. Specifically, the researcher would like to learn more about what medical, psychological, social, and spiritual factors older adults consider as important. You will be asked to describe what you want your end of life to look like and what could be done to make that better. I will also use the information to help me describe you and the other participants, including age, race, gender, diagnosis, etc.

**Why is this study important—What good will the results do?**

The findings will help health care providers understand older adults’ preferences for the treatment of medical illnesses. This will help them provide the type of care that reflects older adults wishes.

**Why have I been asked to take part in this study?**

You responded to an invitation to participate that was presented by someone you know. You told me that you are at least 65 years old and were willing to schedule an initial interview.

**How many other people will be in this study?**

The investigator hopes to interview at least 10 older adults within the next two months.

**What will I be asked to do in this study?**

If you agree to be in this study, Mr. Maynard will interview you your home or a place of your own choosing about your preferences for the treatment of medical illness at the end of life. Both interviews will be tape (audio) recorded to be sure that all your words are captured accurately. Allowing the interview to be tape recorded is necessary for the participation in the study.

I may contact you two to three times to ask you to check my work. I would like to make sure that I understand what you tell me correctly. You do **not** need to participate in the follow-up discussions.

**How much time will I spend being in this study?**

This is the second interview and should last about 30-60 minutes, depending on how much information about your preferences you choose to share.

The follow-up discussions will be brief and should take around 30 minutes.

**Will being in this study cost me anything?**

The only cost to you from this study is your time.

**Will I be compensated for being in this study?**

In appreciation of your time, you will receive a universal \$10 gift card.

**What are the risks (problems or dangers) from being this study?**

The chief risk to you is that you may find the discussion of your experiences and preferences to be sad or stressful. You may get upset by thinking about your death or the death of others. You can control this possibility by not being in the study, by refusing to answer a particular question, or by not telling us things you find to be sad or stressful. I am a licensed graduate social worker and can provide initial support and can recommend a counselor to you if you seem to be upset or depressed. Seeing the counselor would be at your own expense.

**What are the benefits (good things) of being in this study?**

There are no direct benefits to you. Although you may not benefit personally from being in the study, you may feel good about knowing you have helped us gain a better understanding of preferences for medical treatment at the end of life.

**How will my privacy be protected?**

You are free to decide where we will visit you so we can talk without being overheard.

We will visit you in the privacy of your home, in a private room at the senior center, or in another place that is convenient for you. I will use headphones when listening to the interview recording, so no one else can hear what you said.

**How will my confidentiality be protected?**

For your protection, your confidentiality cannot be maintained if you disclose self-harm during our conversation.

The only place where your name appears in connection with this study is on this informed consent. The consent forms will be scanned and stored on a password protected web-based file service. Mr. Maynard will assign you a participant number which will link your data sheet to the interview. When the interview is recorded, we will not use your name, so no one will know who you are on the tape. Once I return to my office, I will listen to the tape and type out what was said. After the interviews are typed, I will destroy the audio files. Typing the interview and destroying the audio files should occur within 30 days of the interview.

I will write research articles on this study but participants will be identified only as “persons from living in West Alabama”. I may use what you say but will identify you as an “older adult” or another general descriptor. No one will be able to recognize you.

**What are the alternatives to being in this study?**

The only alternative is not to participate.

**What are my rights as a participant?**

Being in this study is totally voluntary. It is your free choice. You may choose not to be in it at all. If you start the study, you can stop at any time. If you decide to stop the interview, you will still receive the gift card. Not

participating or stopping participation will have no effect on your relationships with the University of Alabama.

The University of Alabama Institutional Review Board is the committee that protects the rights of people in research studies. The IRB may review study records from time to time to be sure that people in research studies are being treated fairly and that the study is being carried out as planned.

**Who do I call if I have questions or problems?**

If you have questions about this study right now, please ask them. If you have questions later on, please call Mr. Maynard at 205-523-5502. If you have questions or complaints about your rights as a research participant, call Ms. Tanta Myles, the Research Compliance Officer of the University at 205-348-8461 or toll-free at 1-877-820-3066.

You may also ask questions, make a suggestion, or file complaints and concerns through the IRB Outreach Website at <http://ovpred.ua.edu/research-compliance/prco/>. After you participate, you are encouraged to complete the survey for research participants that is online there, or you may ask Mr. Maynard for a copy of it. You may also e-mail us at [rscompliance@research.ua.edu](mailto:rscompliance@research.ua.edu).

I have read this consent form. I have had a chance to ask questions. I **agree** to be audio recorded.

---

Signature of Research Participant Date

---

Signature of Investigator Date

**Can the researcher contact me for follow up discussions?**

I would like to talk to you during the research process. During these discussions you may be asked to review the typed up interview and check if I understood what you said. Participating in the follow-up discussions is voluntary and you may change your mind at any time.

I **agree** to allow the researcher to contact me for follow-up discussions.

---

Signature of Research Participant Date

---

Signature of Investigator Date

I **do not agree** to allow the researcher to contact me for follow-up discussions.

---

Signature of Research Participant Date

---

Signature of Investigator Date

## APPENDIX 7 – First Interview Guide

### Interview Question Guide:

#### **Interview #1**

Thank you for taking time to speak with me today. My name is Quentin Maynard and I am a doctoral candidate in the School of Social Work at the University of Alabama. I study the preferences for treatments for medical illness. I'm going to ask about your preferences for the end of life. I know that this can be a difficult topic to discuss and I appreciate your willingness to discuss this with me.

#### **Introduction Questions:**

1. What prompted you to begin attending the center?
2. You mentioned that you have [the specific chronic illness or chronic illnesses]. What has your doctor told you about the long term treatment for these conditions?

#### **Main interview questions:**

1. Please share a recent experience about someone you know who has died.
  - a. What was the person's illness and how did you perceive her or his experience toward the end of the person's life?
2. Describe what you consider to be a 'good death' (resulting from a medical condition).
3. Now think about how you, personally, want the end of your life to look like.
  - a. If pain and other physical symptoms are well-controlled, what other factors would be most important to you near the end of life. (prompts: psychological, social, spiritual)?
4. Is there anything else you want to share with me today?

## APPENDIX 8 – Second Interview Guide

### **Interview #2:**

Thank you for meeting with me again. I would like to continue our discussion of preferences for treatments for medical illness. Last time we discussed what you consider to be a ‘good death’. Including [include a brief of some of their statements about factors important toward the end of life from the first interview].

1. How well do you think you will be able to ensure that your death is how you would want it to be (advance directives, health care surrogates)?
  - a. What factors might enhance your ability to achieve your conception of a good death? (trust in doctors, advance directives, health care surrogates)
  - b. What factors might prevent you from achieving this?
2. Is there anything else you want to share with me about what we have spoken about during today’s meeting or the previous meeting?

## APPENDIX 9 – PHQ-9

### PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

Over the last 2 weeks, how often have you been bothered by any of the following problems?  
(use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite —being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3

add columns  +  +

(Healthcare professional: For interpretation of TOTAL, TOTAL:   
please refer to accompanying scoring card).

10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	_____
	Somewhat difficult	_____
	Very difficult	_____
	Extremely difficult	_____

APPENDIX 10 – Referral List

**Referral List**

**University Medical Center – Betty Shirley Clinic — 205-348-1770**

**Indian Rivers Behavioral Health Center — 205-391-3131**

**Indian Rivers Behavioral Health Center Crisis Line — 205-391-3131**

**North River Counseling Center — 205-391-9866**

**American Psychiatric Association Answer Center — 888-35-PSYCH (77924)**

**American Psychological Association Public Education Line — 800-964-2000**

**National Suicide Prevention Lifeline — 800-273-8255**

**2-1-1 (United Way of West Alabama Resource Line) — 2-1-1 or 205-345-7775**

APPENDIX 11 – Description of Major Codes and Categories

*Definitions for Major Categories and Codes for a ‘Good Death’*

Code	Description
<i>Physical</i>	Broad category of physical components of a ‘good death’
Minimize physical distress	The management of pain, physical symptoms, and other sources of bodily distress
Type of death or illness	The type of death or illness and how that influences the perception of a ‘good death’
Treatment	The level or type of treatment that an individual wants or does not want
<i>Psychological</i>	Broad category of psychological components of a ‘good death’
Psychological strength and preparation	The psychological preparation needed to achieve a good death, including the individual strength required to get through the physical and psychological issues and how the participant might go about finding acceptance of the end of life
Richness in living	Description about what it important to the participants, what makes life worth living, and quality of life
Mental Abilities	Mental abilities or mental acuity, regardless of the importance the participants place on mental ability
Security	The desire to be free from fear or anxiety, that the situation is considered safe, or the ability to manage the end of life.
Autonomy	The ability to be self-governing or independent to the degree that is possible at the end of life
<i>Social</i>	Broad category of social components of a ‘good death’
Social effect on others	How the death and dying process affects others before, during, or after death
Communication	Communication with social network about various aspects of life and death
Preparation	How preparation influences the social aspects of the participants life, including social motivation for preparation.
Important interpersonal relationships	Interpersonal relationships that are important to the participants, including maintaining or enhancing the relationships
Support	Relationships that provide support to the individual.
<i>Spiritual</i>	Broad category of spiritual components of a ‘good death’
Comfort	How the participant uses spirituality to find comfort when considering the end of life
Support	Spiritual aspects that provide support for the participant
Acceptance	Using spirituality to foster acceptance of death and how this acceptance influences the perception of a ‘good death’

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Identify and  
strengthen spiritual  
growth

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The participant desires to identify or foster spirituality when  
approaching the end of life