Dementia Caregivers: An Exploration of Their Knowledge, Beliefs, and Behavior Regarding Advance Care Planning For End-of-Life Care

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Dementia Caregivers: An Exploration of Their Knowledge, Beliefs, and Behavior Regarding Advance Care Planning for End-of-Life Care

A dissertation submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree at Virginia Commonwealth University

By

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Virginia Commonwealth University
Richmond, Virginia
May 2014
For Andy

With love and gratitude

for making this journey possible
Acknowledgements

There is an old Irish proverb which says “we survive in the shelter of one another.” During this long and challenging doctoral program, I survived because of the love and support of many wonderful people. First among them, is Andy, my dear husband of 38 years, who did not even blink an eye when I told him that I wanted to go back to school at this stage of our lives. He paved a clear path for me so I could focus all the time and attention needed to be successful. He was the cook, the errand runner, the fix-it guy, the soother of raw nerves, the listener of intense whining, the designer of charts and graphs, and the software problem solver. Above all his love kept me buoyant and moving to the next right thing. Without him this dissertation would not have been possible.

My children, Amanda and Nicholas, and their wonderful spouses, Craig and Caitlin, were my best cheerleaders. Always asking how I was doing, what progress I was making, and never having any doubt that I would make it to the finish line. Their confidence kept me going even when mine was flagging.

I am deeply grateful to my advisor in the doctoral program, Ellen Netting. She has been extraordinarily generous with her time and advice. The most remarkable thing was the keen interest she took not only in my work as a doctoral student but also in all that was unfolding in my life. After Ellen retired, Pam Kovacs, graciously stepped into the role as chair of my dissertation committee. I am deeply grateful for her great kindness, keen attention to detail, and remarkable ability to ask questions that get to the heart of the matter. She is generous with her time and interest in my life and exhibits great patience as I struggle to find my way.

When Pam retired this past year, Sarah Kye Price, became dissertation chair. I thank her for taking on this responsibility especially because she was also stepping into her new role as Director of the Ph.D. program. Thank you, Sarah, you are amazingly kind. I appreciate your professionalism, keen judgment, and broad research experience. Thank you for all your help and support in getting me to the finish line.

I am greatly appreciative of the support of all the committee members. In addition to Sarah and Pam, David Fauri and Connie Coogle, have helped shape the study design, listened intently to my explanations of the preliminary findings, and encouraged me to explore issues more deeply by asking thoughtful questions. Above all they encouraged me to keep at it. Thank you.

A special thank you to Mary Secret for helping me understand theory, providing critical support during a problem-plagued semester of teaching, and for her friendship. Thank you to Mary Katherine O’Connor for her help and wise counsel in getting two studies through a challenging IRB process. Mary Katherine taught me to “trust emergence,” a concept that took me a long time to understand and even longer to embrace. In the process of doing data analysis for this grounded theory dissertation, I began to learn how to let go and how to trust that the story is in the data even if I could not see it. This process required both patience and faith. In moments
of despair, I reminded myself that the caregivers’ words contained what I needed to know. It was up to me to listen carefully. Thank you, Mary Katherine, for the greatest lesson of this entire doctoral program.

I was blessed to be in the wonderful 2008 cohort of students. Instead of being competitive with one another, we moved through the doctoral experience as colleagues being helpful and supportive. Given my long career, I understand just how precious and rare this is. A special thank you to Jenny Shadik who served as the peer reviewer for the study. We met every month during the long process of data collection, data analysis, and writing the final chapters. Jenny, thank you for your help, kindness, willingness to endure my mini-meltdowns, and for becoming my good friend in the process.

I want to acknowledge the great support I received from Sherry Peterson, CEO of the Alzheimer’s Association of the Greater Richmond area, and the staff and volunteers. Their help was critical to the success of this study, particularly in assisting in finding caregivers willing to be interviewed. I appreciate all their help with recruitment and their interest in the study’s findings.

I am grateful to all the caregivers who participated in the study. I am deeply appreciative of their willingness to share their remarkable stories and their encouragement to pursue more research regarding end-of-life issues for dementia families.

One of the major findings of this study is how powerful the impact of family illness and death is on caregivers in shaping their attitudes and beliefs regarding end-of-life planning. This is true in my own life. My mother and aunts’ deaths from Alzheimer’s disease, and my mother-in-law’s long illness and death from normal pressure hydrocephalus had a deep impact on me both in my personal and professional life. It caused me to seek knowledge about dementia, caregiving, dying, and advance care planning. It led me to become a volunteer and staff member of the Alzheimer’s Association and ultimately to a doctoral program where I could pursue a research degree. I acknowledge my family members whose experience has made me a stronger advocate for dementia families and sharpened my awareness of the importance of social work practice and research in improving end-of-life care for advanced dementia patients.
Table of Contents

List of Tables ........................................................................................................... x
List of Figures ........................................................................................................... xi
List of Abbreviations ................................................................................................ xii
Abstract .................................................................................................................. xiii
Chapter 1: Overview ............................................................................................... 2
  Introduction ............................................................................................................. 2
  Personal Narrative .................................................................................................. 10
  Purpose of the Study ............................................................................................. 15
  Research Questions ............................................................................................... 15
  The Process of Advance Care Planning ............................................................... 15
  Rationale for Study ............................................................................................... 17
  Rationale for Using A Grounded Theory Method .............................................. 18
  Relevance for Social Work ................................................................................... 19
Chapter 2: Literature Review .................................................................................. 23
  The Problem of Dementia as a Growing Public Health Issue ......................... 23
  The Impact of Dementia Caregiving ................................................................... 26
    Theoretical/conceptual base of dementia caregiving ........................................ 28
    The caregiving career ......................................................................................... 29
  Problems of End-of-Life Care for Dementia Patients and Caregivers ............ 31
    Dying in America today ...................................................................................... 31
The demands for care in late-stage dementia..........................33
The barriers to improved end-of-life care...............................35
Use of life-sustaining measures.........................................39
Use of palliative and hospice care.......................................42
The Historical and Legal Context for Advance Care Planning.....44
Research on Advance Directives and Competent Adults..........50
  Prevalence of ADs among competent adults.........................51
  Key research findings................................................52
Conceptual models of ACP decision making...........................62
Research on Advance Directives and Dementia Caregivers.......69
  Prevalence of ADs for dementia patients............................70
  Key research findings................................................71
Key Factors Related to Completion of Advance Directives.......77
Successful Interventions That Promote ACP........................85
Chapter 3: Research Methodology........................................93
  Purpose of the Study..................................................93
  Research questions....................................................93
  Research paradigm and theoretical framework.....................94
Research Method..........................................................97
  Grounded theory.......................................................97
    Definition of grounded theory.....................................98
    Historical and theoretical base of grounded theory..............98
    Different grounded theory methods...............................101
Impact of the methodological split between Glaser and Strauss..........................103

Selection of modified classic grounded theory method.............106

Sampling and Recruitment of Study Participants..................108

Data Collection Strategy.........................................................113

Ethical Considerations............................................................116

Data Analysis Process.............................................................117

Data Management Procedures...............................................122

Assessing Quality of the Study...............................................122

Product of the Study...............................................................130

Limitations of the Study..........................................................131

Chapter 4: Findings.................................................................133

Description of the Sample.......................................................133

The Caregiving Context...........................................................138

The Grounded Theory: The Dementia Caregiver Advance Care Planning Theory...........................................140

The process of how caregivers do ACP.................................141

Key features of the ACP process............................................149

How caregivers use ACP: Defining the role of decision maker.................................................................157

Key features that shape definition of role as decision maker.................................................................165

Factors That Influence the Caregiver ACP Process..................174

Unanticipated Findings of the Study........................................179
Chapter 5: Discussion and Implications ................................................................. 188

Discussion of Findings .................................................................................. 188

Sample demographics and caregiver context .............................................. 190

The process of ACP ...................................................................................... 192

How caregivers use ACP .............................................................................. 197

Factors that influence the ACP process ....................................................... 200

Implications for Social Work Practice ......................................................... 206

Implications for Social Justice ..................................................................... 211

Policy Implications ...................................................................................... 213

Research Implications and Next Steps ....................................................... 216

Conclusion .................................................................................................. 219

References .................................................................................................... 222

Appendix A: Values History Form ................................................................. 256

Appendix B: Commonwealth of Virginia Advance Directives Form ............... 261

Appendix C: Physician Orders for Life-Sustaining Treatment (POLST) Form .......................................................... 274

Appendix D: Recruitment Documents .......................................................... 275

  Document 1: Flyer/Handout ............................................................... 276

  Document 2: Recruitment Script for Use by Staff and Volunteers of the Alzheimer’s Association .......................................................... 277

  Document 3: Brief Advertisement for Chapter Newsletter ....................... 279

  Document 4: Recruitment Script for Initial Telephone Contact .................. 280
Appendix E: Research Subject Information and Consent Form ......................................................284
Appendix F: Interview Guide.................................................................288
Appendix G: Resource List for Dementia Caregivers.................................293
Vita.................................................................................................295
List of Tables

Table 1: Sample Demographics – Personal Caregiver Characteristics..................136

Table 2: Sample Demographics – Characteristics Related to Patients................137
List of Figures

Figure 1: Visual Representation of Burrell & Morgan’s (1979) Paradigms………………95

Figure 2: Evaluating Theory (Glaser, 1978, 1992).……………………………………124

Figure 3: Evaluating the Research Process (Birks & Mills, 2011)…………………126

Figure 4: Overall Evaluation of Any Grounded Theory Study (Creswell, 2013)……129

Figure 5: The Process of How Caregivers do ACP………………………………………143

Figure 6: How Caregivers Use ACP: Defining the Role of Decision Maker………..159

Figure 7: Differences and Similarities Between Support Group and Non-Support
Group Members Regarding Patient End-of-Life Care…………………………181

Figure 8: Visual Display of the Dementia Caregiver Advance Care Planning Theory….187
List of Abbreviations

ACP:  Advance care planning (also referred to as end-of-life planning)

ADs:  Advance directives (a living will and a health care proxy)

Note to Reader:  Although “AD” is often used as an acronym for Alzheimer’s Disease, in this document “AD” refers to advance directives.

ADLs:  Activities of daily living are basic self care tasks which include:  feeding, toileting, dressing, grooming, bathing, walking and transferring such as moving from bed to chair.

CPR: Cardiopulmonary resuscitation.

Health Care Proxy (also known as health care power of attorney or durable power of attorney for health care): Under state and federal law, an individual has the right to appoint another person to make medical decisions on their behalf should they become unable to make decisions on their own behalf.

POLST: Physician’s Order for Life-Sustaining Treatment

PSDA: Patient Self Determination Act, 1991. Federal law which outlines patient rights to make their own health care decisions, the right to accept or refuse medical treatment, and the right to make an advance health care directive (a living will and appointing a health care power of attorney to make decisions should they become incompetent).
Abstract

DEMENTIA CAREGIVERS: AN EXPLORATION OF THEIR KNOWLEDGE, BELIEFS, AND BEHAVIOR REGARDING ADVANCE CARE PLANNING FOR END-OF-LIFE CARE

By: Mariette L. Klein, Ph.D., M.S.W

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2014.

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The purpose of this study is to explore what knowledge dementia caregivers have about advance care planning (ACP), how they learn to execute formal advance directives (ADs) or have engaged in an informal ACP process, and how they understand their roles as decision makers for the patients. Factors that contribute to the completion of an ACP process such as demographic, psychosocial, and situational factors are identified. From the grounded theory data analysis, a theory emerged about how ACP is accomplished and used by caregivers. Findings reveal that caregivers understand ACP as having the power to shape the dying process for dementia patients. It is not just about executing formal written ADs but how caregivers exercise that power. Caregivers’ knowledge and beliefs are reflected in their behavior regarding ACP in both how they do the ACP process and how they use ACP.

For the caregivers in this study, the process of ACP occurs along a trajectory from: years before dementia to dementia diagnosis to end stage and death. At each of these stages, actions
taken by the caregivers and their motivation are identified. Three key features of the ACP process in all three stages are examined: conversations within the family and with trusted others, gaining knowledge of ACP, and keeping ACP documents. How caregivers use ACP is based on how they define their roles as decision makers for their patients by: accepting responsibility for making difficult decisions regarding treatment for the patients, using ACP as an effective tool to shape the dying process for their patients, and doing battle with health care professionals to honor patients’ wishes. This definition is shaped by the meaning caregivers give to ACP, how caregivers understand life sustaining measures, and caregivers’ knowledge of patients’ end-of-life wishes.

This new theory, the Dementia Caregiver Advance Care Planning Theory, adds new knowledge as the first model specific to dementia caregivers and adds dimension and depth to the current existing ACP models by detailing an ACP process, demonstrating the impact of conversations on the process, and identifying both the most important influences and the primary relationship in the decision making process.
Chapter 1: Overview

Introduction

Other than sudden death, dying in America today can be long and complicated. Until the mid-20th century most people died at home after a short acute illness. Death was a family, community, and often religious event that was common and personal. Today death has been “medicalized.” Most die in hospitals or nursing homes after many years of living with a chronic illness. As a result, many Americans are not familiar with dying as a personal experience, are uncomfortable talking about it, and reluctant to accept it. What contributes to this attitude are the technological and pharmaceutical advances in medical care that offer promise of a long life with diseases that are manageable. There is often reluctance to accept that treatment choices can be exhausted and that the choice of comfort care is in the best interests of the patient.

The road to death can be long particularly for dementia patients who live an average of 8 to 20 years after diagnosis with increasing loss of cognitive and physical function (Alzheimer’s Association, 2011; The Alzheimer’s Study Group, 2009). As the dementia progresses the patient loses cognitive function and is unable to understand the trajectory of their disease, the impact of life-sustaining measures, and to give informed consent for such treatment. The caregiver, by patient’s choice or by default, becomes the surrogate decision maker for patient care.

End-of-life decision making for dementia patients is a daunting and complicated challenge for caregivers. In addition to excessive hospitalizations, advanced dementia patients are particularly vulnerable because research demonstrates that most life sustaining measures do not improve outcomes for this population and in many cases cause undue distress, pain, and new injuries (Alzheimer’s Association, 2006; Evers, Purohit, Perl, Khan, & Marin, 2002; Finucane,
Prior to the 1980s decisions about end-of-life care were determined by physicians. The patient and caregiver had little voice or control in this physician-controlled context. But in the 1980s court cases regarding a patient’s right to die captured Americans’ attention and served as an impetus for the U.S. Congress to pass the 1991 Patient Self Determination Act (PSDA) (Public Law No. 101-508), which was followed in quick succession by state laws. These laws allow for a patient’s right to create a living will concerning choice of life sustaining measures and appointment of a health care proxy to make decisions in case of their incompetence. As a result of PSDA, decision making for end-of-life care is no longer solely physician-controlled. It is intended to be a shared decision making process among patient, caregivers, and physician.

In the 23 years since passage of this legislation, advocates, experts, health care professionals, and legislators have been strong advocates of advance care planning (ACP) (also referred to as end-of-life planning) for all adults (Alzheimer’s Association, 2007; Doukas & Reichel, 2007; Family Caregiver Alliance, 2011; Field & Cassel, 2003; National Hospice and Palliative Care Organization, 2011). Many believe that ACP is critical to improving end-of-life care for dementia patients. It provides a mechanism to halt curative treatment and creates opportunity to request palliative/hospice care (AARP, 2011; Alzheimer’s Association, 2007; American Geriatrics Society Public Policy Committee, 1995; Ditto, Danks, Smucker, Bookwala, Coppola, Dresser, Fagerlin, Gready, Houts, Lockhart, & Zyzanski, 2001; Orentlicher, 1990; U.S. Department of Health and Human Services, 2008). Some of these organizations offer recommendations and general guidelines for completing ACP. The American Geriatrics Society (1995) and the American Medical Association (1996) have moved beyond establishing
guidelines and have written policy statements for the care of the frail elderly at end of life. Recognizing that most dementia patients do not receive a diagnosis until after two to three years of symptom development, these advocates are concerned that there is a very narrow window of opportunity where the patient has sufficient cognitive ability to understand life sustaining measures and give informed consent about what kind of intervention they wish at the end of life based on their beliefs, values, and life experience (Alzheimer’s Association, 2011).

ACP is the process of decision making regarding medical treatment choices for end-of-life care. Key to the success of ACP is a communication process involving patient, caregiver, and physician or other health care professional that takes place over time and allows the patient and caregiver to reflect on their values, beliefs, and life experiences which influence their choices for life-sustaining measures. ACP can be formal resulting in written documents called advance directives (ADs) which includes both a living will and health care proxy (Doukas & Reichel, 2007). A living will states what kind of life sustaining treatments a patient may choose, including use of artificial nutrition, cardiopulmonary resuscitation, intravenous hydration, respirators, and use of antibiotics at end of life (Alzheimer’s Association, 2007; Volicer, 2005).

A health care proxy (also referred to as durable power of attorney for health care) is a person selected by the patient, often a family member, to be the decision maker for their end-of-life care when they are no longer able to make decisions on their own behalf (Doukas & Reichel, 2007). Several studies show that there is a hierarchical pattern that emerges when older adults are asked who they would want to make decisions on their behalf if they are too sick to do so. The pattern of choice is in this order: spouse, adult children, siblings, and other family (High, 1994; High & Turner, 1987; Shawler, 1992). If a family member or friend is not available, health care
professionals often will make medical treatment decisions for incompetent patients (Hare, Pratt, & Nelson, 1992; High, 1993a).

ACP can be informal and characterized by conversations among patients, caregivers, and health care professionals (Doukas & Reichel, 2007). Informal ACP may involve just one conversation with such statements as: “I don’t want to live if my mind goes” or comments to family members: “Don’t keep me alive if I am a vegetable” or “I don’t want anyone changing my diapers.” Sometimes these short comments will be all the information a caregiver has in order to make a substituted judgment about patient care in the absence of formal ADs. In other cases a patient may have many conversations with family members about life sustaining measures and the caregiver feels more confident about understanding patient’s wishes.

In the absence of written ADs, caregivers and other family members are called upon to act as surrogate decision makers to make choices for the patient based on what they know are the patient’s wishes (known as substituted judgment) or what they believe, based on their own values, beliefs, and experiences, is what the patient wishes (known as best interests of the patient) (Emanuel & Emanuel, 1992; Lim, 2005; Pevey, 2003). The burden of surrogate decision making can weigh heavily on caregivers causing stress and guilt during the challenging time at end of life (Caron, Griffith, & Arcand, 2005; Forbes, Bern-Klug, & Gessert, 2000).

Although state laws favor family members as surrogate decision makers, defining family members must be done in the context of contemporary American life which includes alternative lifestyles, alternative marriages, and changes in the structure of the nuclear family. This results in an expanding notion of family to include friends and significant others.

ACP has become of increasing concern due to many factors including older adults perceived loss of control over the dying process; the growing aging population with burgeoning
numbers of patients with age-related dementias; and the rapidly rising cost of end-of-life care. Many older adults express they are not afraid of death but are afraid of the dying process.

ACP, along with ADs, are powerful tools for patients and families to help navigate the perilous waters of end-of-life care. Research provides evidence that ACP offers a language and framework for having conversations about death and dying that helps to organize thoughts and articulate preferences (Cantor & Pearlman, 2003; Doukas & Reichel, 2007; Martin, Thiel, & Singer, 1999). For those whose cultural norms inhibit speaking of death and dying, ACP offers an opportunity to examine values and beliefs which might lead to a new understanding of the dying process. It gives patient and caregiver a measure of control and a voice in the decision making process which helps to keep the dying process patient-centered.

Research on competent adults reveals that ACP can help strengthen relationships in families. It helps both patient and family deal with the emotional burden of the patient dying and the burden of surrogate decision making that falls to the caregiver (Caron, et al., 2005; Forbes, et al., 2000; Martin, et al., 1999; Singer, Martin, Lavery, Thiel, Kelner, & Mendelssohn, 1998).

Caregiving advocates, experts in dementia care, researchers exploring new treatments and cures for dementia, the U.S. Department of Health and Human Services, and the U.S. Congress all have voiced strong support for ACP for dementia families. As one example, the Alzheimer’s Association (2007) encourages all patients immediately after diagnosis to begin ACP with their families as the window of opportunity when the patient is cognitively able to make treatment decisions can be narrow.

Even though ACP is recognized as a way for patient and caregiver to have a voice in end-of-life care, ACP is underused by most American adults. There were high expectations after the passage of PSDA that ACP usage rates would surge among the adult population. However, the
estimates for usage among competent adults remains low (Center for Gerontology and Health Care Research, 2008; Fagerlin & Schneider, 2004; U.S. Department of Health and Human Services, 2008; VandeCreek, Frankowski, & Johnson, 1995). The estimates of usage among dementia caregivers are considered even lower but there is little research evidence to support these estimates (Alzheimer’s Association, 2011; Branco, Teno, & Mor, 1995; Castle & Mor, 1998; Center for Gerontology and Health Care Research, 2008; Degenholtz, Rhee, & Arnold, 2004; McAuley & Travis, 2003; U.S. Department of Health and Human Services, 2008).

The key factors related to ACP can be demographic factors (i.e. age, race/ethnicity, religious affiliation, education, socioeconomic status) or psychosocial factors (i.e. death anxiety, loss of control, and perception of disease burden) (Jones, Moss, & Harris-Kojetin, 2011; Resnick, Schuur, Heineman, Stone, & Weissman, 2004; U.S. Department of Health and Human Services, 2008; Volicer, 2005). To add to the complexity of completing ACP are lack of knowledge of ACP, lack of understanding of life-sustaining measures and their impact on frail elders, and lack of knowledge of disease trajectories (Lambert, McColl, Gilbert, Wong, Murray, & Shortt, 2005; Sachs, Shega, & Cox-Hayley, 2004; U.S. Department of Health and Human Services, 2008; Volicer, 2005).

There are structural problems in the current health care system which impede the initiation of ACP such as lack of communication among patient, family, and physicians; lack of portability of AD from one setting to another; and lack of confirmation that an informal ACP process has unfolded within patient-family relationships. In addition, there is a lack of accountability in the health care system regarding who is responsible for initiating ACP with families and there is no reimbursement mechanism to compensate health care providers for ACP discussions (Cassel, Ludden, & Moon, 2000; Mezey, Dubler, Mitty, & Brody, 2002; Sachs, et

In spite of these challenges, several successful interventions exist that promote ACP and could be replicated for different populations. A few of these exceptional programs have created successful educational tools, initiated use of a values history that encourages people to talk about death and dying, and adapted and updated ACP forms (AARP, 2011; Cantor & Pearlman, 2003; Hammes, 1999; Prendergast, 2001; Shega, et al., 2003). A few studies provide evidence that these programs increase ACP rates (Guo & Harstall, 2004; Molloy, Russo, Stiller, & O’Donnell, 2000; U.S. Department of Health and Human Services, 2008). These programs are expanding and have made notable impact.

A common feature of all these successful interventions is a health care professional who initiates and sustains communication with families during the ACP process. This is a role that is well suited for social workers who are trained to view people in the context of their families, and their cultural, racial, ethnic, and religious values and beliefs. This is essential for the successful completion of ACP.

Chapter one offers a personal narrative by the researcher which explains professional and personal experience relevant to the study and speaks to experience with dementia caregivers. In addition, this chapter states the purpose of the study and the research questions. The process of ACP and use of written ADs are defined. A rationale for conducting this study and using a grounded theory methodology is offered. The relevance of this study for social work practice is discussed.

Chapter two reviews the conceptual and empirical literature on ACP as well as providing an exploration of the critical background issues that impact ACP. These include the growing
public health problem of dementia and the challenges of dementia caregiving, including a theoretical base and explication of the dimensions of the caregiving career. The problems of end-of-life care for advanced dementia patients will be explained against a backdrop of the cultural and social context that currently exists in America regarding death and dying. To better understand the current social and political climate regarding end-of-life planning, the historical and legal context of ACP is explained. Relevant research regarding ACP and competent adults and dementia caregivers, and the factors related to completion of ACP are explored. The chapter concludes with a description of successful interventions that promote ACP.

In addition to a description of the research design, data collection, and data analysis plan for this study, chapter three includes an explanation of the philosophical and theoretical foundation for the study, a review of Glaserian or classic grounded theory methodology, and a product.

Chapter four presents a description of the study sample and an explanation of the caregiving context which influences decisions about ACP. The grounded theory which emerged from data analysis, The Dementia Caregiver Advance Care Planning Theory, is discussed along with key features of the process of how caregivers do ACP and how they use ACP. Particular attention is given to the caregiver’s role as decision maker for the patient. Also included are key factors that influence the ACP process and unanticipated findings of this study.

Chapter five includes a discussion of the key findings and implications for social work practice, social justice, and policy. In addition implications for research and next steps are presented.
Personal Narrative

My strong interest in dementia caregiving is a result of experience in both my work life and personal life. During my career in aging, I worked as an Alzheimer’s Association volunteer, support group leader for caregivers, and program manager which included designing educational programs for caregivers. During my internship for the MSW program, I worked in a continuing care residential facility and designed and implemented an in-house hospice program for dying patients. At AARP my work included building coalitions with local volunteer organizations, such as the Shepherd’s Center and AARP chapters to provide respite from the burden caregivers face daily. While a student in the Ph.D. program, I completed an evaluation of the Greater Richmond Chapter of the Alzheimer’s Association’s Helpline program and presented the findings to their board of directors. In addition, I implemented a new computer-based data collection method for ongoing Helpline calls from caregivers that will facilitate more timely reporting of statistics for both the local chapter and national office.

In my personal life, both my mother and aunt suffered and died from complications of Alzheimer’s disease. I have learned about caregiver burden first hand and know the costs of caring for someone with this long and unrelenting disease. I know that families sacrifice most of their resources – financial, social, work life, health – to care for a person they love. Most families seek institutional care only as a last resort.

Particularly difficult for families is end-of-life decision making when the patient is no longer able to give informed consent for medical treatment. Most family members find themselves in the position of being a surrogate decision maker regarding what life-sustaining measures should be taken to either preserve life or to allow for death. Either by plan or by default, the caregiver is asked to make these decisions on behalf of their loved one. Making life
or death decisions for a person with dementia and maintaining a strong advocate’s voice for the patient is daunting for most caregivers.

As I work on this dissertation study of dementia caregivers and how they perceive advance care planning for end of life, I am in the midst of caregiving for my 90-year-old mother-in-law. My husband and I are her long-distance caregivers. We make decisions about her finances, legal affairs, and medical care. She is in the late stage of normal pressure hydrocephalus. Major symptoms include (1) gait problems that result in regular falls; (2) complete incontinence; and (3) increasing cognitive losses resulting in an inability to perform activities of daily living and to give informed consent regarding most life decisions.

Her fondest wish was to remain at home until she died. We were able to honor that wish for several years by having home health aides look after her for a few hours a day. But in the fall of 2011, her physical and cognitive decline accelerated. She began to burn pots on the stove, drop glasses that shattered on the floor, and order expensive products that she did not need. She forgot how to work a microwave oven to heat dinner and how to operate a telephone. We were no longer able to contact her. She was falling an average of three times a week and pushing her lifeline button which brought the fire department and often the police to pick her up. She would always decline to go to the hospital to be examined for injury. On the advice of her physician and home health care manager, she acquiesced to move into assisted living.

My mother-in-law did not engage with her children or her grandchildren through the years. Only when her need grew great, did she allow us into her life. I have this memory of standing in her kitchen and trying to make decisions on what dishes, glasses, and teaspoons to bring to her new assisted living apartment. I had this sinking feeling that I did not know her well enough to be making these decisions. It flashed in my mind how grateful I was that she had been
thoughtful and careful to execute formal written advance directives for her end-of-life care should she be unable to make decisions on her own behalf. I knew from these documents how she felt about resuscitation, feeding tubes, ventilators, and use of antibiotics, or any treatments that would prolong her life. I knew she had a “Do Not Resuscitate Order” and that her son had power of attorney for health care decisions. I had no confidence that I was making the right decisions on what to pack for the move, but I had a sense of relief that I knew what her wishes were for the end.

Her deep unhappiness over having to leave home made her transition to residential care very difficult. She packed her bags three times and attempted to run away although she was not able to figure out how to make the elevator move. She had several falls that have required hospital emergency room visits. She often refused to talk to staff claiming they annoyed her. She has been such a recluse most of her adult life that she finds having people around all the time painful. Often she locks her door and will not let staff in the room. Her ability to move her body is getting more and more difficult and she struggles making transfers from bed to chair. She remains a good, solid eater that draws praise from the staff.

This move has caused her to retreat from us. She has not spoken to me since moving day. She will only speak to her son when he asks her direct questions. I do not know how long she will remain angry with us but I am prepared that it may be until the day she dies. We have committed the worst sin – moving her into a place where she gets the care she needs, but not the care she wants. But even more painful for her, is this move represents her total loss of independence and it requires her to change her own story. This is the story that we tell ourselves about who we are and where we fit in the world. Her story had been that she was a competent responsible adult who took good care of herself despite her mother’s belief that she would not
amount to anything. Now her story needs to be revised to include her increasing physical disability, cognitive lapses, and need for constant care. She feels as if she has failed.

As my mother-in-law’s story continues to unfold, I realize that we may need to move her into skilled nursing care which would require a new facility and new staff. Perhaps this is just magical thinking but I do cling to the hope that she will stabilize where she is now and the staff will be able to provide the necessary care. I do know that every day in long term care is an adventure and her status can change in an instant.

What I have learned from my caregiving experience is how difficult it is for family members to be the agent for inhibiting an older person’s independence even if it is in the best interests of their health and safety. I have learned from my mother’s and aunt’s end-of-life experience with Alzheimer’s and now my mother-in-law’s journey in long term care, that end-of-life care for advanced dementia patients is fraught with peril for caregivers. It is important for caregivers to have as many tools, such as advance care directives, at their disposal to help navigate this challenging time. In order to be more effective advocates, caregivers need to know how the patient wants to die or be willing to make decisions about the best interests of their loved ones. This is the only way to assure that the voices of family members remain in the decision making process at end of life.

Through these experiences I have gained a deeper understanding of caregiving at the end of life and have strong empathy for families who are facing this. I have developed a keen awareness of my beliefs and values concerning end-of-life planning that must remain central to my thinking as I engage in this project. As my mother-in-law’s condition deteriorates, I realize that I could be a participant in my own study. I am fully aware that engaging with other dementia caregivers in the course of this study will require me to accept my own understanding
of end-of-life planning, while also remaining open, honest, and receptive about how others’ beliefs, values, and experiences shape their understanding.

**Author’s Update:** In the fall of 2012 my mother-in-law was moved from assisted living to a nursing home due to her need for skilled nursing care for pressure sores that would not heal. Her decline was steep. She was no longer able to transfer herself from bed to chair, or to walk on her own. Always a robust eater, she began to eat indiscriminately, even non-food items. She became mute and began to smile at everyone, which was disconcerting to those who knew her, as she smiled rarely. Her physician suggested we discontinue all medications as they were no longer doing her any good. From September through December, she developed eating and swallowing difficulties, her pressure sores worsened even with aggressive wound care, and blood tests revealed that she had a serious infection somewhere in her system. The nursing home doctor recommended further tests and treatment, but my husband, her health care power of attorney, said no. He was determined to honor her wishes by clearing a path to a peaceful death. He requested hospice care. The doctor reluctantly signed the order for the Medicare hospice benefit. On December 28, 2012 two days after the doctor signed the hospice order, my mother-in-law died peacefully in her bed.

Our three years of caregiving during end stage dementia were stressful, filled with worry and dismay at the quality of long term care. The continuous problem solving and anxiety about doing the right thing weighed heavily. Our solace was the feeling of gratitude that she died peacefully and in no pain. And in the end we were able to honor her wishes as she had directed. That was our last gift to her.
Purpose of the Study

The purpose of this study is to explore dementia caregivers’ knowledge, beliefs, and behavior regarding ACP. How dementia caregivers understand ACP, how they learn about the process of completing formal ADs or have engaged in an informal ACP process, and how they understand their role as surrogate decision makers is poorly understood. Factors that may contribute to the ACP process are of special interest and include demographic factors (i.e., age, race, ethnicity, education, socioeconomic status) and psychosocial factors (i.e., death anxiety, locus of control, perception of disease burden) are identified. This is an exploratory study that moves beyond description to identify concepts which emerge from the data and then integrates them into a theory of how dementia caregivers perceive ACP. This inquiry is a good first step and begins to fill a research gap about how caregivers view ACP and whether they perceive it as a helpful tool to negotiate the challenges of end-of-life care. The researcher is hopeful that findings from this study and follow-up studies will lead to new interventions and/or adaptations of existing successful interventions that can be tailored specifically for dementia families.

Research Questions

(1) How do dementia caregivers understand the process of ACP?

(2) What factors influence caregivers’ decision-making process regarding ACP?

The Process of Advance Care Planning

A formal ACP is generally a three-step process:

Step 1: Identifying values and beliefs

The critical component of ACP is ongoing conversations with patient and family which allows for the reflection about death and what one values at the end of life. To support these
conversations within a family and with concerned others is a values history. This history allows the patient and family to reflect upon and consider such questions as:

Do I want to live as long as possible, regardless of the quality of life that I experience?  

or

Do I want to preserve good quality of life, even if this means that I may not live as long?

Also, what quality of life values are most important to the patient? For example, from a list of 14 suggested values statements, the patient might choose the following three as the most important to them:

- I want to avoid unnecessary pain and suffering
- I want to be treated with dignity when I can no longer speak for myself
- I want to be treated in accord with my religious beliefs and traditions

The patient and family can add any other values statements that are important to them. (Doukas & Reichel, 2007; National Hospice and Palliative Organization, 2011). Appendix A offers an example of a values history form.

**Step 2 – Communicating with health care professionals**

Conversations with health care professionals about end of life includes discussion of the patient’s disease, its trajectory, and the patient’s wishes for treatment and comfort care. Central to these conversations are explanations of what life sustaining measures are and how they might impact a patient, particularly how they will or will not improve quality of life or reduce pain. Cantor and Pearlman (2003) report that ACP conversations are more successful when facilitated by a health care professional. This is a particularly good role for social workers. They provide the important, key information about life sustaining measures that educates patient
and family about what they are and in the case of dementia, what is the true impact of these measures when applied to a patient with advanced dementia.

**Step 3: Completing written documents**

The living will specifies what life sustaining measures a person wants or does not want if they are incapacitated. Living wills can direct health care professionals to provide care not just to withhold treatment. Although not all 50 states have uniform standards for living wills most ask whether a person wants specific treatments. In addition, to cover situations not stipulated in the living will, an individual can appoint a health care proxy. Every state and the District of Columbia recognize ADs, but the laws governing directives vary by state (Family Caregiver Alliance, 2011). These documents can be filled out by the family without need for a lawyer. For example, for residents of Virginia the forms can be downloaded from the State of Virginia website ([www.vda.virginia.gov/pdfdocs/AdvMedDir.pdf](http://www.vda.virginia.gov/pdfdocs/AdvMedDir.pdf)). An alternative website for getting state specific forms is Caring Connections at: www.caringinfo.org. (National Hospice and Palliative Care Organization, 2005). A copy of the Commonwealth of Virginia Advance Directives Forms is attached as Appendix B.

**Rationale for the Study**

The collective voice of advocates and experts make a strong statement that ACP is critical in improving end-of-life care for dementia patients. This study is important because it seeks to understand how dementia caregivers understand and experience ACP. This is an understudied population. Most studies on ACP have focused on competent well adults and those with chronic conditions living in the community (Gamble, McDonald, & Lichstein, 1991; Gjerdingen, Neff, Wang, & Chaloner, 1999; High, 1988, 1993b; U.S. Department of Health and Human Services, 2008). These studies ask participants to reflect on hypothetical scenarios of
some end-of-life situations which may develop and what they wish or do not wish under those particular circumstances. These studies have participants visualize what might happen in the future.

Dementia caregivers are in a different place. They are caring for a loved one who has a terminal illness. The patient will die from dementia or succumb to the opportunistic infections that occur along the disease course. The patient at some point in the disease trajectory will be unable to give informed consent for medical treatment. The caregiver will be called upon to be the surrogate decision maker on behalf of the patient. How these specific circumstances of dementia care influences a caregiver’s perception of ACP is largely unknown. Are they more likely to understand and relate to the importance of completing ADs than adults who are not in the same situation? Are dementia caregivers more likely to view ACP as a helpful tool as many advanced cancer and HIV/AIDS patients do? Or do dementia caregivers understand ACP in the same way as many healthy older adults living in the community? This study illuminates key factors in the decision making process that begin to address these questions and shed light on what motivates a caregiver to complete ACP.

**Rationale for Using a Grounded Theory Method**

A grounded theory methodology based on the original Glaser and Strauss (1967) and Glaser (1978, 1992, 2002) was used for this study. It encompasses the hallmarks of high quality qualitative inquiry: constant comparison of data, theoretical sampling, coding, memoing, use of interview and field notes. This is an inductive process which allows for emergence of concepts from the data which, in turn, allows for a core category to emerge. This eventually leads to formation of a hypothesis and a theory about how caregivers understand ACP.
Strauss and Corbin (1998) define grounded theory as “theory that is derived from data, systematically gathered and analyzed through the research process……and because grounded theories are drawn from the data they are likely to offer insight, enhance understanding and provide a meaningful guide to action” (1998, p. 12). Glaser and Strauss, the creators of the grounded theory method, state that “grounded theories are powerful tools that fit empirical situations and provide ‘relevant predictions, explanations, interpretations and application’” (1967, p. 1). Under-researched areas are suited to inquiry using a grounded theory method “as theory and theory development are grounded in empirical data and in acts of everyday social life” (Hunter, Murphy Grealish, Casey, & Keady, 2011). In classic grounded theory the researcher interacts with participants and strives to interpret their social world (Glaser & Strauss, 1967). Nathaniel and Andrews believe that “because of their real-world orientation, grounded theories are particularly appropriate for health care research” (2010, p. 65). Based on such support, grounded theory is an appropriate and well-tested method for beginning to understand a process such as ACP. Grounded theory is a good choice for this study because dementia caregivers are an under-studied population and the ACP process is unknown with dementia caregivers. The researcher is attempting to explore new territory by examining a new population, and attempting to discover the concepts of the ACP process. Eventually through this process a theory emerged to explain how the ACP process works.

**Relevance for Social Work**

Strong research evidence exists that health care professionals are important to the ACP process (Alzheimer’s Association, 2007; U.S. Department of Health and Human Services, 2008; White, 2005). As successful ACP interventions have demonstrated, nurses and social workers are the most likely to begin a communication process with families that leads to ACP and to the
completion of ADs (Laje, 2001; Sansone & Phillips, 1995). Social workers have an important role in end-of-life planning and care (Forbes, et al., 2000; Mezey, Kluger, Maislin, & Mittelman, 1996). They are particularly well suited to this role because they have been trained and work in a person-in-environment context seeking to understand factors that might contribute to patient’s values, beliefs and experiences which impact the ACP process. Cagle and Kovacs suggest that “by educating individuals and their families about relevant end-of-life issues, social workers serve as ‘context interpreters’ which help families put information into perspective and deal with the feelings that are evoked by the information” (2009, p. 18).

The key to success of ACP is sustaining a communication process with patient and caregiver. Social workers have opportunities to interface with families over time (Sachs, 1994). They can spend valuable time with patient and family explaining and honoring patient autonomy and self determination in completing ADs. Social workers are trained in the therapeutic process that involves conveying knowledge and initiating conversations over time that allows learning and understanding to take place. Social workers can facilitate discussions with patients and caregivers regarding their values, beliefs and experiences which influence choices for end of life. They can explain disease trajectories, life-sustaining measures and their impact on dementia patients, and the choice of palliative/hospice care as an alternative to aggressive treatment.

Social workers could be very effective in early intervention with dementia families. Ideally the ACP communication process could begin right after diagnosis, and the social worker would engage the family during the early stage of disease to do a values history, discuss life-sustaining measures, and help the family execute forms. If this is done, the patient has a chance to think about these issues and make some decisions on his/her own behalf, rather than leave them to the caregiver after the patient can no longer give informed consent.
Social workers can be advocates for patients’ rights, facilitate communication among patient, family, community, and health care providers, and guide caregivers through the ACP process. Cagle and Kovacs believe that “social workers have a professional obligation to minimize communication barriers within the health care system because ensuring that patients and families are adequately informed is a prerequisite for client empowerment and self-determination” (2009, p. 18). They are ideally situated in the health care system to facilitate ACP for dementia patients and their caregivers. They work in nursing homes, hospitals, hospice programs, advocacy organizations, state and local government agencies, and other health related organizations. Each of these entities could serve as gateway for initiation of an ACP communication process. For dementia patients living at home, social workers deployed in primary care physicians’ offices or throughout the network of community organizations that support elders, would be well positioned to offer guidance and support through an ACP process.

Geriatric care managers who reach out to dementia families in the community could also be a conduit for ACP conversations with families. Studies demonstrate that social workers are highly effective in helping patients and caregivers complete ADs and communicate about end-of-life care (Gockel, Morrow-Howell, Thompson, Pousson, & Johnson, 1998; Laje, 2001; Osman & Perlin, 1994). Social workers have also been found to be particularly effective in conversations about end of life because of a higher comfort level with death and dying when compared to other health care professionals (Carr & Merriman, 1995-1996; Laje, 2001).

The social worker’s role in end-of-life care is supported by the National Association of Social Workers (NASW). The NASW policy statement that addresses the role of the social worker in end-of-life care focuses on the right of self determination for dying patients and the need for advocacy and support by social workers:
…the appropriate role for social workers is to help patients express their thoughts and feelings, to facilitate exploration of alternatives, to provide information to make an informed choice, and to deal with grief and loss issues (NASW Delegate Assembly, 1993).

The NASW (1993) guide for ethics support patient autonomy which forms the foundation of ADs as supported by federal and state laws. Federal and state law support the voice of the patient and caregiver in the choice of care at end of life and social workers can support the patient’s and caregiver’s implementation of that choice.
Chapter 2: Literature Review

To better understand the importance of shared decision making which supports the voice of the patient and caregiver in end-of-life care, Chapter 2 offers a review of the conceptual and empirical literature on ACP. This chapter provides an exploration of the critical background issues that impact ACP which includes the growing public health problem of dementia, the challenges of dementia caregiving, and a theoretical base and explication of the dimensions of the caregiving career. The problems of end-of-life care for advanced dementia patients are explained against a backdrop of the cultural and social context that currently exists in America regarding death and dying. To better understand the current social and political climate regarding end-of-life planning, the historical and legal context of ACP is presented. Relevant research regarding ACP and competent adults, the existing research on dementia caregivers, and the factors related to completion and/or non-completion of ACP are explored. The chapter concludes with a description of successful interventions that promote ACP.

The Problem of Dementia as a Growing Public Health Issue

As the baby boomers begin to turn 65 the incidence of age-related disorders such as Alzheimer’s disease and related dementias is increasing rapidly. Every 69 seconds someone in America develops dementia. One in eight people aged 65 and older and nearly half of people aged 85 and older have dementia (Alzheimer’s Association, 2011; National Institute of Health, 2010). Currently 5.4 million Americans have dementia. Over the next 20 years, the number of people over age 65 with dementia will increase by more than 50%, to 7.7 million in 2030 (Alzheimer’s Association, 2011; The Alzheimer’s Study Group, 2009). The most common type
of dementia is Alzheimer’s disease which accounts for an “estimated 60 to 80 percent of cases” (Alzheimer’s Association, 2011, p. 5).

It is a growing public health problem reflected in these current alarming statistics:

- It is the 5th leading cause of death for people 65 and older
- It is already the nation’s third most expensive disease after heart disease and cancer; it costs the federal government more than $183 billion per year
- In 2010, 14.9 million family caregivers provided 17 billion hours of unpaid care, a contribution to the nation of $202 billion (Alzheimer’s Association, 2011, p. 25).

Dementia is a progressive, neurodegenerative disease that destroys the brain and leads to loss of physical and cognitive function. It is a terminal illness that has no cure. Dementia is of long duration, often lasting 8 to 20 years after diagnosis and requires increasing demands for care that leads to a need for total care in the late stages. “We cannot halt or reverse it. Nor do we yet understand how to prevent or delay it” (The Alzheimer’s Study Group, 2009, p. 8). Currently, the only treatment for Alzheimer’s disease are five medications that slow symptom development for 6 to 12 months for half of the people who take them.

Dementia triples health care costs for those over age 65 (Alzheimer’s Association, 2011). Medicare payments for dementia patients are three times higher than for Medicare beneficiaries who do not have dementia. On average the cost is $42,072 per year for a dementia patient compared to $13,515 per year for Medicare beneficiaries who do not have dementia (Bynum, 2009; National Institute of Health, 2010).
Twenty years of impressive progress in biomedical research has demonstrated that Alzheimer’s disease and other dementias are complex and will not yield to a simple solution. Dr. Zaven Khachatarian, (2009) one of the leading experts on Alzheimer’s disease recently reported to the U.S. Congress that we need to redefine Alzheimer’s:

- as a biological pathway with a slow degenerative neuropathological process with potentially multiple etiologies and differentiable endophenotypes…..Alzheimer’s is not a simple, discrete disease but a complex heterogeneous condition with multi-pathogenic processes…
- Alzheimer’s is a decades-long process rather than a dichotomous event in which a person makes a discernable shift from normal cognition to dementia (p. 90).

Given this new understanding of Alzheimer’s disease, a cure may not be on the horizon but rather a long, persistent course that will make the needs of patients and caregivers more pressing.

In response to this burgeoning public health crisis the Alzheimer’s Study Group empowered by the U.S. Congress advocated for the development of the Alzheimer’s Solutions Project which pressed the federal government to: (1) develop the capability to delay and prevent Alzheimer’s; (2) develop value-based payments to reimburse for delivery of coordinated care to dementia patients; and (3) establish a dementia solutions office in the federal government to assure successful implementation of items (1) and (2) (The Alzheimer’s Study Group, 2009). As a result of this effort, President Obama signed into law the National Alzheimer’s Project Act (NAPA) (Public Law 111-375) which requires the federal government to create and maintain an integrated plan to prevent and cure Alzheimer’s disease, including coordinating research and services, improving early diagnosis and coordination of care, and improving outcomes for ethnic
and racial minorities (National Alzheimer’s Project Act, 2011). This high-level response is recognition that dementia “poses a grave and growing challenge to our nation…dementia will severely affect the lives of millions of Americans who will either suffer from the disease or care for someone who does. Less appreciated are the grave economic consequences that Alzheimer’s disease, with its cumulative costs, will impose on the country” (The Alzheimer’s Study Group, 2009, p. 4).

**The Impact of Dementia Caregiving**

This grave and growing challenge of dementia is evident in its impact on the daily lives of caregivers and families. Due to the long course of Alzheimer’s disease and other dementias the demand for increasing levels of care puts enormous physical, emotional, and financial stress on family caregivers. Although the patient can experience symptoms of dementia for many years, the need for one-on-one care by a caregiver mostly occurs in the moderate through the late stages of the disease (National Alliance for Caregiving & AARP, 2009; National Institute of Health, 2010). Nearly 70% of dementia patients are cared for at home by family members, most typically a spouse or adult child. The majority of dementia caregivers are women. It is called the “family disease” that places a long-term, progressive burden on those who care for people with the disease (Alzheimer’s Association, 2011; The Alzheimer’s Study Group, 2009; Met Life Market Institute, 2006). Despite the physical, emotional and financial stress most family caregivers prefer to keep the dementia patient at home and only institutionalize as a last resort (Aronson, 1994; Browning & Schwirian, 1994; Liken, 2001; Yaffe, Fox, & Newcomer, 2002).

Caregivers have high emotional stress, role strain, depression, and a strong sense of burden. Compared with other caregivers, dementia caregivers have poorer health, more employment problems, and higher out of pocket expenses (National Alliance of Caregiving, et
Many caregivers are likely to report their health as fair to poor (Schulz, O’Brien, Bookwala, & Fleissner, 1995; Vitaliano, Zhang, & Scanlan, 2003); and to say that caregiving has made their health worse (Alzheimer’s Association and National Alliance for Caregiving, 2004; MetLife Mature Market Institute, 2006). Caregivers are more likely to have high levels of stress, reduced immune function, slow wound healing, hypertension, and coronary heart disease (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Vitaliano, et al., 2003). Many caregivers may become potential “secondary patients” because of the stress of providing such a high level of care; 43% of caregivers reported the physical and emotional stress of caregiving as high to very high (Alzheimer’s Association, 2011).

The burden of caregiving poses challenges to the caregiver’s social support networks, family relationships, and financial security (Alzheimer’s Association, 2011; Liken, 2001; National Alliance for Caregiving, et al., 2009). Many caregivers have to quit work, reduce work hours or take time off because of caregiving responsibilities. They turn down promotions and lose employer contributions to their retirement savings (Alzheimer’s Association, 2011; Liken, 2001; National Alliance for Caregiving, et al., 2009).

Caregivers are a highly diverse population whose gender, race, culture and ethnicity shape their caregiving experience. For example, Connell and Gibson (1997) reviewed empirical research published since 1985 and found that compared to Caucasian caregivers, African American and Hispanics were (1) less likely to be a spouse and more likely to be an adult child; (2) reported lower levels of caregiver stress, burden and depression; (3) endorsed more strongly held beliefs about providing direct care to parents; and (4) more likely to rely on prayer, faith, or religion to bear the burdens of care.
Theoretical/Conceptual Base for Dementia Caregiving

The Stress Process Model

Most current caregiving research is built upon the stress and coping or stress-process models (e.g. Lazarus & Folkman 1984; Pearlin, Mullan, Semple, & Skaff, 1990). Pearlin’s (1990) caregiver stress process model explains how life events, particularly long term caregiving cause enduring role, physical, psychological, and economic strain. The constant strains erode positive concepts of self, self esteem, and mastery and leave caregivers vulnerable to depression. The stress process model describes a process with multi-interrelated components: (1) background and contextual factors; (2) primary stressors (e.g., cognitive status of dementia patient, behavioral problems) or secondary stressors (e.g., job or family conflict, constriction of social life); (3) mediators of stress such as coping and social support which create variability in the caring experience; and (4) the outcomes of stress (e.g., depression, anxiety, physical health, yielding of caregiver responsibilities to others). Caregiver stress is a complex process. It is not an event but rather a sequence of experiences made up of a mix of circumstances, responses, and resources that vary considerably among caregivers. This mix is not stable and a change in one area can cause change in another.

Lazarus and Folkman define coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person” (1984, p. 141). They describe a cognitive stress theory which focuses on caregiver perceptions and consider how cognitive appraisals of stress affect individual outcomes. The authors’ explanation of the difference between problem-focused and emotion-focused coping skills is particularly helpful in explaining the differences found between men and women caregivers.
Although these theories help explain caregiver stress and burden, more recent research has revealed the multidimensional nature of caregiving. In addition to understanding how race/ethnicity/culture impact dementia caregiving, it is critical to understand how caregiving processes and outcomes are influenced by the following demographic changes: (1) the increase in blended and other non-traditional families; (2) the increase in long-distance family caregivers; and (3) the rising number of families with divergent cultural views of definitions and meanings of dementia, caregiver stress, and family caregiving. Different causes of stress and distress among distinct populations of caregivers may require new models or enhancement of current models to incorporate some uniquely tailored prevention or treatment components (Coon, Ory, & Schulz, 2003).

**The Caregiving Career: Caregiver Identity Theory**

In response to these issues, new models of understanding dementia caregiving are emerging. For example, Montgomery and Kosloski (2009) present caregiver identity theory which is based on two premises: (1) there is no single generic caregiver role but rather caregiving emerges from prior role relationships and is integrated into other roles; and (2) caregiving is a dynamic process that unfolds over time with variable durations for different caregivers. This theory explains caregiving as a “career” that is a series of transitions that result from changes in the caregiving context. The key concepts of caregiver identity theory include:

- There is no “average caregiver”. Every caregiving situation is unique.
- There are great differences among caregivers in the pressure they feel to take on the caregiving role, expectations concerning duties, and circumstances that allow them to ultimately relinquish the role.
The caregiving role emerges from an existing role relationship. It is not a new role but the transformation of an existing role relationship.

Caregiving is a career that is characterized by a series of transitions that result from changes in the caregiving context (changing activity patterns, changes in the health of the patient and caregiver).

An individual’s ethnic and cultural background influences expectations because each culture has its own norms relating to caregiving.

This theory describes caregiving as a systematic process of identity change in which an original family relationship (mother-daughter) is transformed into a new relationship characterized by caregiving. Montgomery and Kwak believe “this change in identity influences the type and level of stress or burden for the caregiver and serves as a guide for effectively targeting services” (2008, p. 60).

The caregiver identity theory reflects three critical aspects of dementia caregiving:

1. Caregiver stress is multidimensional and influenced by many factors, such as change in the relationship between the patient and caregiver or a change in the caregiver’s health.
2. Caregivers vary greatly in several ways: duration of time they give care, what tasks they are willing to take on, costs they incur, and benefits they experience in their caregiving role.
3. Caregivers vary in support services they are willing to use; they will not use services that they perceive are not helpful.

Whatever models or theories are used to guide understanding of the caregiving process including use of services, it is crucial to continually reassess how effectively these frameworks
describe the needs of diverse caregivers at different points along their caregiving careers (Coon, Ory, & Schulz, 2003).

**Problems of End-of-life Care for Dementia Patients and Caregivers**

**Dying in America Today**

First among the challenges of end-of-life care for dementia patients and caregivers is facing death, which is as difficult for dementia families as it is for most Americans. Other than sudden death, dying in America today is often a long, complex process. People are living longer and taking longer to die, most often of chronic diseases that they live with for many years. Lacey states that a long chronic disease “blurs the boundary between living and dying and complicates medical decision making” (2004, p. 189). Because of public health improvements and advances in medical technology and pharmaceuticals, people die years after suffering with chronic illness, such as dementia, congestive heart failure, and cancer which can lead to remarkable disability and loss of function. The longevity bonus (the blessing of a long life) is often marred by years of disability and suffering and the dying process prolonged (Dillaway & Byrnes, 2009; Rudberg, Teno, & Lynn, 1997).

Today most Americans die in hospitals or nursing homes or other residential facilities (Field & Cassel, 1997; Jacoby, 2011; Kovacs & Fauri, 2003; Singer, Martin, & Kelner, 1999). Dying has become “medicalized” and is no longer a natural process but a complicated medical process that is directed by health care professionals (Kovacs, Bellin, & Fauri, 2006; Lawhorne, 1999; Lederberg, 1997; McCue, 1995). In hospitals most die in intensive care units supported by life sustaining measures to help with breathing, hydration, and nutrition (Lynn & Goldstein, 2003; Mezey, et al., 2002; Mitchell, Teno, Miller, & Mor, 2005; Volicer, 2005). These measures maintain the patient’s status quo but such treatment is not curative and does not change the
course of the underlying disease; rather it prolongs the time to death (Jacoby, 2011; Volicer, 2005). One third of the entire annual Medicare budget is spent on end-of-life care in hospitals for the ailing elderly (Kaiser Family Foundation, 2010). Jacoby (2011) suggests that the gap between the way that Americans die and the way they say they want to die is due, in part, to procrastination about legal planning that would reduce the number of family fights in the waiting rooms of intensive care units. And procrastination is inseparable from a refusal to face the fact of our own mortality (p. 212).

Caregiving at the end of life has been altered by changes in the American family structure. There are not many family members available at home to care for a dying person. On average most American families have fewer children, most adults are in the work force, and often adult children live a distance from ailing parents (Jacoby, 2011; Kovacs, Bellin, & Fauri, 2006).

Many Americans hold a strong belief that in this age of modern medical advances something can always be done to save a patient. McCue explains that this “encourages our hopes that fatal medical problems will eventually yield to technological innovation – even aging itself” (1995, p.1041). This strong belief in not giving up and maintaining high hopes for a cure drives determination to use aggressive life sustaining measures even in cases where it is not curative, such as in advanced dementia. Gruman traces this determination to an underlying “heroic positivist” philosophy of medicine, that encourages action at all times, even when it is not indicated by a patient’s condition (in McCue, 1995, p. 1041). It is far better to do something,
than to do nothing. Physicians are trained to save patients and cure illnesses and families want all that is possible to be done for the dying patient.

Field and Cassel’s review of the end-of-life literature point to the following factors as having undue influence on end-of-life care: “an active interventionist medical profession, a deeply ingrained public philosophy of individualism, and a general American unwillingness to accept limits – including aging and death” (1997, p. 47). Webb states that “death is viewed as a medical failure rather than an inevitable part of the life cycle” (1997, p. xi). But this attitude can have devastating results for advanced dementia patients at end of life. Callahan suggests that this produces “an unwillingness to let nature take its course and often leads to an impersonal and unwittingly cruel death in a technologic cocoon” (1995, p. 228).

The Demands of Care in Late Stage Dementia

As a patient moves into end-stage dementia the challenges for caregivers increase dramatically. Although the course of Alzheimer’s disease proceeds in predictable stages, the rate of disease progression is not predictable (Kim, Yeaman, & Keene, 2005). However, late stage (or end stage) can last two to three years for a dementia patient (Alzheimer’s Association, 2011). A patient in late stage usually: (1) has difficulty eating and swallowing; (2) needs assistance walking and is eventually unable to walk; (3) needs total help with personal care, including toileting; (4) is vulnerable to infections especially pneumonia; and (5) loses the ability to communicate with words (Alzheimer’s Association, 2007). According to the Functional Assessment Staging (FAST) scale, which allows caregivers and health care professionals to chart the decline of dementia patients, late stage dementia is Stage 7 and indicates very severe cognitive decline and is characterized by: “speech ability declines to about a half-dozen intelligible words; progressive loss of abilities to walk, sit up, smile, and hold up head. The brain
appears to no longer be able to tell the body what to do” (The Stages of Alzheimer’s Disease, 2011).

In addition to the physical needs of the dementia patient, the caregiver deals with issues of communication, pain control, the need for extraordinary vigilance to assure patient safety, and the complexity of coordinating the multiple community and family support systems needed to provide good care (Schulz, Burgio, Burns, Eisdorfer, Gallagher-Thompson, Gitlin, & Mahoney, 2003). In late stage, 40-50% of advanced dementia patients are moved to institutionalized care because the caregiver is no longer able to manage the increasing demands of daily care (Alzheimer’s Association, 2011; National Institute of Health, 2010).

Whether the dementia patient remains at home or is institutionalized, decisions about end-of-life care will rest with the caregiver who is the surrogate decision maker (Mezey, et al., 2002). Caregivers often wrestle with the traumatic decisions regarding withholding or withdrawing treatment which can cause guilt, pain, and regret for the caregiver (Caron, et al., 2005; Mezey, et al., 1996; Travis, Bernard, Dixon, McAuley, Loving, & McClanahan, 2002). They are ambivalent about the patient’s impending death and consider the death both a tragedy and a blessing (Caron, et al., 2005; Forbes, et al., 2000; Gessert, Forbes, & Bern-Klug, 2000).

Caregivers often struggle to make sense of their role as decision maker. They worry about doing the right thing (Henderson, 1990; Lynn & Goldstein, 2003); few have received clear directives from the medical team (Caron, et al., 2005); they have limited understanding of the trajectory of dementia and often do not recognize the patient is moving toward death (Mezey, et al., 1996; Potkins, Bradley, Shrimanker, O’Brien, Swann, & Ballard, 2000; Volicer, 2005). Except in hospice programs, caregivers do not get sufficient emotional and psychological
support from health care workers about decision making (Teno, Clarridge, & Casey, 2004; Volicier, 2005). Kovacs and Fauri believe that “caring for the dying will always be one of life’s most challenging privileges” and that with “proper support, resources, and training both formal and informal caregivers are better able to meet this challenge in a way that enhances not only the lives of persons who are dying, but their own lives as well” (2003, p. 509).

The Barriers to Improved End-of-Life Care for Dementia Patients

Many improvements have been made in the delivery of end-of-life care. For example palliative care training and internships for physicians have increased substantially, as well as major research and training initiatives in end-of-life care funded by organizations such as the Veterans Health Administration, the Robert Woods Johnson Foundation and the Project on Death in America (Sachs, et al., 2004). Academic journals and advocacy groups have published guidelines for improving end-of-life care (Alzheimer’s Association, 2006; Lo, Snyder, & Sox, 1999; McPhee, Rabow, Pantilat, Markowitz, & Winker, 2000). However, most advanced dementia patients continue to receive sub-optimal care at the end of life (Mitchell, et al., 2005; Sachs, et al., 2004; Volicer, 2005). For example, dementia patients experience high usage of life sustaining measures that often do not offer any benefit, but can cause discomfort and new injuries. There are problems with inadequate pain control and low use of hospice programs (Sachs, et al, 2004; Volicer, 2005).

There is a substantial body of research that provides evidence that aggressive life sustaining measures are inappropriate for advanced dementia patients. A review of the literature from 1994 to 2004 (300 studies) revealed that: (1) aggressive life sustaining measures have low rates of success, can cause harm, and hasten death; (2) palliative care is an effective alternative to
use of life sustaining measures; and (3) there are significant barriers to translating this
to knowledge into practice (Volicer, 2005).

**Defining dementia as terminal**

There are many barriers to improving end-of-life care for dementia patients, but chief among them is that often the patient, family, and many health care professionals do not view dementia as a terminal illness. Dementia can run its course in four years or in 20 years. As a result physicians and families have a difficult time viewing dementia as something from which a person dies. Many believe that the dementia patient dies from opportunistic infections such as pneumonia, or urinary/bladder infections instead of from dementia. Guidelines established by the National Hospice and Palliative Care Organization (2011) state that markers for death for advanced dementia patients are: decline in function, recurrent hospitalizations, and 10% percent weight loss or more in six months. But these markers do not hold up for predicting imminent death of dementia patients (Hanrahan, Raymond, McGowan, & Luchins, 1999; Sachs, et al., 2004; Schonwetter, Han, Small, Martin, Tope, & Haley, 2003). Because of the lack of reliable prognostic markers and the variability of survival, estimating time to death is difficult. Physicians often to not recommend dementia patients for hospice as they are not able to predict a 6-month life expectancy with enough accuracy to qualify the patient for the Medicare hospice benefit.

According to researchers and other experts in the field, dementia is terminal (Sachs, et al., 2004; Volicer, 2005; Wolf-Klein, et al., 2007). The American Hospice Foundation (2007) recognizes this problem of failing to think of dementia as terminal and suggests that we reframe the definition as:

the degeneration of our most vital organ, so think about it as ‘brain failure’
much as we would think of heart failure or liver failure. This reinforces the fact that this is a terminal illness...understanding dementia means knowing that it will always be life-changing, and that it will finally become life-ending (p. 5).

**Physicians’ role**

Most physicians are uncomfortable talking to patients about death but particularly communicating with patients and caregivers that dementia is terminal. Rarely do physicians discuss end-of-life care with patients and caregivers and even fewer provide information on ACP (Volicer, 2005; vonGunten, Ferris, & Emanuel, 2000). Research demonstrates that physicians do not talk to patients and caregivers about dying because they do not want to take away the patient’s hope. While the physician waits for the patient to ask, the patient is often waiting for the physician to begin the conversation (Morrison, Morrison, & Glickman, 1994; vonGunten, et al., 2000). Hancock and colleagues (2007) conducted a review of the literature to examine this gap in communication regarding end-of-life care among physician, patient, and caregiver. Results of this review reveal that: (1) patients believe that physicians only offer information when asked by the patient; (2) physicians believe that if patients want information they will ask; (3) caregivers believe that physicians act as “gatekeepers” of information only providing information they think is necessary and; (4) physicians believe that they have provided sufficient information and that the patient and caregiver understood what was said (Hancock, Clayton, Parker, Walker, Butow, & Carrick, 2007). This lack of communication between physician, patient, and caregiver regarding the trajectory of dementia and about dying does not allow the family to adjust to the idea that the patient is in end stage and may be close to death (Volicer, 2005).
Physicians may have little confidence in their ability to manage severe pain and other terminal symptoms. At the time of death emotions run high for patient, families, and for physicians. These intense feelings may be difficult to manage. McPhee et al., suggests that physicians “feel out of place negotiating the complexities of a family’s dynamics at a time when the integrity of the family is most at stake” (2000, p. 2512).

**Structural problems in the current health care system**

There are critical structural problems in the current health care system that impede high quality end-of-life care for dementia patients. Excessive hospitalizations are destabilizing for dementia patients who are at significant risk of delirium and distress when transferred to the hospital (Inouye, Viscoli, Horwitz, Hurst, & Tinetti, 1993). Dementia experts and palliative care experts recommend against sending dementia patients to hospitals for curative interventions. Studies show that repeated hospitalizations cause trauma for patients when transferred from familiar surroundings and increase mortality rates (Fried, Gillick, & Lipsitz, 1997; Morrison & Siu, 2000; Ouslander, Weinberg, & Phillips, 2000).

Financial incentives are built into the health care system that work against providing palliative care for dementia patients (Mace & Rabins, 2009; Zerzan, Stearns, & Hanson, 2000). There is no reimbursement mechanism to pay for palliative care. “Aggressive treatments have explicit reimbursement mechanisms, which hospital-based palliative care lacks” (Cassel, et al., 2000, p. 169). Because of this nursing homes transfer advanced dementia patients to hospitals which reduces their staff costs as comfort care requires more time, and reduces their liability for “allowing a patient to die, as it can be perceived by misinformed family members, and for regulatory citations for weight loss and dehydration that occur as death approaches” (Sachs, et al., 2004, p.1061).
The physicians and health care institutions have financial incentives to admit dying dementia patients to the hospital where they most often receive aggressive treatment for which Medicare pays. Medicare’s fee-for-service reimbursement system pays for each test, doctor’s visit, and hospitalization which provide incentive for physicians to over treat advance dementia patients (Sachs, et al., 2004; Volicer, 2005). In addition physician reimbursement by Medicare is much higher for a hospital visit than for a nursing home visit (Mezey, et al., 2002). Sachs et al., conclude that “the only parties who may not be better off from that transfer are the patient and family” (2004, p. 1060).

In addition, physicians practice “defensive medicine” which is continuing to provide aggressive treatment for patients in order to avoid conflict with family members and the potential for liability lawsuits due to withholding or withdrawing treatment. Bishop, Federman, and Keyhani (2010) conducted a national survey of 1,231 randomly-selected physicians and reported that no matter where in the U.S. a physician practices medicine the majority practice defensive medicine to protect themselves from medical liability lawsuits. About 9 in 10 physicians said they order more tests and procedures than patients need in order to protect themselves and their practice. The authors state that the cost of defensive medicine is “estimated to be $60 billion annually” (p. 1081).

**Use of Life-Sustaining Measures**

The Alzheimer’s Association defines life sustaining measures for advanced dementia patients as “aggressive” medical care that prolongs life but does not cure the disease and causes great distress for the patient. This care includes use of artificial nutrition, cardiopulmonary resuscitation (CPR), intravenous hydration, respirators, and use of antibiotics (Alzheimer’s Association, 2006). Research shows that experts and advocates for dementia patients are
rejecting use of aggressive medical procedures because they are “ineffective in sustaining life and quality of life” (Evers, et al., 2002; Finucane, et al., 1999; Gillick, 2000; Lacey, 2004; Volicer, 2001). Overall life sustaining aggressive medical treatment for advanced dementia patients is “inappropriate for medical reasons, has a low rate of success, and can have negative outcomes that hasten functional decline and death” (Volicer, 2005, p. 2). The Alzheimer’s Association Ethics Advisory Committee concluded “that all efforts at life extension in the advanced stages of Alzheimer’s creates burdens and avoidable suffering for patients who could otherwise live out the reminder of their lives in greater comfort and peace” (Alzheimer’s Association, 2006, p. 25).

**Artificial nutrition (commonly called feeding tubes)** is used if the patient has trouble eating and swallowing which happens often in late stage dementia. Volicer (2005) reports that tube feeding does not increase survival of the dementia patient and does not prevent “aspiration pneumonia, malnutrition, or pressure ulcers. It does not reduce risk of infections or improve functional status or comfort of patient” (2005, p. 3). Tube feeding can cause the need for physical or chemical restraints because the patient may attempt to break free and this may cause new injury to the patient (Alzheimer’s Association, 2006; Lacey, 2004; Mitchell, Kiely, & Hamel, 2004). Restraints, mechanical or chemical, are associated with death in advanced dementia patients and are considered “markers of poor quality of nursing home care” (Mitchell et al., 2004; Morrison, Ahronheim, & Morrison, 1998).

**Cardiopulmonary resuscitation (CPR)** treatment is used to restore a patient’s ability to breathe and retain heart function which keeps blood circulating. For an advanced dementia patient, “CPR may be painful and traumatic, may leave the patient in a worse condition, may not prolong life, and is not recommended by experts when a person is terminally ill” (Alzheimer’s
Lacey (2004) reports that studies for the last 20 years have shown CPR to be “100% ineffective with severely ill or frail adults of all ages (Finucane & Harper, 1999) and the “process of resuscitation often results in physical damage such as broken bones and punctured lungs (Dunn, 2009). Volicer found that “CPR is three times less likely to be successful in a dementia patient than one who is cognitively intact and the success rate is almost as low as in metastatic cancer… Those who survive are taken to intensive care unit where most die within 24 hours” (2005, p. 8).

**Intravenous (IV) hydration** provides fluids to a patient who can no longer drink but it cannot supply nutrition to keep the patient alive. Increasing hydration via intravenous therapy can make the patient uncomfortable and cause trouble with breathing. As a patient moves near death a lack of hydration allows for a more comfortable death over a period of days. Dehydration allows a patient to slip into a coma and contributes to a patient’s sense of comfort as it is believed that it releases endorphins to increase a patient’s sense of well being (vonGunten, et al., 2000). Using artificial hydration prolongs the dying process for weeks and is a physical burden for the patient. It causes painful swelling and worsens other symptoms associated with hydration (Alzheimer’s Association, 2006; Dunn, 2009; Gillick, 2000; Huang & Ahronheim, 2000).

**Respirators** are artificial breathing machines that pump air in and out of a patient’s airways and lungs. It is a substitute for normal breathing. However, “the treatment may cause the person’s body to undergo unneeded stress and can cause greater discomfort” (Alzheimer’s Association, 2006, p. 6). Respirators are not curative but maintain the dementia patient’s medical status quo. Respiratory therapy is recommended for those who are recovering from a trauma or chronic infection and have a good prognosis for recovery. Most experts caution against the use
of respirators for dementia patients (Alzheimer’s Association, 2006; Sachs et al., 2004; Volicer, 2005).

**Use of antibiotics** in late stage dementia for urinary tract and pneumonia infections are common. Often antibiotics are prescribed for the patient but they do not improve the patient’s condition (Alzheimer’s Association, 2006). Use of antibiotics does not improve survival, but causes serious outcomes, including “renal failure, ototoxicity (hearing loss), allergic or drug reactions, antibiotic resistance, use of intravenous lines and mechanical restraints, prolonged time to death, and increased costs” (Evers, et al., 2002, p. 609). Fabiszewski, Volicer, and Volicer (1990) found that antibiotics in end stage dementia demonstrated no improvement in either survival or comfort over comfort measures alone. Researchers have found that as with feeding tubes, one key reason for high use of antibiotics is lack of ADs (Evers, et al., 2002; Sachs, et al., 2004; Volicer, 2005; Wolf-Klein, et al., 2007).

**Use of Palliative and Hospice Care**

Because life sustaining measures are so severe for dementia patients and do not extend life or improve quality of life, experts and advocates believe that palliative care (also referred to as comfort care) should become the dominant paradigm of care for people in end-stage dementia (Callahan, 1995; Lacey, 2004; Post & Whitehouse, 1998; Solomon & Jennings, 1998; Volicer, 2001; Wolf-Klein et al., 2007). Wolf-Klein, et al., state: “The most important objectives are to provide comfort, support and relief from suffering while preserving the patient’s dignity near the end of life” (2007, p. 79). Palliation of symptoms for dementia patients leads to improved comfort, including more pain control, and quality of life (Alzheimer’s Association, 2007; Evers, et al., 2002; Fabiszewski, et al., 1990; Lloyd-Williams & Payne, 2002; Luchins & Hanrahan, 1993; Miller, Teno, & Mor, 2004). Kovacs and Fauri believe that the shift in medical focus to
palliative care means “the need is not necessarily for less care, but for care with a different focus, one with increased attention to the physical, psychosocial, and spiritual needs of the patients and his or her family” (2003, p. 503).

In 2007 the National Hospice and Palliative Care Organization published guidelines for hospice providers regarding the needs of dementia patients. The guidelines cover key issues for dementia patients including decision making for treatment options, communication with patients, pain management, minimizing the burden of medical interventions, and caregiver grief support.

Dementia patients are enrolled in hospice less often than others – only 7% of patients enrolled in hospice in 2001 had dementia (Christakis & Escarce, 1996; Mitchell, et al., 2004; Mitchell, et al., 2005; Sachs, et al., 2004). Javier reports a steady increase in hospice admissions for dementia patients from “12,829 in 1998 to approximately 60, 488 in 2008” (2010, p. 380). The National Hospice and Palliative Care Organization (2011) reports that “in 2001, only 14.4% of Medicare decedents with a dementia diagnosis received 3 or more days of hospice care. By 2007, that proportion had grown to 33.6%” (p. 5). Often dementia patients residing in nursing homes or assisted living facilities are not referred to hospice services (Mezey, et al., 2002). Many nursing homes do not have a contractual relationship with local hospice programs as they believe that they already provide palliative care equal or better than hospice (Mezey, et al., 2002). However, a study by Travis, et al., (2002) found that such palliative care is “not timely, is interrupted by aggressive acute care, and is often delayed until the last few days of life” (p. 61 in Mezey, et al., 2002).

Short hospice stays are a major concern for this population. Dementia patients are referred late to hospice care. The prevalence of hospice stays of seven days or less have increased significantly (Miller, et al., 2004; Miller, Weitzen, & Kinzbrummer, 2003). The
reasons are that doctors refer dementia patients to hospice late due to uncertainty of when the patient will actually die and hospices are reluctant to admit residents who may outlive their prognoses. Other factors mentioned earlier, family and nursing staff not recognizing disease trajectory, and not understanding dementia as terminal also have impact on timing when to begin to consider hospice as an option for care. Short hospice stays do not allow enough time for relief of patient pain and discomfort, and do not allow for preparing family members for the death of the patient (Miller, et al., 2004). Other barriers to use of palliative and hospice care can include: (a) failure to recognize that treatments will not improve patient’s condition; (b) lack of communication among decision makers; (c) no agreement on a course for end-of-life care; and (d) failure to implement a timely end-of-life care plan (Miller, 2004; Travis, et al., 2002).

In Casarett, Takesake, Karlawish, Hirschman, and Clark’s (2002) study caregivers’ view of hospice were positive. Findings revealed that caregivers are ready to have hospice services long before patients are eligible under Medicare rules. Caregivers did not find it distressing to talk about hospice or end-of-life care and support the concept of palliative care for their loved ones. Other studies have found similar caregiver support for use of palliative care for dementia patients (Luchins & Hanrahan, 1993; Miller, et al., 2004; Travis, et al., 2002).

Overall the research provides strong evidence that aggressive life sustaining measures hurt rather than help advanced dementia patients. Most experts advocate for the use of palliative care as the best option for end-of life-care.

The Historical and Legal Context of Advance Care Planning

Given the strong evidence that aggressive, life sustaining measures are mostly harmful for dementia patients and palliative care is recommended, most experts and advocates urge families to engage in ACP. ACP is considered a powerful tool in guiding the caregiver through
the challenges of end-of-life care. In order to understand how ACP came to be so highly valued for the frail elderly, an exploration of the historical and legal context of ACP is offered.

Although most Americans have a high regard for technological medical advances, beginning in the late 1970s there was a growing unease developing that choice regarding end-of-life care was in the hands of medical professionals, and that individuals did not have a voice at the end of their lives. A new interest in patient autonomy, putting the patient’s voice in end-of-life care, and a rejection of physician “paternalism” was becoming a forceful issue. Physicians are primarily guided by the principle of “beneficence” (doing the right thing on a patient’s behalf) rather than the principle of “autonomy” (which is acting on patient and caregiver wishes). The new laws focus on patient autonomy which is about patient wishes, giving informed consent, and having caregivers make decisions as surrogate decision makers (Field & Cassel, 1997).

Driving public interest and concern were a few high profile court cases that stirred strong passions among Americans and gave rise to the right to die movement in the U.S. (Lim, 2005). The first case to capture national attention, was that of Karen Ann Quinlan, a 21-year old who became unconscious, lapsed into a persistent vegetative state, and was kept alive by a respirator and artificial nutrition and hydration. Her parents asked that she be removed from life sustaining care and allowed to die. The doctors and hospital refused this request and a long legal battle ensued. In 1976 the New Jersey Supreme Court decided that Karen’s respirator could be removed. The many friends and relatives who testified that Karen would not want to be kept alive with no hope of recovery were instrumental in the court’s decision. This ruling was key because it helped establish that removing the respirator was the judgment Quinlan would have made if she had not been incapacitated (Lim, 2005; Pevey, 2003; Webb, 1997). After removal of the respirator, Karen lived for another nine years sustained by artificial nutrition and hydration.
Lim states “the Quinlan decision marked a significant turning point in the debate over the right to die….the decision established for the first time a constitutional right of privacy as the basis for refusal of life sustaining treatment, providing legal substance and strength to an individual’s personal wishes regarding the medical treatment s/he received” (2005, p. 10). Also, the Quinlan decision marked a shift away from physician-controlled end-of-life decision making and moved toward a shared-decision making process between patient and family. Thus, legal experts believe that the Quinlan case marked the beginning of the right to die movement in the U.S. and the establishment of multi-disciplinary ethics committees in hospitals (Del Rio, 2010; Humphry & Clement, 2000; Lim, 2005).

Most remarkable about the Quinlan case was the notable impact it had on the American public. It created an awareness that medical technology could be used to keep an individual alive long after any cure was possible. There was a groundswell of support for measures that would make people’s last wishes honored in the medical system and that families could avoid the trauma and legal battles endured by the Quinlans (Humphry & Clement, 2000; Lim, 2005).

In January 1983 the second case that created a media frenzy and captured America’s attention was that of Nancy Cruzan, a 33-year-old woman who suffered severe injuries in an automobile accident which left her in a persistent vegetative state. After six years with no recovery, Nancy’s parents asked that the feeding tube be removed so she could die peacefully. The hospital insisted on a court order to remove the tube and the court ruled that the feeding tube could not be removed unless the family had written documents such as a living will that stated patient wishes. Nancy’s parents did not have formal written documents, but had evidence of informal ADs such as conversations Nancy had with relatives and friends prior to the car accident. Nancy had said that she did not want “to live as vegetable.” If “she couldn’t do for
herself things even halfway, alone or not at all, she wouldn’t want to live that way and she hoped that her family would know that” (Lo & Steinbrook, 1991, p. 895; Pevey, 2003).

In June 1990, the U.S. Supreme Court ruled that competent patients have a “constitutionally protected liberty interest in refusing unwanted medical treatment” but that incompetent patients (such as dementia patients) do not have the same right because they cannot make decisions on their own behalf (Lo & Steinbrook, 1991, p. 895). The Supreme Court urged states to enact laws that protected incompetent patients and allowed for surrogate decision makers. The Supreme Court ruling stated strong support for ADs and suggested that the constitution requires states to respect the decisions of surrogate decision makers even if wishes of incompetent patients are unknown.

The U.S. Supreme Court ruled that before a treatment is refused on behalf of an incapacitated patient there must be “clear and convincing evidence” that the surrogate decision maker or health care professional is acting on the substituted judgment standard – that is, what the patient would have wanted (Pevey, 2003, p. 892; Webb 1997, p. 162). In December 1990 the court ruled that based on informal conversations Nancy had with others that this was “clear and convincing evidence” that her parents were acting on the patient’s expressed wishes. The feeding tube was removed and Nancy died 12 days later. The Cruzan case created public protests, enormous media coverage and opposition of right-to-life groups. Del Rio states that many of the “friend of the court” briefs filed when Nancy’s case went before the Supreme Court “reflected the deep division among Americans regarding the morality of withholding and or withdrawing” feeding tubes (2010, p. 129).

Just as the Quinlan case led states to enact laws authorizing use of ADs, the Cruzan case was the driving force for the creation and implementation of the Patient Self Determination Act
(PSDA). The PSDA was passed by Congress in 1991 as an amendment of the Omnibus Budget Reconciliation Act of 1990. This law requires that hospitals, nursing homes, home health agencies, hospice programs, and other health care institutions receiving Medicare and Medicaid payments provide information to patients about ADs upon admittance to their facility (The SUPPORT Study, 1995). The law states they must provide information to the patient and family and document in the medical record whether a patient has ADs or not. In addition PSDA mandates that facilities educate both staff and the community on ADs and the ACP process (Bradley & Walker, 1998). The PSDA requires that patients have a right to (1) make their own health care decisions (2) to accept or refuse treatment (3) and the right to make advance health care decisions (PSDA, 1991). However, the law does not specify implementation of these mandates including defining educational efforts or the meaning of “community.” No funding was made available to health care organizations for PSDA implementation (Bradley & Walker, 1998). Because the PSDA does not specify the process by which a facility implements these mandates, especially how they would help patients complete ADs and provides no funding, in most cases, facilities do not support an ACP process (Field & Cassel, 1997; Sachs, et al., 2004; Singer, et al., 1999; Volicer, 2005).

After the passage of PSDA, the states that had not already done so passed laws that protect patient autonomy and allow for patients to choose a health care proxy decision maker to make decisions if they are unable to. Currently all 50 states and the District of Columbia have laws protecting patient autonomy, allowing for ADs and appointment of surrogate decision makers (Lo & Steinbrook, 1991; Lim, 2005).

The deep division among Americans regarding withholding and/or withdrawing life support surfaced again in 2005 with the Terri Schiavo case. Terri, age 26, suffered cardiac arrest
and remained in a persistent vegetative state for 15 years supported by artificial nutrition and hydration. Terri’s husband, Michael, the surrogate decision maker, asked the court to remove her feeding tube as there was no hope of recovery. Michael believed this was in Terri’s best interests and what she would have chosen for herself. Schiavo’s parents, Roman Catholics who did not want her feeding tube removed, disagreed. The parents had the support of the Florida state governor, The Vatican, the Florida legislature and a large number of pro-life members of the U.S. Congress (Caplan, McCartney, & Sisti, 2006). After the U.S. Supreme Court refused to hear the case, the Florida State Supreme Court ruled that Michael’s request as the surrogate decision maker to remove the tube be honored. Terri Schiavo died in March 2005 at the age of 41 in a hospice program 13 days after the tube was removed.

Despite the public outcry and the pressure applied by elected officials, in these three cases the courts eventually ruled in favor of the patient and the surrogate decision maker. The courts supported the voice of the patient and caregiver in end-of-life decisions. These high profile cases did not change the consensus that ending life sustaining measures for those who have no hope of recovery is the right thing to do. Caplan states that “there is a general consensus regarding ending life-sustaining treatments within a context of respect for the fundamental rights of privacy and liberty for every American has been forged through religious, philosophical, legal, legislative and medical deliberation in the years since the Cruzan decision. Nearly every hospital, nursing home and hospice in the United States follows policies consistent with those articulated in this consensus….Even in Terri Schiavo’s case, it is argued that the attempt to overturn the consensus did not succeed” (2006, p. 22).

The irony of these three cases is that they were all young women without disabilities prior to their accidents which caused persistent vegetative states. All three had no hope of
recovery and all were without ADs. Yet these three young women’s cases raised public awareness about end-of-life decision making, solidified support for the right to make end-of-life choices, and to have a surrogate decision maker for those who are cognitively impaired. This has greatly benefited older adults with cognitive and physical disabilities that face the same challenges at end of life. What these major cases have demonstrated is that ACP is critical, particularly for the patient who will lose cognitive ability to a disease process. Whether completing written formal ADs or having conversations with family and friends about choices for care at end of life, the ACP communication process is essential to protect the voice of both patient and caregiver in the dying process. Doukas and Reichel state “the biggest lesson from the Schiavo case (and Quinlan and Cruzan cases) is that advance directives when coupled with sound communication with family members who can represent the patients when they cannot speak for themselves, can help the unleashing of a tornado of forces…. and reduce the possibility of family strife concerning who best represents a person’s wishes” (2007, p. 4).

**Research on Advance Directives and Competent Adults**

The majority of studies on ADs and competent adults are conducted with participants who are elderly and may have chronic illnesses, but they are cognitively intact and able to understand life sustaining measures used in end-of-life care (Gamble, et al., 1991; Gjerdingen, et al., 1999; High, 1988, 1993b). Some studies have included young, healthy adults over the age of 18 (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991; Fagerlin, Ditto, Danks, Houts, & Smucker, 2001; Hare, et al., 1992).

Many studies present participants with several health care vignettes of some future state and request they imagine themselves in these situations. After reflecting on these scenarios, participants are asked if they would accept or reject life sustaining measures, such as CPR,
respirators, feeding tubes, and antibiotics (Zweibel & Cassel, 1989). Interestingly most of these studies on the subject of ADs do not ask participants if they would choose palliative or hospice care after declining life sustaining measures. Most studies use the completion of formal ADs as the measure of whether an ACP process has occurred. Few studies have examined the ACP process itself, especially the education and communication components critical to the process. There are very few studies that have examined the informal process within a family context about how a patient reveals end-of-life wishes to the caregiver. Although there are estimates of how many competent adults have completed ADs, there are few, if any, estimates of competent adults who have engaged in an informal process of conversations, notes, etc. expressing their end-of-life choices.

**Prevalence of ADs Among Competent Adults**

Since the passage of the PSDA in 1991 and the ensuing state legislation in support of that Act, there was great hope that most Americans, particularly older adults, would complete formal ADs, both a living will and health care proxy. But in the 23 years since, overall usage is low. In the early 1990s, estimates were reported between 4% and 25% for competent adults and rates were beginning to increase (High, 1993b; Meier, Fuss, O’Rouke, Baskin, Lewis, & Morrison, 1996; Vandecreek, et al., 1995). In 2008, the U.S. Department of Health and Human Services Report to Congress on Advance Care Planning and Advance Directives reported an estimated 18% to 36% of the adult population has completed ADs based on several studies (Brown, 2003; Center for Gerontology and Health Care Research, 2008; Fagerlin & Schneider, 2004; Garas & Pantilat, 2001; Hawkins, Ditto, Danks, & Smucker, 2005; Heffner & Barbieri, 2001; Hickman, Hammes, Moss, & Tolle, 2005; Higginson, Finlay, & Goodwin, 2002; Jennings, Kaebnick, &

Adults with serious medical conditions for whom ACP is particularly important, have only slightly higher rates (Bravo, Dubois, & Paquet, 2003; Kish, Martin, & Price, 2000; U.S. Department of Health and Human Services, 2008). Particular groups of patients, those with HIV/AIDS and cancer are more likely to have ADs than other groups of seriously ill patients (Martin, et al., 1999; Prendergast, 2001; U.S. Department of Health and Human Services, 2008; Virmani, Schneiderman, & Kaplan, 1994).

**Key Findings for Competent Adults and ADs**

**Physician-Patient Communication**

Chief among the barriers to implementing ACP is lack of communication. The research shows that patients and families report that the lack of communication with health care professionals, especially with their physicians, is a barrier to ACP (Cavalieri, Walead, Ciesiolski, Ciervo, & Forman, 2002; Cantor & Pearlman, 2003). Physicians often do not talk to their patients and families about end-of-life issues. The reasons physicians give for this are:(1) lack of time; (2) lack of formal training and knowledge of palliative care; (3) belief that patients and families do not want to talk about death; (4) they associate palliative care with death; and (5) lack of belief that such discussions are needed or helpful (U.S. Department of Health and Human Services, 2008). Many physicians have a lack of understanding of ACP and ADs (Morrison, et al., 1994).

Although most physicians often do not initiate conversations with patients regarding end-of-life treatment choices, research shows that most older patients would welcome such a conversation and are waiting for the physician to initiate it. Emanuel, et al.,’s (1991) study of 405
outpatients of Massachusetts General Hospital and 102 members of the Boston public were
surveyed and asked to complete a medical directive. Ninety-three percent of the outpatients and
89% of the members of the general public said they desired to make their end-of-life wishes
known. Both young patients and middle age patients expressed the same level of interest in
planning as those in poor health age 85 or older. The strongest barrier to completing ADs was
the lack of physician initiating a conversation with them about end-of-life choices.

Virmani, et al., (1994) conducted interviews with 115 seriously ill cancer patients and 22
of their physicians. Physicians were unaware whether their patients had ADs. Patients with ADs
were marginally more likely to have had a discussion with their physician compared to patients
without ADs. However, only 34 (30%) of the 115 participants claimed to have had any
discussion with their doctor about end-of-life treatment. One of the most intriguing aspects of
this study is that although patients had not discussed ADs with their physicians these same
patients were willing to discuss their disease trajectory and wishes for end-of-life treatment
openly on the telephone during interviews for this study with an unfamiliar interviewer. Several
patients asked the interviewer how to go about getting the forms to complete ADs. This suggests
that communication between the physician and patient is not meeting the needs of patients when
faced with end-of-life decision making.

Regarding physician-patient communication, the largest study of its kind was sponsored
by the Robert Woods Johnson Foundation in the mid-1990s. The Study to Understand Prognoses
and Preferences for Outcomes and Risks of Treatment (SUPPORT), was conducted over four
years at five teaching hospitals in the U.S. and examined end-of-life care for critically ill patients
(n=9,105) (The SUPPORT Study Principal Investigators, 1995). The study involved two phases.
Phase I was an observational study that documented lack of communication between patient and
physician, frequency of aggressive treatment, and the characteristics of hospital deaths. A few examples of the findings that revealed serious shortcomings in end-of-life care included: (1) only 47% of physicians knew when their patients preferred to avoid CPR; (2) 46% of DNR orders were written just two days before death; (3) 38% of patients spent their last days in an intensive care unit; and (4) 50% of conscious patients’ families reported patient had moderate to severe pain half the time (The SUPPORT Study Principal Investigators, 1995).

Phase II was an intervention that offered specially trained nurses that had multiple contacts with the patient, family, and physician to “elicit preferences, improve understanding of outcomes, encourage attention to pain control, and facilitate advance care planning and patient-physician communication” (SUPPORT Study Principal Investigators, 1995, p. 1591). The results of Phase II were disappointing. The intervention did not facilitate better communication between the patient, family, and the physician and did not increase the use of ADs. The researchers speculated that the discussions about ADs were initiated too late in the disease process and too close to death that the patient and family had no time to reflect on their wishes.

The authors recommended that physicians should explain to patients earlier their prognoses and the trajectory of their disease to help them prepare for death, and that physicians need to help patients make decisions within their value system and raise these issues prior to conditions becoming critical (Lynn, Arkes, Stevens, Cohn, Koenig, Fox, Dawson, Phillips, Hamel, & Tsevat, 2000; Schwenk, 1995). They reaffirmed that ACP is important for families and is an important part of medical practice. “Our results do provide support to the claim that advance care planning is helpful…we found that 40% of family members reported that advance directives helped a great deal in end-of-life decisions…such findings argue for the widespread use of advance directives. However, we believe that these results highlight important
opportunities to improve and re-engineer the current use of advance directives” (Teno, Lynn, Wenger, Phillips, Murphy, Connors, Desbiens, Fulkerson, Bellamy, Knaus for the SUPPORT Investigators, 1997, p. 506).

Regarding re-engineering the current focus of ADs, some researchers have suggested that the lack of improvement in patient-physician communication in the SUPPORT study is because as far as patients are concerned this is not the central relationship in decision making. But rather the patient and family relationship is central to decision making with input from physicians and other health care professionals (High, 1988, 1993; Martin, et al., 1999; Singer, et al., 1998). This large study suggests there is need for further examination of the informal process of communication that families’ use to make decisions about end of life.

**Preference for family surrogates**

Often older adults have a preference for family members to act as surrogates instead of making their own decisions. High’s (1988) study of 40 men and women (aged 67 to 91) explored participants’ preferences and expectation for ADs and surrogate decision making in the event of cognitive incapacity. The study found that most have a strong expectation that family members will be central to the decision making process. So instead of a strict personal autonomy and total control, the elderly person is more interested in extended autonomy. The notion of individual autonomy is extendable to close family members who they trust will do what is right for them and can be carried forward by family surrogates.

In another High (1990) qualitative study which included a sample of men and women (n=71), aged 65 to 91, the author compared those with families and those with no family regarding the use of ADs and surrogate decision makers. Participants were competent, in fair to good health, and able to discuss end-of-life issues. The findings of this study support that those
with families prefer to make end-of-life decisions within the context of family decision making and do not necessarily feel the need to execute formal written documents. These subjects trust that family members will make the right decisions on their behalf when they are unable to. Instead of personal autonomy, High suggests these adults prefer “family autonomy characterized by invisible loyalties and mutual responsibilities” (1990, p. 303). Those without family, however, view friends and health care providers as surrogates and more often will complete formal ADs.

**AD treatment choices may change over time**

When patients make choices in ADs, they are projecting into the future what care they desire at end of life. But research provides evidence that patients’ preferences may change over time. These changes in thinking may be initiated by a new illness, progression of a current illness, changes in family dynamics, and end-of-life discussions (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Coppola, Ditto, Danks, & Smucker, 2001; Fagerlin & Schneider, 2004; Lockhart, Bookwala, & Fagerlin, 2001; McParland, Likourezos, Chichin, Castor, & Paris, 2003; Prendergast & Puntillo, 2002). Because preferences can change it is critical that a patient’s decisions regarding ADs be revisited with some frequency, especially as a disease process unfolds. Also reflected in research findings is that patient preferences can change based on how AD information is presented and how the ACP process is allowed to unfold (Ford, Schofield, & Hope, 2003; Meeker & Jezewski, 2005; Whitney, 2003). This makes it vitally important that the ACP communication process regarding end-of-life choices be ongoing (McParland et al., 2003; Weissman, Haas, & Fowler, 1999).

Although many studies show patient preferences change over time, there are a few studies that show that patient preferences are moderately stable over time. One such study
(Emanual, Emanuel, Stoeckle, Hummel, & Berry, 1994) reported results of a prospective cohort study of 495 outpatients and 102 members of the public that demonstrated patients’ choices about end-of-life care are stable over time. Participants’ choices improved in stability among those who also had repeated conversations with their physicians and those that revisited their AD decisions periodically.

Overall the research supports that patient preferences may change over time, but for some older adults their AD choices may be moderately stable. In either case, the research supports the need for ongoing conversations among patient, caregiver, and health care professional about how and why a patient’s AD preferences might be changing and that any written formal documents be revised to reflect the changing preferences of the patient.

**Having ADs reduces death anxiety**

Research supports that an intervention that allows patients to reflect on end-of-life treatment with information about what life sustaining measures will do or not do for them, may reduce death anxiety. For example, Henderson (1990) conducted a study of 320 independent residents aged 60 and older of a life care retirement community who had living wills. The study explored whether more specific planning and exercising control over choices during their dying process would decrease their anxiety about death. One of the study participants commented: “I don’t fear death; I fear dying” (1990, p. 480). In this study, an intervention involved counselors engaging participants in discussions about final wishes and the dying process. This produced a significant reduction in death anxiety in the experimental group with no significant reduction in the control group. Henderson reported that the most important impact of this study was that it stimulated lots of conversations among the residents, their families, physicians and other health care team members about resident wishes at end of life. This kind of discussion and
communication is exactly the heart of ACP and what is needed for patients to make informed choices.

Other key studies support Henderson’s findings and report that ACP helps patients and their caregivers face death and helps them cope with the dying process (Martin, et al., 1999); ACP is not only about preparing for incapacity, but also about accepting death and finding security in having made end-of-life wishes known (Singer, et al., 1998); and many older adults are not necessarily afraid of death but fear prolonging life that causes unnecessary pain and is no longer worth living (Lambert, et al., 2005).

**Importance of quality of end-of-life care**

Singer, et al., (1999) conducted a content analysis on data from interviews with patients in three studies. A total of 140 participants in three groups were interviewed: dialysis patients (n=48); patients with HIV (n=54); and residents of long term care (n=38). The results showed that for these patients that quality of end-of-life care includes the following attributes: (1) controlling pain with adequate medications (2) avoiding prolonging life when death is imminent (3) not being a burden on loved ones (4) having a sense of control at the end and (5) strengthening relationships with loved ones (1999, p. 166). This study clearly demonstrated that patients want a voice in choices made at the end of life or if they cannot they want their loved ones to express their wishes. Also the study demonstrated caregivers are greatly relieved when they have had conversations with the patient about their wishes. It relieves them of the burden of having to make decisions on their own which can produce guilt and being unsure they are making the right decisions.

In support of improving end-of-life care, several organizations have undertaken major initiatives, such as the American Medical Association’s Educational for Physicians on End-of-
Life Care Project, Open Society Institute’s Project on Death in America, and the Robert Woods Johnson Foundation’s Last Rites Campaign (Singer, et al., 1999). In addition, frameworks which outline domains of quality end-of-life care and provide guidelines to health care providers and families have been published (American Geriatrics Society, 1997; Emanuel & Emanuel, 1998; Field & Cassel, 1997). Although these guidelines are written from the health care professional point of view rather than the patient and family perspective, they do provide a foundational base which helps define quality of care at end of life (Cleary & Edgeman-Levitan, 1997).

**With dementia, most adults would not choose life sustaining measures**

Patrick, Starks, Cain, Uhlmann, and Pearlman (1994) interviewed 40 well adults and 32 nursing homes residents exploring their understanding of health situations worse than death. They found that most participants evaluated their own health and level of pain as better than death but dementia and coma were considered equal to or worse than death. The authors conclude that participants can and do evaluate some states as worse than death.

Research studies funded by the Agency for Healthcare Research and Quality (2011) have found that many adults who consider dementia as a health state worse than death do not prefer life sustaining measures. For example, Cohen-Mansfield, Droge, and Billig (1992) interviewed 97 elderly hospitalized patients about their preferences for several treatments should they be cognitively impaired. Sixty-six percent of the patients age 64 and over said they desired less treatment if they were to become cognitively impaired. Coppola, Bookwala, and Ditto (1999) found in their study of 50 elderly adults that they are far less likely to accept treatment when presented with a hypothetical scenario for a cognitive impairment such as Alzheimer’s disease than for a physical impairment such as emphysema.
Several studies have confirmed that when asked about life sustaining measures in the presence of severe cognitive decline, most participants wish for no intervention. Gjerdingen, et al., (1999) interviewed 84 cognitively-intact men and women, 65 years and older, from a variety of settings (home, assisted living, nursing homes). Three-fourths of the subjects said they would not want use of a respirator, feeding tube, or CPR with mild dementia and 95% said they would not want any of these treatments if they had severe dementia. Most striking was the fact that “most participants said they would not want to be hospitalized or given antibiotics if they were no longer able to recognize their loved ones or care for themselves” (1999, p. 424). Emanuel, et al., (1991) found in their study of 405 outpatients of a large metropolitan hospital and 102 members of the public that when asked to imagine themselves incompetent with a poor prognosis (in a state such as advanced dementia), the participants decided against life sustaining treatments approximately 70% of the time.

Educational interventions increase understanding of ADs

Research supports that another critical barrier to ACP is lack of knowledge in two key areas: (1) lack of knowledge of what life sustaining measures are and what impact they might have on a patient; and (2) lack of knowledge of how to complete an ACP process (Broadwell, Boisaubin, Dunn, & Engelhardt, 1993; Cantor & Pearlman, 2003; Field & Cassel, 1997). Many adults also report that ADs are too confusing and they do not know how to complete the forms (Kolarik, Arnold, Fischer, & Tulsky, 2002; Meeker & Jezewski, 2005; Silveira, DiPiero, Gerrity, & Feudtner, 2000).

Research demonstrates that educational interventions do increase adults understanding of end-of-life choices, but do not always increase completion of formal ADs. For example, High (1993a) tested the efficacy of three educational interventions to increase the use of ADs among
the elderly. Four hundred and thirty one participants were recruited from senior housing units, from a volunteer research pool at a center on aging, and from two geriatric outpatient clinics. Educational interventions consisted of three types of printed brochures and an invitation to one half the participants to receive counseling regarding ADs and legal assistance, free of charge, to complete ADs. Overall the results did not produce large increases in the use of ADs, but did increase adults understanding of them. The authors conclude that the findings show significant increased knowledge of ADs but more importantly, the educational interventions promoted discussion among patients, caregivers, and health care professionals about end-of-life choices. This may be of greater importance to patients and caregivers as many prefer informal discussions to formal ADs.

Gockel, et al., (1998) tested an educational intervention with 200 patients of an ambulatory clinic of a large urban hospital. Patients were informed in one-on-one sessions with a health care professional about their disease trajectory, life-sustaining measures, and ADs. As a result of this intervention, 60% patients completed ADs at the time of the intervention. In the follow-up session with those that declined, most patients reported that they now understood about life-sustaining measures and ADs. Thirty-percent of the patients refused to complete an AD because they did not want one. They expressed wanting to be kept alive if there was quality of life. The researchers speculate that these patients were struggling to understand ADs and making informed choices in advance of needing care and that these findings may reflect the demographic factors of their sample, particularly socioeconomic status, race/ethnicity, and education. These findings clearly demonstrate that an educational intervention can increase the use of ADs.
These findings lend support to High’s (1993a) concept that a saturation point is reached and that even with consistent educational interventions, the usage of ADs will not increase. Beyond a certain natural level, educational interventions will not sway people who do not wish to write formal documents about end-of-life care. It reflects that many will not choose to prepare formal ADs; or may choose informal conversations to express their wishes; or that they believe that their caregivers will make the right care choices for them when the time comes.

**Conceptual Models of ACP Decision Making**

There are many models of health care decision making including one based on traditional decision theory (McCluskey, 2003) and a consumer-oriented model (The Change Foundation, 2001). However, there are four key conceptual models that have developed specifically around the ACP process. Three of the models evolved as products of research studies with competent adults who had chronic illnesses: older residents of long term care facilities (Lambert, et al., 2005; White, 2005); dialysis patients (Singer, et al., 1998); HIV/AIDS patients (Martin, et al., 1999). One of the models is not based on findings from a specific study, but rather was developed after years of experience and practice with older veterans (Cantor & Pearlman, 2003). None of these models were developed as a result of participation of dementia patients or caregivers in a study.

Each of these four models offers insight into the ACP process and how patients and caregivers make decisions regarding end-of-life care. These conceptual models lead to a better understanding of patient and caregiver perceptions of ACP and how it might be helpful to them. Ultimately these models are designed to help improve not only understanding of ACP but lead to better interventions to improve end-of-life care and to guide the development of policies and procedures that are more responsive to patients’ preferences.
The Charles-Heyland Model of Decision Making (Lambert, 2005)

Lambert et al., (2005) used the Charles-Heyland model as a framework for a qualitative study of 9 competent adults (7 women, 2 men) with chronic illnesses and some limitations of their activities of daily living (ADLs). The Charles-Heyland Model defines the stages of decision making as information exchange, deliberation, and decision (Charles, Gafni, & Whelan, 1999; and later expanded by Heyland, Tranmer, & Feld-Stewart (2000) in their study of dialysis patients). In the information exchange stage, the physician explains all relevant medical information to the patient. During the deliberation stage, the patient and physician discuss and weigh different options available. In the decision stage, the decision is made and formalized by physician order. According to this model the patient’s satisfaction is based on how well the previous stages have been implemented. The researchers discovered key factors associated with the Charles-Heyland information exchange stage: (1) patients’ life experiences with death of others close to them and their own personal experiences with illness influenced attitudes about ACP and (2) there was a lack of knowledge of ACP: participants reported few if any discussions with health care professionals, especially their physicians; they gathered no information from the media; most of their knowledge came from formal health care training.

In the deliberation stage, factors that were most important to participants: (1) spiritual/religious values were important whether or not the participant had a belief in an afterlife; (2) emotional considerations such as sense of having a good long life, not being afraid of death, fear of prolonging life in pain; (3) social considerations (did not want to be a burden to others, did not want to be taken care of by others, great loss of quality of life if cognitive ability is gone, being incontinent, and not able to eat). The collection and weighing of information occurs over the course of a lifetime influenced heavily by what has happened to family members
and friends. Lambert et al., believes that “it was evident that life experience was the most important source of information regarding end-of-life care and that spiritual considerations were, for most participants, the primary factor in deliberation. The descriptions of decision making indicate a rich and highly personal process for all participants” (2005, p. 631).

**Model of Advance Care Planning in Long Term Care Facilities (Cantor & Pearlman, 2003)**

This model was created for residents in long-term care who were cognitively competent to understand end-of-life choices for care. This model is not based on the findings of a specific study but on many years of experience and practice with aging veterans. It frames ACP as a three step process for health care professionals to help guide patients:

**Step One:** Begin discussions with patient and caregiver regarding their values, and beliefs and experiences that would impact their choices for treatment. This model encourages use of such tools as *Your Life, Your Choices* workbook (Silveira, et al., 2000) or the *Five Wishes* documents (Aging with Dignity, 2001). These provide worksheets on health states worse than death and AD forms.

**Step Two:** Ensuring on-going communication process among health care professionals, patient, caregiver about treatment choices and values. The objective is to have a shared understanding of patient choices. Cantor and Pearlman (2003) recommend the use of a values history (Doukas & Reichel, 2007). (See Appendix A for an example of a values history form) to stimulate discussion about what are important values. This is necessary prior to focusing on choosing specific treatments to accept or reject (Doukas & McCullough, 1992).

**Step Three:** Ensure adequate and complete documentation of choices. Using state specific AD forms from advocacy groups (Last Acts, Aging with Dignity, etc) or Physician’s
Order for Life Sustaining Treatment (POLST) form in medical chart is necessary to complete ACP and make sure the patient choices are a matter of record. Cantor and Pearlman (2003) recommend that forms and ADs are reviewed at regular intervals to reflect any changes in patient condition and patient choices.

Cantor and Pearlman acknowledge that ACP does not work for everyone. For example, those who lack decisional capacity, those without a surrogate decision maker, those with cultural/racial backgrounds that value family decision making above individual decision making or those who have a taboo against talking about illness or death and dying will probably not engage in an ACP process. Within these limitations, ACP offers hope of significant benefits to many. “ACP can empower most long-term care residents and ensure that they receive treatments they want, while simultaneously easing the process for healthcare providers confronted with difficult treatment decisions” (2003, p. 106).

Advance Directive Decision Making Model in Long Term Care (White, 2005)

White developed an AD decision making model which was tested in a qualitative study of 13 residents in a long term care facility. The adults were competent but had chronic conditions and some ADL limitations. White conducted a thematic analysis of the data which revealed that decision making was multi-faceted and complex. Decision making was often compromised, sometimes totally derailed, by the stress of moving into long term care. The results showed the factors which are central to AD decision making are: time, stress, health status, knowledge of ADs, concern for others, quality of life, and age. Results supported that many personal factors affect decision making such as: (1) stress related to admission to long term care; (2) time allowed for making a decision; (3) older age; and (4) life experiences. Lack of knowledge about ACP and preparation were identified as barriers to the decision making
process. These findings strongly suggest there is a role for health care professionals in initiating and completing an ACP process with patients.

**Reconceptualizing ACP from the Patient’s Perspective** (Singer, Martin, Lavery, Thiel, Kelner, & Mendelssohn (1998)

Singer, et al., (1998) conducted a study with 48 dialysis patients (30 men and 18 women) with a mean age of 48.3 years who were cognitively competent and undergoing dialysis. They were interviewed 6 months after completing ADs. The purpose of the study was to examine the traditional academic assumptions about ACP which are: (1) the purpose of ACP is preparing for incapacity; (2) ACP is based on personal autonomy and exercising control; (3) the focus of ACP is on completing formal written documents; and (4) most ACP occurs within the patient-physician relationship. The study used a grounded theory methodology which explored these assumptions from the patients’ perspective. The findings did not fully support these traditional assumptions about ACP but rather gave sharper focus to the meaning ACP has for these patients. The study’s findings revealed that patients believe: (1) the purpose of planning is not only preparing for loss of cognitive function but also preparing for death; (2) that planning is not just exercise of personal autonomy or control of events, but also about family relationships and relieving burden on the ones left behind; (3) that the importance of planning is not just about completing written documents but also on the social process; and (4) that ACP does not necessarily occur within the patient-physician relationship but rather among the patients’ close personal relationships.

Although the study was small, it challenged academic assumptions about how adults feel about ACP and how they experience it. Its major strength is twofold: (1) that it causes researchers to examine more closely the process by which patients communicate their wishes
and how they want to communicate them. The absence of written formal documents does not imply that conversations have not taken place within the family that satisfy the patient’s need for communicating their wishes. Singer, et al., state “our research suggests that written ADs are not necessarily the desired output for ACP. Many patients may be more satisfied by a discussion about their wishes with their loved ones” (1998, p. 883); and (2) the study focused on adults who were completing or had just completed the ACP process. It studied their actual experience completing ADs and an ACP process instead of their opinions about the possibility of doing so in the future.

A New model of Advance Care Planning for HIV Patients (Martin, Thiel, & Singer, 1999)

This grounded theory study focused on 140 HIV/AIDS patients who were engaged in an ACP process and were regular visitors to an AIDS health care clinic in Toronto, Canada. The patients were cognitively competent with a mean age of 39.2 years. Similar to the previous study on dialysis patients, this study also focused on developing a model of ACP based on patient perspective. Much like Singer, et al., (1998), this study found that patients believe the primary goals of ACP are preparing for death which means accepting that they are going to die, achieving a sense of control over end-of-life care, and strengthening relationships.

The findings revealed that the ACP process helped participants face the prospect of dying and to accept they were going to die. ACP gave them a way to think about death and dying and increased the ability of the patient and family to cope with impending loss. Patients stated that they placed a high value on self reflection and learned a lot about themselves. In terms of achieving a sense of control, ACP helped the patients increase their belief that they could and should make their own end-of-life decisions. The ACP process allowed for discussion about
what would be acceptable levels of quality of life for the patient and what are preferences for personal and medical care. ACP provided a “language and framework that helped participants organize their thoughts and articulate preferences which is the first step in achieving a sense of control” (Martin, et al., 1999, p. 89).

ACP helped patients strengthen relationships. A major concern for participants was becoming a burden to others. There were two types of concerns: (1) the emotional burden of the patient dying and (2) burden of the caregiver as the surrogate decision maker. ACP and ADs helped patients share thoughts with family which enabled their loved ones to participate in the dying process.

This model demonstrated that for these patients the primary goals of ACP are psychosocial. The authors conclude that this is a new way of looking at ACP and “challenges the notion that the primary goals of ACP is to direct patients’ treatment choices when incompetent” (Martin, et al., 1999, p. 91). The psychosocial benefits of ACP as described by these patients provides a link to the psychosocial benefits of palliative/hospice care. One of the key issues in this study is the finding that although the legal and ethical foundation of ACP is patient autonomy, patients feel that strengthening relationships within their network of loved ones is equally important. The study findings show that ACP provides a way for individuals to deal with death in the shelter of their relationships with the ones they love, in addition to the relationships they have with health care professionals.

Overall these models of ACP decision making reveal the patients’ perspective on how ACP can be helpful to them and their families. Understanding the patients’ perspective sheds light on why the estimates of completion of formal ADs is lower than expected. These models highlight the importance of the informal communication process that occurs among patients and
family members. It is clear from research on competent adults that the ACP process has high value as a means of understanding life sustaining measures and how they would impact quality of life, that patients and caregivers’ have a strong voice in choices at end of life, and that whether or not the ACP process results in written documents, the process of communication helps meet some important psychosocial needs of patient and family at end of life.

**Research on Advance Directives and Dementia Caregivers**

In contrast to the robust research on ADs and competent adults, the research regarding dementia patients and their caregivers and ADs is limited. Overall the research reflects that most of the literature on the care of dementia patients has not focused on end-of-life issues (Evers, et al., 2002; Family Caregiver Alliance, 2011); or ACP planning (Caron, et al., 2005; Lacey, 2004; Laje, 2001); and that palliative care specifically for dementia patients is rarely studied (Shuster, 2000). Those studies that are concerned about end-of-life care choices include interviews with caregivers of dementia patients. Very few exist that include interviews with dementia patients in early stage when sufficient cognitive ability exists to make end-of-life choices (Cantor & Pearlman, 2003; Clayton, Butow, & Tattersall, 2005; Hawkins, et al., 2005).

There a few key studies that shed light on the caregivers’ process of decision making for end-of-life care for the dementia patient and offer substantive leads in understanding caregivers’ perception of ACP. The studies reviewed here reflect the special circumstances of the dementia caregiver including the intensity of the caregiving that is long term, increasingly challenging, and that negatively impacts most aspects of the caregiver’s life. The findings of these studies illuminate the huge burden of caring for someone else including having to make decisions after patients have lost the ability to engage in conversations about end-of-life care and carrying the guilt about doing the right thing.
Also, there are a few studies that highlight how important communication with health care professionals is to the ACP process for dementia caregivers. One example is Engel, Kiely, and Mitchell’s (2006) study of 148 dementia caregivers which found that more time spent discussing ADs with health care providers significantly increased caregiver satisfaction with care. This supports previous research about the primary importance of ACP for families of terminally ill patients (Albinsson & Strang, 2003; Teno, et al., 2004).

**Prevalence of ADs Among Dementia Patients**

Estimates of completion of ADs for dementia patients are difficult to find. Available data from the 1990s estimates that only 15% of patients with dementia have some form of ADs (Branco, et al., 1995; Castle & Mor, 1998; U.S. Department of Health and Human Services, 2008). More recent data suggests that approximately 36-60% of nursing home residents have at least one AD on record. Estimates are that 50% of nursing home residents have cognitive impairment (Center for Gerontology and Health Care Research, 2008; Degenholtz, et al., 2004; McAuley & Travis, 2003; U.S. Department of Health and Human Services, 2008). Missing from these estimates are the approximate 60% of dementia patients who are cared for at home (Alzheimer’s Association, 2011), and dementia caregivers who have engaged in an informal planning process which includes conversations with patients and other family members, etc. regarding what kind of life sustaining care would be desired at the end of life. Although the Alzheimer’s Association (2011) recommends that dementia patients complete ADs soon after initial diagnosis, there are no estimates of how many patients actually do so.

In two studies researchers report low completion rates for ADs in primary care settings particularly for dementia patients (Gamble, et al., 1991; Stefanacci, Cavalieri, Flynn, Forman, & Pomerantz, 1994). However, Jacobson, Kasworm, Battin, Francis, Green, Botkin, and Johnson
(1996) found in their study of 1,114 geriatric hospital patients that there was a high prevalence of appointed health care proxies among patients who died of Alzheimer’s disease. The authors suggest this might be due to the increasing loss of cognitive function of the patient over time and the anticipated loss of ability to make informed decisions and eventual death. Given the narrow window of opportunity for the dementia patient to give informed consent for future treatment, the authors state that further study of this patient population and their caregivers is warranted.

**Key Research Findings**

In 2007 the Alzheimer’s Association conducted a study of 49 experts, including professionals, care providers and researchers from assisted living residences, nursing homes, hospices, the Veterans Affairs medical system, and academia. The purpose of the study was to determine what these experts believe constitutes quality end-of-life care for nursing home residents with dementia. The study findings were remarkable in that there was little disagreement about the key characteristics of quality of end-of-life care for those with dementia. Overwhelmingly the most important issues for the majority of experts are communication and decision-making about care. These issues underlie all other key characteristics of quality end-of-life care. One expert stated that “communication and advance planning are critical to a dignified, comfortable death” (2007, p. 2). The experts reaffirmed the Alzheimer’s Association’s position that the communication process with the patient and family begin right after diagnosis, including conversations about the fact that dementia is terminal, how the disease trajectory might unfold, and advantages and/or disadvantages of life-sustaining measures. The experts agreed that it is “important to plant the seed” for discussion about future care so patients and caregivers have an opportunity to understand fully care options and to begin to accept that life sustaining measures
will not change the course of dementia and can have detrimental effects on patients with advanced dementia.

One of the most revealing studies regarding dementia caregivers and ADs, was conducted by Caron, et al., (2005), which was a grounded theory study of 24 family caregivers of late-stage dementia patients residing in long term care. The purpose of the study was to examine the decision making process regarding end-of-life care for the patient. The key findings of the study demonstrated that some caregivers found the decision making for someone else as “natural and desirable” while for others “decision making was left to the medical team, often because the caregivers saw themselves as ill-equipped to make decisions about the care of their loved one” (p. 123). What emerged from this study is that the caregiver’s perception of the quality of life of the dementia patient is central to the decision making process. Quality of life is measured by the stage of dementia the patient is experiencing and the overall health of the patient. The perceived quality of life by the caregiver determines the level of treatment that they consider justifiable at end of life. Caron, et al., (2005) report that caregivers evaluate quality of life along two dimensions: (1) patient dimensions (current state of physical and cognitive abilities, clinical symptoms, patient preferences, social participation); (2) environmental dimensions (physical and social environment, political and social context of facility, perceived quality of care).

Considering these dimensions, a theory of end-of-life decision making in dementia emerged. Data analysis revealed three difference phases at the end of life: (1) the curative phase (2) the phase of uncertainty and (3) the palliative phase (Caron, et al., 2005). The curative phase is distinguished by a marked event which changes the direction of treatments and perceptions that the caregiver has about the patient’s health. The caregiver understands that the patient’s
situation has changed. For example, the patient may develop pneumonia and the caregiver must make a decision about treatment with antibiotics that will prolong life.

During the “phase of uncertainty” the evaluation of the patient’s health can become difficult. The patient’s ability to verbalize is limited and cognitive alertness fluctuates so that the caregiver is often guessing at how the patient is feeling. Such questions as: “Does the patient still have some quality of life? Is it worth prolonging life?” begin to create doubts about continuing treatment and causes difficulty for the caregiver in decision making.

The palliative phase occurs when the caregiver realizes the dementia patient has lost so much function that quality of life is non-existent and the transition to palliative care begins. The goal of palliative care is to assure that the patient is comfortable, but no curative measures are taken. The goal is to manage pain without extending the patient’s suffering. The palliative phase can arrive without any triggering event, but simply the accumulation of losses of all function or there can be closely repeated episodes of opportunistic infections, such as pneumonia or urinary tract infections.

This study is important in understanding the caregiver’s process of decision making because it identifies quality of life as the driving force behind such decision making. How caregivers assess what quality of life patients are experiencing heavily influences choices for care. The authors conclude that for dementia caregivers end-of-life decision making is highly emotional and fraught with conflict and guilt. Because death is such a taboo in this society, particularly in dementia, there is little opportunity to explore the subject in a safe and supportive place. Given there are few studies about dementia caregivers and end-of-life decision making and few developed guidelines there is not much support for caregivers as they navigate this difficult time at end of life.
Forbes, et al., (2000) conducted a naturalist, descriptive study of 28 families of long term care residents who had moderate to severe dementia. The purpose of the study was to describe the decision-making process that caregivers employed regarding end-of life-care for their family member with dementia. Five themes emerged from data analysis:

**Being a surrogate decision maker created a strong sense of burden:** The researchers report that “for most participants, decisions on behalf of their cognitively impaired relatives were made within an emotional context of overwhelming burden and undying guilt” (2000, p. 253).

**“Insult to life” stories:** Caregivers and patients were unable to complete their life stories as they had hoped and dreamed about. “Life was drastically altered by the disease and changes in personhood” (p. 254). The insult also extended to the caregiver and the family “whose roles changed from spouse or daughter to caregiver, companionship was lost, retirement plans changed, roles changed, and fidelity breached by placing a loved one in a nursing home” (p. 254).

**Two faces of death:** Caregivers struggled with understanding death as both a tragedy and a blessing. Caregivers expressed the loneliness of making these decisions without the support of health care professionals.

**Values and goals of end of life decision making:** were identified in discussion among family members. Examples of important values: quality of life, advocacy, planning ahead, religion and fidelity.

**Unrecognized disease trajectory:** Caregivers were unable to explain the trajectory of dementia and how to recognize the dying process. They understood dying as a major event that would happen suddenly, not the dying by inches that is dementia. They believed their physician would tell them when their family member was dying.
Forbes and colleagues (2000) had assumed that these caregivers would be accepting of death of their loved one with dementia as all the patients were in moderate to late stage dementia. They were startled to learn that their assumption was wrong. The caregivers had not reflected on death and death was not part of their day to day experience.

Forbes et al., stated “the lack of a consistent provider to assist in understanding and providing meaning made decision-making even more difficult” (2000, p. 256). The authors conclude that caregiver needs could be addressed by an ACP process. Such a process includes “good communication with a consistent provider that allows for the translation of medical information into an understanding of the trajectory of disease, the exploration of values and goals, and the reduction of confusion, burden, and guilt” (2000, p. 257). The authors call for more active involvement on the part of health care professionals in initiating and guiding the ACP process based on their focus group interviews with caregivers. They join the chorus of researchers, advocates, and experts in dementia attempting to improve end-of-life care for dementia patients and their families by designing and implementing an ACP process that is effective (Emanuel, von Gunten, & Ferris, 1999; Teno & Lynn, 1996).

Mezey, et al., (1996) conducted a prospective quantitative study of 50 spouses of Alzheimer’s patients seen regularly by the Aging and Dementia Research Center (ADRC) at the New York University Medical Center. Patients were in moderate to severe stage of dementia. The purpose of the study was to examine the anticipated decisions to consent or to forego life-sustaining measures by spouses of Alzheimer’s patients and to describe the relationship of spouse and patient characteristics to predicted decisions. The results of this study show that spouses exhibited a certainty about foregoing life-sustaining measures in the face of coma but were less sure about their choices for critical illness. Especially difficult were choices about use
of antibiotics and feeding tubes. However, when faced with no hope of improvement their choice was for no further treatment. It is important to note that the majority of caregivers in this study applied the “best interests” judgment standard more frequently than the “substituted judgment” standard. Decisions about treatment were not solely based on patient’s wishes but spouses relied on many factors including advice from family, physicians and most often, doing “the most reasonable thing for all involved” (Mezey, et al., 1996, p. 149).

Acknowledging the limitations of their study due to the small sample, the authors suggest that physicians, nurses and social workers need to provide support to caregivers in foregoing or consenting to life sustaining measures for the dementia patient. The authors see an urgent need to investigate what factors caregivers perceive as important to them in the decision making process regarding end-of-life care.

Laje (2001) conducted a quantitative study of 150 Alzheimer’s caregivers who attended a conference on Alzheimer’s disease. The purpose of the study was to examine caregivers’ attitudes toward ACP and which factors predicted completion of ADs. Most notable among the findings were: (1) caregivers who spoke to social workers more frequently about health care proxies and living wills were more likely to have ADs than those who spoke less often to social workers; and (2) factors that predicted having ADs were the caregiver and patient being older and caregiver having his/her own ADs. The study found that comfort with a discussion about death and dying, level of death anxiety, and locus of control did not influence the completion of ADs.

These studies demonstrate the challenges that dementia caregivers face in end-of-life decision making for the patient regardless of whether the patient is in long term care or at home. This decision making causes conflict and a sense of burden and guilt. Some caregivers have
knowledge of ADs; some do not. But mostly all report desiring help with understanding life sustaining measures and discussions with health care professionals in how to make good decisions. The authors of these studies recommend a strong role for professionals, especially social workers, to aid families in the ACP process and encourage more research of dementia caregivers and the ACP process.

Although these studies have small samples and thus have limited generalizability to the population of dementia caregivers, their results taken together illuminate a path to further inquiry: How do caregivers learn about ADs? If they know about them, how do they proceed to actually do them? Who do they talk to about it? Do they understand life sustaining measures? How do they understand their role as surrogate decision maker? This study focuses on dementia caregivers and how they do or do not understand the ACP process, their role as surrogate decision makers, what factors encourage or discourage them from completing ADs, and if knowing the patient’s wishes relieves a sense of burden and guilt for them. Hopefully the findings from this study will add to a relatively young, but expanding body of research on understanding the process by which caregivers make health care decisions for their family member with dementia.

**Key Factors Related to Completion of Advance Directives**

Research indicates that completion of ADs is influenced by individual attitudes (Bergman-Evans, Kuhnel, McNitt, & Myers, 2008; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007), demographic factors (Jones, et al., 2011; Resnick, et al., 2004), health conditions (Ramsaroop, Reid, & Adelman, 2007), cultural beliefs (Johnson, Kuchibhatia, & Tulsky, 2008; Ott, 2008), and trust in health care professionals (Troyer & McAuley, 2006). In the studies that
have explored why people choose to complete ADs the following factors have emerged as
significant:

**Demographic Factors:**

**Age:** Older age is predictive of completion of ADs (Hogan, Lunney, Gabel, & Lynn, 2001; Jones, et al., 2011; Laje, 2001; Lorenz, et al., 2004; Lunney, Lynn, Foley, Lipson, &
Guralnik, 2003; Lunney, Lynn, & Hogan, 2002; U.S. Department of Health and Human Services,
2008; Wenger, Phillips, & Teno, 2000). For example, VandeCreek, et al., (1995) found in their
study of 200 adults that respondent’s age is predictive of AD completion: Twenty-year-old
respondents in the sample had only a 2% chance of having ADs. Those who were 80 years old
had a 46% chance. The authors speculate that age itself does not cause one to complete an AD,
but rather it is a “proxy variable” for changes in attitudes, beliefs and thoughts that change as one
grows older. As the body and mind change it forces one to examine what is important in life
(VandeCreek, et al., 1995, p. 219).

**Religious affiliation:** Allen, DeLaine, Chaplin, Marson, Bourgeois, Dijkstra, and Burgio
(2003) in their quantitative study of nursing home residents (n=78) found that residents who
expressed stronger religious beliefs are more likely to have completed ADs. This is supported by
findings from several other studies (Allen & Shuster, 2002; Carr & Khodyakov, 2007; DeLuca

However, the research findings on the association of religion and AD completion are
mixed. For example, Gockel, et al., (1998) in their study of 200 competent patients at a large
urban hospital found that there was no relationship between religious affiliation and the
completion of ADs. In contrast, Murphy, Palmer, Azen, Frank, Michel, and Blackhall (1996)
found that Catholics and Jewish study participants were significantly more likely to have ADs than Protestants or Buddhists.

Lambert, et al., (2005) found in their grounded theory of nine nursing home residents that spiritual beliefs were important for residents as they considered end-of-life care. Most of the participants were Christian but some spoke of having non-traditional beliefs. Regardless of whether the residents were participating in organized religion or not, they expressed that having these beliefs provided comfort when talking about death.

**Education level:** Carr and Khodyakov (2007) found in their secondary analysis of two waves of data (1992-1993 and 2004) from the Wisconsin Longitudinal Study of community-dwelling adults, aged 64-65 (n=3,383) having 12 years or more of education was positively associated with the completion of formal ADs or having informal conversations with family members about end-of-life care choices. Those with less than eight years of education are less likely to have completed ADs than those with more education (Hanson & Rodgman, 1996; High, 1993; Hopp, 2000; Stelter, Elliott, & Bruno, 1992).

**Socioeconomic status:** The U.S. Department of Health and Human Services (2008) in their report to Congress on the status of ADs and ACP, stated that a review of research findings indicates that higher socioeconomic status is associated with completions of ADs. There are several studies that provide evidence to support this statement (Hogan, et al., 2001; Lorenz, et al., 2004; Lunney, et al., 2003; Lunney, et al., 2002; Wenger, et al., 2000).

**Race/Ethnicity:** Whites complete ADs more often than other racial groups which is related to higher educational levels and higher socioeconomic status (Circirelli, 1997; Jones, et. al., 2011; U.S. Department of Health and Human Services, 2008).
In Circirelli’s (1997) study of 388 Black and White older adults (aged 60-100) responded to 17 hypothetical situations depicting health conditions with very low quality of life. The findings demonstrated that Black participants with lower socioeconomic status (less education and lower occupational status) and greater religiosity believed that all life-sustaining measures should be taken at the end of life. They had fewer ADs than Whites. White participants, who had higher socioeconomic status and less religiosity, believed that quality of life was important, and that there should be limits on end-of-life care.

In another study of 540 of surrogate decision makers (454 White; 86 Black), Hopp (2000) found that Whites were more likely to have ADs, have designated a surrogate decision maker, and were more likely to limit life-sustaining measures and withhold treatment before death. However, Blacks were more likely to want all measures taken in order to prolong life. There are many studies which support these findings (Eleazer, Hornung, Egbert, Egbert, Eng, Headgepeth, McCann, Strothers, Sapir, Wei, & Wilson, 1996; Hopp & Duffy, 2000; Laje, 2001; Miles, Koepp, & Weber, 1996; Murphy, et al., 1996; Rubin, Strull, Fialkow, Weiss, & Lo, 1994). The findings suggest that race continues to be a significant predictor of ACP and treatment choices even after controlling for sociodemographic factors.

Blacks are less likely to complete ADs as they perceive them as removing the family’s prerogative to make changes as necessary. They have little trust in the health care system and view ADs as a means of withholding necessary treatment (Blackhall, Frank, Murphy, Michel, Palmer, & Azen, 1999; Caralis, David, Wright, & Marcial,1993; Laje, 2001; U.S. Department of Health and Human Services, 2008). Blacks are more inclined to request that all life sustaining measures be taken regardless of the condition of the patient (Hanson & Rodgman, 1996; Pevey, 2003). In addition, Blacks and other non-white groups were less knowledgeable about ADs and

Latinos show a lower rate of AD completion than Whites (Laje, 2001; Murphy et al., 1996). Research explains that Latinos are guided by “familismo” which is strong sense of family loyalty and cohesion and is considered one of their most important values. “Familismo” comes from sharing a collectivistic world view of interdependence among family members who are willing to sacrifice the needs of an individual over the needs of the family (Del Rio, 2010, p. 138; Santiago-Rivera, 2003, p. 6). This is in sharp contrast to the western belief of patient autonomy that is the foundation of ACP and ADs. Decisions are made for the good of the family group, not necessarily just to honor an individual’s wishes.

A review of the available literature indicates that (1) Latinos use a family-centered model for decision making rather than a patient-centered model when making end of life decisions; (2) they have little knowledge of ADs; and (3) they favor the use of life sustaining measures and want to be kept alive no matter what their condition. But they often defer to their physicians’ advice to withdraw treatment if the situation is hopeless (Bade, Murphy, & Sullivan, 1999; Blackhall, et al., 1999; Caralis, et al., 1993; Del Rio, 2010; Klessig, 1992; Kwak & Haley, 2005).

Some studies indicate that ADs are not compatible with values and beliefs of Latino, Asian, and Native American cultures. Many in these cultural groups believe that the patient must be protected from the news of their own dying and it is the responsibility of the family members to shield them from such news and to make the appropriate decisions (Blackhall, et al., 1999; Fagerlin & Schneider, 2004; Matsumura, Bito, Liu, Kahn, Kagawa-Singer, & Wenger, 2002; Searight & Gafford, 2005; U.S. Department of Health and Human Services, 2008).
One study of Korean, Mexican, African American, and White participants aged 65 and older (in a stratified sample of n=800), found that Korean and Mexican participants were more likely to have a family-centered model of decision making rather than the individual patient autonomy model favored by African American and White participants. Also the Korean and Mexican participants believed that the patient should not be told about a terminal illness and the patient should not be the one to make decisions about life sustaining measures (Blackhall, Murphy, Michel, & Azen, 1995).

The existing data on Asian Americans is difficult to tease apart. There are fewer studies on Asians than other groups and findings are conflicting. For example, Eleazer et al., (1996) and Murphy, et al., (1996) found lower AD completion rates for Asians than for Whites but Rubin, et al., (1994) found completion rates equal to Whites.

An important study that assessed the relationship between ethnicity and end-of-life decision making, including the use of ADs, was conducted with 1,193 frail older adults (385 non-Hispanic Whites, 364 Blacks, 156 Hispanics, and 288 Asians) in the PACE (Program For All Inclusive Care of the Elderly), a comprehensive managed care program serving frail older participants at ten sites across the U.S. (Eleazer, et al., 1996). The findings reveal that each group differs significantly in their wishes for end-of-life care. Blacks were significantly more likely to choose aggressive treatment and less likely than Whites and Hispanics to complete written ADs. Whites were significantly more likely to complete written ADs. Asians were more likely to choose less aggressive treatment but were more likely not to complete written ADs. One of the most important points that these authors make is that although end-of-life decision making is very personal and made by each patient and family, it is imperative that health care
professionals understand the cross-cultural differences that exist among different population groups.

In addition, on the practical level of ACP implementation, the language barriers that exist among patients, families, and their physicians inhibit the transfer of knowledge about end-of-life choices and does not encourage the communication process that is essential to such planning (U.S. Department of Health and Human Services, 2008).

**Psychosocial Factors Related to Completion of ADs**

**Greater disease burden:** Those who experience greater disease burden such as AIDs patients and advance cancer patients are more likely to complete an ACP process (Elphern, Yellen, & Burton, 1993; Goold, Arnold, & Siminoff, 1993; Hughes & Singer, 1992; Lorenz, et al., 2004; Mansell, Kazis, Glantz, & Heeren, 1999; U.S. Department of Health and Human Services, 2008). Although dementia patients have a high disease burden, caregivers do not complete an ACP process at a high level (U.S. Department of Health and Human Services, 2008).

**Death anxiety:** A positive attitude about being able to discuss death and dying is associated with higher levels of completion of ADs (U.S. Department of Health and Human Services, 2008). Some older people can articulate that they are not afraid of death, but are afraid of the process of dying. High (1993) in his study of 293 elderly people found that death anxiety was not a factor in their completion of ADs. High found that two thirds of the study participants had talked to at least one other person about future health care choices. This confirms earlier exploratory studies (High 1988, 1990) that elderly people do talk to family members about death and end-of-life choices. Laje (2001) found in her study of 150 caregivers that death anxiety was not a significant factor in the completion of ADs.
Locus of Control: Many older adults report they are afraid of losing control over their dying process because they are no longer able to understand life sustaining measures and give consent to withhold or withdraw such treatment (Cohen-Mansfield, et al., 1992; Emanuel, et al., 1991; Lambert, et al., 2005; Singer, et al., 1999; White, 2005). Many fear prolonging death, have concerns about physical suffering, and being in a severely impaired state (Gjerdingen, et al., 1999; Lambert, et al., 2005; Martin, et al., 1999; White, 2005). Martin and his colleagues (1999) found in their study of 140 HIV/AIDS patients that they had a deep concern about achieving a sense of control over their dying. The main factors driving patients to look for a means of control were past experiences with ill health; watching the premature death of many friends; and the impact of intensive medical intervention when curative treatment was no longer able to change the course of the disease. The patients in this study reported that the ACP process helped them achieve a sense of control by allowing an articulation and establishment of their preferences for end-of-life care. In a study of 48 dialysis patients, Singer and his colleagues (1998) discovered that patients believed that the main reason for doing ACP was to maintain control of their dying process and to relieve a sense of burden for their loved ones that they would leave behind. For these patients, controlling treatment meant withholding treatment when they were no longer competent to make decisions so that the dying process would not be extended artificially.

Situational Factors Related to Completion of ADs

Research supports that situational factors significantly increase the completion of ADs:

- Having experience with a previous illness and/or death of a loved one (Lambert, et al., 2005; Martin, et al., 1999; Miles, et al., 1996).
• Having knowledge about ADs and end-of-life options (Miles, et al., 1996; U.S. Department of Health and Human Services, 2008).

• Having a long standing relationship with a primary care physician (Pevey, 2003; U.S. Department of Health and Human Services, 2008).

Successful Interventions That Promote ACP

While acknowledging the challenges of end-of-life care and the barriers to ACP implementation, there are some interventions that have demonstrated good results in establishing a communication process with patients, encouraging the use of ADs, and improving care:

Let Me Decide Program in Ontario, Canada:

This is a comprehensive, systematic, multi-approach educational intervention that allows for patients to have repeated discussions over time with a health care professional. Facilitators guide patients and caregivers through discussions of life sustaining measures and reviews formal AD documents. This process increased completion of ADs, and those patients with ADs were less likely to be hospitalized and costs of end-of-life care were reduced (Cantor & Pearlman, 2003; Prendergast, 2001). A few studies provide evidence that this program increases ACP rates by 45% or more (Guo & Harstall, 2004; Molloy, et al., 2000; U.S. Department of Health and Human Services, 2008). The key to success with this program is the combination of educational materials with repeated discussions over time with a health care professional.

Respecting Your Choices, La Crosse Advance Directive Study (LADS), Wisconsin

A community-wide, multi-component program to increase completion of ACP proved that it is possible to improve use of ACP and complete ADs. A retrospective study (540 deaths over one year) showed that 85% of the people who died during the year-long study had completed ADs and their wishes outlined in the documents were honored more than 90% of the
time (Hammes, 1999; Hammes & Rooney, 1998). These remarkable results were accomplished after a 5-year initiative that included all four major health care providers in the city and long-term care facilities. All facilities agreed to implement the same ACP model and included ongoing facilitated conversations among patients, caregivers and health care professionals. It is noted that La Crosse, Wisconsin is a mostly homogenous community with a largely Caucasian, well-educated population. This population overall is better disposed toward ACP than other cultural/racial groups.

While acknowledging the enormous community-wide effort needed to make this program a success and the limitation of lack of diversity in the population effected, Respecting Your Choices accomplished several key things by:

(1) Implementing ACP as an ongoing process, not a simple one time event

(2) Shifting the focus away from just filling out forms to the importance of conversations about values, beliefs and experiences

(3) Shifting control of ACP away from health care professionals to patient and family conversations

(4) Refocusing conversations from just personal autonomy to include the family context

(5) Effectively working with health care professionals and hospitals to see that copies of ADs are always available

This program changed the standard medical approach to one that is focused on understanding that end-of-life care is complex and emotionally charged and depends on the process of conversations that a patient has “within the network of relationships that are meaningful to a person” (Prendergast, 2001, p. 39).
This program acknowledges that personal autonomy may not be central to many patients when reflecting on end-of-life care. Many wish that caregivers and other family members make decisions on their behalf. For the ACP process to be successful it must center on the relationships that the patient and caregiver believe are most important. Prendergast believes that this gives the patient a sense of control over their dying process and relieves stress for the family (2001, p. 39).

**Comprehensive Home-Based Options for Informed Consent about End Stage Services (CHOICES)**

This is a home-based ACP project for chronically ill, medically-fragile, high risk patients that has demonstrated decreasing use of aggressive treatment in favor of palliative care. (Brumley, Enguidanos, & Cherin, 2003; Stuart, D’Onofrio, Boatman, & Feigelman, 2003). Patients for this program do not meet the Medicare Hospice benefit requirement for the terminally ill (Stuart, et al., 2003). CHOICES is a project of the Sutter Visiting Nurses Association and Hospice of Emeryville, California. Key elements of the program include physician education, enrollment of patients with high disease burden, and co-management of care with primary care physicians. Clinical teams, which include geriatric nurse practitioners, home care nurses, social workers, and physicians, provide in-home management of care, focused education, ACP, and caregiver support. (Stuart, et al., 2003). The team offers “transition management’ working with patients and caregivers at home, managing their care, building trusting relationships and having on-going conversations about choices for end-of-life care. The teams describe the “heart of the project” as working with patients and caregivers and defining their wishes. It supports the evidence that ACP is a process that can only be successful when it is built within a relationship of trust (Stuart, et al., 2003). By reducing the number of medical
crises, emergency room visits, and hospitalizations, CHOICES has demonstrated its value and
cost-effectiveness (Stuart, et al., 2003).

**Physician’s Orders for Life-Sustaining Treatment (POLST)**

This is a structured model of decision-making designed to capture patient’s wishes for
care in a highly visible, accessible and portable form. Many experts are calling this the next
generation of ADs (AARP Public Policy Institute, 2011). It is different than ADs in that it is a
standardized “standing” (has no expiration date) physician’s order form that is placed in a
patient’s medical chart. A POLST form is for patients with advanced terminal illness or
advanced frailty, like dementia, focused on current care. ADs are for use by all adults whether
they have a current illness or not and is focused on future care. (See Appendix C for a copy of
the POLST form). The form documents patient’s preference for four basic treatment choices:
resuscitation, use of antibiotics, artificial nutrition and hydration, and hospitalization (AARP
Public Policy Institute, 2011; Cantor & Pearlman, 2003). Cantor and Pearlman report that
“unlike advance directives POLST forms do not have to be interpreted. Their instructions are
clear and they determine the treatments that are given or withheld” (2003, p. 104). One study
demonstrated that patients who had POLST orders had their wishes honored 100% of the time
and only 2% of the time were “Do Not Hospitalize” orders overridden for the purpose of
extending life (Tolle, Tilden, Nelson, & Dunn, 1998). Many studies have assessed the POLST
intervention and found that patients received more comfort care and were not transferred to acute
care hospitals as frequently for unwanted treatments (Cantor, 2000; Dunn, Schmidt, Carley,
Donius, Weinstein, & Dull, 1996; Lee, Brummel-Smith, Meyer, Drew, & London, 2000; Tolle,
et al., 1998).
POLST began in Oregon in the early 1990s as a way to improve care for seriously ill patients. By 2010 at least 12 states had similar programs (CA, HI, IA, MN, NY, NC, OR, TN, UT, VT, WA). States use different terms for the POLST program including POST (Physician Orders for Scope of Treatment), MOLST (Medical Orders for Life-Sustaining Treatment), MOST (Medical Orders for Scope of Treatment), and COLST (Clinician Orders for Life-Sustaining Treatment). The most recent state to pass legislation was Maryland in the fall of 2011. (Compassion & Choices Newsletter, 2011). Although the POLST form is not a replacement for ADs, it is a translation of patient’s wishes into a standing medical order that is accessible, portable, and available whenever the patient’s condition changes (U.S. Department of Health and Human Services, 2008). Given that the POLST program is geared for those with people with greater disease burden, the addition of a POLST form to ACP would be of great assistance to dementia patients and their caregivers.

In Virginia a Physician Orders for Scope of Treatment (POST) program was piloted by the Palliative Care Partnership of Roanoke Valley (http://pcprv.org/post.html) beginning in 2009 and is now being tested in 10 regions of the state. The local participating agencies include: the major hospital system, a health and rehab center, a recovery and care center, and four hospice programs. The program is designed to encourage all people who live in Roanoke County to complete a POST form which contains orders by a physician who has personally examined the patient and has had a discussion regarding the patient’s treatment preferences for end-of-life care. During the pilot program, social workers, nurses, and other health care professionals who have been trained as POST Advance Care Planning Facilitators help patients and caregivers fill out the form. The form is kept with the patient at all times.
Veterans Administration (VA), (e.g. Dayton, Ohio and Bedford, Massachusetts)

These VA long-term care facilities use “advance proxy planning” in dementia care units. This is a planning process that requires health care professionals (physicians, nurses, social workers) to have conversations with patients and caregivers about end-of-life choices prior to when decisions have to be made due to serious health changes. A form like the POLST form is used to guide these conversations. Volicer, Cantor, and Derse (2002) report that these discussions with patients and caregivers before crises occur alleviates some of the anxiety and stress of end-of-life care. The Veterans National Ethics Committee recommends that all VA long-term facilities consider using this ACP model (Volicer, et al., 2002).

Palliative Excellence in Alzheimer Care Efforts (PEACE)

This model was developed to improve end-of-life care for dementia patients in an effort to bring hospice care to dementia patients who may not be eligible for enrollment in the Medicare hospice benefit. PEACE is a disease management model for dementia patients that attempts to integrate palliative care into primary care. The program includes “Medicaring” which offers ACP, patient-centered care, caregiver support, and palliative care for patients (Lynn, 1996; Shega, et al., 2003).

PEACE is coordinated through the primary care geriatrics practice of the University of Chicago. Initially 150 patients were recruited. Patients and caregivers are interviewed every 6 months for 2 years, and post-death interviews are conducted with caregivers. From these interviews feedback about care is provided to health care professionals to make necessary changes so end-of-life care is enhanced and provides continuous quality improvement for the practice. Results indicate high rates of satisfaction with quality of care, good planning process, attention paid to patient wishes, and two-thirds of patients were able to die at home (Shega, et al.,
2003). Given these results, more patients are being recruited from two clinics close to the University of Chicago, which provides primary care to 2,200 older adults, with 500 of those being dementia patients. The average age of patients in these clinics is 80, two thirds are women, and approximately two thirds are African American (Shega et al., 2003).

Of these six successful ACP interventions, four are designed for frail, competent older adults (Let Me Decide, Respecting Your Choices, CHOICES, POLST) and two interventions are dementia-specific (VA, PEACE). Upon analysis their differences are revealed not in the populations they target, but in the structure and delivery of the intervention itself. For example, Let Me Decide, Respecting Your Choices, POLST, and VA are all examples of how ACP can be tailored and implemented for residents of long term care. All four programs use a variation of Cantor and Pearlman’s (2003) three-step program for ACP: consider values and treatment preferences, provide adequate communication process, implement accurate and complete documentation. All four programs use a structured form for documentation, such as the POLST or the VA advance proxy form.

Both CHOICES (medically-fragile, home-bound older adults) and PEACE (dementia patients) share a common goal for their programs: to decrease the use of aggressive treatment and use of more palliative/hospice care. Both programs use an integrated model of care which includes ACP as a chief component to the model. For example, PEACE, attempts to integrate palliative care into primary care with “Medicaring” which incorporates ACP, patient-centered care, family support, and palliative care from diagnosis through the terminal stages of dementia. CHOICES does the same but also includes clinical teams providing in-home care management and physician education regarding palliative/hospice care. Four of these successful interventions focus strictly on implementing an ACP process and two integrate ACP into a “care package”
which focuses not only on completing an ACP process but also moving the patient from aggressive treatment to a palliative/hospice care model.

All of these successful programs require an on-going process of communication with patients and caregivers over time. Given the structural problems that exist in the current health care system, such as care reimbursement mechanisms and the time and attention required of health care professionals, this poses challenges to replication of these programs in diverse settings. However, given the striking results of these efforts, such as reduced hospitalizations, higher rates of physician compliance with patients’ wishes, and higher rates of satisfaction with care by patients and families, these successful ACP interventions offer great promise for dementia patients and their caregivers. Particularly effective for dementia patients and their caregivers might be an intervention tailored after both the CHOICES and PEACE models. Accomplishing an ACP process along with having the patient receive more palliative/hospice care would transform end-of-life care for dementia patients. Results of these interventions support the use of ACP as an effective tool for families to navigate end of life and to offer some solace to caregivers as they make decisions in the best interests of the dementia patient. These programs demonstrate that ACP can be implemented effectively and helps patients and caregivers. This offers great hope that end-of-life care can be improved for dementia patients.
Chapter 3: Research Methodology

Purpose of the Study

As noted in the previous chapter there are successful interventions which facilitate a communication process with patients and caregivers that help with discussions about end-of-life care. These discussions are crucial for dementia caregivers in order to plan for the time when they will need to make decisions on behalf of the patient who is no longer able. In order to remodel successful interventions specifically for dementia caregivers, it is important to know first how dementia caregivers understand ACP. This study focused on discovering what knowledge dementia caregivers have about ACP, how they learned to execute formal ADs or have engaged in an informal ACP process, and how they understand their role as surrogate decision makers. Factors that contribute to the ACP process are of special interest such as personal factors (e.g. age, race, ethnicity, religious affiliation, education, socioeconomic status); psychosocial factors (e.g. perception of disease burden, death anxiety, locus of control); and situational factors (e.g. experience with previous illness and/or death of loved one, knowledge of AD and end-of-life options, long standing relationship with a physician). Once these factors were identified then a theory of ACP was developed for this sample. This study establishes a foundation for future studies that may lead to adapted models of current successful interventions that would be helpful to dementia families, and those working with them such as professional caregivers.

Research Questions

(1) How do dementia caregivers understand the process of ACP?

(2) What factors influence caregivers’ decision-making process regarding ACP?
Research Paradigm and Theoretical Framework

Guba defines paradigm as a researcher’s worldview that contains a “basic set of beliefs that guide action” (1990, p. 17). A researcher’s beliefs guide the choices made in developing a research study, including the conceptualization, design, method, and implementation of a study. Based on the researcher’s choices, a study “fits” into a broad philosophical and/or a theoretical perspective. This “fit” is defined by the researcher’s assumptions about what is the nature of reality (ontology); how knowledge is acquired (epistemology); and what is human nature and how humans relate to their environment.

A useful tool for understanding these different assumptions is Burrell and Morgan’s (1979) framework. Each perspective leads a researcher down a road of inquiry that can lead to potential problem solving interventions. This framework has two dimensions and four paradigms for the analysis of social theory. The four paradigms are: functionalist, interpretive, radical humanist, and radical structuralist. Each paradigm makes different assumptions about what knowledge is and how knowledge is acquired. Each describes the nature of the relationship between individuals and their environment through different lenses. Based on these assumptions, each paradigm offers a different view for how to approach a research question, how to design a study, what methodology to use, and what kind of outcomes can be obtained.

The vertical continuum from regulation to radical change represents the first dimension of order and conflict. Regulation emphasizes society as orderly, stable, integrated, having functional coordination, and consensus. Radical change emphasizes the view that society is about change, conflict, disintegration, and coercion by those who have power. The horizontal continuum from subjectivity to objectivity reflects two different approaches to research with
subjectivity representing that reality is within individuals and objectivity which represents an outside, concrete reality that can be observed and measured.

**Figure 1: Visual representation of the Burrell and Morgan (1979) paradigms**

![Diagram showing the Burrell and Morgan (1979) paradigms]

Using Burrell and Morgan’s (1979) framework as a guide, this study is set in the functionalist paradigm. A researcher in the functionalist paradigm is seeking objective truth with an understanding that cause can be determined based on finding the facts that are hard and concrete. These facts are observable and measurable. The researcher makes the assumption that there is truth and that truth can be known if approached in a systematic way much like scientists study the natural world. Individuals have their place in the natural world and they can be studied in the same ways as other phenomena. Reality exists outside the individual and research is focused on how individuals relate to their environment. The researcher is a realist and positivist who searches for patterns and causal relationships that predict how the world is and how humans are in the world. This approach seeks a rational explanation of social affairs.
The researcher is deterministic and views individuals as firmly situated in the natural environment that defines and shapes them. The researcher holds a nomothetic view which means that research into human affairs is based upon the systematic scientific approach and method used to study the natural world. This approach is pragmatic and seeks to find practical solutions to problems. The researcher is interested in making things better and incremental change is acceptable. Seeking knowledge for knowledge sake is the goal of good science and the process of research inquiry of building knowledge step by step is how humans expand their knowledge of how the world works. The functionalist assumes the social world is composed of relatively concrete empirical artifacts and relationships that can be identified, studied, and measured. Once knowledge of the world is gained, humans can increase their ability to control it. From this perspective a researcher seeks to explain the “status quo, social order, consensus, social integration, solidarity, need satisfaction and actuality” (Burrell & Morgan, 1979, p. 26). Research is as objective as possible with a focus on concepts and how to measure the relationship among them.

Based on these assumptions, a researcher in the functionalist paradigm would approach a qualitative study with these priorities: (1) make the study as objective as possible by approaching sampling and data collection in a scientific, systematic way; (2) use multiple levels of data collection and data analysis to increase research rigor, which in this study includes prescreening call notes, interview notes, field notes, and memos for data analysis; and (3) present the study findings in a structured, technical report (Creswell, 2013; Miles & Huberman, 1994; O’Connor, 2001).
Research Method

Grounded Theory

Grounded Theory (GT) methodology was chosen for this study as it is an excellent method for investigating an under-studied population in an area with little accumulated knowledge, such as dementia caregivers and end-of-life planning (Birks & Mills, 2011; Caron, et al., 2005). Stern suggested that “the strongest case for the use of grounded theory is in investigations of relatively uncharted waters” (1980, p. 20). In GT, theory development is grounded in empirical data and in processes of everyday social life which makes under-researched topics well suited to this method (Hunter, et al., 2011).

GT has been described as “the most influential paradigm for qualitative research in the social sciences today” (Denzin, 1997, as cited in Patton, 2002, p. 487). GT has its own journal, The Grounded Theory Review and a website devoted to GT methods sponsored by the Grounded Theory Institute, a non-profit organization (www.groundedtheory.com) (Fassinger, 2005). Glaser and Strauss, the creators of the grounded theory method, state that “grounded theories are powerful tools that fit empirical situations and provide ‘relevant predictions, explanations, interpretations and application” (1967, p. 1).

GT has been widely adopted by researchers in a broad range of fields, particularly social work, nursing, education, and health care in general. It is also used extensively in business and in the field of psychology such as clinical, counseling, organizational, and environmental areas (Fassinger, 2005). Nathaniel and Andrews believe that “because of their real-world orientation, grounded theories are particularly appropriate for health care research” (2010, p. 65). Of particular note is GT’s increasing use by researchers exploring end-of-life decision making for HIV/AIDS, dialysis, cancer, and dementia patients (Caron, et al., 2005; Martin, et al., 1999;
Singer, et al., 1998). Based on such support, grounded theory is an appropriate and well-tested method for developing an understanding of the ACP process with dementia caregivers.

**Definition of Grounded Theory**

GT is a research design method which attempts to formulate new theories which emerge from the data. Birks and Mills describe this as an inductive process of “building theory up from the data itself” (2011, p. 11). Strauss and Corbin define grounded theory as “theory that is derived from data, systematically gathered and analyzed through the research process……and because grounded theories are drawn from the data they are likely to offer insight, enhance understanding and provide a meaningful guide to action” (1998, p. 12). The purpose of a GT study is to discover new theory, not merely to describe human experiences (Creswell, 2013). Bernard and Ryan would add that the purpose of GT is “to discover theories or explanations grounded in empirical data that explain how things work” (2010, p. 267).

The new theory generated from the method is “grounded” in the data that participants provide who have experienced a process (Strauss & Corbin, 1998). Creswell expands this idea by stating that the data from the participants is grounded “especially in the actions, interactions and social processes of people” and as a result the researcher generates a “general explanation (a theory) of a process, an action or an interaction shaped by the views of the participants” (2013, p. 83 and 84). Corbin and Strauss claim that GT provides a “unified theoretical explanation for a process” (2008, p. 107).

**The Historical and Theoretical Base of Grounded Theory**

GT evolved from the Chicago School of Sociology and the creation of symbolic interactionism during the period 1920 to 1950. It was heavily influenced by the philosophy of pragmatism developed by John Dewey and George Mead (concept of “the self”) (Fisher &
Strauss, 1978, 1979a, 1979b; Strauss, 1991). Of notable influence was Charles Horton Cooley’s concept of the “looking glass self” which explained how individuals possess a self awareness that is shaped by continuing social interactions with others (Cooley, 1922; Ritzer, 2008).

Kendall (1999) claims that symbolic interactionism developed to challenge the grand functional theories that dominated social science at the end of the 19th to mid-20th century. One such theory was structural functionalism developed by Talcott Parsons and Robert Merton. This grand theory explained that the social world exists as a system with interrelated parts. These parts only have meaning in relation to how they contribute to maintaining the function of the whole system (Bowers, 1988; Kendall, 1999; Ritzer, 2008). In this system, individuals are reduced to a “set of structures, functions and mechanisms whose purpose was to keep society homeostatic, orderly, static and conventional” (Kendall, 1999, p. 743).

Symbolic interactionism was created as an alternative paradigm of the social world defined as a “fluid and dynamic process of ongoing activity and varied and reciprocating interactions” (Kendall, 1999, p. 744). The leading proponents of symbolic interactionism were George Mead, Robert Park, and Herbert Blumer. Blumer (1956) who coined the term “symbolic interactionism,” believed that meaning could only be established through interpersonal interactions: “with whom, with what, and how one interacts becomes a major determinant of how one perceives and defines reality” (Kendall, 1999, p. 744; Ritzer, 2008). Blumer stressed the “role of concepts that are sensitizing rather than definitive, that gain their utility and significance from patterned relationships rather than quantifiable correlations” (Heath & Cowley, 2004, p. 142). Blumer believed a person does not merely respond automatically to situations but is an “acting organism who has to cope with and handle such factors and who, in so doing, has to forge and direct his line of action” (1969, p. 55). Grounded theorists study the meanings created
in these social relationships attempting to discover how groups of people define their realities on
the basis of their understandings of interpersonal interactions (Cutcliffe, 2000; Fassinger, 2005).

Blumer and the Chicago School of Sociology believed a special methodology needed to be developed for the study of human behavior to capture what was happening in these interpersonal interactions. It was from this base that Glaser and Strauss developed the new methodology of GT. GT was developed as both a research methodology based on symbolic interactionism and a method for developing theories of human behavior and the social world by using the process of constant comparison (Kendall, 1999). GT “combined the depth and richness of qualitative interpretive traditions with the logic, rigor, and systematic analysis inherent in quantitative survey research (Charmaz, 2000; Dey, 1999; Glaser & Strauss, 1967; Keddy, Sims, & Stern, 1996; Robrecht, 1995).

In 1965, sociologists Barney Glaser and Anselm Strauss, sociology professors at the University of California, collaborated on a research study on dying hospital patients and published the first grounded theory study, Awareness of Dying. This study developed the constant comparative method which is the hallmark of grounded theory studies today. The findings of this study presented startling revelations about how an awareness of time and mode of death affects patient attitudes and the care delivered by health care providers. The study explored the concept of low or high social worth of the patient which impacts the delivery of care to the patient. For example, people with high education and mothers with young children were perceived as having high social worth. An older person might have low social worth, but if the patient had a pleasing personality, social worth was perceived as higher. Patients with perceived high social worth received more attentive care at end of life than those with low social worth (Nathaniel & Andrews, 2010). Based on this study, in 1967 Glaser and Strauss published
the first book on the grounded theory method, *The Discovery of Grounded Theory*, which emphasized the idea of generating new theory from data as opposed to testing existing theory. In classic grounded theory the researcher interacts with participants and strives to interpret their social world (Glaser & Strauss, 1967). Birks and Mills claim that this idea “resonated with other social scientists and grounded theory as a research design became increasingly popular” (2010, p. 2).

**Different Grounded Theory Methods**

A useful framework for understanding the development of GT methodology is Denzin and Lincoln’s (2005) identification of eight moments of qualitative research that developed at different historical points influenced by the social context of the time. Birks and Mills describe these moments as ones “that never pass, rather they continue today and shape the variety of methodological positions that researchers take in their designs” (2010, p. 6). Denzin and Lincoln (2005) describe GT methodology as developing during the second through the fifth of the eight moments of qualitative research.

Glaser and Strauss (1965, 1967; Glaser, 1978, 1992, 2002) developed the original GT method (also known as classic, traditional, systematic, and Glaserian GT) in the second moment from the end of World War II to 1970. It is known “as the golden age of rigorous qualitative analysis” (Denzin & Lincoln, 2005, p. 16; Stern 1994). Post-positivism was the dominant philosophy with researchers assuming that reality can be discovered working from the position of an objective observer. Annells (1997) describes this moment as expressed by these distinguishing factors:

- Formalization of qualitative methods
- A creative ferment
• Desire to foster rigorous inquiry of social interaction processes

• Rising power of post-positivist paradigm of inquiry

• Efforts to claim the scientific value of qualitative inquiry to become recognized and accepted by the scientific community (p. 121).

According to Denzin and Lincoln (2005) the third moment (called “blurred genres”) were the years from 1970 to about 1986 and stimulated several new issues: (1) ontological, epistemological, and methodological debates about new paradigms of inquiry that were in contrast to postpositivism; (2) questions about the researcher’s presence in the research process; and (3) challenging the rigor of GT studies (Annells, 1997; Birks & Mills, 2011). Beginning in this third moment (1970-1986) and developed strongly in the fourth moment called the “crisis of representation” (1986-1995), was a methodological split between Glaser and Strauss which changed the landscape of GT and created two different methods (Annells, 1997). Strauss and Corbin published a new book on GT in 1990 and a remodeled version of GT was born. It is known as Straussian GT (Strauss 1987; Strauss & Corbin, 1990, 1998) and is also referred to as remodeled classic GT (Boychuck-Duchscher, & Morgan, 2004; Hunter, et al., 2011; Stern, 1994).

It was also the time that Charmaz developed a new version of GT called constructivist grounded theory that was interpretative and more subjective rather than functionalist and objective (Creswell, 2013; Greckhamer & Koro-Ljungberg, 2005). Birks and Mills (2011) state that Charmaz’s work focused on the “place of the author in the text, their relationship with participants, and the importance of writing in constructing a final text that remains grounded in the data (Charmaz, 2000; 2006). In the fifth moment, post modernist thought gave rise to Clarke’s (2005) work on situational analysis (Birks & Mills, 2011; Denzin & Lincoln, 2005).
She expands GT after the “post modern turn” and according to Creswell “relies on postmodern perspectives, (i.e. the political nature of research and interpretation, reflexivity on the part of researchers, a recognition of problems of representing information, questions of legitimacy and authority, and repositioning the researcher away from the ‘all knowing analyst to the acknowledged participant’” (Clarke, 2005, pp. xxvii, xxviii found in Creswell, 2013).

**The Impact of the Methodological Split Between Glaser and Strauss**

Although the split between Glaser and Strauss caused researchers to closely examine the differences between the two GT methods and to carefully choose which method met the needs of their particular studies, it did not alter the basic critical features of GT. Both Glaser’s and Strauss’ versions of GT include: coding, the constant comparison method, questions, theoretical sampling, interviewing, developing a core category, and generating theory (Walker & Myrick, 2006). Both methods are systematic, are philosophically and theoretically situated in positivism/postpositivism, and reasonably fit the assumptions of Burrell and Morgan’s (1979) functionalist paradigm.

The key differences between the two methods center around how data analysis is conducted and the purpose of theoretical sampling. Strauss and Corbin (1990) remodeled the GT method to be more “user friendly” for novice researchers in an attempt to make the data coding process more understandable and to be able to construct grounded theories in a more consistent manner. Glaser denounced Strauss and Corbin’s approach for being more about “conceptual description than emergent theory” (1992, p. 745). Kendall (1999) claims that key to the debate is the use of axial coding in the data analysis process. Glaser in classic GT explains two types of data coding processes: substantive (open and selective) and theoretical and Strauss and Corbin in remodeled GT describe three: open, axial, and selective (Creswell, 2013; Kendall,
1999; Walker & Myrick, 2006). The first step in the data analysis process for both methods is “open coding” where the data is broken down or fractured into categories and coded. Glaser (1978) describes substantive coding (part 1 is open coding where data is broken up to be closely examined and compared for differences and similarities and part 2 is selective coding where categories are formed) as a way “to generate an emergent set of categories and their properties which fit, work, and are relevant for integrating into a theory” (p. 56). Glaser stresses that the researcher allow the codes and understandings to emerge from the data. In the second step of this process, Strauss and Corbin employ “axial coding” which puts the data back together by making connections between the categories but uses a “paradigm model” which “organizes the data with six predetermined subcategories that guide further data collection and analysis: conditions, phenomena, context, intervening conditions, actions/strategies, and consequences” (Kendall, 1999, p. 747). Glaser criticized this method as “too prescribed, too structured” (Creswell, 2013, p. 84; Stern, 1994). This process has been criticized as an over-prescribed, and complex coding scheme which forces the data into categories and relies less on allowing the data to emerge (Heath & Cowley, 2004; Hunter, et al., 2011; Stern, 1994). Robrecht (1995) claims this causes the method to be more focused on the “how to” steps than on theory development and encourages the production of poorly integrated theoretical explanations.

The last coding step for Strauss and Corbin (1990) is selective coding and for Glaser (1978, 1992) is theoretical coding. Theoretical coding integrates the data around a central theme, hypothesis, or story (Glaser, 1978). Both selective coding and theoretical coding lead the researcher to identify a core category which Kendall defines as “that category of data that accounts for most of the variation of the central phenomenon of concern and around which all the other categories are integrated” (1999, p. 747). Strauss and Corbin’s selective coding differs
from Glaser’s theoretical coding in the timing of the processes. Walker and Myrick (2006) explain that Strauss and Corbin first fracture the data in open coding, then relate and integrate the data in axial coding, and then select and integrate in selective coding. Glaser first fractures and selects in substantive coding then relates and integrates in theoretical coding. Unlike Glaser, Strauss and Corbin use a conditional/consequential matrix which is an analytic diagram of concentric circles of influence designed to show relationships among conditions, actions, and consequences. This extends the paradigm model used in axial coding (Strauss and Corbin’s second stage of coding). It is criticized as being too proscriptive which works against the goals of inductively derived theory and has great potential to force the data in preconceived ways (Fassinger, 2005; Kendall, 1999; Walker & Myrick, 2006).

Another area of strong debate regarding the two GT methods is around theoretical sampling. Theoretical sampling is defined as “the process of ongoing data collection for the purpose of generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (Glaser, 1978, p. 36). Strauss and Corbin (1998), on the other hand, believe that the purpose of theoretical sampling is to “maximize opportunities to compare events, incidents, or happenings to determine how a category varies in terms of its properties and dimensions” (1998, p. 202). Glaser believes that Strauss and Corbin seek to “verify or refute their preconceived hypotheses rather than intending to enter the field with no idea what is to be studied until it emerges” (Glaser, 1992, p. 105). In both cases, use of axial coding with the paradigm model and the stated purpose of theoretical sampling, reflect what Glaser believes to be a forcing of the data instead of allowing it to emerge and inform the researcher (Boychuck-Duchscher, & Morgan, 2004; Heath & Cowley, 2004; Hunter, et al., 2011).
Selection of a Modified Classic Grounded Theory Method for this Study

After careful analysis of these two GT methods, a modified classic GT method was selected for this study based on the original Glaser and Strauss (1967) and Glaser (1978, 1992, 2002). Compared to Straussian GT, classic GT is more focused on trusting emergence rather than forcing the data. Glaser (2001) suggested that the researcher must stay open and allow the theory to emerge from the data which requires the researcher to stay immersed in the data. “By trusting the data, engaging in further comparison, allowing one’s creativity to be engaged, and facilitating the accessing and application of tacit knowledge the real value and reward of GT is actualized” (Cutcliffe, 2004, p. 426; Altheide & Johnson, 1994; Cutcliffe, 2003). The researcher finds the Straussian method over prescriptive and complex particularly the paradigm model which when used to develop and make connections among categories can limit conceptual development and become an “end in itself” (Hunter, et al., 2011, p.10; Kendall, 1999). Melia suggests that “the procedures are getting in the way; the technical tail is beginning to wag the theoretical dog” (1996, p. 376). Axial coding is probably not needed as the theoretical coding outlined by Glaser (1978, 1992) “brings the data back together, conceptually telling the story of how the categories are related to each other” (Hunter, et al., 2011). Although this approach takes patience and a tolerance for ambiguity during the data analysis process, Glaser believes that if the researcher keeps faith in the constant comparison of data, categories will emerge and a core category will be identified (Glaser, 1978,1992; Hunter, et al., 2011).

The classic GT method was **modified** for this study in the following two ways:

**Use of research questions as opposed to “general wonderment”:**

In classic GT, Glaser (1978, 1992) declared that the GT researcher begins a study without deciding on research questions. He states:
The grounded theory researcher, whether in qualitative or quantitative data, moves into an area of interest with no problem. He (sic) moves in with the abstract wonderment of what is going on that is an issue and how it is handled (Glaser, 1992, p. 22).

According to Glaser the key issue or processes will emerge during the study. However, today’s expectations for completing a doctoral dissertation and meeting the requirements of a university institutional review board, impose “a need for the researcher to demonstrate a focused research topic” (Birks & Mill, 2011; Cutcliffe, 2004). In order to bridge the gap between Glaser’s belief that research develops from “abstract wonderment” (1992, p. 22) and the demand of current requirements for research, this study stated broad research questions which “reflected a problem-centered perspective of those experiencing or living the phenomenon to be studied” (Birks & Mills, 2011, p. 21).

**Knowledge and use of literature prior to data collection:**

Glaser (1998) believes that a literature review in the substantive area should be delayed until the grounded theory is almost complete in the final sorting of data and the writing up of the study findings. At this point the results of a literature search in the substantive area can be integrated into the new theory as more data is generated from the constant comparison method. Glaser (1992, 1998) is opposed to the literature search at the beginning of the project to avoid “forcing the data” with the researcher’s preconceptions. However, as Cutcliffe states no researcher is an “empty vessel” that approaches an area of study with an entirely a-theoretical stance” (2004, p. 424). Even Glaser and Strauss (1967) acknowledged that no researcher enters the “field as a blank slate” (found in Birks and Mills, 2011, p. 22). In the case of this study, the researcher has had a long career in aging and direct clinical and administrative practice with
caregivers and dementia patients. During a master’s program in social work, the researcher conducted literature reviews and wrote academic papers regarding dementia caregiving, in addition to completing an internship with advanced dementia patients. During the doctoral program, the researcher has gained deeper knowledge due to further literature reviews, and a directed research project for the Alzheimer’s Association of the Richmond area which evaluated the Helpline program, a resource for dementia caregivers. This bell cannot be unrung. However, three key points are relevant here: (1) although the researcher has extensive knowledge in the broad category of dementia caregiving, the specific topic of end-of-life planning for dementia caregivers is new to the researcher. The literature search revealed how limited the research is in this area. There is not a wealth of knowledge that exists. In addition, the knowledge that does exist is about cancer, HIV/AIDS and dialysis patients; (2) the result of the completed literature reviews helped with the identification of the knowledge gap that exists in this area concerning dementia caregivers and end-of-life issues; and (3) as with stating a broad research question(s), the current requirements for a doctoral dissertation require a thorough literature review.

Fassinger believes that the research “must strike a delicate balance between enough knowledge to focus the sampling and data collection effectively and yet not so much immersion in existing perspectives that the investigation becomes circumscribed by preordained constructs and limited expectations” (Fassinger, 2005, p. 158; Cutcliffe, 2000; Henwood & Pidgeon, 2003). Other than these two stated modifications, this study adhered as closely as possible to the basic critical features of the classic GT method.

**Sampling and Recruitment of Study Participants**

In the beginning stage of the study, a maximum variation technique was used to identify a demographically diverse sample in the population of interest. Maximum variation is a purposive
sampling strategy that seeks to assure that the widest range of experience is represented in the sample. Sampling variation was created by using caregiver dimensions such as: gender, age, race/ethnicity, relationship to dementia patient, duration of caregiving, patient’s current stage of dementia, current residence of dementia patient (home, assisted living, nursing home, etc.), and whether or not caregiver has completed ADs or engaged in an informal ACP process. In addition, caregivers vary in regard to being support or non-support group members.

This sampling technique also identified important common patterns that cut across these variations (Fassinger, 2005; Miles & Huberman, 1994). Patton states that “any common patterns that emerge from great variation are of particular interest and value in capturing the core experience and central, shared dimensions of a setting or phenomenon” (2002, p. 235). The common patterns across these variations included wide understanding and use of advance care planning by caregivers, understanding of life sustaining measures, on-going self education about dementia and end-of-life issues, on-going conversations in the family about patient end-of-life wishes, and seeking support throughout the dementia illness. The goal of this maximum variation technique was to seek as wide a sample of the greater Richmond area population of dementia caregivers as possible.

A key element of the maximum variation strategy is identifying and exploring divergent cases. Miles and Huberman state that this means looking for “outlier cases to see whether main patterns still hold” (1994, p. 28). Pursuing participants with “contradictory experiences helps to capture the full complexity of the data and add depth and density to the emerging theory” and increases confidence in the conclusions (Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011, p. 42). Outlier cases were sought and found for this study. Of particular interest were those caregivers who did not execute a formal ACP process and had strong feelings about not doing so.
Also included were caregivers who were not (1) end-of-life planners regarding financial or legal matters; (2) had no or few conversations with family members regarding end-of-life; and (3) were not concerned with the dying process for the dementia patient.

The maximum variation technique is particularly effective when sample size is small which in this study was 22 caregivers. This sample size was flexible (could be larger or smaller than anticipated) as explained by Padgett: “because of a fundamental concern with quality over quantity, we sample not to maximize breadth or reach, but to become saturated with information about a specific topic” (2008, p. 57). Patton believes that when selecting a small sample of wide variation, the data collection and analysis provide both “(1) high-quality descriptions of each case, which are useful for documenting uniqueness, and (2) important shared patterns that cut across cases and derive their significance from having emerged out of heterogeneity. Both are important findings in qualitative inquiry” (2002, p. 235).

Although purposive sampling was used in the early stage of the study to collect initial data from participants, *theoretical sampling* was used as the study progressed because theory development necessitates more focused information (Charmaz, 2000; Cutcliffe, 2000; Fassinger, 2005). Glaser defines theoretical sampling as “the process of ongoing data collection for the purpose of generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (1978, p. 36). Based on early and continuous data analysis, the researcher sought study participants based on what emerged in the data. For example, after approximately 10 interviews with caregivers who were support group members the question emerged: Do non-support group caregivers resemble those who are support group members regarding how they understand ACP? To answer this question, the researcher sought out caregivers who were not
attending support groups. Caregivers who had been interviewed by the researcher told their friends, neighbors, and colleagues about the study. These potential participants contacted the researcher by phone or email. The researcher passed out flyers and cards with contact information for interviewed caregivers to give others.

As categories of a theory emerged, it became critical for the researcher to seek more diversity regarding the patient’s current stage of the disease. Many of the early interviews were with caregivers whose family member was in end stage dementia or had recently died. When it became clear that essential components of the theory might include what meaning a caregiver gives to ACP, life sustaining measures, and understanding the patient’s end-of-life wishes, it was important for the researcher to seek interviews with caregivers whose family member was in the early to moderate stage of the disease to answer the question: Are concerns about honoring patient end-of-life wishes relative to just caregivers currently experiencing end of life or is this a concern for those early on in the disease process as well? Theoretically this served to provide a balanced view of how caregivers interpret their role as decision makers and how they may or may not view ACP as effective tool for shaping the dying process for the dementia patient.

Theoretical sampling continued by adding new participants to the study until data saturation occurred. Morse defines saturation as “data adequacy” and is achieved when collecting data no longer elicits new information (1995, p. 147). Morse encourages researchers to be careful and deliberate regarding saturation as “the more complete the saturation, the easier it is to develop a comprehensive theoretical model” (1995, p. 149). Creswell (2013) suggests that the GT researcher will typically conduct 20 to 30 interviews in order to reach saturation. After the completion of 22 interviews, the researcher made a reasoned judgment that saturation was reached. As a result of long and deep interviews with caregivers, the data was rich, full, and
complete. The researcher knew theoretical saturation was occurring when participants were no longer providing new information and contributions to the developing categories. This process was discussed with dissertation committee members and the peer reviewer for the study.

Recruitment of caregivers began following approval of the study by the Institutional Review Board (IRB) of Virginia Commonwealth University. Study participants were recruited through the staff and volunteer network of the Richmond chapter of the Alzheimer’s Association. The researcher had confirmed access to this network from the CEO Sherry Peterson and Program Director Mary Ann Johnson. (The researcher has worked with the staff of the Alzheimer’s Association during the last few years which included completing an evaluation of their Helpline program and transforming the program from a paper-based process into a computerized assessment and evaluation system. Findings from the study were presented to the chapter’s board of directors).

Regarding IRB regulations, for this study the chapter was not “engaged” in human subject research as stipulated in Section III, Interpretation of Engagement of Institutions in Human Subjects Research (Guidance on Engagement of Institutions in Human Subjects Research. [www.hhs.gov/ohrp/policy/engage08.html](http://www.hhs.gov/ohrp/policy/engage08.html)). In Section III, B. 4, the chapter was not “engaged” because the staff and volunteers did only the following: (a) informed prospective subjects about the availability of the research; (b) provided prospective subjects with information about the study but did not get subject’s consent; (c) provided prospective subjects with information about contacting the investigator for information and enrollment; and/or (d) sought prospective subjects’ permission for investigator to contact them or obtain permission from the subject to provide name and contact information to the investigator. The staff and volunteers of the chapter were not engaged in data collection for this study.
Recruitment resources were: (1) referrals from support group leaders and key volunteers involved in advocacy, education, and fundraising events held throughout central Virginia; (2) referrals from the chapter’s Helpline (a resource for services available to dementia caregivers); (3) word of mouth from caregivers who were participants in the study telling friends, neighbors, and colleagues about the study. A Recruitment Script for Use by Staff and Volunteers of the Alzheimer’s Association (Appendix D, Document 2), and copies of a flyer/handout (Appendix D, Document 1) with self/addressed, stamped return envelopes, were provided to staff and volunteers that described the study and requested caregiver referrals. The recruitment script welcomed caregivers to participate in the program: (1) if they were decision makers (or will be in the future) for the patient’s health, safety, legal, and financial matters; (2) whether or not they provide daily direct care for the patient; and (3) whether or not they have done end-of-life planning. After completing an interview with a caregiver, the researcher asked for referrals for other caregivers who might be interested in participating in the study and left contact cards for sharing with others.

Data Collection Strategy

As caregivers expressed interest in the study, the researcher called them to: (1) present the researcher’s credentials; (2) give a short overview of the project; (3) explain how the participant could be involved and clarify status as a primary dementia caregiver; and (4) ask a few relevant pre-interview questions (See Appendix D, Recruitment Document 4, for the Recruitment Script for Initial Telephone Contact). During the initial phone call, informed consent was explained along with all the safeguards for participation. After receiving caregiver oral consent to participate in the study, an interview was scheduled. Interviews were completed for 22 caregivers, one caregiver declined to participate, and four caregivers contacted the
researcher after the interviewing phase of the study was concluded. During the phone call the researcher told the participant that a Research Subject Information and Consent Form (Appendix E) would be sent prior to the interview for review. The caregiver was asked to read the consent form carefully and the researcher would answer any questions/concerns prior to the beginning of the interview. After the phone call the researcher sent the consent form via mail or email per the caregiver’s preference.

At the beginning of the interview the researcher reviewed the informed consent protections orally with the participant and reaffirmed that the participant was willing to engage in the study. After answering any participant questions, the researcher then asked the participant to sign the consent form. After the interview the researcher sent a signed copy of the consent form to the participant for their records.

Face-to-face, semi-structured interviews were conducted with all participants. The interviews varied from 90 minutes to 3 hours in duration. Given the researcher’s experience working with dementia caregivers and personal experience with family caregiving, connection with the participants was established quickly. Participants were eager to tell their stories about the current status of the dementia patient and the challenges and complications of caregiving. The participants held up very well during the interviews despite their obvious fatigue and the potential for the subject matter of the interview to be difficult terrain. The researcher continuously monitored the caregiver’s demeanor and body language to assure capacity to continue the interview. The researcher was sensitive to the fact that the caregiver was being interviewed about planning for the patient. While describing how difficult caregiving was for them personally, caregivers mostly kept the focus on the dementia patient during the discussion. The caregiver was asked how the patient has been (or continues to be) involved in discussions
about choices for end of life care. This honors the value of *personal autonomy* and extends it to *shared autonomy* as appropriate.

The interviews were relaxed and conversational in tone and the guiding questions asked in a value-neutral manner (Rodwell, 1998). The researcher asked open-ended guiding questions accompanied by prompts (Interview Guide, Appendix F). As the interviews and data analysis proceeded, the interview guide was modified to follow up on any theoretical issues emerging from the data (Lambert, et al., 2005; Lawrence, et al., 2011; Singer, et al., 1998). For example, after preliminary analysis of data from the first several interviews, it became clear that the researcher needed to pursue the following ideas in more depth: (1) what meaning the caregiver gives to ACP; (2) how they understand life sustaining measures; (3) how they understand the patient’s final wishes; and (4) how they interpret their role as decision maker. To accomplish this, the researcher spent more time with caregivers on questions 1-4 and question 6 of the interview guide and probed more deeply. The researcher asked permission to call the caregiver again to ask additional questions or to check information that had emerged from other interviews.

The interviews were long and deeply personal. Some caregivers expressed that they had never talked to anyone outside the family about these issues before. Several expressed that few had asked them how they were feeling about the challenges of caregiving. The researcher was aware that these interviews were an intervention for the caregivers. After the interview questions were completed many asked questions about planning for end of life, the trajectory of end stage dementia, and assessing quality of life for the patient. The researcher answered the questions and provided a Resource List for Dementia Caregivers (Appendix G) which includes online resources for caregiving issues and local greater Richmond area resources for in person and/or
telephone contact. Also the caregiver was offered a choice of thank you gifts: (1) an Alzheimer’s Association caregiver notebook that is designed as a reference tool to help caregivers navigate the different stages of the disease, to handle many common situations that arise, and to provide ways to find more in depth information and help when needed; or (2) if the caregiver expressed interest in pursuing ACP, this highly readable, consumer friendly book is helpful: *Planning for Uncertainty: Living Wills and Other Advance Directives for You and Your Family* by David Doukas and William Reichel, 2007, Johns Hopkins University Press.

The caregiver was interviewed at a time and place of their choosing (home, hotel conference room, coffee shop, restaurant, office, assisted living/nursing home facility). Flexibility on place of interview was necessary due to the demands on intensive caregiving that often inhibit the caregiver’s ability to relax or concentrate at home. In keeping with the classic GT method, the interviews were not audio taped, but rather the researcher took interview notes which focused on recording themes, key concepts, and direct quotations. Directly after each interview, the researcher wrote extended field notes to capture any ideas and thoughts about the emergence of concept categories, any relationships between categories, and/or patterns (Glaser, 1978, 1992). The researcher recorded any observations, such as the caregiver’s demeanor when talking about end-of-life issues and how they have or have not planned for the death of the dementia patient. In addition the field notes included anything that might help generate concepts for the emerging theory. Glaser’s (2001) statement that “all is data” is fundamental to this GT process.

**Ethical Considerations**

The long duration of dementia and the demands for increasing levels of care causes enormous physical, emotional, and financial stress for caregivers. Dementia caregivers have
high emotional stress, role strain, depression, and a strong sense of burden compared to other caregivers (Alzheimer’s Association, 2011). Given this, the researcher was mindful to move forward with great care and compassion in the initial contact phone call and the interview process. Another important consideration was that discussion regarding end-of-life issues may cause some caregivers discomfort. Research on well older adults reveals that many are often eager and willing to talk about planning for death (Brown, 2003; Center for Gerontology and Health Care Research, 2008; Fagerlin, et al., 2001; Hawkins, et al., 2005). The same holds true for HIV/AIDS, advanced cancer, and dialysis patients (Martin, et al., 1999; Prendergast, 2001; U.S. Department of Health and Human Services, 2008; Virmani, et al., 1994). However, this is not generalizable to all individuals and the researcher did not assume this is true of dementia caregivers. The researcher proceeded carefully and thoughtfully during the interviews with a keen awareness that this may be difficult for some. Throughout the study process the researcher abided by the ethical standards of the university and the core values and ethics of the social work profession.

Data Analysis Process

The data analysis process was based on the procedures and techniques outlined by Glaser (1978, 1992) and Glaser and Strauss (1967). As the data collection began so did the data analysis. Creswell describes it as a “zigzag” process of the researcher out to the field to gather information, back to the office to analyze the data, and back out to the field to get more information (2013, p. 86). Several of the interviews needed to be scheduled close together to take advantage of caregivers who were willing to be interviewed. As a result only preliminary analysis was done after some interviews. Formal analysis and line-by-line coding began after many of the interviews were completed. Understanding that this is not optimal, the researcher
was careful to make thorough field notes and memos to capture all data from each interview. The researcher was able to write extended field notes after each interview and before the next one occurred.

The first step was to transcribe all the notes regarding each caregiver, including prescreening phone interview, answers to interview questions, and extended field notes. All notes were entered into the computer as Microsoft Word documents and hard copies were printed for coding. To begin data analysis, the researcher read each set of interview notes one or more times to develop a sense of the overall context of the data. Printed copies of the notes were hand coded. Through the process of open coding, (part 1 of substantive coding) data was sorted and broken down into units of meaning (or concepts), labeled, and interrogated for alternative meanings. For Glaser open coding is a line by line analysis, coding the data in as many ways as possible, writing memos about the conceptual and theoretical ideas that emerge in the course of analysis” (Walker & Myrick, 2006).

As the open coding proceeded, the researcher captured ideas that occurred during this process by writing memos. The memos were designed to capture ideas quickly before losing them without disrupting the coding process. This memoing process occurred throughout the analysis. Glaser explains that “memos are the theorizing write-up of ideas as they emerge, while coding for categories, their properties, and their theoretical codes. They are written up as they strike the analyst when constantly comparing, coding, and analyzing” (1992, p. 108). Birks and Mills (2011) claim that memos in grounded theory research are the “cornerstone of quality” and are the “records of thoughts, feelings, insights, and ideas” regarding the emerging concepts and theory (2011, p. 40). Memoing is essential as it is fundamental to the development of grounded theory (Birks & Mills, 2011; Lempert, 2007). Stern (2007) believes that memos are the mortar
that holds the data together as the building blocks of a grounded theory. The key functions of memoing are: (1) mapping research activities which supports an audit trail; (2) extracting meaning from the data which increases theoretical sensitivity and better equips the researcher to answer Glaser’s question – ‘what is actually happening in the data’ (1978, p. 57); and (3) maintaining momentum by allowing the researcher to record and revisit earlier thinking and reorient to the research when the analytical process become complex. (Birks, Chapman, & Francis, 2008). Pre-screening phone interview notes, interview notes, field notes, and memos are all sources of data that were analyzed to generate concepts and theory for this study.

In selective coding (part 2 of substantive coding) these coded units of meaning were compared to other coded units of meaning and the concepts gradually grouped or lumped together into categories (Glaser & Strauss, 1967; Lincoln & Guba, 1985; Rodwell, 1998). Selective coding “simply marks the transformation from ‘running the data’ open to delimiting the coding process around a core category” (Walker & Myrick, 2006, p. 553). As more data was collected, coded concepts continued to be compared to existing data and were re-categorized. Fassinger states “the categories constantly undergo modification to incorporate new information and are continually interrogated for coherence and explanatory capacity” (2005, p. 160). This process is central to classic GT data analysis and is called constant comparison. Glaser believes that the constant comparison process involves two analytic procedures: (1) the researcher makes comparisons of incident to incident to generate categories and then compares new incidents to these categories; and (2) the researcher examines the data by asking neutral questions such as “what category does this incident indicate? (Glaser, 1978, p. 57; Walker & Myrick, 2006, p. 551). Birks and Mills describe it as the analysis of “incident to incident, incident to codes, codes
to codes, codes to categories, and categories to categories” which continues throughout the study until a grounded theory is fully integrated (2011, p. 11).

In the last phase, theoretical coding, the researcher integrated the data around a central theme, hypothesis, or story to generate a theory. Glaser states that “theoretical codes emerge from the cues in the data, are integrative at the conceptual level, and work to weave the fractured story back together again” (1978, p. 72). Glaser’s coding scheme could be succinctly described as “a method to fracture and select in substantive coding, then relate and integrate in theoretical coding” (Walker & Myrick, 2006, p. 556).

In the classic GT method, staying close to the data is paramount. There is controversy about the use of computers which centers around the fact that “fragmentation of the data are meant to be interpreted holistically” and the researcher is not to create too much distance from the “nuanced interpretive process” (Fassinger, 2005, p. 165). Creswell believes that for some a computer program “puts a machine between the researcher and the actual data and this can cause an uncomfortable distance between the researcher and his or her information” (2013, p. 202). Charmaz points out that there is a danger that computer programs “may unintentionally foster an illusion the interpretative work can be reduced to a set of procedures” (2000, p. 520). Fassinger says that this “dismisses deep reflection that constitutes theoretical sensitivity at its best” (2005, p. 165). Patton states that the use of a computer software program is a personal decision based on “individual style, comfort with computers, amount of data to be analyzed, and personal preference” (2002, p. 446). After careful reflection, the researcher used a low tech method for data management and analysis. This decision was based on several factors: (1) only one group was interviewed for this study so the volume of data was less than in a multi-group design; (2) this researcher is concrete and wanted to have what Patton describes as a “physical feel for the
data that isn’t possible with a computer” (2002, p. 446); (3) a belief that the more the researcher interacts with the data the more categories and patterns will appear; and (4) hand-coding appeals to this researcher, including making multiple copies of data and cutting it into individual chunks, and physically manipulating the data by grouping chunks. This process facilitated both recognizing emerging themes and a core category. For this researcher this method was “hands-on” and supported the effort to stay as close to the classic GT method as possible.

In addition to coding by hand and keeping very detailed code and memo books, the researcher used a design wall to keep the whole study in mind while in the process of data analysis. Such a design wall is often used by a variety of artists who work on complex designs, particularly quilters. For this study, a clean white wall was outlined in blue painters’ tape. As codes emerged they were noted on post-it notes and attached to the design wall. As the analysis continued, categories for the codes were added and then diagrams of the emerging theory were added. Throughout the data analysis, the researcher spent time studying the wall and reflecting on how the story of ACP was unfolding. It provided a visual picture of the patterns emerging and allowed for connections to be made between codes and developing categories. For example, while scrutinizing the wall, it occurred to the researcher that the “role of decision maker” was not just one of four factors driving how caregivers use ACP as an effective tool to shape the dying process for the dementia patient, but it was the key concept that is defined by the remaining three important factors (i.e., meaning of ACP, meaning of life sustaining measures, and knowledge of patient end-of-life wishes). Reflecting on the design wall also allowed the researcher to discover that: (1) the process of ACP occurs along a timeline for this sample (years before dementia, at dementia diagnosis, and moving into end stage toward death); (2) there exists substantial differences between support group members and non-support group members regarding the use
of ACP; and (3) it was essential to compare the caregivers whose family members were in early/moderate stage of dementia to those whose family members were in end stage or had died. This was necessary to assess whether these two caregiver groups held similar views of the use of ACP for decision making. The design wall allowed for a large visual picture of the whole study and kept it in full view which was of great assistance to the researcher. It was a constant reminder the data was telling a story about ACP and it was the job of the researcher to stitch the story together and assure that it fit and truly reflected the caregivers’ words.

**Data Management Procedures**

Data collected for the study was managed as follows. Contact forms with caregiver’s personal information were stored in a locked file cabinet and not entered into the researcher’s computer files. Each caregiver was assigned a random case number to protect confidentially and privacy of their personal information and for the purpose of keeping documents and notes organized properly. Pre-screening notes, interview notes, field notes, and memos were entered into password protected Microsoft Word documents. These documents were stored in individual de-identified case files. All printed documents, original or copies of field notes, interview notes or memos were kept locked in a file cabinet in the researcher’s home office. Other than the researcher and the principal investigator, no one else had access to the computer, the data stored on the computer, or hard copies of documents in the files. Data from the project has been stored in a locked file cabinet during the study and will continue to be upon completion of the research project.

**Assessing the Quality of the Study**

Glaser and Strauss (1967) discuss evaluation of the quality of a study in the context of credibility which emphasizes rigor in the methods, strategies and techniques that are used to
discover a new theory grounded in the data. Birks and Mills state that “presentation of a clear, integrated theory that draws the reader in and provides evidence of logical conclusions and their relationship to the data is seen by the authors as the key element of a credible grounded theory” (2011, p. 149). In addition, Creswell (2013) provides overall criteria for evaluating any grounded theory regardless of the specific method used. Thus, the credibility of a grounded theory is about assessing both the quality of the product and the quality of the research process itself. While a variety of evaluation approaches exist, this study is evaluated by three sets of criteria:

- Evaluating the research process: Birks and Mills (2011)
- Overall evaluation of any grounded theory study regardless of specific method employed (Creswell, 2013)

These criteria for assessing quality of this study are delineated in the tables below. Statements made regarding each criterion are supported by study data in the various chapters indicated. They are explained here to provide a framework for assessing the credibility of the study findings and the fit of the methodology used.


Glaser (1978, 1992) defined rigor in the classic GT method in six domains: fit, work, relevance, modifiability, parsimony, and scope. They are described in the table below.

Statements made here are supported by data presented in chapter four.
**Domain 1: Fit**

The theory fits the data and fits within the field of its intended use. The theory should be understandable by those who work in the area, be general enough to be flexible in application, while allowing user control over its use.

The theory created by this study is a good fit with the data. The findings do make sense. The audit trail establishes that the findings can be directly linked to the experiences of the caregivers who took part in the study. Because the researcher captured both the process of how caregivers accomplish ACP and how they use ACP to shape the dying process for the dementia patient, the theory is well integrated and the categories fit into a whole story about how caregivers understand the ACP process. The theory is understandable as it is pragmatic and flexible, and in its current form could be used well by practitioners to modify existing ACP interventions that would help dementia families prepare for end stage.

**Domain 2: Work**

The theory has explanatory and predictive power and must be readily be understandable by those concerned with the area of study.

This study has explanatory power for an understudied population, dementia caregivers, in regard to understanding and using ACP to shape the dying process of a family member. Findings in chapter four contain rich, thick descriptions of the process and the theory of ACP for this sample. The findings are well developed and easily understood by others. They demonstrate the connections between the categories and sub-categories and most importantly, how these fit together as a whole and tell the story of ACP for these caregivers. The theory’s predictive power is the new knowledge gained about how caregivers understand their role as decision makers. How caregivers understand this role directly affects how they use ACP and is defined by: (1) how they understand the meaning of ACP; (2) how they understand life sustaining measures; and (3) their knowledge of the patient’s wishes for end-of-life care.

**Domain 3: Relevance**

Because the theory has fit and has explanatory and predictive power, the theory has relevance; the core category works in the view of researchers, participants and practitioners.

The core category for this study works as it contains the theory of not only how caregivers implement the process of doing ACP, but also how they use ACP in end stage dementia. This works for researchers as it illuminates a path to further studies particularly around the role of decision maker, including the quality and quantity of conversations with the patient and family member about end-of-life issues; the influence of outside support, such as support groups; the nature of “doing battle” with health care professionals regarding withholding/withdrawing treatment; and assessing quality of life for the patient.

It works for practitioners and caregivers as it highlights points of possible intervention during the long disease process, such as at dementia diagnosis (helping caregivers evaluate personal
values to implement ACP) and at end stage moving toward death (helping caregivers understand the trajectory of dementia, understanding the impact of life-sustaining measures, and assessing patient quality of life to make treatment decisions).

<table>
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<th>Domain 4: Modifiability</th>
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<tr>
<td><strong>The theory is readily changeable when new data are discovered.</strong></td>
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<tr>
<td>Because this theory is pragmatic and flexible, it is readily changeable as new data is discovered. For example, in future studies about the quality of family end-of-life conversations new knowledge could be incorporated easily into this theory to further explicate the caregiver role as decision maker. In addition, findings from studies regarding caregivers’ understanding of life sustaining measures for advanced dementia patients and the impact of seeking outside resources on decision making would expand this study’s theory and enhance its usefulness to both practitioners and caregivers.</td>
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<th>Domain 5: Parsimony and Scope</th>
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<tr>
<td><strong>The concepts are simple and explain the whole of the variation in a minimum of ways, i.e. all the data should relate to the core category and applying the core category should account for all the data (Birks &amp; Mills, 2011; Cutcliffe, 2004; Glaser, 1978, 1992; Hunter, et al., 2011).</strong></td>
</tr>
<tr>
<td>The concepts in this study are simple, straight forward, and easily understood. As described specifically in the findings in chapter four the core category accounts for all the data. This is demonstrated by how the concepts are well integrated into the core category, like pieces of a complex puzzle. Once the pieces were put in place, the theory emerged which tells whole story of how caregivers understand the ACP process.</td>
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**Evaluating the research process (Birks & Mills, 2011)**

Birks and Mills (2011) establish criteria for assessing the research process in grounded theory studies which includes the following domains: (1) researcher expertise; (2) methodological congruence, and (3) procedural precision. These criteria are described in Figure 3 below.
Figure 3: Evaluating the Research Process (Birks and Mills, 2011)

<table>
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<tr>
<th>Domain: Researcher’s Expertise</th>
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<tr>
<td><strong>Criterion 1:</strong> Does the researcher demonstrate skills in scholarly writing?</td>
<td>Yes.</td>
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<td>Researcher writes clearly and uses the research literature well to support statements made. The flow of the writing demonstrates how the sub-categories fit in the categories, how the categories fit in the theory, and how the theory fits as a whole. Also, the researcher’s writing reveals understanding of this caregiving population due to her direct practice experience and her academic work in research and writing. (See chapters two, three and four).</td>
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| **Criterion 2:** Is there evidence that the researcher is familiar with grounded theory methods? | Yes. |
| Researcher provided a definition and history of grounded theory and described different grounded theory methods in a useful framework which identified the eight moments of qualitative research (Denzin & Lincoln, 2005). In addition, the researcher explained the impact of the methodological split between Glaser and Strauss including how these methods are the same and how they vary. (See chapter three). |

| **Criterion 3:** Has the researcher accessed and presented citations of relevant methodological resources? | Yes. |
| Researcher cited 69 scholarly publications in the description of the methodology for this study. The citations supported statements made regarding the historical and theoretical base for grounded theory methodology, the difference among grounded theory methods, the rationale for the selection of a specific grounded theory method for this study, and the implementation of the method chosen. (See chapter three). |

| **Criterion 4:** Are limitations in the study design and research process acknowledged and addressed where possible? | Yes. |
| The researcher addresses the limitations of the study in chapter three. |

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<th>Domain: Methodological Congruence</th>
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<td><strong>Criterion 1:</strong> Has the researcher articulated their philosophical position?</td>
<td>Yes.</td>
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<tr>
<td>See chapter three: “Research Paradigm and Theoretical Framework”</td>
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| **Criterion 2:** Is grounded theory an appropriate research strategy for the stated research questions? | Yes. |
| Grounded theory is appropriate based on the following: (1) this is understudied population and end-of-life for dementia patients is an under-researched area; (2) grounded theory is especially appropriate for health care research; (3) and it is a well-tested method for beginning to understand a process such as ACP. See chapter one: “Rationale for Using a
Grounded Theory Method.

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<th>Criterion 3: Do the outcomes of the study answer the stated questions?</th>
<th>Yes. (See chapter four).</th>
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<tr>
<td>Criterion 4: Is a grounded theory presented as the end product of the research?</td>
<td>Yes. (See chapter four).</td>
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<tr>
<td>Domain: Procedural Precision</td>
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<td>Criterion 1: Is there evidence that the researcher has employed memoing in support of the study?</td>
<td>Yes.</td>
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<td>The researcher used note cards to record all thoughts regarding comparisons of codes, categories, and ideas about emerging theory. In addition, as the codes were examined and integrated into categories, a memo was written for each category and complied in a memo book. These memos guided the development of the preliminary diagrams of a potential theory and helped the researcher develop a visual picture of the emerging theory by arrangement of codes and categories on a large design wall. (See chapter three: Data Analysis Process).</td>
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<td>Criterion 2: Has the researcher indicated the mechanisms by which an audit trail was maintained?</td>
<td>Yes. (See chapter three: Assessing Quality of the Study).</td>
</tr>
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<td>Criterion 3: Are procedures described for the management of data?</td>
<td>Yes. (See chapter three: Data Management Procedures).</td>
</tr>
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<td>Criterion 4: Is there evidence that the research has applied the essential grounded theory methods appropriately in the context of the study described?</td>
<td>Yes.</td>
</tr>
<tr>
<td>The essential elements of grounded theory are described in the study: coding, the constant comparison method, questions, theoretical sampling, interviewing, developing a core category, and generating theory. (See chapter three).</td>
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<tr>
<td>Criterion 5: Does the researcher make logical connections between the data and the abstractions?</td>
<td>Yes.</td>
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<td>This is evident in the clear connections made between the categories and sub-categories. For example, regarding the “role of decision maker” the researcher defines the sub-categories (the meaning of ACP, understanding life sustaining measures, and knowledge of patient end-of-life wishes) that defines this role and explains how caregivers use ACP as an effective tool. (See chapter four).</td>
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<tr>
<td>Criterion 6: Is there evidence that the theory is grounded in the data?</td>
<td>Yes.</td>
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<td>The researcher includes a large amount of descriptive details in the thick, rich description of</td>
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the sub-categories, categories, and the emergent theory. Quotations from caregivers are provided when appropriate to illustrate statements made. In appropriate places the researcher captured the specific language used by the caregivers, for example, caregivers describe “doing battle” with health care professionals, comments made by the patient regarding end-of-life issues, and the conflict in the family around shared decision making. (See chapter four).

The researcher chose a data analysis process of hand coding and compiled a detailed, thorough code book. The constant comparative process was demonstrated by a detailed memo book which delineates the comparisons of categories to categories. The design wall was effective in allowing for a visual comparison of categories and sub-categories and helped to integrate these categories into a theory. All these procedures allowed the researcher to stay very close to the data and caused close scrutiny by forcing the question: “Is this the idea of the researcher or is the data saying this?” (See chapter three: Methodology).

**Criterion 7: Is the final theory credible?** Yes.

The final theory is credible because it has fit, it works, has relevance, can be modified, and has parsimony and scope as per Glaser’s (1978, 1992) defined rigor for classical grounded theory. (See chapter three: Methodology and chapter four).

**Criterion 8: Are potential applications examined and explored?** Yes.

The implications of findings are delineated in chapter five and includes research, practice, social justice, policy, and social work implications. Included in the practice implications is a discussion of how findings of this study inform current successful ACP interventions for dementia caregivers. (See chapter two: Successful Interventions that Promote ACP).
Figure 4: Overall Evaluation of Any Grounded Theory Study (Creswell, 2013)

<table>
<thead>
<tr>
<th>Criterion 1: Is this a study of a process, an action, or an interaction as the key element in the theory? Yes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>This study describes in great detail the process of ACP along a timeline. In addition it describes how caregivers use ACP as the patient moves from end stage to death. (See chapter four).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Criterion 2: Does this study demonstrate a coding process that works from the data to a larger theoretical model? Yes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>The data analysis process explains the coding process that leads from initial codes to formation of categories, to integration of categories into the core category. This process was accomplished by hand with the researcher staying close to data and use of a design wall to help with integration of codes into categories into theory. (See chapter three: Data Analysis).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Criterion 3: Is the theoretical model presented in a figure or a diagram? Yes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>The theoretical model is presented in two diagrams and a visual display of the entire theory. (See chapter four).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Criterion 4: Is there a story line or proposition that connects categories in the theoretical model and that presents further questions to be answered? Yes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a story line presented that explains how caregivers do ACP and how they use ACP as an effective tool. (See chapter four). Future questions suggested by this story are presented. (See chapter five).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Criterion 5: Does the study demonstrate the use of memoing throughout the process of research? Yes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memoing was done throughout the research process. Memos were written prior to interviews, after the interviews, during the substantive coding (includes both open and selective coding) and in theoretical coding, and as a result of reflecting on the visual display of the category connections revealed on the design wall. (See chapter three: Data Analysis).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Criterion 6: Was there reflexivity or self-disclosure by the researcher about his or her stance in the study? Yes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>The reflexivity and self-disclosure by the researcher was revealed in three different ways: (1) in the personal narrative in chapter one of the study; (2) in describing the researcher’s philosophical stance regarding research in chapter three; and (3) in the memos written throughout the research process regarding the content and context of interviews.</td>
</tr>
</tbody>
</table>
The quality of this grounded theory was assessed by the researcher and a peer reviewer, Jenny Shadik, who is the researcher’s colleague and fellow grounded theory researcher. To enhance rigor an audit trail was established by the use of field notes, interview notes, and memos which indicated the decisions made regarding data collection, coding, and analysis (Lincoln & Guba, 1985; Padgett, 2008). In addition, the researcher demonstrated an audit trail from initial code to sub-category to category to inclusion of the category in the emergent theory. Those relevant codes chosen during the selective coding process and then integrated around the core category during theoretical coding can be traced from the initial transcript through the process to the theory.

Peer review of the coding strategy and data analysis process was conducted (Brudenell, 1996; Padgett, 1998, 2008). The peer reviewer examined the code book, the memo book, and process of memoing. The development of concepts and the diagrams of both the process of how caregivers do ACP and how caregivers use ACP were reviewed. The theoretical model outlined on the design wall was reviewed and the theory development process was found to be thorough, logical, and consistent. No gaps were identified in the theory.

**Product of the Study**

The product of this study is a full description of the key concepts that explain a basic social process of ACP among dementia caregivers demonstrated by specific examples in the data. Equally important is the identification of the key factors (demographic, psychosocial, and situational) that influence a caregiver’s decision to implement an ACP process. To fulfill the promise of a true grounded theory study, the researcher conducted further analysis to demonstrate how the categories relate to each other and made the selection of a core category that fits all the data (Annells, 1997; Heath & Cowley, 2004; O’Connor, Netting, & Thomas,
2008). From this the findings tell the story about the process. Birks and Mills state that “the final product of a grounded theory study is an integrated and comprehensive grounded theory that explains a process or scheme associated with a phenomenon” (2011, p. 12). A conceptual model that depicts a basic social process and the key factors that influence that process was developed. A basic social process focuses only on those concepts that are related to the core category and those which are necessary in “relation to resolving the problematic nature of the pattern of behavior to be accounted for” (Glaser, 1978, p. 93). It is through the articulation and explanation of this basic social process that an explanatory theory emerged (Jones & Alony, 2011).

Limitations of the Study

Although the researcher employed a maximum variation technique to recruit as broad a sample as possible, this study is limited by a lack of racial/ethnic diversity. Of the 22 caregivers interviewed, 20 were Caucasian and 2 were African American. In addition, this sample overall has a high level of education with a majority having a college bachelor’s degree or higher. Although this sample reflects the population that contacts the Alzheimer’s Association for support (whether calling Helpline or attending support groups), it does not reflect the overall population of the greater Richmond community.

Regarding gender, the sample is overwhelmingly female (17 caregivers) and males (5 caregivers). The researcher had hoped to recruit more males, but as reflected in the research, caregiving is largely a female responsibility in families.

Although the sample shows little diversity regarding race/ethnicity, educational level, and gender, it does reflect diversity along other dimensions: age, religious preference, level of income, relationship to patient, time providing caregiving, current stage of patient dementia, and whether the caregiver is a support group member or not.
Another limitation of the study is that the sample is skewed to those caregivers who have completed an ACP process. Twenty of the twenty-two caregivers in this study have done so. This is an unexpected finding as previous research would indicate the reverse would be true due to the reported prevalence rates of ACP completion among adults in the community. This limitation is the direct result of the recruitment process which was conducted among the network of staff and volunteers of the Greater Richmond Chapter of the Alzheimer’s Association. The Alzheimer’s Association advises all families to complete an ACP process as soon after dementia diagnosis as possible in order for patients to be included in the decision making. This advice is given to all families who contact the chapter either through the Helpline, educational workshops, support groups, or via their website.
Chapter 4: Findings

The purpose of this study was to explore what knowledge dementia caregivers have about ACP, how they learn to execute formal ADs or have engaged in an informal ACP process, and how they understand their role as decision makers for the patients. Also of interest were specific factors that influence behavior regarding ACP which might include demographic, psychosocial, and situational factors. Upon completion of the analysis, a theory emerged from the data that provides new insight and knowledge regarding the study’s research questions:

1. How do dementia caregivers understand the process of ACP?
2. What factors influence caregivers’ decision-making process regarding ACP?

This chapter offers a detailed description of the sample demographics to set the “caregiver context” which provides insight regarding the challenging circumstances under which the process and use of ACP are accomplished. The grounded theory which emerged in this study is presented and the factors that influence this process are identified and explained. In addition, unanticipated findings are reported regarding caregivers’ understanding and use of ACP in comparisons of: (1) support group and non-support group members and (2) caregivers of early/moderate stage patients and caregivers of end stage/death stage patients. Also included is a brief note regarding how caregivers understand and differentiate between the terms “end-of-life planning” and “advance care planning.”

Description of the Sample

Twenty-two caregivers of dementia patients were interviewed for this study. The caregivers reside in the greater Richmond area. Table 1 provides a list of sample demographics of personal caregiver characteristics. There are 17 females and 5 males in this sample. The range
of age of the caregiver is broad with the youngest 38 years of age and the oldest 88 years of age. The average age is 64.7 years (SD 10.9). Regarding educational level achieved, the majority of the sample (15) hold bachelor’s degrees with seven having graduate degrees at the master’s or Ph.D. level. Some attended college for a year or more (6) and one caregiver attended high school only. The majority of the sample (18) expressed a specific religious affiliation and four expressed no preference. Of those who identified a religious affiliation they are: Protestant (12), Catholic (4), Jewish (1), and Mormon (1). Regarding income level, the majority of the sample describe their financial situation as “money is not a problem” (9) or “have enough money with a little extra” (5). The remaining caregivers state they are “just managing to get by” (4), “having trouble making ends meet” (3), and “can’t make ends meet” (1). The sample’s ethnicity is non-Hispanic. Twenty are Caucasian and two are African American. The majority of caregivers describe their personal overall health as “excellent” (9) or “good” (9) and four describe their health as “fair.”

Table 2, Sample Demographics of Personal Caregiver Characteristics, includes caregivers’ responses to questions regarding the dementia patient. Caregivers indicate their relationship to the patient as: spouse (11), adult child (9), daughter-in-law (1), and granddaughter (1). The time the caregiver has provided care to the dementia patient ranges from one year to 12 years, with the average 5 years (SD 2.6). Primarily dementia patients in this sample are diagnosed with Alzheimer’s disease (12), but others have different types: frontotemporal dementia (3); normal pressure hydrocephalus (1); alcohol-induced dementia (2); Dementia with Lewy Bodies (DLB) (2); and vascular dementia (2). Currently the dementia patient lives at home with the caregiver (7), in assisted living (5), or in nursing homes (3). Seven of the dementia patients are deceased. In terms of the current stage of the patient’s dementia, over half
are in late stage (1), end stage (4), or have died (7). One patient is in early stage and nine are in moderate stage.

When asked about ACP, the caregivers responded overwhelmingly that they have formal written documents. Twenty of 22 caregivers in the sample have executed an ACP process and only two have not. The majority (16) of those with written documents accomplished this years before the dementia diagnosis with four executing ACP shortly after the patient received a diagnosis of dementia. In addition to the formal ACP process, the majority of caregivers (17) describe having informal conversations with the patients and with family members about the patients’ end-of-life wishes. Five caregivers state not having informal conversations in the family.

As a result of the data analysis, the following two sample characteristics were discovered: the sample divided into two sets of groups: support group members (11) and non-support group members (11); and into early/moderate stage of patient dementia (10) and end stage/death stage of patient dementia (12).
<table>
<thead>
<tr>
<th>Case Number</th>
<th>Age</th>
<th>Gender</th>
<th>Race</th>
<th>Education</th>
<th>Religious Affiliation</th>
<th>Income*</th>
<th>Health Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1050</td>
<td>78</td>
<td>M</td>
<td>Caucasian</td>
<td>2 yrs college</td>
<td>Lutheran</td>
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<td>Excellent</td>
</tr>
<tr>
<td>1051</td>
<td>60</td>
<td>F</td>
<td>Caucasian</td>
<td>1.5 yrs college</td>
<td>Catholic</td>
<td>1</td>
<td>Excellent</td>
</tr>
<tr>
<td>1052</td>
<td>74</td>
<td>F</td>
<td>African American</td>
<td>Bachelors</td>
<td>Catholic</td>
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<td>Excellent</td>
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<tr>
<td>1053</td>
<td>65</td>
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<td>Baptist</td>
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<td>Fair</td>
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<td>Excellent</td>
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<td>Methodist</td>
<td>1</td>
<td>Fair</td>
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<td>Caucasian</td>
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<td>Catholic</td>
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<td>Fair</td>
</tr>
<tr>
<td>1058</td>
<td>79</td>
<td>M</td>
<td>African American</td>
<td>Masters</td>
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<td>Excellent</td>
</tr>
<tr>
<td>1059</td>
<td>61</td>
<td>F</td>
<td>Caucasian</td>
<td>Bachelors</td>
<td>Methodist</td>
<td>1</td>
<td>Good</td>
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<tr>
<td>1060</td>
<td>67</td>
<td>F</td>
<td>Caucasian</td>
<td>Bachelors</td>
<td>Methodist</td>
<td>3</td>
<td>Good</td>
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<td>F</td>
<td>Caucasian</td>
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<td>Methodist</td>
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<td>Excellent</td>
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<td>88</td>
<td>M</td>
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<td>Catholic</td>
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<td>63</td>
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<td>Bachelors</td>
<td>Episcopalian</td>
<td>4</td>
<td>Good</td>
</tr>
<tr>
<td>1064</td>
<td>56</td>
<td>F</td>
<td>Caucasian</td>
<td>Bachelors</td>
<td>None</td>
<td>3</td>
<td>Excellent</td>
</tr>
<tr>
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<td>49</td>
<td>F</td>
<td>Caucasian</td>
<td>1 yr. college</td>
<td>None</td>
<td>3</td>
<td>Good</td>
</tr>
<tr>
<td>1066</td>
<td>65</td>
<td>F</td>
<td>Caucasian</td>
<td>Masters</td>
<td>Episcopalian</td>
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<td>Excellent</td>
</tr>
<tr>
<td>1067</td>
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<td>F</td>
<td>Caucasian</td>
<td>Masters</td>
<td>Protestant</td>
<td>1</td>
<td>Good</td>
</tr>
<tr>
<td>1068</td>
<td>55</td>
<td>F</td>
<td>Caucasian</td>
<td>Masters</td>
<td>Mormon</td>
<td>2</td>
<td>Good</td>
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<tr>
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<td>79</td>
<td>M</td>
<td>Caucasian</td>
<td>Bachelors</td>
<td>Protestant</td>
<td>4</td>
<td>Fair</td>
</tr>
<tr>
<td>1070</td>
<td>65</td>
<td>F</td>
<td>Caucasian</td>
<td>9th Grade</td>
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<tr>
<td>1071</td>
<td>38</td>
<td>F</td>
<td>Caucasian</td>
<td>2 yrs. college</td>
<td>Christian</td>
<td>2</td>
<td>Good</td>
</tr>
</tbody>
</table>

Mean: 64.7 years  
SD 10.9

*1 = Money not a problem  
2 = Enough money with a little extra  
3 = Just manage to get by  
4 = Having trouble making ends meet  
5 = Can’t make ends meet
### Table 2  
Sample Demographics

<table>
<thead>
<tr>
<th>Case Number</th>
<th>Caregiver Relationship to Patient</th>
<th>Years Caregiving</th>
<th>Current Patient Residence</th>
<th>Current Stage of Patient Dementia</th>
<th>Have Written ADs for Patient</th>
<th>Had Conversations RE: EOL wishes</th>
<th>Caregiver Attends Support Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1050</td>
<td>Spouse</td>
<td>10</td>
<td>Caregiver Home</td>
<td>Moderate</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1051</td>
<td>Spouse</td>
<td>4</td>
<td>Caregiver Home</td>
<td>Early</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>1052</td>
<td>Spouse</td>
<td>3</td>
<td>Deceased</td>
<td>Deceased</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1053</td>
<td>Adult Child</td>
<td>8</td>
<td>Assisted Living</td>
<td>End Stage</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>1054</td>
<td>Adult Child</td>
<td>3</td>
<td>Deceased</td>
<td>Deceased</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>1055</td>
<td>Adult Child</td>
<td>7</td>
<td>Assisted Living</td>
<td>Moderate</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>1056</td>
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<td>Nursing Home</td>
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<td>No</td>
<td>No</td>
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<tr>
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<td>No</td>
<td>No</td>
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<tr>
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<td>Yes</td>
<td>No</td>
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<tr>
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<td>Yes</td>
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<td>Yes</td>
<td>Yes</td>
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<td>No</td>
<td>Yes</td>
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<td>Yes</td>
<td>Yes</td>
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<tr>
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<td>Caregiver Home</td>
<td>Moderate</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Mean: 5 yrs.  
SD 2.6
The Caregiving Context

The majority of caregivers in this sample are experiencing the impact of long term caregiving. For this sample the average duration of caregiving is five years. They report anxiety about decision making, the burden of continuous and unrelenting problem solving, and “money troubles.” They worry about how they will continue to finance long term care, behavioral problems of the dementia patient which jeopardizes placement in residential care, and battling extreme fatigue. More than half say they are overwhelmed by the demands of dementia care and feel “trapped” in the disease. They say such things as: “Can’t go back, can’t go forward.” “Feel under siege.” “Feel like I live in limbo.” One woman sums it up for most: “I am exhausted, fatigued, can’t sleep well, and worried all the time.” For the seven caregivers whose family members have died, each one expressed a sense of relief that “it is over.” One male caregiver expressed: “The nightmare for my mother and for our family is over. This long, cruel disease is done and we can breathe again.”

Some express their grief over the loss of the patient’s function in terms such as: “He does not know me anymore.” “I am losing him by inches.” “I cannot stay in the nursing home too long. Seeing her like this breaks my heart.” Caregivers understand that dementia is terminal and know they must prepare themselves to face death: “He will die from this, I know it. I just have to figure out how to do this.” “It is fatal. Her disease is progressing and I am scared.” “I know where this disease is going and it hurts. This is so hard and so disappointing.” Several caregivers express anticipatory grief about what is to come such as: “I mourn him every day. There are so many small and big losses. But I am still in mourning.”

Some express a pragmatic attitude toward dementia: “It is what it is.” “It is not the life I imagined, but it is the life I have.” And others use “the good life defense”: “I am 78 years old. I
have had a fortunate life being born in America. I had the opportunity to build a good life. I am grateful.” Another caregiver said: “I am grateful for all life’s blessings. We have lived well. We all have to die of something.” Yet another stated: “Death is just another stage in life. It is what happens if you have a good, long life. It will come to an end.”

The majority of caregivers are thoughtful and planful in approaching care for dementia patients. They plan for day-to-day care of the patient; they have done ACP, and have arranged for cremation and funerals. Many have “right-sized” their homes and have begun to give away cherished items to their children and grandchildren. Others talk about doing things that matter now: “Telling the children that we love them every chance we get.” “We try and find joy in every day. We take a ride in the convertible and go get ice cream.” Planning is important to these caregivers. As one said: “We are planners. We planned for everything except dementia.” Others express such feelings as: “It is hard to do nothing. Just waiting for dementia to unfold is hard.” “We take a head-on approach to Alzheimer’s. We educate ourselves and reach out for resources.” “There is nothing I can do to make it better or to fix this. I just keep doing the next right thing.”

Planning and acting on that plan seems to help some caregivers reduce their anxiety: “I do what is needed. Helps me stay in problem solving mode and reduces my anxiety. Makes me feel useful.” “I am planning because it makes me feel less stressed.” “I do planning so I will not be paralyzed.” “I plan to ward off anxiety over the mess that my life has become.” Yet some caregivers express an opposite view: “Planning is difficult. I do not have time or energy to reflect. The day-to-day care is hard enough.” Others just feel totally bereft and lost in the caregiving: “A tsunami washes over me and I know that I am drowning and there is nothing I can do about it.” “Life is just too much.” “There is nothing I can do. I don’t know what to do.”
But in this sample of caregivers, the overall attitude about planning is reflected in one elderly male’s comment: “Planning is the gift you give to the family left behind.”

More than half the caregivers have had to retire from their jobs or work part time in order to care for the dementia patient. Many have given up their volunteer work and social engagements with friends and family because of the demands of care. They report being very involved with day-to-day care whether the patient is at home with them or in residential care. Although the majority of caregivers report their own health status as “excellent” or “good,” they worry about what will happen to the dementia patient if they become sick and/or die. One caregiver who has suffered a severe stroke asked: “What happens if I cannot care for her?” Most intend to take care of the patient until the end out of love, a sense of obligation, and belief it is the right thing to do. As one woman said: “He does not know me any longer. But I feed him dinner at the nursing home each night and hold his hand. He knows that someone loves him.”

**The Grounded Theory:**

**The Dementia Caregiver Advance Care Planning Theory**

In this challenging caregiving context a grounded theory emerged from the data about how ACP is done and used to shape the dying process for the dementia patient. During selective coding (part 2 of substantive coding in Glaser’s model) while comparing category to category and reflecting on the story of the data depicted on the design wall, a core category began to emerge. The core category was robust enough to absorb the other relevant categories and was the beginning of answering the research question: How do dementia caregivers understand the process of ACP? The core category is: The majority of caregivers understand ACP as having the power to shape the dying process for the dementia patient. It is not just about executing formal written ADs but how caregivers exercise that power of choice. Caregivers’ knowledge
and beliefs are reflected in their behavior regarding ACP in both (1) how they do the ACP process and (2) how they use ACP.

**The Process of How Caregivers Do ACP**

The majority of caregivers in this sample have completed written AD documents (20 out of 22 caregivers interviewed for this study). The two caregivers that have not done ACP understand what a living will and health care proxy are but do not see the value in doing them for the dementia patient or for themselves. Both express not having any family experience with ACP and do not see how it would be helpful in the dying process. One caregiver said:

Don’t like talking about dying so much. I need all my energy to get through my day. I don’t have the stamina to think about the future. In the end, it doesn’t really matter how we die, does it? Why plan for something that you cannot change.

The second caregiver expressed:

Not sure why we did not do them [ADs]. We never talked about dying. We never even talked about growing older. Not sure I’d call it death anxiety. Just all used up living day to day. Caregiving takes all my energy. It’s more than enough for me. We just get through the day…in any case, not sure they [ADs] would help any especially now she cannot tell me things. Besides she relies on me to do the right thing. When the time comes I will know what to do.

For these two caregivers ACP has little value also because it is perceived as being for people with assets to leave behind for the family: “Mom had no assets so did not do a will either. Honestly she left absolutely nothing behind – except 10 angry and bewildered children.”
The other said: “When this is over [dementia] we will have nothing left to leave the kids. How would a living will help with that?”

For the majority of caregivers in the sample, the process of doing ACP occurs along a trajectory from: (1) years before dementia, (2) at dementia diagnosis, (3) to end stage and death. (See Figure 5: The Process of How Caregivers do ACP).

**Years Before Dementia**

The majority of this sample executed ACP documents (both a living will and health care proxy) for both the patient and the caregiver. The ACP was done for both as spouses often serve as each other’s health care proxy or an adult child will serve as a parent’s proxy. Several report having done it “25 years ago when the children were small” or “10 years ago after we married for a second time.” The reasons they give for having done ACP was to protect their dependents and name a guardian for them should they die and to protect their assets. Many expressed that they sought out the family lawyer to execute a will and do financial planning, and that the living will and health care proxy were “tacked on” to the financial planning almost as an afterthought. At the time they gave little thought to the importance of ACP. One caregiver stated: “Didn’t think about it as a young person.” Another said: “Did not really understand how important it [ACP] was until my husband went into the nursing home.” Yet another caregiver expressed: “Our lawyer did not spend much time talking about advance directives. Kind of like it did not matter. But the thing with dementia is you have to do it [ACP] early and you really don’t understand how critical it is until you get to the end. That’s a shame.”

Caregivers expressed their chief motivation for doing ACP was previous experience in the family with illness and death. Often the death of a parent or a sibling made them feel powerless over the dying process, burdened by watching a loved one in pain, struggling with
### Figure 5
The Process of How Caregivers Do ACP

<table>
<thead>
<tr>
<th>Years Before Dementia</th>
<th>At Dementia Diagnosis</th>
<th>Moving into End Stage to Death</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Action Taken: Do Initial ACP</strong></td>
<td><strong>Action Taken: Make changes to ACP</strong></td>
<td><strong>Action Taken: Use ACP in decision making for patient</strong></td>
</tr>
<tr>
<td>- To protect dependents</td>
<td>- To respond to threat of patient losing ability to give consent</td>
<td>- To make difficult decisions regarding withholding/withdrawing/continuing treatment for patient</td>
</tr>
<tr>
<td>- To protect assets</td>
<td>- To find ways to finance long term care</td>
<td>- To choose hospice care</td>
</tr>
<tr>
<td>- Do living will/POA “tacked” on to financial planning</td>
<td>- To protect family assets</td>
<td>- To honor patient wishes by “doing the right thing”</td>
</tr>
<tr>
<td>- To keep patient voice in dying process</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Motivated by:**
- Previous family experience with illness and death
- | Motivated by: |
- Desire to “do the right thing”
- Desire to problem solve and plan
- Advice from doctors, lawyers, support groups, etc.
- | Motivated by: |
- Change in patient health status
- Change in perceived patient quality of life

#### Key Features of the Process

- **In the family**
  - Content: Difficult death of family member
  - Dying well with little pain
- **Lawyers**
  - Media stories
  - Family/other

- **In family without patient**
  - With others (doctors, lawyers, friends, neighbors, support groups, etc.)

- **Elder law attorneys**
  - Health care professionals
  - Educating self via internet sites

- **Keep forms at home, with lawyer**
  - Accessible by family members usually parents, siblings

- **In family with patient**
  - Content: Learning about dementia, death
  - Problem solving in present
  - Planning for future care

- **Elder law attorneys**
  - Health care professionals
  - Educating self via internet sites

- **Keep forms at home, with lawyer**
  - Bank security box
  - Accessible by patient, spouse, some adult children

- **In family without patient**
  - With others (doctors, AL/NH staff, friends, neighbors, support groups, etc.)

- **Elder law attorneys**
  - Health care professionals
  - Educating self via internet sites

- **Keep forms at home, AL/NH facilities, with lawyer**
  - Accessible by POA usually spouse, adult child
increasing conflict in the family, and recognizing that they did not want to experience dying in this way. Some expressed their feelings:

Regarding feeling powerless over the dying process:

My brother-in-law died of a heart attack in his 30s. We watched as his life support was pulled out. It was awful when his wife decided to end it. It was traumatizing for us. We are haunted by that experience.

My father had Parkinson’s disease. He had a feeding tube and pulled it out. He just wanted to go home. Health care workers pushed it back in and restrained him. It was awful. I told them to take it out. Staff was mad at me. They said I was killing my father.

Regarding the burden of watching a loved one in pain:

My mother was the caregiver for my father who had a long illness due to heart disease. She was forever changed by watching him in so much pain and vowed that she would not let that happen to her. She did it [ACP] about 20 years before she slipped into dementia.

Regarding conflict in the family:

When my mother-in-law was dying, there was conflict in the step family. Disagreement among the siblings because they did not know what she wanted at the end. She never said and had no documents. She did not talk to her kids about her wishes. There was lots of disagreement about her stuff and who would get what. It was the most miserable experience of my adult life until dementia.
Recognizing they did not want to experience dying in this way:

When my mother was ill in a nursing home and unable to eat, the staff wanted to put in a feeding tube. I had the POA [power of attorney] and said no. They gave me a lot of grief about not doing it. But it was the right thing to do for my mother. I could not be swayed to do otherwise…

experience with my mother changed my thinking. My experience with my mother was so bad. After what happened to her thought it could happen to us. So we had are living wills and POAs done. That was 21 years ago.

From these family experiences, the caregivers learned how the dying process was different for those who had done ACP and those who had not:

My in-laws did end-of-life planning, but my father did not. This caused great distress when the time came. My mother had done her planning. She had a DNR [Do Not Resuscitate Order] for herself. What a difference it made…having ACP takes the guilt away when having to make decisions for others.

My experience with end-of-life care was calling for hospice for my dying aunt. She had ACP and a DNR. The hospice team was very helpful to the family. Because we were able to make good choices her death was peaceful and calm.

**At Dementia Diagnosis**

At the time of dementia diagnosis, most of the caregivers made changes to their
ACP. The most frequent changes included changing the health care proxy and reviewing the list of life sustaining measures delineated in the living will. For the majority of caregivers, making changes to ACP were in direct response to the threat of the dementia patient losing the ability to understand end-of-life choices and to give consent for withholding or withdrawing treatment. One spousal caregiver said: “I fear my husband will lose the ability to make decisions. I want to make those decisions for him based on what he truly wants at the end.” Another stated: “She was afraid she would not be able to make decisions for herself.” And another caregiver who had made changes to their ADs said: “We had the good sense to do planning [ACP] before he was not able to understand anything.”

Another important reason caregivers expressed about making changes to ACP after the diagnosis, was to seek ways to finance long term care when the time came and they were no longer able to care for the dementia patient at home. The majority of caregivers are deeply concerned about financing the high cost of nursing home care. One caregiver said: “My husband will not qualify for Medicaid to cover nursing home costs as he receives income from a farm the family owns in Iowa. But we need money to live on…I don’t know how we will do this.”

Other critical reasons caregivers gave for making changes to ACP included protecting family assets and keeping the voice of the dementia patient in the dying process. For the 11 spousal caregivers in the study, they were very concerned about not only paying for the dementia patient’s care, but worried about having resources to take care of themselves and to provide for the care they might need as they aged. As one caregiver said: “Caring for my wife is running me bankrupt. I am out of money. Selling our things to raise some cash. I cannot do this much longer. I worry there will be nothing left for me to live on when this is over.” Another stated: “I don’t want to be a burden to my kids. But the cost of care is leaving me empty.”
At dementia diagnosis, the majority of caregivers consulted elder law attorneys instead of the family lawyer that they consulted when doing initial ACP. In the early 1990s, elder law emerged as a law specialty practice focused on issues that affect the growing aging population. The three major areas of focus are: (1) estate planning and administration, especially tax issues; (2) spending down to qualify for Medicaid to pay for long term care; and (3) guardianship for those elders who have no family members giving care (National Academy of Elder Law Attorneys, 2013). Based on their particular family financial situations, three spousal caregivers in this sample were advised by elder law attorneys to divorce the dementia patient in order to impoverish the patient and allow qualification under Medicaid rules to pay for nursing home care. Two of these caregivers have done so, and the third walked out of the attorney’s office distressed and determined not to divorce her husband. This caregiver sought out another attorney.

Many of the caregivers stressed the importance of keeping the voice of the dementia patient in the dying process as they believe it was one of the last things they could do in the face of dementia. As one caregiver stated: “I cannot do much about changing the course of his dementia, but I can see to it that they honor his wishes for the end.” One caregiver summed it up by stating: “By being strong and making the tough decisions, I can give him this last gift.”

Some were highly motivated to make changes to ACP due to the advice they received from their doctors, mostly neurologists, who diagnosed the dementia. Some neurologists were very clear with the caregivers that dementia is terminal. One caregiver reported the doctor saying: “You will die from this. There is no cure.” Another stated: “The doctor was so straight with us. He said: ‘You will die from Alzheimer’s. In the time you have left make a difference, find a voice, and find an attorney.’ And that is what we did.” Caregivers expressed “wanting to
do the right thing” for the patient and felt that ACP was part of the planning and problem solving that was their job since dementia had entered their lives.

**Moving into End Stage, Toward Death**

Moving into end stage the caregivers begin using ACP more frequently in decision making for the dementia patient regarding treatment. At this point, the patient is no longer able to have conversations about choices and is not able to give consent. The decision making rests with the caregiver. This sample of caregivers understand their role as decision maker for the patient and understand there will be difficult decisions to make regarding withholding, withdrawing, or continuing treatment.

They wrestle with when and if to choose hospice. And as in the earlier stages of the disease, they are deeply concerned about “doing the right thing” by “honoring the patient’s wishes.” Chief among their concerns for the patient at this point are assessing the impact of changes in the patient’s health status and how that alters the patient’s quality of life. All 22 caregivers in this sample, including the two who had not done ACP, spoke of the importance of quality of life and the need to assess the patient’s status. One caregiver expressed: “I consider quality of life first in all my decisions.” Another stated: “quality of life means being able to eat, drink, and move.” Yet another feels: “My husband’s health status matters a lot. It influences whether he has any quality of life and my decision to let him go.” One spousal caregiver expressed his measure of his wife’s quality of life: “She has adored opera her whole life. When she can no longer listen to the music it is over for her.”

They express being troubled by understanding the trajectory of dementia. It is mostly understood that end stage dementia can last two to three years. But these caregivers want to know where the patient is in end stage. They feel they get little help in understanding markers
for the end (presence of one or more markers co-occurring, i.e., pressure sores that will not heal, losing ability to speak and to transfer from bed to chair, total incontinence, feeding and swallowing problems, and breathing problems). Most of these caregivers feel that health care professionals do not talk to them about what is happening and doctors are very late in getting dementia patients into hospice. One caregiver stated: “The doctors are letting dementia patients down by not getting them into hospice sooner.”

**Key Features of All Three Phases of the ACP Trajectory**

During all three phases along the ACP trajectory, key features are present throughout: (1) conversations in the family, with the patient (prior to loss of ability to understand and give consent), and with others; (2) efforts to gain knowledge about ACP; and (3) finding and keeping ACP forms.

**Conversations in the family and with others**

In the “years before dementia” phase, equally important as family experience with illness and death in caregivers’ motivation to do an initial ACP process, were on-going conversations in the family regarding end-of-life choices and care. These conversations often centered around a dying parent or sibling. The conversations were often brief, off-hand comments for some and for others were regular and lengthy conversations in the family group. For example when reflecting on his brother’s painful death from cancer, a patient said to his caregiver: “Don’t let this happen to me. Put me in front of a train first.” Another commented to his wife during his mother’s last days: “Don’t let them do anything to me. Let me die when the time is right.” One woman told her family: “Don’t keep me alive longer than necessary or I will come back and plague your heart out.” Another one said: “If I cannot talk, hear, or if I am just a shell do not keep me alive.”

Over half the caregivers stated there were open conversations in the family regarding
death, dying, and last wishes, long before dementia entered their world. Many reported frequent conversations in the family such as:

Both my parents were planners. They were very organized, very thoughtful. They talked directly to me and my brother about what they wanted at the end of life. “Don’t talk about dying, Daddy,” I would scream and run out of the room. Daddy would call me back and make me sit and listen. He was persistent. Vehement. Insisted that I hear him out.

Another caregiver reported:

My mother was a nurse and talked openly to us about death. “We all have to die someday.” She prepared us for death with her attitude and her doing pre-planning with wills and POAs. Mother did private duty nursing and lots of end-of-life care. From this experience she learned how important it was to plan and let others know what you want. She said all the time “there are worst things than death.” It was very helpful that mother thought this way and talked to us about it. She said “no matter what do the best for the person. Go for the living need.”

Beginning with the “at dementia diagnosis” phase, the caregivers report that conversations in the family are ongoing, and more frequent due to the diagnosis. The content of the conversations tends to be around planning for future care, problem solving in the short term, and learning about dementia. There are more conversations not only between the patient and caregiver, but with adult children and siblings. One caregiver describes: “Conversations with
my son and daughter are ongoing and very hard. My daughter cries. We try to avoid talking about it [dementia] but it surfaces all the time. It is present daily.” Another reports:

Had conversations with my husband about end of life a lot after diagnosis.

We talked about having an abundant life. And we remembered the conversations we had with his father prior to his end stage about his last wishes for care….it helped us begin talking about what he wanted at the end.

A spousal caregiver reports conversations with the patient:

Our conversations were not long, but short and to the point. She would say “don’t ever let me live like a vegetable. That is not living any more. That is keeping my body going when the rest of me is dead. That is just not right.”

Yet another caregiver states:

The first week after diagnosis we began the conversations in the family and did the legal things, revised the POA, living will…my brother helped us with this…and my daughter who is a law student gave us wills for a Christmas gift.

Not all caregivers report conversations with the patient regarding end of life care. A few caregivers expressed thoughts such as: “We didn’t talk at all about death or accepting that one would die. My mother does not let us talk that way. So we do not stress her with that.”

Although the majority of caregivers in this study feel strongly about doing their best to honor patients’ wishes in a few cases the patient’s request is beyond what they are willing to do. Three caregivers report that in conversations with the patient, the patient asked the caregiver to kill them or assist in ending their lives. One caregiver states:
My mom was mad at me because I would not help her kill herself. She said that she did not want to live this way and I had an obligation to help her die. I could not make that happen for her and it caused great distress for us both. I wanted to honor her wishes but this was going too far for me.

Another female caregiver reports:

After my husband’s diagnosis, he would often say to me “I want to step out into traffic and get hit by a car”….I could not honor his wish to put him in front of a speeding car, but I could see to it that he did not get treatment that prolonged his life.

And a third caregiver states:

After his [husband] diagnosis, he said often that he would kill himself and said he wanted me to see that it was done. We have lots of guns in the house. It scared me. I cannot help him end his life. I would do anything for him but not this….So I called the sheriff’s office and had him come and impound all 38 weapons and ammunition in the house.

Many caregivers have conversations with people outside the family, such as friends, long-term neighbors, and members of the clergy. A female caregiver reports:

After diagnosis which took some time, I talked to good friends who are helping me through this…they have been our friends for years and are easier for me to talk to than my kids sometimes. But we still have conversations in the family too, mostly about what we are learning about dementia and how this is going to go and then how to share the care.
Another reports: “I am an active and involved Mormon. I talk to people and leaders in our church and they help me and my family...end-of-life care is important in our faith.”

Moving into end stage, conversations in the family continue and change in character. Conversations with the patient are usually no longer possible due to loss of cognitive function and language. One caregiver states: “Momma has always been real clear about what she wanted. It was an open conversation until the dementia has kind of taken over. She is still angry at God for leaving her like this.” Discussions are more about the patient’s change in health status, the trajectory of the disease, and the quality of care the patient is receiving in long term care. Comments such as the following are frequent in this sample:

I wish I understood where Mom is in end stage. No one at the nursing home talks about that. My wife and I talk about it every day and try to understand when we need to talk to the doctor about hospice.

My children and I talk about the care my wife is receiving in the nursing home...there is not enough staff to feed her, so I go everyday to do that. They leave her in bed all day. It is bad for her skin to lay there like that. They do not check her diapers very often and do not change the sheets. I pay all this money and they do so little.

The discussions about ACP change too. It becomes about how to use ACP by exercising the power to shape the dying process. It becomes not about doing ACP, but about using ACP as effectively as possible. Many of the caregivers express thoughts such as this:

I did not understand the use of it [ACP] at first. When my husband went into a
nursing home that all changed… I saw it as my job to say what was appropriate for my husband. There is a real struggle once he was no longer at home. You lose control. Having a POA gave me control back. I insisted they ask me first before they did anything for him… My daughter and I talk about this every day now…..they are always pushing for more treatment.

Having advance directives gives me some backbone and if I cannot work with a certain doctor I ask for another one. I did the same for my father. And my brother and I did the same for my mother… I talk with my kids and my brother constantly… there are problems that come up daily.

**Gaining knowledge of ACP**

The second key feature of the process which is true of all three phases of the ACP process is the effort that caregivers make to gain knowledge about dementia, end-of-life care, and ACP. The main sources of information are: lawyers, support groups, health care professionals (mostly doctors and social workers), stories in the media, and family and others. Many caregivers sought out the same lawyers who their parents had used for years, were referred to a lawyer known to a trusted family member, or asked for a referral to an elder law attorney from the Alzheimer’s Association Helpline or support group. A few reported that others encouraged them to do ACP: clergy, financial planners, staff at senior centers and home health agencies, and other family members. Half the sample of caregivers gained knowledge of ACP through their participation in support groups sponsored by the Alzheimer’s Association.

Many of the caregivers were impressed by the media stories concerning families
caught in end-of-life conflict regarding a patient in a persistent vegetative state with little hope of recovery. Caregivers mentioned the Karen Anne Quinlan (1976), the Nancy Cruzan (1983), and the Terry Schiavo (2005) cases specifically. These were high profile cases that involved the mainstream media and high level public officials. One caregiver commented: “We talked a lot about the Karen Anne Quinlan case when it was in the paper and TV. The conflict in that family was horrible. We were unnerved by this. It made us revise our forms [ACP] then.” Another reports: “Heard about cases in the media and they made me think. The Terry Schiavo and the Karen Anne Quinlan cases stand out the most.” An adult daughter says:

The Terry Schiavo case on TV impressed me. I followed the whole story.

My mother had a will and a living will since I was little. But because of the Schiavo case and right after her heart surgery we redid her advance directives.

An adult son talks about his mother:

My mother read about the cases in the media about families fighting over what kind of care a person should be receiving. She did not want that for herself. She wanted to make those choices herself. That is why she was so good at doing her advance directives.

A caregiver comments on her disabled son and her parents with dementia:

I learned a lot about end of life care in the media. When those sensational stories were all over the news it made me think about my son and my parents with no one to be a voice for them.

And one female stressed the emotional impact of the Schiavo case:

I learned about advance directives when the Schiavo case was in the news.

It influenced me. It is outrageous that the parents would not let it end. So
sad for the entire family and ruined relationships because the parents could not
deal with reality.

Many of the caregivers in this study gained knowledge about ACP through self education
mostly through websites such as those concerned with: aging (i.e., National Institute on Aging
of the National Institute of Health); health (i.e., WebMD, Mayo Clinic); caregiving (i.e., Family
Caregiver Alliance); and dementia (i.e., Alzheimer’s Association). Some caregivers reported
following caregiving blogs and a few reported taking part in caregiving exchanges on the web.

**Finding and Keeping Signed Forms**

Nineteen of the twenty caregivers in this study who executed a formal ACP process were
given forms by their lawyer. Only one caregiver understood that a lawyer was not essential to
completing an ACP process and bought living will and health care proxy forms at Staples, an
office supply store. She completed them and had them signed by appropriate witnesses. Under
both federal and state law these are recognized legal documents.

The majority of caregivers know where the signed forms are kept, mostly at home in a
file drawer cabinet. These forms are accessible. One caregiver reported not knowing where the
forms are kept. Several others have their signed forms in a locked security box at their bank.
These forms are not accessible by others. Five caregivers reported that signed forms are
dispersed among significant others such as their lawyer, doctor, assisted living facility where the
patient resides, and with adult children. In answer to the question, “Who knows where the forms
are kept?” the majority of caregivers answered that their spouse or adult child knows where the
signed forms are kept and can access them when needed. Eleven caregivers reported that two or
more people close to them know where the forms are located and could retrieve them in an
emergency. Only five caregivers in the study are aware they need to hand carry their ACP documents when they travel with the patient to acute care facilities or upon entering an assisted living or nursing home facility.

**How Caregivers Use ACP**

Having written advance directives gives the caregiver legal authority to exercise power of choice for the patient. But how the caregiver understands that power and uses it is influenced by how the caregiver interprets the role as decision maker. In this study, the caregivers define the role of decision maker as:

1. Accepting responsibility for making difficult decisions regarding withholding, withdrawing, or continuing treatment for the patient;
2. Using ACP as an effective tool to exercise power and control for shaping the dying process for the patient; and
3. Accepting that they may “do battle” with health care professionals to honor the patient’s wishes

(See Figure 6: How Caregivers Use ACP: Defining the Role of Decision Maker)

**Defining The Role of Decision Maker**

**Making Difficult Decisions**

The majority of caregivers in this study take full responsibility for making difficult decisions for the patient as they move through dementia. While they have been making decisions with and for the patient during the moderate stage of dementia, most of the caregivers in this study state that the decisions become more difficult in end stage as they relate to: (1) withholding, withdrawing, and continuing treatment; (2) assessing patient’s quality of life; (3)
assessing changes in patient’s health status; and (4) wrestling with conflict in the “gray areas” of treatment, e.g., use of antibiotics. They acknowledge the decisions are very difficult, but feel strongly that they are responsible for making them and will not defer that responsibility to health care professionals. Such comments as these are common among the caregivers: “It is my responsibility to make those hard decisions. I cannot pass that task on to anyone else.” “I saw it as my job to say what was appropriate for him [husband].” “I know that I will have to make hard choices. All the decisions are hard. There is no backing up this road.” A male caregiver said: “She [wife] trusts me to do the right thing. I will not shirk from doing it. I will not waiver.” Another stated: “I have to separate my wishes from his [husband] wishes. In the end I need to live with myself when this whole thing is over.”

Although caregivers seek counsel and advice from other family members and some trusted outsiders, they stand firm in their belief that they are responsible for the final decisions. One female caregiver stated: “I seek advice from my children and my brother. But in the end I need to make the final decisions.” Another said simply: “It is up to me.”

This responsibility for decision making weighs heavily on the caregivers. Many expressed such thoughts as: “It is very uncomfortable for me to be making these choices for him.” Another said: “It is most difficult to watch your loved one die by withholding treatment. Your rational self says let them go, but your emotional self is in conflict.” Yet another commented: “I will make the decisions and give the final order. But I am not ready to let her [wife] go.” An older male caregiving for the first time said: “I will make all the
1) Accepting responsibility for making difficult decisions regarding withholding/withdrawing/continuing treatment for patient
2) Using ACP as effective tool to exercise power and control for shaping the dying process for patient
3) Accepting doing battle with health care professionals to honor patient wishes

This Definition is Shaped by Three Key Features

<table>
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<tr>
<th>The Meaning Caregivers Give to ACP</th>
<th>How Caregivers Understand Life Sustaining Measures</th>
<th>Caregivers’ Knowledge of Patients’ End-of-life Wishes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shows respect for the dying process</td>
<td>Articulate what life sustaining measures are and what they do</td>
<td>Knowledge of patient wishes is foundation of strength for holding firm on decisions</td>
</tr>
<tr>
<td>Preserves patient voice in the dying process</td>
<td>Understand measures as treatment that will not cure or change the course of dementia</td>
<td>Knowledge of patient wishes based on conversations with patient prior to cognitive loss, close family members and friends</td>
</tr>
<tr>
<td>Gives power and control to “do the right thing” for patient</td>
<td>Understand the “gray area” of using antibiotics as both treatment and comfort measure</td>
<td>Conflict in family occurs over implementing patient wishes and shared decision making</td>
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<tr>
<td>Gives framework for decision making</td>
<td>Have some knowledge of impact of life sustaining measures on advanced dementia patients</td>
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<td>Influenced by religious/spiritual beliefs and some cultural beliefs (i.e. patient autonomy, taking care of one’s own, etc.)</td>
<td>Articulate the complexity of decision making in end stage as making decisions on case by case basis as issues arise</td>
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<td>Influenced by caregivers’ feelings about having ACP for patient (i.e., eases sense of burden, reduces some stress, brings measure of comfort)</td>
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</tbody>
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medical decisions. That worries me. Not sure what those decisions will be but I know that I owe her not to make her suffer any more than necessary.” One female caregiver expressed: “I have an overwhelming sense of responsibility. What if I am wrong and make a bad decision?” Despite the difficulty of decision making, several caregivers expressed thoughts such as: “It is a gift to do this for him [husband]. One of the last things I can do for him.”

All 22 caregivers in this study (including the two caregivers who have not done ACP), express worry about withholding/withdrawing treatment. For them quality of life of the patient is the most important criterion for making decisions about treatment. Many expressed the idea that “quality of life is more important than quantity.” One caregiver defined quality of life for the patient as: “Most important is that he can eat, breathe, and recognize people.” Another expressed “Quality of life means being able to eat, drink, and move.” Yet another stated: “Quality of life is everything to me. If I cannot sing, laugh, and pray my life is over.” Others describe the patient reaching a “tipping point” where quality of life is no longer evident: “My mother has lost all independence. She cannot move, speak, toilet, dress, or eat by herself. She has no quality of life. It is time for her to die.” Another caregiver stated: “The tipping point came for my mother when she could no longer swallow and could not eat. It was her favorite thing. She has no quality of life anymore. It is all gone.” Yet another caregiver expressed:

I think quality of life impressed me the most. She [mother] could no longer do anything for herself and there was no interest in anything. She even stopped playing bingo. Her favorite. She no longer had anything she enjoyed…my decisions about stopping meds [medications], no more tests, and certainly no more surgery were based on my belief that she had no quality of life to speak of and she wanted to die.
Caregivers are aware that assessing patient’s quality of life is on-going and changes as the patient’s health status changes. One caregiver stated: “I assess quality of life every day.” Another shares: “My father’s health status changes day to day and means that I keep redefining his quality of life.” One spouse caregiving for her husband states:

His health status matters a lot. If his health declines so much that he cannot eat or drink or move from his bed that means his quality of life is gone and that would influence my decision to let him go and not try and save him anymore.

The caregivers express “wrestling with” the conflict created in the “gray area” of decision making. Although they have strong feelings about the use of feeding tubes, resuscitation, and artificial hydration, they struggle with the use of antibiotics in end stage. Many see antibiotics for the treatment of conditions such as urinary/bladder infections and pneumonia as extending the life of the patient when they are making decisions to clear a path to a peaceful death. But others feel strongly that antibiotics are a comfort measure. As one female caregiver said, “as many women have experienced, a UTI [urinary tract infection] is very uncomfortable. You can hardly sit still. I could not let my mother go on like that without treatment. I consider it a comfort measure.” But some caregivers expressed the challenge of withholding antibiotics: “the line between giving and not giving treatment is broad and gray. It is not clear cut.” Another stated: “The decision about using antibiotics is torturing me. I have such conflict.” One adult child stated it succinctly: “We stopped Dad’s meds. Dementia is getting worse. Family in anguish.”
Using ACP as an Effective Tool

Many of the caregivers express that ACP gives them the power to make decisions on behalf of patients and they use it as an effective tool to shape the dying process. Comments such as these were frequent: “Everyone needs to do advance directives.” “It is essential. Without it you are powerless.” “It is vital for survival. Gives me control over the decision making.” “You have to be active using it [ACP] otherwise the decisions will not be yours. Someone else will take that away from the family.” Others talk about the impact of having ACP: “It keeps conflict out of the family and keeps legal and financial matters straight.” “It allows me to ask tough questions and I do ask the doctors and nurses all the time. And it allows me to say no.” One caregiver stated: “Because he [husband] told me what his wishes are I can be strong in making decisions.” Another shared: “Having the planning [ACP] done is honoring my husband’s wishes. I will use that power so see that happens.” One young female who is a caregiver for her grandmother stated: “It is all awful. But with advance directives, I can make them listen to me and do what is right for her. I only want comfort care for her now. That is the only power I have.” Yet another caregiver expressed: “Everything else in my life is slipping away. All I have now is the power to help my husband get good care and let him die when his time comes.”

Yet some caregivers express not using ACP as an effective tool even though they have completed a formal ACP process. Comments such as these were noted: “Having these documents does not change things.” “Life is hard. Dying will be harder. It [ACP] cannot make that easier.” But for the majority of caregivers, their belief in ACP is reflected in this comment by an adult daughter: “The best thing to do is ACP. I cannot imagine how much harder the dying process would be if I did not have the power to make decisions for my dad.”
Doing Battle with Health Care Professionals

Caregivers acknowledge that in the process of making difficult decisions they may “do battle” with health care professionals who continue to provide treatment to a patient whose quality of life and health care status are in serious decline with no hope of recovery. The caregivers use combative language to express their feelings about this:

“I am doing battle with health care professionals every day”.

“Facing off with health care professionals…”

“Wrestling with…”

“Standing my ground”.

“I don’t want to fight anymore”.

“Need to be on guard”.

“I raise a ruckus when they do not follow what I tell them.”

“I am always vigilant…..on guard”

Caregivers fight to withhold/withdraw treatment and to be listened to by health care professionals. This story is a common occurrence for these caregivers:

The doctor in the nursing home called and said my mother’s hemoglobin count was low. He said we should begin blood transfusions immediately. They would have to be repeated almost every week and require transporting her to the hospital. I asked the doctor how my mother would benefit from this. He said her hemoglobin count would go up. That made no good sense to me. My mother is dying with no cure available and he is recommending transfusions for what purpose? I said no. He was angry and told me so. I said no again.
I could not see putting my mother through that discomfort when all she wanted was a peaceful death.

One adult daughter said: “The doctors don’t like you saying no to treatment. They are used to always making the decisions and everyone just going along. But I just stand my ground. Comfort care only for my mom.” A spouse stated: “I must be vigilant and present to be sure that health care professionals do the right thing.” Yet another feels strongly: “I am fulfilling my wife’s wishes. I will not tolerate interference.” And one caregiver worn out with the fight expressed:

They did not always like me speaking up but that is what I thought I needed to do…They kept pressing to do more. I knew he [husband] wanted to die peacefully. I felt powerless. All I could do was say no to treatment and stand my ground.

Another female caregiver stated:

When mother was in rehab after one of her falls, the staff would not give her a shower unless I produced my POA. So I have learned to have that with me all the time as things change so fast. In the morning everything is stable and by afternoon it has all gone to hell.

In addition to decisions regarding treatment, many of the caregivers are concerned about getting hospice care for the patient when the time is right. Some caregivers expressed that the nursing home doctors were too slow in admitting the patient to hospice. One caregiver stated: “The doctor was reluctant to sign the order for the Medicare hospice benefit for my mother. He dragged his feet on this and finally my mother was admitted to hospice care two days before she died. That simply is not good enough care.”
With difficult decision making, the caregivers find the strength to “stand their ground” because (1) they believe that ACP gives them the legal right to decide what is best for the patient; (2) they believe they have knowledge of the patient’s wishes and will honor them because it is the right thing to do; and (3) they believe that keeping the patient comfortable is important after treatment is no longer effective and may lead to a more peaceful death.

**Key Features That Shape the Definition of Role of Decision Maker**

This definition of the role of decision maker develops and is shaped by three key features: (1) The meaning caregivers give to ACP; (2) how caregivers understand life-sustaining measures; and (3) caregivers’ knowledge of the patient’s end-of-life wishes.

(See Figure 6: How Caregivers Use ACP: Defining the Role of Decision Maker)

**The Meaning Caregivers Give to ACP**

In addition to understanding ACP as an effective tool to shape the dying process for the patient, caregivers express that ACP shows respect for the dying process because it preserves the patient’s voice and allows the caregiver to “do the right thing by honoring the patient’s wishes.” This understanding of ACP is influenced not just by previous family experience with illness and death but also by cultural and religious beliefs and is expressed by the feelings they share about having ACP for the patient.

Regarding showing respect for the dying process, these types of comments were noted by several caregivers: “Having advance directives brings a reverence to end of life care.” “It [ACP] makes the dying matter just as much as the living did.” One caregiver said of ACP “it gives me a framework for decisions. It allows me to reflect on what kind of treatment may help Mom and what I think will just make things worse for her. We cannot cure her dementia. She
will die from that.” One spousal caregiver expressed it this way: “Death is not a failure of health
care. We need to have respect for dying.”

Many mentioned preserving the voice of the patient in the dying process: “It [ACP] gives
me a voice for my wife and makes me not so afraid of her dying.” “It gives me a voice in the
decision making and it helps me keep my Dad’s voice in the dying.” “The health care system
does not protect the patient’s voice. Only the caregiver can do that with ACP.” One young
caregiver expressed the reason why preserving her mother’s voice in the dying process was so
important: “It is the only way I can help her die. She is done now and wants to go. She has that
right. I cannot do anything better for her now.”

Over half the caregivers expressed strong religious beliefs and believe that their
religious faith helped shape their ideas about end-of-life care. They profess a strong belief in
God but just as strongly believe they have the right to make their own end-of-life decisions.
Some even expressed that they have an “obligation to make choices for end of life.” One
caregiver described her beliefs as: “I believe in God and the afterlife. God has given us high-
tech health care. We should use it. But that does not take away our right to make choices.”
One caregiver expressed: “It is God’s will to do ACP.” One caregiver who is a devout Mormon
stated: “We have strong beliefs about taking care of our parents. ACP is part of this. End of life
is especially important in the Mormon belief system.” One caregiver who describes himself as
deeply Christian explained: “Death is rejoicing. Not being afraid. Doing ACP planning is part
of a good death.” And another says: “My father believes that God has a plan for us. So when
the time comes to die, he does not want medical treatment getting in the way. That is defying
God’s will.” Another stated: “I am a strong Catholic but that does not mean I value life at all
costs. I believe that nature and God will take its course.”
Four caregivers claimed no specific religious affiliation but expressed a strong spirituality and belief in God. They stated that their belief in God had no impact on their decisions regarding ACP. These caregivers said that their decision to do ACP was based on their personal values, belief in patient autonomy, and the importance of keeping the voice of the patient in the dying process. Like those with a religious preference, these caregivers expressed the same strong belief that ACP was an important part of end-of-life planning. Reflecting on having planning completed one older caregiver summed it up this way: “If there is a God, all things are taken care of and I have done my part. I do not have to worry. If there is no God, then I have had a good life. It’s been awesome.”

One caregiver, who described herself as a staunch Catholic and did not complete an ACP process, said: “It is life at all costs. We have no right to interfere with God’s plan for us. God will take us home when the time is right…it does not matter what the patient wishes. It is about what God wants that matters.”

The majority of caregivers in this study were middle class Caucasian people by their own description. Almost half the sample expressed thoughts about American cultural values having an impact on their thinking about ACP. For example, one elderly male, talked about the impact of his military values on caregiving for his wife. In reflecting on his devotion to his wife’s care he stated: “You never leave a man down. You take care of your own.” Several mentioned the idea of patient autonomy and the right each one has to make decisions about end-of-life care. Others believe that Americans are overly optimistic about what medical technology can do to save us. One caregiver said: “American culture is heavy pro-treatment no matter what. We think we are invincible and there are no limits.” Another expressed: “I have a strong belief in the good of advanced health technology. But it is not for everyone at all times. We have to pick
and choose how to use it.” Yet another feels: “Overtreatment is an unfortunate waste of money. Especially in the face of dementia where nothing can be done to change its course.” Four caregivers claimed that American cultural beliefs did not enter into their thinking regarding ACP. Regarding the two African American caregivers in this sample, one expressed that being African American had no impact on the decision to do ACP and the other caregiver has not done ACP.

The meaning caregivers give to ACP is also expressed in their feelings about having ACP for the patient. Many of the caregivers state that having ACP for the patient “eases a sense of burden” for them: ‘I know my father’s thoughts about how he wants to die and that eases the burden for me.” “I have no guilt making these hard decisions because having done the planning relieves that burden from me.” “Doing planning [ACP] is a gift to me and the rest of the family. I don’t feel burdened doing the right thing for mother.” However, a few caregivers expressed that although ACP relieves a sense of burden on one hand, it does not provide the caregiver complete relief. “Having this [ACP] relieved a lot of stress but, it is still a burden to have to make these hard decisions.” And one caregiver explained that having ACP “did not ease my burden. It is not helpful in the dying. Nothing makes dying easier.” In the context of thinking about easing the burden of decision making, several caregivers mentioned having “peace of mind” because of ACP: “All the planning is done. I can breathe. I know there are big decisions ahead, but I know what my husband wants and that will guide me.” “It gives me peace of mind to have the planning done.” “This is not guess work for me. This [ACP] takes care of the important things.”

The majority of caregivers state that having ACP causes them less stress regarding decision making. Such comments as these were frequent: “It relieves stress knowing that what I say happens.” “It relieves stress for me knowing I have all the legal work done. Gives me some
power.” “I feel less stressed to know my husband’s wishes and I don’t have to make choices in the dark.” “I don’t worry so much. Having ACP helped with that. It would be terrible for my mother if we had not done the planning beforehand.” “I feel less stress because I know what to do when the time comes.”

Along with easing a sense of burden and feeling less stress about decision making, several caregivers expressed a feeling of having some comfort having done ACP. “It is a comfort knowing that I am doing what mother wishes.” “It is a comfort knowing what I need to do for her [wife] next. I do not have to decide alone because I know I am doing what she wants.” “It is comfort knowing the meds [medications] will relieve her pain. Relieve her suffering.” Given the challenge of making final decisions for the patient, one woman caregiver expressed the emotional impact of this responsibility: “I just need a little piece of comfort where I know I am on firm ground.”

**How Caregivers Understand Life Sustaining Measures**

The majority of caregivers (21 out of 22) state they have knowledge of life sustaining measures which include: artificial nutrition (feeding tubes), cardiopulmonary resuscitation (CPR), intravenous hydration, respirators, and use of antibiotics. Most of the caregivers believe that life sustaining measures will not turn the tide on dementia and are not a cure. As one caregiver stated: “They keep you alive. And they don’t cure Alzheimer’s.” Another stated frankly: “They just keep your body going with tests and treatments when you cannot be cured.” An older male caring for his wife expressed: “It is just putting off death that you know is coming.” Caregivers make the distinction between the use of life sustaining measures for illnesses that have a chance of a cure and those that do not. One male stated: “Understand about
these measures. If I had cancer I would want a feeding tube. There is a chance that I could survive. But dementia is different.”

Caregivers express strong emotion about why they would not choose life sustaining measures for the dementia patient: “Using life sustaining measures is cruel. It is simply cruel to let him [husband] go on living this way.” “Life support is horrible. It is cruel. We treat our dogs better.” “I would never choose a feeding tube because quality of life is so diminished.”

As with the “gray area” of decision making regarding the use of antibiotics, these caregivers are divided on whether antibiotics are either a life sustaining measure or a comfort measure. Some caregivers understand that under varying circumstances antibiotics can be either. In treating a UTI it can bring immediate comfort to the patient, but treating repeated bouts of pneumonia might not be considered comfort, but life sustaining. One caregiver described the use of a feeding tube as a comfort measure: “Saying yes to a feeding tube was comfort for my husband as he could not feed himself anymore.” Yet another expressed: “We stopped my Dad’s heart meds [medications]. Is this a comfort measure or is this just keeping him alive longer than he wants to be?” Caregivers understand the complexity of decision making regarding life sustaining measures. This conflict between life sustaining measures and comfort care are reflected in their comments: “Different situations need different treatments.” “Decision making is different for each measure. Each needs to be decided case by case.” “Too many factors feed into decisions about life sustaining measures.” A few caregivers are challenged by the patient’s wishes: “My grandmother wants all treatment done right to the end. Yet she tells me she does not want to live like a vegetable. How do I manage to honor both those wishes?” In addition, two caregivers express thoughts about life sustaining measures similar to their views about ACP: “Only God can take a life. We cannot withhold treatment under any circumstances.” “You can’t
take a life. Need to wait for God to call a person home. No withholding treatment. Ever.”

When caregivers were asked about whether they had knowledge of the impact of life sustaining measures on advanced dementia patients, eleven of the caregivers said they do not know the specific impact on dementia patients, but in general objected to using life sustaining measures for anyone with an incurable illness. The other half of the caregivers expressed some knowledge of the impact of life sustaining measures on dementia patients due to their experience in the family with disease and disability. One caregiver said: “I know that certain types of anesthesia and meds [medications] can increase confusion and feeding tubes can cause infections. It happened to my father.” Another stated: “I know from my mother’s experience that life sustaining measures can’t do any good. Does not change dementia…it just extends life…no one benefits except health care folks that bill the heck out of Medicare.”

Caregivers’ Knowledge of Patients’ Wishes for End-of-Life Care

Caregivers’ knowledge of patients’ wishes for end-of-life care is the foundation of their strength in meeting the challenges of decision making. Their strength for making the difficult decisions necessary is based on their belief that they know the patient’s wishes and they are doing the right thing by honoring them. Their knowledge of patients’ wishes come from the written ACP documents, but their understanding is expanded and fortified by the conversations they have had with the patient prior to late dementia, the conversations they have within the family, and with trusted outsiders. As reported in “Key Features of Phases of the ACP Timeline: Conversations in family and with others,” the conversations between the caregiver and patient were usually either brief, off-hand comments or regular conversations about end-of-life care. More than half the caregivers reported having conversations regarding future care and making plans for death. Comments such as these were expressed by many: “We talked to our daughter
about what we wanted at the end. I knew my wife’s wishes because we talked about that.

There was no doubt about what she wanted. That helped me make the decision about no feeding tube.” “Dad was clear that he did not want life sustaining measures. He said it repeatedly. So I know what to do when we get there.” “My mom did not talk about this much. But she made her wishes known anyway but saying over and over. ‘Don’t let them do anything to me. Let me die.’ One caregiver spoke frankly: “We talked about death openly and to accept that it is coming. We have no fear about that….but do not want to be hooked up to machines. Quality of life matters.” One male caregiver expressed: “My wife gave me all the ammunition I needed to battle the docs [doctors]. She told me not to keep her alive if she could not smile at me and give me a kiss good night.”

Some caregivers reported no conversations with the patient regarding end-of-life wishes, but rely completely on what is written in the living will and base their decision making on the “best interests” of the patient (what the caregiver believes the patient wants based on their own values, beliefs, and experiences). Among this group of caregivers, these comments were common: “We did not talk about end-of-life care, but we did talk about loss of function, need for a nursing home down the road, giving away our possessions, and funeral planning.” “We had few if any conversations with Mom about dying or anything else for that matter. She was not close to the family.” “Dad did not want to talk about the past or the future. Planning was difficult with him.” “Mom would talk about funeral plans but not about dying or what she wanted.” “My husband put off all talk of dying. He was suspicious. Thought he was tempting fate. Makes horrible things happen.”

Conversations within the family group about choices for the patient often results in
conflict. Several caregivers in the study indicate there is lack of agreement among family members about withholding/withdrawing treatment for the patient. One caregiver reports that she was angry at her stepfather (who was her mother’s health care proxy) about not treating her mother’s pneumonia with antibiotics. “He had no right to withhold treatment from her. He allowed her to die.” Another female caregiver reports that her stepchildren are suing her for guardianship for her husband with dementia because she is implementing his wishes for end of life.

In this study, caregivers report knowing the patients’ wishes for care. The conflict arises not always from family members disagreement with patient choices for care, but rather with the shared-decision making established in some families. In an effort to reduce conflict among his three adult daughters, one caregiver named his oldest daughter’s husband as health care proxy for him and his wife. Such an arrangement did not work well among the daughters and caused more conflict than the caregiver had expected. He stated: “dementia creates a lot of conflict in the family as we try to figure out what to do.” In another family, the three adult daughters share the care and responsibility for their mother with dementia. The eldest has the health care proxy and is in charge of medical issues; the second daughter handles the legal and financial matters, and the youngest daughter helps mother with day-to-day care. This arrangement held up well during the early to moderate stages of dementia, but as mother has advanced in her illness, the decision to treat or not treat is getting difficult. The three daughters cannot reach agreement on whether to withhold treatment or not. As the eldest daughter said: “I wish I had the power to make all the decisions for Momma then this nightmare would be over.” Many families report no conflict in the family because they know the patient’s last wishes and are willing to accept and act on those wishes. They manage their disagreements and are able
to share the care of the patient.

In addition, several caregivers expressed the idea that having ACP documents is not enough but conversations with the patient and in the family are needed to create understanding and a willingness to go along with patient wishes. One spousal caregiver stated: “We did planning [ACP] early on but dementia is a long thing and I don’t believe the written papers are enough. It may be enough for the medical professionals but the family needs more. We need to talk about dying more and what we want at the end. We have to prepare the family for what is coming.” Another claims: “Paperwork [ACP] is not enough. We have to talk and get family onboard with what we want. Otherwise we leave a mess behind.”

Factors That Influence the Caregiver ACP Process

In response to the second research question for this study (What factors influence caregivers’ decision-making process regarding ACP?), key demographic, psychosocial, and situational factors emerged from the data which are relevant to the process. These factors influence why people choose to complete an ACP process and research has shown they are predictive of having ADs. See Figure 8 which presents a visual display of the entire Dementia Caregiver Advance Care Planning Theory, including the theory components and the factors that influence the process.

Demographic Factors

In this study, education (both formal and informal), socioeconomic status, and religious beliefs influenced caregivers regarding what meaning they give to the ACP process.

Education level: Among these caregivers the formal educational level is high with 15 holding college degrees and six having attended one year or more of college. Only one caregiver
has a high school diploma. As explained in “Gaining Knowledge about ACP,” these caregivers self-educate at a high level. Half the sample attends support groups, contacts the Alzheimer’s Association Helpline to find resources and information, and attends educational workshops about various stages of dementia. Most of the caregivers use the internet and explore websites concerned with health, legal, and financial issues affecting dementia families. Some also explore and are involved in websites which allow interaction and sharing information such as caregivers’ blogs. The majority of caregivers report having knowledge of the various stages of dementia and life sustaining measures. They understand the legal implications of a dementia patient not able to give consent for treatment and the need to find ways to finance long term care for end-stage dementia. Based on this knowledge, the majority of caregivers seek needed community resources, i.e., day care programs, senior center programs, assisted living/nursing home facilities, home health agencies, etc. Nineteen of the twenty-two caregivers in this study have reached out to lawyers or elder law attorneys for ACP planning, estate planning, and information on financing long term care.

**Socioeconomic status:** Although the caregivers in this study are deeply concerned about how to finance long term care for the patient should such care be needed, the majority of the caregivers report that their income is sufficient and “money is not a problem.” Nine of the caregivers report that they “just manage to get by,” or are “having trouble making ends meet.”

**Religious affiliation:** Caregivers in this study report a high level of religious affiliation. Eighteen of the twenty-two caregivers identify with a specific religious group, predominantly Protestant. Four expressed no religious affiliation, but describe themselves as “spiritual” with a strong belief in God.
Psychosocial Factors

In this study greater disease burden, anxiety, and locus of control for decision making influenced caregivers’ understanding and use of ACP.

Greater disease burden: Twenty of twenty-two caregivers in this study completed a formal ACP process motivated by previous family experience with illness and death. The majority of caregivers made changes to ACP after the dementia diagnosis due to the threat of the patient losing the ability to give consent for end-of-life care and concern that the caregiver maintain the power and control to make decisions on behalf of the patient. The caregivers express the challenges of decision making for the patient and the responsibility for honoring the patient’s wishes weighs heavily on them. These caregivers experience a high disease burden which influences the meaning they give to planning and their use of ACP.

Death Anxiety: As described in the “Caregiving Context” the caregivers in this study experience high levels of anxiety due to fatigue, worry, and the unpredictability and intensity of the problem solving required to care for the dementia patient. They did not describe having anxiety about death. Regarding using ACP they describe their anxiety about assessing quality of life for the patient, understanding the trajectory of end stage, and losing control of the dying process for the patient. The majority of caregivers express that ACP gives them power to act on behalf of the patient and some measure of control over whether or not life sustaining measures are used, when to stop medications for the patient, and when to withhold, withdraw, or continue treatment and request palliative/hospice care.

Locus of control for decision making: For the majority of these caregivers the locus of control for decision making is internal to themselves. They express high levels of self responsibility for making the difficult decisions regarding end-of-life care for the patient. They
acknowledge these decisions will be emotionally challenging but they feel strongly it is their duty to “do the right thing” by “honoring the patient’s wishes.” They express deep concern about the patient having a peaceful death with pain that is well controlled. Caregivers report consulting and seeking support from other family members (i.e. siblings, spouses, adult children), and others outside the family (i.e., clergy, doctors, friends, and neighbors). But the locus of control for decision making, stays firmly in the family with the ultimate decision regarding withholding or withdrawing treatment made by the caregiver.

**Situational Factors**

Situational factors that influenced caregivers’ understanding and use of ACP include: experience with illness and death of family members, having knowledge of ACP and life sustaining measures, contact with doctors, and seeking support from others.

**Experience with illness and death of family members:** For the majority of caregivers in this study family experience with illness and death is the chief driver of initiating an ACP process. These caregivers completed ACP years before the dementia diagnosis based on their experiences with illness and death of parents, grandparents, and siblings. At dementia diagnosis, the caregivers revised ACP due to the dementia threat but also with clear memories of watching their parents or significant others die without the patient’s voice in the dying process. Many expressed dismay that their parents had not planned for the end and had no living will. Others expressed gratitude that family members had talked about their wishes prior to the end and had done ACP.

**Knowledge of ACP and life sustaining measures:** In line with the high ACP completion rate, these caregivers overall demonstrate a high level of understanding about living wills, health care proxies, and life sustaining measures. As explained in “education level” in
addition to having a high level of formal education, these caregivers are self-educated regarding dementia and legal, financial and health care planning. They state having an understanding that the patient has a right to make choices about end-of-life care. They understand that ACP gives them the legal power to assure that those choices are implemented as the patient moves closer to death.

**Contact with doctors:** Several of the caregivers in this study attribute contact with the patient’s doctor as the reason why they sought an elder law attorney after diagnosis to revise their ACP forms. They report this contact was often with the neurologist who diagnosed the dementia. In several cases, the neurologist explained to the family that dementia is terminal and that there is a narrow window of opportunity while the patient is still cognitively able to do ACP. Many of the caregivers report that the long-standing relationship with their primary care doctor had ended due to the patient moving into a nursing home. Upon entering a nursing home, it is standard practice that the primary care physician transfers the care of the patient to the doctors who are on staff at the nursing home.

**Seeking outside support:** Just as they reach out to seek information about dementia, the majority of these caregivers also seek support outside the family to help with (1) care for the patient, (2) planning, and (3) help for themselves to boost their level of self-care. Half the sample report the knowledge gained in their support groups helped them reach out to gather necessary resources and to prepare for the changes that occur as dementia progresses. In seeking outside help, they learn about the local resources available to support their caregiving and learn how to plan for future care, i.e. home health assistance, day care programs, and patient transfer to residential care. In addition, they seek advice about the legal, financial, and health care planning that is needed during the long journey of dementia. In this process, they revise their ACP plan
and make financial plans for how to handle the costs of long term care. In addition, these caregivers report a high level of other aspects of end-of-life planning including: (1) funerals, (2) cremation, (3) organ donation, and (4) disposition of their property and personal treasures.

**Unanticipated Findings of this Study**

Although the study was not designed to compare groups, in the course of data analysis two sets of groups emerged in the data: (1) support group and non-support group members and (2) caregivers with patient in early/moderate dementia and caregivers with patient in end stage to death.

**Support Group and Non-Support Group Members**

The sample splits evenly between support group members (11) and non-support group members (11). When comparing these two groups several differences and similarities emerge regarding their attitude toward dementia, coping with dementia, conversations about end-of-life care, the meaning they give to ACP, and feelings about having ACP for the patient. They express differences in how they gain knowledge about ACP and where they keep their ACP documents. They express similarities about the role of decision maker and the timing of doing ACP. Figure 7: Differences and Similarities Between Support Group and Non-Support Group Members Regarding Patient End-of-Life Care delineates the differences and similarities of these two groups.

The highlights of the comparison of these two groups demonstrate that compared with non-support group members, support group members can be described as doing more of the following:

- expressing the impact of dementia and caregiving on their family with a language for sharing their feelings about how they have absorbed dementia into their lives.
• planning proactively

• having conversations in the family and with the patient about end-of-life planning

• seeking support from multiple sources in the community

• understanding and using ACP more as an effective tool

• having knowledge about the impact of life sustaining measures on dementia patients

• knowing where the ACP documents are kept and making them accessible to other family members and health care professionals
Figure 7  
Differences and Similarities Between Support Group And Non-Support Group Members Regarding Patient End-of-Life Care

<table>
<thead>
<tr>
<th></th>
<th>Support Group Members</th>
<th>Non-Support Group Members</th>
</tr>
</thead>
</table>
| 1. Attitude regarding dementia | • Pragmatic view of dementia (“What will be, will be;” “It is not the life I imagined, but is the life I have”) | • Few express pragmatic view.  
• Express being “used up living day to day,” “caregiving takes all my energy” |
| 2. Coping with dementia     | • Planful, proactive. Focused on problem solving in present and for future care  
• Seeks support from family and other sources (i.e. friends, neighbors, support groups).  
• Feels overwhelmed by caregiving due to money worries and continuous problem solving | • Reactive problem solving. Focused on next problem that arises.  
• Seeks support from family. Some support from Helpline.  
• Same |
| 3. Conversations about end of life | • More conversations with patient about wishes and more with family about dementia, dying, and end-of-life choices.  
• Conversations about end of life reduces some conflict in the family.  
• Some report lack of agreement regarding patient choices and problems with shared decision making. | • Fewer conversations with patient and family about any aspect of dementia, dying, or end-of-life choices.  
• Same  
• Same |
| 4. Meaning of ACP           | More express ACP as effective tool:  
• Allows for active charge of patient care  
• Gives power and control to caregiver  
• Keeps patient voice in dying process  
• Helps patient die peacefully | Fewer express ACP as effective tool:  
• Little mention  
• Same  
• Same  
• No mention  

Impact of religious beliefs on ACP:  
• Express deep religious beliefs but don’t want treatment getting in way of dying.  
• Those not religious, express spiritual beliefs but feel this has no impact on decisions about ACP. | Impact of religious beliefs on ACP:  
• Majority express this  
• Same |
<table>
<thead>
<tr>
<th></th>
<th>Support Group Members</th>
<th>Non-Support Group Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.</td>
<td><strong>Feelings about having ACP for patient</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Express emotional pain of patient losing cognitive abilities and function – have language for feelings “this is hard, disappointing;” “these are not golden years”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Express grief over loss of patient: “someone you love disappearing”</td>
<td>• Express few feelings regarding this.</td>
</tr>
<tr>
<td></td>
<td>• Do not want to prolong patient’s pain</td>
<td>• Few express this feeling.</td>
</tr>
<tr>
<td></td>
<td>• Less stress regarding decision making.</td>
<td>• Few express this feeling.</td>
</tr>
<tr>
<td></td>
<td>• Sense of comfort</td>
<td>• Some express less stress regarding decision making</td>
</tr>
<tr>
<td></td>
<td>• Eases burden</td>
<td>• Same</td>
</tr>
<tr>
<td></td>
<td>• Express few feelings regarding this.</td>
<td>• Same</td>
</tr>
<tr>
<td></td>
<td>• Few express this feeling.</td>
<td>• Same</td>
</tr>
<tr>
<td></td>
<td>• Few express this feeling.</td>
<td>• Same</td>
</tr>
<tr>
<td></td>
<td>• Some express less stress regarding decision making</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Same</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td><strong>Role as decision maker</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Believe strongly in “doing the right thing” by honoring patient wishes</td>
<td>• Same</td>
</tr>
<tr>
<td></td>
<td>• Takes responsibility for making difficult decisions</td>
<td>• Same</td>
</tr>
<tr>
<td></td>
<td>• Understand may do battle with health care professionals</td>
<td>• Same</td>
</tr>
<tr>
<td>7.</td>
<td><strong>Gaining knowledge of ACP, dementia</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Report more conversations with lawyers, health care professionals, others</td>
<td>• Report few conversations with others outside the family</td>
</tr>
<tr>
<td></td>
<td>• More self educating by reading books, exploring internet sites</td>
<td>• Report use of Helpline and websites</td>
</tr>
<tr>
<td></td>
<td>• Have more knowledge of impact of life sustaining measures on advanced dementia patients</td>
<td>• Little knowledge of impact of life sustaining measures on advanced dementia patients</td>
</tr>
<tr>
<td></td>
<td>• High level of knowledge about what life sustaining measures are and what they do</td>
<td>• Same</td>
</tr>
<tr>
<td>8.</td>
<td><strong>Timing of ACP</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Do initial ACP years before dementia diagnosis</td>
<td>• Same</td>
</tr>
<tr>
<td></td>
<td>• Makes changes to ACP at diagnosis</td>
<td>• Same</td>
</tr>
<tr>
<td>9.</td>
<td><strong>Keeping ACP Documents</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Keep documents at home and with lawyer. Some in safe deposit boxes in bank</td>
<td>• Same</td>
</tr>
<tr>
<td></td>
<td>• Other family members (usually spouse, adult child, siblings) can access documents when needed</td>
<td>• Few have documents accessible by others</td>
</tr>
</tbody>
</table>
Caregivers With Patient in Early/moderate Dementia and Caregivers With Patient in End Stage to Death

Two more groups emerged from the data analysis: caregivers of patients in the early to moderate stage of dementia (10) and caregivers of patients in end stage to death (12). Upon comparison caregivers of patients in end stage to death are different from caregivers of patients in the early to moderate stage in the following ways:

Coping with dementia: They are more proactive in planning and describe themselves as “planning people.” They report that focusing on problem solving relieves anxiety for them. They have done more planning regarding funerals, cremation, and disposition of their possessions.

Seeking support: Caregivers seek more support from home health agencies, daycare programs, assisted living, and nursing home facilities. They find their doctors more helpful in planning for the patient’s cognitive and physical changes that occur in dementia.

Feeling overwhelmed by caregiving: This group expresses more stress about caregiving, money problems, the burden of continuous problem solving, exhaustion, and feeling “trapped in the care.”

Conversations about end-of-life care: Caregivers report more family conversations about end of life, the trajectory of dementia and using ACP. More report having had conversations with the patient about wishes for care. They state that because they have ACP there is less conflict in the family about patient’s wishes but there are problems with shared-decision making.
The meaning of ACP: Caregivers express strong belief that having ACP keeps the patient’s voice in the dying process and they are willing to use ACP as an effective tool to that end.

Role as decision maker: These caregivers say “no” to the use of antibiotics more often than the early/moderate stage group. They report having little knowledge of the impact of life sustaining measures on advanced dementia patients. They worry about assessing the quality of life of the patient on a daily basis and accept that they will (and are currently) “doing battle” with health care professionals regarding withholding/withdrawing treatment. They stand firm in their belief that the patient must be kept comfortable and they choose hospice care more frequently. They include more family members in their discussion about patient care but reserve final decisions as their personal responsibility. Caregivers display a strong sense of purpose in their decision making for patients because they believe they know what patients wish and will do everything they can to honor those wishes.

The early/moderate group and the end stage/death group also share similarities. Caregivers in both groups are:

- Devoted to patient care
- Believe they are doing right thing by honoring patient wishes
- Understand that dementia is terminal
- Understand and accept that will have to make difficult decisions
- Understand ACP and what life sustaining measures are
- Seek support from trusted others
Comparison of Support Group/Non-Support Group Members With Caregivers of Early/Moderate Stage Patients and Caregivers of End Stage to Death Patients

Upon further analysis the comparison of both sets of groups reveal that in the early/moderate group, more caregivers are support group members than not (support group members, 7; non-support group members, 3). In the end stage to death group, the reverse is true: support group members (4) and non-support group members (8). In the end stage group, caregivers are more similar in behavior to support group members whether they belong to a support group or not. They are similar in the following ways:

- more proactive planners, problem solvers
- have more conversations in the family about patient’s choices and care
- more use of ACP as an effective tool

Defining End-of-Life Planning and Advance Care Planning

Another unanticipated finding of this study is how the caregivers define both “end-of-life planning” and “advance care planning.” Several caregivers stated that they had not heard the term “advance care planning” before but did recognize and understand the term “end-of-life planning.” Caregivers were clear about the meaning of a living will and health care proxy but did not always understand this as “advance care planning.” Researchers often use these terms interchangeably. Many caregivers expressed having a living will and a health care proxy is a vital part of end-of-life planning which also includes funeral planning, organ donation, and disposition of their personal belongings and treasures.
On the following page is Figure 8 which presents a visual display of the entire Dementia Caregiver Advance Care Planning Theory, including theory components of how caregivers do ACP, how caregivers use ACP, and the factors that influence the process.
### Figure 8: The Dementia Caregiver Advance Care Planning Theory

<table>
<thead>
<tr>
<th>Theory Components</th>
<th>Trajectory of ACP</th>
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<tbody>
<tr>
<td><strong>How Caregivers Do ACP</strong></td>
<td><strong>Years Before Dementia</strong></td>
</tr>
<tr>
<td></td>
<td>Action taken: Do Initial ACP</td>
</tr>
<tr>
<td></td>
<td>• To protect dependents, assets</td>
</tr>
<tr>
<td></td>
<td>• Do living will/POA tacked on to financial planning</td>
</tr>
<tr>
<td></td>
<td>Motivated by: family experiences with illness and death</td>
</tr>
</tbody>
</table>

**Influencing Factors**
- **Demographic** (age, education, SES, religious affiliation)
- **Psychosocial** (greater disease burden, death anxiety, locus of control)
- **Situational**: (experience with family illness/death, knowledge of ACP, contact with doctors, seeking outside support)

**Key Features of Process**
- **Conversations**
  - In the family
    - Content: Difficult death of family member, Dying well with little pain
    - With others (doctors, lawyers, friends, neighbors, support groups, etc.)
    - Content: Learning about dementia, death, Problem solving in present, planning for future care
  - In the family with patient
  - With others (doctors, AL/NH staff, friends, neighbors, support groups, etc.)
    - Content: Assessing change in patient health status and quality of life; assessing disease trajectory
    - Concerns regarding patient care in AL/NH

- **Gaining knowledge of ACP**
  - Lawyers, media, family, trusted others
  - Elder law attorneys, health care professionals, Educating self, media stories
  - Elder law attorneys, health care professionals, educating self

- **Keeping ACP Documents**
  - Keep forms at home, with lawyer; accessible by family members
  - Keep forms at home, with lawyer, bank security box; Accessible by patient, spouse, adult child
  - Keep forms at home, AL/NH facilities, with lawyer; accessible by POA usually spouse, adult child

**How Caregivers Use ACP**
- **Beginning after dementia diagnosis and continuing into end stage to death**
  - Role of Decision Maker
    1) Accept responsibility for making difficult decisions regarding withholding/withdrawing/continuing treatment for patient
    2) Use ACP as effective tool to exercise power and control for shaping the dying process for patient
    3) Accept doing battle with health care professionals to honor patient wishes
  - Key features that shape this role
    1) The Meaning Caregivers Give to ACP
    2) How Caregivers Understand Life Sustaining Measures
    3) Caregivers’ Knowledge of Patients’ End-of-life Wishes
Chapter 5: Discussion and Implications

This is an exploratory study that examined a sample of an understudied population, dementia caregivers, regarding an understudied issue, end-of-life planning for the dementia patient. The findings of this study contribute to advancing knowledge about how caregivers understand ACP and how they use ACP to shape the dying process for the dementia patient. When compared to the existing conceptual models of ACP planning, this new theory, The Dementia Caregiver Advance Care Planning Theory, adds new knowledge specific to dementia caregivers, provides a trajectory for ACP, and a definition of the caregiver’s role as decision maker for the patient. (These models are delineated in Chapter Two, Conceptual Models of ACP Decision Making). The new theory adds dimension and depth to the current existing models in the following ways:

**Detailed ACP Process:** In addition to the three-step ACP process explained by the Lambert (2005) and Cantor and Pearlman (2003) models, this new theory presents a more comprehensive, detail-rich process that includes the timing of ACP, motivation for actions, conversations inside and outside the family, gaining knowledge of ACP, and the keeping of ACP documents. It includes the impact of media stories about families conflicted over end-of-life care and advice from professionals (lawyers, health care professionals, clergy, advocacy groups, etc). It is important to note that the ACP process is not just one of executing formal documents, but an ongoing informal process within the family. This supports what other studies have found that ACP is ongoing and doing the written formal documents is just the beginning of the process (SUPPORT Study Principal Investigators, 1995; The SUPPORT Study, Teno, et al., 1997).
Impact of conversations on ACP process: This new study supports what other conceptual models have discovered: on-going conversations both inside the family and outside with trusted others has a major impact on how ACP is understood and used to shape the dying process. On-going conversations serve to help the caregiver understand patient wishes for the end, to prepare family members for the death of the patient, and to fortify the strength of the caregiver when faced with “doing battle” with health care professionals regarding withholding and/or withdrawing treatment. These findings support research evidence that ACP offers a language and framework for having conversations about death and dying that helps to organize thoughts and articulate preferences (Cantor & Pearlman, 2003; Doukas & Reichel, 2007; Martin, et al., 1999).

This new knowledge challenges researchers to examine more closely the process by which patients communicate their wishes and how they want to communicate them. The absence of written formal documents does not imply that conversations have not taken place within the family that satisfy the patient’s needs for communicating their wishes. Because these conversations are central to the ACP process, they require further exploration. In all ACP phases knowing the quantity, quality, and content of the conversations is vital to understanding ACP and would add depth to this new theory.

Most important influences on ACP process: This new study supports that the most important influences on the ACP process are previous experience in the family with illness and death and spiritual and religious beliefs (Lambert, 2005; Martin, et al., 1999; Singer, et al., 1998).

Primary relationship in ACP process: This new study supports prior assertions that the most important relationship regarding ACP planning and end-of-life choices is that of the patient
and caregiver with trusted others, not the physician-patient relationship (e.g., Lambert, 2005; Martin, et al., 1999; Singer, et al., 1998). Health care professionals can help guide ACP discussions, even get them started in some families, but the relationship of the patient and caregiver to the physician is not the central relationship of the process. Caregivers want some control over decision making for the patient and for themselves at end of life. They do not believe the decision making should be in the hands of health care professionals. These caregivers believe the power of decision making rests with the caregiver and the family. This challenges the traditional academic assumption that ACP occurs within the physician-patient relationship.

Most importantly what this new theory adds to the existing models is a better understanding of the role of decision maker. Dementia patients are in a unique situation at end of life compared to some other patients with greater disease burden. Dementia patients rely totally on their caregivers to act on their wishes as they are no longer able to do so on their own behalf. This places a heavy burden on caregivers who want to “do the right thing.” Caregivers are making these decisions in the context of the long-term, progressive burden of dementia care. These caregivers describe fatigue, sleep problems, worry, focus on problem solving, and money and job-related problems. This study begins a line of inquiry to further explore how dementia caregivers make these decisions and the nature of their battle with health care professionals. The findings of this study illuminate a path to further research especially regarding conversations in the family and with trusted others and how they interpret their role as decision makers.

**Sample Demographics and Caregiver Context**

Caregivers in this study are predominantly women (17 women, 5 men). This is consistent with most research on caregiving, domestic or global. Caregiving for children and elders is largely women’s work. More women leave the work force due to caregiving issues than men.
This holds true for dementia caregiving as well (Alzheimer’s Association, 2011). Although the majority of caregivers in this study describe their health as “excellent” or “good,” they describe experiencing the impact of long term caregiving as high levels of fatigue, worry, and sleep problems. Older caregivers in the study worry about their own health holding up while caring for the dementia patient. Dementia caregivers usually describe their health as “fair” and often describe that stress and health problems are impacting them in negative ways (National Alliance for Caregiving and AARP, 2009). The mean caregiving time in this study is five years. On average dementia patients after diagnosis live with the disease from 4 to 20 years with one-on-one care by a caregiver occurring from moderate to end stage (Alzheimer’s Association, 2011). It is possible that their self-described health status is related to the length of time caregiving, but more likely is related to a strong self-definition as caregiver for the patient and a need to see this job through to the end. Staying strong and “doing battle” on behalf of the patient is vitally important to these caregivers and they may be understating the impact of intense caregiving on their own health. Teasing apart this health status question will require further inquiry.

Caregivers in this study report a high level of withdrawal from work, social and leisure activities due to the demands of care for the patient. This is consistent with research findings on dementia caregiving in general (Alzheimer’s Association, 2011; Liken, 2001; National Alliance for Caregiving, et al., 2009). The overall description of the impact of caregiving (i.e. fatigue, sleep problems, worry, focus on problem solving, money problems) is also consistent with caregiving research. Dementia is called the “family disease” because it places a long-term, progressive burden on those who are the caregivers (Alzheimer’s Association, 2011; The Alzheimer’s Study Group, 2009, Met Life Market Institute, 2006).
The Process of ACP

A surprising finding is that 20 of the 22 caregivers in this study have completed an ACP process with written formal documents, both a living will and health care proxy. This is a high prevalence compared to competent adults in the community with an estimated completion rate of 18% to 36% of the adult population (Center for Gerontology and Health Care Research, 2008). ACP completion rates for dementia patients from the 1990s estimates that only 15% have ADs but more recent data indicates that 36%-60% of nursing home residents have at least one AD, usually a DNR (U.S. Department of Health and Human Services, 2008). The majority of the sample completed an initial ACP process many years prior to the dementia diagnosis motivated primarily by experience with family members’ illness and death. In addition, these caregivers may have a high incidence of ACP completion due to the fact that half of the sample are members of support groups sponsored by the Alzheimer’s Association. The Alzheimer’s Association advises dementia families to seek out elder law attorneys to do end-of-life planning as soon after diagnosis as possible to assure that the patient has a voice in the planning. Caregivers report that advice from other caregivers was influential in their doing ACP quickly. The other caregivers in the study who are not support group members have a high prevalence of ACP completion which they attribute to advice from others, often doctors or other family members, and they self educate about planning for end stage dementia.

A driving force for the majority of these caregivers, whether support group members or not, is planning for what is to come down the long road of dementia. A new finding not yet explored in research is that caregivers plan, including ACP, because it reduces their anxiety and offers a sense or perception of control in an uncontrollable disease process. They plan because
they do not want to be paralyzed and they want to help. Planning helps distract them from their worry.

At dementia diagnosis, most caregivers seek out elder law attorneys to change ACP documents and to seek ways to finance long term care. The vast majority of caregivers in this study were not aware that an attorney is not required to complete formal written ACP documents. Only one caregiver was aware of this and acted on it. More adults might complete ACP documents if they were made aware that an attorney is not required and no money is needed to complete them. The forms can be downloaded free-of-charge from specific state websites or from advocacy organizations, such as Five Wishes.

The two caregivers in this study who did not complete an ACP process felt they had no assets to pass on to family members after their death and thus believed there was no reason to do ACP. There is cause for concern that adults believe ACP to be strictly about financial issues and not about the power to shape a good death. Decoupling financial planning for end stage and ACP would be difficult due to the fact that health care costs are rising substantially for end-of-life care and long term care poses an economic threat to most families. However, ACP should be more than “tacked on” to financial planning. Having the power to honor the patient’s wishes at end of life for these dementia patients has a high value for caregivers. Many feel this is all they have to give the dementia patient in the end. As one caregiver expressed: ‘It [ACP] makes the dying matter as much as the living did.” Given the importance that caregivers attach to having the power to make good choices for the patient, ACP should be explained to families in the same depth and with the same care that financial matters are.

It was striking to note that three caregivers in the study had been advised by elder law attorneys to divorce the dementia patient in order to protect family assets and pay for long term
Divorcing the dementia patient allows for the required Medicaid “spend-down” to qualify for coverage for long term care by impoverishing the patient. Divorce is just one asset-sheltering strategy recommended by financial advisors and attorneys to avoid the “Medicaid trap.” There is great controversy around this issue. Some critics say Medicaid is a public program intended for those in poverty, not as a form of estate planning to protect assets to be inherited by the children. Family assets should be spent on long term care. Others claim families should take advantage of Medicaid eligibility laws and plan for nursing home costs. This is not immoral or illegal. Good government should share the costs of long term care and end-of-life care as right now families carry the full burden of caregiving costs. The moral and ethical issues posed by this controversy require further inquiry. There is a need for this research as currently Medicaid is the primary government payer for long term care and covers 36% of nursing home costs (Moody, 2010, p. 200). With two-thirds of the Medicaid budget paying for nursing home residents, the costs are rising rapidly as the 80-plus population increases. Research would form a foundation from which questions regarding sustainability of Medicaid expansion and shared responsibility for the costs of long term care could be addressed.

A novel finding in this study is that at dementia diagnosis the caregivers reported the neurologist who diagnosed the dementia talking to the family directly about the fact that dementia is terminal. “You will die from this; There is no cure.” These statements confront the conspiracy of silence that physicians have had with families about the dementia diagnosis. Most earlier studies report that doctors do not tell patients that dementia is terminal and rarely prepare the family for the patient’s decline and death. Mostly physicians treat the symptoms that the patient presents with and do not explain the symptom in the context of a fatal illness. There is some evidence in the literature that physicians do not discuss end-of-life care with patients and
caregivers and even fewer provide information on ACP (Volicer, 2005; vonGunten, et al., 2000). The fact that some physicians are telling patients dementia is terminal is a new development in the research and may reflect a deeper understanding about the relationship between dementia and death. Patients die from dementia. It is “brain failure” just as we have “heart failure” or “liver failure.” As the American Hospice Foundation suggests we need to reframe the definition “….to understand dementia means knowing that it will always be life-changing, and that it will finally become life-ending” (2007. Downloaded on January 5, 2012 from www.americanhospice.org/articles-mainmenu-8/about-hospice). It is striking to note that the caregivers in this study, whether a health care professional had told them that dementia is terminal or not, were keenly aware that the patient will die from dementia.

This sample of caregivers, in addition to having a high level of formal education, also self-educate at a high level. These caregivers understand the stages of dementia, have a good understanding of living wills and health care proxy, and have knowledge of life sustaining measures. They have less understanding of the specific impact of life sustaining measures on advanced dementia patients and are frustrated by lack of help understanding the trajectory of end stage dementia. Unlike earlier studies these caregivers do not experience a lack of knowledge about ACP, how to do ACP, or life sustaining measures (Broadwell, et al., 1993; Cantor & Pearlman, 2003; Field & Cassel, 1997). Although having lack of ACP knowledge was an important finding for two conceptual models (Lambert, 2005; White, 2005), the finding did not hold in this new study. Instead caregivers in this study are struggling with understanding markers for end stage, when to ask for hospice care, and assessing quality of life of the patient.

Caregivers self educate using the internet and search for information on dementia, dying, caregiving, and for local resources. To find support some use interactive sites in caregiving
blogs and on-line support groups (i.e., Alzheimer’s Association online message boards and chat rooms; AARP Caregiving Resource Center online discussion groups and blogs). This is new in the research and reflects the rapid rise of web-based tools for caregivers. A high level of self education using technology may become a predictor of ACP completion and will require on-going research to verify.

Where caregivers keep the signed ACP documents is an important concern. In the fractured U.S. health care system, it is important for each family to hand carry these documents to acute care facilities, assisted living and nursing home facilities. The staff of these facilities are required by law to ask a caregiver if they have ACP for the patient, but if the caregiver does not have the documents they are not entered into the patient’s medical record and the facility will proceed as if the patient has none. The Patient Self Determination Act 1991 mandated that facility staff ask a caregiver if the patient has documents but they are not required to explain the living will and health care proxy to them nor to help them complete the forms. It becomes a vital issue that the caregiver knows where the forms are located and that they are accessible in times of emergency. Also, it is necessary for others (family members or friends) to know where the forms are located. Some states (13) have moved to a Physicians Order for Life Sustaining Treatment (POLST) which is a one sheet document as the first page of a medical record. It identifies the patient, illness, wishes for end-of-life care, and identifies their health care proxy. As medical records become digitized as the standard of practice, the hand-carrying of the ACP forms may not be necessary. But currently, it is imperative for caregivers and families to maintain custody of the ACP forms.

Although the POLST forms will be convenient and available to medical personnel, it will not replace the ACP process that needs to occur within the family. Understanding the rights of a
patient in the dying process, gaining knowledge about ACP and life sustaining measures, reflecting on personal, religious, and cultural values, making end-of-life choices, and sharing conversations in the family and with others will still need to be ongoing. As the findings of this study indicate, completing ACP documents is not sufficient to manage the difficult decision making at the end. One spousal caregiver stated: “We did ACP early on but dementia is a long thing and I don’t believe the written papers are enough. If may be enough for the medical professionals but the family needs more. We need to talk about dying more and what we want at the end. We have to prepare the family for what is coming.”

**How Caregivers Use ACP**

The majority of caregivers use ACP for decision making regarding the patient. Even those in the moderate stage of dementia feel they need to remind health care workers that they make the decisions about daily care, medications, transfer to acute care facilities, treatment or non-treatment. One caregiver stated: “I keep her health care proxy with me in the nursing home at all times. The staff asks to see it to even give my mother a shower.” These caregivers are very proactive in using ACP more so than reported by other research (Caron, et al., 2005; Forbes, et al., 2000; Mezey, et al., 1996). They have a strong resolve to be the final decision makers for the patient and they do not put it off on others, either other family members or health care professionals. Previous research has shown that many caregivers have deferred to health care professionals or other family members to make these difficult decisions on behalf of patients (High, 1988; 1990).

What is noteworthy about the caregivers in this study is acceptance of their roles of decision makers. They do not shrink from this challenging job. Even while admitting it is the hardest thing they have to do, they accept responsibility for making the tough decisions about
care. However, families desire input from health care professionals to make better decisions for the patient.

Moving into end stage toward death, these caregivers are keenly aware that their roles as decision makers for the patient will be difficult and complex. They understand they will have to make decisions one by one on matters that are not always predictable. There is no road map in end stage that offers guidance. In addition to making choices about life sustaining measures (feeding tubes, hydration, respirators, etc.), they make decisions about starting and stopping different medications, dialysis, transfusions, antibiotics, transfer to acute care, surgery, and other such treatments. The caregivers believe that the health care proxy gives them the power to make choices for the patient whether treatments were listed specifically in the living will or not. This is important to note as previous research indicates that not knowing what treatments a patient may require in end stage limits the effectiveness of living wills and causes many not to complete such a document. Some studies document that adults do not think the living will powerful enough because it is not specific and cannot possibly encompass all the issues that may arise (Center for Gerontology and Health Care Research, 2008; U.S. Department of Health and Human Services, 2008). This does not seem to cause the caregivers in this study any hesitation or concern. The caregivers understand that living wills, because they are often completed long before a patient reaches end stage, cannot possibly contain all the treatment possibilities which occur as the patient moves toward death. These caregivers believe that the power to make choices about whatever condition arises exists within their power as health care proxies and they are willing to make decisions based on “substituted judgment” (knowing what the patient wishes) or about what is in the “best interests” of the patient (i.e. decisions based on the caregiver’s own knowledge and experience of the patient). The most important thing for these
caregivers is that ACP allows them to say “no” to treatment and to ask questions. For them this is the power and control that is important to them in decision making.

In end stage, caregivers struggle with assessing the quality of life of the patient as health status changes and understanding the trajectory of the disease. They understand that end stage can last two to three years but want to know “where is my husband in end stage?” “What are the markers indicating movement to death?” They would welcome help from healthcare professionals and staff at assisted living/nursing homes who would be willing to talk to them about the patient dying and about the “grey area” of decision making, especially about the use of antibiotics. Sometimes it is viewed as a comfort measure; sometimes it is a life sustaining one. Caregivers complain that the dementia patient is accepted into hospice care too late and the doctors are unwilling to sign the order for Medicare hospice. They are ready to make the difficult decisions but feel alone in this process.

As end stage decision making gets more complicated and demanding, the caregivers report not so much conflict over implementing the patient’s choices for care, but rather more conflict over the structure that some families create around shared decision making. Some families have delegated decision making to more than one adult child or to other relatives and this may cause more conflict than intended. Some families handle the shared decision making quite well. But for the majority of caregivers in this study who are the health care proxy for the patient, they are clear with other family members that they are willing to listen to everyone’s thoughts, but they alone will make the final decision for the patient. For most caregivers in this study this model works best in the effort to honor the patient’s last wishes.
Factors that Influence the ACP Process

Demographic Factors:

**Age:** Although many studies have reported that advanced age is a predictor of higher ACP completion rates, for the caregivers in this study even the younger caregivers have done ACP. The age range for caregivers in this study is broad from 38 to 88 years with an average of 64.7 years. Although older age is predictive of a higher completion rate for ACP, data from this study indicates this may be changing. The younger caregivers seemed as informed about ACP and aware of their role as decision makers as the older caregivers. This is most likely due the high level of self education of this sample. Some studies suggest that age is a “proxy variable” for changes in attitudes, beliefs, and thoughts that change as one grows older (Lorenz, et al., 2004; VandeCreek, et al., 1995). The findings of this study would suggest that, in addition to changes in attitude regarding ACP due to age, changes in attitude are also strongly influenced by the experience of family illness and death.

**Religious Affiliation:** In general research findings on the association of religious affiliation and ACP completion is mixed. Some research demonstrates that strong religious beliefs are associated with higher ACP completion rates (Allen & Shuster, 2002; Carr & Khodyakov, 2007). This sample has high religious affiliation and believe that ACP is compatible with their personal religious beliefs. Having a strong faith in God and the afterlife does not deter these caregivers from believing they have a right and responsibility to make choices for the patient and for themselves. As one caregiver stated: “Planning is what God expects us to do.”

Other studies have found no relationship between religious affiliation and ACP completion (Gockel, et al., 1998; Lambert, et al., 2005). In this study, four caregivers, who expressed no religious affiliation but hold strong spiritual beliefs, take a firm stand on the need for ACP planning. The findings from this study suggest that, whether or not caregivers express
strong religious or spiritual beliefs, they believe that ACP is important in end-of-life planning and that having ACP brings them some comfort in the patients’ dying process.

**Education level:** Caregivers in this study have a high level of formal education which is predictive of higher prevalence of ACP completion. Even more impressive is the high level of self education among these caregivers, even for those who had achieved a lower level of formal education. In this study, self-educating leads to more knowledge building about dementia, ACP, life sustaining measures and use of community resources. Self educating includes attending support groups and educational programs regarding dementia and caregiving; using the internet to explore topics and find local resources; and having conversations with doctors, lawyers, social workers, and others. In future studies it will be important for researchers to capture and define the level of self education of caregivers that is occurring as this may be more predictive of ACP completion than formal education level.

**Socioeconomic status:** Along with higher educational levels, a relatively high socioeconomic status is associated with higher levels of ACP completion (U.S. Department of Human Services, 2008). The majority of caregivers in this study report their financial status as either “money is not a problem,” or “have enough money with a little extra.” This is consistent with the sample’s high level of formal education and high level of ACP completion.

**Race/Ethnicity:** Although race and ethnicity are predictive of ACP completion, there was not enough data in this study to make such comparisons. The entire sample was non-Hispanic. Twenty of the twenty-two caregivers in this study were Caucasian and two were African American. Future research studies designed to test this new theory would be enhanced if there was more diversity regarding race and ethnicity in order to capture a representative sample of dementia caregivers.
Psychosocial Factors:

Greater disease burden: The World Health Organization (2010) defines greater disease burden as the impact of a health problem as measured by financial cost, mortality, and morbidity, and is often defined in terms of quality-adjusted life years or disability-adjusted life years both of which quantify the number of years lost due to disease. It is measured on both personal and global levels. The caregivers in this study resemble other groups of patients that experience a greater disease burden, such as HIV/AIDS, advanced cancer patients, and dialysis patients. These groups complete ACP at significantly higher rates than the general adult population (Elphern, et al., 1993; Lorenz, et al., 2004; U.S. Department of Health and Human Services, 2008). In the most recent report to Congress on the status of ACP, the U.S. Department of Health and Human Services (2008) reported that although dementia patients have a high disease burden, caregivers do not complete an ACP process at a higher level than the general public. The findings from this study suggest that further research needs to be done to confirm that this remains accurate. Given the high rate of ACP completion among these caregivers, the incidence of ACP completion may be increasing.

Death Anxiety: A positive attitude about being able to discuss death and dying is associated with high levels of completion of ACP (U.S. Department of Health and Human Services, 2008). The majority of caregivers in this study were able to discuss death and dying and had high rates of ACP completion. The anxiety that caregivers expressed was not about the patient dying from dementia, but rather about being able to exert some control over the dying process. Caregiver anxiety revolves around decision making for the patient, worry about assessing quality of life, and understanding the trajectory of end stage dementia. In order to better understand caregiver anxiety further study is needed to develop a more comprehensive
model of the relationship between caregiver anxiety and (1) end stage dementia and (2) the planning process from dementia diagnosis to end stage/death.

**Locus of control for decision making:** The caregivers in this study exhibit a strong locus of internal control for decision making for the patient. This is consistent with research on older adults who express fear of losing control over the dying process (Cohen-Mansfield, et al., 1992; Emanuel, et al., 1991; Lambert, et al., 2005; Singer, et al., 1999; White, 2005). Studies have shown that patients with a greater disease burden (i.e, HIV/AIDS, advanced cancer, and dialysis patients) exhibit a higher completion rate of ACP and have an internal locus of control for decision making (Martin, et al., 1999; Singer, et al., 1998). The main factors driving patients to look for a means of control were past experiences with ill health; witnessing death of family and friends; and the impact of intensive medical intervention when curative treatment was no longer able to change the course of the disease. The patients in these studies reported that an ACP process helped them achieve a sense of control by allowing an articulation and establishment of their choices for end-of-life care. The findings of this study provide further evidence that there is a strong association among greater disease burden, internal locus of control for decision making, and ACP completion. Further research would be needed to examine the intersection of these three key factors and what impact it might have on end-of-life care for the dementia patient.

**Situational Factors:**

Situational factors that influence caregivers’ understanding and use of ACP include: experience with illness and death of family members, having knowledge of ACP and life sustaining measures, contact with doctors, and seeking support from others. In general, these situational factors are related to higher ACP completion rates. For the caregivers in this study
these situational factors vary in importance to the ACP process and its use. In this order, these factors influence understanding and use of ACP for these caregivers:

1. Having experience with a previous illness and/or death of a family member
2. Having knowledge of ACP and life sustaining measures
3. Seeking support outside the family
4. Having a long standing relationship with a primary care physician

Unanticipated Findings

The comparison of support group members and non-support group members reveals that support group members have a language for sharing their feelings about how they have absorbed dementia into their lives. Those in a support group are asked to share their story frequently and are in a trusted space where they feel heard and are safe with others who share similar stories. They are practiced in telling their story and report this helps sustain them through the long course of caregiving. In addition to having a language for their feelings about dementia in their lives, support group members engage in more of the following: they plan proactively, engage in conversations in the family and with the patient, seek support from multiple sources, use ACP more as an effective tool, and keep ACP documents accessible. Because the differences between support group and non-support group members are substantial it would be important to further explore these differences as they may critically affect decision making in end stage and ultimately the kind of care the patient receives.

When comparing caregivers with patients in early/moderate dementia and caregivers with dementia patients in end stage to death, the findings were consistent with other populations experiencing a greater acute disease burden, i.e. HIV/AIDS, advanced cancer, and dialysis patients. End-stage caregivers express being more proactive in planning, not just for patient care,
but also regarding funerals, cremation, and disposition of possessions. Also, they seek more support from community resources, feel more overwhelmed by the caregiving, have more conversations within the family about dying, and express a stronger belief in keeping the patient’s voice in the dying process. In their role as decision makers they worry more about assessing the patients’ quality of life and are more worn down by “doing battle” with health care professionals.

Another interesting finding is that in end stage, whether the caregiver is a support group member or not, more of the following behaviors occur: more proactive planning, more conversations in the family about patient’s choices and current care, and more use of ACP as an effective tool. Conversations are happening in the family that may not have occurred prior to end stage. They are planning more with more daily problems to solve, and using ACP to shape the dying process for the patient. In end stage the demands on the caregiver increase substantially. There is an increasing need to make daily decisions about treatment and care based on the constantly changing health status of the patient. The press of health care professionals to do more tests and treatment, along with conflict in the family about what is the best option, weigh heavily on the caregiver. Ongoing fatigue and worry about doing the right thing and ambivalence about the patient dying create high stress. This constellation of forces may be creating a need for the caregiver to engage in these behaviors in order to manage and survive end stage. Future research may examine end stage more thoroughly to determine what causes more of these behaviors to occur and the impact that might have on caregiver decision making for the patient.
Implications for Social Work Practice

Given the trajectory suggested by this theory of how caregivers engage in an ACP process, two points seem most promising for developing interventions designed for dementia caregivers: “at dementia diagnosis” and “moving into end stage toward death.” At these two critical phases social workers could offer significant support to caregivers. At dementia diagnosis, the caregiver is in planning mode to begin dealing with the changes dementia imposes on family life and as a means to reduce their anxiety about what the future will bring. Caregivers need help understanding the dementia diagnosis and that it is terminal, planning for future care, learning about local resources for themselves and for patients, and educating themselves about the stages of dementia. Caregivers need more conversations about the importance of ACP as the patients move forward in dementia. There is a time pressure to execute an ACP process in order to take advantage of the patient having the cognitive ability to understand and give consent for end-of-life care. For those families who do not have financial resources to hire a lawyer to draw up ACP documents, social workers can explain that caregivers can download the forms free of charge and have their signatures witnessed. These become legal documents under federal and state law.

Moving into end stage, caregivers need more help understanding: (1) the trajectory of dementia and the constellation of physical changes that tend to occur moving the patient closer to death; (2) how to use ACP in decision making and the impact of life sustaining measures on advanced dementia patients; and (3) how to assess quality of life. Caregivers struggle making decisions about withholding/withdrawing/continuing treatment and negotiating the “grey areas” of treatment versus comfort care. Caregivers need to understand that with the current fragmented health care system, they are in charge of having the ACP forms accessible for any situation that
may arise. Social workers are key to helping families negotiate these challenges of end stage and dying.

Conversations both within the family and with trusted outsiders are critical to how caregivers implement and use ACP. Central to encouraging families to engage in conversations about death, dying, and dementia is encouraging discussions about personal values and experiences, including religious, spiritual, and cultural beliefs that impact the decisions about end-of-life choices. Social workers have many tools that help initiate such conversations in families. For example, Doukas and Reichel (2007) have a highly readable values history form that suggests values statements one might choose about quality of life versus quantity of life. A new development is found with the availability of online social networking sites that encourage more open discussion about dying and choices for the end. One such site is The Conversation Project, co-founded by Ellen Goodman and colleagues (The Conversation Project, 2013). Ellen Goodman is a widely syndicated columnist concerned with chronicling social change and its impact on American life. The project’s purpose is expressed as follows:

- Too many people are dying in a way they wouldn’t choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain.
- It’s time to transform our culture so we shift from not talking about dying to talking about it. It’s time to share the way we want to live at the end of our lives….We believe that the place for this to begin is at the kitchen table – not in the intensive care unit – with the people we love, before it’s too late (The Conversation Project, 2013. Accessed December 18, 2013 via http://theconversationproject.org).
This website offers a starter kit for conversations including steps for how to begin conversations in the family, how to talk to your doctor about your wishes, and how to document your choices in an ACP process. Other new grassroots efforts spreading via social internet sites include “Death Over Dinner: - “Let’s have Dinner and Talk about Death” (2013) and “The Death Café” (2013). These sites offer novel approaches to engaging people in conversations about death and making choices for end-of-life care. These are non-profit organizations, led and run by volunteers and charge no fees for inclusion in their events. The websites offer information and guidance regarding inviting others to hold events such as dinners in a private home with friends and family or events in cafes/restaurants for cake and tea for anyone interested in joining. Results of these events are often written in blogs on these websites to provide feedback from participants. These grassroots efforts are an effort to fill the void created by health care professionals avoidance of speaking directly to patients and families about dying and ACP.

Another emerging grassroots effort to shape end-of-life care is “slow medicine.” It includes doctors and family caregivers in advocating for a “family-centered, less expensive way” to rescue older adults from standard medical care. Slow medicine can be defined as encouraging physicians to use less aggressive care for the elderly and encouraging patients and caregivers to decline emergency room trips and hospitalizations designed for those whose conditions are treatable. Dr. Dennis McCullough (2008), a family physician and geriatrician at the Dartmouth Medical School who is a chief advocate for slow medicine describes it as:

…shaped by human kindness, grounded in traditional medicine yet receptive to alternative therapies. Slow medicine is a measured treatment of “less is more” that improves the quality of patients’ extended late lives without bankrupting their families financially or
emotionally. Expensive state of the art medical interventions do not necessarily deliver superior outcomes….gentle, personal care often yields better results, not only for elders in late life, but for the families who love them (Accessed December 18, 2013 via http://mymotheryourmother.com).

Other voices are emerging in support of “slow medicine” as “more humane and realistic” medical care for the last phase of life. Butler (2013) in her memoir states that “the antidote for overtreatment is not undertreatment; it’s appropriate care. When the body can no longer be healed, there can still be healing for the family – and for the soul” (p. 269). Butler’s memoir of her father’s last days is just the most recent of such stories coming online as adult children deal with their parents’ deaths in old age. These stories capture some of the key findings of this study: the influence of illness and death in the family and media stories about families’ struggling with end stage, the problem of continued high level treatment when no cure is available, and the unsustainable costs of end-of-life care. Perhaps most important is the awareness that our health care system is subjecting frail dementia patients and their families to the wrong kind of care and causing unnecessary suffering.

Social workers could serve a critical role in connecting dementia families to these new grassroots efforts and online and local sources of information. This would provide families with more tools to encourage frequent conversations that lead to more participation in an ACP process to develop better understanding of their role as decision maker for the patient.

The findings regarding the differences between support group and non support group members, offers social workers evidence that attending support groups can help dementia caregivers. They help particularly with: (1) developing a language of feelings regarding the
dementia experience which helps them cope with its many challenges; and (2) planning and using ACP better than non-support group members. However, not all caregivers will attend support groups for various personal and family reasons. Those who do not like the group experience can be encouraged to use interactive websites like those mentioned above. The non-support group members in this study were more likely to call the Alzheimer’s Association Helpline to find local resources, or gain knowledge about dementia and dying from caregiving blogs on the web. These methods offer more control over divulging family issues to outsiders for those who have concerns with privacy and offers the opportunity to access information and help at any time that fits in the caregiver’s demanding schedule.

In practice social workers need to be attuned to how caregivers define and differentiate the terms “advance care planning” and “end-of-life planning.” The findings of this study indicate that there is confusion about what these terms mean. Although practitioners and researchers tend to use the terms interchangeably, many caregivers in this study did not recognize the term, “advance care planning.” Caregivers were able to define a living will and health care proxy. They believe that the ACP process is a vital part of “end-of-life planning” which also includes funeral planning, organ donation, and disposition of their personal possessions.

Strong research evidence exists that health care professionals, especially social workers, are important to the ACP process (Alzheimer’s Association, 2007; U.S. Department of Health and Human Services, 2008; White, 2005). As successful ACP interventions have demonstrated, nurses and social workers are most likely to begin a communication process with families that lead to ACP and to the completion of ADs (Laje, 2001; Sansone & Phillips, 1995). The findings from this study confirm the critical nature of on-going conversations in the family and social
workers are well deployed to assist with this. They are ideally situated in the health care system to facilitate ACP for dementia families. They work in nursing homes, hospitals, hospice programs, advocacy organizations, state and local government agencies, and other health related organizations. Each of these entities could serve as a gateway for initiation of an ACP communication process. For dementia patients living at home, social workers can be deployed in primary care physicians’ offices and in offices of specialists, such as neurologists, and would be well positioned to offer help and support at the critical intervention points of “at dementia diagnosis” and “moving into end stage.” Whether in physicians’ offices or in assisted living facilities, social workers, because of their training and higher comfort level with death and dying compared to other health care professionals, could be highly effective in helping dementia families understand and use ACP.

**Implications for Social Justice**

The irony of the fragmented U.S. health care system is that dementia patients are for the most part receiving sub-optimal care at end of life while receiving the most expensive level of care in hospital intensive care units. Many living in nursing homes are granted access to hospice too late to provide comfort care for them and bereavement support to their families. Few if any health care workers talk to the families about the patient moving toward death, and caregivers are regularly doing battle to withhold or withdraw treatment to honor patient’s wishes.

End-of-life care needs to be improved for dementia patients and their families. Research provides strong evidence that dementia patients experience high usage of life-sustaining measures that often do not offer any benefit, and can cause discomfort and new injuries. There are problems with inadequate pain control and low use of hospice programs (Sachs, et. al, 2004; U.S. Health and Human Services, 2008; Volicer, 2005). Most experts and
advocates are calling for a transformation of care for dementia patients. Because currently there is no cure or treatment that is effective for dementia, patients should be identified and given palliative care as the primary course of care and when appropriate given hospice care in end stage. Dementia patients should not die in intensive care units at hospitals where the care they receive will not heal them or change the course of their disease, and may deny them a peaceful death.

There is a substantial body of research that provides evidence that aggressive life-sustaining measures are inappropriate for advanced dementia patients. A review of the literature from 1994 to 2004 (300 studies) revealed that: (1) aggressive life-sustaining measures have low rates of success, can cause harm, and hasten death; (2) palliative care is an effective alternative to use of life-sustaining measures; and (3) there are significant barriers to translating this knowledge into practice (Volicer, 2005). In the most recent report to the U.S. Congress (2008) on the status of advance care planning, the authors re-affirmed the use of life-sustaining measures for advanced dementia patients as contraindicated, and made a strong case for the use of palliative care for this population. The Alzheimer’s Association Ethics Advisory Committee concluded “that all efforts at life extension in the advanced stages of Alzheimer’s creates burdens and avoidable suffering for patients who could otherwise live out the remainder of their lives in greater comfort and peace” (Alzheimer’s Association, 2006, p. 25).

Although ACP is a tool to improve end-of-life care for the patient, caregivers need the support of health care professionals to achieve a good death for the patient and a health care system designed to support dying as much as it invests in curative treatment. As one caregiver in the study said: “Death is not a failure of health care. We need to have more respect for dying.” In order to have more respect for dying, the last stage of life, we need:
• to encourage Physician Orders for Life Sustaining Treatment (POLST) for everyone with advanced illness

• to encourage more conversations about dying

• to help more people plan for end of life including completing ACP

• to call a halt to treatment that will not cure

Social workers, advocates, experts, researchers, and families have a moral and ethical obligation to press for improved care for dementia patients at end of life. We need to champion palliative care as the humane and compassionate course for dementia patients. We begin that change by encouraging families to have conversations about death and dying and by helping families understand and use ACP to shape the dying process for the patient. Keeping the voice of the patient in the dying process is the last gift that caregivers can give.

**Policy Implications**

The findings of this study reveal how individual caregivers struggle to shape a good death for dementia patients against a health care system that works to treat disease and tends to deny death. In order to better support these families, policies need to be adapted to reflect the reality of diseases, like dementia, that cannot be cured.

On the national level, there are critical structural problems in the health care system that impede high quality end-of-life care for dementia patients. Dementia patients experience excessive hospitalizations which are destabilizing for them and cause trauma. Financial incentives are built into the health care system that work against providing palliative care for dementia patients. There is no reimbursement mechanism to pay for palliative care. Medicare’s fee-for-service reimbursement system pays for each test, doctor’s visit, and hospitalization which provides incentives for physicians to over treat advanced dementia patients. In addition
physicians practice “defensive medicine” which is continuing to provide aggressive treatment for patients in order to avoid conflict with family members and the potential for liability lawsuits due to withholding or withdrawing treatment. Recent research reveals that 9 out of 10 physicians said they order more tests and procedures than patients need in order to protect themselves and their practice. The authors state that the cost of defensive medicine is “estimated to be $60 billion annually” (Bishop, et al., 2010, p. 1081).

In order to tame the cost of end-of-life care for Medicare beneficiaries (which is one-third of the entire annual Medicare budget) and improve end-of-life care for dementia patients, Medicare would have to make the following changes:

- Create a reimbursement mechanism for palliative care for those, like dementia patients, who cannot be cured
- Revise the fee-for-service model to pay for quality of care outcomes which for advanced dementia patients would be moving them from active treatment to palliative care
- Ease time restrictions on the hospice benefit beyond 6 months, so more dementia patients would be eligible earlier

In response to the practice of defensive medicine, tort reform is necessary to provide protection to physicians and other health care professionals who withhold/withdraw/continue treatment based on ACP documents provided them by the patient and/or the caregiver.

To improve health care professionals care of advanced dementia patients, the following is needed:

- Continue to educate health care professionals about the dying process. Dying is not a failure but rather helping people through the last stage of living.
• Increase the number of palliative specialists in hospitals

• Develop new standards of practice for advanced dementia patients which includes palliative care as the evidenced-based practice of choice

To improve understanding of the ACP process and encourage more people to complete AD documents, the following is needed:

• Revise the PSDA of 1991 to include a mandate for acute care hospitals and clinics, assisted living facilities and nursing homes, and physician’s offices not only to ask if one has ADs, but to help begin conversations about end-of-life care and complete the forms.

• To cover the cost of these facilities providing this service to those over 65 and the most vulnerable to dementia, revise Medicare regulations to pay for this free counseling to complete ACP just as Medicare now pays for a free physical upon becoming a new beneficiary.

• In addition to encouraging more conversations in families about death and choices for end-of-life care and for completing ACP, implement POLST (also known as POST, MOLST, and COLST and essentially the same physician standing orders for life sustaining treatment) in all states. Currently 13 states have implemented POLST and Virginia is piloting POST (Physician Orders for Scope of Treatment) in 10 regions of the state. This POLST form is the first (pink) sheet in the medical record. It states whether the patient desires CPR, artificially administered nutrition, and comfort measures only. The form indicates that the physician has discussed this with the patient or the legally recognized decision maker and indicates whether or not the patient has ADs. It carries the signatures of the physician and the patient or legally
recognized decision maker. Having this signed physician order in the medical record eliminates the problem of families forgetting to hand carry their documents in times of emergencies. Also a copy of this signed form is sent with the patient or caregiver whenever the patient is discharged or transferred from the acute care facility.

- Revise the Commonwealth of Virginia state-specific ACP form to include: (1) a values history to enable adults to formulate their ideas for end-of-life care based on their values and experiences; (2) add cues to the write-in section to allow for reflection on other kinds of treatment, such as blood transfusions, surgery, etc. and the choice of palliative and/or hospice care.

These policy changes would help transform end-of-life care for dementia patients and help support caregivers who are struggling against a health care system that is not responding to their intent to “do the right thing” by “honoring the patients’ wishes.”

**Research Implications and Next Steps**

The majority of studies regarding ACP use the completion of the formal AD documents as the primary measure. The findings of this study would suggest, as a few key studies have before (i.e. Caron, et al., 2005; The Support Study, 1995, 1997) that simply examining whether or not AD documents have been executed does not tell the whole ACP story. ACP is both a formal process (executing legal documents) and an informal process (conversations, gaining knowledge, keeping forms accessible). For researchers to capture the whole of the ACP process both the formal and informal aspects of the process will need to be examined. With this new understanding, new measures will need to be created. Given that little research currently exists,
focused inquiry regarding the informal ACP process that unfolds within the dementia patient’s relationships with trusted others would contribute substantially to this new theory.

A critical finding of this study is how caregivers use ACP in their roles as decision makers to shape the dying process for the patient. The role of decision maker as defined by the caregivers in this study needs further scrutiny. The key features that shape the definition of this role (the meaning of ACP, understanding life sustaining measures, and caregiver knowledge of patient’s wishes) need to be examined to determine the relationships among them and how these impact the choices made by the caregiver on behalf of the patient.

This is an exploratory study that illuminates a path to future research. The next step would be to conduct a mixed methods study with a large sample of dementia caregivers to test this new theory. The quantitative part of the study would explore if the ACP trajectory for how caregivers do ACP holds up in a larger sample and if the definition of the role of decision maker changes. The qualitative part of the study would explore in depth the kind of conversations that families are having about death, dying, and end-of-life choices and explore further the role of decision maker. How conversations shape the decision making in end stage would be important to know and lead to a better understanding of the informal ACP process. More in-depth knowledge is needed about the nature of caregivers “doing battle” with health care professionals. It would be important to learn more about why the caregivers’ resolve is so strong in their role as decision makers in the face of a resistant and intractable health care system.

The findings of this study indicate that dementia caregivers are self-educating at a very high level. Future research might examine how this impacts caregiver knowledge of ACP and life sustaining measures, and whether it increases ACP completion and the use of ACP in end-stage dementia. In addition, an examination of caregivers seeking support from multiple sources
outside the family and its impact on ACP completion rates would add important information to this new theory and its application to practice.

The unanticipated findings of this study pose more questions than are answered. Why do caregivers whose family members are in end stage behave more like support group members even when they are not? What are the demands of end stage that cause this to occur? Findings show that support group members have a language for their feelings about dementia, caregiving, and end-of-life issues. What is it about the support group experience that influences this? More research is needed to investigate these questions to understand how support group participation influences caregivers and impacts their behavior in end-stage dementia.

The conflict in dementia families regarding the choices the patient has made for end-of-life care needs further inquiry. When the caregiver does not agree with the patient’s choices, do they feel committed to implement them anyway? Do they honor them as the right thing to do? Also exploring the problem of shared decision making in the family is needed to better understand the pressures of end-stage care.

This new theory provides a beginning point from which to launch new inquiry into areas of critical importance regarding the ACP process for dementia patients and their families. These include having a deeper understanding of (1) the key factors that influence the role of decision maker; (2) the impact of conversations in the family that shape the dying process for the patient; and (3) how caregivers gain knowledge of ACP and translate it into an effective tool for end-of-life care. Research in these areas would expand and modify this new theory and provide a strong evidenced-based foundation from which successful ACP interventions could be tailored specifically for dementia patients and their families.
These recommendations for further research are all vital to building further knowledge about this issue. However, based on the critical need to create successful ACP interventions for families, these studies could be prioritized as follows:

Study 1: To test the new theory with a representative sample, including gathering more knowledge of informal conversations within the family and with trusted others and the role of decision maker.

Study 2: To develop a more comprehensive model of the relationships between caregiver anxiety and (1) end stage dementia and (2) the planning process from diagnosis to end stage.

Study 3: To examine end stage more thoroughly to determine what causes more of these behaviors to occur (planning, conversations, use of ACP).

Study 4: To explore the moral and ethical issues posed by the controversy regarding “spending down” to qualify for Medicaid funds to pay for long term care.

Study 5: To examine the differences between support group and non-support group members as they may critically affect decision making.

Conclusion

Understanding the ACP process and learning how it is used by dementia caregivers to help shape the dying process for patients was the purpose of this study. The findings help in a small way to chart a course for research and practice for how we might support these families at end of life. The road ahead would include a larger study to test this new theory and see if it holds true for a representative sample of the dementia caregiver population. Based on the results of such a study, some successful interventions could be adapted specifically for dementia families.

There is sufficient research evidence that two intervention models, CHOICES (for medically-fragile, home-bound older adults who do not meet criteria for the Medicare hospice benefit)
(Brumley, et al, 2003; Stuart, et al., 2003), and PEACE (disease management model for dementia patients that includes ACP, patient-centered care, caregiver support, and palliative care) (Lynn, 1996; Shega, et al, 2003), might prove particularly effective for dementia patients and their families on a large scale. Both these programs accomplish an ACP process along with the patient receiving more palliative/hospice care. They share a common goal for their programs: to increase communication with the family about end-of-life choices, to decrease the use of aggressive treatment, and increase the use of more palliative care. Results have been striking: reduced hospitalizations, higher rates of physician compliance with patients’ wishes, and higher rates of satisfaction with care by patients and caregivers. Results of these interventions support the use of ACP as an effective tool for families to navigate end of life and to offer some support and solace to caregivers to feel less alone in making difficult decisions on behalf of dementia patients. The hope is that adapted ACP interventions for this population would help improve the quality of end-of-life care for the patient and provide some measure of relief to the caregiver.

In addition to engaging in an ACP process, dementia families should complete POLST forms where available. Both ACP and POLST are needed to strengthen the patient voice in the dying process. ACP is for all adults. As digital medical records become the norm this will become easier to achieve.

Given the structural problems that exist in the current health care system such as care reimbursement mechanisms and the time and attention required of health care professionals, this poses challenges to replication of successful, sustainable programs in diverse settings. Social work advocates, researchers, and practitioners have a long road ahead. However, because the need is growing so great based on epidemic numbers of people developing dementia, the increasing activism on the part of caregivers who “stand their ground” doing battle with health
care professionals, the accelerating use of social media by both patients and caregivers to organize and influence public opinion, and the debilitating and unsustainable costs of end-of-life care, we are headed into a transformative period of understanding death, the dying process, the patient’s right to make choices, and how caregivers can support these choices. This study contributes uniquely to this national conversation by creating the groundwork for understanding how these choices are made. Moving forward with future research and informed practice, this offers great hope that end-of-life care can be improved for dementia patients and their families.

In addition to the larger issues of policy, research, and practice, it is important that the findings of this study do not “remain on the shelf” out of reach of those who could benefit the most. In the last report to the U.S. Congress (2008) on the status of ACP, chief among the problems is that research remains strictly within the academic domain. In response to this, the dissemination of the findings of this study will include presentations to the CEO, staff, volunteers, and board of directors of the Alzheimer’s Association. A written summary of findings will be sent to the caregivers interviewed for this study with a note of thanks from the researcher who is deeply appreciative of their time and interest in this study.
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APPENDICES
APPENDIX A

The Values History

This Values History records my specific value-based directives for various medical interventions. It is to be used in health care circumstances when I may be unable to voice my preferences. These directives shall be made a part of my medical record and shall be used as supplements to my living will and/or durable power of attorney for health care if I am terminally ill and unable to communicate, if I am in an irreversible coma and/or persistent vegetative state, or if I am in end-stage dementia and unable to communicate.

Values Section

There are several values important in decisions about end-of-life treatment and care. This section of the Values History invites you to identify your most important values.

Basic Life Values

Perhaps the most basic value in this context concern length of life versus quality of life. Which of the following two statements most accurately reflects your feelings and wishes? Write your initials and the date next to the number you choose (initials/date).

_________I want to live as long as possible, regardless of the quality of life that I experience.

_________I want to preserve a good quality of life, even if this means I may not live as long.

Quality of Life Values

There are many values that help us define for ourselves the quality of life that we want to live. The following values appear to be those more frequently used to define quality of life. Review this list and circle the values that are most important to your definition of life. Feel free to elaborate on any of the items in the list, and to add to the list any other values that are important to you.

1. I want to maintain my capacity to think clearly
2. I want to feel safe and secure
3. I want to avoid unnecessary pain and suffering.
4. I want to be treated with respect.
5. I want to be treated with dignity when I can no longer speak for myself.
6. I do not want to be an unnecessary burden on my family.
7. I want to be able to make my own decisions.
8. I want to experience a comfortable dying process.
9. I want to be with my loved ones before I die.
10. I want to leave good memories of me for my loved ones.
11. I want to be treated in accord with my religious beliefs and traditions.
12. I want respect shown for my body after I die.
13. I want to help others by making a contribution to medical education and research.
14. Other values or clarification of values above:

Directives Section

The following directives are identified to clarify what you want and do not want if one day you are terminally ill and unable to communicate, are in an irreversible coma or persistent vegetative state, or are in end-stage dementia and unable to communicate. Some directives involve a simple yes or no decision. Others provide for the choice of a trial of a therapeutic intervention to determine medical benefit. Write your initials and the date next to the number for each directive you complete (initials/date).

__________I want to undergo cardiopulmonary resuscitation.
   ___YES
   ___NO

   Why?

__________I want to be placed on a ventilator.
   ___YES
   ___TRIAL for the time period of__________
   ___TRIAL to determine effectiveness using reasonable medical judgment
   ___NO

   Why?

__________I want to have an endotracheal tube used in order to perform items 1 and 2
   ___YES
   ___TRIAL for the time period of__________
   ___TRIAL to determine effectiveness using reasonable medical judgment
   ___NO

   Why?

__________I want to have total parenteral nutrition administered for my nutrition.
   ___YES
   ___TRIAL for the time period of__________
   ___TRIAL to determine effectiveness using reasonable medical judgment

   Why?

   Why?
____NO

Why?

_______ I want to have intravenous medication and hydration administered. Regardless of my decision, I understand that intravenous hydration, to alleviate discomfort, or pain medication will not be withheld from me if I so request them.

____YES
____TRIAL for the time period of___________________
____TRIAL to determine effectiveness using reasonable medical judgment
____NO

Why?

_______ I want to have all medications used for the treatment of my illness continued. Regardless of my decision, I understand that pain medication will continue to be administered, including narcotic medications

____YES
____TRIAL for time period of___________________
____TRIAL to determine effectiveness using reasonable medical judgment
____NO

Why?

_______ I want to have nasogastric, gastrostomy, or other enteral feeding tubes introduced and administered for my nutrition.

____YES
____TRIAL for the time period of___________________
____TRIAL to determine effectiveness using reasonable medical judgment
____NO

Why?

_______ I want to be placed on a dialysis machine.

____YES
____TRIAL for the time period ________________
____TRIAL to determine effectiveness using reasonable medical judgment
____NO

Why?
I want to have an autopsy done to determine the cause(s) of my death.

YES
NO
Why?

I want to be admitted to an intensive care unit (ICU)?

YES
NO
Why?

If I am a patient in a long-term care facility or receiving care at home and experience a life-threatening change in health status, I want 911 called in case of a medical emergency.

YES
NO
Why?

Other directives

Proxy Negation: I request that the following person(s) NOT be allowed to make decisions on my behalf in the event of my disability or incapacity.
I consent to these directives after receiving honest disclosure of their implications, risks, and benefits from my physician, being free of constraints, and being of sound mind.

Signature:_______________________________________ Date:___________________

Witness name/address:____________________________________________________

Witness name/address:_____________________________________

Adapted from:

APPENDIX B

VIRGINIA
Advance Directive
Planning for Important Health Care Decisions

Caring Connections
1731 King St., Suite 100, Alexandria, VA 22314
www.caringinfo.org
800/658-8898

CARING CONNECTIONS

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve care at the end of life.

It's About How You LIVE

It's About How You LIVE is a national community engagement campaign encouraging individuals to make informed decisions about end-of-life care and services. The campaign encourages people to:

- Learn about options for end-of-life services and care
- Implement plans to ensure wishes are honored
- Voice decisions to family, friends and health care providers
- Engage in personal or community efforts to improve end-of-life care

Note: The following is not a substitute for legal advice. While Caring Connections updates the following information and form to keep them up-to-date, changes in the underlying law can affect how the form will operate in the event you lose the ability to make decisions for yourself. If you have any questions about how the form will help ensure your wishes are carried out, or if your wishes do not seem to fit with the form, you may wish to talk to your health care provider or an attorney with experience in drafting advance directives.

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Using these Materials

BEFORE YOU BEGIN
1. Check to be sure that you have the materials for each state in which you may receive health care.

2. These materials include:
   - Instructions for preparing your advance directive, please read all the instructions.
   - Your state-specific advance directive forms, which are the pages with the gray instruction bar on the left side.

ACTION STEPS
1. You may want to photocopy or print a second set of these forms before you start so you will have a clean copy if you need to start over.

2. When you begin to fill out the forms, refer to the gray instruction bars — they will guide you through the process.

3. Talk with your family, friends, and physicians about your advance directive. Be sure the person you appoint to make decisions on your behalf understands your wishes.

4. Once the form is completed and signed, photocopy the form and give it to the person you have appointed to make decisions on your behalf, your family, friends, health care providers, and/or faith leaders so that the form is available in the event of an emergency.

5. Virginia maintains an Advance Directive Registry. By filing your advance directive with the registry, your health care provider and loved ones may be able to find a copy of your directive in the event you are unable to provide one. You can read more about the registry, including instructions on how to file your advance directive, at https://www.virginiaregistry.org.

6. You may also want to save a copy of your form in an online personal health records application, program, or service that allows you to share your medical documents with your physicians, family, and others who you want to take an active role in your advance care planning. Virginia is expected to establish an official electronic advance directive registry. You may want to save your advance directive in this registry when it becomes available.
Introduction to Your Virginia Advance Directive

This packet contains a Virginia Advance Directive, which protects your right to refuse medical treatment you do not want or to request treatment you do want in the event you lose the ability to make decisions yourself. You may complete Part I, Part II, Part III, or all parts, depending on your advance-planning needs. You must complete Part IV.

**Part I, Appointment and Powers of My Agent**, lets you name someone, your “agent”, to make decisions about your health care—including decisions about life-prolonging procedures—if you can no longer speak for yourself. This is especially useful because it appoints someone to speak for you any time you are unable to make your own medical decisions, not only at the end of life.

Part I goes into effect when your doctor determines that you are no longer capable of making or communicating your health care decisions.

**Part II, My Health Care Instructions**, lets you state your wishes about health care in the event you cannot speak for yourself, including if you develop a terminal condition or you are in a persistent vegetative state. If you are an organ, eye or tissue donor, your instructions will be applied so as to ensure the medical suitability of your organs, eyes and tissues for donation.

Part II goes into effect when your doctor determines that you are no longer capable of making or communicating your health care decisions and a condition you have given instructions for arises.

Part III allows you to record your organ and tissue donation wishes.

**Part IV** contains the signature and witnessing provisions so that your document will be effective.

This form does not expressly address mental illness. If you would like to make advance care plans regarding mental illness, you should talk to your physician and an attorney about an advance directive tailored to your needs.

*Note: This document will be legally binding only if the person completing it is a competent adult (at least 18 years old).*
Completing Your Virginia Advance Directive

How do I make my Virginia Advance Directive legal?

You must sign your advance directive in the presence of two adult witnesses. Any person over the age of 18—including a spouse, other relative, or healthcare provider—can witness your Virginia Advance Directive.

Whom should I appoint as my agent?

Your agent is the person you appoint to make decisions about your health care if you become unable to make those decisions yourself. Your agent may be a family member or a close friend whom you trust to make serious decisions. The person you name as your agent should clearly understand your wishes and be willing to accept the responsibility of making health care decisions for you.

You can appoint a second person as your alternate agent. The alternate will step in if the first person you name as an agent is unable, unwilling, or unavailable to act for you.

Should I add personal instructions to my Virginia Advance Directive?

One of the strongest reasons for naming an agent is to have someone who can respond flexibly as your health care situation changes and deal with situations that you did not foresee. If you add instructions to this document it may help your agent carry out your wishes, but be careful that you do not unintentionally restrict your agent’s power to act in your best interest. In any event, be sure to talk with your agent about your future medical care and describe what you consider to be an acceptable “quality of life.”

What if I change my mind?

You may revoke your Virginia Advance Directive at any time by:
  • signing and dating a written revocation,
  • physically cancelling or destroying your document, or directing another to do so in your presence, or
  • orally expressing your intent to revoke the document.
Your revocation becomes effective when you notify your attending physician.
Virginia Advance Directive

I, ________________________________, willingly and voluntarily make known my wishes in the event that I am incapable of making an informed decision about my health care, as follows in this document.

This advance directive shall not terminate in the event of my disability.

PART I: APPOINTMENT OF AGENT

(CROSS THROUGH AND INITIAL IF YOU DO NOT WANT TO APPOINT AN AGENT TO MAKE HEALTH CARE DECISIONS FOR YOU)

I hereby appoint ________________________________ (primary agent) of ________________________________ (address and telephone number) as my agent to make health care decisions on my behalf as authorized in this document. If the person I have appointed above is not reasonably available or is unable or unwilling to act as my agent, then I appoint ________________________________ (alternate agent) of ________________________________ (address and telephone number) to serve in that capacity.

I grant to my agent, named above, full power and authority to make health care decisions on my behalf as described below whenever I have been determined to be incapable of making an informed decision. My agent's authority hereunder is effective as long as I am incapable of making an informed decision.

In making health care decisions on my behalf, I want my agent to follow my desires and preferences as stated in this document or as otherwise known to him or her. If my agent cannot determine what health care choice I would have made on my own behalf, then I want my agent to make a choice for me based upon what he or she believes to be in my best interests.
POWERS OF MY AGENT
(CROSS THROUGH AND INITIAL ANY LANGUAGE YOU DO NOT WANT AND ADD ANY LANGUAGE YOU DO WANT)

The powers of my agent shall include the following:

1. To consent to or refuse or withdraw consent to any type of health care, including, but not limited to, artificial respiration (breathing machine), artificially administered nutrition (tube feeding) and hydration (IV fluids), and cardiopulmonary resuscitation (CPR). This authorization specifically includes the power to consent to dosages of pain-relieving medication in excess of recommended dosages in an amount sufficient to relieve pain. This applies even if this medication carries the risk of addiction or of inadvertently hastening my death.

2. To request, receive, and review any oral or written information regarding my physical or mental health, including but not limited to medical and hospital records, and to consent to the disclosure of this information as necessary to carry out my directions as stated in this advance directive.

3. To employ and discharge my health care providers.

4. To authorize my admission, transfer, or discharge to or from a hospital, hospice, nursing home, assisted living facility, or other medical care facility.

5. To authorize my admission to a health care facility for treatment of mental illness as permitted by law. (If I have other instructions for my agent regarding treatment for mental illness, they are stated in a supplemental document.)

6. To continue to serve as my agent if I object to the agent’s authority after I have been determined to be incapable of making an informed decision.

7. To authorize my participation in any health care study approved by an institutional review board or research review committee according to applicable federal or state law if the study offers the prospect of direct therapeutic benefit to me.

8. To authorize my participation in any health care study approved by an institutional review board or research review committee according to applicable federal or state law that aims to increase scientific understanding of any condition that I may have or otherwise to promote human well-being, even though it offers no prospect of direct benefit to me.
VIRGINIA ADVANCE DIRECTIVE — PAGE 3 OF 8

9. To make decisions regarding visitation during any time that I am admitted to any health care facility, consistent with the following directions:

10. To take any lawful actions that may be necessary to carry out these decisions, including the granting of releases of liability to medical providers.

11. Additional powers or limitations, if any:

I give the following instructions to further guide my agent in making health care decisions for me:

(attach additional pages if needed)
PART II: HEALTH CARE INSTRUCTIONS

[YOU MAY USE ANY OR ALL OF PARTS A, B, OR C IN THIS SECTION TO DIRECT YOUR HEALTH CARE EVEN IF YOU DO NOT HAVE AN AGENT. IF YOU CHOOSE NOT TO PROVIDE WRITTEN INSTRUCTIONS, DECISIONS WILL BE BASED ON YOUR VALUES AND WISHES, IF KNOWN, AND OTHERWISE ON YOUR BEST INTERESTS. IF YOU ARE AN ORGAN, EYE OR TISSUE DONOR, YOUR INSTRUCTIONS WILL BE APPLIED SO AS TO ENSURE THE MEDICAL SUITABILITY OF YOUR ORGANS, EYES AND TISSUES FOR DONATION.]

A. Instructions If I have a Terminal Condition

I provide the following instructions in the event my attending physician determines that my death is imminent (very close) and medical treatment will not help me recover:

____ I do not want any treatments to prolong my life. This includes tube feeding, IV fluids, cardiopulmonary resuscitation (CPR), ventilator/respirator (breathing machine), kidney dialysis or antibiotics. I understand that I still will receive treatment to relieve pain and make me comfortable.

OR

____ I want all treatments to prolong my life as long as possible within the limits of generally accepted health care standards. I understand that I will receive treatment to relieve pain and make me comfortable.

OR

____ I direct the following regarding health care when I am dying:

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

(attach additional pages if needed)
B. Instructions if I am in a Persistent Vegetative State
I provide the following instructions if my condition makes me unaware of myself or my surroundings or unable to interact with others, and it is reasonably certain that I will never recover this awareness or ability even with medical treatment:

____ I do not want any treatments to prolong my life. This includes tube feeding, IV fluids, cardiopulmonary resuscitation (CPR), ventilator/ respirator (breathing machine), kidney dialysis, or antibiotics. I understand that I still will receive treatment to relieve pain and make me comfortable.

OR

____ I want all treatments to prolong my life as long as possible within the limits of generally accepted health care standards. I understand that I will receive treatment to relieve pain and make me comfortable.

OR

____ I want to try treatments for a period of time in the hope of some improvement of my condition. I suggest ________ (insert time period) as the period of time, after which such treatment should be stopped if my condition has not improved. The exact time period is at the discretion of my agent or surrogate in consultation with my physician. I understand that I still will receive treatment to relieve pain and make me comfortable.

OR

____ I direct the following regarding when I am unaware of myself or my surroundings or unable to interact with others, and it is reasonably certain that I will never recover this awareness or ability even with medical treatment:

(attach additional pages if needed)
C. Other Instructions Regarding My Health Care

I further direct the following regarding my health care when I am incapable of making my own health care decisions:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

(attach additional pages if needed)
PART III: ORGAN DONATION

[YOU MAY USE THIS DOCUMENT TO RECORD YOUR DECISION TO DONATE YOUR ORGS, EYES AND TISSUES OR YOUR WHOLE BODY AFTER YOUR DEATH. IF YOU DO NOT MAKE THIS DECISION HERE OR IN ANY OTHER DOCUMENT, YOUR AGENT CAN MAKE THE DECISION FOR YOU UNLESS YOU SPECIFICALLY PROHIBIT HIM/HER FROM DOING SO, WHICH YOU MAY DO IN THIS OR SOME OTHER DOCUMENT. CHECK ONE OF THE BOXES BELOW IF YOU WISH TO USE THIS SECTION TO MAKE YOUR DONATION DECISION.]

☐ I donate my organs, eyes, and tissues for use in transplantation, therapy, research and education. I direct that all necessary measures be taken to ensure the medical suitability of my organs, eyes, or tissues for donation. I understand that I may register my directions at the Department of Motor Vehicles or directly on the donor registry, www.DonateLifeVirginia.org, and that I may use the donor registry to amend or revoke my directions;

OR

☐ I donate my whole body for research and education.

I direct the following regarding donation of my organs, eyes, and tissues:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

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2011 Revised.
PART IV: EXECUTION

Affirmation and Right to Revoke: By signing below, I indicate that I am emotionally and mentally capable of making this advance directive and that I understand the purpose and effect of this document. I understand I may revoke all or any part of this document at any time.

_________________________          _____________
(signature of declarant)          (date)

_________________________
(printed name)

The declarant signed the foregoing advance directive in my presence.

Witness Signature ___________________________ Date ___________

Printed name ___________________________

Witness Signature ___________________________ Date ___________

Printed name ___________________________


Courtesy of Caring Connections
1731 King St., Suite 100, Alexandria, VA 22314
www.caringinfo.org, 800/658-8898
You Have Filled Out Your Health Care Directive, Now What?

1. Your Virginia Advance Directive is an important legal document. Keep the original signed document in a secure but accessible place. Do not put the original document in a safe deposit box or any other security box that would keep others from having access to it.

2. Give photocopies of the signed original to your agent and alternate agent, doctor(s), family, close friends, clergy, and anyone else who might become involved in your health care. If you enter a nursing home or hospital, have photocopies of your document placed in your medical records.

3. Be sure to talk to your agent(s), doctor(s), clergy, family, and friends about your wishes concerning medical treatment. Discuss your wishes with them often, particularly if your medical condition changes.

4. Virginia maintains an Advance Directive Registry. By filing your advance directive with the registry, your health care provider and loved ones may be able to find a copy of your directive in the event you are unable to provide one. You can read more about the registry, including instructions on how to file your advance directive, at https://www.virginiaregistry.org.

5. You may also want to save a copy of your form in an online personal health records application, program, or service that allows you to share your medical documents with your physicians, family, and others who you want to take an active role in your advance care planning. Virginia is expected to establish an official electronic advance directive registry. You may want to save your advance directive in this registry when it becomes available.

6. If you want to make changes to your documents after they have been signed and witnessed, you must complete a new document.

7. Remember, you can always revoke your Virginia document.

8. Be aware that your Virginia document will not be effective in the event of a medical emergency. Ambulance and hospital emergency department personnel are required to provide cardiopulmonary resuscitation (CPR) unless they are given a separate directive that states otherwise. These directives called "prehospital medical care directives" or "durable do not resuscitate orders" are designed for people whose poor health gives them little chance of benefiting from CPR. These directives instruct ambulance and hospital emergency personnel not to attempt CPR if your heart or breathing should stop.

Currently not all states have laws authorizing these orders. We suggest you speak to your physician if you are interested in obtaining one. Caring Connections does not distribute these forms.
APPENDIX D
Recruitment Documents

VCU IRB # HM14915

Document 1: Flyer and Handout

Document 2: Recruitment Script for Use by Staff/Volunteers of the Alzheimer’s Association

Document 3: Brief Advertisement for Newsletter

Document 4: Recruitment Script for Initial Call with Participants
Attention Caregivers of Dementia Patients……

The Virginia Commonwealth University School of Social Work, under the auspices of Virginia Commonwealth University, invites you to participate in a new research study. The purpose of the study is to find out how caregivers understand planning for end-of-life care and their role as the decision maker for their family member with dementia. The knowledge we gain from the study will help us better understand how caregivers view end-of-life planning and how health care professionals can assist families in planning. We welcome you to participate in this study:

- If you are helping the dementia patient (or will in the future) with health care, legal or financial decision making
- Whether you are providing direct daily care for the patient or not
- Whether you have considered end-of-life planning or not

The study involves an initial phone call and a one-hour interview at a time and location of your choice. We assure you that all your information will be kept confidential. A thank you gift will be offered after the interview. To learn more about the study, please contact:

Mariette Klein, MSW
(804) 262-3740 or (703) 229-7800 cell
Email: kleinml@vcu.edu

Or if you prefer, you can fill out the bottom part of this form with your contact information and mail in the self-addressed, stamped envelope attached. Your information will be given to the researcher who will contact you directly. Filling out your contact information does not mean that you are agreeing to participate in the study, but only that you would like to be contacted with more information.

___ Yes, I would like to receive more information about the VCU Study regarding dementia caregivers and end of life planning.

Your Name:__________________________________________

Do you prefer to be contacted by (choose one):

____ Phone Please list preferred phone number:______________________________

The best time(s) to reach me by phone are:____________________________________

____ Email Please list preferred email address:_______________________________

Please mail form to researcher in self-addressed, stamped envelope attached.
Document 2

Recruitment Script for Use by Staff/Volunteers of the Alzheimer’s Association

IRB # HM14915

To: Staff and Volunteers of the Greater Richmond Chapter Alzheimer’s Association:

My name is Mariette Klein. I am a doctoral student at Virginia Commonwealth University. I am conducting a study about how caregivers understand planning for end-of-life care and their role as decision makers for their family member with dementia. This study has been approved by the VCU Institutional Review Board and is supervised by the principal investigator, Sarah Kye Price, Associate Professor, VCU School of Social Work, (804) 828-0579. Email: skprice@vcu.edu. Sherry Peterson, CEO of the Alzheimer’s Association Richmond chapter, has graciously invited me to contact you regarding finding caregivers who may wish to participate in this study. I would appreciate your help in letting caregivers know about the study so all that are interested may be included.

Please share the following information with potential participants:

The VCU School of Social Work invites caregivers of dementia patients to participate in a new research study. The purpose of the study is to find out how caregivers understand planning for end-of-life care and their role as the decision maker for their family member with dementia. The knowledge we gain from the study will help us better understand how caregivers view end-of-life planning and how health care professionals can assist families in planning. We welcome you to participate in this study:

- If you are helping the dementia patient (or will in the future) with health care, legal, or financial decision making
- Whether you are providing direct daily care to the patient or not
- Whether you have considered end-of-life planning or not

The study involves an initial phone call and a one-hour interview at a time and location of your choice. Written notes will be taken during the interview, but the interview will not be audio taped. We assure you that all your information will be kept confidential. A thank you gift will be offered after the interview.

If you are interested in learning more, please contact:

Mariette Klein, MSW
Ph.D. Candidate, VCU Adjunct Faculty
(804) 262-3740
(703) 229-7800 cell
Email: kleinml@vcu.edu

OR
Or if you prefer, you can fill out the bottom part of the recruitment flyer with your contact information and mail in the self-addressed, stamped envelope. Your information will be given to the researcher who will contact you directly. Filling out your contact information does not mean that you are agreeing to participate in the study, but only that you would like to be contacted with more information.
VCU School of Social Work researchers invite caregivers of dementia patients to participate in a new study. The study is about how caregivers understand planning for end-of-life care and their role as decision makers for their family member with dementia. You will be interviewed for one hour at a location and time of your choice. Please call Mariette Klein at (804) 262-3740 or send an email to kleinml@vcu.edu for more information.

OR

Caregivers are often called upon to make decisions for dementia patients regarding end-of-life care. VCU School of Social Work invites you to participate in a study about how caregivers understand end-of-life planning and their role as decision makers for their family members with dementia. One-hour interviews will be held at a location and time of your choice. Please call Mariette Klein at (804) 262-3740 or send an email to kleinml@vcu.edu for more information.
Recruitment Script for Initial Telephone Contact with Participants

IRB # HM14915

Hello, My name is Mariette Klein. I am a doctoral student in the School of Social Work at Virginia Commonwealth University. We are conducting a study about how caregivers understand planning for end-of-life care and their role as decision makers for their family member with dementia.

We welcome caregivers to participate in this study:

- If you are helping the dementia patient (or will in the future) with health care, legal or financial decision making.

  Do you help the dementia patient with decision making?  _____Yes  _____No

  If the answer to this question is No. Thank the caregiver for their time and end the call.  
  If the answer to this question is Yes. Continue with the script.

  It does not matter:
  - Whether you are providing direct daily care for the patient or not
  - Whether you have considered end-of-life planning or not

May I have your permission to talk to you about this new study?

- If no, say thank you and end the call.
- If yes, continue as below.

If you agree to participate, this study will involve a one-hour interview at a time and location of your choice. We will explore how you understand end-of-life planning and your role as a decision maker for the patient. Written notes will be taken during the interview, but the interview will not be audio taped.

Consent: The risks for participating in this study are minimal. However, some people feel discomfort talking about end-of-life issues. If at any time in the interview you experience this discomfort, you may choose not to answer the question.

There are no direct benefits to you for participating in this research study. However, you may gain knowledge of end-of-life planning that may help you and your family. You will be offered a thank you gift at the end of the interview.

There are no costs to you for participating in this study other than the time you will spend in an interview. You will receive no payment for participating in this study.
We assure you that we will keep your information confidential.

Your participation in this study is completely voluntary. You have a right to withdraw from this study at any time without penalty.

After this phone call, I will send you a Research Information and Consent Form in the mail for you to review and sign prior to the interview. Any questions you have about the study I will answer for you.

Do you have any questions now?

Do you think you would be interested?

- If no, say thank you and end of the call.
- If yes, continue below.

May I ask you some screening questions to help prepare for the interview?

1. What is your relationship to the person with dementia? (spouse, adult child, sibling, grandchild, other family member, friend/neighbor)?
2. How long have you been providing care to this person?
3. Where does the person currently live? (alone, with you, assisted living, nursing home, other)
4. What stage of the disease is the person currently experiencing? (early, middle, late) 
   (Note: Will use the FAST Scale to assist in identifying dementia stage if needed)
5. Do you have written advance directives (living will and health care proxy) for the person?
6. If not, have you had informal conversations with the person about wishes for end-of-life care?
7. Gender caregiver: Male or Female

We would like to set up a convenient time to meet for a one hour interview.

- Review dates/times/location for interview.
- Give contact name, phone number and email for caregiver to reach if it is necessary to change meeting times.

Thank you for your time and for agreeing to participate in this study. I will send you a Research Information and Consent form. Please read it and sign it and bring the completed form to the interview. If you have questions, please contact the researcher: Mariette Klein, MSW Ph.D. Candidate, VCU School of Social Work, (804) 262-3740; (703) 229-7800 Email: kleinml@vcu.edu
FAST SCALE ADMINISTRATION

The FAST scale is a functional scale designed to evaluate patients the more moderate-severe stages of dementia when the MMSE no longer can reflect changes in a meaningful clinical way. In the early stages the patient may be able to participate in the FAST administration but usually the information should be collected from a caregiver or, in the case of nursing home care, the nursing home staff.

The FAST scale has seven stages:

1 which is normal adult
2 which is normal older adult
3 which is early dementia
4 which is mild dementia
5 which is moderate dementia
6 which is moderately severe dementia
7 which is severe dementia

FAST Functional Milestones:

Stage 1: normal adult with no cognitive decline

Stage 2: older adult with very mild memory loss

Stage 3: early dementia with memory loss apparent to co-workers and family; patient may be unable to remember names of persons just introduced to them.

Stage 4: mild dementia with difficulty with finances, counting money, and travel to new locations; memory loss increases; knowledge of current and recent events decreases.

Stage 5: moderate dementia: needs more help to survive; help choosing clothing; increasing difficulty with serial subtraction; may not know date and year or where they live.

Stage 6: moderately severe dementia: may begin to forget names of family members and friends; needs more assistance with ADLs; may develop delusions, hallucinations, or obsessions; show increased anxiety and may become violent; begins to sleep during the day and stay awake at night.

Stage 7: severe dementia: all speech is lost; loss of urinary and bowel control; loses ability to walk; most become bedridden and die of sepsis or pneumonia.
**Functional Assessment Staging of Alzheimer’s Disease (FAST)**

Stage 1: No difficulties, either subjectively or objectively

Stage 2: Complains of forgetting location of objects. Subjective word finding difficulties.

Stage 3: Decreased job function evident to co-workers; difficulty traveling to new locations; decreased organizational capacity.

Stage 4: Decreased ability to perform complex tasks (e.g. planning dinner for guests), and handling personal finances (forgetting to pay bills), difficulty marketing, etc.

Stage 5: Requires assistance in choosing proper clothing to wear for day, season, occasion

Stage 6a: Difficulty putting clothing on properly without assistance

6b: Unable to bathe properly, e.g. difficulty adjusting bath water temperature occasionally or more frequently over the past weeks

6c: Inability to handle mechanics of toileting (e.g. forgets to flush the toilet, does not wipe properly or properly dispose of toilet paper) occasionally or more frequently over the past weeks.

6d: Urinary incontinence, occasional or more frequent.

6e: Fecal incontinence (occasional or more frequently over the past week).

Stage 7a: Ability to speak limited to approximately a half dozen different words or fewer in the course of an average day or in the course of intensive interview.

7b: Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the same word over and over).

7c: Ambulatory ability lost (cannot walk without personal assistance).

7d: Ability to sit up without assistance lost (e.g. the individual will fall over if there are no lateral rests (arms on chair).

7e: Loss of the ability to smile.

APPENDIX E

IRB# HM14915

Research Subject Information and Consent Form

Title of Study: Dementia Caregivers: An Exploration of Their Knowledge, Beliefs and Behavior Regarding Advance Care Planning for End-of-Life Care

If any information contained in this consent form is not clear, please ask the researcher to explain any information that you do not fully understand. This consent form will be sent to you by mail after the initial phone call. You will have time to read it carefully and think about it prior to your interview. Please bring this signed consent form to your interview.

Purpose of the Study: The purpose of the research study is to explore how caregivers understand planning for end-of-life care and their role as the decision maker for their family member with dementia. You are being asked to participate in this study because you are a caregiver for a family member who has dementia.

Description of your involvement: During an initial telephone, the study will be explained to you and you will be asked if you wish to participate. During this initial phone call you will be asked questions like these:

- Are helping the dementia patient now (or will have in the future) with health care, legal, or financial decision making?
- What is your relationship to the dementia patient (spouse, adult child, etc.)?
- How long have you been providing care for the dementia patient?

If you agree to participate, a one-hour interview will be scheduled at a time and location of your choice. In the interview you will be asked questions like these:

- Have you heard of advance directives (living will and health care power of attorney)?
- How did you learn about advance directives?
- Have you completed written documents?
- Have you had conversations within the family about end-of-life treatment choices?

The interview will not be audio taped, but the researcher will take notes. At the beginning of the interview, the researcher will review the basic elements of informed consent and confirm that you are willing to participate. The researcher will collect this signed consent form that you will bring to the interview.
If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

Significant new findings developed during the course of the research which may relate to your willingness to continue participation will be provided to you.

**Risks and Discomforts:** The risks for participating in this study are minimal. However, some people feel discomfort talking about end-of-life issues. If at any time in the interview you experience this discomfort, you may choose not to answer the question. You may stop the researcher at any time if you do not wish to continue. You do not have to talk about any subjects you do not want to talk about, and you may stop the interview at any time. If you become upset, the researcher will give you names of counselors to contact so you can get help in dealing with these issues.

**The benefits of participating in this study:** There are no direct benefits to you for participating in this research study. However, you may gain knowledge of end-of-life planning that may help you and your family in the future. And the knowledge that we gain from the study will help us better understand how caregivers view end-of-life planning and how health care professionals can assist families in planning.

**Costs:** There are no costs to you for participating in this study other than the time you will spend in an interview.

**You will receive no payment for participating in this study.** At the end of the interview, you will be offered one of two choices of thank you gifts: (1) Alzheimer’s Association Caregiver Notebook or (2) a copy of *Planning for Uncertainty: Living Wills and Other Advance Directives for You and Your Family* by Doukas and Reichel.

**Confidentiality:** Potentially identifiable information about you will consist of information from the initial telephone call and interview notes. Data is being collected only for research purposes. Your personal identifying information will be assigned a code number. The list connecting your name to this code will be kept in a locked file in the office of the Principal Investigator at the VCU School of Social Work. When the study is complete and the data have been analyzed, this list will be destroyed.

The data collected from the telephone call and the interview will only be identified with a code number and stored separately from your personal identifying information.

All personal identifying information will be kept in protected files and these files will be destroyed one year after the conclusion of the study. Access to data will be limited to study personnel. A data and safety monitoring plan is established.
We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

**Voluntary Participation and Withdrawal:** You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped at any time by the researcher without your consent. The reasons might include:

- the researcher thinks it necessary for your health or safety;
- you have not followed study instructions;
- administrative reasons require your withdrawal.

**Questions:** If you have any questions, complaints, or concerns about your participation in this research, contact:

**Researcher:**

Mariette Klein, MSW  
Ph.D. Candidate and Adjunct Faculty  
School of Social Work  
Virginia Commonwealth University  
(804) 262-3740 (home)  
(703) 229-7800 (cell)  
Email: kleinml@vcu.edu

The researcher named above is the best person to call for questions about your participation in this study.

**Principal Investigator and Faculty Advisor:**

Sarah Kye Price, Ph.D.  
Associate Professor  
School of Social Work  
Virginia Commonwealth University  
(804) 828-0579  
Email: skprice@vcu.edu
If you have questions about your rights as a participant in this study, you may contact:

Office of Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
(804) 827-2157

Contact this number for general questions, concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at http://www.research.vcu.edu/irb/volunteers.htm.

Consent:

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

<table>
<thead>
<tr>
<th>Participant name printed</th>
<th>Participant signature</th>
<th>Date</th>
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________________________________________________ _______________________
Signature of Person Conducting Informed Consent     Date

Discussion / Witness

________________________________________________ _______________________
Principal Investigator Signature (if different from above)     Date

287
APPENDIX F
Interview Guide

IRB # HM14915

Title of Study: Dementia Caregivers: An Exploration of Their Knowledge, Beliefs, and Behavior Regarding Advance Care Planning for End-of-Life Care

Initial Interview Guide

Date of Interview: ________________________ Time of Interview: __________

Place of Interview: _______________________________________

Participant Number: ___________________________________________________

Thank you for meeting with me today. When we talked on the phone you agreed to participate in this study and I sent you a consent form for your review. Did you read it and understand all the information? Did you bring the form with you today? (If so, proceed)

Do you have some questions about the study? (Answer any questions that participant has).

Do you wish to participate in the study by proceeding with the interview?

(If participant did not bring signed consent form to interview, offer a new form and review with participant and ask if he/she wishes to participate. If so, have participant sign the form).

Just to remind you: (1) your participation in this study is voluntary; (2) if any of the questions make you uncomfortable you do not have to answer them; (3) you may discontinue the interview at any time; (4) at the end of the interview you will be given a thank you gift for participating in the study, a list of resources for caregiving and advance care planning information, and my contact information should you have any questions later. Within three days, I will mail you a copy of your signed consent form which contains information about the study.

The title of this study is: Dementia Caregivers: An Exploration of Their Knowledge, Beliefs, and Behavior Regarding Advance Care Planning for End-of-Life Care.

The purpose of the study is: to explore how caregivers understand and plan for end–of-life care and how they understand being a decision maker for their family member with dementia. This is a dissertation study and the knowledge gained from this study will help health care professionals better understand and assist caregivers in such planning.

Guiding Questions and Prompts:

(Note: the word “patient” is used here to denote the family member with dementia.)
During the interview the researcher will make it personal by referring to the “patient” as “mother, father, spouse, etc.”

Questions for all participants:

1. How do you understand end-of-life planning (it is sometimes called advance care planning)?
   - What is it?
   - What experience have you had with ACP for yourself, parents, others?
   - How could it help you and your family member with dementia?

2. How do you understand life-sustaining measures at end of life?
   - What are they? (i.e. cardiopulmonary resuscitation (CPR), respirator, feeding tube, IV hydration, use of antibiotics)
   - What do they do? (i.e. measures that keep a person alive but do not offer a cure)
   - What impact do they have on dementia patients?

3. Is the patient currently able to have discussions with you about choices for end-of-life care? Is the patient able to give consent for treatment choices?

4. Questions for those who have written advance directives:
   (If participant does not have advance directives, skip to Question 5)

During our phone call, you indicated that you have written advance directives (living will and health care proxy) for the patient

4a. What motivated you to do advance directives?
   - Personal experience with illness?
   - Death of a loved one?
   - Other caregiving experiences?
   - Long term relationship with physician who advised it?
   - Advice from others? Who?

4b. What did you consider when making the decision to do advance directives?

   - Understanding that patient will lose ability to make decisions on own?
   - Acceptance of death?
   - Experiencing stress because of patient’s increasing physical and cognitive losses?
   - Fear of prolonging the patient’s pain?
   - Doing the right thing by honoring patient’s wishes?
   - Wanting some control over the patient’s dying process?
   - Religious beliefs?
   - Cultural beliefs and practices?
4c. Did you have conversations with the patient about their wishes for end-of-life care?
   - What did you discuss?

Tell me the process about how you did advance directives.

4d. How did you learn about ADs?
   - Talked to professional (doctor, lawyer, social worker, nurse)
     - Did you begin the conversation about advance directives?
     - Or did the professional?
   - Talked to other family members?
   - Heard about ADs in the media?
   - Online searches about dementia?
   - Check advocacy organizations like, Alzheimer’s Association
     Family Caregiver Alliance, AARP, etc.?

4e. How did you find the forms?

4f. Does the living will specify palliative/hospice care (often called comfort care)
   instead of life-sustaining measures?

4g. Where do you keep the signed forms?

4h. Have you made any changes to the forms since signing them?

4i. Can you share with me your thoughts and feelings about having AD’s for the patient?
   - Does it relieve stress knowing patient wishes?
   - Does it relieve a sense of burden or guilt knowing patient’s wishes?
   - Does it provide comfort in knowing what the patient wishes?

5. Questions for caregivers who do not have written advance directives:

During our phone call, you indicated that you do not have written advance directives (living will and health care proxy) for the patient.

5a. Have you heard about advance directives?
   - If so, from whom?
     - Professionals (doctors, nurses, social workers, lawyers)
     - From friends or other family members?
     - From other sources?

5b. Can you share with me your thoughts about why you do not have written advance directives for the dementia patient?
• Anxiety talking about death or dying?
• Stress of caregiving leaves little time for this?
• Do not believe patient will die from dementia?
• Physician has not talked to me about it yet?

5c. If you knew how to do advance directives, would you complete one for the patient?
   • What might be some benefits to you and the patient in having them?
   • What might be some barriers to completing advance directives?

5d. Have you had conversations with the patient about their wishes for end-of-life care?
   If so, what was the nature of these conversations?
   • Talk of death and dying
   • Just occasional passing comments (i.e. I don’t want to live like a vegetable)

5e. Has the patient written any notes/letters/emails about what they wish for end of life?

5f. Has your doctor or other health care professional talked to you about the patient losing the ability to make decisions about end-of-life care?

Questions for all participants:

6. How do you understand your role as a decision maker for the dementia patient (also called health care proxy)?
   • What decisions might you be asked to make when the patient is no longer able to decide?
   • Would you make those decisions alone or would you include other family members, professionals or clergy?
   • What would be your concerns in making these decisions?
     – Patient’s current health status?
     – Patient’s current quality of life?
     – Patient’s expressed wishes?
     – Your values and/or beliefs?

Questions about caregiver:

During our phone call, you were asked a few questions about your family member with dementia. Here are a few questions about you that would be helpful to the study:
7. What is the highest grade you completed in school? ________________  
(For college, write 13 for first year; 14 for second year, etc.)

8. What is your current religious preference? (i.e. Jewish, Catholic, Protestant, etc)  
____________________________________________________________________

9. How do you describe your level of income?  
   ____ Can’t make ends meet  
   ____ Just manage to get by  
   ____ Enough money with a little extra  
   ____ Money is not a problem  
   ____ Don’t know/unsure

10. Please rate your health status  
   ____ Excellent  
   ____ Good  
   ____ Fair  
   ____ Poor

11. Please indicate your ethnicity (Hispanic or Non-Hispanic)  
____________________________________________________________________

12. Please indicate your race (African American, Caucasian, Asian)  
____________________________________________________________________

13. What is your age? ________________

Thank you for participating in this interview. As I review the interview notes, if I have any questions, may I contact you by phone or by email?  
Yes_____ No_______

To thank you for helping us with this study, here are two thank you gifts. Please choose the one that may be helpful to you: Alzheimer’s Association Caregiver Notebook or a book, Planning for Uncertainty, which explains how to do advance directives. In addition, we offer you a copy of the Resource List for Dementia Caregivers if it might be helpful to you.
APPENDIX G

Resource List for Dementia Caregivers

IRB # HM14915

**General dementia-specific resources:**

Alzheimer’s Association

**24/7 Helpline** provides reliable information and support to all those who need assistance. Call toll-free, day or night at 1-800-272-3900. The Helpline serves people with memory loss, caregivers, health care professionals and the public.

**Care Center:** ([www.alz.org.care](http://www.alz.org.care)) offers the following online programs to help caregivers find useful tools for decision making and care:

- **Care Finder:** interactive tool that helps users learn about options ranging from home and community-based care to assisted living and nursing home care. By entering personal needs and preferences, you will be able to receive customized care recommendations.

- **Lotsa Helping Hands:** A free on-line program that provides an easy-to-use, private group calendar to organize helps who can pitch in with meal deliveries, rides and other tasks.

- **Senior Housing Finder:** This free tool, dementia-specific senior housing database, helps families locate appropriate options across all types of senior housing, based upon level of care needs and lifestyle preferences.

**Caregiver Stress Check** ([www.alz.org/stresscheck](http://www.alz.org/stresscheck)). Answer 8 questions to identify areas that are causing stress and get customized resources to help.

Alzheimer’s Association **Green-Field Library** is a national, privately funded resource facility providing information, materials and services on Alzheimer’s disease. The library can help answer questions about Alzheimer’s disease and related dementias, search for material on topics, find a certain title, article, or video and can connect you with resources. It is a virtual on-line library that can be found at [www.alz.org/library/about.asp](http://www.alz.org/library/about.asp). Check out the online catalog and learn how to borrow the items you want. Contact information is:

- Online: Ask a Librarian
- Email: greenfield@alz.org
- Phone: (312) 335-9602 or (800) 272-3900 (ask to be transferred to the Green-Field Library)

**Local Alzheimer’s Association Chapter:** Greater Richmond Chapter provides supportive programs and services to help people with dementia and their caregivers deal with the disease
and its impact on their lives. The chapter offers information and referral, care consultation, support groups, safety services, education, and early-stage programs.

Contact information: 4600 Cox Road, Glen Allen, Virginia 23060  
Phone: (804) 967-2580  
Website: [www.alz.org/grva](http://www.alz.org/grva)

This site provides links to information on caregiving from government agencies and nonprofit organizations.

**Resources for advance care planning for end-of-life care**

To download Commonwealth of Virginia state-specific advance directive forms:  

To get referrals to elder law attorneys, contact the Alzheimer’s Association Helpline,  
(1-800-272-3900) who can provide contact information for local Greater Richmond attorneys who work with dementia families or check on chapter website ([www.alz.org/grva](http://www.alz.org/grva)) under Community Resources Finder.

Other useful websites:

**AARP ([www.aarp.org/families/caregiving](http://www.aarp.org/families/caregiving))**  
Offers wide variety of information on caregiving and end-of-life planning.

**Aging with Dignity’s “Five Wishes” ([www.agingwithdignity.org/5wishes.html](http://www.agingwithdignity.org/5wishes.html))**  
The “Five Wishes” helps someone explain the kind of medical treatment they want if they are unable to explain for themselves and to identify the person to make health care decisions for them.

**Caring Connections ([www.caringinfo.org/](http://www.caringinfo.org/))**  
Provides state-specific forms for all states and the District of Columbia.

**Department of Veterans Affairs ([www.hsrdr.research.va.gov/publicaitons/internal/ylyc.htm](http://www.hsrdr.research.va.gov/publicaitons/internal/ylyc.htm))**

**U.S. Living Will Registry ([www.uslivingwillregistry.com/forms.shtm](http://www.uslivingwillregistry.com/forms.shtm))**
Vita

Mariette Louise Klein was born on March 8, 1950 in Chicago, Illinois, and is an American citizen. She graduated from St. Francis de Sales High School in Riverside, California in 1968. She received a Bachelor of Arts degree from Notre Dame de Namur University in Belmont, California in 1972. She received a Masters in Social Work from Virginia Commonwealth University in 1997. After a long career working with older adults, she returned to complete a Ph.D. program in social work at Virginia Commonwealth University in Richmond, Virginia graduating in May 2014.

Education:

Ph.D. May 2014. Virginia Commonwealth University, School of Social Work, Richmond, Virginia

M.S.W. May 1997. Virginia Commonwealth University, School of Social Work, Richmond, Virginia

B.A. May 1972. Notre Dame de Namur University Belmont, California. Major: English

Professional Experience:

AARP National Office, Washington, D.C.
Director of Volunteerism, State Operations: April 2007 – June 2008

- Managed day-to-day operations of 20-person staff whose mission was to support recruiting, training and retention of volunteers in AARP’s 53 state offices (including D.C., Puerto Rico and Virgin Islands)
- Designed and implemented training programs for state staff to increase their capacity to manage volunteers
- Designed and implemented major restructuring plan for how to deliver volunteer services in State Operations
- Designed plan and assisted in implementation to establish volunteerism as central to overall AARP mission. This plan included design and establishment of a new, high level Office of Volunteerism and Civic Engagement

AARP National Office, Washington, D.C.
Manager, Chapters and Community Networks: October 2005 – April 2007

- Managed day-to-day operations of 6 person staff whose mission was to support the 1,200 AARP local chapters across the U.S. Support included conducting the legal, financial, liability insurance compliance for these incorporated chapters.
• Designed and produced chapter communications and products that facilitated chapter work
• Successfully initiated system changes to chapter team to improve customer service our 1200 chapters, state office partners, and 22 Information Centers.

AARP Virginia State Office, Richmond, Virginia
Associate State Director: September 2000 – October 2005.

• Recruited, trained and managed the Program and Community Service Team comprised of 7 geographically-based teams of volunteers in Virginia.
• Designed and conducted annual state planning meetings with each of 7 teams to implement AARP’s advocacy and educational agenda
• Developed new volunteer structure using a community action model: small teams of well-trained volunteers charged with performing environmental scans, developing community partnerships, and implementing state-plan events.
• Designed and implemented new state-wide recruitment plan targeted at younger (boomer age) members interested in episodic, issue-driven volunteer opportunities with AARP
• Working with state offices, designed and implemented an integrated model for training chapter officers and appointed volunteers in state/regional meetings.
• Expanded Faith in Action partnerships across the state. Established working relationships with three FIA agencies, Vienna/Oakton, Loudoun County and Page County
• Designed and implemented Volunteer Leadership Training Institute for AARP state and local volunteers, Richmond Virginia, June 2004, June 2005. Included skill building workshops on building community partnerships, planning community events, and communication and media skills.
• Designed and implemented a Volunteer Recognition and Awards Program for state and local volunteers
• Designed and delivered training workshops to increase volunteers’ capacity to recruit local volunteers for AARP initiatives
- Designed and delivered **workshops** on various subjects of interest to AARP members and older adults in Virginia communities. I was the key presenter.
  - **Update on Social Security** (presented 10 workshops across state)
  - **What Everyone Should Know about Long Term Care** (presented 7 workshops across the state)
  - **Family Caregiving of Older Adults** (presented 11 workshops across the state)
  - **Coping with Grief and Loss: An Overview**
    Virginia Retired Teachers Association Annual Meeting, Blackstone, VA

- Designed and implemented and was key presenter at **regional forums** on subjects of interest to AARP members, older adults, and community stakeholders:
  - **Looking Ahead: Consumer Issues of Concern to Older Americans** (Identify Fraud, Telemarketing and Charities Fraud, Investment and Securities Fraud)
    - South Hill, Harrisonburg, and Fairfax, VA
  - **Medicare: What Everyone Needs to Know** (Understanding Medicare Part a and Part B; Know your Medicare Rights, Become a Medicare Fraud Fighter)
    - Alexandria, Covington, Fredricksburg, Salem, Staunton, South Boston, Winchester, VA
  - **Medicare and You: New Coverage That Can Help With Your Prescription Drug Costs** (educational program on new Medicare Part D prescription drug plan). Delivered 22 workshops across the state to 3,500 AARP members and the public
  - **Smart Choices: Help with your Healthcare Decisions** (Richmond, and Roanoke). Partners: Virginia Health Quality Center, SeniorNavigator.org
  - **Eyes of Diversity: A Multi-Cultural Perspective on Grief and Loss**
    - Virginia Beach and Salam, VA
  - **Understanding Grief: Strategies, Challenges and Multicultural Perspectives: A Conference for Families and Professionals** – Annandale, VA. Partner: The Hospices of the National Capital Region Fairfax County Grief Programs
  - **Staying Ahead of the Curve: Employer Best Practices for Mature Workers**
    - Richmond: Partner: Greater Richmond Chapter of Commerce
    - Hampton Roads: Partner: Hampton Roads Chamber of Commerce

- Designed, managed and implemented a **state-wide** conference
  - **Caring Choices: Aging in Virginia. Virginia Governor’s Conference on Aging**
  - Governor Mark Warner and AARP Virginia invited 400 policy makers, business leaders, advocates and general public to examine the current experience of aging in Virginia and explore ideas for creating a better future.
Alzheimer’s Association, Northern Virginia Chapter, Fairfax, VA  
Program Manager, Alzheimer’s Association: May 1998 – July 2000

Designed and implemented Safe Return, a safety program for people with dementia living in their communities, for the Northern Virginia Chapter:

- Recruited Safe Return Advisory Committee and community partners to raise awareness about the program
- Wrote and received grants from community partners to offer Safe Return program to families free of charge
- Conducted community educational events on dementia patient safety
- Designed and developed educational materials to support program

Alzheimer’s Association, Northern Virginia Chapter, Fairfax, VA  
Coordinator of Educational Programs: June 1996 – May 1998

Developed and delivered educational workshops to dementia families on various topics of concern for them, e.g. transition to nursing home care, dementia basics, handling difficult behaviors, legal and financial issues with dementia, helping a dementia patient during hospitalization, early on-set dementia,

Goodwin House West, Falls Church, VA.  

- Provided clinical assessment and counseling services to residents of Goodwin House West under the supervision of licensed social work staff. Residents were living independently, in assisted living or in nursing care.
- Developed and implemented an in-house hospice program to support residents and their families during the last months of life

Northern Virginia Training Center, Fairfax, VA  

Provided clinical assessment and counseling services to physically, mentally, and emotionally challenged full time residents of this facility under the supervision of licensed social work staff.

The Women’s Center, Vienna, VA.  

- Designed and implemented over 100 educational workshops for women and their families, particularly regarding issues of divorce and separation,
children’s needs during this difficult family time, and support resources available in the community.

- Conducted media relations and community networking for all programming

**Woodburn Center for Community Mental Health, Annandale, VA.**

**Administrative Assistant, Office of Training, Research and Evaluation:**

**October 1977 – March 1979.**

Assisted Director of Training in selecting MSW interns for work at the Center, planned in-service training for Center professionals, and assisted in research for evaluations of Center programs.

**Teaching Experience:**

**Spring 2011**  
**Human Behavior in the Social Environment II**

**Masters in Social Work Program, Virginia Commonwealth University**

Foundation course covering life course from conception through late adulthood and death. Includes influences of biological, psychological, spiritual, economic, political, and sociocultural forces on individuals and families coping and adaptation.

**Research Experience:**

**Ph.D. Dissertation Study:** Dementia Caregivers: Their Knowledge, Beliefs, and Behavior Regarding Advance Care Planning for End of Life Care. Dissertation approved March 5, 2014.

**Graduate Research Assistant.**

**Virginia Commonwealth University School of Social Work, Richmond, VA**

**August 2009 – May 2010**

- Conducted literature search to update textbook chapter on older adults
- Conducted focus groups for program evaluation for Jewish Community Center in Fairfax, Virginia
- Transcribed audio tapes and analyzed qualitative data
- Conducted literature search for social work dissertations testing interventions
- Coded data from surveys and entered into SPSS for analysis

2009 As member of a program evaluation research class assisted in data analysis for Virginia Department of Health evaluation of program for child-bearing women at risk for diabetes. Results of the data analysis were presented in a **poster session**
At Women’s Health Research Day, April 15, 2009, sponsored by VCU, Institute for Women’s Health.

2009-2010 As graduate research assistant worked on a program evaluation for Coming of Age which is a joint program of the Jewish Social Service Agency and the Jewish Community Center of Northern Virginia. Responsibilities included: attending focus groups and taking notes; transcribing focus group tapes, analyzing the data collected, writing up notes and writing text for interim report.

2009-2010 Program Evaluation for Helpline Program, Alzheimer’s Association, Greater Richmond Chapter, Glen Allen, VA. Designed program evaluation project and trained data collectors. Analyzed secondary data from telephone surveys and intake forms. Presented findings to board of directors meeting in May 2010.

Publications


Honors

2014 Elaine Rothenberg Award in recognition of academic achievement, service to the School of Social Work, and commitment to the ideals of the social work profession, and exceptional personal qualities of compassion and leadership.

2011 Elaine Rothenberg Award in recognition of academic achievement, service to the School of Social Work, and commitment to the ideals of the social work profession, and exceptional personal qualities of compassion and leadership.

2008 VCU Graduate Fellowship, School of Social Work

2009 Phi Kappa Phi Scholarship for Academic Achievement, Virginia Commonwealth University, Richmond, VA

2005 AARP Award for Outstanding Leadership in Programming for Seniors and in Volunteer Recruitment and Management, AARP Virginia State
Office, Richmond, VA

2003 Extraordinary Effort and Creativity Award for AARP Day of Service, AARP Virginia State Office, Richmond, VA

2001 AARP Award for Home Modification Demonstration Projects for Low-Income Seniors, AARP Virginia State Office, Richmond, VA

2001 Outstanding Achievement Award, Independent Living Project which served over 400 older adults living at home and created several new partnerships with community agencies. AARP Virginia State Office, Richmond, VA

2000 Award for Development of The Safe Return Program for Dementia Patients and Their Families, Northern Virginia Chapter, Alzheimer’s Association, Fairfax, VA

1999 Leadership Award for Support Group Activities, Alzheimer’s Association Northern Virginia Chapter, Fairfax, VA

1999 Outstanding Achievement Award, 2nd Annual Education and Training Academy Conference, Dimensions of Dementia, Alzheimer’s Association, Northern Virginia Chapter, Fairfax, VA

1997 Inducted into Phi Kappa Phi Honor Society

1972 Inducted into Delta Epsilon Sigma, National Scholastic Honor Society Life Member

1972 California State Scholarship Federation Life Member

1968 – 1972 College of Notre Dame Competitive Academic Scholarships

Professional Memberships

2009-2011 Member, Council on Social Work Education (CSWE)

2008-2014 Member, Gerontological Society of America (GSA)

2008-2013 Member, Society on Aging (ASA)

2000-2014 Member, National Association of Social Workers (NASW)

1997-2014 Member, Phi Kappa Phi Society
1994-2014  Member, Social Workers in Aging, NASW-VA Chapter
1972-2014  Lifetime Member, Delta Epsilon Sigma, National Scholastic Honor Society

**Professional Service**

2010-2011  Faculty Search Committee, Ph.D. student representative, VCU, School of Social Work
2001-2008  Volunteer, AARP Day of Service
2006-2007  Volunteer, Life@50 Events
2007  Member, Planning Team, AARP National Volunteer Leadership Forum Baltimore, MD
       Member, National Chapter Engagement and Resource Team (NCERT), AARP National Office, Washington, D.C.
       Member, State Metrics Team, AARP National Office, Washington, D.C.
1997-2001  Volunteer, Memory Walks, Alzheimer’s Association
       Volunteer, Helpline Program, Alzheimer’s Association
       Board Member, Social Workers in Aging, NASW, VA Chapter
1993-1997  Volunteer, Social Workers in Aging, NASW, VA Chapter
       Volunteer, Coordinator Education Programs, Alzheimer’s Association
       Volunteer, Support Group Leader, Alzheimer’s Association

**Community Service**

2009-2013  Volunteer, American Heart Association, Vienna, Virginia
2009–2014  Volunteer, Alzheimer’s Association, Richmond, Virginia
2001-2008  Volunteer, Fox Creek Home Owners Association
1997-2001  Volunteer, Falls Church High School PTA
       Volunteer, Falls Church High School, Boys’ baseball team
1993-1997  Volunteer tutor, Falls Church High School
       Volunteer, Falls Church High School, PTA
       Volunteer, Girls Softball team, Falls Church High School
1991-1994  Volunteer, local political campaigns in VA  
Volunteer tutor, Camelot Elementary School.  
Volunteer, leadership conference, The Women’s Center, Vienna, VA  
Volunteer Clinic Aide, Luther Jackson School and Camelot Elementary  
Volunteer, Bethany House, Falls Church, VA  
Volunteer, Cub Scouts, Den 8  
PTA Board member, Luther Jackson School  
PTA Board member, Camelot Elementary School

1984-1990  Volunteer, Camelot School PTA  
Volunteer, Camelot Library  
Chairperson, Book Fair, Camelot School  
Volunteer, Ravensworth Mothers Day Out Program  
Volunteer, Annandale Boys and Girls Club  
Volunteer, Girl Scouts, Troop 923  
Volunteer, Camelot Swim Team