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Exploring the Advance Care Planning Experiences among Persons with Mild Cognitive Impairment: Individual and Spousal Perspectives

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by

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Table of Contents

List of Tables

Abstract

Advance Care Planning has been advocated for over 20 years as a way in which individuals who are no longer able to speak for themselves, may still convey their preferences regarding a wide of array of decisions, including medical care. Advance care planning may not be initiated by individuals for many reasons, and even when initiated, may not be specific enough to help guide decision making. Recent advance care planning models have utilized disease specific information to help guide end of life health care decision-making. Persons diagnosed with mild cognitive impairment face an increased possibility of developing dementia at some point in the future, but may retain decision making capability for a window of time, and thus the opportunity to participate in advance care planning. The advance care planning experiences of individuals with mild cognitive impairment have not been extensively studied.

This study explored the advance care planning experiences of persons with mild cognitive impairment and their care partners' understanding and views of advance care planning, and if the diagnosis of mild cognitive impairment affects the advance care planning practices of these two groups. A convenience sample of 10 individuals with mild cognitive impairment and their 10 care partners (n=20) were recruited and interviewed. Using a grounded theory qualitative analysis approach, four themes were identified (1) decreased awareness regarding advance care planning from individuals with mild cognitive impairment versus a heightened awareness for the care partners; 2) the preference for comfort care measures only; 3) preferences for future end of life healthcare

decisions largely influenced by previous end of life experiences with family and friends; and 4) lack of discussion of end of life healthcare decisions related to dementia and/or artificial nutrition and hydration by physicians or other healthcare providers. In addition two latent themes emerged including from the care partners, the importance of the mild cognitive impairment support group and lawyers for advance care planning and from both care partners and the mild cognitive impairment participants, trying to maintain autonomy, to 'hang on' to self were identified. Study implications include the need for structured advance care planning interventions with individuals diagnosed with mild cognitive impairment to focus on common end of life scenarios, such as whether to use artificial nutrition and hydration, which will require future surrogate decision making.

Chapter One

Introduction

For much of the 20th century, the focus of the healthcare system was on saving lives from infection, heart attacks, accidents, cancer, and preventing 'premature' deaths. Rapid technological advances resulted in Intensive Care Units where persons with previously 'futile' cases could be kept alive for days, weeks or even months (Colby, 2006). Deaths no longer occur suddenly and unexpectedly, but rather are likely to occur slowly and in old age (Wilkerson & Lynn, 2001). This is particularly true of dementia, which is currently the fifth leading cause of death for persons 65 and older and has been slowly rising in the rankings over the past 20 years (United States Census Bureau, 2012). Persons with dementia are most likely to experience years in which others will be required to make decisions for them (Volicer, 2005). In particular, the decision to administer artificial nutrition and hydration (ANH) will likely arise as this disease progresses (Dharmarajan, Unnikrishnan, & Pitchumoni, 2001; Post, 2001; Volicer; Volicer & Bloom-Charette, 1999).

Advance care planning (ACP) has been advocated in recent years as a way in which individuals that are no longer able to speak for themselves, may still convey their preferences regarding a wide of array of decisions, including medical care (Black, 2004; Fischer, Arnold & Tulsky, 2006). ACP has been identified as a process that can involve many steps including: initiation of the topic, disclosure of information, identification of a surrogate decision maker, discussion of treatment options, and elicitation of patient

values in collaboration with healthcare professionals, and significant others (Black, 2004; Emanuel, von Guten, & Ferris, 2000; Fischer, Arnold & Tulsky, 2006; Sudore et al. 2008) . Physicians play a crucial role in ACP, especially in the area of discussing treatment options that patients may not understand, yet they may be reluctant to engage in ACP discussions with their patients for a variety of reasons (Emanuel, von Gunten, & Ferris, 2000; Fischer, Arnold & Tulsky, 2006).

Recently models of health behavior, including the Transtheoretical Model (TTM) and the Health Belief Model (HBM), have been used to explain engagement in ACP (Fried, Bullock, Iannone, & O'Leary, 2009; Pearlman, Cole, Patrick, Starks & Cain, 1995; Prochaska, DeClemente, & Norcross, 1992). In these models, constructs which influence ACP may include; perceived susceptibility, self-efficacy, and the barriers to and benefits of changing one's behavior. These models have been utilized to develop disease specific interventions to promote ACP, and a national movement for new physician initiated advance directives (Physician Orders for Life Sustaining Treatment or POLST) have been shown to be useful in ensuring end of life wishes are honored (Hickman et al., 2011).

Individuals with dementia often lack the ability to make healthcare decisions, particularly at the end of life and must rely on family and/or previously appointed healthcare agents (HCA). One of the most common end of life decisions that this population faces is that of receiving artificial nutrition and hydration (ANH). Teno et al. (2011) found that ANH is frequently initiated, often only after a brief conversation with a physician, despite a lack of clinical evidence of efficacy (Chouinard, 2000; Dharmarajan et al., 2001; Finucane, Christmas & Travis, 1999; Gillick, 2000; Volicer, 2005).

Persons diagnosed with mild cognitive impairment (MCI) face an increased possibility of developing dementia at some point in the future, but may retain decision making capability for a window of time, and thus the opportunity to participate in ACP. The ACP experiences of individuals with MCI have not been extensively studied. Do these individuals perceive that they are at risk for not being able to make healthcare decisions in the future? Have physicians discussed end of life wishes or have persons with MCI discussed end of life preferences with their care partners (CPs)? If individuals with MCI do participate in ACP are they more likely to articulate wishes regarding ANH at the end of life and/or to appoint a surrogate healthcare decision maker and/or re-examine/revise existing ACP? The purpose of this dissertation is to explore the ACP experiences with persons with MCI and MCI CPs' understanding and views of ACP. This dissertation also sought to explore if the diagnosis of MCI affects the ACP practices of individuals with MCI and their CPs.

Contribution

This study addresses a gap in the literature regarding the understanding of ACP planning practices of individuals with MCI and their CPs. Individuals with MCI have a higher probability of progressing to dementia but retain a window of time in which ACP can be initiated or reviewed with their CPs, designated HCA and/or healthcare providers (Plassman et al., 2011). A review of the literature reveals few other studies that have examined the ACP practices of individuals with MCI (Garand, Dew, Lingler and DeKosky, 2011; Lingler et al. 2008). Because of the limited research on the ACP practices of individuals with MCI, this study has critical practice implications.

Organization of the Dissertation

Chapter one begins with a brief overview and introduction of the issues, the current gaps in the literature, how this study will address these issues and the organization of the dissertation. In Chapter two, a review of the current literature on ACP, including the physician's role in ACP, conceptual models of ACP, the TTM and HBM and ACP, ACP and dementia and the role of family in ACP is presented. Quality indicators for dementia end- of- life care are examined, specifically examining ANH for this population. A discussion of MCI and what is currently known regarding its progression to dementia is presented. Finally, a review of the impact of the MCI diagnosis and current knowledge regarding ACP in this population is discussed.

Chapter three presents the study questions, design, methods and data analysis. Chapter four provides the themes identified as a result of the analysis along with representative examples of each theme. Chapter five reviews and discusses these themes in relation to existing research and the TTM. Finally, Chapter six presents practice implications, study limitations, design issues, and future directions for research.

Chapter Two

Advance Care Planning (ACP)

Overview of advance directives. When individuals are able to communicate their treatment wishes with their healthcare providers and family, those wishes can be honored. For many older adults, however, it is likely that at some point, they may not be able to make decisions for their care as their disease progresses, particularly in advanced dementia. In the United States, the ability of the patient to participate in medical treatment decisions, even if they are no longer able to communicate their wishes, can be preserved through the use of advance directives. Advance directives express a patient's wishes regarding treatment decisions in the event that they are no longer able to participate in those decisions. Living Wills are the most common form of advance directives, but many states also recognize the designation of a healthcare decision maker, sometimes referred to as a surrogate or a proxy.

The ability of an individual to indicate preferences regarding end-of-life healthcare decisions in advance of incapacity through instruments such as advance directives is recognized by both the Florida Supreme Court and Federal Supreme Court (Cruzan, 1990; In re guardianship of Estelle M. Browning, 1990). The Cruzan decision recognized the right of individuals to make medical decisions even if those decisions may hasten death. Furthermore, this right could be maintained in the event of future incapacity through the use of advance directives. In both cases, a fundamental question was whether the administration of nutrition through a medically implanted tube was considered a

medical treatment, or normal care and comfort. These decisions also recognized the administration of ANH as a medical treatment, and like other medical treatments, could be declined.

In the wake of this Supreme Court decision, the Patient Self Determination Act (PSDA, 1990) was passed by Congress in 1990 and went into effect in December of 1991. The purpose of this act was to increase awareness of advance directives and to encourage its use so that patient's wishes would be known in advance, thus preserving patient autonomy. This act requires healthcare organizations such as hospitals, nursing homes, home health agencies and hospices, which receive Medicare funding, to comply with certain requirements. These include asking patients at the time of admission whether they have completed advance directives, offering them information on advance directives, and educating the patient, staff and community about advance directives. There are no requirements in the law as to who should discuss advance directives with patients, and consequently, in many organizations, this task is designated to a clerical person at the time of admission to the organization. The focus of this law has been on the completion of a legal document regarding future healthcare decisions, but there is no requirement of discussion of this with a physician or any other healthcare provider.

This lack of required involvement of a healthcare provider in the discussion and execution of an advance directive has likely contributed to problems with both completion of and adherence to these documents. Although patients have expressed interest in completing advance directives (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991), many wait for physicians to initiate this discussion (Perkins, 2007). In nursing homes, in which many patients with advanced dementia reside, families have

reported that physicians are 'missing in action' limiting the opportunities for discussion of end-of-life care wishes (Wetle, Shield, Teno, Miller & Welch, 2005).

Patients and families may be reluctant to discuss end-of-life wishes due to denial of death or fear of having treatment limited at end of life. Physicians may believe that discussing such issues may undermine hope or may wait for patients and families to bring up the topic themselves, indicating their readiness to have such a discussion. Even when patients have advance directives, the documents may not be accessible to healthcare providers and the preferences of the patient not known (Morrison, Olson, Mertz & Meier, 1995; SUPPORT Principal Investigators, 1995). In the absence of advance directives, the default is to provide all available care, which may be contrary to the patient's wishes.

Physicians' role in ACP. Many have called for physicians to become more involved in discussing end-of-life care preferences with patients and families and have proposed guidelines for these discussions (Emanuel, 1995; Fisher, Arnold, & Tulsky, 2006; Lang & Quill, 2004; Perkins, 2007). There has been a realization that far from being a simple process of completing a legal document, the discussions and completion of documents are part of an ongoing ACP process. Simply discussing life sustaining treatments and patient preferences is not sufficient and can leave both patients and physicians with misconceptions and misunderstandings (Fischer, Tulsky, Siminoff & Arnold, 1998). The ACP process includes discussing goals of care based on the patient's current health situation, discussions regarding knowledge and attitudes towards life sustaining treatments such as mechanical ventilation, providing information and documenting preferences for care, and review and updating of documents with final

application in identified situations. (Emanuel, von Gunten, & Ferris, 2000; Fischer, Arnold & Tulsky, 2006).

Physicians may be reluctant to enter into ACP with patients and families for a variety of reasons. The focus of much of the medical education provided is on identification and cure of disease. Discussions of end of life and death have been avoided in many cultures for many generations. Tolstoy wrote the following words from the *Death of Ivan Ilych* over a century ago, and it remains apt today: "What tormented Ivan Ilych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result" (Tolstoy, 1960, p. 134). Only his servant Gerasim acknowledged that death was imminent, and only with him did Ilych feel some sense of comfort. In Behar's (1996) anthropologic study of rural life in Spain in 1978, she describes a culture that is beginning to shift from waiting "patiently in bed, rosary in hand, for death to come, surrounded by kin, neighbors, the priest, Christ and the Virgin" to a modern death, where, "one must take action, seek out doctors, spend money and above all struggle against death" (p. 49).

Rather than wanting to avoid discussion of end of life, research indicates that individuals desire discussion of end-of-life care, and when these discussions occur, outcomes include less aggressive medical care and earlier hospice referrals (Batchelor, Winsemius, O'Conner, & Wetle, 1992; Emanuel et al., 1991; Flynn, Smith, & Vanness, 2006; Kass-Bartelmes, Hughes, & Rutherford, 2003; Wright et al., 2008). Fewer end-of-life discussions and resultant aggressive end-of-life care have been found to be associated

with worse patient quality of life and worse bereavement adjustment for survivors (Wright et al.).

An example of how these recommendations for ACP have been operationalized can be found in the Physician Orders for Life Sustaining Treatments (POLST) Paradigm Program (Center for Ethics in Health Care, 2012). The program seeks to improve quality of life at the end of life, through communication of patient's wishes, documentation of medical orders on a standardized form that is transferable and recognized by healthcare professionals across different healthcare settings. This form differs from other advance directives in that it is a physician order form. This medical order form addresses four categories of treatment: cardiopulmonary resuscitation (CPR); medical interventions; antibiotics; and ANH. A recent study demonstrated that this tool has been useful in ensuring that individual end-of-life treatment preferences are honored (Hickman et al., 2011).

POLST programs are currently recognized in 13 states with planned implementation throughout the nation (Center for Ethics in Health Care, 2012). In states where POLST has been endorsed, two main routes have been taken for implementation. One route is through legislation which recognizes the form; the second is through voluntary compliance by healthcare institutions leading to regulatory recognition (Spillers & Lamb, 2011). Although this program holds much promise for future end-of-life care, many hurdles remain in having it available throughout the United States. For example, in the wake of the Schiavo case, which involved a very public and emotional debate and prolonged court battle between family members of a young woman in a persistent vegetative state which eventually made its way to the Florida legislative body,

Florida legislative representatives have not been open to revisiting end-of-life care legislation and regulations (Blendon, Benson, & Herrmann, 2005). Despite this, many individuals and organizations from the state of Florida have continued to meet and network to identify strategies for introducing POLST to the state (Center for the Collaboration of Law and Medicine, 2012). At this point in time, several pilot programs are underway with the hope that through these efforts of voluntary compliance, regulatory recognition may follow (Spillers & Lamb, 2011).

Conceptual models of ACP. In this section, general conceptual models will be examined and more specific models will be described in detail in the following section. Conceptual models of ACP include those that describe the process as well as those that seek to explain correlates or predictors of ACP. Those that describe the process all share constructs which include: initiation of the topic, disclosure of information, identification of a surrogate decision maker, discussion of treatment options, elicitation of patient values in collaboration with healthcare professionals, and significant others (Black, 2004; Emanuel, von Gunten, & Ferris, 2000; Fischer, Arnold & Tulsky, 2006; Sudore et al. 2008).

Further testing of these general models have identified increased age, higher educational attainment and female gender to be associated with greater likelihood of completing this process, while living alone, chronic health conditions and religious status were associated with less planning (Black, 2008; Black & Reynolds, 2008). In an interventional study in which participants were exposed to advance directives, and then later contacted about their ACP, Sudore et al. (2008) found that 61% had contemplated advance directives, 56% had discussed with family, 22% had discussed with their

physician, but only 13% had completed an advance directive. Those who had contemplated advance directives were more likely to discuss with family and physicians, and those who had discussed with family and physician were more likely to complete advance directives, indicating the importance of family and physicians as part of the ACP process. Fried, Bullock, Iannone and O'Leary (2009) found a variable readiness to engage in ACP and did not show progression from one component of ACP to another. Their study also identified the importance of family, citing prior healthcare decision making for loved ones having a strong influence on perceptions of susceptibility and engagement in ACP.

Transtheoretical model, health belief model and ACP. The Transtheoretical Model (TTM) was first proposed as a way to understand both the stages and the processes of change associated with addictive behaviors (Prochaska, DiClemente & Norcross, 1992) and has more recently been proposed as a way to understand ACP (Fried et al., 2009). In this model, there are five stages involved in changing health care behavior: 1) precontemplation; 2) contemplation; 3) preparation; 4) action and 5) maintenance. Precontemplation is the stage in which there is no intention of changing behavior and may be no awareness of the need for a change. In contemplation, there is awareness that there is a need to change, but no commitment to take action. Preparation involves the intention to take action in the near future. Action is the stage in which behaviors, experiences and/or environments are modified. Finally, maintenance involves stabilization. This model also can involve a spiral in which these steps are revisited over time. Processes which are used during these stages include consciousness raising, self-

reevaluation and self-liberation, which can be used as strategies to increase readiness for participation in ACP (Fried et al., 2009; Prochaska et al., 1992).

The Health Belief Model (HBM) is a health behavior theory which has also been used to explain engagement in ACP (Pearlman et al., 1995). The HBM was introduced over a decade ago as a way to understand ACP; however, no studies to date have used it as a framework for ACP interventions. The HBM was developed as a way to understand how individuals seek to avoid illness via beliefs surrounding specific health behaviors (Hare & Nelson, 1991). In the context of ACP, an individual desires to avoid unwanted care that may result in suffering and believes that the process of communicating their wishes to loved ones and health care providers as well as completing advance directives, will improve health care decisions when they lack decision-making capacity.

The constructs in the HBM include perceived susceptibility (i.e., one's belief regarding the chance of getting a condition); perceived severity (i.e., one's belief of how serious a condition and its consequences are); perceived threat (i.e., combination of perceived susceptibility and perceived severity); self-efficacy (i.e., one's confidence in one's ability to take action); demographic variables (i.e., modifiers that may change an individual's perceptions and thus indirectly influence health behavior); and likelihood of behavior change (Strecher, Champion, & Rosenstock, 1997; Janz, Champion, & Strecher, 2002). In a recent study of chronically ill older adults (N=157) (Dobbs, Emmett, Hammarth & Daaleman, 2012), three major HBM domains (perceived susceptibility, perceived threat, and cue to action) were predictive of engaging in ACP. People who had higher levels of social support, stronger religious beliefs, less fear of death about end-of-life care decisions were more likely to engage in some form of ACP. Using focus groups

to explore models of health behavior change and ACP, Fried et al. (2009) found that ACP could be conceptualized as a set of health behaviors with individuals having variable readiness, barriers and benefits and perceptions of susceptibility.

ACP becomes even more important when dealing with patients with dementia or MCI. Patients who have dementia may have lost most of the ability to participate in end-of-life decision making, so families and/or HCAs become key in making healthcare decisions whether ACP has been completed or not. Individuals with MCI still retain decision making ability, and thus have the opportunity to initiate, revisit and/or revise ACP. The next section will address ACP and healthcare decision making with individuals with dementia.

ACP and Dementia

ACP decisions with dementia. Even when ACP and advance directives are initiated, they may be vague or not focus on the end-of-life scenarios most often encountered by those persons with dementia. Examples of the types of treatment options and end-of-life care that should be addressed for these individuals include cardiopulmonary resuscitation (CPR), do not hospitalize orders, use of antibiotics, ANH, referral to hospice, and use of palliative care for pain and symptom management (Mezey, Dubler, Mitty, & Brody, 2002; Volicer, 2005). CPR has been found to be three times less successful for a person with dementia than for a cognitively intact person (Volicer, 2005). Persons with advanced dementia are hospitalized more often than cognitively intact individuals, and while hospitalized, often receive distressing treatments of limited benefit, including the placement of a percutaneous endoscopic gastrostomy (PEG) tube to provide ANH (Mezey et al., 2002; Mitchell, Teno, Intrator, Feng, & Mor, 2007; Volicer,

2005). Infections are common with persons with advanced dementia, but use of antibiotics does not appear to improve survival, is not necessary for symptom management and may cause adverse effects, such as diarrhea, gastrointestinal problems, and allergic reactions (Volicer, 2005). One study found that 34% of nursing home residents with advanced dementia had ANH (Mitchell, Teno, Roy, Kabumoto, & Mor, 2003), yet multiple reviews have not documented any evidence supporting the use of ANH in this population (Chouinard, 2000; Dharmarajan et al., 2001; Finucane, Christmas, & Travis, 1999; Gillick, 2000). Pain and other symptom management is underreported and undertreated in this population (Volicer, Mezey et al., 2002).

Triplett et al. (2008) found in reviewing the advance directives of 123 nursing home residents in Maryland, that none addressed preferences regarding hospitalization, and few indicated preferences for other interventions such as ventilators, antibiotics, or dialysis. Interestingly, over 50% indicated a desire not to receive ANH or tube feeding. Few indicated preferences for palliative interventions such as food and water by mouth, or hospice care, but 36% indicated a desire for 'comfort care' and 41% indicated they wanted pain treatment. Some studies have asked family members to look back retrospectively and identify factors that might have facilitated ACP. A recent study seeking to identify factors that facilitate or hinder ACP in patients with advanced dementia found that both passive and active avoidance were the biggest factors hindering ACP (Hirschman, Kapo & Karlawish, 2008). Passive avoidance took the form of not realizing the importance of ACP until it was too late to have the discussion, and active avoidance simply avoided those discussions. Families who had discussed ACP indicated they wished they had discussed more specific health care treatments such as feeding

tubes. Family members who find themselves in the role of making treatment decisions for their loved ones are thus left little guidance for decisions involving such issues as hospitalization for condition changes, even when advance directives have been completed.

One of the most critical ACP decisions is the designation of a healthcare decision maker or health care agent. In the study by Triplett et al. (2008), 86% of residents with advanced dementia and advance directives had indicated a health care agent. When health care agents are not designated, state law dictates who will make these decisions. These laws vary from state to state and may place an individual who has little knowledge of the patient's preferences in the decision making role. Spouses are usually the first in line to be the health care agent when one has not been designated by the patient, but may be emotionally and/or physically unable act as the health care agent at a time of crisis. Even in the presence of a health care agent, providers may feel the need to initiate more aggressive life sustaining treatments and hospitalizations if faced with family members who offer conflicting opinions regarding treatment decisions. In appointing a HCA, individuals may only be contemplating that individual making a decision regarding withdrawal or withholding of a life sustaining treatment at a specific point in the future. In reality, with dementia, there may be years of major and minor healthcare decisions that must be made for the patient.

The role of family in ACP for persons with dementia. A qualitative study was conducted by Caron, Griffith, & Arcand (2005) to develop a substantive theory of decision making with HCAs for persons with dementia. In their study, HCAs felt their role as decision maker was not clear and did not know what was expected of them.

Quality of life was a central concept in decision making for HCAs, and determined their decision making regarding end-of-life care. They describe four phases in which this decision making takes place; the transitory phase (in which it is slowly being recognized that the individual does not have decision making capability), curative stage (in which all treatment options are pursued), phase of uncertainty (in which the HCA begins to question what treatments are beneficial) and the final phase (in which death is anticipated).

In the transitory phase, the person with dementia is in stable health and the HCA perceives a good quality of life is experienced by the individual and intensity of medical treatments is high (Caron et al., 2005). As the individual enters the 'curative stage,' usually through a pivotal event that marked a change in condition, there was still a perception of a good quality of life and a gradual decrease in intensity of treatments. During the phase of uncertainty, the HCA experiences doubt about whether person with dementia is experiencing a good quality of life. These doubts, in turn, complicate decision making. In the final phase, the HCA perceives that the person with dementia has a very poor quality of life and decisions involve avoiding suffering and promoting comfort. During each of these phases, the authors describe a complex interplay in which dimensions associated with the person with dementia (health, preferences, quality of life) interact with dimensions of the HCA (points of reference, values, relationship to patient, interpretation of experiences). Other dimensions include the context of interactions with healthcare providers (quality of relationships, frequency of contact, trust, values and beliefs), absence or presence of other family contact (supportive or problematic) and treatments (invasiveness, side effects, and contribution to quality of life).

This model could be expanded so that the focus on avoiding suffering and promoting comfort was not a priority only at the very end of the dementia process. This, in fact, should be a consideration and the increasing priority from the time of diagnosis of dementia. The most common forms of dementia do not currently have a cure and therefore are considered a terminal diagnosis. If the models proposed focused on goals of care rather than on treatment decisions, the goals of avoiding suffering and promoting comfort would be met throughout the course of the disease.

While the focus of ACP is often on what treatments a person would or would not desire and the role of family in honoring those treatment choices, research is demonstrating that outcomes may be of more importance than specific treatment decisions. In a study to identify the desired features of end-of-life decision making in older adults, Rosenfeld, Wenger & Kagawa-Singer (2000) found that individuals were more concerned with the outcomes of illness rather than the specific treatment utilized to achieve those outcomes. Individuals were interested in treatments only to the extent that it might return them to valued life activities. Gillick (2004) proposed that healthcare professionals focus their ACP discussions on who the HCA will be rather than on the treatment decisions themselves, and on helping patients articulate and prioritize goals of care. Emanuel (2004) asserts that "when the care goals are clear and shared by all parties, the specific decisions usually fall into place coherently and comfortably" (p. 642). In a study examining older adults and HCAs' attitudes regarding advance directives and end-of-life care decisions, it was found that very few wished to document specific treatment preferences (Hawkins, Ditto, Danks, & Smucker, 2005). Most desired to express values and goals for care, and to allow their HCA leeway in decision making.

Since caregivers for individuals with dementia must assume greater decision making responsibility as the disease progresses, one possible contributor to the patient's perceived quality of life is the degree to which their previously expressed wishes regarding care are honored. As indicated in all the ACP and advance proxy planning models, communication is critical in ensuring that wishes are honored. Engaging individuals in discussions of goals of treatments has been seen as an obligation and responsibility of physicians (Gillick, 2004; Rosenfeld et al. 2000), yet as indicated previously, does not routinely occur in many settings. Many of the models discuss the need to hear the narrative of the patient and family stories, yet without communication and trust, this will not occur. Hawkins (1999) called for a drastic revision of medical education so that, "the individuality of the patient is recognized and honored both in theory and in practice, and the beliefs, assumptions and attitudes of patients become an intrinsic concern in actual medical practice" (p. xi).

Giving voice to both HCAs and persons with dementia is crucial to the ACP process with this population. As indicated in the models presented, there are a multitude of factors that intersect at the end of life. As Gelfand, Raspa, Briller and Schim (2005) (2005) indicated in their model, individuals approach end of life within a narrative and cultural construct, bringing a lifetime of stories that impact the individual, family and community. Abby's story in their book tells of an Ojibwa woman with advanced dementia (Gelfand et al., 2005). Her daughter, as her HCA, sought to share her mother's experiences and beliefs as well as her own as she navigated the end-of-life decision making process with her siblings who did not share those same beliefs, and dealing with a nursing home that was unfamiliar with those beliefs and practices. Through 'hearing' the

daughter's voice and through her, Abby's voice, the nursing home staff and siblings responded to her desire to honor the traditional Ojibwa preparations for her final journey.

Hawkins (1999) expands upon this social ethic stating, "Sickness is meaningful not just for the individual sufferer but for the larger society as well. Constructed around the belief that each individual is part of an intricate web of the biosphere, such pathographies (individuals' accounts of dealing with illness) warn us by example of what can happen if we continue to ignore this interdependence" (p. 184). Charon (2006) also expands on the need to bear witness to patients and families, "Our narrative efforts toward ethicality and intersubjectivity enable us to not just feel on a patient's behalf but to commit acts of particularized and efficacious recognition that lead beyond empathy to the chance to restore power or control to those who have suffered" (p. 181).

Shared decision making is increasingly being recognized as a way to not only facilitate ACP, but also to improve communication and care delivery at the end of life. Engelhardt et al. (2009) studied the advanced illness coordinated care program (AICCP) in a large health system. Individuals with advance cancer, congestive heart failure, end stage pulmonary disease or end stage renal failure were assigned to a control group or to the AICCP group. Participants and their families in the AICCP group received non directive health counseling, education and care coordination. Information included understanding illness, treatment expectations, emerging symptoms, communication with health professional and ACP specific to their disease process. AICCP significantly improved communication and care delivery, and ACP.

A similar shared decision making process is the Respecting Choices program in La Crosse County, Wisconsin (Hammes, Rooney, & Gundrum, 2010). The program

identifies six goals: 1) reflect and discuss future healthcare relevant to their stage of illness; 2) provide assistance by trained non-physicians in the planning process; 3) written plans are accurate, as specific as possible and understandable to all; 4) written plans are stored, transferred and retrievable in all care settings; 5) plans are updated and are more specific as illnesses progress; and 6) plans are reviewed and honored at the right time (Hammes, Rooney, & Gundrum, 2010). A recent study examining the effectiveness of this approach with patients with congestive heart failure and end stage renal disease demonstrated their surrogates had significantly better understanding of patient goals and preferences (Kirchhoff, Hammes, Kehl & Briggs, 2010).

In further consideration of ACP for individuals with dementia and/or for those with MCI who may progress to dementia, it is important to understand what constitutes quality of life at the end of life for this population. The following section will explore the current literature on this issue.

End-of-Life Care for Persons with Dementia

Quality indicators. Optimal end-of-life care for all individuals is a topic of research that has only recently emerged, but has quickly become a focal point of concern across many disciplines and in many settings. Within the broad category of end-of-life care, persons with dementia present special challenges and represent a growing concern. As a disease associated with aging, and with the growing aging population, the number of individuals with advanced dementia will continue to rise. Unlike diseases such as cancer and heart disease in which patients may be able to communicate their wishes and participate in their care well into the disease process, individuals with advanced dementia

have usually lost this ability, posing challenges to evaluating whether their care needs are being met.

As dementia progresses, issues of depression, maintenance of mobility, management of eating difficulties, infections and other medical conditions, comfort, and symptoms of agitation and resistiveness need to be addressed (Volicer & Bloom-Charette,1999). Volicer (2005) and the Alzheimer's Association (2006) found that 67% of dementia-related deaths occur in nursing homes; 71% of residents died within 6 months of admission to a nursing home, but only 11% were referred to hospice care, and nonpalliative care, such as tube feeding, laboratory tests, restraints and intravenous treatments are common. They and others have identified quality indicators for end-of-life care for persons with dementia which include symptom management, referral to hospice, preference discussions with surrogates, documentation of patient preferences, medical intervention decisions and post death assessment of pain, symptoms, spiritual concerns, caregiver burden, assistance needs and ACP (Lorenz et al. 2008; Lorenz, Rosenfeld, & Wenger, 2007). ACP and communication with healthcare providers have been found to contribute to optimal care for persons with dementia, while lack of ACP and communication are more likely to result in nonpalliative treatments, including ANH which may be contrary to the individuals' previously expressed wishes. (Engel, Kiely, & Mitchell, 2006; Volicer 2005; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007; Lorenz, Rosenfeld, & Wenger, 2007). The issue of providing ANH at the end of life for persons with dementia has been addressed in much detail in the literature and deserves specific attention.

ANH and quality of end-of-life care for persons with dementia. The use of ANH is an issue that cuts across many of the QOL at the end-of-life care indicators that have been identified for patients with advanced dementia and has been the focus of many reviews and research over the past decade (Chouinard, 2000; Dharmarajan et al., 2001; Post, 2001; Volicer, 2005; Volicer & Bloom-Charette, 1999). These studies have documented that patients with progressive dementia experience many nutritional issues, including weight loss, apraxia, chewing problems and food refusal. Often, once these problems begin to manifest themselves, ANH is initiated through the use of a PEG tube.

A review of the literature specific to patients with advanced dementia who received ANH through PEG tubes indicates that this medical intervention does not achieve many of the stated goals for placement, and may result in decreased quality of life at the end of life for patients with advanced dementia (Chouinard, 2000; Dharmarajan et al., 2001; Finucane, Christmas, & Travis, 1999; Gavi, Hensley, Cervo, Nicastri, & Fields, 2008; Gillick, 2000). Goals of ANH cited include improved nutrition and hydration, prevention and treatment of pressure sores and infections, and prevention of aspiration. Studies to date have not born out that these goals of care are met by the use of AHN (Buff, 2006; Chouinard, 2000; Dharmarajan et al. 2001; Finucane et al. 1999; Gillick, 2000; Volicer, 2005). Contrary to the goal of comfort care at the end of life, ANH has been associated with social isolation, depression and denial of the taste and texture of food and liquids in the mouth. ANH can also be associated with increased use of restraints, both physical and pharmacological, to keep the patient from pulling out the PEG.

Moral, ethical and legal issues are raised as reasons patients receive ANH through PEG tubes. ANH has been designated a medical treatment in both Florida Supreme Court and Federal Supreme Court decisions (Cruzan, 1990; In re Guardianship of Estelle M. Browning, 1990). The court decisions also established that as a medical treatment, individuals could decline ANH, and the ability to make a decision to decline could be preserved even if incapacitated through the use of advance directives. Despite this, many still view ANH as different from other medical treatments. Foster (2006, p. 27) points out that 'language creates our reality.' The use of the term feeding tube implies that this mode of providing nutrition and hydration is 'just like' normal nutritional intake, when in fact this describes an artificial mode of introducing nutrients into the body through a medical intervention.

Colby (2006) describes how attitudes towards ANH can be impacted by high profile end-of-life cases and how they are portrayed in the media. Following the Quinlan and Cruzan cases, many individuals talked about how they would not want artificial interventions such as tubes and machines to keep them alive in similar situations. The Schiavo case, which involved a young woman in a persistent vegetative state who lacked written advance directives, produced a highly charged emotional discussion as to whether she should be allowed to 'starve to death,' legislators and individuals voiced concerns about withholding ANH as being cruel and potentially causing suffering (Blendon, Benson, & Herrmann, 2005). Many also wrongly believe that to withdraw ANH once started is illegal, when in fact there is no such prohibition. In discussion with families, physicians may fail to emphasize that the provision of ANH is a medical intervention (Casarett, Kapo, & Caplan, 2005). A recent study reported that physician discussion

about ANH initiation with families was either absent or shorter than 15 minutes (Teno et al., 2011).

Instead of providing for comfort, ANH may increase discomfort and require more intensive symptom management. Teno et al. (2011) reported that family members of relatives who died from dementia with ANH reported that the decedent was often physically or pharmacologically restrained and they were less likely to report excellent end-of-life care than those who did not receive ANH. It is difficult to equate dignity and respect of persons to a situation in which one must be restrained and isolated to receive ANH. Families can not receive full information and communication to make informed decisions regarding treatments if healthcare professionals are not aware of the evidence or lack of evidence for treatment. Finally, honoring previously expressed wishes may be difficult due to beliefs regarding standard of care, misunderstanding of legal and ethical issues regarding provision of ANH, and organizational factors.

A story related by Zaner (2004) in which a physician feels that ANH is no longer indicated and feels frustrated by a spouse whom he perceives wants everything done illustrates the complexities of this one aspect of care. After much discussion, the real issue is not the ANH at all. The husband feels guilt over his wife's hospitalization, guilt that he did not allow her to talk about her wishes regarding end-of-life care, and now guilt that he was not able to get her back home, so she could be among her things. He feels that the physician has tried to force him into a decision he could not voice. Zaner discusses the power physicians have in relation to patients and their family members. It is "a power for (acting on the patient's behalf as they define it regardless of whether I agree); a power over (paternalism, acting on the patient's behalf as I define it, ignoring

their wishes) and a power with (shared decisions, mutual trust, acting on the patient's behalf as has been worked out over a course of time and shared concern)" (p. 65). When one has not participated in a shared history, one can no longer take for granted shared values, outlooks and conversations.

As indicated previously, while individuals with dementia often lack the ability to participate in decision making regarding end-of-life care and ACP, individuals with MCI do have the ability to initiate, revisit and/or revise ACP. An overview of what is known about MCI and the ACP practices of individuals with MCI will be presented.

Mild Cognitive Impairment

Overview. As awareness of Alzheimer's disease and other dementias has grown over the past decade, a category of individuals who are experiencing slight impairment in cognitive function, yet retaining normal performance in activities of daily living has been identified. These individuals are described as having MCI, also termed cognitive impairment, not dementia (CIND). The main difference between CIND and MCI is that CIND requires either complaint of a problem or impaired test performance, while MCI requires both (Plassman et al., 2011). For the purposes of this paper, I will refer to MCI. MCI has been described as a transitional phase between normal aging and mild dementia (Petersen 2004, Petersen, 2005). Several categories of MCI have been identified including: amnestic, multiple domains and non-memory domains (Petersen). Amnestic MCI is the most common, and for many people appears to be a transitional state between normal aging and the earliest presentation of dementia (Petersen, 2003, Tuokko & McDowell, 2006).

Just as with Alzheimer's disease, there are no definitive diagnostic tests for MCI; however, practice guidelines for early detection of memory problems were published by the American Academy of Neurology (Petersen, et al., 2001). These guidelines identified the following criteria for an MCI diagnosis: e confirmed report of memory problems, greater than normal memory problems with standard memory assessment tests, normal general thinking and reasoning skills, and ability to perform daily activities. Three basic approaches to diagnosing MCI have been described (Tuokko & McDowell, 2006); norm based, criterion based and use of clinical judgment. Each has advantages and disadvantages. In norm based diagnosis, an individual's performance is compared to the known distribution of scores of the cognitively normal sample, however there is overlap between those who truly have MCI and those who are 'normal' but have a low score. In the criterion approach, a score on a reference test is used to determine impairment, but the problem is in identifying the correct test to use. In utilizing clinical judgment, the practitioner is examining the overall presentation of the patient, but reliability can be affected by the patient's characteristics, the measurement tools and the rater's characteristics.

Recent studies have found that the incidence of MCI or CIND is greater than the incidence of dementia (Plassman, et al., 2011; Plassman, et al., 2008). These studies found that the incidence of CIND/MCI is approximately 40% more than the number of incident dementia cases of Alzheimer's disease in the age group 72+ in the United States. Individuals with MCI have been found to progress to dementia at a higher rate than those with no impairment, but studies to date have revealed significant variation (Alzheimer's Association, 2011). Early studies looking at subjects with amnestic MCI have shown the

progression to AD to occur at a rate of 10-15% per year, compared to control subjects at 1-2% per year, and an overall conversion of 80% during 6 years (Petersen et al. 2001). As more long term studies have been completed, varying rates of conversion have been found to exist. In a pooled analysis of 15 long term studies, Mitchell and Shiri-Feshki (2008) found the annual conversion rate to be 4.2% with a cumulative conversion rate of 31.4% over five years or longer. Recent research has shown that the use of different criteria for MCI produced different conversion rates, varying from a cumulative rate of 7.4% up to a rate of 41.5% over five years or longer (Saxton et al. 2009).

Overall, when a high threshold for identifying MCI is set, there is a high rate of conversion, and when a low threshold is set, conversion is also lowered (Tuokko & McDowell, 2006). Measures of executive functioning, episodic memory and perceptual speed appear to be most effective at identifying at-risk individuals, however there is much overlap in scores between those who will go on to develop dementia and those who will not (Backman, Jones, Berger, Laukka & Small, 2004; Backman, Small, & Fratiglioni, 2001). Plassman et al. (2011) recently reported over 50 % of individuals with CIND did not progress to dementia. Future research will be needed to determine a more accurate conversion rate; however, the risk for conversion to dementia does appear to be elevated in the MCI population.

Impact of diagnosis of MCI. As MCI has become more recognized, researchers have begun to examine the impact of this diagnosis to individuals and their CPs. In a study looking at patients presenting with memory complaints, Elson (2006) found that 86% of individuals wanted to know the cause. The most common reason they wanted to know was to allow them the opportunity to plan for future decisions, however, ACP was

not cited as one of the anticipated planning activities. Carpenter et al. (2008) also found that a diagnosis of MCI or early dementia did not affect levels of depression in those individuals or their CPs, and in fact offered some level of relief that there was a reason for the problems they were experiencing. The researchers believed that the diagnosis may have given these individuals and their CPs a sense of self-efficacy by being able to take a more active role in managing their illness.

In addressing quality of life for individuals with MCI, or dementia as compared to controls, Ready, Ou and Grace (2004) found there were no significant differences in individual's evaluation of quality of life, suggesting that when faced with this challenge, standards of evaluation may shift to accommodate the challenge and to preserve feelings of well being. Several qualitative studies have sought to better understand the experience of living with MCI. In a study examining the patient's experience of living with MCI, it was found that while positive feelings regarding the diagnosis were expressed, they were in the context of relief that the diagnosis was not dementia (Linger, et al. 2006). Lu, Hasses, and Farran (2007) found that individuals with MCI struggled with this diagnosis and attributed memory loss to other causes. A study of individuals with MCI and their CPs also revealed uncertainty regarding the diagnosis and little support or information for patients or their CPs (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007).

Garland, Dew, Eazor, DeKosky and Reynolds (2005) examined caregiver burden in spouses of persons with MCI. They found the burden was less than those dealing with dementia however; spouses were experiencing increased levels of distress associated with increased caregiving responsibilities. In a study examining the perceptions of illness, coping and well-being of both the individual with MCI and their care partner, McIlvane,

Popa, Robinson, Houseweart, and Haley (2008) also found less distress than that found in Alzheimer's caregivers. Both CPs and persons with MCI reported normal levels of well-being, and tended to minimize the likelihood of conversion to dementia. CPs, however, reported providing an average of 24 hours of caregiving per week, indicating the persons with MCI did require substantial assistance. They also found that both groups endorsed mental and physical exercise, optimism, dietary changes and stress reduction as strategies to prevent conversion.

Several autobiographical narratives have been written by persons diagnosed with dementia (it could be argued that since they were able to write their own stories, they may in fact have had MCI). In these accounts there is also some relief of having a diagnosis, however, there were varying responses in terms of well-being, including a frank discussion of the contemplation of suicide by one individual (he decided against it after talking with his wife) (Davis, 1989; Debaggio, 2002; Lee, 2003).

MCI and ACP. Decision- making skills can remain intact for a period of months to years following a diagnosis of MCI. Values clarification, an essential component for ACP has been found to be consistent over a nine month period for individuals with dementia (Karel, Moye, Bank & Azar, 2007). Although many studies have examined ACP practices of older adults, the presence of advance directives for patients with dementia and the end-of-life decisions made for them by family, very few studies have addressed the ACP practices of individuals with MCI. Harris (2006) found major concerns expressed about future decision making, but no mention of ACP. Several studies have described that receiving a diagnosis of MCI led to contemplation of planning

for the future, but, again, no mention was made of ACP (Blieszner et al., 2007; Lu, Haase, & Farran, 2007; Lingler et al., 2006).

Garand, Dew, Lingler and DeKosky (2011) reviewed ACP rates of individuals with MCI and early Alzheimer's disease who had no advance directives prior to presenting to the memory disorders clinic. They looked at whether ACP documents were initiated over a five year period and found that only a minority of individuals (39%) had initiated ACP. They did not study whether those who had advance directives at the time of presentation to the clinic re-examined or made changes to existing advance directives.

In pathographies (biographies which focus on a person's illness) about dementia, planning for the future is frequently mentioned, but usually in regards to financial planning or insurance needs (Debaggio, 2002; Lee, 2003). In only one pathography was there explicit discussion of ACP (Davis, 1989). Davis had served as a pastor for over 30 years and had many encounters with individuals at the end of life, including those with dementia. He expressly indicated that these experiences prompted him to plan for his future end-of-life care with his wife, and completing an advance directive, but there is no mention of discussion of ACP with his physician.

One might expect that a diagnosis of MCI would prompt ACP, especially since these diagnoses often are provided at Memory Disorder clinics where specific resources and experts in the field of dementia are available. A study assessing physicians' ACP discussions with patients with mild to moderate Alzheimer's disease found that 81% reported counseling their patients regarding these issues (Cavalieri, Latif, Ciesielsky, Ciervo & Forman, 2002). The issue of whether the provision of counseling influences ACP and end-of-life decision making is one that should be further explored. McIlvane

and colleagues (McIlvane, Popa, Robinson, Houseweart, & Haley, 2008) discovered that individuals with MCI tended to minimize the possible conversion to Alzheimer's disease, which might indicate that ACP would not be pursued at greater levels than that found in those with normal patterns of aging. An initial retrospective exploration into the ACP of individuals with MCI and Alzheimer's disease in fact, found that they were no more likely to designate a healthcare decision maker and/or complete an advance directive than were healthy older adults (Lingler et al. 2008). Another retrospective study found that among individuals with MCI who had not yet initiated ACP, only a minority had initiated ACP after five years (Garland, Dew, Lingler & DeKosky, 2011). Whether a diagnosis of MCI prompts initiation of or revision of ACP has not been explored to date.

Study Goals

As previously presented, individuals with dementia will have many healthcare decisions that must be made for them over periods of time. Some of these decisions will include whether to be placed in nursing homes, whether to have antibiotics or other medical interventions and whether or not to have ANH. Family members and/or HCAs will be in the position of making these decisions, with or without ACP. Individuals with MCI have been shown to progress to dementia at high rates than those without this diagnosis. Since they are at risk for dementia, and the possibility of having others make healthcare decisions for them in the future, it would seem that this is a group for whom ACP would be very important. Specifically, the issue of whether the individual would want ANH would seem to be one that should be specifically addressed with this population, since this is a frequent decision that will face a person with end stage dementia.

Studies reviewed to date have not shown that ACP is occurring, nor that their CPs are participating in discussions regarding ACP. This study will seek to fill gaps in the existing knowledge reviewed above in: the ACP experiences of individuals with MCI; the experiences of the care partner's understanding and views of ACP; and if the diagnosis of MCI affected the ACP practices of individuals with MCI or those of their CPs.

Chapter Three

Research Methods

Research questions. Little is known regarding the ACP practices of individuals diagnosed with MCI. Additionally, we also do not know much about what CPs' views and understanding of ACP are. Since individuals with MCI are known to progress to dementia at a rate higher than those with normal aging patterns, there is a time period in which these individuals might initiate, discuss and/or re-engage in ACP and end-of-life decisions. Since individuals who develop dementia must rely on others to make healthcare decisions for them after they lose capacity, a diagnosis of MCI might prompt the CPs of these individuals to initiate and/or discuss ACP. The aim of this research is to explore the answers to the following research questions:

1. What are the ACP experiences of individuals with MCI?
2. What are the experiences of the CPs for individuals with MCI understanding and views of ACP?
3. Did the diagnosis of MCI affect the ACP practices of individuals with MCI or those of their CPs?

Within these broad questions seeking to understand the experiences of ACP with these individuals, this research will further explore the individuals' perceived susceptibility for developing dementia, their understanding of possible future end-of-life treatment decisions (perceived severity), if they have participated in ACP such as contemplation and/or completion of advance directives, communicating with physician

and family (perceived benefits), if they have not participated in ACP (perceived barriers), if ACP has occurred and/or been revisited, what prompted this (cues to action), and if there has been an experience with ACP how does the individual view their future ACP being honored (self efficacy)?

Grounded theory. Grounded theory was developed in the 1960's by Glaser and Strauss as a way of systematically developing mid-range theory from data (Glaser, 1978). Data is analyzed using joint coding and analysis following systematic guidelines. Codes are developed from the data rather than from predetermined categories. Constant comparison is utilized to ensure consistency within and between codes. This approach has the goal that the theory produced meets the criteria of fit, relevance and work (Glaser, 1978), where fit refers to the components of the theory corresponding to the data, relevance means that the theory captures the essence of the phenomenon, and work explains variation and predicts future phenomena.

Design. The purpose of this research is to explore the ACP experiences of individuals with MCI in order to better understand these experiences and to identify variables that may be measured in future studies. Qualitative methods such as the use of grounded theory have been recommended by some researchers for this type of phenomenological inquiry (Berg, 2009; Creswell, 2007). In order to understand these complex experiences which are influenced by many factors, questionnaires were developed incorporating open ended research questions that were asked in order to increase knowledge and allow for unanticipated responses and probing beyond the prepared questions (Berg, 2009; Creswell, 2007). The same basic questionnaire format was utilized for both individuals with MCI and their CPs (Appendices A & B). A semi-

structured, face to face, interview format was utilized to examine in depth the experiences of ACP with patients with MCI, the understanding and views of the family members of MCI patients, and the experiences of ACP. IRB approval was obtained from the University of South Florida IRB, #Pro00000945.

Participants. A purposive sampling was performed to recruit subjects with MCI and their CPs (10 MCI participants and 10 CPs). The sample of MCI participants and their CPs were recruited from the MCI Support Group conducted by the Sarasota Memorial Memory Disorder Clinic. Participants in this group have been diagnosed with MCI through this Florida State designated Memory Disorder Clinic, where a comprehensive physical, psycho/social and neurological work-up has been performed. Every effort was made to enroll individuals who have been diagnosed within the last 6 months, but due to a lack of sufficient numbers of individuals meeting this criterion, it was expanded to include those diagnosed within the last year.

Presentations were made to the support group on three separate occasions explaining the research as well as through two announcements in the group's newsletter, which was approved by the University of South Florida Institutional Review Board. One individual signed up after reading about it in the newsletter, which is mailed to 100 individuals throughout the community. Fifteen individuals initially signed up for the interviews after presentations at the support group which was attended by 16 MCI participants and their CPs at the first presentation and 30 at the second presentation. One individual was excluded because she could not identify a CP. One couple was not available to be interviewed during the study time due to previously scheduled travel plans. One couple declined when contacted for an interview date. The three remaining

couples were contacted for an interview date and a message left. After interviewing ten couples, data saturation was achieved, so in view of the exploratory nature of this inquiry, those remaining couples were not re-contacted for interviews (Berg 2009, Creswell, 2007, Kvale, 1996).

CPs were identified by the individual with MCI and confirmed with that CP at the time of recruitment into the study. Informed consent was obtained from all participants including both the participant with MCI as well as their CP. A copy of the informed consent form was provided to each individual, and was discussed with them. Opportunity was given to ask questions, and they were given the opportunity to withdraw from the study and/or stop the interview at any point. Signed consent was obtained and copies given to the participants, while the original forms were retained by the researcher.

Data collection. Data collection took place from fall 2010 through spring of 2011. At the time of recruitment, participants were offered the choice of being interviewed at the site of the support group meeting or in their home. All but one couple chose to be interviewed at home, while one couple asked to be interviewed at nearby senior site, immediately following the Support Group meeting, due to the distance to their home. Interviews were conducted on the day and time of the participants' choosing. Separate interviews were conducted with each participant, first with the participant with MCI, then with their CP.

All participants were interviewed using an interview guide (Appendix A) with open-ended questions regarding ACP, both prior to and since the diagnosis of MCI. These questions covered discussions with family, physicians, completion of advance directives and whether ANH had been specifically addressed as part of ACP. Descriptive

information including age, education, race, and relationship of patient to CP, employment status and finances were also obtained. Interviews were conducted using the technique of theoretical saturation or until no new themes or categories were uncovered in the data (Glaser, 1978; Kvale, 1996). As anticipated based on previous phenomenological studies, 10 participants in each group were interviewed (Berg, 2009; Creswell, 2007; Kvale, 1996).

All interviews were digitally recorded and transcribed verbatim for analysis by a medical transcriptionist. Once transcriptions were received back from the transcriptionist, they were verified by this researcher against the original recordings and corrections made for transcription errors, and identifying information removed. Two couples (four participants) were randomly selected to review transcriptions for verification of information gathered during the interview. They were contacted via telephone and asked if they would be willing to review the transcription and verify the information collected. Both couples agreed, so transcriptions were mailed to the couples (both participant with MCI and CP) with self addressed stamped envelopes and instructions on reviewing and inviting them to correct and/or add any information they felt was incorrect or missing. All four participants sent back transcriptions as originally transcribed.

Data analysis. A grounded theory approach was used in the analysis of the data. The verified transcriptions were loaded into the Atlas.ti version 6 software program. Participants were identified by number (interview #1, #2, etc.), by MCI and CP. Data were initially coded by CPE, a doctoral candidate in gerontology and a gerontological nurse practitioner with over 25 years experience in healthcare and ACP with older adults

and qualitative methodological training. The data were first reduced into meaningful segments and naming these segments utilizing both a priori and in vivo codes (Berg, 2009; Creswell, 2007; Janesick, 2004). These codes were then classified according to themes. This coding and classification was concurrently reviewed by a PhD trained gerontological sociologist with experience in qualitative research, for agreement on the final set of codes. Disagreements were resolved through consensus agreement. Once the final codes were identified and agreed upon, the data were further analyzed to identify overall themes within the major codes. Finally all the codes and themes were reviewed by a geriatric social worker with experience in qualitative research to ensure that the codes and themes identified accurately reflected the data. The consolidated criteria for reporting qualitative research (COREQ) were utilized to ensure that key aspects of qualitative research were included in the study design and analysis (Tong, Sainsbury & Craig, 2007). Descriptive statistics were conducted on the demographic variables collected.

Chapter Four

Results

Demographics. Ten individuals with MCI were interviewed as well as their respective CPs. All of the individuals interviewed were Caucasian, and while socio-economic information was not collected, none of the participants were living in subsidized or substandard housing. All but one individual had at least graduated from high school, with the majority having some college experience and seven with advanced degrees. All participants were retired. Of the individuals with MCI, the average age was 77.7 with a range of 70-89. The gender of the participants was evenly divided. Of the CPs, their average age was 75.5 with a range of 63-86. All CPs were the spouse of the individual with MCI. All CPs reported that both they and their spouse with MCI had completed some form of advance directive, although many of the MCI participants did not remember doing this. The majority of both individuals with MCI and their CPs indicated they had communicated with family about their end-of-life decisions. In contrast none of the MCI participants thought they had communicated with their physicians while the majority of the CPs reported they had.

Table 3.1 Demographics

	MCI	CPs
	Sex	
Male	5	5
Female	5	5
	Age	
< 65	0	1
65-74	2	3
75-84	7	5
>85	1	1
	Highest education completed	
< High school	1	0
High school	2	1
Junior college	4	3
Bachelor	0	2
Graduate degree	3	4
	Completion of Advance directive	
	10*	10
	Indication of ANH choice	
	3*	3
	Appointment of HCS	
	9*	9
	Communicated with family	
	7	9
	Communicated with MD	
	0	5**

*CP report
**Communicated about their ACP/Spouse

Themes

Four main themes emerged from the data: 1) decreased awareness regarding ACP from individuals with MCI versus a heightened awareness for the CPs; 2) the preference for comfort care measures only; 3) preferences for future end-of-life healthcare decisions of both MCI participants and CPs largely influenced by previous end-of-life experiences with themselves, other family members and/or friends, not by the diagnosis of MCI; and 4) lack of discussion of end-of-life healthcare decisions related to dementia and/or ANH by physicians or other healthcare providers. Two overall latent themes emerged: from

the CPs, the importance of the support from the MCI support group and lawyers for ACP; and from both CPs and the MCI participants, trying to maintain autonomy, to 'hang on' to self.

Theme 1: Decreased awareness regarding ACP for MCI individuals versus heightened awareness for CPs. MCI participants reported they were unaware of completion of advance directives or future planning, even though all CPs reported that both the CP participant and the MCI participant had completed a living will or some other form of advance directive and several had purchased long term care (LTC) insurance or moved to a congregate care retirement community (CCRC) or assisted living facility (ALF).

The MCI participants did not report designating a health care decision maker, but most assumed it would be their spouse and/or children, a term that myself and other researchers had previously identified as 'deferred autonomy' (Daaleman, Emmett, Dobbs, & Williams, 2008). Several described this perceived lack of need for planning through a subtheme of "Why discuss details" in which they felt there was no need for planning until faced with a situation requiring decisions as reflected by: "there are so many potential problems… why contemplate them all?" (MCI participant #2). "If I get sick, she (wife) is to make the decision…what other decision making would I have to consider?" (MCI participant #3). This deferred autonomy also manifested itself through MCI participant #4's comment: "I figure I shouldn't have to worry about it because I won't be around."

CPs, as compared to the MCI participants had a heightened awareness of the need for ACP, not only of advance directives but for LTC insurance and for future housing

needs, having moved to a CCRC or ALF, or were in the process of contemplating those future needs.

> " I know of situations where a spouse will say, 'Will you keep me at home regardless,' and there are times that that just doesn't necessarily work even though you want it to, that you can't get enough help, or whatever, for all kinds of reasons. So I think having our long term care insurance does cover care at home, which not all does, so that we are covered there, but in my mind I know that sometime it's just not enough. So whatever has to be has to be as far as I see it" (CP participant #5).

> "I realized we needed to get LTC insurance. I took out a policy in 2004 and we were both approved. He recently was diagnosed with MCI and I've just filed a claim with the LTC insurance. We have to pay for a companion to come for a few hours a day every day for the next 3 months, during the eligibility period and after that the policy will begin to pay… Our policies do not have any limit and they increase the benefits every year. I just checked and this year it will pay up to $190/day and one of the nice ALFs we've looked at is charging $180/day, so I think we will be OK" (CP participant #7).

The focus of the ACP for many was to stay out of nursing homes or ALFs. These quotes from four different CP respondents exemplify this subtheme:

> "My instructions were that my wife would never be sent to a nursing home. I've made that very clear to all my children. They can spend the entire inheritance to do that" (CP participant #1).

> "Both of us hate the idea of assisted living. And, so, we'll probably stick it out here as long as we can" (CP participant #2). "I know that I want to keep him home as much as I can, you know, and if I need help, we even discussed having someone come in if I need that" (CP participant #3).
>
> "We want to stay in our home as long as we can… But, I can't get the additional care that he has, and we really don't want to go into a long-term care facility unless it's absolutely necessary, and I think we can deal with staying home. As bull-headed as he is, and as hard-headed a Swede as he is, yeah, we'll deal with it" (CP participant #6).

All CPs had completed advance directives along with their spouses. Many CPs had also completed the Florida state do not resuscitate order (DNRO) form for their spouse. In response to the question of what prompted them to complete the DNRO, the CP responded, "We both want to go when it's our time, we don't want to linger. We've had a good life" (CP participant #1). Another commented,

> "We have taken the steps with healthcare directives and healthcare surrogacy's, and Living Wills. I've had a Living Will for years. I have had a heart attack and two strokes, so we both know that we don't want feeding tubes, and we don't want to be kept alive in a persistent vegetative state, and we don't want… you know, there's a DNR for both of us" (CP participant #6).

Response from CP participant #7 shows an awareness of the need for planning for the DNRO in the near future,

> "Well, the DNR we haven't talked about yet, but I know we need to. I know that they can be ignored, but now that we have the companion, she asked if we had a

DNR and I realized that we hadn't had that conversation yet and we really need to. I need to know if he collapses, does it want me to call 911, or does he just want to go. That's going to be the next conversation and if he wants to just go, then we are seeing the doctors in March and can get them to sign it, because I know that the Dr. has to sign."

Most CPs and MCI participants had very comprehensive documents and had conversations with their spouse, children and even friends regarding their wishes as indicated in CP participant #7's response:

"We have trusts, living wills and all of that. I've taken his name off the living wills, so he will no longer be listed as the decision maker for me, but I'm still his decision maker.

Well, it's actually called a Healthcare Declaration and it has the living will and the Health Care Surrogate designation. I'm the designee for my husband and his brother is listed second. In Delaware, I did a separate Declaration that lists me first and a very close friend in Delaware second. Both my friend and his brother have copies of the Declaration. Oh yes, we're very open with those types of discussions. We don't want any life prolonging measures, nothing artificial."

In describing conversations with family members about ACP, CPs' responses included:

"Yes, we talk constantly. They're happy that it is all spelled out. They know the forms are here and they have copies as well" (CP participant #1).

"We've talked about the fact that we're asking them to make a final decision for us as to whether or not we should continue to be on some form of treatment, or just stop all treatment and let what's gonna happen, happen" (CP participant #2).

"She was a little reluctant on accepting that at first because she said, you know, "I might not agree with this," and I said, "You better agree to it or I'll come back and haunt you." (Laughter) So I said, you know, we've lived a good long life, I don't want somebody to put us on machines to sustain a life. I was very definite about that" (CP participant #4).

"Oh yes, we're very open with those types of discussions. We don't want any life prolonging measures, nothing artificial" (CP participant #7)

"She (daughter) understands our wishes and supports us both" (CP participant #10).

Specific end-of-life preferences were generally expressed in general terms for the individuals with MCI:

"Not to have artificial life, I guess would be one term. No external stimulus if in a persistent vegetative state and no tube feeding" (MCI participant #6).

"Well, my Living Will is that I do not want any extraordinary things done. Just don't keep me alive" (MCI participant #5).

"I know it's at the end no unusual measures, or whatever that is" (MCI participant #10).

CPs were more aware of the actual advance directives that had been executed and what the specific end-of-life directives stated, but most were still general in nature and did not address specific issues such as ANH.

"We both want to go when it's our time, we don't want to linger. We've had a good life" (CP #1).

"Yeah, if there's no hope of full recovery, forget about it.… don't drag it out. If I

can come back to normal, you know, fine. If not, forget about it" (CP #2).

"It spells it out as it says that in the case of emergency treatment that no heroics and that sort of thing. She (daughter) was a little reluctant on accepting that at first because she said, you know, "I might not agree with this," and I said, "You better agree to it or I'll come back and haunt you." (Laughter) So I said, you know, we've lived a good long life, I don't want somebody to put us on machines to sustain a life. I was very definite about that" (CP participant #4).

"Would not want to live in a vegetative state on breathing support" (CP participant #5).

"They give the instructions that I'm not to be plugged up on a machine to be kept alive. I don't want that. I've seen a lot of that and I think it's sad, real sad" (CP participant #9).

"Pull the plug" (CP participant #10).

Both MCI participants and their CPs related that they did not wish to have ANH even when that was not reflected in their ACP.

Theme 2: Desire not to have extraordinary treatment at the end of life.

Despite reporting a lack of awareness of the MCI participants regarding ACP, all were able to express their desire not to have extraordinary treatment at the end of life. Participants commented, "at the end, no unusual measures" (MCI participant #2), "whoever wants to can pull the plug" (MCI participant #9), "let life system take its course" (MCI participant #7), "no external stimulus" (MCI participant #6), "I do not want any extraordinary things done" (MCI participant #4), and "just don't keep me alive" (MCI participant #1). Although the majority of individuals with MCI did not think they

had given directions as to ANH in the future, most were not in favor of that intervention. In fact one individual who answered most of the interview questions with a simple yes or no, when asked if she would want that intervention, responded emphatically, "I don't want any of that!" (MCI participant #8).

Theme 3: End-of-life preferences based on personal end-of-life experiences. Both MCI participants and their CPs described personal experiences with themselves, family members or friends when discussing their end-of-life preferences, not the MCI diagnosis or reflecting on what that particular diagnosis might mean for future health decisions. MCI participants shared the following:

> "No out of the ordinary things to keep me alive. I recall I could have stepped over the line when I had the aneurysm, but I woke up the next morning and said thank you Lord for the extra days. No feeding tubes. I just don't want those tubes. I leave it in God's hands. I believe deeply in the Lord. My doctors say I am a miracle, that I'm alive is a miracle. Every day since the stroke has been a gift. My husband and I have discussed this and that's where we are now" (MCI participant #1).
>
> "He (father) was taken into the hospital, EMS took him in, and he had a massive coronary, a stroke, or I don't know, something like that, and the physician who was taking care of him at the time, I asked her, "What the prognosis?" "You know, your father could stay alive for a long time." I said, what kind of life would he lead, what's the quality of life? "Well, he'll be like he is now and we'll send him to a nursing home and he could be there for years." I said, wait a minute. My father wouldn't want this, and I discussed it with my sister and my

brother, and we decided no. So then I talked to a physician friend of ours, and he said, "I'll take care of it," and they disconnected him from the life support. And I hope that when my time comes, I'd want the same thing to happen to me. And, my Living Will says that" (MCI participant #5).

"She (daughter) had had very severe and uncontrollable epilepsy for many years, and finally she was unresponsive, totally, and had to make the decision whether to remove the external stimulus or not. She was on the ventilator for a period of time, and then a decision had to be made whether to remove that or to continue. I'm sure she was dead" (MCI participant #6).

CPs also shared that personal experience and those of family and friends contributed to their end-of-life preferences. In the following excerpts, CP share experiences which have influenced them to limit treatment at end of life.

"I've seen several people die of cancer, some have gotten chemo and treatment, some haven't, but I haven't seen anyone saved" (CP participant #1).

"I mean based upon situations in the family that we've not had control of but discussed. I do not want that type of life support, and I think he knows that. I think we're very much in agreement in terms of end of life decisions" (CP participant #5).

Personal experience with of their own and with children also informed more specific decisions for this couple:

"His daughter (who died). And that was a big part of his decision making. I had a grandmother who had ALS and we both feel pretty much the same about end-of-life decisions, and we did talk about it. We have taken the steps with healthcare

directives and healthcare surrogacy's, and Living Wills. I've had a Living Will for years. I have had a heart attack and two strokes, so we both know that we don't want feeding tubes, and we don't want to be kept alive in a persistent vegetative state, and we don't want… you know, there's a DNR for both of us"(CP participant #6).

For one couple, family experience with hospice provided an alternative view from aggressive treatment in an acute care facility:

> "Well my husband and I don't want to be kept alive artificially; we're both very clear about that. We've had family experiences with Hospice, it's very spiritual" (CP participant #7).

Experiences in hospital setting provided another CP with her perspective on avoiding ANH:

> "Well, I don't know, I really don't. See when I worked in the hospital… I really don't know that I would even want that (ANH) unless a doctor really pushed for it" (CP participant #9).

A family experience which lasted some time and through much expense offered another CP the perspective that it would be better not to wait until the very end to limit treatment:

> "And, we have seen her brother languish for the last year. It was a million dollar period and he never was going to come out, and at one point he asked her, he was very close… it was just the two of them…and probably for this period, much closer to her than he was actually to his wife for advice, and he asked her what should I do, and she said, "just give up," and he couldn't do it. He said, "No, I don't want to." We feel when you know you're terminal it's the time to give up,

not at the end of the terminal period. The blood work, being in a hospital, being incapacitated. They say pneumonia is the one that rescues you from your problem, you die, and he's in the hospital, so protected against any germs, we come in fully gowned, and he can't even get pneumonia to die. So I am probably, maybe more so than her even, would take an earlier exit" (CP participant #10).

Theme 4: Lack of end-of-life discussions with physicians and other healthcare providers. There appeared to be a lack of discussion by healthcare professionals with the MCI participants and their CPs about what particular end-of-life decisions they might be faced with in the future. Specifically, no CP or MCI participants reported that any healthcare professional had discussed potential future needs for decisions regarding ANH, even though this is a very common decision that would be faced by family members, should the MCI progress to dementia. While the CPs were aware of the potential for further memory loss and a possible diagnosis of Alzheimer's disease, the ACP related more to planning for future care needs such as LTC insurance, moving to ALFs or CCRCs, and hiring in-home assistance. The possible need for ANH if the memory loss did progress to Alzheimer's disease was not something that neither any MCI participant, nor their CP discussed.

The diagnosis of MCI might have prompted completion of advance directives and/or review/revision of existing documents with their physician or healthcare providers, but this was not the case for any of the participants. Most of the CPs talked about having their advance directives completed with an attorney.

"We used the same lawyer that did all my family's legal work for our advance directives" (CP #7).

> "When we moved permanently to Florida we saw a lawyer at that time because we're from Connecticut originally and the laws of that state are different. So we went to a lawyer here and he set up both things" (CP participant #8).

For two couples, changes had been made because of the lawyer's advice that the Florida advance directive laws had changed.

> "I heard that FL law had changed about Living Wills and wanted to make sure they were up to date. We hadn't redone anything in over 20 years" (CP participant #1).

> "I think he's updated maybe four or five years ago, something or other in there. I think the law did change about five or six years ago" (CP participant #8).

Several CPs did share that advance directives had been updated to remove the spouse as designated decision maker for themselves, but no other substantive changes/revisions were made.

When both MCI and CPs were asked about whether their physicians had talked with them about advance directives, the answer was no. In cases where there had been a conversation with a physician, it was the MCI and/or the CP participant who had initiated the conversation.

> "Our doctors have been very good at doing what we want. When we first go to a new family doctor, which we've had to do a couple of times, we tell him that we don't want anything artificial or prolonged and make sure he's in agreement. We've never shown them the living wills, they're here if we have to go to the hospital" (CP participant #1).

"(I've talked with) my family doctor. I do have a piece of paper, I carry that around, because he's had mini strokes, and it says there Do Not Resuscitate, you know" (CP participant #3).

If they had not talked with their physician, the question elicited the response that they felt they should initiate that conversation.

"We probably should (talk with the doctor)" (CP participant #7).

"As a matter of fact I thought I should take him one (copy of the advance directive)" (CP participant #9).

Latent Themes

Importance to the CPs of the support from the MCI support groups and lawyers for ACP. Several CPs expressed that the MCI support group, the leader of the group and the neuropsychologist who assists with the group had been of help and support to them in understanding MCI and in thinking about ACP. In response to the question of who had been helpful in understanding MCI, the MCI support group was frequently cited:

"All the people in the MCI Support Group, (the support group leader and the MCI Neuropsychologist) and all the speakers they have had" (CP participant #7).

"Basically the group. I'd love it to be more than once a month" (CP participant #8).

In addition to the MCI support group, additional professionals were also identified as being of help:

"You mean other than the support group? There have been times that, oh, maybe once a year, there was a therapist that I would see, just sort of a healthy baby

check up or whatever. I think my background in terms of my caregiving skills, which is what took me in education probably… I mean I'm sure as a nurse you know there's certain caregiving skills that if you were put in the position would come more naturally than to somebody else. I've had support from friends too, but a lot of it… and you know our attorney and accountant have been helpful in terms of things that I needed to take over" (CP participant #5).

"Well, (the neuropsychologist) has been a tremendous help. She did his work up, and she was a tremendous help, and I went online and did a lot of reading" (CP participant #4).

Although all the MCI participants had been seen at the Memory Disorders Clinic, and all had physicians in the community, none expressed that a physician had communicated with them about what to expect or about ACP. No one described initiating or revising an advance directive based on conversations with physicians or other health care professionals, while several expressed that they had completed advance directives with their attorneys. One in particular was critical of the Memory Disorders Clinic physician's lack of communication:

"Basically as it was explained, and I will have to shoot a barb at the doctor when he came in and did the final diagnosis. He literally read it. He had never looked at it before I don't think, and didn't really answer any questions. And then he left. And it's like, okay, and we're paying for this visit? (The MCI Support Group Leader) was very helpful. She explained in the simplest terms. She said you know there's not a vitamin deficiency that noticeable, there's no real obvious brain damage that popped up in the MRI, although there was a little bit, some of

it's normal aging, but we have noticed the following things, and they said, you know, that someone with a Ph.D. thought processes are generally up here. She said, "you and me, you know, 1 to 10, if we think on 10 we're doing really great. That's fine." She said (her husband) normally thought at a 14 or a 15, and now he's down at about an 8, which for him is a big loss in cognitive powers, and that there is a possibility that it could get worse, and there's a possibility it could stay the same. At this point with MCI, they're not telling us a whole lot. They don't know. I think it is a very individual… it could go to dementia, it could go to Alzheimer's. I don't know. So we live with it. We live one day at a time" (CP participant #6).

Hanging on to self. Throughout the interviews, both CPs and individuals with MCI communicated that despite the diagnosis of MCI, they were still intent on hanging on to their autonomy and to themselves, and that despite the diagnosis, life goes on. Individuals with MCI discussed taking precautions to try and preclude worsening of the disease:

"I think it will get worse, but in a very loving marriage, and he's always saying to me, "Well, that's not that bad," and I'm actually seeing more slipping in some of my friends than where I am, and so I think… I'm embracive, we've got a big family, and you know we talk about it and they just say, "Don't worry about it." So we'll see what happens.

We're both really so much on the same page with all of this. And I think it's also that we're absolutely shocked that we're this old. We just put in to move to Sunnyside. We're 78th on the list for the unit we wanted. We thought, why didn't

we think of this when we were 75 instead of 79, but we don't… it's not a refusal to face it, I think we're just so engaged in life that we don't realize it's time to make these… so this is why I was so interested in talking with you, because it's time for us to focus more on these things" (MCI participant #10).

"I hope it doesn't get any worse" (MCI participant #9).

Many MCI participants discussed specific activities that they were engaged in:

"I mean I'm taking all the right precautions and I'm reading a lot about memory disorder and so forth, and my wife's been very supportive, and I haven't given up on anything. I'm still doing about everything I've ever done" (MCI participant #5).

"My wife and I walk two miles every morning and we do a lot of exercise, we play a lot of tennis, and we both keep very fit, and you know we keep our weight down and eat properly, and so forth, and go ahead, you ask some more questions" (MCI participant #7).

Emotional and practical considerations also appeared to be motivating factors for these preventive measures:

"I don't know. It's frightening really, and having always been in academics and being very sure of myself, sometimes now I'm not. And so I would like to do everything I can to preclude any more failure" (MCI participant #6).

"Well, just stop for a second. I looked at it this way. I'm older than she is, and most likely I'll go first, so I'd like her to be prepared to take care of herself and the children are taken cover of themselves, they're fine. So that's the only thing I have in mind. I don't know when that should happen. Should it happen now or

later, I don't know. I never gave it much thought because I never thought I'd reach, what time is it to do that. Am I making sense? So that's it, in fact I've been mulling it around in my mind, you know, hey, better get going on that, and see what it will be. And I don't think it's gonna be a problem because I'll probably go first because I'm older than she is, and so that's about it. I'll base that upon that, you know, that make sense?" (MCI participant #3).

Some CPs seemed to take the view that while their spouse had been diagnosed with MCI, it either wasn't progressing, or was not a real issue for concern:

"Oh, definitely. Well it's doing better. He's got a positive attitude. Now, there is one thing they told him at both places. His motor skills are excellent. We are what we call a silver tongue, and so people could sit down and visit with him for hours and not pick it up" (CP participant #9).

"It's like everybody, and if she's required to remember where she put something, she will remember, but otherwise she might be rather loose and put something down and an hour later she can't find it. It's always eventually found. We've seen fellow senior citizens and you know, it's a slow falling off the cliff as far as it seems memory and Alzheimer's and any cancer, whatever. Until you get started… and I don't think she's changed that much since she has been in the memory clinic" (CP participant #10).

Other CPs acknowledged the diagnosis and probability of decline, but still focused on the positive and living in the moment:

"Well, it's gonna get worse. I can't see it getting better. And, when it finally gets down to the point where it's a threat, well then we'll have to do something. What

it is I don't know. We're not even talking about it. Both of us hate the idea of assisted living. And, so, we'll probably stick it out here as long as we can. If she should become incapacitated, I would have to go to assisted living. I can't function very long. I can go a week maybe, but pretty soon the floor is littered with things that I can't pick up and that sort of thing. And, so we'll probably talk about it when it becomes a real problem" (CP participant #2).

"Um, I think the thing that I noticed, I just noticed things going on and finally convinced him that perhaps, and someone had told me about the Memory Center, because I really had no idea where to start with such a thing, but I was referred to them by a friend and he agreed to go, and as it turned out he was actually relieved because he knew there were changes and he was deathly afraid of Alzheimer's, which he had not expressed until after the diagnosis. So he seems to have been very comfortable with this, and you know, and fortunately in many ways I've been able to make life go on… you know there was a strong possibility that it could go into Alzheimer's. But, you know, I feel very fortunate for both of us that at this point it has not. I mean he's gone downhill, but not drastically cause I do see things that go on in the support group where people have had much bigger falls over the time than we've had to deal with" (CP participant #5).

"I don't know. It's going very slow. I'm just hoping that it just stays that way. You know, I take it day by day and just hope for the best. Accept it, there's nothing else I could do" (CP participant #3).

The focus for many of the CPs and MCI participants was not the MCI diagnosis, but rather dealing with the day to day concerns.

Chapter Five

Discussion

ACP practices. The fact that all of these couples already had advance directives at the time of the MCI diagnosis is perhaps reflective of the educational level and socio-economic status of the participants. Although no socio-economic information was collected, the education and professional backgrounds shared during the interview process appeared to reflect a higher socio-economic status for most participants. Additionally, the educational level was very high for both MCI participants and their CPs. All described having their advance directives completed with their attorneys. In my 25+ year history of working with the community to encourage the use of advance directives, I have frequently encountered this scenario in southwest Florida, where many attorneys will have completion of a living will or HCA document as part of the estate planning process, without discussion with a physician or other healthcare professional as to the specific ACP needs for the person completing this document.

Most CPs and many individuals with MCI felt that they had sufficient conversations with family and that they were aware and would honor their advance directives and their wishes regarding LTC placement, as well as DNRO requests. These discussions though, were general in nature and consisted of vague instructions, such as 'pull the plug' and 'no extraordinary measures'. These vague instructions could leave family in a difficult position as they attempt to navigate the decision of whether or not to institute ANH as previously identified (Caron, Griffith, & Arnold, 2005).

Readiness of ACP for MCI participants and CPs. It is perhaps not surprising that the majority of individuals with MCI reported decreased awareness of ACP decisions that had previously been made, as memory loss is a hallmark of the diagnosis. Even with this lack of awareness, most articulated a desire not to have extraordinary treatments at the end of life and assumed that their spouse and/or children would make decisions. This type of deferred autonomy, in which individuals assume their family members will know what decisions to make, or to make the right decision according to the circumstances has been described before in previous research (Daaleman, Emmett, Dobbs, & Williams, 2008) and other research has shown that most individuals want their family members to have leeway in decision making (Hawkins, Ditto, Danks & Smucker, 2005).

This also fits with the TTM in which the MCI participants did not perceive their diagnosis as increasing their risk for future problems with dementia or other health problems, therefore placing them in the category of precontemplation, in which there was no perceived need to plan for future end-of-life decisions. Like previous studies of MCI participants, the participants in this study may have minimized the possible conversion to dementia and were more focused on preserving current function, than on future planning (Linger et al. 2006; McIlvane et al., 2008).

Focus of ACP. While all of the individuals with MCI and their CPs had executed advance directives, the focus of ACP for CPs was not on end-of-life care, but on financial planning and avoidance of future nursing home placement. Most CPs had taken the step of removing their spouse who had MCI as HCA, but no other changes to advance directives were described as a result of the MCI diagnosis. This fits with the TTM in

which the CPs were taking action and maintaining their actions to preserve current or future living situations. The perceived threat of possible nursing home placement is probably the most obvious future scenario that CPs can imagine. Nursing home placement is a very visible transition and several of these couples have had experience with a relative or friend who required nursing home placement, based on the interview comments. Previous studies have also described planning for the future in terms of financial and housing decision, but not end-of-life decisions (Blieszner et al., 2007; Elson, 2006; Lu, Hasses, & Farran, 2007).

ANH and ACP. ANH, while being a very common decision that is faced by individuals and their families dealing with dementia, may take place months to years after nursing home placement out of the eye of the community at large. Although both MCI participants and their CPs discussed not wanting general aggressive treatments at the end of life, neither talked about any scenario in which they imagined ANH in relation to a diagnosis of dementia as a possible decision that might need to be made in the future, even though most CPs were aware of the possibility of dementia and many even commented that they were continuing to see decline in their spouse.

As indicated previously, individuals desire discussions with their physician regarding ACP (Kass-Bartelmes, Hughes, & Rutherford, 2003; Wright et al., 2008), and research has indicated that these discussions need to be ongoing and include goals of care related to the disease process (Emanuel, von Gunten, & Ferris, 2000; Fischer, Arnold & Tulsky, 2006), yet these discussion did not occur. Since all of the participants had some form of advance directives, one might assume that these individuals might have brought up these issues with their physician, but none had, instead, like participants in other

studies, appeared to wait for the physician to bring up the discussion when it would be appropriate.

Shared decision making models. Research on ACP in recent years has focused on shared decision-making models in which a specific treatment decisions which a person may be faced with have been discussed and values and goals of care clarified (Engelhardt et al. 2009; Hammes, Rooney, & Gundrum, 2010; Kirchhoff, Hammes, Kehl & Briggs, 2010), and research has demonstrated that individuals do desire to have their physician discuss their treatment options (Flynn, Smith, & Vanness, 2006). These models have focused on congestive heart failure, chronic renal failure, cancer and chronic obstructive pulmonary disease. MCI, with its high rate of conversion to dementia would seem an obvious target for future efforts with this model, with discussions regarding ANH being at the core of the EOL planning.

In addition to having some form of advance directive, several MCI participants also had DNRO orders which would cover sudden cardiac events in the home or community settings. While three couples knew that their documents contained specific instructions regarding ANH they equated this to not wanting to be kept alive as a vegetable or in a persistent vegetative state. The view of advance directives seemed to be more on acute care situations, not on the series of small decisions that might need to be made in the event of moderate to end stage dementia. No CP participant articulated that they might need to make a decision regarding ANH if the MCI diagnosis progressed to dementia, even though most seemed aware of the likelihood for in home services or possible placement in the future.

The lack of specific directions supports the communication of goals of care for future ACP decisions for this population (Hawkings, Ditto, Danks, & Smucke, 2005), as well as discussion of common end-of-life scenarios such as the decision regarding ANH or nursing home placement. While several participants articulated their desire to not live in a nursing home, the reality for many who progress from MCI to dementia is that that may be the more appropriate care setting at the end of life depending on the family's resources and ability to provide care as the disease progressed. Focusing on keeping the individual comfortable no matter what the care setting might ease caregiver's in the decision making process in the future.

The role of personal end-of-life experiences and ACP. Although no one discussed revisiting their advance directives based on the diagnosis of MCI, many discussed the need for these documents while describing family experiences. These family experiences consisted mainly of acute hospital situations, but none dealt with end stage dementia. Personal experiences included acute heart conditions, cancer and stroke. The personal experiences that were described that had occurred with themselves or close family members seemed to exert a powerful desire not to 'linger' or have life prolonged with no hope for recovery. This is in line with Carr and Khodyakov's study (2007) which found that recent experience with a painful death significantly predicted completion of advance directives and discussion of end-of-life preferences with others.

Stories and shared experiences are part of what Gelfand et al. (2005) discussed in their interdisciplinary team model of end-of-life decision making. Others have also discussed the power of family and personal experiences in increasing ACP participation (Fried et al., 2009; Lambert et al., 2005). Stories of acute treatments for

cardio/pulmonary events and cancer are very prevalent in our culture. While more individuals are aware of dementia and it's progression through experiences with family and friends, or through national stories such as Ronald Reagan, the actual end-of-life experiences and whether or not ANH was considered have not been part of our national stories, nor perhaps, are they shared among family unless they are intimately involved in the care decisions. There may be concern that if a decision was made to not initiate ANH that the family would be viewed as 'starving the person to death'.

While several CPs reported talking to physicians regarding their advance directives, the conversations appeared to be initiated by the CPs, and did not include discussion of ANH. Both CPs and MCI participants felt that doctors and especially the staff of the MCI support group had been helpful in their understanding of MCI and what might happen in the future, but none reported discussions regarding ANH, despite this being the most common end-of-life decision for a person with dementia. While many expressed general desires to limit aggressive treatment, ANH is often viewed differently than CPR or use of a ventilator. If specific wishes have not been previously expressed, the default is usually to provide ANH. It could be that both CPs and the healthcare professionals feel that this decision is too far down the road to begin the discussion at the time of diagnosis of MCI.

The time frame in which one might continue to have decision making capacity can not be predicted, so frank and open discussion of the possibility for making this decision should be considered relatively early in the course of MCI. Following the TTM this would allow the process of precontemplation, contemplation, action and maintenance to be initiated (Pearlman et al., 1996). As outlined by Fried et al., (2009), the quality of

ACP could be most effective by this type of customization focusing on disease specific decisions such as ANH and perhaps inviting reflection on past end of life experiences with significant others. It could be that staff at the MCI clinic and/or support group did bring this up, but that both MCI participants and their CPs did not see this as a possible scenario in their future.

Many of the participants in the study either had identified no ANH in their ACP documents or articulated a desire not to have ANH at the end of life. Most seemed to associate the need for ANH with being in a persistent vegetative state, which is not surprising given the media attention for both Nancy Cruzan and Terri Schiavo's court cases. Although the emerging research on MCI does indicate associations with future planning, the planning is focused on financial and living arrangements, not on end of life. Only in the pathography of Davis (1989) who had years of experience in ministering to individuals with dementia at the end of life of nursing homes, did he focus explicitly on his desire not to have ANH as his dementia progressed. Other research with MCI participants has also found a lack of response in initiating ACP after diagnosis (Garland et al., 2011; Lingler, 2008). Hirschman, Kapo, and Karlawish (2008) described both passive and active avoidance of end-of-life discussions with MCI participants and their physicians. In the case of this MCI population, advance directives were seen as being taken care of with no new revisions needed with the diagnosis of MCI other than to remove the participant with MCI from the CP's advance directive as HCA.

Interestingly only one participant cited hospice when discussing end-of-life care. With shared decision making and documents such as the POLST, hospice can be introduced as an option early in the end-of-life decision making process. Individuals with

MCI could articulate goals of care that included referral to hospice to manage end-of-life symptoms, even if progression to dementia was not seen as a real possibility.

The role of MCI support groups and lawyers for ACP. As was indicated in the literature (Gillick, 2004; Rosenfeld et al. 2000), communication is key in ACP and the CPs appeared to have received the most direct help and communication from the MCI support group and staff facilitating that group. As the diagnosis of individuals with MCI becomes more prevalent, more MCI support groups may form, just as there are currently numerous Alzheimer's and related disorders support groups around the nation. These support groups may be one location to focus interventions such as the shared decision making model and/or initiation of the POLST document. While the POLST needs to be signed by a physician, in many settings, the discussion of the document is initiated by a nurse or social worker. MCI participants and their CPs expressed a trust and reliance on these groups and the individuals facilitating them, and would probably be receptive to ACP interventions from them.

This particular group may not be indicative of other groups throughout the country, and may be uniquely staffed and supported. Blieszner et al. (2007) found that participants of an MCI center felt they did not get the needed information and support. A meta-analysis of interventions with caregivers of person with dementia showed no significant effect on caregiver ability or knowledge, so support groups may not provide the most effective venue for these types of interventions (Pinquart & Sörensen 2006). While this would obviously be of assistance to individuals who seek out and attend these types of groups, other mechanisms would have to be developed to target those who do

not participate in these groups. MCI clinics might include this as a part of the follow up with participants once a diagnosis is made.

ACP was viewed as necessary by the CPs but was focused initially on LTC and the need to secure financial arrangements and/or living arrangements. In this view of ACP, lawyers were viewed as the professional to turn to for advice and support, not physicians. This is perhaps not surprising, given that many individuals in the cohort have probably had experiences with friends and families who have had to place individuals in nursing homes, and most do not want to have to make that decision in the future. Fewer individuals are aware of the end-of-life needs and decisions that are made for persons with dementia probably because these usually occur in hospitals and nursing homes, away from the eyes of the public. Elder care attorneys are more aware than estate planning attorneys of the need for discussion of ANH and the need for designation of a HCA, but many lay persons do not go to elder care attorneys. Efforts to educate all lawyers of the need for discussion of ACP documents with healthcare professionals need to be ongoing. Fried and colleagues (2009) also advocate for ACP to be visited as part of other ongoing planning such as funeral planning. Although many individuals are aware of dementia, there has been little to no public discussion of ANH with this group and only recently has there been vigorous discussion in the professional community about this issue.

Hanging on to self. Since the individuals with MCI do express the desire to retain autonomy and hanging on to self, and as expressed through these interviews, still have strong opinions as to future end-of-life care, this appears to be a population that would be receptive to discussion regarding ACP for end of life. Specific discussions

regarding possible scenarios involving decisions, not only about potential NH placement but ANH at the end of life can and should be reviewed with this population. Hirschman, Kapo and Karlawish (2008) found there was both passive and active avoidance of discussion of ACP; however families wished that they would have initiated those discussions in retrospect. Although there is fear that these discussions may cause distress, studies have demonstrated that families who have had these discussions are better able to cope following the death of their loved ones (Fried et al., 2009; Wright et al., 2008). The individuals with MCI and their CPs were focused on doing what they could to retain current function, and part of retaining control could include active participation in shared decision making, and/or execution of documents such as the POLST.

Contributions

This study explored the ACP experiences of persons with MCI and that of their CPs and contributed information to a current gap in the literature. The study demonstrated that although persons diagnosed with MCI face an increased possibility of developing dementia at some point in the future, they did not appear to perceive themselves at being at increased risk for being unable to make healthcare decisions in the future, while their spouses did appreciate this increased risk, in most cases deleting them as HCA from the CPs' advance directives.

Additionally, the participants in this study reported that physicians did not discuss end-of-life wishes with participants with MCI, nor with their care partners. The diagnosis of MCI in and of itself did not serve as a trigger for initiation and/or reexamination of ACP for the MCI participant, although it did serve as a trigger for the CP to change the

HCA in their advance directives. The discussion of ANH (one of the most common end-of-life decisions for a person with dementia) at the end of life was not discussed with any of the participants. This study points out the need for healthcare providers to address possible specific scenarios such as ANH with individuals diagnosed with MCI.

Chapter Six

Conclusions

Opportunities. Advance directives alone have not been shown to be effective despite several decades of use. Researchers in recent years have focused on shared decision models and/or use of documents such as the POLST which incorporate specific directions related directly to the individuals' situation. Studies looking at use of this model with individuals with chronic heart, lung and kidney disease as well as cancer have been demonstrated to be effective in honoring individuals' goals of care.

Individuals with MCI are a growing population in this country and many will progress to dementia over time. Once diagnosed with MCI there is a period of time in which the individual retains decision making capacity, and this is a crucial time in which shared decision making and/or POLST could be initiated. ANH is one of the main end-of-life decisions that individuals with dementia will face, and many would benefit from the end-of-life services provided by hospice. Discussion of this with MCI individuals could give them an opportunity to continue to exercise their autonomy and retain self, as well as offering family feedback on goals of care and guidance for future end-of-life care.

The emergence of MCI as a diagnosis has also prompted the emergence of support groups to assist both the individual with MCI and their CPs in coping with the diagnosis. As evidenced by this study, individuals found that the support group and its facilitators offered support to them, and may be a setting in which to offer the shared decision model and/or initial discussion of POLST. Since individuals diagnosed with

MCI often receive this diagnosis at a memory disorders clinic, the clinics themselves may be the best site to initiate the shared decision model and/or POLST, as that would capture individuals that may be less likely to participate in support groups as well. Physicians did not play a strong role in the ACP of these participants, but by initiating the discussion at the MCI support group level or in MCI clinics, many MCI participants and their CPs may be empowered to then discuss their goals of care with their physicians.

Limitations. This study relied on a convenience sample from a local MCI support group. This support group is located in a community which is largely Caucasian and has a higher socioeconomic level than most of Florida, as well as the nation. This likely contributed to the lack of diversity in the sample population. The participants appeared to have a high socio-economical level, and had a higher education level than the general population. The participants were self selected, and may not reflect the same views as those who chose not to participate in the study. All were diagnosed at the same MCI clinic, and attended the same support group, so there may be different results from different clinics. Specifically, these more affluent, well educated participants may have been more likely to utilize attorneys for ACP and to have a focus on financial planning versus end-of-life care. Individuals who do not attend a support group may be less likely to initiate ACP as well. While the participants in this study were very positive about the support they had received from the MCI support group and its facilitators, this may not be the same experience at other support groups.

All participants knew that the focus of this research was on ACP and may have chosen to participate because they had already engaged in ACP and were interested in more information regarding ACP. It may be that individuals who had not yet engaged in

ACP were less likely to participate in this research. Although this qualitative study reached data saturation with ten couples, it could have been that the small sample size limited the findings since the participants did not vary in terms of ethnicity, and were well educated.

All participants in this study were married and their identified CP was their spouse. Experiences of ACP may differ with individuals who are widowed, divorced, separated and whose CP is not a spouse. Although each MCI participant reported having a physician, there were no specific questions asked about neither the individuals' primary care provider, nor the type of physician (Internal medicine, family practitioner, geriatrician, etc). This would be important to consider in future research as the type of physician may influence the degree of involvement in initiating ACP discussions and the types and depth of these discussions.

Although the interviewer did have many years experience as a nurse in talking with individuals about ACP, there was a lack of experience in conducting open ended interviews, which may have resulted in lack of follow up for more in depth probing questions to elicit more information in some cases. Individuals with MCI were not screened for level of impairment. This had been considered during the proposal process, but was deemed not to be necessary. In retrospect, minimal screening with the mini mental status exam or St. Louis University mental status exam would have provided helpful baseline information to compare responses.

Recommendations. The MCI population represents a prime opportunity to initiate/revisit ACP to specifically address potential end-of-life decisions and other potential ACP decisions that may be faced if the diagnosis proceeds to dementia as is

likely for a large number of those receiving this diagnosis. MCI support groups offer support and education to both MCI participants and their CPs and, in the population studied were a trusted source of information for this study population. MCI clinics are also a potential source of ACP information. A pilot study should be conducted in this setting utilizing the shared decision model and/or initial discussion of the POLST. Participants would be encouraged to continue the discussion with their primary care physician and continued support could be offered by the MCI clinic staff or support group. A model put forth by Sudore and Fried (2010) proposes a model for healthcare practitioners that could be easily utilized in such a pilot that involves identifying the HCA, clarifying values and establishing leeway in HCA decision making.

Although recent attempts to promote ACP through public policy have been met with misunderstanding, this does not mean that those attempts should be halted. Fried and Drickamer (2010) call for the development of a public message that ACP is part of preventive health care. This would emphasize that personal participation in ACP takes place on a clinical level between the patient and clinician, but encouraging participation in ACP must occur on a population level, by increasing the public's awareness of ACP, the benefits and the potential negative effects of not participating. This might also aid in the fact that while most individuals desire to have these types of conversations with their clinicians, they are waiting for clinicians to initiate. By sending a strong public health message that the time to discuss these issues is sooner rather than later, individuals may go to their clinicians and initiate the discussion themselves instead of waiting for the clinician to initiate.

Although much literature has been published in the past decade regarding ACP, end-of-life care and dementia, very little is known regarding the ACP experiences of individuals with MCI. ACP has been found to involve a complex interplay between individuals, their family and physicians, and their knowledge and understanding of future health outcomes. As indicated earlier, individuals with dementia will usually experience prolonged periods prior to death in which a multitude of healthcare decisions will be made for them. Individuals diagnosed with MCI progress to dementia at a higher rate than those without this diagnosis. Perhaps in no other group of individuals is the need for ACP more important. Any additional information that sheds light on the process by which these decisions are contemplated and executed will be of immense value in helping to guide efforts to engage this group in ACP.

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Appendix A

Interview Guide for Advance Care Planning/MCI

Thank you for meeting with me this afternoon.

I'm interested in finding out about what kind of healthcare planning older adults and their families have thought about and/or already have done. I understand that you were seen at the Sarasota Memory Disorders Clinic?

INTRODUCTORY QUESTIONS

What was the reason you were seen at the Clinic?

Follow-up:

What were you told about your memory?

Who helped you in understanding what was going on (physician, family, friends, others)?

What do you think will happen to your memory in the coming years?

TRANSITION

Has anyone talked with you about planning for healthcare decisions that may need to be made in the future? (If yes, prompts to explore further-who, what was discussed)

Have you heard the term Advance Directive (AD)? (If no- explain term)

If yes, Have you completed one? (If have not completed but know about AD, explore reasons not completed)

(If AD completed, explore when it was completed, what does it say, is HCS/DPOA-HC part of AD, who is HCS/DPOA-HC, has the AD been revised since MCI Dx? Explore reasons decision were made and when they were made, have they changed over time and/or since MCI Dx. If they have not appointed a HCA, but know about it, why not?)

Have you discussed/shared any of these decisions/documents with your family? (Explore what was discussed or if no discussion, why not?)

Have you discussed/shared any of these decisions/documents with your physician(s)? (Explore what was discussed and if no discussion, why not?)

Have you discussed/shared any of these decisions/documents with other persons, such as a spiritual advisor (priest, pastor, rabbi) or other health care provider (social worker, nurse)? (Explore what was discussed and if not discussion, why not?)

CLOSURE

Is there anything I didn't ask about planning for future healthcare decisions that you would like to talk about?

Would you like further information on ACP?

Thank you for visiting with me today.

Appendix B

Interview Guide for Advance Care Planning/MCI CP

Thanks for meeting with me this afternoon.

I'm interested in finding out about what kind of healthcare planning older adults and their families have thought about and/or already have done. I understand that you are the CP for (fill in name) who was seen at the Sarasota Memory Disorders Clinic?

INTRODUCTORY QUESTION

Personal History

How long have you been the CP for (individual with MCI)?

Relationship

Age

Education

How long have you lived here?

What was the reason (fill in the name) was seen at the Clinic?

Follow-up:

What were you told about (Fill in the name) their memory?

Who helped you in understanding what was going on (physician, family, friends, others)?

What do you think will happen to (fill in the name) memory in the coming years?

TRANSITION

Has anyone talked with you and (fill in name) about planning for future healthcare decisions that may need to be made in the future? (If yes, prompts to explore further-who, what was discussed)

Have you heard the term Advance Directive (AD)? (If no- explain term)

If yes, has (fill in the name) completed one? (If have not completed but know about AD, explore reasons not completed)

(If AD completed, explore when it was completed, what does it say, is HCS/DPOA-HC part of AD, who is HCS/DPOA-HC, has the AD been revised since MCI Dx? Explore their understanding of the reasons decisions were made and when they were made, have they changed over time and/or since MCI Dx. If a HCA has not been appointed, why do they feel this has not been done?)

Have you discussed/shared any of these decisions/documents with your (fill in name)? (Explore what was discussed or if no discussion, why not?)

Have you discussed/shared any of these decisions/documents with your physician(s)? (Explore what was discussed and if no discussion, why not?)

Have you discussed/shared any of these decisions/documents with other persons, such as a spiritual advisor (priest, pastor, rabbi) or other health care provider (social worker, nurse)? (Explore what was discussed and if not discussion, why not?)

CLOSURE

Is there anything I didn't ask about planning for future healthcare decisions that you would like to talk about?

Would you like further information on ACP?

Thank you for visiting with me today.

Appendix C

UNIVERSITY OF SOUTH FLORIDA

DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-5618

Catherine Emmett,
School of Aging Studies

RE: **Expedited Approval** for Initial Review
IRB#: Pro00000945
Title: What are the Advance Care Planning (ACP) Experiences of Persons with Mild Cognitive Impairment (MCI)?

Dear Catherine Emmett:

On 7/26/2010 the Institutional Review Board (IRB) reviewed and **APPROVED** the above referenced protocol**.** Please note that your approval for this study will expire on 7-26-2011.

Approved Items:
Protocol Document(s):

Study Protocol	6/22/2010 5:23 PM	0.02

Consent/Assent Document(s):

IC.pdf	7/27/2010 8:34 AM	0.01

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and

(2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

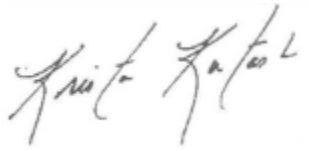
(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program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

Please note, the informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,



Krista Kutash, PhD, IRB Chairperson
USF Institutional Review Board

Cc: Various Menzel, CCRP
USF IRB Professional Staff

Appendix D

USF
UNIVERSITY OF SOUTH FLORIDA

DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-5618

July 11, 2011

Catherine Emmett,
School of Aging Studies

RE: **Expedited Approval** for Continuing Review
IRB#: Pro00000945
Title: What are the Advance Care Planning (ACP) Experiences of Persons with Mild Cognitive Impairment (MCI)?

Study Approval Period: 7/26/2011 to 7/26/2012

Dear Ms. Emmett,

On 7/8/2011 the Institutional Review Board (IRB) reviewed and **APPROVED** the above protocol **for the period indicated above**. It was the determination of the IRB that your study qualified for expedited review based on the federal expedited category number:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

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

Please reference the above IRB protocol number in all correspondence regarding this protocol with the IRB or the Division of Research Integrity and Compliance. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John A. Schinka, Ph.D.

Appendix E

UNIVERSITY OF SOUTH FLORIDA

DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-5618

June 27, 2012

Catherine Emmett
School of Aging Studies
234 Delmar Ave.
Sarasota, FL 34243

RE: **Expedited Approval** for Continuing Review
IRB#: Pro00000945
Title: What are the Advance Care Planning (ACP) Experiences of Persons with Mild Cognitive Impairment (MCI)

Study Approval Period: 7/26/2012 to 7/26/2013

Dear Ms. Emmett,

On 6/27/2012 the Institutional Review Board (IRB) reviewed and **APPROVED** the above protocol **for the period indicated above**. It was the determination of the IRB that your study qualified for expedited review based on the federal expedited category number:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

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

Protocol Document(s): Study Protocol

Please reference the above IRB protocol number in all correspondence regarding this protocol with the IRB or the Division of Research Integrity and Compliance. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John Schinka, PhD, Chairperson
USF Institutional Review Board