

**End-of-Life Decision Making for African American Older Adults with  
Dementia**

Karen Olivia Moss  
Charlottesville, Virginia

ASN, College of the Bahamas, 1999  
BSN, Adventist University of Health Sciences, 2008  
MSN, University of Virginia, 2012

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### **Dedication**

This dissertation is dedicated to my family: Kenny (husband), Kennedi and Kerrington II (children), Solomon and Monica Stuart (parents), who sustained me in many ways throughout this journey, and without whom my success would not be possible. I love and appreciate you. You all underwent this journey with me. To you and my extended family, I am grateful for the continued support and encouragement. To The Almighty, without whom this dissertation would not be possible, and everyone else not mentioned by name, I am ever grateful.

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## Abstract

**Background:** African American older adults with dementia are at an increased risk of facing the end of life without advance care plans in place and, thus, are vulnerable to receiving unwanted interventions. This often leaves family caregivers struggling to make surrogate end-of-life decisions.

**Purpose:** The objectives of this study were to learn more about African American surrogate end-of-life decision making for older adults with dementia. The specific aims were to: 1) capture end-of-life decision making for African American older adults with dementia by their family caregivers, including understanding and use of terminology; and 2) determine if the presence of formal or informal end-of-life care plans for older adults with dementia would be associated with higher or lower health-related quality of life in older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making.

**Design/Methods:** This descriptive, correlational, pilot study used a mixed methods approach for cross-sectional data collection from African American dementia family caregivers (N=65). A subset of family caregivers ( $n=18$ ) completed qualitative interviews. These data were analyzed using simple content and thematic analyses guided by Miles and Huberman's<sup>1</sup> methods of qualitative analyses. Family caregivers rated their health-related quality of life using the Short Form Health Survey-36 version 2 as well as that of their care recipient using the Alzheimer's Disease Related Quality of Life instrument. Family caregiver self-efficacy for surrogate decision making was also measured using the Surrogate Decision Making Self-Efficacy Scale.

**Results:** Both family caregivers and care recipients were mostly female. Family

caregivers were often daughters caring for a parent with dementia. Care recipients were mostly community dwelling with a diagnosis of Alzheimer's disease. Most family caregivers (63%) reported the existence of a formal end-of-life care plan for their care recipient. Family caregivers' interpretation of end-of-life terminology varied based on available resources and personal experiences. End-of-life decision making is most often a family decision and involves resources such as healthcare providers, and faith/spirituality, and was based on past experiences. Family caregivers rated their care recipients' health-related quality of life as well as their own self-efficacy for surrogate decision making as high, however, neither measure was associated with the existence of a formal end-of-life care plan. Evidence supports that a relationship exists between the existence of formal end-of-life care plans and care recipient's age ( $p=0.012$ ) and number of comorbidities ( $p=0.021$ ).

**Implications:** Study findings support the Institute of Medicine 2014 report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*<sup>2</sup> that the foundation for effective communication is that the meaning patients and families attach to healthcare terminology should be aligned with healthcare providers' understanding of the terminology. Results of this study provide a basis for future intervention studies to help empower African Americans caring for older adults with dementia to make more informed, timelier end-of-life decisions.

**Keywords:** African American, dementia, end of life, family caregivers, quality of life

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## CHAPTER ONE: INTRODUCTION

The *Patient Self-Determination Act* of 1990 requires Medicare and Medicaid funded healthcare organizations to empower patients to refuse or accept medical care and execute advance directives.<sup>3</sup> In 1995, *The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)* confirmed substantial shortcomings of healthcare for seriously ill patients near the end of life.<sup>4</sup> Results of this landmark study indicated the need for increased commitment to end-of-life care as an important healthcare outcome.<sup>4</sup> From this study came the 1997 Institute of Medicine's report, *Approaching Death: Improving Care at the End of Life*, which further demonstrated the need for evidence-based end-of-life care models to improve this healthcare outcome.<sup>5</sup> Most recent is the 2014 Institute of Medicine consensus report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, which calls for improvements in quality of life through the end of life.<sup>2</sup> This report highlights the need for culturally relevant, person- and family-centered end-of-life care with a focus on the mentally incapacitated.<sup>2</sup> This report also stresses the fact that terminology matters when discussing end-of-life issues.<sup>2</sup> Family caregivers' understanding of end-of-life terms may differ from healthcare provider expectations, particularly when cultures differ.<sup>6</sup> This disconnect may lead to misunderstanding or inaccurate interpretations, negatively impacting end-of-life decision making.

### Aging and End of Life

The combination of old age and modern medicine has the potential to inflict a more difficult and protracted death than in previous decades.<sup>5</sup> More than 70% of deaths that occur are in individuals who are 65 years or older, for whom the death experience

tend to be more extended.<sup>5</sup> Approximately 70% of healthcare expenditures are for older adults,<sup>5</sup> with monthly Medicare spending increasing in the last year of life due to rapid accelerations in inpatient hospital spending.<sup>7</sup> *End-of-life care* is the broad term used to describe the attention and support given during the time period leading to death.<sup>8</sup> *Advance directives* are a mechanism to safeguard control over decision making when one can no longer express preferences for end-of-life care.<sup>9</sup>

### **African Americans and End of Life**

Literature suggests that African Americans/Blacks do not prepare for the end of life.<sup>10-19</sup> It is well documented that this population is least likely to complete advance directives and use hospice services.<sup>9,13,18-23</sup> The propensity among Blacks to choose life-sustaining measures increases the likelihood of death in acute care hospital settings.<sup>23,24</sup> In this dissertation, the terms African Americans and Blacks will be used interchangeably to include persons of Sub-Saharan African or Caribbean heritage<sup>25</sup> acclimated through socialization based on residing in the United States (US) from birth or migration.

### **Dementia and Caregiving**

Not considered a normal part of aging, dementia remains the sixth leading cause of death in the US, and the fifth leading cause for those 65 years or older.<sup>26</sup> *Dementia* is a general term used to describe a decline in mental ability, severe enough to interfere with daily life.<sup>27</sup> As such, dementia is not a specific disease but an overall term that describes a wide range of symptoms associated with a decline in thinking skills or memory, severe enough to reduce a person's ability to perform everyday activities.<sup>27</sup> More than five million Americans are living with dementia.<sup>27</sup> The occurrence of dementia accompanied by behavioral disturbance and pervasive memory loss is a major public health concern.<sup>28</sup>

Alzheimer's disease is the most common form of dementia accounting for 60% to 80% of all dementia cases.<sup>27</sup> In 2016, there are 5.4 million Americans currently living with Alzheimer's disease.<sup>27</sup> This number is projected to increase to 13.8 million by 2050.<sup>29</sup> This disease cannot be cured.<sup>27</sup> In 2016, overall costs for persons with all dementias were estimated at \$236 billion, including at least \$160 billion in Medicare and Medicaid costs.<sup>27</sup> Medicare costs for Alzheimer's disease are predicted to be \$1.2 trillion by 2050.<sup>27</sup> Currently, one in three older adults die with Alzheimer's disease or another dementia.<sup>27</sup> More specifically, 700,000 people are expected to die in 2016 because they have Alzheimer's disease.<sup>27</sup> Quality of life in Alzheimer's disease is an important concept that cannot be understated,<sup>30</sup> as is self-efficacy for surrogate decision making and family caregiver HRQOL.<sup>31</sup> Additionally, proxy measurement of HRQOL in dementia has proven beneficial due to the level of cognitive impairment that may exist with this disease.<sup>32</sup>

### **Surrogate Decision Making**

Over the course of illness, persons with dementia become increasingly dependent on one or more care providers for assistance and supervision.<sup>28,33</sup> A majority of people with dementia receive care in the context of family units.<sup>34</sup> These family care providers are unpaid individuals such as a spouse/partner, other immediate or extended family members, friends, or neighbors involved in assisting another with activities of daily living and or medical tasks.<sup>35</sup> They provide the bulk of care to individuals with dementia and will likely continue to be the largest providers of long-term care services.<sup>36</sup> In 2015, 15.9 million family and other unpaid caregivers provided 18.1 billion hours of unpaid care to those with Alzheimer's disease and other dementias.<sup>27</sup>

Family caregiver concerns are vast and include advocating for their care recipients while honoring the care recipient's integrity.<sup>37-39</sup> Dementia is a life-limiting illness that affects decision making in older adults, increasing the need for surrogate decision making.<sup>40,41</sup> Few scientific studies exist with regards to the end-of-life experience for people with dementia and their families.<sup>42</sup> It is important to adequately prepare families for decision-making roles and assure a level of comfort for them in this process.<sup>42</sup>

### **Scope of the Problem in Terms of Cost of Caring**

In 2015, the direct costs to American society for caring for those with Alzheimer's disease are estimated at \$221.3 billion.<sup>27</sup> Family caregivers often spend a great deal of time providing physical assistance to loved ones with important tasks or activities of daily living, such as feeding, bathing and dressing.<sup>33</sup> They devote significant amounts of resources over extended periods providing assistance to loved ones with dementia and coping with primary stressors of anxiety, depression, wandering, and agitation in their loved one with dementia, while addressing secondary stressors, such as family role changes, financial difficulties, and work strain in their own lives.<sup>33</sup> Over time, these stressors can result in physical and emotional problems of caregiver burden and could have detrimental effects on the quality of their own lives.<sup>27,33,43-50</sup>

### **Scope of the Problem for African Americans and Dementia**

African American older adults are two times more likely to develop dementia than Caucasians.<sup>27</sup> African Americans account for 13% of family caregivers in the U.S.<sup>51</sup> The number of them caring for relatives with dementia is greater than that of Caucasians in similar situations.<sup>51</sup> Regardless of prognosis, African Americans are more likely than



Caucasians to request life-sustaining treatments towards the end of life.<sup>10,12,13,15-18</sup> They use the highest amount of intensive care and the lowest amount of hospice care when compared to other races.<sup>52</sup> End-of-life spending in the last six months of life was 32% (\$26,704) more for African Americans than for Caucasians (\$20,166) among Medicare recipients.<sup>52</sup> As such, African American older adults with dementia are at an increased risk of facing the end of life without advance care plans and are vulnerable to the receipt of unwanted interventions,<sup>53</sup> often leaving family caregivers struggling to make surrogate end-of-life decisions.

### **Problem Statement of End of Life in Dementia**

End-of-life decision making for an individual who lacks capacity to make their own decisions is different from advance care planning for someone who is cognitively able to assess pain and other physical symptoms, and is often complicated when the individual cannot verbally communicate their distress.<sup>54</sup> Support for these families through the long, deteriorating end stages of dementia can be challenging.<sup>54</sup> It is imperative that healthcare providers support family caregivers in planning ahead and ensure that end-of-life care wishes of persons with dementia are respected and the person dies comfortably and peacefully.<sup>55</sup>

According to one source, time from diagnosis to death varies from as little as three or four years if the person is older than 80 years when diagnosed, to as long as 10 or more years if younger.<sup>56</sup> Complications of the disease such as aspiration pneumonia as a result of major feeding difficulties in advanced dementia can result in recurring hospitalizations.<sup>57</sup> This can lead to care that is poorly organized as well as frequent and inappropriate hospitalizations because of lack of planning and care coordination.<sup>57</sup>

### **Study Purpose and Research Questions**

The purpose of this descriptive, correlational, pilot study was to examine end-of-life decision making for African American older adults with dementia by their family caregivers, while measuring care recipient and family caregiver HRQOL and family caregiver self-efficacy for surrogate decision making. The research questions were: 1) In what ways, if any, do family caregivers of African American older adults with dementia make end-of-life decisions for their loved one with dementia; and 2) How do care recipient HRQOL (as perceived by the family caregiver) and family caregiver self-efficacy levels for surrogate decision making contribute to this decision-making process?

## CHAPTER TWO: LITERATURE REVIEW

Confluences of multiple factors influence advance care planning (formal, informal or no advance care plans) for African Americans with dementia and/or their surrogates or family caregivers.<sup>58</sup> Among these, the following four factors are noteworthy: (1) individual and familial belief systems, (2) culture and socialization, (3) religion and spirituality, and (4) past events in history that led to mistrust of US healthcare systems.

### Individual and Familial Belief Systems

The family operates as a multilevel social system with interdependent relationships rather than as a simple collection of members operating independently.<sup>59</sup> Family orientation is a hallmark for many African Americans,<sup>60</sup> and may influence a family-centered approach to end-of-life decision making.<sup>10,11,40,61-63</sup> In this population, the importance of using trusted family members to voice patient wishes is considered culturally relevant, rather than completing an advance directive.<sup>9,10,21,63</sup> Reasoning may be because of a common belief that a distrustful healthcare system otherwise holds responsibility for healthcare decision making.<sup>64</sup> Family practices are often passed down from previous generations becoming a basis for plans surrounding death. An example of this is the “*sit up*”, a gathering of family and friends that takes place following the death of a loved one.<sup>65</sup> African Americans believe in honoring older adult family members by taking care of them, so much so that those without will establish “*fictive kin*”, considered adoptive/foster family members to serve in this role.<sup>11,66,67</sup> In a recent study, Kypriotakis et al<sup>68</sup> stressed the importance of focusing on individual belief systems in providing end-of-life care. Respect for individual differences is also crucial in addressing end-of-life care needs.<sup>69</sup>

### **Culture and Socialization**

*Culture* is defined as a complex, multifaceted construct shaped by the interaction between various socio-demographic factors and is continuously redefined by social realities and historical experiences.<sup>21,58</sup> *Socialization* is defined as a set of learned beliefs, rules, and expectations within a society.<sup>58</sup> The belief system that one is acculturated or socialized into is influential in defining health and end-of-life decisions.<sup>20,21,70</sup> As found in the literature, a prevailing cultural discomfort among African Americans is to avoid discussions or plans for death, often resulting in an emphasis on living as long as possible under any circumstance.<sup>71</sup> Self-determination as a part of US societal norms may not mesh well with African American cultural belief systems, which are more family-centered.<sup>19</sup> These attitudes, spiritual beliefs and mistrust are common cultural influences of preferences for continued “cure-focused” care. Subsequently, such attitudes are often at odds with the philosophy of hospice care and may have strong influences on the preference of African Americans against its use.<sup>19</sup> Because the Black population in the US consists of individuals from various ethnic backgrounds, generalizations regarding African Americans/Blacks should consider between group variability and the heterogeneity of this population.<sup>11,72,73</sup>

### **Religion and Spirituality**

While the concepts of religion and spirituality often overlap, they may differ for many,<sup>74</sup> and play a pivotal role in planning for life after death and serve as buffers for coping with suffering, poor prognoses and quality of life for African Americans.<sup>12,21,22,41,75-78</sup> *Religion* refers to one’s relationship with God and preparation for the afterlife, while *spirituality* involves more personal reflection and self-examination.<sup>74</sup>

Individual or familial religious/spiritual belief systems can influence how coping with and treatment of illness is approached.<sup>70</sup> Blacks tend to defer end-of-life decision making to belief in a higher power and in miracles, believing that God has the power over life and death.<sup>20,21,79-82</sup> Older African Americans consider spirituality to be important,<sup>83</sup> but continue to choose aggressive medical treatment, especially when levels of religiosity/spirituality are high with a heavy reliance on God's will for the outcome.<sup>10</sup>

### **U. S. History as a Factor of Distrust**

Long histories of racial discrimination and health disparities have affected African Americans' trust in healthcare institutions,<sup>11,62,77</sup> and participation in end-of-life research.<sup>40</sup> Black Americans often cite distrust of formal healthcare providers as reason for choosing more aggressive healthcare options,<sup>21,63</sup> and as such it is seen as a barrier to improving end-of-life care.<sup>84</sup> The Tuskegee Syphilis Study (1932-1972) persists in the minds of many African Americans as an example of racial discrimination by the US government.<sup>63,70</sup> Without proper consent, African American men in Macon County, Georgia were denied treatment for syphilis to allow the natural progression of the disease to be studied even after the discovery of Penicillin as the gold standard treatment for the disease.<sup>85</sup> Additionally, the cancer cells of a poor Black woman named Henrietta Lacks "HeLa Cells" are still being used to advance science worldwide, without consent.<sup>86</sup> Mrs. Lacks' identity was linked to her cells (1951) raising issues of trust, race and medicine, class, access to education and healthcare as with the Tuskegee Study.<sup>87</sup> End-of-life care goals for those who have experienced discrimination over the life course may be inconsistent with that of healthcare systems.<sup>88</sup> The legacies of these and similar events still remain in the hearts and minds of many African Americans today as two examples of

healthcare and race-related, unethical treatment of Blacks that contribute to the distrust in the healthcare system,<sup>10,21,87,89</sup> and subsequently a lack of formal end-of-life care planning.

### **Health-Related Quality of Life**

For the last three decades, quality of life as an outcome is referred to in much of healthcare literature as a broad, multidimensional construct, inclusive of self-reported outcome measures of cognitive, physical, and social health.<sup>26,90</sup> The 1997 Institute of Medicine's report, *Approaching Death: Improving Care at the End of Life* recommended a focus on the study of HRQOL and caregiving dimensions.<sup>5</sup> The National Institute of Nursing Research's current strategic plan identifies quality of life as a focal area in need of further research.<sup>91</sup>

### **Care Recipient Health-Related Quality of Life**

Care recipient HRQOL, as perceived and reported by family caregivers, determines the level of treatment that family caregivers consider justifiable in the context of end-of-life decision making for their older adult care recipient.<sup>42,92,93</sup> When care recipient's quality of life is perceived as poor, there is a tendency for family caregivers to reject certain therapeutic treatments.<sup>42,89</sup> Because of the care recipients' cognitive impairment, family caregivers may be in a better position to estimate how persons with dementia may interpret their own quality of life than healthcare professionals.<sup>94</sup> In such instances, external evaluation of this patient reported healthcare outcome is often relied on to provide insight on quality of life for the cognitively impaired.<sup>95</sup> Proxy assessment of HRQOL may help to resolve conflict in medical decision making,<sup>50</sup> such as at the end of life. This indicator of a loved one with dementia's health status also affects the health

of the family caregiver.<sup>50,96,97</sup>

### **Family Caregiver Health-Related Quality of Life**

Family caregivers face stressors that can result in physical and emotional problems and could have detrimental effects on the quality of their lives,<sup>33</sup> particularly as it relates to the nature of the disease process in dementia.<sup>49</sup> The declining general, physical health of the family caregiver is a major area of concern.<sup>33,45-50</sup> The functional abilities of older adults with dementia have a significant effect on family caregiver quality of life.<sup>50</sup> Bruvik et al<sup>32</sup> reported that family caregivers who live together with the individual with dementia experienced poorer quality of life than those who did not. Yaffe et al<sup>98</sup> found that ethnic minority groups were less likely to place family members with advanced dementia into nursing homes and were more likely to absorb the cost of informal caregiving. Studies have shown that African American dementia caregivers demonstrated better well-being and lower levels of stress than White caregivers.<sup>95,99,100</sup> African Americans are also less likely to place loved ones in nursing homes often due to family values and desires to care for them at home.<sup>101-103</sup> The influence of time also has significant value in caregivers' HRQOL as those who were in the role for a shorter duration often reported better HRQOL.<sup>104</sup> In an unpublished systematic literature review focused on effective interventions for African American and Hispanic Alzheimer's disease family caregivers, Lokensgard<sup>105</sup> reviewed 12 articles and found that there remains a need for cross-cultural support and interventions to promote quality of life, particularly among African American family caregivers. This finding is evidence of the need for further investigation of quality of life in a solely African American population.

### **Family Caregiver Self-Efficacy for Surrogate Decision Making**

Family caregiver self-efficacy is identified as a predictor for managing dementia symptoms.<sup>106</sup> Treatment decision making may have negative consequences for both the older adult with dementia as well as the family caregiver as surrogate decision maker.<sup>107</sup> Family caregiver self-efficacy for surrogate decision making measures the caregiver's confidence level in assuming the decision-making role.<sup>108</sup> Dementia family caregivers reported achieving a sense of self-efficacy when successful in advocating for and making decisions for their older adult with dementia.<sup>109</sup> Family caregiver self-efficacy for end-of-life decision making is important in understanding how caregivers adjust to the demands of caring for loved ones near the end of life.<sup>110</sup> Self-efficacy has the potential to influence changes in end-of-life decision making, which may result in improved end-of-life experiences. Yet, family caregivers do not always consider themselves competent to make end-of-life decisions for a loved one with dementia and the possibility of the imminent loss of a loved one makes the decision making all the more complex.<sup>42</sup> An individual's perceived self-efficacy is defined as beliefs about their capacity to exercise control over events that affect their lives, and influences how they feel, think, and act.<sup>111</sup> The concept of self-efficacy is integral to decision making and has previously been used to examine end-of-life issues in various populations.<sup>84,112-114</sup> African American family caregivers often lack understanding of values and goals of care for their loved ones.<sup>115</sup> Therefore, the level of perceived self-efficacy this population of family caregivers possess in order make surrogate end-of-life decisions, may provide useful information to potentially assist in understanding their ability to satisfactorily execute this difficult undertaking.



At least two recent studies focused on self-efficacy in dementia family caregivers.<sup>84,114</sup> In one study focused primarily on Caucasians, researchers provide evidence of higher perceived self-efficacy for surrogate decision making being associated with less uncertainty in decision making.<sup>114</sup> Bonner et al<sup>84</sup> found self-efficacy to be statistically significantly higher following an end-of-life intervention in a sample of African American dementia family caregivers. Higher levels of self-efficacy are expected to lead to improvements in physical and mental health and health-promoting behaviors in family caregivers.<sup>108</sup> Caregiver self-efficacy and coping strategies are key contributors to perceptions of caregiver burden and may influence coping mechanisms for addressing this encumbrance.<sup>116</sup> Hesitancy in decision making was also described as it relates to family caregiver uncertainty regarding when to intervene, the benefits and risks of treatment options, and illness trajectories.<sup>113</sup>

### **Formal and Informal End-of-Life Care Planning**

Formal and informal end-of-life decision making in patients with serious life-limiting conditions such as dementia should be a core aspect of their care. Informal plans involve talking to family members of persons with dementia and others about one's wishes<sup>117</sup> with oral/verbal plans being of particular importance to African Americans.<sup>118,119</sup> A finding of high numbers of care recipients with informal (oral/verbal) plans as opposed to formal plans was likely due to the literature supporting the decreased likelihood that African Americans prepare for the end of life.<sup>10-19</sup> Written plans often include end-of-life wishes or treatment decisions written informally, such as on a plain piece of paper (tucked away in a family Bible), and can be legally binding if evidence exists that the individual wrote it themselves, that they were competent to do so at that

time, and that there is no evidence that they changed their mind after writing it.<sup>120</sup> Formal plans are the preparation of legal documents known as advance care directives or living wills.<sup>117</sup> These documents are widely advocated as a mechanism for individuals to express preferences for life-sustaining treatments based on the assumption that they will improve family caregivers' comfort and accuracy with end-of-life decision making.<sup>114</sup>

Blacks cited mistrust and negative experiences as reasons for not completing formal advance care plans, for fear of receiving less care than Caucasian counterparts.<sup>10,20</sup> An example of this was found in a study conducted by Conner and Chase,<sup>60</sup> where Black family caregivers promised to carry out verbal/oral expressed wishes of loved ones in the absence of formal documentation. This leads to varying degrees of avoidance, lack of information sharing, and apprehension for fear of exploitation.<sup>121</sup>

### **Knowledge Gaps Related to End-of-Life Care Planning**

Based on a literature review of 28 studies on end of life in African Americans, evidence exists to support a need for improvements in end-of-life planning.<sup>10-19</sup> A recent 2016 Cochran Review<sup>122</sup> on end of life confirmed that there remains a need for end-of-life care pathways to guide effective end-of-life care and decision making. In addition to this, the high rates of dementia among African Americans serve as evidence of the need to address the outcome of end-of-life planning in this population.<sup>27</sup>

A goal of this study was to address knowledge gaps in the literature that focus on African American dementia family caregivers and end-of-life decision making. Dementia affects the quality of life of individuals with this disease as well as that of persons closest to them.<sup>36</sup> Therefore, it is important that family caregivers are included in such studies. Research on end-of-life decision making in African American older adults more often

occurs in the oncology,<sup>22,68,123</sup> and nephrology,<sup>124-128</sup> populations with only a few studies examining some aspects of this issue in dementia caregivers.<sup>84,128,129</sup> There remains a need for research specifically in this area conducted in this minority population.<sup>11,60</sup> Hence the focus of this dissertation study.

In a recent systematic integrated review of end-of-life planning among African Americans, Sanders et al<sup>130</sup> found that a majority of studies were moderate to low quality quantitative studies, focused primarily on advance directive completion. A smaller number of studies used qualitative analyses and helped to explain relationships between factors impacting end-of-life care.<sup>130</sup> According to Polit and Beck,<sup>131</sup> there is a need for higher level studies that build on previous qualitative findings. Studies in the literature reviewed by Sanders et al<sup>130</sup> often compared by race, particularly when secondary data analyses of large datasets were conducted. Additionally, use of quantitative data from large datasets can be deficient in some ways.<sup>131</sup> For example, they may not adequately address specific needs of a population such as African American dementia family caregivers. Data that are unrepresentative, inappropriate or poor quality can lead to inaccurate conclusions.<sup>132</sup>

### **Conceptual Framework**

Surrogate decision making is a difficult psychological task.<sup>133</sup> *The Dimensions Associated with Decision Making at the End of Life of a Relative with Dementia* is a theory of human action developed by Caron, Griffith and Arcand<sup>42</sup> using grounded theory methods of constant comparison and dimensional analysis. This framework arose from data collected from the perspective of dementia family caregivers related to end-of-life issues.<sup>42</sup> According to this theory, family caregivers' level of quality of life is central to

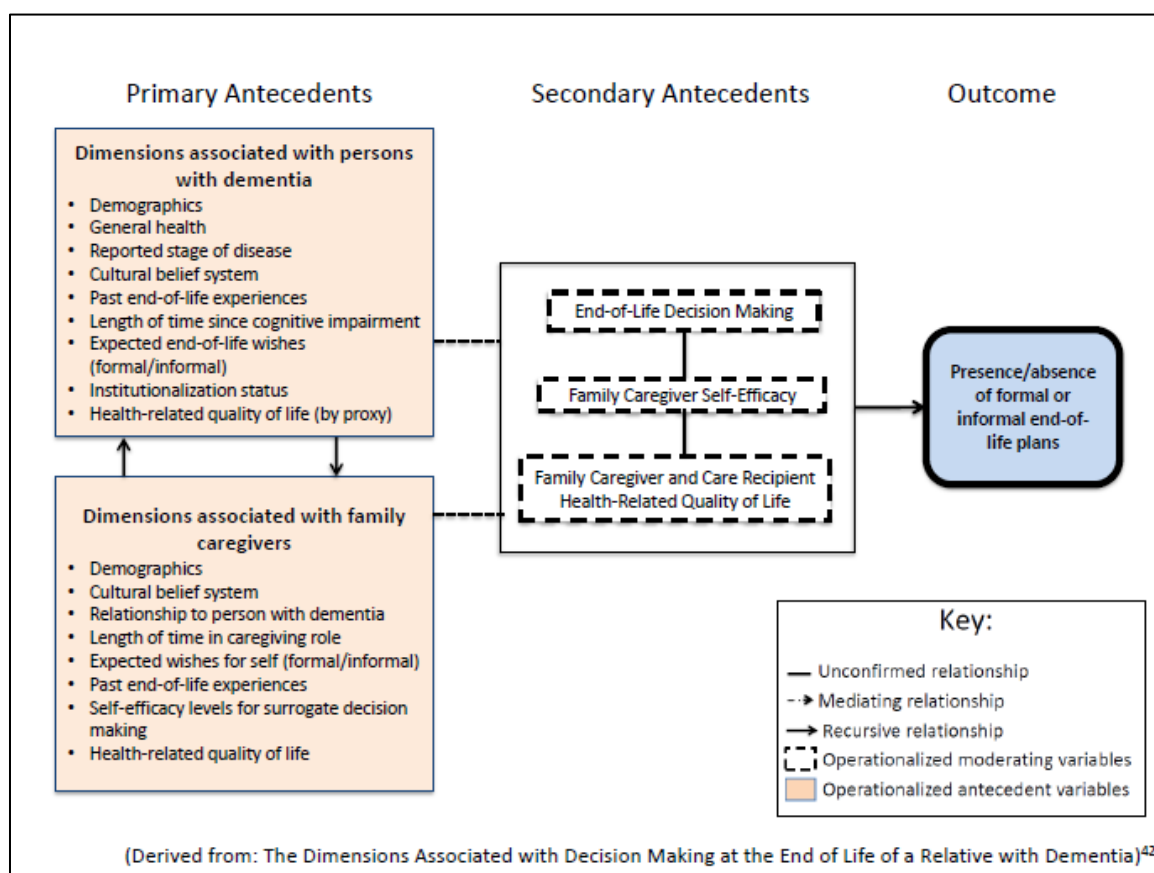
their end-of-life decision making for a loved one with dementia.<sup>42</sup> Quality of life that is in concert with the caregivers' perceptions of their role as decision makers creates a complex interplay whereby these decisions are made.<sup>42</sup> This theory of decision making consists of five dimensions of end-of-life decision making in dementia; 1) dimensions associated with the person with dementia; 2) dimensions associated with the family caregiver; 3) family context; 4) treatment; and 5) context of interaction with the medical team.<sup>42</sup>

The framework for this proposed study is focused on two of the dimensions which Caron et al<sup>42</sup> found to be involved in the decision-making process: 1) dimensions associated with the older adult with dementia, and 2) dimensions of the family caregiver. The Framework of End-of-Life Decision Making in Dementia by Family Caregivers will guide this proposed dissertation study (see Figure 1). Literature supports the use of this framework for end-of-life decision making as it provides a basis for improving plans for more effective healthcare outcomes inclusive of the provision of family-centered care.<sup>134</sup> It is imperative to personalize end-of-life care plans to meet individual and family goals of care.<sup>135</sup> Moreover, there remains a need to strengthen the overall understanding of ways to improve care provided to Black patients and families approaching death.<sup>5</sup> This is the essence of this research study and this framework provides a basis for understanding this outcome.

Primary antecedents in the Framework of End-of-Life Decision Making in Dementia by Family Caregivers each fall under either the dimension associated with the older adult with dementia or the family caregiver. Older adult dimensions include: demographics, general health status, reported stage of the disease, cultural belief system, past end-of-life experiences, length of time since cognitive impairment, wishes for end of

life (if any), institutionalization status and HRQOL. Family caregiver dimensions include: demographics, cultural belief system, relationship to the person with dementia, length of time in caregiving role, end-of-life wishes for self, past end-of-life experiences, self-efficacy for surrogate decision making and HRQOL.

**Figure 1. Framework of End-of-Life Decision Making in Dementia by Family Caregivers**



End-of-life decision making, HRQOL for both of the older adult with dementia (by proxy – via the family caregiver) and for the family caregiver themselves as well as family caregiver self-efficacy for surrogate decision making were examined in this study. It is hoped that a successful outcome would better prepare family caregivers for the care recipient's end of life, improve satisfaction with care received near the end of life by the

older adult with dementia and subsequently enable family caregivers to prepare for their own end of life in a manner that will be pleasing to them and their family members. The Framework of End-of-Life Decision Making in Dementia by Family Caregivers includes specific data collected via qualitative descriptive methods as well as HRQOL and self-efficacy variables that were measured via quantitative methods. This mixed methods study used a descriptive, correlational design to explore two aims.

### **Specific Aims**

Based on findings from the review of literature, the **specific aims** of this pilot study were to: 1) capture end-of-life decision making for African American older adults with dementia by their family caregivers, including understanding and use of terminology; and 2) determine if the presence of formal or informal end-of-life care plans for older adults with dementia was associated with higher or lower HRQOL in older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making.

Because this study is a pilot study, it primarily examined trends and effect sizes.<sup>131</sup> However, it was hypothesized that, higher rates of formal or informal end-of-life care plans for older adults with dementia would be associated with lower HRQOL for older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making. The following care recipient characteristics were taken into account: age, number of comorbidities, length of time since diagnosis of cognitive impairment, institutionalized or non-institutionalized status. Comorbid conditions along with dementia are associated with increased mortality.<sup>136</sup> Additionally, older adults tend to have more comorbid conditions.<sup>137,138</sup> According to the National Institute on Aging,<sup>56</sup> the time period

from diagnosis to death from dementia can range from 3 to 10 or more years. Increased age and institutionalization status are associated with having an end-of-life care plan.<sup>139,140</sup> In addition, the following family caregiver characteristics were taken into account: age, education level, income level, and length of time in caregiving role. About one third of dementia family caregivers are 65 years or older, and are sometimes themselves faced with failing health.<sup>27</sup> This may potentially lead family caregivers to consider aspects of end-of-life planning for themselves, and subsequently for their care recipients. Socioeconomic status is often measured as a combination of education, income and occupation and has the potential to affect end-of-life decision making and quality of life.<sup>141</sup> The American Psychological Association recommends including measurements of socioeconomic status in all research, particularly those involving end-of-life and/or minorities.<sup>141</sup> Socioeconomic status of the family caregiver in this study may be an indicator of that of the care recipient, though this association is not assumed. According to Caron, Griffith and Arcand, in the *Dimensions Associated with Decision Making at the End of Life of a Relative with Dementia*,<sup>42</sup> care recipient general health and quality of life were also described as elements influential to the decision-making process. Also included in this framework were ‘schemes of reference’ of the family caregiver.<sup>42</sup> While these schemes of reference were not clearly defined by the framework’s authors due to space limits in the paper, the length of time in the caregiving role was considered a potential influencer to the family caregiver. Therefore, these variables were thought to potentially be influencers for end-of-life planning.

### **CHAPTER THREE: STUDY METHODS**

Dementia family caregivers are the participants in this study. Throughout this dissertation, family caregivers are considered the surrogate or proxy decision makers for persons with dementia and as such the terms are often interchanged. The older adult being cared for is referred to as the care recipient. As such, all data were collected from the family caregiver via self-report. No data were retrieved from the older adults with dementia themselves, nor was this permissible in accordance with the Institutional Review Board's (IRB) approvals as this was not part of the aims of this research study. The specific aims of this research study were to: 1) capture end-of-life decision making for African American older adults with dementia by their family caregivers, including understanding and use of terminology; and 2) determine if the presence of formal or informal end-of-life care plans for older adults with dementia was associated with higher or lower health-related quality of life in older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making.

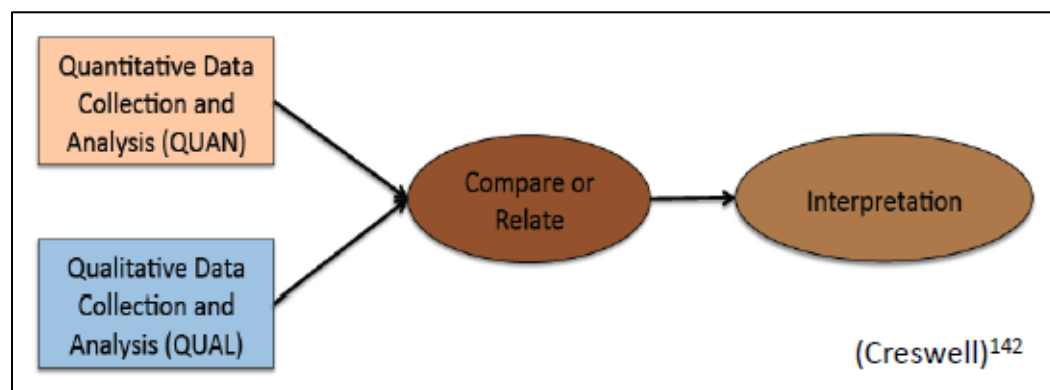
#### **Research Design**

This study was a descriptive, correlational, pilot study. A mixed methods approach was used to address the specific aims of this research study. The convergent parallel, mixed methods design was used to collect both qualitative and quantitative data at a single time point (see Figure 2).<sup>142</sup> A mixed methods approach is useful in providing a more complete understanding of changes needed for marginalized populations.<sup>142</sup> In the first phase a descriptive design informed by Miles and Huberman's<sup>1</sup> methods for qualitative analyses were used for content and thematic analyses of responses to semi-structured interview questions from the Interview Guide (see Appendix A). Only a subset



of the study population completed interviews until thematic saturation was achieved via data analyses. In the second phase, a correlational design was used to determine if the presence of formal or informal end-of-life care plans for older adults with dementia was associated with higher or lower health-related quality of life (HRQOL) in older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making. Both sets of data were collected at the same data collection point. Together, the interpretation of results using these two methods of investigation provided better insight as to how African American family caregivers approached end-of-life planning for their older adult care recipient. Reasoning for use of a qualitative approach provided insight for the researcher regarding family caregiver understanding of end-of-life terminology and the quantitative approach, using survey data, was complementary and verified family caregivers' assessment of the older adult's HRQOL, and how confident family caregivers were in making these end-of-life decisions.

**Figure 2. Convergent Parallel Mixed Methods Design**



In the past, a majority of studies that examined the issue of end of life in African American older adults did so from a racially comparative perspective using solely quantitative methods or only qualitative methods, each method providing limited insight into the underlying phenomenon of decision-making processes that families use. Within

the African American diaspora, social variables may differ and can contribute to within-group differences.<sup>72</sup> Therefore, further research using a different approach is warranted.

### **Specific Aims**

The specific aims of this study were to: 1) capture end-of-life decision making for African American older adults with dementia by their family caregivers, including understanding and use of terminology; and 2) determine if the presence of formal or informal end-of-life care plans for older adults with dementia would be associated with higher or lower HRQOL in older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making. The following care recipient characteristics were taken into account: age, number of comorbidities, length of time since diagnosis of cognitive impairment, and institutionalized or non-institutionalized status. In addition, the following family caregiver characteristics were taken into account: age, education level, income level, and length of time in caregiving role.

**Specific Aim 1:** To accomplish the first aim, semi-structured interview questions were used to capture end-of-life decision making for African American older adults with dementia by their family caregivers, including meaning, understanding and use of terminology. Interviews lasted from 6 to 34 minutes. The Interview Guide consisted of the following 10 questions and two closure questions that were used to guide the interview:

- 1) How do you know when you need to make a decision for [your family member] with memory impairment?
- 2) How do you obtain information to make an informed decision?

- 3) How do you weigh the risks and benefits of various treatment options (e.g., use of breathing machines, feeding tubes, antibiotics, IV fluids, CPR, chest compressions, tests or procedures, surgeries)?
- 4) How capable do you feel that you will make the best decisions for [your family member] with memory impairment?
- 5) If the point came in which [your family member] was not able to express his/her preference for treatment, how would you know what treatment options [your family member] would choose?
- 6) Healthcare providers (nurses and doctors) often use the term '*end of life*.' What does this term mean to you?
- 7) When you hear the term '*end of life*', do you automatically think of before death, or after death, (or both)?
- 8) They often use the terms '*advance directive*' or '*living will*.' What do these terms mean to you?
- 9) What does '*quality of life*' mean to you?
- 10) How would you rate your quality of life? And that of your loved one?

The following two questions were used for closure following the session:

- a. What advice would you give to other family caregivers who are in a position similar to yours?
- b. What advice would you give to healthcare providers who care for people with memory impairment as their family members?

**Specific Aim 2:** The second aim sought to determine if the presence of formal or informal end-of-life care plans for older adults with dementia was associated with higher

or lower HRQOL in older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making. A correlational design was used to examine trends and effect sizes.<sup>131</sup> Covariates for determining the effect included the following care recipient characteristics: age, number of comorbidities, length of time since diagnosis of cognitive impairment, and institutionalized or non-institutionalized status. Covariates for family caregiver characteristics included: age, education level, income level, and length of time in caregiving role.

### **Setting and Recruitment**

Recruitment for this study included dementia family caregivers of all ethnic backgrounds within the African American/Black diaspora in the US. They were recruited from within older adult care facilities and communities across the Commonwealth of Virginia and via Program of All-Inclusive Care for the Elderly (PACE) Programs managed by Riverside Health System Center for Excellence in Aging and Lifelong Health. PACE is a Medicare program and state option for Medicaid that provides community-based nursing home level of care to persons at least 55 years of age.<sup>143</sup> If the older adult has Medicaid, they do not pay for services.<sup>143</sup> However, if the older adult has Medicare and does not qualify for Medicaid, they are required to pay a monthly premium for services.<sup>143</sup> Persons enrolled in PACE Programs are usually non-institutionalized, that is, they reside at home with their loved ones. This was the case for all PACE care recipients referenced in this study. The PACE sites accessed for this study are located in Charlottesville, Hampton Roads, and Richmond, Virginia, most of which include large numbers of African American participants (see Appendix B). Family caregivers of African American older adults with dementia were recruited by identification of potential

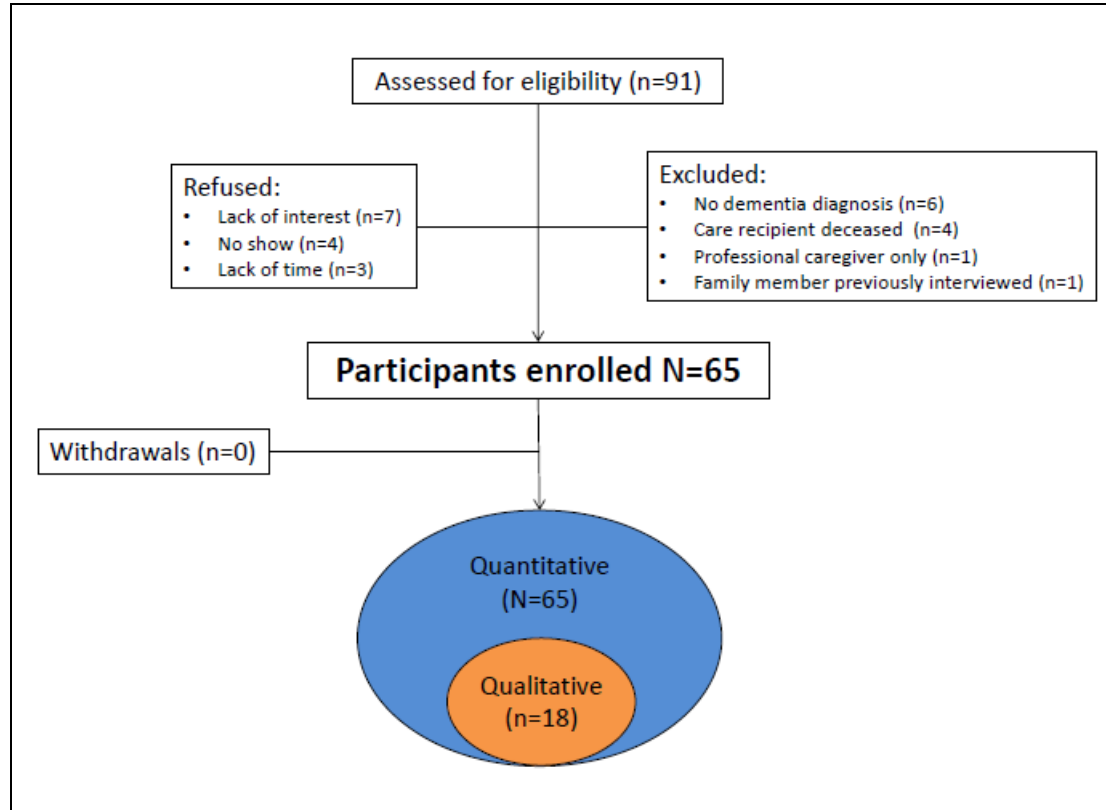
participants enrolled in PACE Centers, community events/health fairs, as well as via snowball methods in the community (e.g., personal referrals). IRB-approved fliers (see Appendix C) were distributed at community events, such as health fairs. Such events were most often associated with primarily African American communities. The researcher, a volunteer with the Alzheimer's Association, often hosted a booth representing this organization, and shared information on services offered for persons with dementia and their caregivers at these events. Additionally, IRB-approved recruitment invitations shared via email (see Appendix D) were distributed to community partners and potential participants. Data collection of all required documents was performed at an identified location chosen by the caregiver. This was most often the caregivers' homes. Recruitment occurred over a period of 11 months (February – December 2015).

Community partners assisted with recruitment efforts and were often social workers, or admissions coordinators, center directors or nurse managers of a PACE Program. Pastors, pastor's wives, hair stylists, adult daycare center or nursing home directors, and Alzheimer's Association partners were also key community partners. All community partners received a note of thanks via email or text message (see Appendix E) per their preference at study closure also alerting them of the need to no longer recruit potential participants as well as thanking them for assisting the researcher with this process.

### **Sample and Sampling Plan**

The unit of analysis was an individual family caregiver of an African American older adult with dementia. A convenience sample of 91 African American older adults

with dementia was assessed for participation in the study. Of the 91, 14 family caregivers declined to participate, and another 12 did not meet the study inclusion criteria, leaving 65 who were enrolled in the study. Attrition rate was zero (see Figure 3). Eligibility criteria were that the family caregiver: 1) self-identified as African American/Black; 2) was at least 21 years old; 3) was an “assigned” family caregiver (as identified by the family caregiver) to an African American/Black older adult with a diagnosis of dementia (as reported by the family caregiver) who was 55 years or older at the time of study enrollment; and 4) possessed the ability to read, speak and understand the English language. Exclusion criteria were: 1) if the family caregiver possessed any form of cognitive impairment as determined via self-report during the screening and consenting process; 2) if the older adult care recipient was acutely hospitalized with a life threatening illness; and 3) if the older adult care recipient was actively dying (see Appendix F). Rationale for the lower age limit of the care recipient was because 55 years of age is the requirement for participation in PACE programs,<sup>143</sup> as these sites were used for recruitment of study participants. No upper age limit for the care recipient was mandated since there was a lower age limit of 55 years. Lastly, attempts to conduct this study in family caregivers who were actively involved in an acute hospitalization or the dying process of the older adult care recipient were excluded as the study could have posed additional undue burden on the family caregiver during a time most often characterized by extreme physical and emotional stress.

**Figure 3. Participant Flow Chart**

### Power Analysis of the Sample

**Specific Aim 1:** For the qualitative analysis, the concept of data saturation was used, at which point no new themes or information emerged from data collected.<sup>144</sup> Based on research conducted by Guest et al<sup>144</sup> it was estimated that approximately 12-20 participants would be required to complete the qualitative interviews. A total of 18 participant interviews ( $n=18$ ) were included in this study (see Figure 3).

**Specific Aim 2:** Power analyses were conducted using nQuery 7.0 Software.<sup>145</sup> First,  $t$ -tests were performed, comparing both the mean HRQOL of the older adult with dementia and the mean family caregiver self-efficacy for surrogate decision making, over the two groups: those with and without an end-of-life care plan. Estimates of the proportion of African Americans who have an end-of-life care plan vary. A nationally

representative sample estimated a 51.5% completion rate for a signed durable power of attorney or a living will in African Americans.<sup>118</sup> With that proportion, a sample size of  $N=129$  (66 with a plan, 63 without) would have 80% power to detect a medium effect size of 0.5 in a two-sided, two-group *t*-test at the 0.05 level of significance.<sup>146</sup> On the other hand, Johnson, Kuchibhatla, and Tulskey<sup>24</sup> used a sample of persons who were receiving care at a primary care clinic and estimated that 35.5% of African Americans had a durable power of attorney or living will. Using that proportion, a sample size of 141 (50 with a plan, 91 without) would have 80% power to detect a medium effect size of 0.5 in the same *t*-test.<sup>146</sup> For this pilot study, such large samples were not possible, and a sample of 65 was enrolled in an 11-month period due to limited resources and time.

The *t*-tests were followed by logistic regressions to see if the relationship between the two continuous variables above and the dichotomous outcome (end-of-life care plan: Yes/No) was affected by the presence of certain covariates. Harrell<sup>146</sup> provides guidance for a fitted regression model to be reliable: that for each predictor in the model there should be at least 10 to 20 observations having the less frequent outcome. For the specific outcome used—written end-of-life care plan reported (Yes/No)—41 of the 65 in the sample reported such a plan, 24 did not. Harrell's<sup>146</sup> guideline was stretched and three predictors were included in the models.

### **Instruments**

All 65 study participants were asked to complete the Family Caregiver Information Form (FCIF), Documentation Form of End-of-Life Care Plans (DF-EOLCP), Alzheimer's Disease Related Quality of Life (ADRQL), Short Form Health Survey-36 version 2 (SF-36v2) and the Surrogate Decision Making Self-Efficacy Scale (SDM-SES)



instruments (see Appendix G, H, I, J, K). A subset of 18 participants ( $n=18$ ) responded to questions from the Interview Guide prior to form completion.

The **Family Caregiver Information Form (FCIF)**, developed by the researcher, was used to obtain self-report demographics for both the family caregiver and the older adult with dementia. The following information was obtained about the care recipient: relationship to the family caregiver, age, gender, ethnicity, comorbidities, and length of time since diagnosis of cognitive impairment and the presence of formal or informal end-of-life care plans. Information about the family caregiver included: age, gender, ethnicity, income level, marital status, level of education, employment status, type of insurance, living arrangements, length of time as a caregiver, and presence of formal or informal end-of-life care plans for self. Completion time for this instrument was approximately 10 minutes.

The **Documentation Form of End-of-Life Care Plans (DF-EOLCP)**, developed by the researcher, captured self-report data regarding various forms of end-of-life care plans. The presence of informal handwritten or typed documents would indicate having a plan once it could be confirmed that the older adult completed/signed the document and had the capacity to do so at that time.<sup>120</sup> Determining if the older adult with dementia had capacity for decision making was determined to be true if the document was notarized by an attorney. There were no reports of informal handwritten or typed documents possessed by any of the care recipients referenced in this study. The presence of *informal end-of-life care plans* referred to any evidence provided to suggest verbalized (oral) plans related to continuing or stopping medical care for the older adult with dementia based on desires expressed by the older adult care recipient or the family.<sup>117</sup> *Formal end-of-life care plan*

*documents* referred to any of the following completed documents containing plans related to continuing or stopping medical care for the older adult with dementia: advance directive, living will, Do Not Resuscitate (DNR) or Physician Order for Scope of Treatment (POST) form or any other document outlining end-of-life care plans. *Formal documents of agency* referred to the existence of a Power of Attorney/Health Care Surrogate (POA/HCS), or any other document designating decision making power to another individual. Family caregivers were asked to indicate the existence of any such documents on this form. Approximate completion time was 5 minutes.

The **Alzheimer's Disease Related Quality of Life** (ADRQL) is a 40-item proxy-based instrument that asks family caregivers to rate the HRQOL of their care recipient with dementia using a 2-week recall. This behavior-based instrument was used to assess HRQOL for persons with dementia by their family caregivers. The ADRQL assesses five domains (subscales) of HRQOL: social interaction, awareness of self, feelings of mood, enjoyment of activities and response to surroundings.<sup>147</sup> The total scale value is derived from all of the responses.<sup>147</sup> The ADRQL was developed by systematic involvement of panels of family caregivers, health care professionals who provide care to people with Alzheimer's disease as well as national experts in the field.<sup>147</sup> It has been used in the past for family caregivers to assess HRQOL in individuals with Alzheimer's disease across all stages of the disease as well as other types of dementia.<sup>147</sup> Each item is a statement about the person with dementia and the respondent was asked to check Agree or Disagree.<sup>147</sup> Items have different assigned weights.<sup>147</sup> A positive HRQOL response is given an item score equal to the item weight, and these scores are summed.<sup>147</sup> The scale score is the 100 times the sum divided by the maximum possible scale score.<sup>147</sup> Scale and subscale scores

range from 0 to 100, with higher values corresponding to greater quality of life for the person with dementia.<sup>147</sup>

A sample of individuals diagnosed with dementia residing in nursing homes ( $n=89$ ), the community ( $n=146$ ), and assisted living facilities ( $n=134$ ) was used for the psychometric analysis of this instrument.<sup>147</sup> Item internal consistency was 67.5%.<sup>147</sup> Reliability coefficients varied across subscales but were above 0.70 for the total ADRQL.<sup>147</sup> Cronbach's alpha was 0.86.<sup>147</sup> Internal consistency was good overall (by subscale and across settings).<sup>147</sup> Construct validity was supported by the instrument's ability to discriminate among individuals based on responsiveness, physical function, and cognitive function, and behavior.<sup>147</sup> Predictive validity was determined by older adults with dementia who died within three years of baseline, having significantly lower overall mean scores than did survivors.<sup>147</sup> Very low numbers of missing data were found in the results.<sup>147</sup> One of the indications for use of the ADRQL is specifically to improve end-of-life care and decision making.<sup>147</sup> Completion time was approximately 15 minutes for this instrument.

The **Short Form Health Survey-36 version 2** (SF-36v2) instrument measured family caregiver's HRQOL using a 4-week recall. This 36-item instrument measures eight dimensions of the physical and mental aspects of HRQOL: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health.<sup>148</sup> The SF-36v2 items uses a norm based scoring system (mean=50, SD=10) and the Likert method of scoring.<sup>149</sup> Higher scores indicate a higher HRQOL.<sup>150</sup> Each item is used to score only one subscale. Responses for each of the questions differ and provide the meaning of each of the scores at the low and high levels. This instrument

was scored as instructed by the developer using developer software. The SF-36v2 can be administered to anyone from age 14 to 18 years or older yielding a high level of data quality within approximately 5-10 minutes.<sup>33,148</sup> A favorable response consistency index and completion rates is based on 15 pairs of items from the instrument.<sup>150</sup> Across a demographically diverse population, an 88% to 95% completion rate was obtained with this instrument.<sup>151</sup> Cronbach's alpha coefficient was used to estimate internal-consistency reliability for each score.<sup>151</sup> Reliability scores for the SF-36v2 instrument exceed the standard of 0.80 for each of the eight domains, excluding social functioning which had a median reliability of 0.76.<sup>152</sup> McHorney et al<sup>151</sup> measured reliability in a demographically diverse group of individuals and reported coefficients of 0.65 to 0.94 across the scales of the measure. A total of N=1,014 persons with minor medical conditions ( $n=683$ ), serious medical condition ( $n=168$ ), psychiatric conditions only ( $n=163$ ), and psychiatric and serious medical conditions ( $n=45$ ) were assessed.<sup>153</sup> Using the test-retest method, reliability coefficients ranged from 0.77 to 0.94. This instrument demonstrated 80% to 90% of its empirical validity in studies meeting both the mental and physical health criteria.<sup>150,153</sup> Factor analysis revealed physical and mental health factors that account for 80% to 85% of reliable variance across all domains.<sup>152</sup> Completion time was approximately 10 minutes. Results from this analysis of this instrument will be reported in a future study.

The **Surrogate Decision Making Self-Efficacy Scale (SDM-SES)** was used to score self-efficacy levels for surrogate decision making in family caregivers. This is a 5-item Likert rating scale to assess perceived self-efficacy for surrogate decision making in the caregiver of an older adult. The dimensions in this scale include: (a) knowing when to

make decisions, (b) ability to obtain information to make informed decisions, (c) ability to weigh risks and benefits of treatment options, (d) ability to make the best treatment decisions, and (e) knowing what treatment options the individual with memory impairment would select.<sup>107,114</sup> Scores range from (1) strongly disagree, (2) disagree, (3) agree, to (4) strongly agree. The SDM-SES scale score is the mean of the 5-item scores and can range from 1 to 4, with higher scores being indicative of more perceived self-efficacy for surrogate decision making.<sup>114</sup> Psychometric evaluation of this instrument examined content validity using three gerontological nurse experts who pilot tested the instrument and achieved a Fleiss' kappa of 0.90 and reported that the instrument was an accurate, relevant and credible measurement of self-efficacy for surrogate decision making.<sup>114</sup> Confirmatory factor analysis, using the Amos 19 Likelihood Program, was used to obtain support for construct validity within the sample of 155 surrogates.<sup>107</sup> The chi-square result for the one-factor model was significant ( $\chi^2=6.85$ ;  $p=0.03$ ). Comparative Fit Index (0.99) and Tucker-Lewis Index (0.98) resulted in high goodness of fit.<sup>107</sup> On the single factor model, all items had statistical and practical significance, ranging from 0.63 to 0.86.<sup>107</sup> The readability index of the instrument was measured using Flesch-Kincaid and the grade level was determined to be 7.6.<sup>107</sup> The response rate for completion of the instrument was reported to be 30%, as 155 of 500 surrogates completed and returned the survey administered via mail. Mean item scores ranged from 3.20 to 3.28 and standard deviations were 0.58 to 0.64.<sup>107</sup> Skewness and a 95% confidence interval were also calculated for each item.<sup>99</sup> The Cronbach's alpha coefficient was calculated at 0.87, suggesting that all five items measured the same underlying construct.<sup>107</sup> Approximate completion time was 5 minutes.

## **Procedures**

The researcher served as the study nurse. Approvals from the UVA IRB-Social and Behavioral Sciences (SBS) section and Riverside Health System Center for Excellence in Aging and Lifelong Health were obtained prior data collection.

### **Researcher Procedures**

The following initial steps were followed by the researcher: 1) PACE sites provided a listing of potential family caregivers' contact information to the study nurse, indicating family caregiver provision of permission to be contacted for this study, 2) IRB-approved fliers were shared with community partners, and 3) the researcher contacted family caregivers either in person or via telephone to inquire about their potential interest in participating in the study.

### **Participant Procedures**

The following participant procedures were taken: 1) once the family caregiver agreed to participate, a date and time for consent form completion and data collection was scheduled, 2) participants completed either the UVA or Riverside Health System Center for Life Long Health consent form (depending on which site they were recruited from), and Contact Information form (see Appendix L, M & N), 3) Interview Guide was completed (only for a subset of participants until thematic saturation was reached  $n=18$ ), 4) the FCIF, DF-EOLCP, ADRQL, SF-36v2 and SDM-SES forms and instruments were completed, 5) all interviews were recorded using two digital recording devices, 6) a leisure break (with or without refreshments) was offered prior to the start of the interview, 7) once thematic saturation was reached for the interviews, all additional participants were asked to complete only the FCIF and DF-EOLCP followed by the

ADRQL, SF-36v2 and SDM-SES instruments, 8) following data collection, each participant was compensated for his or her time and participation with a \$10 Walmart gift card along with a thank you letter (see Appendix O). A Debriefing Form (see Appendix P for UVA-specific form and Appendix Q for Riverside Health System-specific form) was provided outlining how they were chosen to participate in the study, if required, follow-up instructions were provided at this time, 9) following data analysis, a letter briefly outlining the study findings in layman's terms was mailed out to each family caregiver, as they all indicated that they wished to receive a copy, 10) Study findings (in aggregate form) were shared with leaders at Riverside Health System Center for Excellence in Aging and Lifelong Health, 11) participants who demonstrated emotional distress were offered the opportunity to discontinue the interaction and to exit the study, 12) they would have been provided a letter of thanks (See Appendix R) and connected to their primary health care provider via an immediate, investigator initiated phone call for treatment to address any emotional needs or additional follow-up care, 13) Appendixes S, T, U, and V contain the enrollment, refusal, ineligibility and incentive logs used in this study and were completed throughout the study.

The Study Schema (see Table 1) outlines the study measures by time point. The maximum total time required for participation of the family caregiver was estimated at 105 minutes. If family caregivers were not required to participate in the interview, the total time needed for study participation was reduced to 60 minutes. However, meeting times with participants lasted as long as 3.5 hours (with interviews) and as long as 2 hours (without interviews). Time use was at the discretion of both the participant and researcher. Interview data were analyzed as outlined in the next section.

**Table 1. Study Schema of Participants and Measures by Time Points**

| Person/Measure   | Administration Time | Screening | Recruiting | Consenting | Data Collection |
|--|---------------------|-----------|------------|------------|-----------------|
| <b>STUDY NURSE</b>   |                     |           |            |            |                 |
| Review of Patient Demographics                                     | 15 min              | x         |            |            |                 |
| Inclusion/Exclusion Criteria Form                                  | 2 min               |           | x          |            |                 |
| <b>FAMILY CAREGIVER</b>  |                     |           |            |            |                 |
| Family Caregiver Consent Form                                      | 15 min              |           |            | x          |                 |
| Family Caregiver Information Form (FCIF)                           | 10 min              |           |            |            | x               |
| Documentation Form of End-of-Life Care Plans (DF-EOLCP)            | 5 min               |           |            |            | x               |
| Interview Process  | 45 min              |           |            |            | x               |
| Alzheimer's Disease Related Quality of Life (ADRQL)                | 15 min              |           |            |            | x               |
| Short Form Health Survey (SF-36v2)                                 | 10 min              |           |            |            | x               |
| Surrogate Decision Making Self-Efficacy Scale (SDM-SES) Instrument | 5 min               |           |            |            | x               |

Total time for family caregiver = 105 minutes

Total time for family caregiver (without interview) = 60 minutes

### **Data Analysis Procedures**

**Specific Aim 1:** Semi-structured interviews were conducted until saturation of themes occurred. Data collection using the FCIF and DF-EOLCP forms and ADRQL, SF-36v2 and SDM-SES instruments for the remaining participants continued until 65 participants were enrolled. For the qualitative approach, a descriptive design using content and thematic analysis was initially used to examine tenets of naturalistic inquiry of thoughts, feelings and attitudes.<sup>154</sup> These analyses were informed by Miles and Huberman's<sup>1</sup> methods of qualitative analyses.

Interviews were conducted until thematic saturation was achieved resulting in a total of 18 interviews ( $n=18$ ). Participants were asked permission to audio record and were informed that it was the researcher's intention to speak minimally during the



interviews so as to allow their words to be captured more so. They were also informed that the researcher may write down a few notes using pen and paper (field notes) during the interview. Interviews were audio recorded using two independent recording devices to ensure accuracy and avoid technological glitches from interrupting data collection. Data were transcribed verbatim via Accutype Transcription, a vendor whose services are approved for use by the UVA's IRB. The researcher then re-verified the transcripts along with the recorded interviews to make corrections and clarify misunderstood words spoken. Once transcripts were verified, transcriptions and audio were uploaded into Dedoose for further analysis. Dedoose® Version 6.1.18, is a web application for managing, analyzing, and presenting qualitative and mixed method research data.<sup>155</sup> Informational redundancy and reflexivity were strategies used to enhance trustworthiness of the findings.<sup>156,157</sup> Once all data were verified, digital recordings on both devices were erased.

Qualitative data analysis was iterative. As described by Miles and Huberman's<sup>1</sup> methods of qualitative analyses, data were reduced, displayed, and concluded/verified. Based on experiences with the initial interviews, the researcher became aware of the need to restate questions when indicated, based on the ability of the participant to understand questions being asked. This was a necessary step to ensure participants were able to clearly interpret what was being asked of them. This change in data collection was done to achieve better understanding, therefore increasing internal validity. An example of this was the addition of a question asking family caregivers if their understanding of the term *end-of-life* refers to 'before death', 'after death', or 'both'. This additional question helped to reveal pivotal information regarding understanding of this term.

Coding was achieved both deductively from variables the researcher brought to the study and inductively through emergence from data.<sup>1</sup> Three cycles of coding were conducted. The first cycle was conducted using Dedoose and used descriptive coding and assigned labels to data by summarizing using a word or short phrase.<sup>1</sup> Deductive coding also was used as some codes were already predetermined in the mind of the researcher as data were approached.<sup>1</sup> This was also based on researcher experiences with data collection as the sole interviewer which enabled familiarity with and closeness to these data, as well as understanding. Still, other codes emerged from data. For example, the many types of resources, as well as caregiver experiences with these resources, were coded as transcripts were analyzed.

The second round of coding was more explanatory in nature and was conducted using holistic coding methods.<sup>1</sup> Using this method, larger units of data were grouped and helped with contextual understanding.<sup>1</sup> Along with both of these methods, analytical memos were made in Dedoose to remind the researcher of details, such as the context surrounding data extracted. Noting when a participant was being sarcastic or when emotions such as sadness or crying were observed were examples of this. For the third round of coding, data were printed onto hardcopy and reanalyzed using paper, pen and highlighters. These additional memos were made onto the hardcopy as necessary. With each round of coding, codes became more refined, were rearranged, and reclassified.<sup>158</sup> From these, data were then displayed using a variety of methods as will be described in the results section (Chapter IV).

The researcher consulted with qualitative and mixed methods research experts who served as dissertation committee members. Member checking with two participants

was used to verify if understanding of data rang true to them.<sup>157,159</sup> A letter to participants outlining study results was shared with key participants beforehand to ensure ease of understanding of results prior to dissemination to all participants.

**Specific Aim 2:** Data analyses were conducted using SPSS Statistical Software® Version 23 (see Table 2).<sup>160</sup> Data sources were the FCIF, DF-EOLCP, ADRQL, SF-36v2 and the SDM-SES. Descriptive statistics were used to describe the characteristics of the sample. Prior to any regressions, *t*-tests were performed to compare mean HRQOL for the older adults with dementia and the mean family caregiver self-efficacy level between the two groups of participants (those with end-of-life care plans and those without a plan). Bivariate tests were conducted (*t*-tests/chi-square tests/Mann-Whitney U) between the outcome variable of having an end-of-life care plan (Yes/No) and each of the following covariates under consideration for the care recipient characteristics: age, number of comorbidities, length of time since diagnosis of cognitive impairment, and institutionalized or non-institutionalized status. Family caregiver characteristics were also examined as covariates: age, education level, income level, and length of time in caregiving role. The eight covariates were selected based on findings from the literature.<sup>27,42,56,136-141</sup> Logistic regressions were used to estimate the effect of the two factors: HRQOL of the older adult with dementia and family caregiver self-efficacy for surrogate decision making, on rates of formal end-of-life care plans for older adults with dementia, while controlling for eight covariates listed above. Covariates for family caregiver characteristics were controlled as well: age, education level, income level, and length of time in caregiving role. A series of eight logistic regressions were carried out with the dependent variable in each model being existence of an end-of-life care plan

(Yes/No). With 41 family caregivers in the sample with a formal plan, and 24 without, the number of predictors in each regression was limited to three. Each model included the older adult with dementia's HRQOL and family caregiver self-efficacy level as predictors, plus one of the eight covariates. Two-tailed tests at the 0.05 level of significance were used in all cases.

Qualitative and quantitative data were analyzed separately and then brought together in a side-by-side comparison. Both types of data were compared and related to how each provided further explanation for the other as outlined in the results section (Chapter IV).

**Table 2. Approach for Quantitative Analyses (N=65)**

| Hypothesis   | Outcome Variable   | Independent Variables   | Covariates to be Adjusted  | Analysis Methods   |
|--|--|---|--|--|
| <u>Higher</u> rates of formal or informal end-of-life care plans for older adults with dementia will be associated with <u>lower</u> health-related quality of life for older adults with dementia and with <u>greater</u> family caregiver self-efficacy for surrogate decision making. | Existence of formal (written) end-of-life care plan (Yes/No) | <ul style="list-style-type: none"> <li>Family caregiver's appraisal of <u>HRQOL</u> of the older adult</li> <li>Perceived <u>self-efficacy</u> level for surrogate decision making</li> </ul> | <u>Care recipient characteristics:</u> <ul style="list-style-type: none"> <li>age</li> <li>number of comorbidities</li> <li>length of time since diagnosis of cognitive impairment</li> <li>institutionalized/non-institutionalized status</li> </ul> <u>Family caregiver characteristics:</u> <ul style="list-style-type: none"> <li>age</li> <li>educational level</li> <li>income level</li> <li>length of time in caregiving role</li> </ul> | Bivariate tests: t-test/ Chi-Square/ Mann-Whitney U<br><br>Logistic Regression |

### **Ethical Considerations: Human Subject Protection**

The potential risks for participants in this study were minimal. Due to the psychological risk of being enrolled in this study because of the sensitive nature of end-of-life discussions, there was a potential for added caregiver burden. To assist in reducing this risk, the study design/procedures were flexible and data collection was conducted at a

time and location that was convenient for the family caregiver. All interviews were conducted face-to-face (in person) so as to ensure that authentic communication was achieved and accurate information captured. Family caregivers were encouraged and allowed to take breaks (with refreshments) at their discretion during the consenting and interview process. They were free to check on their older adult loved one as often as they desired. Participants were informed of their right to withdraw from the study at any time without repercussion. If the older adult was a participant/resident of an older adult care facility, the family caregiver was reassured that withdrawing from the study would not affect care their loved one with dementia received. Any participant who exhibited signs of psychological or physical distress during the interview was given the opportunity to exit the study and be connected to their primary health care provider via an immediate, investigator initiated phone call for treatment to address any emotional needs or additional follow-up care. However, no participant withdrew.

### **Recruitment and Informed Consent**

Recruitment of family caregivers for research can be a challenge. Layer on the variable of time and intricacies of research participation challenges among African Americans because of their distrust/mistrust in the healthcare system, and this challenge may increase substantially.<sup>84,161-166</sup> To address this, PACE was identified as a primary recruitment organization and permission for recruitment was obtained via their IRB. Snowball methods, reduced lower age limit (than the Medicare standard of 65 years) of 55 years for the older adults per PACE enrollment,<sup>143</sup> excluding an upper age limit for the care recipient, flexibility with interview times/locations, ensured researcher presence at

sites for recruitment and including an honorarium were strategies used to assist in offsetting this challenge.

Informed consent for this study was obtained from the family caregiver. After obtaining IRB approval from both the UVA and Riverside Health System Center for Excellence in Aging and Lifelong Health, the protocols were strictly followed. Specifically, the consenting process was carried out as outlined in the protocols. Withdrawal from the study remained an option for participants throughout the course of the study.

The importance of this study (benefits to society) was explained. While participants were required to read and understand English, the researcher was consistently available to assist with reading and understanding of all study documents. Participants were made aware of and permissions sought for interviews to be audio recorded. They were reminded to pose questions/concerns throughout. This ensured that participants were provided the best opportunity to comprehend study procedures. In an attempt to ensure that the most accurate data were collected, if a family caregiver indicated any form of cognitive impairment (as assessed via self-report), this person was not eligible to participate in the study. No family caregiver reported or indicated cognitive impairment for themselves.

### **Vulnerable Populations**

This study included vulnerable populations of women and minorities. Sixty percent of family caregivers are female.<sup>26,167</sup> As such there are inherent ethical and practical/methodological challenges. Discussing sensitive topics in trusted environments is important for African Americans.<sup>84</sup> They most often chose their homes as the site for

data collection. It was also important to compensate participants for their time while avoiding coercion. All participants were provided a \$10 Walmart gift card at the end of data collection. Assurances on confidentiality, planning for a slower rate of recruitment as well as placement of a reminder phone call prior to scheduled interviews were provided. Once IRB approved, study fliers included a picture of African American individuals. These efforts were intended to address the importance of self-determination, full-disclosure and justice<sup>131</sup> in this vulnerable group. Lastly, family caregivers under the age of 21 years were not included in the study.

### **Protection Against Risk**

This study posed minimal psychological risks for most; but, there was a potential risk for participants. Participation in conversations on the topic of end-of-life planning may evoke strong emotional responses to the death of loved ones on the family caregiver participants if one is still grieving over the loss of a loved one. While this exercise proved to be cathartic for some, it could have been devastating for others. The following 12 strategies were in place as outlined to address this risk:

- 1) Prior to data collection, participants were informed that they did not have to respond to any question that made them feel uncomfortable.
- 2) Participants were reminded that they were able to withdraw from participating in the study at any point.
- 3) The researcher remained attentive to any signs of extreme stress due to discussions about end of life or any unstable physical or emotional conditions during the interviews.

- 4) With approval from the family caregiver, contact would have been made with the next-of-kin to alert them of the situation if the family caregiver became unstable.
- 5) Immediate referral to the participants' primary healthcare provider would have been made via an immediate, investigator initiated phone call once the participant was in agreement.
- 6) A letter prepared by the researcher explaining the family caregiver's participation in the study and the potential need for grief counseling would have been provided.
- 7) If noted during data collection that the process was becoming too emotionally difficult for a participant, the session would have ended (once the participant is in agreement).
- 8) Any urgent physical, medical issues that arose would have been immediately referred to proper medical emergency personnel via 911 access.
- 9) The researcher remained attentive to both verbal and nonverbal cues for signs of physical or emotional distress, such as crying or anger during data collection.
- 10) If a participant had to be withdrawn from the study or expressed a desire to do so at any point during the study, they would have been able to do so and provided a letter of thanks for participation in the study along with a \$10 Walmart gift card (once consent was obtained).



- 11) Any information the participant would have provided up until this point (before the decision to withdraw) would not be used for data analyses.
- 12) Any adverse reactions noted in participants as well as follow up procedures would have been reported to the IRB of both UVA and Riverside Health System Center for Excellence in Aging and Lifelong Health within the respective timeframes outlined by each Board.
- 13) Solicitation of participants was not sought from family caregivers of older adults actively involved in acute hospitalization or the dying process as these could have posed additional undue burden on the family caregiver during a time already characterized by extreme physical and emotional stress.

### **Data Safety Monitoring**

Each participant was given a study identification number that was linked to the interview recording, transcripts and a preferred means of contact (i.e., telephone number) via an assigned numeric code. Phone numbers were needed in order to request, schedule, confirm and notify participants of the interview dates, time and location. Once transcription of audio was completed and verified, the recordings were destroyed per IRB protocols. As transcripts were de-identified by removing identifying data components, loss of this information would not have put participants at risk because the participant identification number was the only identifying information on the document and only the researcher was able to link this number to the actual participant for the duration of the study. The researcher retained a master list that links the names of participants to the assigned de-identifying codes that link data, such as the contact information and

addresses of the participants to their study data. This master list will remain stored in a separate filing cabinet, both within a locked room in the Office of Nursing Research in the School of Nursing at the UVA. The researcher and her advisor alone are able to access these data, decreasing the risk of participant information being revealed. In the unforeseeable event that any personal information belonging to the participants is lost or revealed, the participant and respective IRBs will be notified of this occurrence. Every attempt was made to maintain the confidentiality of the participants and to secure all data collected. HIPAA-compliant, encrypted data is stored on password-protected computers within the Office of Nursing Research. These data were not stored on personal computers or external hardware devices.

Steps were taken to eliminate or reduce the risks involved in this research study. Items/devices containing personal information of the participants such as the digital recorder (which contains interviews), field notes from interviews, consent forms, completed research instruments and results of data analysis were stored in a locked cabinet within a locked room at the UVA School of Nursing, in the Office of Nursing Research. Data stored on hard drives will also remain secured in an encrypted form on a secured server at the UVA's School of Nursing. The researcher and the academic advisor alone have access to these data.

### **Monitoring for Adverse Events**

Based on previous studies with this population, definitions related to adverse events and reporting mechanisms are the following: Adverse Events (AEs) are defined as distress or discomfort related to sensitive questions related to end-of-life care of a family member. Any breach of confidentiality would also be an adverse event. Severe Adverse

Events (SAEs) are defined as unstable physical or emotional problems. These were outlined in the IRB protocols. The researcher handled any emotional or physical concerns as stated above. The researcher, academic advisor and other dissertation committee members primarily conducted monitoring for this non-invasive study. The researcher was prepared to identify adverse events and reviewed any in aggregate at least monthly with this team. Based on the nature of this non-invasive study with family caregivers, adverse events were believed to be possible. As a precaution, the appropriate IRB was notified when any form of distress was noted as outlined in the protocol. In these instances, no additional action was required as this possibility was identified beforehand in the protocol. The respective IRB would have been notified of any occurrence of AEs or SAEs as outlined in their protocols.

### **Risk-Benefit Ratio**

The benefits outweighed the risks for this non-invasive, cognitive-behavioral study. It was predicted that participation in the interview will be cathartic for some participants. The process of participating in this study may compel some family caregivers to begin to address the issue of end-of-life care for their older adult care recipient or themselves. If family caregivers are able to observe a more peaceful death experience in their older adult care recipient, this may compel them to make arrangements for their own end-of-life care in advance. This would be an added, but not immediate, potential benefit of being a participant in this study, the measurement of which was beyond the intended goals of this research study.

## **CHAPTER FOUR: RESULTS**

This descriptive, pilot study examined end-of-life decision making for African American older adults with dementia by their family caregivers, while measuring care recipient and family caregiver health-related quality of life (HRQOL) and family caregiver self-efficacy for surrogate decision making. The specific aims of this study were to: 1) capture end-of-life decision making for African American older adults with dementia by their family caregivers, including understanding and use of terminology; and 2) determine if the presence of formal or informal end-of-life care plans for older adults with dementia would be associated with higher or lower HRQOL in older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making. Data analyses were conducted using SPSS Statistical Software® Version 23<sup>160</sup> and Dedoose® Version 6.1.18, web application.<sup>155</sup>

### **Sample Description**

Family caregivers were the study participants for this study. Each family caregiver participant represented one care recipient who was an older adult with dementia. All data were collected via self-report from the family caregiver. Table 3 reports caregiver and care recipient characteristics.

#### **Family Caregiver Characteristics**

Family caregivers all self-identified as African American or Black. Family caregivers were mostly female (87.7%) and most often daughters (49.2%) caring for a parent with dementia. Participants caring for a spouse represented 13.8% of family caregivers. Others were relatives, such as sons (9.2%), nieces (9.2%), and sisters (6.2%) caring for a loved one with dementia. Less frequently, family caregivers were

granddaughters, great granddaughters, nephews, cousins, daughters- or sisters-in-law.

Mean family caregiver age was 59.5 years (Range: 25-82 years). Over half of them were single, widowed, separated or divorced (60%), and the other 40% were married. Annual family caregiver income was greater than \$25,000 for most (66.2%). Just over half (55.4%) of family caregivers were employed in a full- or part-time position. The vast majority (70.8%) had completed college, graduate and/or doctoral studies, while 29.2% had a high school diploma but nothing more. Only a few of them (4.6%) did not have a high school education.

Most family caregivers had one or more forms of insurance (public, private, and/or military), as only 4.6% of family caregivers reported being uninsured. Family caregivers self-described the location of their residences as rural (26.2%), urban (36.9%), or suburban (36.9%). Almost half of family caregivers (49.2%) described paying for basics as ‘not difficult at all’ while the other 50.8% indicated some degree of difficulty. The average length of time in their caregiving role was four years.

### **Care Recipient Characteristics**

Care recipients were mostly female (73.8%). Mean age was 82.8 years (Range: 62-104 years). Most care recipients were living in home settings, therefore non-institutionalized (83.1%). Care recipients enrolled in Program of All-Inclusive Care for the Elderly (PACE) Programs resided at home with family members and were receiving adult daycare or homecare services through the PACE Program. These PACE enrollees represented 24.6% of all care recipients. Family caregivers reported care recipients’ dementia diagnoses more specifically as Alzheimer’s disease (35.4%) most commonly, followed next by Vascular dementia (15.4%). For 40% of care recipients the family

caregiver did not know the specific type of dementia. Length of time since diagnosis of memory loss averaged four years.

**Table 3. Demographics**

| <b>Family Caregiver Characteristic (N=65)</b> | <b>N (%)</b>     |
|---|------------------|
| Gender  |                  |
| male  | 8 (12.3%)        |
| female  | 57 (87.7%)       |
| Age   |                  |
| 21-29 years                                   | 2 (3.1%)         |
| 30-39 years                                   | 1 (1.5%)         |
| 40-49 years                                   | 8 (12.3%)        |
| 50-59 years                                   | 16 (24.6%)       |
| 60-69 years                                   | 28 (43.1%)       |
| 70-79 years                                   | 6 (9.2%)         |
| 80-89 years                                   | 4 (6.2%)         |
|   | <b>Mean (SD)</b> |
| Age (years)                                   | 59.5 (11.5)      |
| Marital Status                                |                  |
| single  | 17 (26.2%)       |
| separated or divorced                         | 17 (26.2%)       |
| married                                       | 26 (40.0%)       |
| widowed                                       | 5 (7.7%)         |
| Annual Income                                 |                  |
| \$25,000 or less                              | 20 (30.8%)       |
| above \$25,000                                | 43 (66.2%)       |
| unknown                                       | 2 (3.1%)         |
| Employment Status                             |                  |
| employed                                      | 36 (55.4%)       |
| not employed                                  | 29 (44.6%)       |
| Years of School Completed                     |                  |
| grades 8-11                                   | 3 (4.6%)         |
| grade 12                                      | 16 (24.6%)       |
| 1-3 years college                             | 21 (32.3%)       |
| 4 years college                               | 7 (10.8%)        |
| some graduate school                          | 2 (3.1%)         |
| graduate degree                               | 11 (16.9%)       |
| some doctoral work                            | 2 (3.1%)         |
| doctorate degree                              | 3 (4.6%)         |
| Insurance Coverage <sup>1</sup>               |                  |
| public  | 29 (44.6%)       |
| private                                       | 46 (70.8%)       |
| military                                      | 3 (4.6%)         |
| none  | 3 (4.6%)         |

|   |                     |
|---|---------------------|
| Residence Location (self-described)         |                     |
| rural                                       | 17 (26.2%)          |
| urban                                       | 24 (36.9%)          |
| suburban                                    | 24 (36.9%)          |
| Difficulty Paying for “Basics”              |                     |
| not difficult at all                        | 32 (49.2%)          |
| not very difficult                          | 9 (13.8%)           |
| somewhat difficult                          | 19 (29.2%)          |
| very difficult                              | 5 (7.7%)            |
| Relationship to Care Recipient              |                     |
| spouse                                      | 9 (13.8%)           |
| daughter                                    | 32 (49.2%)          |
| son   | 6 (9.2%)            |
| sister                                      | 4 (6.2%)            |
| niece                                       | 6 (9.2%)            |
| other relative                              | 8 (12.3%)           |
|   | <b>Median (IQR)</b> |
| Length of time in caregiving role (years)   | 4 (4)               |
| <b>Care Recipient Characteristic</b>        | <b>N (%)</b>        |
| Gender                                      |                     |
| male  | 17 (26.2%)          |
| female                                      | 48 (73.8%)          |
| Age   |                     |
| 60-69 years                                 | 5 (7.7%)            |
| 70-79 years                                 | 18 (27.7%)          |
| 80-89 years                                 | 27 (41.5%)          |
| 90-99 years                                 | 14 (21.5%)          |
| 100-109 years                               | 1 (1.5%)            |
|   | <b>Mean (SD)</b>    |
| Age (years)                                 | 82.8 (8.5)          |
| Institutionalization Status                 |                     |
| institutionalized                           | 11 (16.9%)          |
| non-institutionalized                       | 54 (83.1%)          |
| Type of Memory Loss (Caregiver Self-Report) |                     |
| Alzheimer’s disease                         | 23 (35.4%)          |
| Vascular dementia                           | 10 (15.4%)          |
| unknown/unclassified                        | 26 (40.0%)          |
| other dementias                             | 6 (9.2%)            |
| PACE <sup>2</sup> Enrolled                  | 16 (24.6%)          |
|   | <b>Median (IQR)</b> |
| Length of time since diagnosis (years)      | 4 (3)               |
| Number of comorbidities                     | 3 (3)               |

<sup>1</sup>Some family caregivers had more than one type of insurance coverage

<sup>2</sup>Program of All-Inclusive Care for the Elderly

For the subset of participants who responded to the interview questions ( $n=18$ ), family caregiver and care recipient demographics were very similar to that of the larger study sample. Only one interviewee was male (5.6%), whereas, 12.3% of the larger study

sample were male. Of those interviewed, 50% of the care recipients were enrolled in a PACE program, while only 24.6% of care recipients in the larger study sample were in a PACE program.

### **Formal End-of-Life Care Plans**

How an individual is able to document end-of-life wishes varies based on personal preference and locale.<sup>168</sup> Across the U.S., various documents are used to specify these wishes. For example, various states and healthcare systems often have different variations of an advance directive form. Therefore, details therein can vary by form, even for those with the same title. Existence of the following forms was assessed in this study: advance directives, living wills, Do Not Resuscitate (DNR), Physician Orders for Scope of Treatment (POST), Power of Attorney/Health Care Surrogate (POA/HCS), and guardianship. All of these forms except POA/HCS and guardianship speak to an individual's plans for their desires for care towards the end of life. In this study these forms are referred to as "*formal end-of-life care planning documents.*" While POA/HCS and guardianship forms designate a surrogate decision maker, agent, proxy, or surrogate, they do not necessarily include nor are they required to accompany the individual's wishes for the end of life. Caregivers were not specifically asked whether a guardianship form had been completed, but some volunteered it.

In the Commonwealth of Virginia, an advance directive includes the designation of a healthcare agent.<sup>168</sup> However, because a person is able to have a designated power of attorney or healthcare agent in the absence of a formal end-of-life care document, it was important to be able to capture the existence of such a document. It is also recognized that designation of a power of attorney, healthcare agent or guardian does not necessarily



equate to having an end-of-life care plan. These documents bestow legal powers, but are not required to accompany a document entailing end-of-life care plans.<sup>168</sup> In this study the POA/HCS and guardianship forms are referred to as “*documents of agency*.”

### **Specific Aim 1**

For specific aim #1, a subset of 18 of the 65 family caregivers were asked to provide responses to semi-structured interview questions regarding the meaning of end-of-life terminology. The goal of this aim was to capture end-of-life decision making for African American older adults with dementia by their family caregivers, including understanding and use of terminology. Family caregivers were specifically asked to share their understanding of the following terms: *end of life, quality of life, and advance directive/living will*. The complete Interview Guide contained specific questions asked during the interview. Interviews were clustered primarily toward the beginning of the study, beginning with the first participant. Once thematic saturation was achieved, others only completed the forms and instruments. Transcribed data were analyzed as outlined in the methods section (Chapter III).

During the interviews, two participants experienced emotional distress, but chose not to end the meeting or to exit the study. Such a possibility was outlined in both IRB applications, therefore, measures were in place to address this concern. Tissues were on hand and the researcher was prepared to console and encourage the participant as well.

### **End-of-Life Terminology**

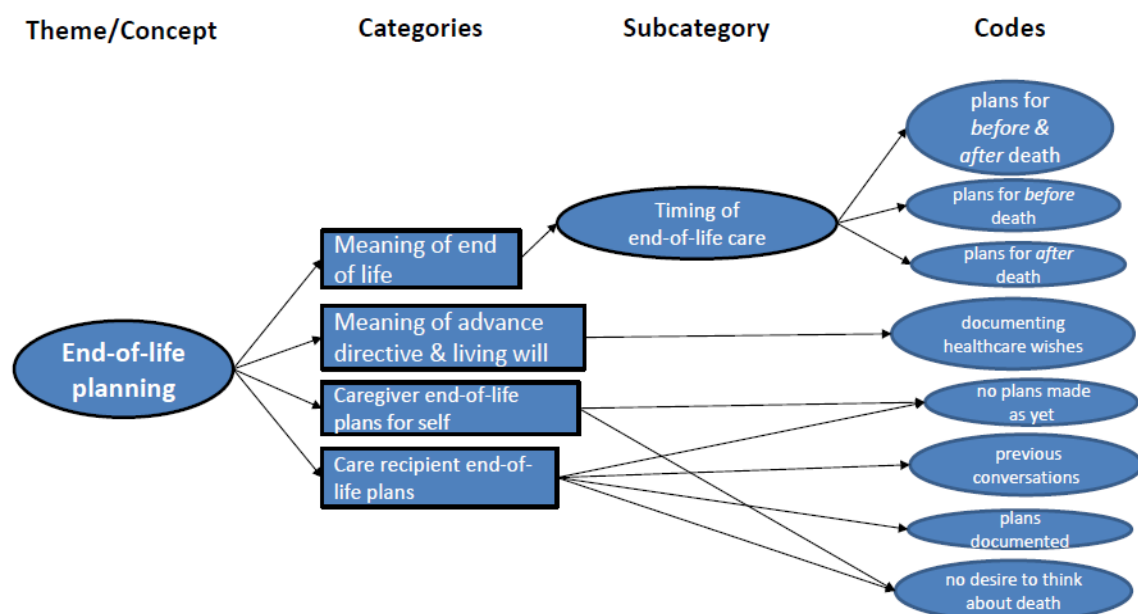
The term, *end of life*, was unanimously associated with “death.” One caregiver shared, “End of life means you know that we’ve done basically all we can do for you. We’ve tried every option. It’s now really up to you and the good Lord.” This statement

referenced the time period prior to death. Family caregivers sometimes interpreted the term, *end of life*, as “healthcare received prior to death”, such as whether or not a breathing machine or cardiopulmonary resuscitation (CPR) is used, versus “funeral/burial arrangements” following death, or both. When family caregivers were asked specifically if their understanding of the term *end of life* relates to before or after death, responses varied between both options. In one instance, a family caregiver responded, “Before we die.” Another went further on to say, “She has already expressed to me that she does not want to prolong her life by being on a ventilator.” These words clearly indicating the care recipient’s oral/verbal expression of healthcare wishes for the end of life. In the latter instance, neither formal end-of-life care planning documents nor documents of agency existed for the care recipient.

In instances when the researcher asked about the meaning of *end of life* and response options included ‘before death’, ‘after death’ or ‘both’, ‘both’ was always the preferred response. However, the topic of the family caregivers’ next statement was indicative of that which was most prominent in their minds. For example, in one instance, a family caregiver responded, “Both. My prayer is that my mom will remain in her home.....I don’t want her to have to go into a hospital and suffer....I really don’t want her to go to a nursing home and live. And after death is not a problem because insurance and a lot of things are, they are paid for so...” For this caregiver, the focus was seemingly on preparation prior to and following death. Responses to the meaning of *end-of-life* often referenced burial insurance, or burial plot payment as security, or funeral plans. This was evident by one family caregiver expressing, “Both, because of funeral arrangements and all that sort of thing.”

Figure 4 displays the categories and codes which resulted from analysis of meaning of the term *end of life*. There were differences in family caregivers who admitted that they did not like to talk about death versus those who were content with sharing that there were plans already in place, either formal or informal. With half of family caregivers interviewed having a loved one enrolled in a PACE Program, this could have significance as a majority of interviewees were comfortable speaking about death. Family caregivers for care recipients enrolled in PACE programs often also had an in-depth understanding of the meaning of end-of-life terminology as anticipated by healthcare providers focusing on healthcare wishes before death. Through conversation it seemed as though their expectations were aligned with their understanding of their loved one's condition. While they were not ready for them to die, they were able to confidently express their care recipients' healthcare wishes toward the end of life.

**Figure 4. End-of-Life Codes**



### **Advance Directive/Living Will**

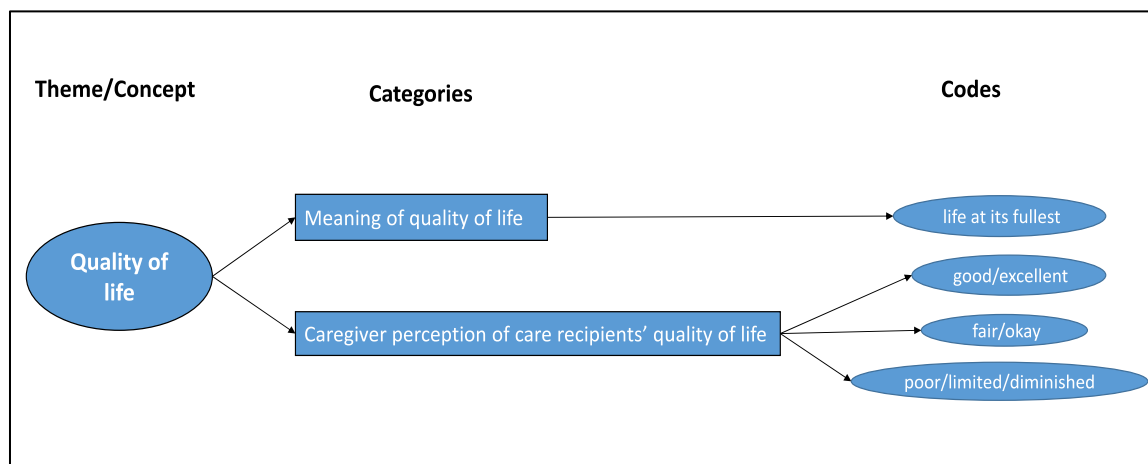
The terms *living will* and *advance directive* were associated with “putting wants/wishes in writing”, whether healthcare-related or not. Some family caregivers admitted that they were confused about the differences between the meaning of an advance directive and a living will. There was often difficulty differentiating between the two documents. Often times they were able to accurately identify the purpose for one of the documents, but not the other. Living will was often confused with a Will that often designates personal property. For example, one family caregiver stated, “But the living will just kind of makes sure the families don’t get to fighting about possessions or I want this or I want that.” All family caregivers identified them both as written documents and were in agreement that it/they were a good thing to have in order to make one’s wishes known.

### **Quality-of-Life Terminology**

Family caregivers described their understanding of the meaning of *quality of life*. Codes that emerged primarily included reflections on past activities that evoked feelings of “happiness or contentment” by their loved ones and the preservation of “dignity and respect.” Family caregivers were asked to describe their loved ones’ quality of life. The range of responses provided varied from descriptions such “poor” or “diminished” to being “good” or “excellent.” Interestingly, some family caregivers used some of the same terms to describe their own quality of life. Family caregivers rated their care recipients’ HRQOL using the Alzheimer’s Disease Related Quality of Life (ADRQL) instrument. Often times their reported descriptions corresponded with their ADRQL score. For example, one family caregiver reported “I would say she is in a good place.....I say her

quality of life is good.” This family caregiver rated the care recipient’s overall HRQOL score as 87 on the 0-100 scale. Figure 5 displays quality-of-life categories and codes that emerged.

**Figure 5. Quality-of-Life Codes**



### Decision Making

In concordance with healthcare literature, end-of-life decisions made by family caregivers were not autonomous (independent acts). Family involvement was quite evident. Decisions were made in collaboration with either care recipients themselves (in instances when they were able to contribute), loved ones i.e., children, grandchildren, siblings, etc. and/or healthcare providers. As a result these decisions were also seemingly made over time through appropriate consultations with key stakeholders, i.e., care recipient (when possible), other family members, healthcare providers, and God.

Family involvement in care of these African American older adults with dementia was significant. A change in behavior or health status in the care recipient was the most frequent indicator provided by the family caregiver that prompted the need for decision making. One participant stated “We put our heads together and make a decision.” *We*, in this instance referred to the family. Conversations were often held with other family

members and included the care recipient, particularly prior to the recipient's memory loss. Interestingly, even in instances where memory loss was evident (and the care recipient provided input), family caregivers often provided opportunities for their care recipient's choices to be considered. In such instances, oral or verbal plans were most significant, especially when previous conversations and past experiences were important factors that emerged as key influencers in end-of-life decision making among family caregivers. Such previous conversations with an older adult with dementia mattered, especially when there were no decision documented.

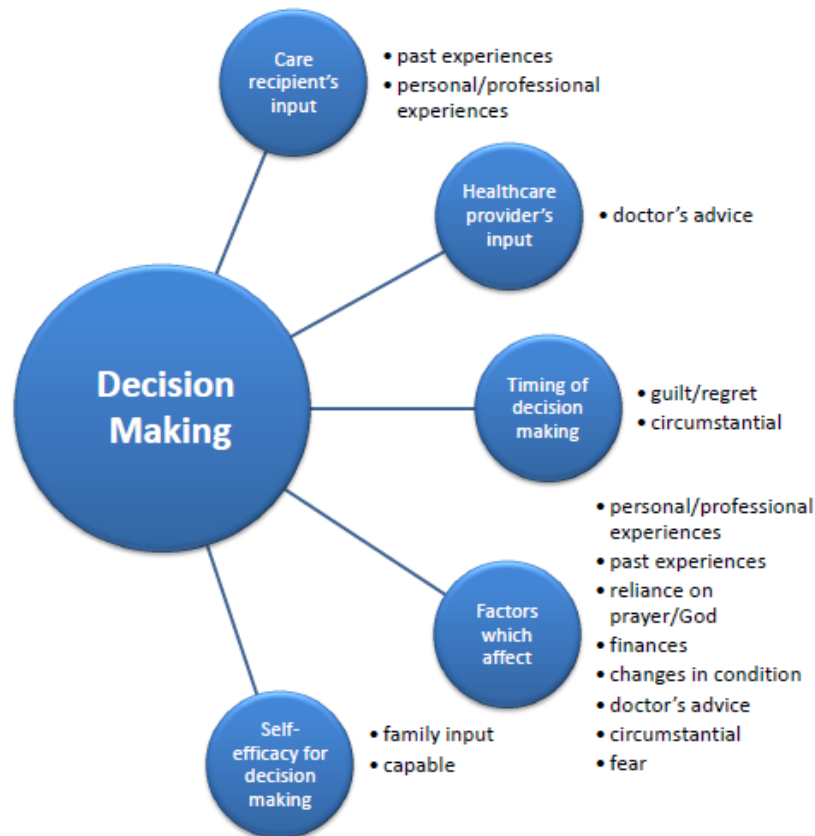
Past experiences that the care recipients had often had with other loved ones dictated how the care recipients felt about what they wanted for themselves and affected the family caregiver's decision making process. An example of this was when a family caregiver recounted the death experience of a care recipient's sibling with an indication that the care recipient "did not want to suffer like she did." In this instance, when the care recipient had previously been in the caregiving role, the care recipient gained first-hand experience of the difficulties of caregiving near the end of life. As a result of this, the care recipient was able to express (prior to memory loss) that he did not want to choose the same fate.

Professional experiences and backgrounds of the care recipient and the family caregiver were also influential in the decision-making process. During interviews, family caregivers sometimes made direct reference to care recipients' past experiences that shaped the way their loved ones would choose to oversee their wishes toward end-of-life decisions. A few participants came from professional healthcare backgrounds. This background influenced responses to questions posed by the researcher in many areas. It

also clearly framed their thinking about healthcare towards the end of life. These family caregivers were most comfortable about discussing end of life.

Family caregivers in this study provided evidence that they rely heavily on healthcare providers for advice surrounding healthcare decision making. Oftentimes they referenced physicians and social workers with programs such as PACE where they received the bulk of information on end-of-life planning. Figure 6 displays the categories and codes discovered that related to decision making.

**Figure 6. Decision-Making Categories and Codes**



### **Self-Efficacy in Decision Making**

Family caregivers interviewed ( $n=18$ ) in this study all reported feeling very capable of making the best decisions for their loved one with dementia. This was also the

consensus reflected by responses to the Surrogate Decision Making Self-Efficacy Scale (SDM-SES) completed by all study participants (N=65). In one instance, a family caregiver pointedly remarked that she was “Probably more capable than anybody in the family.” Her reasoning for this opinion was that her care recipient lives with her, she talks to her often, and by doing so has been able to learn more about her.

### **Resources**

PACE Programs were sources of information sharing for family caregivers. Family caregivers with loved ones enrolled in PACE Programs (8 of the 18 interviewed) were often well versed on end-of-life decisions. In all but one instance for a loved one enrolled in a PACE Program, formal end-of-life care plans were documented. In this lone instance, end-of-life conversations were already underway towards completing an advance directive with assistance with advance care planning facilitators through the PACE Program. Unprompted, family caregivers often described resources used and openly shared about their experiences with them. For those enrolled in PACE Programs, their frame of reference for resources centered on all that their care recipient received via PACE. Often times, they also interjected resources that PACE provided that were focused on them as caregivers. They often lauded the program and its staff for the assistance it provided them.

Figure 7 displays categories and codes that emerged as they relate to resources. Emphasis on faith/spirituality also arose as a common resource for decision making and other aspects of family caregiving. Family caregivers described prayer and their relationship with God as key influencers and sources. As the conversation shifted to focus on death and dying, one family caregiver described:

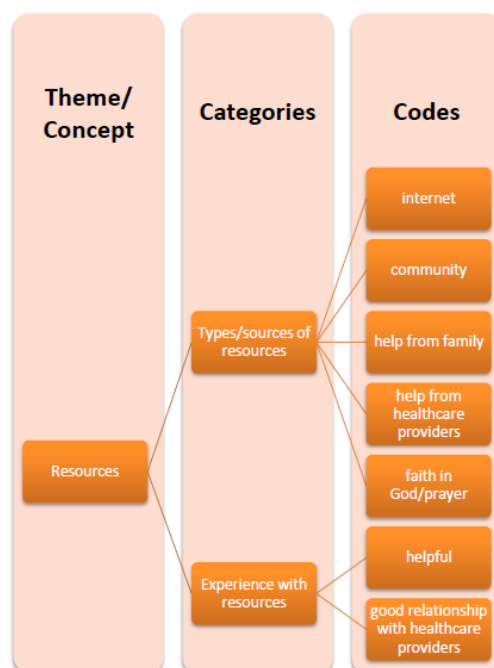
“You know that at some point you will be leaving this earth so therefore you have [some]



time. Actually it is, it's a good thing. Some people don't see it that way. But if you have time to plan that's good cause some people just leave just like that without saying goodbye. You have time to make amends and a whole lot of other things."

She went on to describe her care recipient as "a praying woman" prior to the dementia. Reference to preparation for death became clearer as she described her care recipient no longer "suffering" with dementia. This caregiver also described the time before death as preparation to "reflect [and] rejuvenate" and make amends with others. She went on to describe, "And after you have done all that you can, [you can] say God, I'm ready." This conversation reiterated the role of faith/spirituality when discussing end of life. From each family caregiver interviewed it was clear that regardless of one's belief system, each person was likely to have a perception of what happens after death.

**Figure 7. Resource Codes**



From these data and through personal interactions, there is evidence to support that family caregivers in this study are protective of their older adult loved one with

dementia. As anticipated, due to the diagnosis of dementia they were very much involved in decision-making processes that occurred as a family, and with the use of internal and external resources such as faith/spirituality or PACE Programs.

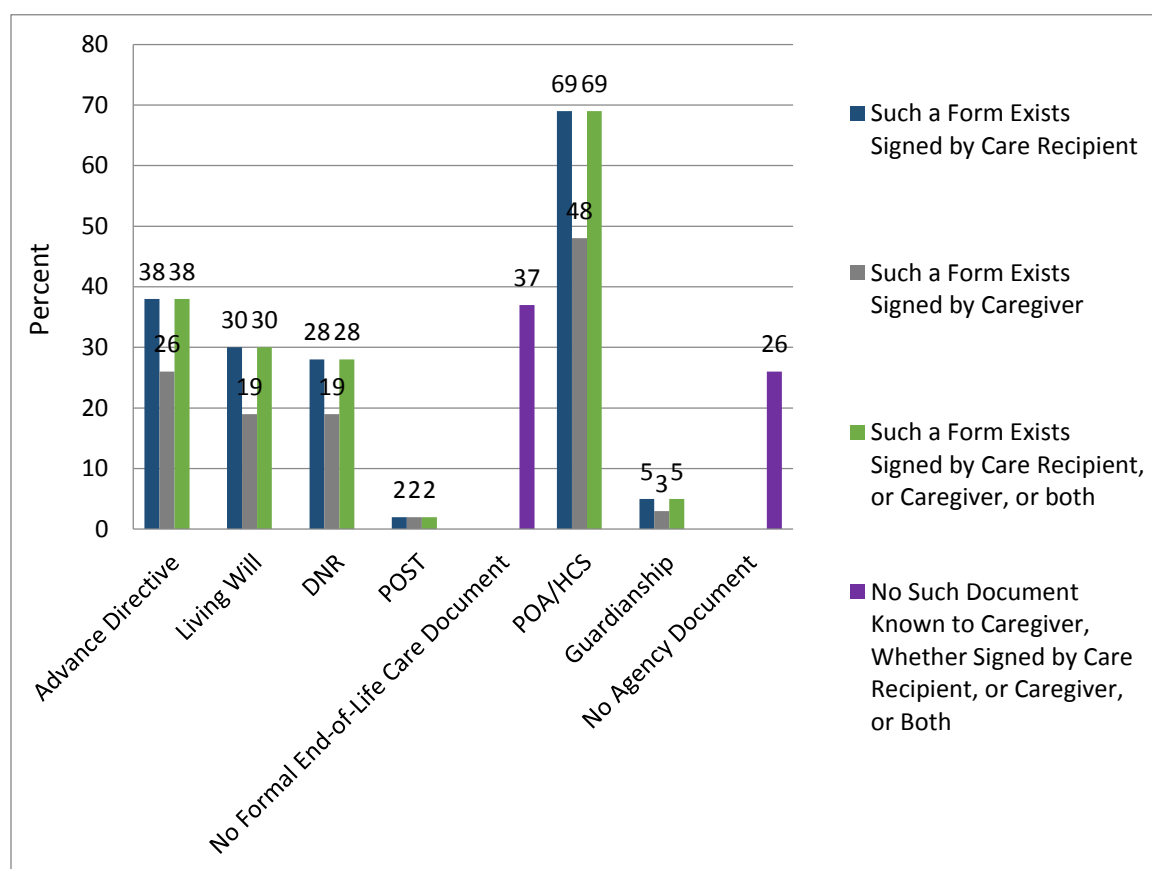
### **Formal End-of-Life Care Planning Documents**

Formal documents containing end-of-life care plans are the gold standard for end-of-life planning. In this study, having a formal end-of-life care planning document refers to possession of one or more of the following: advance directive, living will, DNR, and/or POST forms. Having an agency document refers to possession of a Power of Attorney, Healthcare Surrogate, or guardianship document for the care recipient. It is recognized that particularly in dementia, there may be instances where family caregivers complete health-related decision-making forms on behalf of a loved one who is cognitively impaired. For this reason, family caregivers were asked to indicate if they themselves had signed any of the documents in question on behalf of their care recipients as well as if their care recipients themselves had signed any such document for themselves. Figure 8 presents the possession rates for each type of document, for those reportedly signed by the care recipient and documents signed by the family caregiver because depending on the care recipient's decision-making capacity, the care recipient may have participated in signing one or more documents.

A majority of care recipients (74%) possessed at least a POA/HCS or guardianship form (see Figure 8). However, possession of one or both of these documents was not considered having a formal end-of-life care plan because these do not necessarily indicate that plans for the end of life exist, but rather that there is an assigned surrogate decision maker. These documents often existed in the absence of a formal end-of-life care

planning document. Care recipients often possessed more than one formal end-of-life care planning document. Sometimes both the care recipient and the caregiver had signed the same kind of document for the recipient. However, in every case when the caregiver had signed one of these documents, the care recipient had also signed such a document. For example, 17 caregivers indicated that they had signed an advance directive for their care recipient, and in all 17 cases they also indicated that the care recipient had signed such a document.

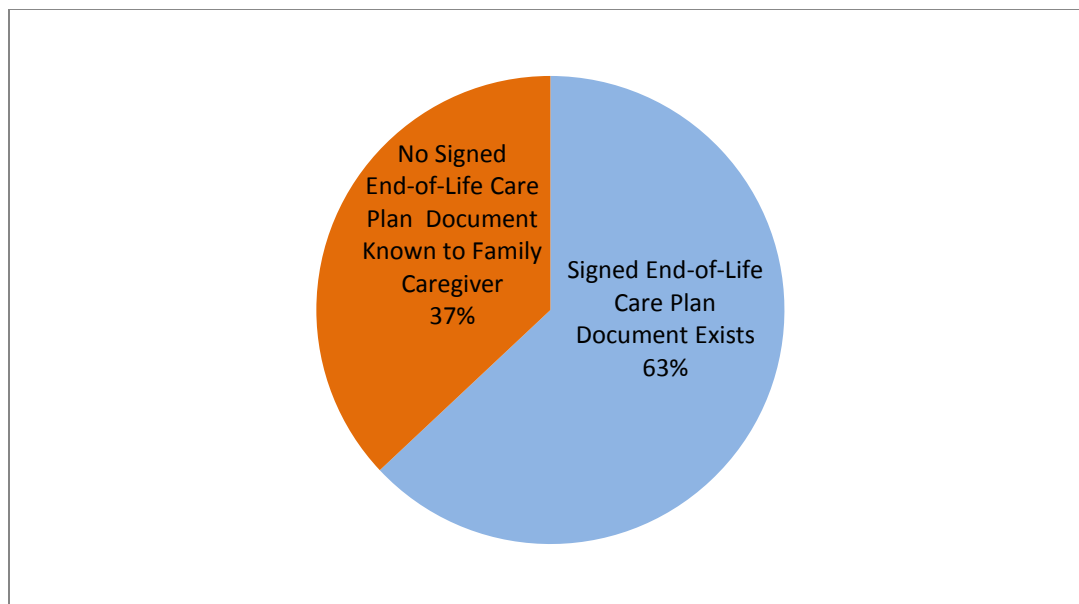
**Figure 8. Possession Rates for Care Recipient Formal Documents**



Overall, 63% of family caregivers stated possession of formal end-of-life care planning document(s) for the care recipient, signed either by themselves, their care recipient or both (see Figure 9). The remaining 37% of family caregivers included 6.2%

who reported that they were unaware if their care recipient had signed a formal end-of-life care planning document or documents of agency. Others in the 37% either did not indicate possession or stated that there were no such signed documents.

**Figure 9. Care Recipient or Family Caregiver Signed End-of-Life Care Planning Document**

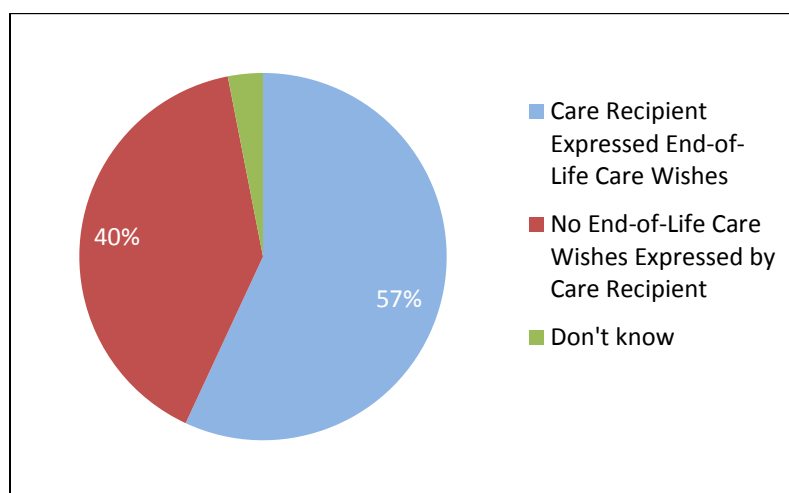


### **Informal End-of-Life Care Plans**

Family caregivers were asked to indicate ('Yes', 'No' or 'Don't Know') to a question asking if oral/verbal end-of-life care plans were ever expressed by their care recipient. For the purpose of this study, an informal end-of-life care plan referred to any report of care recipient self-expressed oral/verbal plans regarding wishes for the end of life. Family caregivers reported that 57% of care recipients had expressed oral/verbal wishes for the end of their lives. This compared to 40% of family caregivers who reported that their care recipients had not orally/verbally expressed such wishes to anyone. Only 3% of family caregivers had no knowledge if there were oral/verbal end-of-life care plans expressed by their care recipients regarding their wishes towards life's end

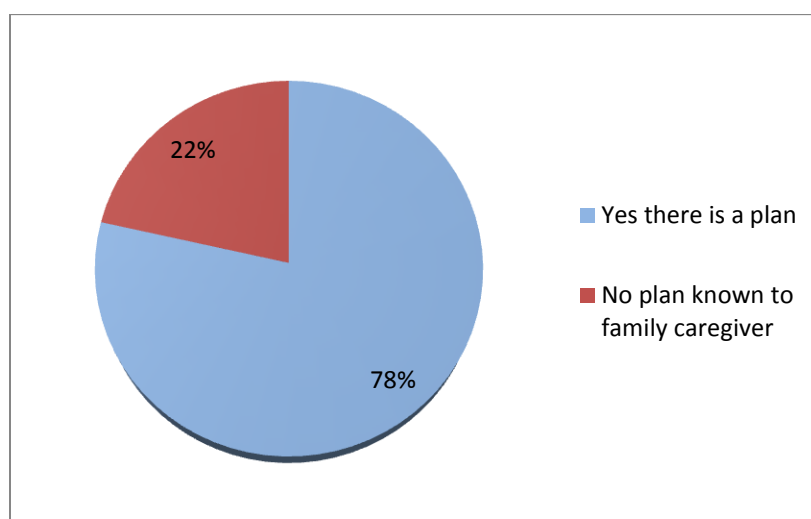
(see Figure 10).

**Figure 10. Informal (Orally-Expressed) Care Recipient End-of-Life Care Plans**



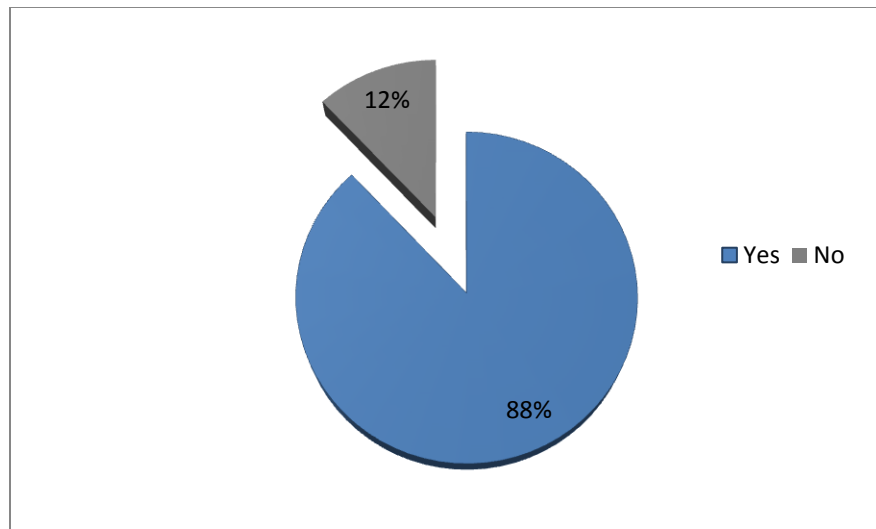
In examining care recipients who had formal and/or informal end-of-life care plans, 78% of family caregivers reported that there were formal and/or informal end-of-life care plans in place for their care recipient (see Figure 11). The other 22% of care recipients had neither a formal nor informal end-of-life care plan. These results show that for the majority of care recipients in this study, at least, a strategy existed for how healthcare received at the end of their lives would be executed.

**Figure 11. Formal or Informal End-of-Life Care Plans for Care Recipient**



When agency documents were included, 88% of caregivers possessed at least some document or information concerning end-of-life care for the care recipient, or at least had an assigned surrogate. (See Figure 12)

**Figure 12. Any Written Document, Including Agency Document, and/or Oral/Verbal Plan**



### **Specific Aim 2**

This specific aim sought to determine if the presence of formal or informal end-of-life care plans for older adults with dementia would be associated with higher or lower HRQOL in older adults with dementia and with greater family caregiver self-efficacy for surrogate decision making. The effects of two predictors on the existence of formal end-of-life care planning documents were examined; 1) care recipient HRQOL and 2) self-efficacy for surrogate decision making. First, bivariate tests determined whether each predictor had a direct relationship with the existence of formal end-of-life care planning documents. Next, logistic regressions estimated the effects of each of the two predictors of interest on the presence of formal end-of-life care planning documents when a covariate was taken into account. Covariates examined were care recipient

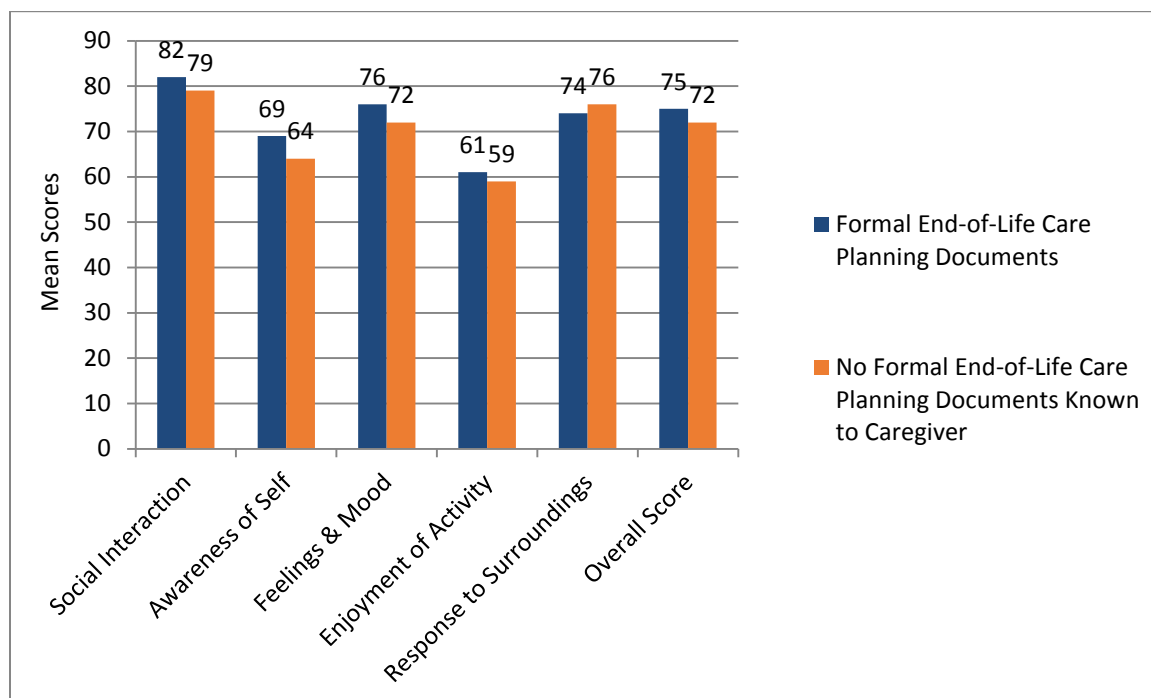
characteristics: age, number of comorbidities, length of time since diagnosis of cognitive impairment, institutionalized or non-institutionalized status, and family caregiver

characteristics: age, education level, income level, and length of time in caregiving role.

### **Relation Between Presence of End-of-Life Care Plans and Care Recipient HRQOL**

Family caregivers rated their care recipients' HRQOL using the Alzheimer's Disease Related Quality of Life (ADRQL). Overall ADRQL scores ranged from 33.4 to 100 ( $M=73.7$ ,  $SD=16.3$ ) out of a possible range of 0-100. Figure 13 shows each of the domains measured for those care recipients with a formal end-of-life care planning document as compared with those without. On the individual domains the means of the two groups were close in every case, and in four of the five domains, the mean was higher for those with a planning document. Mean scores by domain range from 61 to 82 for those with formal end-of-life care planning document(s) and 59 to 79 for care recipients without a formal end-of-life care planning document. Highest scores were in the 'social interaction' domain and lowest were in the 'enjoyment of activity' domain. Overall HRQOL for care recipients with a formal end-of-life care planning documents (75) was only slightly higher than that of care recipients without a formal end-of-life care planning document (72). Family caregiver HRQOL was also measured in this study using the Short Form Health Survey 36-Version 2 (SF-36v2). These data will be analyzed and reported in a future study.

**Figure 13. Perceived Care Recipient Health-Related Quality of Life, by Existence of a Formal End-of-Life Care Plan<sup>1</sup>**



<sup>1</sup>Mean Score by domain of the Alzheimer's Disease Related Quality of Life (ADRQL)

An independent samples *t*-test was conducted to compare mean total HRQOL between those with and without formal end-of-life care planning documents. There was no significant difference between the mean total HRQOL scores for care recipients with at least one formal end-of-life care planning document known to the caregiver ( $M=74.8$ ,  $SD=15.7$ ) and for those with no formal end-of-life care planning document ( $M=71.7$ ,  $SD=17.6$ );  $t(63)=0.74$ ,  $p=0.464$ . These results suggest that possessing a formal end-of-life care planning document is not related to care recipient perceived HRQOL.

An independent samples *t*-test was also conducted to compare mean total HRQOL for those with and without formal or informal end-of-life care plans. There was no significant difference in mean total HRQOL scores between care recipients who possessed formal or informal end-of-life care plans ( $M=74.8$ ,  $SD=15.7$ ) and those with no



formal or informal end-of-life care plans known to the caregiver ( $M=69.6$ ,  $SD=18.6$ );  $t(63)=1.06$ ,  $p=0.295$ . These results suggest that possession of a formal or informal end-of-life care plan is not related to perceived care recipient HRQOL.

### **Relation Between Presence of End-of-Life Care Plans and Caregiver Self-Efficacy**

Family caregivers rated their self-efficacy for surrogate decision making using the Surrogate Decision Making Self-Efficacy Scale (SDM-SES). Higher scores indicate higher levels of self-efficacy for surrogate decision making. Scores in this sample ranged from 2.8 to 4 ( $M=3.66$ ,  $SD=0.37$ ) out of a possible 1-4.

An independent samples  $t$ -test was conducted to compare mean self-efficacy scores for surrogate decision making between those with and without formal end-of-life care plan. There was no significant difference in the overall mean caregiver self-efficacy scores between care recipients with at least one formal end-of-life care plan ( $M=3.66$ ,  $SD=0.37$ ) and for those with no formal end-of-life care plan known to the caregiver. ( $M=3.68$ ,  $SD=0.38$ );  $t(63)=0.17$ ,  $p=0.866$ . These results suggest that having a formal end-of-life care planning document is not related to family caregiver self-efficacy for surrogate decision making.

An independent samples  $t$ -test was also conducted to compare mean self-efficacy for those with and without formal or informal end-of-life care plans. There was also no significant difference in the mean overall between mean family caregiver self-efficacy scores between care recipients with formal or informal end-of-life care plans ( $M=3.68$ ,  $SD=0.38$ ) and those with no formal or informal end-of-life care plan known to the caregiver ( $M=3.60$ ,  $SD=0.37$ );  $t(63)=0.73$ ,  $p=0.470$ .

### Logistic Regressions

Logistic regressions were used to estimate the effect of the two factors: HRQOL of the care recipient and family caregiver self-efficacy for surrogate decision making, on rates of formal end of life care plans for older adults with dementia, while controlling for eight covariates: care recipient characteristics: age, number of comorbidities, length of time since diagnosis of cognitive impairment, institutionalized or non-institutionalized status, and family caregiver characteristics: age, education level, income level, and length of time in caregiving role. These eight care recipient and family caregiver characteristics were selected for their possible impact on the presence of end-of-life care plans based on current literature. As noted earlier, for a fitted regression model to be reliable, for each predictor in the model there should be at least 10-20 observations having the less frequent outcome.<sup>146</sup> In the case of formal end-of-life care plans, there were 24 with the less frequent outcome – not having such a plan. For this investigation, the limit was stretched, and three predictors were allowed in the models. Logistic regressions were not able to be conducted on the outcome of having a written and/or oral end-of-life care plan because there were only 14 care recipients (22%) without a plan.

Bivariate tests (*t*-tests, Mann-Whitney U tests and chi-square tests) were carried out first to see whether each of the eight covariates differed on the two outcome groups – those with and without a formal end-of-life care plan. There was a significant difference in the mean age between care recipients with formal end-of-life care plans ( $M=85.0$ ,  $SD=7.61$ ) and those with no formal end-of-life care plan known to the caregiver ( $M=79.0$ ,  $SD=8.84$ );  $t(63)=2.87$ ,  $p=0.006$ . There was also a significant difference in the mean number of comorbidities between care recipients with formal end-of-life care plans

( $M=3.22$ ,  $SD=2.08$ ) and those with no formal end-of-life care plan known to the caregiver ( $M=1.96$ ,  $SD=1.65$ );  $t(63)=2.54$ ,  $p=0.014$ . There was no significant difference in the following family caregiver characteristics: caregiving timeframe ( $p=0.620$ ); age ( $p=0.399$ ); education level ( $p=0.376$ ); and income level ( $p=0.129$ ), between care recipients with formal end-of-life care plans and those without a formal end-of-life care plan known to the caregiver. There was also no significant difference in the care recipient timeframe for the dementia diagnosis ( $p=0.838$ ) and in the care recipient's institutionalization status ( $p=0.966$ ) between care recipients with formal end-of-life care plans and those without a formal end-of-life care plan known to the caregiver.

Next, eight logistic regressions were conducted, with three predictors in each model. In every case, the dependent variable was having a written end-of-life care planning document or not. Two of the independent variables were always care recipient HRQOL and family caregiver self-efficacy for surrogate decision making, while the third independent variable was one of the eight covariates, cycling through each one of those in turn.

The two predictors of interest, care recipient HRQOL and family caregiver self-efficacy for surrogate decision making were not significant predictors in any of the regressions. In every regression, care recipient HRQOL had a very small positive effect on the odds of there being a formal end-of-life care planning document, and self-efficacy for surrogate decision making had a very small negative effect, but neither had a statistically significant effect in any of the eight regressions.

Two of the covariates, however, did have significant estimated effects on the outcome: age of care recipient ( $p=0.012$ ) and number of comorbidities for the care

recipient ( $p=0.021$ ). The estimated odds ratio of 1.095 for the effect of the age of the care recipient indicates that the probability of having a formal end-of-life care plan increases as the age of the care recipient increases. (See Table 4)

**Table 4. Logistic Regression of Existence of Formal End-of-Life Care Planning Document on Care Recipient Age, Perceived HRQOL of Care Recipient and Caregiver Self-Efficacy**

| Variables   | <i>p</i> Value | Odds Ratio |
|---|----------------|------------|
| Age of Care Recipient   | 0.012          | 1.095      |
| ADRQL (perceived HRQOL of care recipient)                       | 0.764          | 1.005      |
| SDM-SES (caregiver self-efficacy for surrogate decision making) | 0.795          | 0.832      |

The estimated odds ratio of 1.426 as reported in the next table indicates that the probability of existence of a formal end-of-life care planning document increases as the number of care recipient comorbidities increases (Table 5).

**Table 5. Logistic Regression of Existence of Formal End-of-Life Care Planning Document on Care Recipient Number of Comorbidities, Perceived HRQOL of Care Recipient and Caregiver Self-Efficacy**

| Variables   | <i>p</i> Value | Odds Ratio |
|---|----------------|------------|
| Number of Comorbidities of the Care Recipient                   | 0.021          | 1.426      |
| ADRQL (perceived HRQOL of care recipient)                       | 0.587          | 1.009      |
| SDM-SES (caregiver self-efficacy for surrogate decision making) | 0.948          | 0.953      |

These results suggest that care recipient age and number of comorbidities are related to the presence of at least one formal end-of-life care planning document. There was no strong evidence in the results of the logistic regressions to support a relationship between any of the six other covariates (care recipient's length of time since diagnosis of cognitive impairment ( $p=0.757$ ) and institutionalization status ( $p=0.982$ ) nor family caregiver's age ( $p=1.018$ ), educational level ( $p=0.401$ ), income level ( $p=0.168$ ) or length of time in caregiving role ( $p=0.588$ )) and the existence of a formal end-of-life care document. These analyses were limited by the sample size ( $N=65$ ). With a much larger sample, both predictors of interest (HRQOL and self-efficacy for surrogate decision making) would have been included with all eight covariates in the same model. Family caregiver HRQOL was also measured in this study using the SF-36v2. Its effects on the existence of an end-of-life care plan will be analyzed and reported in a future study.

### **Analysis of Formal Non-Planners**

There were two family caregivers from the interview sample who reported not having formal end-of-life care planning documents. The care recipient of the first participant that will be discussed was enrolled in a PACE Program. However, this care recipient was newly enrolled. Though there were no formal end-of-life planning documents completed, advance care planning facilitators from the PACE Program had already begun discussions about end-of-life planning. The family caregiver was able to describe having already received the paperwork towards form completion. Though the care recipient was incapable of making decisions at the time of the interview, the family caregiver expressed that based on previous conversations with him, she had knowledge of his desires for the end of life. She would then place in writing what she knew from these

prior conversations concerning his wishes for end-of-life care, and would base her care decisions on those wishes.

In her own words, this participant described herself as being “very capable” of making decisions for her care recipient. Similarly, she rated her self-efficacy for surrogate decision making score as 4.0, the highest level on the scale, confirming her confidence in making decisions on behalf of her care recipient.

As she described her care recipient’s quality of life, she stated that “he has had the best of it.” She then reflected on how he is “no longer the same person that he used to be.” Using the ADRQL to rate her care recipient’s HRQOL she rated it at 67.6 out of 100 on the scale indicating a moderate HRQOL.

“End of life” for this family caregiver focused on after death. Based on the interview it was clear that there was some confusion regarding a Last Will and Testament as used for property distribution verses a living will to refer to healthcare wishes towards the end of life. This became evident during the interview when the family caregiver was asked about a living will, she expressed during the interview that she had recently completed a “Will” on both herself and her spouse. However, when she described what was entailed in the document it became clear to the researcher that she was referencing a Last Will and Testament. On the survey, which listed various end-of-life care planning documents, as well as documents of agency, she responded “none of the above.” She then went on to inform the researcher that she had been provided information and had begun conversations with PACE advance care planning facilitators toward form completion regarding her care recipient’s healthcare decision making towards the end of life. Having both sets of data (interview and survey) to compare and contrast in this way allowed the

researcher to gain a better, more accurate, understanding of the family caregiver's understanding and interpretation of the important information in question. From these data it was also clear that the process of documenting the care recipient's wishes was not hasty as time was being allowed for education to take place.

The other family caregiver who indicated that there were no formal end-of-life care planning documents was caring for a loved one with memory loss who was institutionalized in a long-term care facility. Self-reliance and advice from God through prayer and supplication were described as sources when the caregiver was seeking help in making decisions for the care recipient. This family caregiver described herself as being capable of making decisions for her care recipient. The care recipient had previously expressed her desires for the end of life. This family caregiver rated her self-efficacy for surrogate decision making as 3.80 out of 4, a fairly high rating.

Quality of life was described as "everything being the best for her [care recipient]." The care recipient's quality of life was described as "wanting to get better." This was indicative that both the family caregiver and care recipient were not content with the care recipient's quality of life at this time. HRQOL for the care recipient was rated as 65.29 out of 100, a moderate rating.

"End of life" to this family caregiver meant that "they [an individual] would not be here much longer." Advance directives and living wills were described as "a wise decision" which would focus on preparation both before and after death. While no formal end-of-life planning document existed the care recipient had previously expressed oral or verbal wishes for the end of life. However, it was unclear if these wishes were regarding before or after death.

## **CHAPTER FIVE: DISCUSSION**

This descriptive, correlational pilot study examined end-of-life decision making for African American older adults with dementia by their family caregivers and measured care recipient and family caregiver health-related quality of life (HRQOL) and family caregiver self-efficacy for surrogate decision making. The primary objective of this study was to better understand end-of-life decision making among African American family caregivers of older adults with dementia. This discussion first addresses the characteristics of the study sample as compared to national demographics of persons with dementia and their family caregivers. Secondly, study analyses by specific aim with consideration of current research in this area are addressed. Lastly, issues pertaining to the research design of this study and directions for future research in this area are addressed.

### **Population Characteristics**

All care recipients in this study self-identified as Black or African American, a racial group recognized as being at high risk for the development of dementia, as compared to Caucasians.<sup>27</sup> Family caregiver and care recipient characteristics in this study closely resemble national data, as family caregivers in this study were mostly female, married, and have a college education.<sup>27</sup> The majority of care recipients in this study were ages 70 to 99 years. From a national perspective, those suffering with dementia are most often 75-85 years or older.<sup>27</sup> Vascular dementia is the form of dementia most commonly seen in African Americans.<sup>51</sup> However, in this study only about one quarter of care recipients were reported to be diagnosed specifically with this form of dementia. The majority were described as having either Alzheimer's disease or



unknown/unclassified. This may be due to a lack of specific testing required for diagnosis to determine the specific type of dementia or because data were all self-reported by the family caregivers, thus challenges may exist with validity and data accuracy.<sup>131</sup>

African Americans with dementia tend to reside in a family home with loved ones, rather than in nursing homes.<sup>169</sup> They are also more likely to be cared for by loved ones outside of nursing homes.<sup>101-103</sup> Data from this study were consistent with national data as the majority of care recipients were non-institutionalized (83.1%). However, it is noteworthy that 24.6% of care recipients in this study were enrolled in a Program of All-Inclusive Care for the Elderly (PACE) Program, decreasing the likelihood of residence in an institution.

### **Specific Aim 1**

According to the recent 2014 Institute of Medicine report on *Dying in America*, death remains a deeply personal experience.<sup>2</sup> The growing cultural diversity, inclusive of larger numbers of African American older adults in the population in the U.S. was part of the contextual factors in support of the development of this report.<sup>2</sup> This makes it ever more important for healthcare providers to approach all patients as individuals, without assumptions or judgment regarding care choices they might make.<sup>2</sup> As seen in this study, understanding and meaning of end-of-life terminology differs. Understanding of healthcare terminology is important as it relates to end-of-life planning, particularly among Blacks.<sup>6</sup> African American family caregivers in this study demonstrated that they are engaged in end-of-life decision making for their loved ones with dementia. This was demonstrated by high completion rates of both formal end-of-life care planning documents and documents of agency. Additionally, informal plans existed at a high rate

(57%), even in the absence of formal documentation in this study. For these family caregivers, end-of-life decision making was family centered and involved communication with healthcare providers as a resource. These findings were in keeping with other recently published literature.<sup>130,170</sup> This serves as a reminder for healthcare providers to focus on specific needs of the individual and families.

There are often inconsistencies with healthcare providers' expectations regarding understanding of end-of-life terminology and that of patients and families. Healthcare providers must be open to educating patients and families on this subject as well as patients and families being receptive to this education. This consideration should be recognized by healthcare providers as a preference of the individual and family and honored when possible. In instances where issues exist with disconnection in care provision or communication, healthcare providers need to recognize that this may be a potential difference in understanding. Healthcare providers also must be prepared to ensure that patients and families are thoroughly educated on what the provider is referencing when terms such as 'end of life' are used in the healthcare setting/context. As seen in this study, definitions varied and a more complete picture could be given once healthcare providers and patients/families understand each other.

Characteristics of the group of family caregivers in this study are somewhat unique in relation to rates of end-of-life planning and its process. Most often when researchers measure the presence or absence of an end-of-life care plan, most included possession of a power of attorney, health care surrogate (POA/HCS), or guardianship form.<sup>118,171</sup> Because of the nature of a diagnosis such as dementia, recognition of the need for an individual to make decisions on behalf of the person with dementia, either

immediately or in the near future, is highly likely.<sup>172</sup> While having an assigned POA/HCS or guardian is an extremely important step in the right direction, these forms did not always ensure that there were formal or informal end-of-life care plans in place for the care recipient with dementia. Also, because data collected were self-reported and did not explore details contained within the advance directives themselves, specifics on what the plans entailed remained unknown.

For the process of assigning names to the groups of documents identified in this study as formal end-of-life care planning documents or documents of agency, expert advice was sought via written communication (April 2016) from attorney and partner of the international healthcare law group McGuire Woods, LLP Mr. Nathan Kottkamp. To help ensure clarity of understanding, the researcher sought advice from Mr. Kottkamp regarding the grouping and naming of the formal documents referenced in this dissertation. Mr. Kottkamp is based in Richmond, Virginia and is the founder and chair of National Healthcare Decisions Day®,<sup>173</sup> an event held in the United States on the day after taxes are due each year in April.<sup>173</sup> It is a day set aside to remind the public as well as healthcare providers of the importance of advance care planning through education, inspiration, and empowerment.<sup>173</sup> This initiative seeks to encourage patients to express their healthcare wishes and for providers to respect them, regardless of what they are.

While there are various ways to document one's healthcare wishes for the end of life, access to this information remains an issue. It is important for surrogate decision makers to be aware of the existence of formal end-of-life planning documents, their location and the details therein. Black et al<sup>172</sup> confirmed that the usefulness of an advance directive is limited to its content. Therefore, it is important that family caregivers are also

aware of the details within the existing end-of-life care planning document. In addition to the benefits of completing such a document, individuals and families may choose to upload advance directives to the National Living Will Registry®.<sup>174</sup> This may help to ensure documents are stored; however, they must remain updated at least annually or when there is a change in an individual's health condition. However, costs that may be associated with this service may be a barrier to use for some individuals and families.

Average completion rates of formal advance care planning documents among African Americans are low.<sup>118,130,171,175</sup> Higher than normal averages of both formal end-of-life care planning documents and documents of agency completion seen in this dissertation are potentially due to the dementia diagnosis and the lack of (or impending lack of) decision-making capacity that characterizes this disease. Additionally, the inclusion of PACE participants may have increased the number of care recipients with formal end-of-life care plans because of a focus in this program on including end-of-life discussions early on in the plan of care. However, the study results are evidence to support possible new trends in improvements in end-of-life planning among African Americans.<sup>176</sup> This information provides hope regarding this important healthcare outcome. For these individuals, dementia may add another layer of complexity to disparities in medical decision making faced by racial and ethnic minorities such as African Americans.<sup>2</sup> Potential factors related to these differences were previously discussed in the literature review section (Chapter II).

End-of-life planning among the group of African Americans with dementia referenced in this study contradicts what is often found in healthcare literature. Reasons for this finding are possibly multifactorial and include: 1) all care recipients had

dementia, 2) influence of PACE Program advance care planning policies, and 3) only African Americans were studied, as there was no comparison group. African Americans when compared to non-African Americans, particularly Caucasians, may continue to fall short in terms of end-of-life planning. However, these results and that of a recent dissertation study<sup>176</sup> support that there may be a shift in end-of-life planning among African Americans for the better. This change will hopefully result in improvements in death experience for these individuals as well as those who love and care for them.

### **Specific Aim 2**

Family caregivers in this study rated their care recipients' overall HRQOL as high. For the group of African Americans studied in this dissertation, unlike in other research studies, the numbers of those with formal or informal end-of-life care plans were also high. Nevertheless, those two outcomes were not found to be related. The mean overall HRQOL for care recipients with a formal end-of-life care planning document (75) was only slightly higher than that of care recipients without a formal end-of-life care planning document (72). There was no statistically significant difference in mean total HRQOL scores for care recipients with at least one formal end-of-life care planning document and those with no formal end-of-life care planning document known to the caregivers. It must be noted however, that the family caregiver's perceived HRQOL for the care recipient at the time of completion of the end-of-life care plan document was unknown, and it is possible that that would be related to the existence of a plan. A specific question is whether a particular level of perceived HRQOL triggers the completion of an end-of-life care plan.

In a study of African American dialysis surrogates' predictions of end-of-life

preferences for their loved ones Song et al<sup>177</sup> found that when care recipients preferred comfort care (67.2%-69%), family caregiver predictions were congruent only 34.5% of the time. This level of inaccuracy towards goals of care persisted even when surrogate self-efficacy levels were high.<sup>177</sup> These findings further stress the need for formal end-of-life care planning as documented evidence of understanding of care recipient preferences as oftentimes assumptions may be inaccurate, resulting in failure to honor a loved one's healthcare wishes towards the end of life.

### **Impact of Program of All-Inclusive Care for the Elderly**

Among care recipients who were enrolled in PACE programs, only one did not have a formal end-of-life care plan. However, this individual was newly enrolled. The family caregiver confirmed that conversations were already underway regarding end-of-life planning for the care recipient. This finding was indicative of the efforts of PACE programs to address this important decision in advance of imminent death or further decline in health. The model of care used at PACE programs involves a holistic care team that includes a social worker, chaplain, nurse and physician, all whom can be involved in the advance care planning process. With the PACE model, participants and their families are provided the opportunity to begin the end-of-life planning process and ask questions. This includes the ability to revisit plans as needed. Assistance with actual form completion is also provided. This is done without the usual time pressures as in acute care settings, during serious illness or imminent death. In addition to this finding, family caregivers of loved ones enrolled in PACE programs were well versed on meaning of words commonly associated with end of life and end-of-life planning, more so than those family caregivers who were not. An example of this is that those family caregivers

associated with PACE programs often spoke comfortably about death and their care recipients' wishes towards the end of life. This model should serve as an exemplar for healthcare organizations to consider.

Findings of this pilot study provide empirical evidence to support the fact that African Americans do plan for the end of life. As seen in this study, this plan sometimes includes a completed document and other times oral or verbal discussion with loved ones. The latter, if nothing else, provides a basis on which family caregivers can make decisions that are somewhat aligned, as best they can, with the values of their loved ones. Armed with this information, family members can potentially feel less regretful of their decisions as healthcare providers provide direction based on the medical status of their loved one. This study consisted entirely of family caregivers for an individual with dementia. Evidence exists that this can be a game changer when it comes to end-of-life planning and decision making. With this disease, the older adult with dementia and or the family caregiver is usually made aware that the care recipient's capacity for decision making has ceased or will cease to exist in the future. This is also true for almost any end-stage chronic disease (and also some acute) which results in death, as the likelihood is great that many individuals will one day require a trusted family member or friend to make very important (life and death) decisions on their behalf.

Programs such as PACE are influential in ensuring that end-of-life education and follow through on completion of advance care planning documents (formal end-of-life care plans) are a priority.<sup>82</sup> In the current study, PACE enrollees were more likely to have an end-of-life care plan document than those not enrolled in PACE (75% for PACE enrollees, 59.2% for those not in PACE). In the general U.S. population, persons who are

institutionalized are more likely to have a plan,<sup>139,140</sup> These findings support the benefits of the end-of-life planning support offered by PACE Programs to assist in meeting the end-of-life wishes of PACE participants and their loved ones. In this study, family caregivers of PACE enrollees often spoke highly of the PACE social workers and nurses and of the education and support which they have received from them on a continued basis.

During participant interactions where care recipients were enrolled in PACE programs, family caregivers were more apt to communicate their care recipients' end-of-life wishes with confidence. This finding may be because PACE programs offer to assist their participants and families with addressing and revisiting this process. For example, according to Director of Advance Care Planning, Carol Wilson, (written communication, April 2016) with Riverside Health System Center for Excellence in Aging and Lifelong Health, advance care planning facilitators are certified through Respecting Choices®.<sup>178</sup> Respecting Choices is an evidence-based advance care planning model of care that provides a coordinated, systematic approach to transforming care.<sup>178</sup> It is used by many healthcare systems nationally and internationally.<sup>178</sup> Trained facilitators at Riverside PACE Programs are typically social workers and chaplains. Nurses are also sometimes trained. It is recommended that PACE physicians and nurse practitioners attend the Respecting Choices® Training Program in its entirety. According to Ms. Wilson, through a very coordinated effort, PACE has devised a process of identifying existing plans such as advance directives, medical power of attorney, Physician Orders for Scope of Treatment (POST) at or before enrollment. This promotes strategic maintenance of such important documents. Also according to Ms. Wilson, (written communication, April



2016) the healthcare provider (physician or nurse practitioner) completes a clinical assessment, discusses the care recipient's condition and establishes the care recipient's goals as longevity, function or comfort. The goal is that there is an explicit agreement on an advance care plan within 30 days of enrollment. For instance, family caregivers with loved ones enrolled in PACE programs were well educated on the subject of end-of-life planning. Therefore, they knew that when a healthcare provider asked about end-of-life, they were referencing plans before death.

Originally included in the 2010 *Patient Protection and Affordable Care Act*, a provision for healthcare provider reimbursement for advance care planning was removed due to the association with “death panels” as hailed by a group of pundits, bloggers, op-ed writers, talk-show hosts and legislators.<sup>2</sup> However, as of January 1<sup>st</sup> 2016, Centers for Medicare and Medicaid Services permits healthcare providers to include and bill Medicare beneficiaries for advance care planning.<sup>179</sup> Any coinsurance and deductible are waived if the advance care planning occurs as part of their annual wellness visit.<sup>179</sup>

### **Conceptual Framework Revisited**

The *Dimensions Associated with Decision Making at the End of Life of a Relative with Dementia*,<sup>180</sup> was used to develop the Framework of End-of-Life Decision Making in Dementia by Family Caregivers which guided this study. According to this framework care recipient quality of life was central to the decision-making process.<sup>180</sup> This concept was recognized as important as described by family caregivers qualitatively. Quantitative measurements revealed that the mean overall HRQOL for care recipients with a formal end-of-life care planning documents was only slightly higher than that of care recipients without a formal end-of-life care planning document. However, no significant

relationship was found between the existence of a care plan and the family caregiver's perceived HRQOL for the care recipient, as measured at the time of this study. It is still possible that there is a relationship between the existence of an end-of-life care document and the HRQOL, if the latter is measured at the time the end-of-life care document is created. In this study sample, age (demographics) and number of comorbidities (general health) of the care recipient were significantly associated in the model with the existence of a formal end-of-life care planning document.

### **Dementia, Age, and Comorbidities**

The 2014 Institute of Medicine report on *Dying in America*, focuses on changing demographics including an aging society, a more culturally diverse and vulnerable population.<sup>2</sup> In this dissertation study, because of the focus on family caregivers of persons with dementia, there was a particular tendency to need a surrogate decision maker and/or end-of-life care plans due to the diagnosis of dementia and concomitant advanced age of the care recipients. Older persons tend to have higher rates of chronic conditions.<sup>138</sup>

Dementia is primarily a disease of old age.<sup>2</sup> As demonstrated in this study, increased age was estimated to raise the likelihood care recipients possessed a formal end-of-life care planning document. Perhaps, the older care recipients were, the more ill/frail they were, prompting a need for advance care planning. Increased numbers of comorbidities also correlated with increased formal end-of-life care plan completion. Increased comorbidities may also make frailty of the older adult more obvious and thus increased the expectation of the future (or near future) need for surrogate end-of-life decision making. Also, increased comorbidities may increase the need for more medical

specialists on the care recipient's healthcare team, increasing the likelihood of end-of-life planning being discussed and documented. While care recipient age and number of comorbidities might be expected to be correlated as they represented two measurements of the same influence, in fact, the correlation between them was 0.007.

### **Study Limitations**

Although these results show huge promise in increased end-of-life planning among African Americans, some limitations are noted. Participant recruitment, socially desirable responses, and limits with the study design were inherent limitations that reduce generalizability of this study.

### **Participant Recruitment**

Challenges persist with recruitment of African Americans into research studies because of potential distrust/mistrust of the U.S. healthcare system.<sup>10-19</sup> This may have inhibited some persons from participating in this dissertation study. The strategic selection of the study recruitment sites (because of the higher numbers of African American in the populations) and lower care recipient age limits was an attempt to offset this issue. The snowball method of recruitment was adopted as a strategy to seek potential participants. Racial similarity of the researcher to potential participants may have served as a positive component for establishing and maintaining a trusting relationship.

The researcher found that community engagement was hugely beneficial to recruitment among African Americans. Opportunities such as health fairs and other community-based events provided prime opportunities for accessing this population. This method allowed potential study participants to remain in a non-threatening environment

allowing for open sharing of information. Additionally, the researcher was also Black and this may have facilitated the recruitment process or reduced barriers of discussing this sensitive issue of end-of-life decision making.

### **Limits of Study Design**

Data collection for this study was cross-sectional. One point-in-time measurement does not capture the dynamic fluctuation of uncertainty across trajectory, and any significance determined in this pilot study, must be interpreted with caution.<sup>181</sup> Further research is critical to understanding this experience longitudinally, along with knowledge of the stage of dementia at the time of data collection.<sup>181</sup> This study crossed several geographic communities, resulting in little time for the study nurse to establish relationships in them all (as suggested by Corbie-Smith et al., in 2007).<sup>161</sup> However, careful consideration was placed on courtesy and respect with all participants. Mixed methods analysis is time intensive,<sup>142</sup> as such time had to be allocated for this process. Therefore, the researcher placed much effort into organizing around time and details of this study.

The researcher conducted all data collection for consistency. Timing of everyday calendar events and other life experiences such as holidays, family member visits or childbirth were used to assist caregivers in accuracy of recall for timing of memory loss/diagnosis of dementia in the care recipient. The small sample size limits generalizability, but will likely provide valuable data and information for improvements for a larger, fully-powered, more rigorous study.

### **Collection of Socially Desirable Responses**

For this study six strategies were delineated based on lessons learned in studies conducted by Shavers-Hornaday and Lynch,<sup>182</sup> and by Yancey, Ortega, and Kumanyika<sup>183</sup> These strategies included: 1) the researcher uniformly conduct all interviews; 2) qualitative and research practicum coursework provide insight into and opportunities to conduct the interview process; 3) attention paid to researcher self-awareness by withholding what could have been perceived as decisional cues; 4) special attention given to wording of questions on the study forms and Interview Guide to help ensure that they remain non-biased; 5) avoidance of verbal and nonverbal prompts during the interview process to circumvent any suggestions as to which responses were considered more appropriate; and 6) prior to the interview, participants were reminded to report authentic responses regardless of any perceived threats of judgment.

### **Conclusions**

This dissertation contributes to the growing body of literature on end of life in African Americans. Findings revealed high completion rates of formal end-of life care planning documents (advance directives, living will, DNR, and /or POST forms) as well as documents of agency (power of attorney/healthcare surrogate or guardianship forms) in this group of African American older adults with dementia. Mean scores for care recipient HRQOL as measured by the ADRQL, and for family caregiver self-efficacy for surrogate decision making as measured by the SDM-SES, were also high. However, no significant relationship was found between the existence of a formal end-of-life care planning document and either care recipient HRQOL or family caregiver self-efficacy for surrogate decision making. Age and number of comorbidities of the care recipients did

have significant estimated effects on the outcome of having a formal end-of-life care plan. Specifically, the probability of having a formal end-of-life care plan was estimated to increase as the age of the care recipient and the number of comorbidities increase. High rates of oral/verbal end-of-life care plans were also observed in this sample.

Evidence of differences in meaning of end-of-life terminology was demonstrated through qualitative interviews. Study participants provided empirical evidence that end-of-life decision making in this population of African American older adults with dementia is a process which involves family members and multiple resources such as healthcare providers, reliance on faith or spirituality, and past experiences. This study is the initial work of this researcher towards a future research trajectory focused on this important healthcare outcome.

### **Implications for Future Research**

The population of focus for this dissertation study is African American/Blacks as they represent a very specific subset of society that remains significantly understudied, particularly as it relates to end-of-life planning. Evidence supports recognition of nurses along with the remainder of the healthcare team as key influencers to this decision-making process. Therefore, involvement of physicians, social workers, chaplains, and healthcare administrators is important towards improving this healthcare outcome. Particularly, among African Americans, key community stakeholders such as church leaders (pastors, priests, deacons, and elders) may be instrumental in accessing this population. These individuals have a unique ability to “open doors” to this population and encourage those in it towards improving health outcomes. Thus programs offered by churches that focus on starting and maintaining the important conversations can be

beneficial to improving end-of-life planning. An example of this is the *Faith to Fate Advance Care Planning Initiative* that targets African Americans via local churches in Richmond, Virginia via a locally accessible, affordable, legally assisted advance care planning program. According to program director, Ivan Tolbert, this award-winning program has assisted 450 individuals in legally completing their advance care planning documents free of charge (written communication, May 2016).

Empirical evidence exists as proof of the impact of end-of-life education interventions. In a longitudinal study containing 141 African American patients with renal failure (67.4% of the sample) and 142 of their surrogates, researchers using the Sharing Patient's Illness Representations to Increase Trust (SPIRIT) program educated dialysis dyads and found an association between dyad preparation for end-of-life decision making and surrogate bereavement outcomes.<sup>184</sup> This was also observed in a preceding randomized control trial of SPIRIT in a population of African Americans.<sup>124,184</sup> In both of these studies success of this program was attributed to the fact that the focus was on assisting patients and surrogates to discuss possibilities of end-of-life decision making and feelings about options near the end of life versus advance directive completion.<sup>124</sup> However, additional work testing a community-based end-of-life education program in dementia is warranted. Such a program can potentially meet individuals and families as is convenient and comfortable for them. More importantly, studies may be required to examine perceptions of end-of-life education further in dementia family caregivers longitudinally to determine family caregiver outcomes of end-of-life planning for themselves in relations to end-of-life experiences for those whom previously served as surrogate decision makers. Additionally, details contained within the formal end-of-life

care planning documents need to be examined by researchers. If these high rates of end-of-life planning among African American dementia family caregivers hold true in fully powered studies, this subset of individuals may serve as exemplars for other groups of African Americans as well as other ethnicities.

One poignant reminder of the fatality of dementia was the fact that the researcher (unprompted and unsolicited) received reports of the demise of two care recipients whose family caregivers were previously enrolled in this study. A recent, refreshing, reminder of improvements in death outcomes due to dementia was a retrospective decline in the dementia risk in the *Framingham Heart Study*.<sup>185</sup> Satizabal et al<sup>185</sup> reported in April 2016 that *Framingham Heart Study* researchers noted a decline in the rate of dementia cases among 60<sup>+</sup> year old study participants who had at least a high school education.<sup>185</sup> This progressive risk reduction was measured over three decades (1975-2005) and contributing factors towards this decline remain largely unexplained.<sup>185</sup> Specific racial demographics of this sample with this positive outcome were not reported.<sup>185</sup> Literature remains sparse as it relates to specific demographic characteristics on African Americans with dementia, therefore more research is needed to provide this information.<sup>27</sup>

### **Future Research**

Findings from this study support the statement from the 2014 Institute of Medicine report on *Dying in America*<sup>2</sup> that quality and availability of medical/social services for patients and families may enhance quality of life through the end of life.<sup>2</sup> Also in keeping with the findings of this landmark report, this dissertation study also supports the foundation for effective communication is that the meaning patients and families attach to healthcare terminology should be aligned with the healthcare providers'



understanding of the terminology.<sup>2</sup> Results of this study provide a basis for future interventions studies to help empower African Americans caring for older adults with dementia to make more informed, timelier end-of-life decisions. Further data are needed to examine the number of African Americans with dementia with advanced care plans, whether or not they are associated with a healthcare facility (daycare or long-term care) and compare these findings with their quality of life as perceived by their family caregivers. The results of this study will inform a program of research that will provide the basis for future interventions to help empower African Americans caring for their older adults with dementia to make more informed, timelier end-of-life decisions.

In addition to future research based on findings from this analysis, data collected during this study on HRQOL in dementia family caregivers will be analyzed. These data were collected using the Short Form Health Survey version 2 (SF-36v2) and will be compared and contrasted with the qualitative data collected on family caregiver HRQOL and also the results presented in this dissertation. Additionally, this work will be used to help to provide additional data to support the results of existing research on distance caregiving based findings from a recent systematic literature review.<sup>186</sup>

The importance of the knowledge gained from this pilot study is potentially large. Knowledge gleaned can provide a means by which to personalize the approach used to address end-of-life care in the African American dementia population. It is hoped that by gaining insight on this subject, this program of research will assist African American individuals in making informed end-of-life care choices in a timely manner. By honoring the wishes of care recipients near the end of life within this dementia population other members of the family unit may be compelled to make necessary plans for the end of

their own lives. Another benefit of the knowledge gained may assist researchers in developing and testing a culturally tailored intervention specific to the needs of this African American population. These study findings provided both quantitative and qualitative data that can assist healthcare providers in improving the care that African American care recipients with dementia receive.

The benefits greatly outweighed the risks for this non-invasive, cognitive-behavioral, pilot study. There is a chance that participation in the interview was cathartic for some individuals enrolled in the study. This process might also motivate some family caregivers to begin to address the issue of end-of-life care for their care recipient. If family caregivers are able to observe a more peaceful death experience in their care recipient, this may inspire them to make arrangements for their own end-of-life care in advance. This would be an added, but not immediate, potential benefit of being a participant in this study.

## REFERENCES

1. Miles MB, Huberman AM, Saldana J. *Qualitative data analysis: A methods sourcebook*. 3rd ed. Thousand Oaks, California: Sage Publications Inc.; 2014.
2. Institute of Medicine of the National Academies. Dying in America: Improving quality and honoring individual preferences near the end of life. 2014.  
[http://www.nap.edu/catalog.php?record\\_id=18748](http://www.nap.edu/catalog.php?record_id=18748); Accessed September 17, 2014.
3. The Library of Congress Thomas. Patient self-determination act of 1990. 101st Congress. H.R.4449. <http://thomas.loc.gov/cgi-bin/query/z?c101:H.R.4449.IH>: Accessed February 14, 2011.
4. Connors AF, Jr, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously III hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA*. 1995;274(20):1591-1598.
5. Institute of Medicine of the National Academies. Approaching death: Improving care at the end of life. In M. J. Field & C. K. Cassel (Eds.). 1997.  
[http://www.nap.edu/catalog.php?record\\_id=5801](http://www.nap.edu/catalog.php?record_id=5801) Accessed January 12, 2012.
6. Moss KO, Williams IC. End-of-life preferences in Afro-Caribbean older adults: A systematic literature review. *Omega: Journal of Death & Dying*. 2014;69(3):271-282.  
<http://search.ebscohost.com/login.aspx?direct=true&db=ehh&AN=98623086&site=ehost-live>. doi: 10.2190/OM.69.3.c.
7. Hogan C, Lunney J, Gabel J, Lynn J. Medicare beneficiaries' costs of care in the last year of life. *Health Affairs*. 2001;20(4):188-195. doi: 10.1377/hlthaff.20.4.188.
8. End of life. NIH Senior Health National Institutes of Health Web site.  
<http://nihseniorhealth.gov/endoflife/preparingfortheendoflife/01.html>. Published 2012.

Accessed June 15, 2014.

9. Volker DL. Control and end-of-life care: Does ethnicity matter? *American Journal of Hospice and Palliative Medicine*. 2005;22(6):442-446.

doi:10.1177/104990910502200610

10. Waters CM. Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. *Qualitative Health Research*. 2001;11(3):385-398. doi: 10.1177/104973201129119172.

11. Barrett RK. Dialogues in diversity: An invited series of papers, advance directives, DNRs, and end-of-life care for African Americans. *Omega: Journal of Death & Dying*. 2005;52(3):249-261.

12. Johnson KS, Kuchibhatala M, Sloane RJ, Tanis D, Galanos AN, Tulsky JA. Ethnic differences in the place of death of elderly hospice enrollees. *J Am Geriatr Soc*. 2005;53(12):2209-2215.

13. Winter L, Dennis MP, Parker B. Religiosity and preferences for life-prolonging medical treatments in African-American and white elders: A mediation study. *OMEGA*. 2007;56(3):273-288.

14. Daaleman TP, Emmett CP, Dobbs D, Williams SW. An exploratory study of advance care planning in seriously ill African-American elders. *J Natl Med Assoc*. 2008;100(12):1457-1462.

15. Allen JY, Hilgeman MM, Allen RS. Prospective end-of-life treatment decisions and perceived vulnerability: Future time left to live and memory self-efficacy. *Aging & Mental Health*. 2011;15(1):122-131. doi: 10.1080/13607863.2010.505229.

16. Kelley AS, Ettner SL, Morrison RS, Du Q, Wenger NS, Sarkisian CA. Determinants of medical expenditures in the last 6 months of life. *Ann Intern Med.* 2011;154(4):235-242. Accessed February 15, 2011.
17. Nicholas LH, Langa KM, Iwashyna TJ, Weir DR. Regional variation in the association between advance directives and end-of-life Medicare expenditures. *JAMA.* 2011;306(13):1447-1453. Accessed October 5, 2011.
18. Carr D. The social stratification of older adults' preparations for end-of-life health care. *Journal of Health and Social Behavior.* 2012;53(3):297-312. doi: 10.1177/0022146512455427
19. Wicher CP, Meeker MA. What influences African American end-of-life preferences? *J Health Care Poor Underserved.* 2012;23(1):28-58.  
doi:<http://dx.doi.org/10.1353/hpu.2012.0027>. Accessed October 10, 2012.
20. Bullock K. Social work series. Promoting advance directives among African Americans: A faith-based model. *J Palliat Med.* 2006;9(1):183-195.
21. Bullock K. The influence of culture on end-of-life decision making. *Journal of Social Work In End-Of-Life & Palliative Care.* 2011;7(1):83-98.
22. Campbell CL, Williams IC, Orr T. Factors that impact end-of-life decision making in African Americans with advanced cancer. *Journal of Hospice & Palliative Nursing.* 2010;12(4):214-224. doi: 10.1097/NJH.0b013e3181de1174.
23. Johnson KS, Kuchibhatla M, Payne R, Tulsky JA. Race and residence: Intercounty variation in Black-White differences in hospice use. *J Pain Symptom Manage.* 2013;46(5):681-690. doi: <http://dx.doi.org/10.1016/j.jpainsymman.2012.12.006>.

24. Johnson KS, Kuchibhatla M, Tulsy JA. What explains racial differences in the use of advance directives and attitudes toward hospice care? *J Am Geriatr Soc*. 2008;56(10):1953-1958. doi: 10.1111/j.1532-5415.2008.01919.x.
25. The Black population: 2010. United States Census Bureau Web site. Updated 2011. Accessed September 12, 2012.
26. *National vital statistics reports*. Centers for Disease Control & Prevention Web site. <http://www.cdc.gov/nchs/products/nvsr.htm#vol63>. Updated 2014. Accessed May 1, 2014.
27. Alzheimer's Association. 2016 Alzheimer's disease facts and figures. [http://www.alz.org/documents\\_custom/2016-facts-and-figures.pdf](http://www.alz.org/documents_custom/2016-facts-and-figures.pdf). Accessed April 20, 2016.
28. Vickrey BG, Hays RD, Maines ML, Vassar SD, Fitten J, Strickland T. Development and preliminary evaluation of a quality of life measure targeted at dementia caregivers. *Health Qual Life Outcomes*. 2009;7:56. doi: <http://dx.doi.org/10.1186/1477-7525-7-56>. Accessed October 13, 2013.
29. Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology*. 2013. doi:10.1212/WNL.0b013e31828726f5.
30. Ready RE, Ott BR. Quality of life measures for dementia. *Health Qual Life Outcomes*. 2003;1:11. doi:10.1186/1477-7525-1-11. Accessed January 16, 2008.
31. Kuo L, Huang H, Hsu W, Shyu YL. Health-related quality of life and self-efficacy of managing behavior problems for family caregivers of vascular dementia and Alzheimer's

disease patients. *Dement Geriatr Cogn Disord*. 2014;38(5-6):310-320. doi:

<http://dx.doi.org/10.1159/000360414>. Accessed October 17, 2014.

32. Bruvik FK, Ulstein ID, Ranhoff AH, Engedal K. The quality of life of people with dementia and their family carers. *Dement Geriatr Cogn Disord*. 2012;34(1):7-14. doi: 10.1159/000341584; 10.1159/000341584.

33. Arango-Lasprilla JC, Lehan T, Drew A, Moreno A, Xiaoyan Deng, Lemos M. Health-related quality of life in caregivers of individuals with dementia from Colombia. *American Journal of Alzheimer's Disease and Other Dementias*. 2010;25(7):556-561. doi: 10.1177/1533317510382287.

34. Ducharme JK, Geldmacher DS. Family quality of life in dementia: A qualitative approach to family-identified care priorities. *Qual Life Res*. 2011;20(8):1331-1335. Accessed September 22, 2011. doi: <http://dx.doi.org/10.1007/s11136-011-9852-4>.

35. Fact sheet: Selected caregiver statistics. Family Caregiver Alliance National Center on Caregiving Web site. [https://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=439](https://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439). Updated 2012. Accessed March 23, 2013.

36. Rose KM, Williams IC. Family matters. Family quality of life in dementia. *J Gerontol Nurs*. 2011;37(6):3-4. doi: 10.3928/00989134-20110503-06; 10.3928/00989134-20110503-06.

37. Allen RS, Kwak J, Lokken KL, Haley WE, Haley WE. End of life issues in the context of Alzheimer's disease. *Alzheimer's Care Q*. 2003;4(4):212; 212-230; 230. doi:[10.1901/jaba.2003.4-312](https://doi.org/10.1901/jaba.2003.4-312)

38. Elliott BA, Gessert CE, Peden-McAlpine C. Family decision-making in advanced dementia: Narrative and ethics. *Scand J Caring Sci*. 2009;23(2):251-258. doi: 10.1111/j.1471-6712.2008.00613.x.
39. Gardner DS, Kramer BJ. End-of-life concerns and care preferences: Congruence among terminally ill elders and their family caregivers. *Omega: Journal of Death & Dying*. 2009;60(3):273-297. doi: 10.2190/OM.60.3.e.
40. Campbell CL, Ash CR. Keeping faith. *Journal of Hospice & Palliative Nursing*. 2007;9(1):31-41.
41. Braun UK, Beyth RJ, Ford ME, McCullough LB. Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *JGIM: Journal of General Internal Medicine*. 2008;23(3):267-274. doi: 10.1007/s11606-007-0487-7.
42. Caron CD, Griffith J, Arcand M. End-of-life decision making in dementia: The perspective of family caregivers. *Dementia*. 2005;4(1):113-136. doi: 10.1177/1471301205049193.
43. Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. *J Adv Nurs*. 2012;68(4):846-855. doi: 10.1111/j.1365-2648.2011.05787.x [doi].
44. Bekhet AK. Resourcefulness in African American and Caucasian American caregivers of persons with dementia: Associations with perceived burden, depression, anxiety, positive cognitions, and psychological well-being. *Perspect Psychiatr Care*. 2015;51(4):285-294. doi: 10.1111/ppc.12095 [doi].
45. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: A



clinical review. *JAMA*. 2014;311(10):1052-1060. doi:10.1001/jama.2014.304. Accessed 20140312.

46. Guerra M, Ferri CP, Fonseca M, Banerjee S, Prince M. Helping carers to care: The 10/66 dementia research group's randomized control trial of a caregiver intervention in Peru. *Revista Brasileira de Psiquiatria*. 2011;33(1):47-54.

47. Takai M, Takahashi M, Iwamitsu Y, et al. The experience of burnout among home caregivers of patients with dementia: Relations to depression and quality of life. *Arch Gerontol Geriatr*. 2009;49(1):e1-e5. doi: <http://dx.doi.org/10.1016/j.archger.2008.07.002>.

48. Gusi N, Prieto J, Madruga M, Garcia JM, Gonzalez-Guerrero JL. Health-related quality of life and fitness of the caregiver of patient with dementia. *Medicine & Science in Sports & Exercise*. 2009;41(6):1182-1187. Accessed May 25, 2009.

49. Belle SH, Burgio L, Burns R, et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Ann Intern Med*. 2006;145(10):727-738.

50. Andrieu S, Rive B, Guilhaume C, et al. New assessment of dependency in demented patients: Impact on the quality of life in informal caregivers. *Psychiatry Clin Neurosci*. 2007;61(3):234-242. doi: 10.1111/j.1440-1819.2007.01660.x.

51. Serving African American families home and community based services for people with dementia and their caregivers. Alzheimer's Association. n.d. [www.aoa.gov/AoARoot/AoA.../Toolkit4\\_AfricanAmericans.pdf](http://www.aoa.gov/AoARoot/AoA.../Toolkit4_AfricanAmericans.pdf) Accessed September 16, 2013.

52. Hanchate A, Kronman AC, Young-Xu Y, Ash AS, Emanuel E. Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites? *Arch Intern Med*. 2009;169(5):493-501. doi:10.1001/archinternmed.2008.616.
53. Phipps E, Braitman LE, True G, Harris D, Tester W. Family care giving for patients at life's end: Report from the cultural variations study (CVAS). *Palliative & Supportive Care*. 2003;1(2):165-170.
54. *Achieving good end of life care for people with dementia*. St. Christopher's Hospice Web site. 2014. <http://www.stchristophers.org.uk/education/course/achieving-good-end-of-life-care-for-people-with-dementia>. Updated 2014. Accessed July 15, 2014.
55. Volicer L. Goals of care in advanced dementia: Quality of life, dignity and comfort. *J Nutr Health Aging*. 2007;11(6):481.
56. *About Alzheimer's disease: Alzheimer's disease basics*. National Institute on Aging Website. n.d. <http://www.nia.nih.gov/alzheimers/topics/alzheimers-basics>. Accessed August 5, 2014.
57. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med*. 2009;361(16):1529-1538. doi: 10.1056/NEJMoa0902234 [doi].
58. Walker A. Culture, socialization, and end-of-life decision making. In Meagher, D. K. & Balk, D. E. (Eds.). *Handbook of thanatology: The essential body of knowledge for the study of death, dying, and bereavement*. 2<sup>nd</sup> ed, pp. 53-61: New York, NY; Routledge. 2013
59. Bandura A, Caprara GV, Barbaranelli C, Regalia C, Scabini E. Impact of family efficacy beliefs on quality of family functioning and satisfaction with family life. *Appl Psychol*. 2011;60(3):421-448. doi: 10.1111/j.1464-0597.2010.00442.x.

60. Conner NE, Chase SK. Decisions and caregiving: End of life among Blacks from the perspective of informal caregivers and decision makers. *American Journal of Hospice and Palliative Medicine*. 2014. doi: 10.1177/1049909114529013.
61. Jenkins C, Lapelle N, Zapka JG, Kurent J E. End-of-life care and African Americans: Voices from the community. *J Palliat Med*. 2005;8(3):595-592.
62. Mazanec PM, Daly BJ, Townsend A. Hospice utilization and end-of-life care decision making of African Americans. *American Journal of Hospice and Palliative Medicine*. 2010;27(8):560-566. doi: 10.1177/1049909110372087.
63. Dupree CY. The attitudes of Black Americans toward advance directives. *Journal of Transcultural Nursing*. 2000;11(1):12-18. doi: 10.1177/104365960001100104.
64. Perkins HS, Geppert CM, Gonzales A, Cortez JD, Hazuda HP. Cross-cultural similarities and differences in attitudes about advance care planning. *Journal of General Internal Medicine*. 2002;17(1):48-57. doi: [10.1046/j.1525-1497.2002.01032.x](https://doi.org/10.1046/j.1525-1497.2002.01032.x)
65. Barrett RK. The African American call to gather: An enduring cultural tradition. *The FORUM: Association for Death Education and Counseling, Inc*. 2012;38(1):11.
66. Johnson CL, Barer BM. Families and networks among older inner-city Blacks. *The Gerontologist*. 1990;30(6):726-733. doi: 10.1093/geront/30.6.726.
67. Campbell CL. Respect for persons: Engaging African Americans in end-of-life research. *Journal of Hospice & Palliative Nursing*. 2007;9(2):74-78.  
doi:10.1097/01.NJH.0000263528.91929.0d.
68. Kypriotakis G, Francis LE, O'Toole E, Towe TP, Rose JH. Preferences for aggressive care in underserved populations with advanced-stage lung cancer: Looking beyond race

and resuscitation. *Supportive Care in Cancer*. 2014;22(5):1251-1259. doi:

10.1007/s00520-013-2079-x. Accessed March 28, 2014.

69. Berlinger N, Jennings B, Wolf SM. *The Hasting's center guidelines for decisions on life-sustaining treatment and care near the end of life*. 2<sup>nd</sup> ed. New York, NY: Oxford University Press. 2013.

70. Corr CA, Corr DM. Culture, socialization & dying. In Meagher, D. K. & Balk, D. E. (Eds.). *Handbook of thanatology: The essential body of knowledge for the study of death, dying, and bereavement*. 2<sup>nd</sup> ed, pp. 3-8, New York, NY: Routledge. 2013.

71. Johnson KS, Kuchibhatla M, Tulsky JA. Racial differences in self-reported exposure to information about hospice care. *J Palliat Med*. 2009;12(10):921-927. doi: 10.1089/jpm.2009.0066.

72. Whitfield KE, Allaire JC, Belue R, Edwards CL. Are comparisons the answer to understanding behavioral aspects of aging in racial and ethnic groups? *Journals of Gerontology Series B-Psychological Sciences & Social Sciences*. 2008;63(5):P301-8. doi: 10.1093/geronb/63.5.P301. Accessed September 8, 2012.

73. DeSpelder LA, Strickland AL. Culture, socialization & death education. In Meagher, D. K. & Balk, D. E. (Eds.). *Handbook of thanatology: The essential body of knowledge for the study of death, dying, and bereavement*. New York, NY: Routledge. 2013.

74. Lattanzi-Licht M. Religion, spirituality and dying. In Meagher, D. K. & Balk, D. E. (Eds.). *Handbook of thanatology: The essential body of knowledge for the study of death, dying, and bereavement*. 2<sup>nd</sup> ed, pp. 9-16). New York, NY: Routledge. 2013.

75. Gerst K, Burr JA. Planning for end-of-life care: Black-White differences in the completion of advance directives. *Research on Aging*. 2008. doi: 10.1177/0164027508316618.
76. Steinhauser KE, Alexander SC, Byock IR, George LK, Olsen MK, Tulsky JA. Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *J Palliat Med*. 2008;11(9):1234-1240. doi: 10.1089/jpm.2008.0078. Accessed November 21, 2013.
77. Barrett RK. *Sociocultural considerations: African Americans, grief, and loss*. In: Doka, K. J. & Tucci, A. S, ed. *Living with grief: Diversity and end-of-life care*. Washington, D.C: Taylor & Francis Publishers, Inc.; 2009:83-96.
78. Dose AM, Leonard B, McAlpine CP, Kreitzer MJ. The meaning of spirituality at the end of life. *Journal of Hospice & Palliative Nursing*. 2014;16(3):158-164. doi: 10.1097/NJH.0000000000000041.
79. True G, Phipps EJ, Braitman LE, Harralson T, Harris D, Tester W. Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. *Annals of Behavioral Medicine*. 2005;30(2):174-179.
80. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "You got to go where he lives". *JAMA*. 2001;286(23):2993-3001. doi:10.1001/jama.286.23.2993.
81. Torke AM, Garas NS, Sexson W, Branch WT. Medical care at the end of life: Views of African American patients in an urban hospital. *Journal of General Internal Medicine*. 2003;18(Supplement 1):277. doi:10.1089/jpm.2005.8.593.

82. Nath SB, Hirschman KB, Lewis B, Strumpf NE. A place called LIFE: Exploring the advance care planning of African-American PACE enrollees. *Soc Work Health Care*. 2008;47(3):277-292. doi: 10.1080/00981380801985432.
83. Taylor RJ, Chatters LM, Jackson JS. Correlates of spirituality among African Americans and Caribbean Blacks in the United States: Findings from the national survey of American life. *J Black Psychol*. 2009;35(3):317-342. doi: 10.1177/0095798408329947
84. Bonner GJ, Wang E, Wilkie DJ, Ferrans CE, Dancy B, Watkins Y. Advance care treatment plan (ACT-plan) for African American family caregivers: A pilot study. *Dementia*. 2012. doi: 10.1177/1471301212449408.
85. Reverby S. *Tuskegee's truths: Rethinking the Tuskegee syphilis study*. Chapel Hill, NC: University of North Carolina Press. 2000.
86. Skloot R. *The immortal life of Henrietta Lacks*. New York, NY: Crown Publishing Group. 2011.
87. Gamble VN. The immortal life of Henrietta Lacks reconsidered. *Hastings Center Report*. 2014;44(1):1. doi:10.1002/hast.239 Accessed January 10, 2014.
88. Bullock K, Hall JK, Leach MT. End-of-life care among older minorities. In Whitfield, K. E. & Baker, T. A. (Eds.), *Handbook of minority aging* (265-276). New York, NY: Springer Publishing Company. 2014.
89. Skloot R. *The immortal life of Henrietta Lacks: A reader's guide*. n.d. [http://rebeccaskloot.com/wp-content/uploads/2011/03/HenriettaLacks\\_RGG.pdf](http://rebeccaskloot.com/wp-content/uploads/2011/03/HenriettaLacks_RGG.pdf). Accessed July 12, 2014.

90. Hollen PJ. A clinical profile to predict decision making, risk behaviors, clinical status, and health-related quality of life for cancer-surviving adolescents: Part 2. *Cancer Nurs.* 2000;23(5):337-343. Accessed October 20, 2013.
91. *Bringing science to life NINR strategic plan.* National Institute of Nursing Research Website. 2010. <http://www.ninr.nih.gov/aboutninr/ninr-mission-and-strategic-plan> Accessed May 12, 2011
92. Mezey M, Kluger M, Maislin G, Mittelman M. Life-sustaining treatment decisions by spouses of patients with Alzheimer's disease. *J Am Geriatr Soc.* 1996;44(2):144-150. doi: 10.1111/j.1532-5415.1996.tb02430.x
93. Givens JL, Lopez RP, Mazor KM & Mitchell SL. Sources of stress for family members of nursing home residents with advanced dementia. *Alzheimer Dis Assoc Disord.* 2012;26(3):254-259. doi: 10.1097/WAD.0b013e31823899e4.
94. Sousa MFB, Santos RL, Arcoverde C, et al. Quality of life in dementia: The role of non-cognitive factors in the ratings of people with dementia and family caregivers. *International Psychogeriatrics.* 2013;25(07):1097-1105. doi:10.1017/S1041610213000410.
95. Lawton MP. Quality of life in Alzheimer disease. *Alzheimer Disease & Associated Disorders.* 1994;8(Suppl 3):138-150. Accessed October 26, 2013.
96. Thomas P, Lalloué F, Preux P, et al. Dementia patients caregivers quality of life: The PIXEL study. *Int J Geriatr Psychiatry.* 2006;21(1):50-56. doi: 10.1002/gps.1422.
97. Clay OJ, Grant JS, Wadley VG, Perkins MM, Haley WE, Roth DL. Correlates of health-related quality of life in African American and Caucasian stroke caregivers.

*Rehabilitation Psychology*. 2013;58(1):28-35. doi: 10.1037/a0031726. Accessed February 26, 2013.

98. Yaffe K, Fox P, Newcomer R, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA*. 2002;287(16):2090-2097. doi:10.1001/jama.287.16.2090.

99. Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *The Gerontologist*. 2002;42(2):237-272. doi: 10.1093/geront/42.2.237.

100. Bradley CJ, Clement JP, Lin C. Absence of cancer diagnosis and treatment in elderly Medicaid-insured nursing home residents. *J Natl Cancer Inst*. 2008;100(1):21-31. doi: 10.1093/jnci/djm271

101. Hargrave R. Caregivers of African American elderly with dementia: A review and analysis. *Annals of Long-term Care*. 2006;14(10).

102. Gaugler JE, Leach CR, Clay T, Newcomer RC. Predictors of nursing home placement in African Americans with dementia. *J Am Geriatr Soc*. 2004;52(3):445-452. doi: 10.1111/j.1532-5415.2004.52120.x

103. Weintraub D, Raskin A, Ruskin PE, et al. Racial differences in the prevalence of dementia among patients admitted to nursing homes. *Psychiatr Serv*. 2000;51(10):1259-1264. doi: 10.1176/appi.ps.51.10.1259 [doi].

104. Riedijk SR, De Vugt ME, Duivenvoorden HJ, et al. Caregiver burden, health-related quality of life and coping in dementia caregivers: A comparison of frontotemporal dementia and Alzheimer's disease. *Dement Geriatr Cogn Disord*. 2006;22(5-6):405-412. doi: 10.1159/000095750.



105. Lokensgard C. *A systematic literature review of effective interventions for African American and Hispanic Alzheimer's caregivers*. [Master's Degree of Social Work]. St. Catherine University University of St. Thomas School of Social Work; 2015.
106. Gallagher D, Ni Mhaolain A, Crosby L, et al. Self-efficacy for managing dementia may protect against burden and depression in Alzheimer's caregivers. *Aging & Mental Health*. 2011;15(6):663-670. doi: 10.1080/13607863.2011.562179. Accessed August 15, 2011.
107. Lopez RP, Guarino AJ. Psychometric evaluation of the surrogate decision making self-efficacy scale. *Res Gerontol Nurs*. 2012:1-6. <http://pubget.com/paper/23244566>; <http://dx.doi.org/10.3928/19404921-20121203-02>. doi: 10.3928/19404921-20121203-02.
108. Fortinsky RH, Kercher K, Burant CJ. Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging & Mental Health*. 2002;6(2):153-160. doi: 10.1080/13607860220126763.
109. Lopez RP, Mazor KM, Mitchell SL, Givens JL. What is family-centered care for nursing home residents with advanced dementia? *American Journal of Alzheimer's Disease & Other Dementias*. 2013;28(8):763-768. doi: 10.1177/1533317513504613. Accessed December 23, 2013.
110. Keefe FJ, Ahles TA, Porter LS, et al. The self-efficacy of family caregivers for helping cancer patients manage pain at end-of-life. *Pain*. 2003;103(1-2):157-162.
111. Bandura A. Perceived self-efficacy in the exercise of personal agency. *Journal of Applied Sport Psychology*. 1990;2(2):128-163.  
<http://www.tandfonline.com/doi/abs/10.1080/10413209008406426>. doi: 10.1080/10413209008406426.

112. Lopez R. Suffering and dying nursing home residents: Nurses' perceptions of the role of family members. *Journal of Hospice and Palliative Nursing*. 2007;9(3):141-149.
113. Lopez RP. Decision-making for acutely ill nursing home residents: Nurses in the middle. *J Adv Nurs*. 2009;65(5):1001-1009. doi: 10.1111/j.1365-2648.2008.04958.x.
114. Lopez RP, Guarino AJ. Uncertainty and decision making for residents with dementia. *Clinical Nursing Research*. 2011;20(3):228-240. doi: 10.1177/1054773811405521.
115. Song M, Ward SE, Lin F, et al. Racial differences in outcomes of an advance care planning intervention for dialysis patients and their surrogates. *J Palliat Med*. 2016;19(2):134-142. doi: <http://dx.doi.org/10.1089/jpm.2015.0232>. Accessed February 4, 2016.
116. Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: A review of the literature. *J Am Acad Nurse Pract*. 2008;20(8):423-428. doi: 10.1111/j.1745-7599.2008.00342.x.
117. Bauer-Wu S, Yeager K, Norris RL, et al. Communication and planning at the end-of-life: A survey of women with advanced stage breast cancer. *Journal of Communication in Healthcare*. 2009;2(4):371-386.
118. Welch LC, Teno JM, Mor V. End-of-life care in Black and White: Race matters for medical care of dying patients and their families. *J Am Geriatr Soc*. 2005;53(7):1145-1153. DOI: 10.1111/j.1532-5415.2005.53357.x
119. Hammes BJ. Respecting choices. In R. A. Szucas (Chair). Advance care planning discussion. Presentation conducted at the meeting of Richmond Academy of Medicine, Richmond, Virginia. 2013.

120. Cartwright C. Planning for the end of life for people with dementia. *Alzheimer's Australia Living with Dementia*. 2011. [www.alzheimers.org.au](http://www.alzheimers.org.au) Accessed June 22, 2013
121. Terrell F, Taylor J, Menzise J, Barrett R. *Cultural mistrust: A core component of African American consciousness*. Thousand Oaks, CA: Sage Publications Inc. Neville, H. A., Tynes BM, Utsey SO, ed. *Handbook of African American Psychology*. 2009.
122. Chan RJ, Webster J, Bowers, A. End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Database of Systematic Reviews*. 2016(2).
123. Loggers ET, Maciejewski PK, Paulk E, et al. Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *Journal of Clinical Oncology*. 2009;27(33):5559-5564. doi: 10.1200/JCO.2009.22.4733.
124. Song M, Ward SE, Happ MB, et al. Randomized controlled trial of SPIRIT: An effective approach to preparing African-American dialysis patients and families for end of life. *Res Nurs Health*. 2009;32(3):260-273. doi: 10.1002/nur.20320.
125. Song M, Hanson LC. Relationships between psychosocial-spiritual well-being and end-of-life preferences and values in African American dialysis patients. *J Pain Symptom Manage*. 2009;38(3):372-380. doi: 10.1016/j.jpainsymman.2008.11.007
126. Song M, Donovan HS, Piraino BM, et al. Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease. *Applied Nursing Research*. 2010;23(2):65-72. doi: 10.1016/j.apnr.2008.05.002
127. O'Hare AM, Rodriguez RA, Hailpern SM, Larson EB, Kurella Tamura M. Regional variation in health care intensity and treatment practices for end-stage renal disease in older adults. *JAMA*. 2010;304(2):180-186. doi: 10.1001/jama.2010.924
128. Modi S, Velde B, Gessert CE. Perspectives of community members regarding tube

feeding in patients with end-stage dementia: Findings from African-American and Caucasian focus groups. *Omega - Journal of Death & Dying*. 2010;62(1):77-91.

129. Watkins YJ, Bonner GJ, Wang E, Wilkie DJ, Ferrans CE, Dancy B. Relationship trust in physicians, demographics, and end-of-life treatment decisions made by African American dementia caregivers. *Journal of Hospital Palliative Nursing*. 2012;14(3):238-243.

130. Sanders JJ, Robinson MT, Block SD. Factors impacting advance care planning among African Americans: Results of a systematic integrated review. *J Palliat Med*. 2016;19(2):202-227. doi: <http://dx.doi.org/10.1089/jpm.2015.0325>. Accessed February 4, 2016.

131. Polit DF & Beck CT. *Nursing research: Generating and assessing evidence for nursing practice*. 9th ed. New York, NY: Lippincott, Williams & Wilkins, Inc.; 2012.

132. Garmon Bibb SC. Issues associated with secondary analysis of population health data. *Applied Nursing Research*. 2007;20(2):94-99. doi: <http://dx.doi.org/10.1016/j.apnr.2006.02.003>.

133. Dionne-Odom JN, Bakitas, M. Why surrogates don't make decisions the way we think they ought to: Insights from moral psychology. *Journal of Hospice & Palliative Nursing*. 2012;14(2):99-106. doi:10.1097/NJH.0b013e31823cc791.

134. Wiegand DL, Grant MS, Cheon J, Gergis MA. Family-centered end-of-life care in the ICU. *J Gerontol Nurs*. 2013;39(8):60-68. doi: 10.3928/00989134-20130530-04. Accessed October 10, 2012.

135. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *Journal of General Internal*

*Medicine*. 2009;24(6):695-701. doi: 10.1007/s11606-009-0952-6

136. Coleman AME. End-of-life issues in caring for patients with dementia: The case for palliative care in management of terminal dementia. *American Journal of Hospice and Palliative Medicine*. 2012;29(1):9-12. doi: 10.1177/1049909111410306.

137. Toscani F, van der Steen JT, Finetti S, et al. Critical decisions for older people with advanced dementia: A prospective study in long-term institutions and district home care. *J Am Med Dir Assoc*. 2015;16(6):535.e13-535.e20. doi: 10.1016/j.jamda.2015.02.012 [doi].

138. McLean S, Sheehy-Skeffington B, O'Leary N, O'Gorman A. Pharmacological management of co-morbid conditions at the end of life: Is less more? *Ir J Med Sci*. 2013;182(1):107-112. doi: 10.1007/s11845-012-0841-6 [doi].

139. Jones A, Moss A, Harris-Kojetin L. Use of advance directives in long term care populations. *NCHS Data Brief*, 54, 2011.

140. Centers for Disease Control. Advance care planning: Ensuring your wishes are known and honored if you are unable to speak for yourself. *National Association of Chronic Disease*. n.d.

141. American Psychological Association. End-of-life & socioeconomic status fact sheet. n.d.

142. Creswell JW. *Research design: Qualitative, quantitative, and mixed methods approaches*. 4th ed. Thousand Oaks, California: Sage Publications, Inc.; 2014.

143. *Program of all-inclusive care of the elderly*. Medicaid Website. <http://www.medicaid.gov/Medicaid>. Updated 2014. Accessed October 12, 2012.

144. Guest G, Bunce A, Johnson L. How many interviews are enough?: An experiment

with data saturation and variability. *Field Methods*. 2006;18(1):59-82. doi: 10.1177/1525822X05279903.

145. nQuery Advisor. (Version 7.0) [Computer software]. Los Angeles, CA: Statistical Solutions Ltd. 2012.

146. Harrell FE. Jr. *Regression modeling strategies: With applications to linear models, logistic regression, and survival analysis*. New York, NY: Springer-Verlag. 2001.

147. Black BS, Rabins PV, Kasper, JD. *Alzheimer's disease related quality of life user's manual*. 2<sup>nd</sup> ed. Baltimore, MD. 2009.

148. Quality Metric Incorporated. *Quality metric incorporated*.

<http://www.qualitymetric.com/WhatWeDo/SFHealthSurveys/SF36v2HealthSurvey/tabid/185/Default.aspx>. Updated 2013. Accessed January 12, 2014.

149. Ware JE,Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36): I. conceptual framework and item selection. *Med Care*. 1992;30(6):473-483.  
<http://www.jstor.org/stable/3765916>.

150. Ware JE Jr. *SF-36 health survey update*. <http://www.sf-36.org/tools/sf36>. Updated n.d.

151. McHorney CA, Ware JE,Jr, Lu JF, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): III. tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Med Care*. 1994;32(1):40-66. Accessed February 10, 2014.

152. The SF-36 health survey: Development and use in mental health research and the IQOLA project. *International journal of mental health*. 1994;23(2):49; 49-73; 73.

153. McHorney CA, Ware JE,Jr, Raczek AE. The MOS 36-item short-form health survey (SF-36): II. psychometric and clinical tests of validity in measuring physical and mental

health constructs. *Med Care*. 1993;31(3):247-263. Accessed April 15, 2014.

154. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23(4):334-340. doi: 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G.

155. Dedoose. (Version 6.1.18) [Computer Software]. (2015). Los Angeles, CA: SocioCultural Research Consultants, LLC. [www.dedoose.com](http://www.dedoose.com)

156. Chiovitti RF, Piran N. Rigour and grounded theory research. *J Adv Nurs*. 2003;44(4):427-435. doi: 10.1046/j.0309-2402.2003.02822.x.

157. Pyett PM. Validation of qualitative research in the “Real world”. *Qualitative Health Research*. 2003;13(8):1170-1179. doi: 10.1177/1049732303255686.

158. Saldana J. *The coding manual for qualitative researchers*. 3rd ed. Thousand Oaks, California: Sage Publications Inc.; 2016.

159. Lincoln YS GE. *Naturalistic inquiry*. Beverly Hills, CA: Sage; 1985.

160. IBM SPSS Statistics for Windows. (Version 23.0) [Computer software]. (2014). Armonk, New York: IBM Corp.

161. Corbie-Smith G, Williams IC, Blumenthal C, Dorrance J, Estroff SE, Henderson G. Relationships and communication in minority participation in research: Multidimensional and multidirectional. *J Natl Med Assoc*. 2007;99(5):489-498.

162. Dennis BP, Neese JB. Recruitment and retention of African American elders into community-based research: Lessons learned. *Arch Psychiatr Nurs*. 2000;14(1):3-11. doi: [http://dx.doi.org/10.1016/S0883-9417\(00\)80003-5](http://dx.doi.org/10.1016/S0883-9417(00)80003-5).

163. Dancy BL, Wilbur J, Talashek M, Bonner G, Barnes-Boyd C. Community-based research: Barriers to recruitment of African Americans. *Nurs Outlook*. 2004;52(5):234-

240. doi: <http://dx.doi.org/10.1016/j.outlook.2004.04.012>.

164. Jones RA, Steeves R, Williams I. Strategies for recruiting African American men into prostate cancer screening studies. *Nurs Res*. 2009;58(6):452-456. doi:

10.1097/NNR.0b013e3181b4bade

165. McLennon SM, Habermann B. Accruing the sample: Strategies for recruiting older adult and African Americans caregivers for persons with Alzheimer's disease. *Applied Nursing Research*. 2012;25(1):e1-e6. doi: <http://dx.doi.org/10.1016/j.apnr.2011.06.001>.

166. Williams IC, Utz SW, Jones R, Hinton I, Steeves R, Alexander G. Recruitment of rural African Americans for research projects: Lessons learned. *South Online J Nurs Res*. 2011;11(1). doi: 10.1177/0145721705275517

167. DeFries Bouldin E, Andresen E. *Caregiving across the United States*.

<http://www.alz.org>. Updated 2010. Accessed May 12, 2012.

168. Virginia General Assembly. *Code of Virginia*.

<http://law.lis.virginia.gov/vacode/title54.1/chapter29/section54.1-2986/>. n.d. Accessed 4/29, 2016.

169. Administration on Aging. A statistical profile of Black older Americans aged 65+.

[http://www.aoa.acl.gov/Aging\\_Statistics/minority\\_aging/Facts-on-Black-Elderly-plain\\_format.aspx](http://www.aoa.acl.gov/Aging_Statistics/minority_aging/Facts-on-Black-Elderly-plain_format.aspx). Updated 2015. Accessed May 23, 2014.

170. Smith-Howell ER, Hickman SE, Meghani SH, Perkins SM, Rawl SM. End-of-life decision making and communication of bereaved family members of African Americans with serious illness. *J Palliat Med*. 2016;19(2):174-182. doi:

<http://dx.doi.org/10.1089/jpm.2015.0314>. Accessed February 4, 2016.

171. Johnson KS, Kuchibhatla M, Tanis D, Tulskey JA. Racial differences in hospice



revocation to pursue aggressive care. *Arch Intern Med*. 2008;168(2):218-224.

doi:10.1001/archinternmed.2007.36.

172. Black BS, Fogarty LA, Phillips H, et al. Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care. *J Aging Health*. 2009;21(4):627-650. doi: <http://dx.doi.org/10.1177/0898264309333316>. Accessed May 13, 2009.

173. National healthcare decisions day. NHDD Web site.

<https://www.uslivingwillregistry.com/>. n.d. Accessed April/25, 2016.

174. U.S. Living Will Registry. U.S. living will registry.

<https://www.uslivingwillregistry.com/>. Updated 2016. Accessed May/2016, 2016.

175. Waters CM. End-of-life care directives among African Americans: Lessons learned -- a need for community-centered discussion and education. *J Community Health Nurs*. 2000;17(1):25-37.

176. Smith-Howell E. *End-of-life decision making among African Americans with serious illness*. [dissertation]. Bloomington, IN. Indiana University; 2015.

177. Song M, Ward SE, Lin F. End-of-life decision-making confidence in surrogates of African-American dialysis patients is overly optimistic. *J Palliat Med*. 2012;15(4):412-417. Accessed 20120416. doi: <http://dx.doi.org/10.1089/jpm.2011.0330>.

178. Gundersen Health System. Respecting choices advance care planning.

<http://www.gundersenhealth.org/respecting-choices>. Updated 2016. Accessed April/2016, 2016.

179. Centers for Medicare and Medicaid Services. Advance care planning (ACP) as an optional element of an annual wellness visit (AWV). *MLN Matters*. 2015;9271.

180. Caron CD, Griffith J, Arcand M. Decision making at the end of life in dementia:

How family caregivers perceive their interactions with health care providers in long-term-care settings. *Journal of Applied Gerontology*. 2005;24(3):231-247. doi: 10.1177/0733464805275766.

181. Penrod J. Commentary on uncertainty and surrogate decision making. *Clinical Nursing Research*. 2011;20(3):241-244. doi: 10.1177/1054773811411151.

182. Shavers-Hornaday V, Lynch CF. Why are African Americans under-represented in medical.. *Ethn Health*. 1997;2(1):31. doi:10.1080/13557858.1997.9961813

183. Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. *Annu Rev Public Health*. 2006;27:1-28. Accessed March 13, 2006.

184. Song M, Ward SE, Fine JP, et al. Advance care planning and end-of-life decision making in dialysis: A randomized controlled trial targeting patients and their surrogates. *American Journal of Kidney Diseases*. 2015;66(5):813-822. doi: <http://dx.doi.org/10.1053/j.ajkd.2015.05.018>.

185. Satizabal CL, Beiser AS, Chouraki V, Chene G, Dufouil C, Seshadri S. Incidence of dementia over three decades in the Framingham heart study. *N Engl J Med*. 2016;374(6):523-532. doi: 10.1056/NEJMoa1504327 [doi].

186. Douglas SL, Mazanec P, Lipson A, Leuchtag M. Distance caregiving a family member with cancer: A review of the literature on distance caregiving and recommendations for future research. *World J Clin Oncol*. 2016;7(2):214-219. doi: 10.5306/wjco.v7.i2.214 [doi].

## **APPENDIXES**

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## Appendix A

### INTERVIEW GUIDE

#### Sample Semi-Structured Interview Questions

- 1) How do you know when you need to make a decision for [your family member] with memory impairment?
- 2) How do you obtain information to make an informed decision?
- 3) How do you weigh the risks and benefits of various treatment options?
- 4) How capable do you feel that you will make the best decisions for [your family member] with memory impairment?
- 5) If the point came in which [your family member] was not able to express his/her preference for treatment, how would you know what treatment options (e.g. use of breathing machines, feeding tubes, antibiotics, IV fluids, CPR, chest compressions, tests or procedures, surgeries) [your family member] would choose?
- 6) Health care providers (nurses and doctors) often use the term “end of life.” What does this term mean to you?
- 7) When you hear the term ‘*end of life*’, do you automatically think of before death or after death, (or both)?
- 8) They often use the terms ‘*advance directive*’ or ‘*living will*.’ What do these terms mean to you?
- 9) What does ‘*quality of life*’ mean to you?
- 10) How do you rate your quality of life? And your loved one’s?

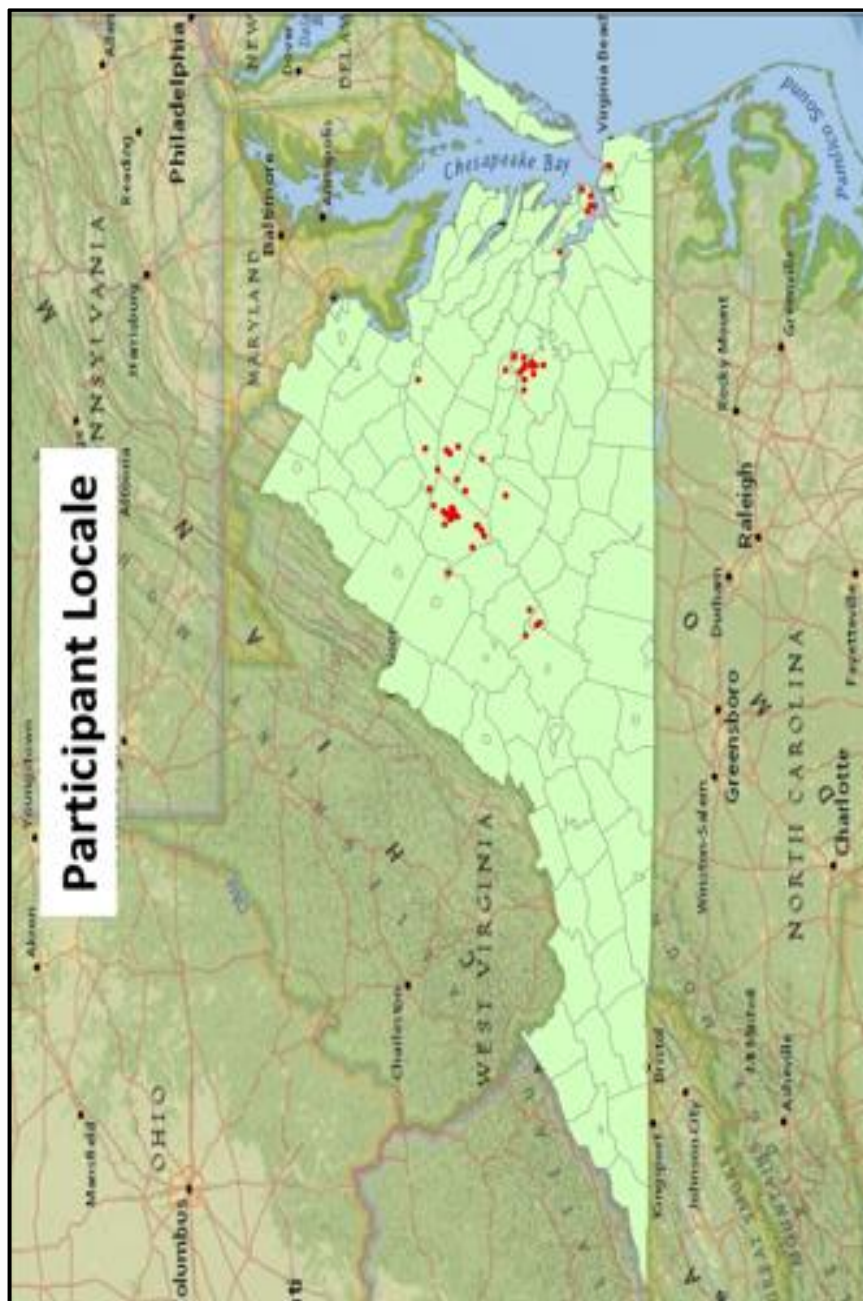
#### Closure Questions:

What advice would you give to other family caregivers who are in a position similar to yours?

What advice would you give to healthcare providers who care for people with memory impairment as their family members?

## Appendix B

## Map of Participant Locale



## Appendix C Study Flier

## Decisions for African American Older Adults with Dementia



Are you a family caregiver for an African American older adult with dementia? If so, you may be eligible to participate in a study to examine how you plan to make decisions for your older adult loved one near the end of his or her life. Karen Moss, School of Nursing PhD Candidate of the University of Virginia, is conducting this study.

**1.5 hours of interview time required**  
**\$10 Visa gift card for family caregiver participant**

## Contact Information

For more information please contact principal investigator:

Karen Moss, MSN, RN, CNL  
McLeod Hall  
PO Box 800782  
202 Jeanette Lancaster Way  
Charlottesville, VA 22908-0826  
Tel: 407-765-2416  
Email: [kos2fr@virginia.edu](mailto:kos2fr@virginia.edu)

- IRB-SBS #2014-0462-00 (University of Virginia)
- IRB # 0000-0000 (Riverside Health System)

*Your participation is greatly appreciated.*

[illegible]

## Appendix D Recruitment Email

The following IRB-approved statement was shared via email and used along with the IRB-approved study flier to provide potential participants and community partners with details on the study:

***"Are you a family caregiver for an African American older adult with memory loss? If so, you may be eligible to participate in a study to examine how you plan to make decisions for your older adult loved one near the end of his or her life. This study will require about one and half hours of your time. A thank you gift in the form of a \$10 Walmart gift card will be given to you in gratitude for your time. If you or someone you know meet these criteria, please contact me, Karen Moss, School of Nursing PhD Candidate of the University of Virginia by telephone at [407-765-2416](tel:407-765-2416) or by email at [kos2fr@virginia.edu](mailto:kos2fr@virginia.edu)."***

**Appendix E**  
**Note of Thanks – Community Partners**

January 11<sup>th</sup> 2016

Dear [Individual's Name Here]:

It is with heartfelt thanks that I write.

Words can hardly express the gratitude I have for all that you did to assist me in recruiting study participants for the *Decisions for African American Older Adults with Dementia Study*. We were successful in recruiting a total of 65 dementia caregivers. The study is now officially closed to recruitment as I am currently analyzing these data.

I am optimistic that the study results will serve as evidence towards understanding and making improvements towards end-of-life planning. The possibility of which could not have occurred were it not for the support you offered to assist in this important process.

With this, I say thank-you and wish you [and your organization] continued success for the church in 2016 and beyond!

Please confirm receipt of this email.

Karen Moss



## Appendix F ELIGIBILITY SCREENING FORM

ID#: \_\_\_\_\_

Date: \_\_\_\_\_

### Decisions for African American Older Adults with Dementia Study

Principal Investigator: Karen O. Moss, MSN, RN, CNL

### INCLUSION/EXCLUSION CRITERIA FINAL CHECKLIST

**Directions:** Please **check** (✓) and complete the following as a final check for study enrollment for this family caregiver:

#### Inclusion Criteria for Older Adult: (All must be met)

- |  |                          |
|--|--------------------------|
| <input type="checkbox"/> Confirmed diagnosis of dementia (any form)                  | [Diagnosis: ____]        |
| <input type="checkbox"/> African American/Black race by family caregiver self-report | [Self-report: ____]      |
| <input type="checkbox"/> 55 years or older at enrollment                             | [Date of Birth: ____]    |
| <input type="checkbox"/> Possess a family caregiver                                  | [Family caregiver: ____] |

#### Inclusion Criteria for Family Caregiver: (All must be met)

- ☐ Read and speak and understand English language
- ☐ An assigned family caregiver (direct or indirect) for an older adult with dementia
- ☐ African American/Black race by self-report
- ☐ At least 21 years of age

#### Exclusion Criteria for Older Adult: (If any, then exclude)

- ☐ Current hospitalization with a life threatening illness
- ☐ Actively dying

#### Exclusion Criteria for Family Caregiver: (If any, then exclude)

- ☐ The presence of cognitive impairment

#### Summary: Subject is eligible?

- ☐ No
- ☐ Yes

Investigator's Signature: \_\_\_\_\_

## Appendix G

### FAMILY CAREGIVER INFORMATION FORM (FCIF)

ID#: \_\_\_\_\_

Date: \_\_\_\_\_

#### *Decisions for African American Older Adults with Dementia Study (DAADS)*

Principal Investigator: Karen O. Moss, MSN, RN, CNL

Administrative Site: University of Virginia

Department: School of Nursing

Address: Charlottesville, VA 22908-0782

**Instructions:** Please provide some background information about yourself by **checking** (√) your response. If you do not care to answer a question, leave it blank.

#### GENERAL INFORMATION ABOUT YOU

1. What is your gender? (0) Male \_\_\_\_ (1) Female \_\_\_\_
2. What is your marital status? Are you:
  - 0) Single (never married) \_\_\_\_
  - 1) Separated or divorced (not living with a husband / wife) \_\_\_\_
  - 2) Married (living with a husband / wife) \_\_\_\_
3. How old were you at your last birthday? \_\_\_\_
4. What is the annual income of your family?
  - \_\_0) under \$10,000
  - \_\_1) \$10,000 - \$24,999
  - \_\_2) \$25,000 - \$39,999
  - \_\_3) \$40,000 or more
5. What is your current employment status?
  - \_\_0) Employed at a job for pay, full-time
  - \_\_1) Employed at a job for pay, part-time
  - \_\_2) Homemaker, not currently working for pay
  - \_\_3) Not currently employed, retired
  - \_\_4) Not currently employed, not retired
6. How many years of school have you completed?  
(choose only one)
  - \_\_ 0) 6<sup>th</sup> grade or less
  - \_\_ 1) 7<sup>th</sup> – 12<sup>th</sup> grade
  - \_\_ 2) High school graduate
  - \_\_ 3) Some college
  - \_\_ 4) College graduate

- ☐ 5) Graduate school graduate
- ☐ 6) Some post graduate study
- ☐ 7) Other

---

please explain

7. Type of insurance coverage

- ☐ 0) Public (Medicare/Medicaid)
- ☐ 1) Private
- ☐ 2) Military
- ☐ 3) None

8. You consider yourself to be of which of the following ethnic backgrounds (Please CHECK ALL that apply):

- ☐ 0) African
- ☐ 1) African American
- ☐ 2) Caribbean
- ☐ 3) Hispanic
- ☐ 4) Latino
- ☐ 5) Unknown

9. How far must you travel for EMERGENCY medical care? In answering this question think about a potential emergency such as a serious cut from broken glass. How far (ONE WAY) must you travel to get assistance such as stitches? Please try to be as accurate as possible when recording the distance, for example 8 city blocks or 3 ¾ miles, etc.

- ☐ Number of Miles (one way)
- ☐ Approximate Travel Time (one way)

10. I would describe myself as living: (Please CHECK only ONE response)

- ☐ 0) rural
- ☐ 1) urban
- ☐ 2) suburban

11. How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Would you say it is:

- ☐ 0) Not difficult at all
- ☐ 1) Not very difficult
- ☐ 2) Somewhat difficult
- ☐ 3) Very difficult

12. How many people are living in your home **excluding** yourself? \_\_\_\_\_person(s)

13. Do you have any of the following written documents indicating **your** preferences for life-sustaining treatments for **yourself**?

- ☐ 0) Advance directive
- ☐ 1) Living Will
- ☐ 2) Do Not Resuscitate (DNR) order
- ☐ 4) Physicians Orders for
- ☐ 3) Designated Power of Attorney or health care surrogate

☐ 4) None of the above

14. Have you ever expressed verbal/oral/by mouth wishes or desires for **your** healthcare decisions in if you develop a life-limiting illness/disease?

☐ 0) No

☐ 1) Yes

### INFORMATION ABOUT YOUR CARE RECIPIENT

**Instructions:** Please provide some background information about your older adult care recipient by **checking** (✓) your response. If you do not care to answer a question, leave it blank.

---

15) What is your relationship to the older adult with memory loss?

☐ 0) Spouse

☐ 1) Daughter

☐ 2) Son

☐ 3) Other relative

☐ 4) Friend/neighbor

☐ 5) Other

16. What is the age of your older adult care recipient (in years)? \_\_\_\_\_

17. What is the gender of your care recipient? (0) Male \_\_\_\_\_ (1) Female \_\_\_\_\_

18. Your care recipient is considered to be of which of the following ethnic backgrounds (Please CHECK ALL that apply):

☐ 0) African

☐ 1) African American

☐ 2) Caribbean

☐ 3) Hispanic

☐ 4) Latino

☐ 5) Unknown

19. What is the length of time since your care recipient was diagnosed with memory loss? (provide number of months or years) \_\_\_\_\_months OR \_\_\_\_\_years

20. Which kind of memory loss does your care recipient have?

☐ 0) Alzheimer's Disease

☐ 1) Vascular Dementia

☐ 2) Dementia with Lewy Bodies

☐ 3) Mixed Dementia

☐ 4) Parkinson's Disease

☐ 5) Frontotemporal Dementia

☐ 6) Creutzfeldt-Jakob disease

☐ 7) Normal pressure hydrocephalus

- ☐ 8) Huntington's Disease
  - ☐ 9) Wernicke-Korsakoff Syndrome
  - ☐ 10) Unclassified
  - ☐ 11) Unknown
21. What is your care recipient's current stage of memory loss?
- ☐ 0) Unknown
  - ☐ 1) Early Stage
  - ☐ 2) Middle Stage
  - ☐ 3) Late/End Stage
22. Does your care recipient have any of the following other medical conditions?
- ☐ 0) None
  - ☐ 1) Diabetes
  - ☐ 2) Hypertension (High Blood Pressure)
  - ☐ 3) Hyperlipidemia (High Blood Cholesterol)
  - ☐ 4) Heart disease (Heart Attack, Heart Failure)
  - ☐ 5) Cerebrovascular disease (Stroke)
  - ☐ 5) Cancer (any form)
  - ☐ 6) Please list any other medical conditions
- 
- 
23. How long have you been a caregiver for you older adult with dementia? (provide number of months or years) \_\_\_\_\_months OR \_\_\_\_\_years

**Thank you**

## Appendix H

ID#: \_\_\_\_\_

Date: \_\_\_\_\_

### *Decisions for African American Older Adults with Dementia Study* (DAADS)

Principal Investigator: Karen O. Moss, MSN, RN, CNL

Administrative Site: University of Virginia

Department: School of Nursing

Address: Charlottesville, VA 22908-0782

### DOCUMENTATION FORM OF END-OF-LIFE CARE PLANS (DF-EOLCP)

Please provide the most accurate responses to the following statements:

1. Has **your older adult care recipient** with memory impairment signed any of the following written documents (a written document indicating his/her preferences for life-sustaining treatments)?

- ☐ 0) Advance Directive
- ☐ 1) Living Will
- ☐ 2) Do Not Resuscitate (DNR)
- ☐ 3) Designated Power of Attorney or Health Care Surrogate
- ☐ 4) Physician Order for Scope of Treatment (POST)
- ☐ 5) None of the above
- ☐ 6) Other handwritten or typed document
- ☐ 7) Other

---

please explain

2. If **your older adult care recipient** has any one of the above documents, where is the document kept?

- ☐ 0) Secured at home
- ☐ 1) Secured in a deposit box (outside of home)
- ☐ 2) Lawyer or attorney
- ☐ 3) With a family member
- ☐ 4) With a friend
- ☐ 5) Kept by a religious leader (priest, pastor, etc.)
- ☐ 6) In a bible
- ☐ 7) Not applicable, there is no such document
- ☐ 8) Other \_\_\_\_\_

3. Does any of the following persons have a copy of **your older adult's** end-of-life plan?

- ☐ 0) Healthcare provide (physician, nurse practitioner etc.)
- ☐ 1) Lawyer or attorney
- ☐ 2) Religious leader (priest, pastor, etc.)
- ☐ 3) family member
- ☐ 4) friend
- ☐ 5) Not applicable, there is no such document
- ☐ 6) Other \_\_\_\_\_

4. Has **your older adult care recipient** expressed verbal/oral wishes or desires for healthcare decisions in the face of serious or life-threatening illness?
- ☐ 0) No
  - ☐ 1) Yes
  - ☐ 2) Unknown
5. Have you and your family discussed verbal/oral wishes or desires for healthcare decisions **for your older adult care recipient** in the face of serious or life-threatening illness?
- ☐ 0) No
  - ☐ 1) Yes
  - ☐ 2) Unknown
6. If there has been formal or informal end-of-life care plans for **your older adult care recipient**, when did these plans occur?
- ☐ 0) in the past month
  - ☐ 1) in the past 6 months
  - ☐ 2) in the past year
  - ☐ 3) 1-3 years ago
  - ☐ 4) 3-5 years ago
  - ☐ 5) 5-10 years ago
  - ☐ 6) 10 or more years
  - ☐ 7) Not applicable, there is no plan
  - ☐ 8) Other \_\_\_\_\_
  - ☐ 9) Unknown
7. If there are end-of-life plans for **your older adult care recipient** can you recall what stage of memory loss was he/she at during the time when these plans were made?
- ☐ 0) Unknown
  - ☐ 1) Early Stage
  - ☐ 2) Middle Stage
  - ☐ 3) Late/End Stage
8. Have you thought about *your* preferences for life-sustaining treatments **for your older adult care recipient**?
- ☐ 0) No
  - ☐ 1) Yes
9. Do you have preferences in mind for life-sustaining treatments **for your older adult care recipient** if she or he is faced with a serious or life-threatening illness?
- ☐ 0) No
  - ☐ 1) Yes
10. Have you signed any of the following written documents concerning the care of **your older adult care recipient**?:
- ☐ 0) Advance Directive
  - ☐ 1) Living Will
  - ☐ 2) Do Not Resuscitate (DNR)
  - ☐ 3) Designated Power of Attorney or Health Care Surrogate
  - ☐ 4) Physician Order for Scope of Treatment (POST)

- ☐ 5) None of the above
- ☐ 6) Other handwritten or typed document
- ☐ 7) Other

---

please explain

**Thank you!**



## Appendix I

### Alzheimer's Disease Related Quality of Life (ADRQL)

ID#: \_\_\_\_\_

Date: \_\_\_\_\_

#### *Decisions for African American Older Adults with Dementia Study (DAADS)*

Principal Investigator: Karen O. Moss, MSN, RN, CNL  
Administrative Site: University of Virginia  
Department: School of Nursing  
Address: Charlottesville, VA 22908-0782

#### Alzheimer Disease Related Quality of Life™ (ADRQL™)

**Interviewer:** Read the following instructions aloud to the respondent.

Quality of life means how someone feels about different areas of his or her life. To find out about quality of life, people are usually asked to answer questions about themselves. Because of the effects of dementia, it is hard to ask people with this illness questions about their own lives. Instead, this questionnaire has been developed so that it can be answered by someone who spends time with and cares for a person with dementia.

There are several areas that make up a person's quality of life. I will briefly describe each area and then I will read statements about these. As I read each statement, please think about Mr/Mrs/Ms \_\_\_\_\_ and whether the statement describes him/her over the last 2 weeks. If you agree that the statement describes Mr/Mrs/Ms \_\_\_\_\_ over the last 2 weeks, please answer "Agree." If you disagree, because the statement does not describe Mr/Mrs/Ms \_\_\_\_\_ over the last 2 weeks, please answer "Disagree."

Let me give you an example. I might read the statement, "He/She does not respond to his/her own name." If this statement describes Mr/Mrs/Ms \_\_\_\_\_ over the last 2 weeks, you should say "Agree." If the statement, "He/She does not respond to his/her own name," does not describe him/her in the last 2 weeks, you should answer "Disagree." Do you have any questions?

**Interviewer:** Pause, respond to any questions and finish reading these instructions aloud.

I am going to begin the questionnaire now. Please tell me if you want me to speak louder, slow down, repeat a statement or stop so you can think about a statement. Also let me know if you want me to review the instructions.

**Interviewer:** Read aloud the introductory statements and each item exactly as they are written in sections A-E below. Place an **X** in one box to the right of each item in the correct response column.

|      |   |                               |                          |
|------|---|-------------------------------|--------------------------|
| 1.   | These statements are about <u>relating to and being around other people</u> . After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms _____ in the last 2 weeks or answer "Disagree" if it does not. |                               |                          |
|      |   | <u>AGREE</u>                  | <u>DISAGREE</u>          |
| A1.  | He/She smiles or laughs when around other people.....   | A1. <input type="checkbox"/>  | <input type="checkbox"/> |
| A2.  | He/She does <u>not</u> pay attention to the presence of others.....   | A2. <input type="checkbox"/>  | <input type="checkbox"/> |
| A3.  | He/She will stay around other people.....   | A3. <input type="checkbox"/>  | <input type="checkbox"/> |
| A4.  | He/She seeks contact with others by greeting people or joining in conversations.....  | A4. <input type="checkbox"/>  | <input type="checkbox"/> |
| A5.  | He/She talks with people.....   | A5. <input type="checkbox"/>  | <input type="checkbox"/> |
| A6.  | He/She touches or allows touching such as handshakes, hugs, kisses, pets.....   | A6. <input type="checkbox"/>  | <input type="checkbox"/> |
| A7.  | He/She can be comforted or reassured by others.....   | A7. <input type="checkbox"/>  | <input type="checkbox"/> |
| A8.  | He/She reacts with pleasure to pets or small children.....  | A8. <input type="checkbox"/>  | <input type="checkbox"/> |
| A9.  | He/She smiles or laughs or is cheerful.....   | A9. <input type="checkbox"/>  | <input type="checkbox"/> |
| A10. | He/She shows delight.....   | A10. <input type="checkbox"/> | <input type="checkbox"/> |
| A11. | He/She shows a sense of humor.....  | A11. <input type="checkbox"/> | <input type="checkbox"/> |
| A12. | He/She sits quietly and appears to enjoy the activity of others even though he/she is not actively participating.....   | A12. <input type="checkbox"/> | <input type="checkbox"/> |

(Continued)

2. These statements are about a person's special identity and important relationships. After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms \_\_\_\_\_ in the last 2 weeks or answer "Disagree" if it does not.

|     |   | AGREE                        | DISAGREE                 |
|-----|---|------------------------------|--------------------------|
| B1. | He/She talks about or still does things related to his/her previous work or daily activities.....                                 | B1. <input type="checkbox"/> | <input type="checkbox"/> |
| B2. | He/She is aware of his/her place in the family such as being a husband/wife, parent, or grandparent....                           | B2. <input type="checkbox"/> | <input type="checkbox"/> |
| B3. | He/She makes or indicates choices in routine daily activities such as what to wear, what to eat, or where to sit.....             | B3. <input type="checkbox"/> | <input type="checkbox"/> |
| B4. | He/She shows interest in events, places or habits from his/her past such as old friends, former residences, church or prayer..... | B4. <input type="checkbox"/> | <input type="checkbox"/> |
| B5. | He/She does <u>not</u> respond to his/her own name.....   | B5. <input type="checkbox"/> | <input type="checkbox"/> |
| B6. | He/She does <u>not</u> express beliefs or attitudes that he/she always had.....   | B6. <input type="checkbox"/> | <input type="checkbox"/> |
| B7. | He/She talks with people on the telephone.....  | B7. <input type="checkbox"/> | <input type="checkbox"/> |
| B8. | He/She gets enjoyment from or is calmed by his/her possessions or belongings.....   | B8. <input type="checkbox"/> | <input type="checkbox"/> |

3. These statements are about different types of behavior in the last 2 weeks. After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms \_\_\_\_\_ in the last 2 weeks or answer "Disagree" if it does not.

|      |   | AGREE                         | DISAGREE                 |
|------|---|-------------------------------|--------------------------|
| C1.  | He/She squeezes, twists or wrings his/her hands.....  | C1. <input type="checkbox"/>  | <input type="checkbox"/> |
| C2.  | He/She throws, hits, kicks or bangs objects.....  | C2. <input type="checkbox"/>  | <input type="checkbox"/> |
| C3.  | He/She calls out or yells or curses or makes accusations.....   | C3. <input type="checkbox"/>  | <input type="checkbox"/> |
| C4.  | He/She locks or barricades himself/herself in his/her room/house/apartment.....                             | C4. <input type="checkbox"/>  | <input type="checkbox"/> |
| C5.  | He/She is irritable or easily angered.....  | C5. <input type="checkbox"/>  | <input type="checkbox"/> |
| C6.  | He/She cries, wails, or frowns.....   | C6. <input type="checkbox"/>  | <input type="checkbox"/> |
| C7.  | He/She is restless and wound up, or repeats actions such as rocking, pacing, or banging against walls.....  | C7. <input type="checkbox"/>  | <input type="checkbox"/> |
| C8.  | He/She resists help in different ways such as with dressing, eating or bathing, or by refusing to move..... | C8. <input type="checkbox"/>  | <input type="checkbox"/> |
| C9.  | He/She appears to be content or satisfied.....  | C9. <input type="checkbox"/>  | <input type="checkbox"/> |
| C10. | He/She becomes upset or angry when approached by another person.....  | C10. <input type="checkbox"/> | <input type="checkbox"/> |
| C11. | He/She pushes, grabs or hits people.....  | C11. <input type="checkbox"/> | <input type="checkbox"/> |
| C12. | He/She is upset or unsettled in his/her living environment.....   | C12. <input type="checkbox"/> | <input type="checkbox"/> |

4. These statements are about usual activities in the last 2 weeks. After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms \_\_\_\_\_ in the last 2 weeks or answer "Disagree" if it does not.

|     |   | AGREE                        | DISAGREE                 |
|-----|---|------------------------------|--------------------------|
| D1. | He/She enjoys doing activities alone such as listening to music or watching TV.....                             | D1. <input type="checkbox"/> | <input type="checkbox"/> |
| D2. | He/She does <u>not</u> take part in activities he/she used to enjoy, even when encouraged to take part.....     | D2. <input type="checkbox"/> | <input type="checkbox"/> |
| D3. | He/She shows <u>no</u> signs of pleasure or enjoyment when taking part in leisure activities or recreation..... | D3. <input type="checkbox"/> | <input type="checkbox"/> |
| D4. | He/She dozes off or does nothing most of the time.....  | D4. <input type="checkbox"/> | <input type="checkbox"/> |

(Continued)

|   |   |                              |                          |
|---|---|------------------------------|--------------------------|
| 5. The last statements are about <u>behavior in a person's living environment</u> . After each statement, please answer "Agree" if the statement describes Mr/Mrs/Ms _____ in the last 2 weeks or answer "Disagree" if it does not. |   |                              |                          |
|   |   | <u>AGREE</u>                 | <u>DISAGREE</u>          |
| E1.   | He/She talks about feeling <u>unsafe</u> or says his/her belongings are <u>not safe</u> ..... | E1. <input type="checkbox"/> | <input type="checkbox"/> |
| E2.   | He/She is upset or unsettled when in places other than where he/she lives.....                | E2. <input type="checkbox"/> | <input type="checkbox"/> |
| E3.   | He/She talks about wanting to leave or go home.....   | E3. <input type="checkbox"/> | <input type="checkbox"/> |
| E4.   | He/She says he/she wants to die.....  | E4. <input type="checkbox"/> | <input type="checkbox"/> |

That concludes the questionnaire. Thank you very much for your help.

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**Appendix J**  
**SHORT FORM HEALTH SURVEY (SF-36v2)**  
**HEALTH-RELATED QUALITY OF LIFE SURVEY**

**Decisions for African American Older Adults with Dementia Study  
(DAADS)**

Principal Investigator: Karen O. Moss, MSN, RN, CNL  
 Administrative Site: University of Virginia  
 Department: School of Nursing  
 Address: Charlottesville, VA 22908-0782

ID#: \_\_\_\_\_  
 Date: \_\_\_\_\_

## Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark an ☒ in the one box that best describes your answer.

1. In general, would you say your health is:

|                            |                            |                            |                            |                            |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Excellent                  | Very good                  | Good                       | Fair                       | Poor                       |
| ▼                          | ▼                          | ▼                          | ▼                          | ▼                          |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

2. Compared to one year ago, how would you rate your health in general now?

|   |  |                                      |   |  |
|---|--|--------------------------------------|---|--|
| Much better<br>now than one<br>year ago | Somewhat<br>better<br>now than one<br>year ago | About the<br>same as<br>one year ago | Somewhat<br>worse<br>now than one<br>year ago | Much worse<br>now than one<br>year ago |
| ▼                                       | ▼  | ▼                                    | ▼   | ▼                                      |
| <input type="checkbox"/> 1              | <input type="checkbox"/> 2                     | <input type="checkbox"/> 3           | <input type="checkbox"/> 4                    | <input type="checkbox"/> 5             |

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

|  | Yes,<br>limited<br>a lot<br>▼    | Yes,<br>limited<br>a little<br>▼ | No, not<br>limited<br>at all<br>▼ |
|--|----------------------------------|----------------------------------|-----------------------------------|
| a <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports ..... | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| b <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf..... | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| c Lifting or carrying groceries .....  | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| d Climbing <u>several</u> flights of stairs .....  | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| e Climbing <u>one</u> flight of stairs .....   | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| f Bending, kneeling, or stooping .....   | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| g Walking <u>more than a mile</u> .....  | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| h Walking <u>several hundred yards</u> .....   | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| i Walking <u>one hundred yards</u> .....   | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |
| j Bathing or dressing yourself.....  | <input type="checkbox"/> 1 ..... | <input type="checkbox"/> 2 ..... | <input type="checkbox"/> 3        |

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

|   | All of the time                 | Most of the time                | Some of the time                | A little of the time            | None of the time           |
|---|---------------------------------|---------------------------------|---------------------------------|---------------------------------|----------------------------|
|   | ▼                               | ▼                               | ▼                               | ▼                               | ▼                          |
| a Cut down on the <u>amount of time</u> you spent on work or other activities.....                        | <input type="checkbox"/> 1..... | <input type="checkbox"/> 2..... | <input type="checkbox"/> 3..... | <input type="checkbox"/> 4..... | <input type="checkbox"/> 5 |
| b <u>Accomplished less</u> than you would like .....  | <input type="checkbox"/> 1..... | <input type="checkbox"/> 2..... | <input type="checkbox"/> 3..... | <input type="checkbox"/> 4..... | <input type="checkbox"/> 5 |
| c Were limited in the <u>kind of</u> work or other activities .....                                       | <input type="checkbox"/> 1..... | <input type="checkbox"/> 2..... | <input type="checkbox"/> 3..... | <input type="checkbox"/> 4..... | <input type="checkbox"/> 5 |
| d Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort) ..... | <input type="checkbox"/> 1..... | <input type="checkbox"/> 2..... | <input type="checkbox"/> 3..... | <input type="checkbox"/> 4..... | <input type="checkbox"/> 5 |

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

|  | All of the time                 | Most of the time                | Some of the time                | A little of the time            | None of the time           |
|--|---------------------------------|---------------------------------|---------------------------------|---------------------------------|----------------------------|
|  | ▼                               | ▼                               | ▼                               | ▼                               | ▼                          |
| a Cut down on the <u>amount of time</u> you spent on work or other activities..... | <input type="checkbox"/> 1..... | <input type="checkbox"/> 2..... | <input type="checkbox"/> 3..... | <input type="checkbox"/> 4..... | <input type="checkbox"/> 5 |
| b <u>Accomplished less</u> than you would like .....                               | <input type="checkbox"/> 1..... | <input type="checkbox"/> 2..... | <input type="checkbox"/> 3..... | <input type="checkbox"/> 4..... | <input type="checkbox"/> 5 |
| c Did work or other activities <u>less carefully than usual</u> .....              | <input type="checkbox"/> 1..... | <input type="checkbox"/> 2..... | <input type="checkbox"/> 3..... | <input type="checkbox"/> 4..... | <input type="checkbox"/> 5 |

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

|                            |                            |                            |                            |                            |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Not at all                 | Slightly                   | Moderately                 | Quite a bit                | Extremely                  |
| ▼                          | ▼                          | ▼                          | ▼                          | ▼                          |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

7. How much bodily pain have you had during the past 4 weeks?

|                            |                            |                            |                            |                            |                            |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| None                       | Very mild                  | Mild                       | Moderate                   | Severe                     | Very severe                |
| ▼                          | ▼                          | ▼                          | ▼                          | ▼                          | ▼                          |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

|                            |                            |                            |                            |                            |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Not at all                 | A little bit               | Moderately                 | Quite a bit                | Extremely                  |
| ▼                          | ▼                          | ▼                          | ▼                          | ▼                          |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

|   | All of<br>the time         | Most of<br>the time        | Some of<br>the time        | A little of the<br>time    | None of<br>the time        |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| a Did you feel full of life? .....  | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| b Have you been very nervous? .....   | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| c Have you felt so down in the<br>dumps that nothing could<br>cheer you up? ..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| d Have you felt calm and<br>peaceful? .....                                       | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| e Did you have a lot of energy? .....   | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| f Have you felt downhearted<br>and depressed? .....                               | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| g Did you feel worn out? .....  | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| h Have you been happy? .....  | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| i Did you feel tired? .....   | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

| All of<br>the time         | Most of<br>the time        | Some of<br>the time        | A little of<br>the time    | None of<br>the time        |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |



**11. How TRUE or FALSE is each of the following statements for you?**

|   | Definitely<br>true         | Mostly<br>true             | Don't<br>know              | Mostly<br>false            | Definitely<br>false        |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
|   | ▼                          | ▼                          | ▼                          | ▼                          | ▼                          |
| a I seem to get sick a little<br>easier than other people ..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| b I am as healthy as<br>anybody I know .....                    | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| c I expect my health to<br>get worse.....                       | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| d My health is excellent.....                                   | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

***Thank you for completing these questions!***

## Appendix K

### SURROGATE DECISION MAKING SELF-EFFICACY SCALE (SDM-SES)

ID#: \_\_\_\_\_

Date: \_\_\_\_\_

#### *Decisions for African American Older Adults with Dementia Study (DAADS)*

**Principal Investigator:** Karen O. Moss, MSN, RN, CNL**Administrative Site:** University of Virginia**Department:** School of Nursing**Address:** Charlottesville, VA 22908-0782

#### Perceived Self-Efficacy for Surrogate Decision Making (Lopez, 2010)

Please circle the number that most closely measures how much you agree or disagree with each statement.

Circle one number on each line.

|   | Strongly Agree | Agree | Disagree | Strongly Disagree |
|---|----------------|-------|----------|-------------------|
| I am confident that I know when I need to make decisions for the individual with memory impairment.   | 4              | 3     | 2        | 1                 |
| I am confident that I can obtain the information I need to make informed decisions for the individual with memory impairment.                           | 4              | 3     | 2        | 1                 |
| I am certain that I can weigh the risks and benefits of various treatment options for the individual with memory impairment.                            | 4              | 3     | 2        | 1                 |
| I am capable of making the best treatment decisions for the individual with memory impairment.  | 4              | 3     | 2        | 1                 |
| I am confident that I know what treatment options the individual with memory impairment would choose if he/she was able to express his/her preferences. | 4              | 3     | 2        | 1                 |

Scores range from 5-20.

Higher scores indicate more perceived self-efficacy for surrogate decision making.

## Appendix L – Consent Form – University of Virginia

Project Title: End-of-Life Decision-Making for African American Older Adults with Dementia

### Informed Consent Agreement

Please read this consent agreement carefully before you decide to participate in the study.

**Purpose of the research study:** The purpose of the study is to better understand end-of-life decisions for African American older adults with memory loss by their family caregivers.

**What you will do in the study:** In this study, you will be asked to describe how end-of-life decisions are made for your loved one with memory loss. You will complete two forms: one about basic information regarding you and your loved one with memory loss and another about any existing end-of-life plans for the same loved one. You will complete three additional surveys about the following: your quality of life, the quality of life of your loved one with memory loss, and another on how confident you are to make these decisions for your loved one with memory loss. You may also be asked to verbally answer questions related to end-of-life decisions for your loved one with memory loss, quality of life and your confidence to make decisions for your loved one with memory loss. This interview part of the study will be audio recorded using a digital voice recorder. You may skip any portion of the surveys or interview that makes you feel uncomfortable and may request to have the recorder turned off at any time. Additionally, you can stop the survey or interview at any time.

**Time required:** The study will require one and a half hours of your time all in one session. Feel free to take any breaks you need, either to regroup or for refreshment as needed.

**Risks:** Because we will be discussing the potentially emotional subject of death and dying, this study may cause emotions of grief for you. Though the chances of this happening are minimal, to address this possibility you will be allowed to take breaks as needed. If you feel that it is too much for you to continue responding to the questions, you may choose to end the study or I as the researcher may choose to end it. If necessary, you will be asked to visit your primary healthcare provider beginning with me placing a call to them (with your permission) to explain your participation in the study and your reaction for follow up care.

**Benefits:** There are no direct benefits to you for participating in this study. The study may help healthcare providers better understand end-of-life decision making for African Americans with dementia as well as better plan future studies on this issue.

**Confidentiality:** The following personal information will be collected from you during this study: your name (to identify and call you by name during the interview or if there is a need to contact you via phone), phone number (to setup appointments for consent and data collection), physical address (if the interview will be collected in your home and the researcher needs to locate your physical address), initials/signature (collected on payment log to ensure payment is received by you), and audio (voice) recording to ensure accuracy of the information you provide. All information collected from you for this

Revision date: 11/01/11

Page 1

|                         |               |             |
|-------------------------|---------------|-------------|
| IRB-SBS Office Use Only |               |             |
| Protocol #              | 2014-0462-00  |             |
| Approved                | from: 1/28/15 | to: 1/27/16 |
| SBS Staff               | EEM           |             |

Project Title: End-of-Life Decision-Making for African American Older Adults with Dementia

study will be stored in this secure manner and will be kept secure for future use to build better research studies. Because of the nature of information collected from you, it may be possible to determine your identity; however, there will be no attempt to do so and your information will be reported in a way that will not identify you.

**Data linked with identifying information:** The information that you give in the study will be handled confidentially. Your information will be assigned a code number. The list connecting your name to this code will be secured at the University. When the study is completed and information is examined, this list will be destroyed. Your name will not be used in any report. The audio containing the interview will be destroyed once the interview is converted to words.

**Confidentiality cannot be guaranteed:** Every attempt will be made to ensure that your information is kept confidential. Your information will not be reported in an individual, but in a combined format. This will reduce the chances of you being identified. All information will be stored on password-protected computers and the information will be scrambled so that it will not be identifiable if the information is accessed by anyone not related to the study. In the unlikely event that any personal information belonging to you is lost, you as well as the ethics boards will be notified.

**Voluntary participation:** Your participation in the study is completely voluntary and as such participating in this study will not affect any medical care your loved one with memory loss receives from any facility where he/she receives care.

**Right to withdraw from the study:** You have the right to withdraw from the study at any time without penalty. Should you choose to withdraw from the study, any information you provided would not be used in the study results. Any audio recordings that you have completed thus far will be destroyed.

**How to withdraw from the study:** To withdraw from the study, simply inform the researcher right way and you can simply leave the room. There is no penalty for withdrawing. However, should you decide to withdraw once the consent form is completed, you will receive the \$10 Walmart gift card in gratitude for your time and participation thus far. If you no longer wish to participate in the study after your information has been submitted, please contact the researcher by phone or email.

**Payment:** You will receive a \$10 Walmart gift card immediately after the survey and interview information is collected. You will be asked to initial or sign a payment issuance log as proof that payment was received. Only your participant number and not your name will be on this form.

**If you have questions about the study, contact:**

Karen O. Moss, MSN, RN, CNL  
School of Nursing  
McLeod Hall

Revision date: 11/01/11

Page 2

|                         |               |             |
|-------------------------|---------------|-------------|
| IRB-SBS Office Use Only |               |             |
| Protocol #              | 2014-0462-00  |             |
| Approved                | from: 1/28/15 | to: 1/27/16 |
| SBS Staff               | 9281          |             |



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Project Title: End-of-Life Decision-Making for African American Older Adults with Dementia

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University of Virginia, PO Box 800782  
 202 Jeanette Lancaster Way  
 Charlottesville, VA 22908-0826  
 Telephone: (407) 765-2416  
 Email address: [kos2fr@virginia.edu](mailto:kos2fr@virginia.edu)

Faculty Advisor: Karen Rose, PhD, RN, FAAN, FGSA  
 School of Nursing  
 202 Jeanette Lancaster Way  
 University of Virginia, P.O. Box 800782  
 Charlottesville, VA 22908  
 Telephone: (434) 924-5627  
 Email address: [kmr5q@virginia.edu](mailto:kmr5q@virginia.edu)

**If you have questions about your rights in the study, contact:**

Tonya R. Moon, Ph.D.  
 Chair, Institutional Review Board for the Social and Behavioral Sciences  
 One Morton Dr Suite 500  
 University of Virginia, P.O. Box 800392  
 Charlottesville, VA 22908-0392  
 Telephone: (434) 924-5999  
 Email: [irbsbshelp@virginia.edu](mailto:irbsbshelp@virginia.edu)  
 Website: [www.virginia.edu/vpr/irb/sbs](http://www.virginia.edu/vpr/irb/sbs)

**Agreement:**

I agree to participate in the research study described above.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

You will receive a copy of this form for your records.

Revision date: 11/01/11  
 Page 3

|                         |               |             |
|-------------------------|---------------|-------------|
| IRB-SBS Office Use Only |               |             |
| Protocol #              | 2014-0462-00  |             |
| Approved                | from: 1/28/15 | to: 1/27/16 |
| SBS Staff               | [Signature]   |             |

## Appendix M – Consent Form – Riverside Health System

Project Title: End-of-Life Decision-Making for African American Older Adults with Dementia

### Informed Consent Agreement

RHS IRB APPROVAL DATE:

4-1-15

Please read this consent agreement carefully before you decide to participate in the study.

**Purpose of the research study:** The purpose of the study is to better understand end-of-life decisions for African American older adults with memory loss by their family caregivers.

**What you will do in the study:** In this study, a total of 80 family caregivers, such as you, will be asked to describe how end-of-life decisions are made for your loved one with memory loss. You will complete two forms: one about basic information regarding you and your loved one with memory loss and another about any existing end-of-life plans for the same loved one. You will complete three additional surveys about the following: your quality of life, the quality of life of your loved one with memory loss, and another on how confident you are to make these decisions for your loved one with memory loss. You may also be asked to verbally answer questions related to end-of-life decisions for your loved one with memory loss, quality of life and your confidence to make decisions for your loved one with memory loss. This interview part of the study will be audio recorded using a digital voice recorder. You may skip any portion of the surveys or interview that makes you feel uncomfortable and may request to have the recorder turned off at any time. Additionally, you can stop the survey or interview at any time.

**Time required:** The study will require one and a half hours of your time all in one session. Feel free to take any breaks you need, either to regroup or for refreshment as needed.

**Risks:** Because we will be discussing the potentially emotional subject of death and dying, this study may cause emotions of grief for you. Though the chances of this happening are minimal, to address this possibility you will be allowed to take breaks as needed. If you feel that it is too much for you to continue responding to the questions, you may choose to end the study or I as the researcher may choose to end it. If necessary, you will be asked to visit your primary healthcare provider beginning with me placing a call to them (with your permission) to explain your participation in the study and your reaction for follow up care.

**Benefits:** There are no direct benefits to you for participating in this study. The study may help healthcare providers better understand end-of-life decision making for African Americans with dementia as well as better plan future studies on this issue.

**Confidentiality:** The following personal information will be collected from you during this study: your name (to identify and call you by name during the interview or if there is a need to contact you via phone), phone number (to setup appointments for consent and data collection), physical address (if the interview will be collected in your home and the researcher needs to locate your physical address), initials/signature (collected on payment log to ensure payment is received by you), and audio (voice) recording to ensure accuracy of the information you provide. All information collected from you for this study will be stored in this secure manner and will be kept secure for future use to build better research studies. Because of the nature of information collected from you, it may be possible to determine your identity; however, there will be no attempt to do so and your information will be reported in a way that will not identify you.

**Project Title: End-of-Life Decision-Making for African American Older Adults with Dementia**

**Data linked with identifying information:** The information that you give in the study will be handled confidentially. Your information will be assigned a code number. The list connecting your name to this code will be secured at the University. When the study is completed and information is examined, this list will be destroyed. Your name will not be used in any report. The audio containing the interview will be destroyed once the interview is converted to words. **Confidentiality cannot be guaranteed:** Every attempt will be made to ensure that your information is kept confidential. Your information will not be reported in an individual, but in a combined format. This will reduce the chances of you being identified. All information will be stored on password-protected computers and the information will be scrambled so that it will not be identifiable if the information is accessed by anyone not related to the study. In the unlikely event that any personal information belonging to you is lost, you as well as the ethics boards will be notified.

**Voluntary participation:** Your participation in the study is completely voluntary and as such participating in this study will not affect any medical care your loved one with memory loss receives from any facility where he/she receives care.

**Right to withdraw from the study:** You have the right to withdraw from the study at any time without penalty. Should you choose to withdraw from the study, any information you provided would not be used in the study results. Any audio recordings that you have completed thus far will be destroyed.

**How to withdraw from the study:** To withdraw from the study, simply inform the researcher right way and you can simply leave the room. There is no penalty for withdrawing. However, should you decide to withdraw once the consent form is completed, you will receive the \$10 Walmart gift card in gratitude for your time and participation thus far. If you no longer wish to participate in the study after your information has been submitted, please contact the researcher by phone or email.

**Payment:** You will receive a \$10 Walmart gift card immediately after the survey and interview information is collected. You will be asked to initial or sign a payment issuance log as proof that payment was received. Only your participant number and not your name will be on this form.

**If you have questions about the study, contact:**

Karen O. Moss, MSN, RN, CNL  
 School of Nursing  
 McLeod Hall  
 University of Virginia, PO Box 800782  
 202 Jeanette Lancaster Way  
 Charlottesville, VA 22908-0826  
 Telephone: (407) 765-2416  
 Email address: [kos2fr@virginia.edu](mailto:kos2fr@virginia.edu)

**Project Title: End-of-Life Decision-Making for African American Older Adults with Dementia**

Faculty Advisor: Karen Rose, PhD, RN, FAAN, FGSA  
School of Nursing  
202 Jeanette Lancaster Way  
University of Virginia, P.O. Box 800782  
Charlottesville, VA 22908  
Telephone: (434) 924-5627  
Email address: [kmr5q@virginia.edu](mailto:kmr5q@virginia.edu)

**If you have questions about your rights in the study, contact:**

Jennifer Brown, BS, CTR  
Institutional Review Board Manager  
Riverside Health System  
12100 Warwick Blvd, Suite 101  
Newport News, VA 23601  
Phone: (757) 594-3054  
Fax (757) 534-5089  
[Jennifer.brown@rivhs.com](mailto:Jennifer.brown@rivhs.com)

**Agreement:**

I agree to participate in the research study described above.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

You will receive a copy of this form for your records.



**Appendix N – Contact Information Form**

*Decisions for African American Older Adults with Dementia Study*  
**(DAADS)**

**Principal Investigator:** Karen O. Moss, MSN, RN, CNL

**Administrative Site:** University of Virginia

**Department:** School of Nursing

**Address:** Charlottesville, VA 22908-0782

Date: \_\_\_\_\_ ID#: \_\_\_\_\_

**PARTICIPANT CONTACT INFORMATION FORM**

Name: \_\_\_\_\_

Phone Contact: \_\_\_\_\_

Email Address: \_\_\_\_\_

Physical Address: \_\_\_\_\_

Date Enrolled: \_\_\_\_\_

Agree to receive a copy of study results:    YES    NO

**Appendix O – Thank-You Letter – Participants**

RE: Thank You

Dear [Participant Name Here]:

I wish to thank you for your participation in the research study to examine End-of-Life Decision-Making for African American Older Adults with Dementia. I appreciate you taking the time to participate in this study and providing valuable information to further examine this important topic. It has been a pleasure to meet you and I wish you all the best for the future.

Sincerely,

Karen Moss  
(electronically signed)

Karen Moss, MSN, RN, CNL  
PhD Candidate  
University of Virginia  
407-765-2416  
kos2fr@virginia.edu

## **Appendix P – Debriefing Form – University of Virginia**

### **Debriefing Form: End-of-Life Decision-Making for African American Older Adults with Dementia**

Thank you for agreeing to participate in this study! The general purpose of this research is to better understand end-of-life decisions for African American older adults with memory loss.

We invited African American family caregivers who are at least 21 years of age caring for an African American loved one diagnosed with memory loss who is 55 years or older. In this study, you were asked to describe how you make end-of-life decisions for your loved one with memory loss and complete two forms; one about basic information about you and your loved one as well as information on any existing end-of-life plans for your loved one. You were also asked to respond to three forms about your quality of life and that of your loved one with memory loss as well as one on how confident you are with making such decisions for your loved one with memory loss. This information requested relates to the purpose of this study, which is to learn more about how persons such as you make end-of-life decisions for loved ones with memory loss. The results from this study will allow researchers and healthcare providers to learn from you as you provided valuable information to help conduct further studies to learn even more about this important decision-making process. The goal is to eventually find ways to better help persons such as yourself and your loved one with memory loss with these difficult decisions.

If you feel especially concerned about how the information collected from this study may be used we encourage you to contact the researcher. If you begin to get feelings of being extremely saddened or depressed as a result of our discussions, please feel free to phone Karen Moss at 407-765-2416 for referral to your primary healthcare provider. I would be happy to contact your healthcare provider directly to explain your participation in the study and arrange any follow-up care needed with that service. Alternatively, you could also phone the UVA Counseling and Psychological Services (434-243-5556) or the Mary D. Ainsworth Psychological Clinic in the psychology department (434-982-4737).

Thank you for your participation in this study. If you have further questions about the study, please contact Karen Moss, MSN, RN, CNL, PhD Candidate, School of Nursing, University of Virginia, McLeod Hall, P.O. Box 800782, 202 Jeanette Lancaster Way, Charlottesville, VA 22908-0826. Telephone: (407) 765-2416. In addition, if you have any concerns about your rights in the study, you may contact Tonya Moon, Ph.D., Chair, Institutional Review Board for the Social and Behavioral Sciences, One Morton Drive, Suite 500, University of Virginia, P.O. Box 800392, Charlottesville, VA 22908-0392. Telephone: (434) 924-5999.

Additional Reading:

End-of-life brochure for family caregivers from the Alzheimer's Association:

[http://www.alz.org/national/documents/brochure\\_endoflifedecisions.pdf](http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf)

End-of-life decisions information from the National Institute on Aging:

[http://www.nia.nih.gov/sites/default/files/end\\_of\\_life\\_helping\\_with\\_comfort\\_care\\_0.pdf](http://www.nia.nih.gov/sites/default/files/end_of_life_helping_with_comfort_care_0.pdf)

## **Appendix Q – Debriefing Form – Riverside Health System**

Debriefing Form: End-of-Life Decision-Making for African American Older Adults with Dementia

Thank you for agreeing to participate in this study! The general purpose of this research is to better understand end-of-life decisions for African American older adults with memory loss.

We invited African American family caregivers who are at least 21 years of age caring for an African American loved one diagnosed with memory loss who is 55 years or older. In this study, you were asked to describe how you make end-of-life decisions for your loved one with memory loss and complete two forms; one about basic information about you and your loved one as well as information on any existing end-of-life plans for your loved one. You were also asked to respond to three forms about your quality of life and that of your loved one with memory loss as well as one on how confident you are with making such decisions for your loved one with memory loss. This information requested relates to the purpose of this study, which is to learn more about how persons such as you make end-of-life decisions for loved ones with memory loss. The results from this study will allow researchers and healthcare providers to learn from you as you provided valuable information to help conduct further studies to learn even more about this important decision-making process. The goal is to eventually find ways to better help persons such as yourself and your loved one with memory loss with these difficult decisions.

If you feel especially concerned about how the information collected from this study may be used we encourage you to contact the researcher. If you begin to get feelings of being saddened or depressed as a result of our discussions, please feel free to phone Karen Moss at 407-765-2416 for referral to your primary healthcare provider. I would be happy to contact your healthcare provider directly to explain your participation in the study and arrange any follow-up care needed with that service. Alternatively, you could also contact the local PACE Center (where your loved one is a member). Here social workers and chaplains are available to discuss subjects regarding grief and loss and are certified to assist people with end-of-life planning.

Thank you for your participation in this study. If you have further questions about the study, please contact Karen Moss, MSN, RN, CNL, PhD Candidate, School of Nursing, University of Virginia, McLeod Hall, P.O. Box 800782, 202 Jeanette

Lancaster Way, Charlottesville, VA 22908-0826. Telephone: (407) 765-2416. In addition, if you have any concerns about your rights in the study, you may contact Jennifer Brown, BS, CTR, Institutional Review Board Manager, Riverside Health System, 12100 Warwick Blvd, Suite 101, Newport News, VA 23601, Phone: (757) 594-3054, Fax (757) 534-5089 Jennifer.brown@rivhs.com  
Additional Reading: End-of-life brochure for family caregivers from the Alzheimer's Association:

[http://www.alz.org/national/documents/brochure\\_endoflifedecisions.pdf](http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf)

End-of-life decisions information from the National Institute on Aging:

[http://www.nia.nih.gov/sites/default/files/end\\_of\\_life\\_helping\\_with\\_comfort\\_care\\_0.pdf](http://www.nia.nih.gov/sites/default/files/end_of_life_helping_with_comfort_care_0.pdf)

## **Appendix R – Thank-You Letter – Drop Outs**

RE: Gratitude for Participation

Dear Study Participant Name Here:

I wish to thank you for your participation in the research study to examine End-of-Life Decision-Making for African American Older Adults with Dementia. I understand the need for you to no longer participate in this study at this time. It has been a pleasure to meet you and I wish you all the best for the future.

Sincerely,

Karen Moss  
(electronically signed)

Karen Moss, MSN, RN, CNL  
PhD Candidate  
University of Virginia  
407-765-2416  
kos2fr@virginia.edu

## Appendix S

*Decisions for African American Older Adults with Dementia Study  
(DAADS)*

**Principal Investigator:** Karen O. Moss, MSN, RN, CNL

**Administrative Site:** University of Virginia

**Department:** School of Nursing

**Address:** Charlottesville, VA 22908-0782

## ENROLLMENT LOG

[illegible]



## Appendix T

### *Decisions for African American Older Adults with Dementia Study (DAADS)*

**Principal Investigator:** Karen O. Moss, MSN, RN, CNL

**Administrative Site:** University of Virginia

**Department:** School of Nursing

**Address:** Charlottesville, VA 22908-0782

### REFUSAL LOG

| IDENTIFICATION | DATE OF REFUSAL | REASON FOR REFUSAL (IF GIVEN) |
|----------------|-----------------|-------------------------------|
| R001           |                 |                               |
| R002           |                 |                               |
| R003           |                 |                               |
| R004           |                 |                               |
| R005           |                 |                               |
| R006           |                 |                               |
| R007           |                 |                               |
| R008           |                 |                               |
| R009           |                 |                               |
| R010           |                 |                               |

## Appendix U

### *Decisions for African American Older Adults with Dementia Study (DAADS)*

**Principal Investigator:** Karen O. Moss, MSN, RN, CNL

**Administrative Site:** University of Virginia

**Department:** School of Nursing

**Address:** Charlottesville, VA 22908-0782

### INELIGIBILITY LOG

| IDENTIFICATION | DATE OF<br>INELIGIBILITY | REASON FOR INELIGIBILITY |
|----------------|--------------------------|--------------------------|
| IN001          |                          |                          |
| IN002          |                          |                          |
| IN003          |                          |                          |
| IN004          |                          |                          |
| IN005          |                          |                          |
| IN006          |                          |                          |
| IN007          |                          |                          |
| IN008          |                          |                          |
| IN009          |                          |                          |
| IN010          |                          |                          |

## Appendix V

### *Decisions for African American Older Adults with Dementia Study (DAADS)*

**Principal Investigator:** Karen O. Moss, MSN, RN, CNL

**Administrative Site:** University of Virginia

**Department:** School of Nursing

**Address:** Charlottesville, VA 22908-0782

### INCENTIVE DISBURSEMENT LOG

| Participant ID | Date of Disbursement | Location | Participant Signature |
|----------------|----------------------|----------|-----------------------|
| 1001           |                      |          |                       |
| 1002           |                      |          |                       |
| 1003           |                      |          |                       |
| 1004           |                      |          |                       |
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| 1037           |                      |          |                       |

