

DECIDING TO ENGAGE IN ADVANCE CARE PLANNING:
A COMPARISON OF PARTICIPANTS' EXPERIENCES

By

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ABSTRACT

DECIDING TO ENGAGE IN ADVANCE CARE PLANNING: A COMPARISON OF PARTICIPANTS' EXPERIENCES

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Advance care planning (ACP) is a dynamic decision-making process that assists people to construct and communicate their preferences for end of life care. Two decades of research have shown that when preferences are not known, undesirable outcomes may occur for individuals and other surrogate decision-makers. Barriers to advance planning can be addressed through educational programs, especially through existing community-based groups. The purpose of this study was to examine internal and external influences within the decision-making context that may affect individuals' decisions to engage and re-engage in ACP. The *Decision Process Model for Advance Care Planning* provided the conceptual framework for this secondary analysis of data from a prospective quasi-experimental research project. Study participants were 147 adults from existing community groups in the Midwestern United States who attended an ACP educational program provided by certified ACP Facilitators. Participants completed pre- and post-program Participant Surveys, which included personal influences on decision (information, individual characteristics, values, and prior experiences) and the personal decision factor self-efficacy (ability and likelihood to engage in ACP conversations). Results of this study describe the prevalence and associations of personal influence and decision variables among participants. Statistically significant differences exist in most variables when participants with and without previous ACP experience are compared. After attending the ACP educational program, participants' perceptions of their

knowledge, importance, ability, and likelihood to have ACP conversations were significantly increased. When participants with and without previous ACP experience were compared, the impact of the ACP program intervention remained significant in the areas of knowledge, ability, and likelihood. Understanding the prevalence and associations of internal personal variables and the impact of an external ACP intervention on these internal variables can help health care professionals target community-based educational interventions to promote ACP.

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Wherever you go, may God go with you.

Whatever you need, may God provide.

Whenever you falter, may God forgive.

Whenever you stumble, may God save.

And when, at the end of your days, you lay yourself down
for the last time, may God raise you up for all time. Amen.

William B. Lawrence

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CHAPTER 1

PROBLEM AND PURPOSE

Each year in the United States an average of 2.4 million people die (Centers for Disease Control, 2006), most without their preferences¹ for end of life care known or honored (Kass-Bartelmes, Hughes, & Rutherford, 2003). When people's preferences are not known, undesirable outcomes may occur. For the individual, end of life care may be incongruent with personal preferences (Gillick, 2001), impose burden and possible suffering (Connors et al., 1995), or incur unnecessary health care costs (Field & Cassel, 1997). In addition, unawareness of preferences causes increased distress for others, such as family members (Tilden, Tolle, Nelson, & Fields, 2001) and health care providers (Daly, 2006; Hurley, Volicer, Rempusheski, & Fry, 1995). These people often become surrogate decision makers when the individual is no longer able to participate in decision-making.

Because end of life may take several trajectories, ranging from a sudden critical injury or illness to a persistent decline from a recurring condition (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003), individuals may or may not have planned for end of life care. When end of life care at last is needed, the capacity to make decisions may be severely limited (Pierce & Hicks, 2001). Therefore, advance care planning (ACP) for end of life preferences is highly desirable (Hammes & Briggs, 2002b).

ACP is defined, for the purposes of this proposal, as a dynamic decision-making process that helps people construct and communicate their preferences for end of life care. Because ACP is viewed as a decision-making process, further definitions of its components are drawn from the decision-making literature. Decision-making is defined

¹ A glossary of key terms used throughout the proposal is included in Appendix E.

as the evaluation of information about alternatives according to personal values (Mazur, 2003). The process of decision-making includes decisions, behaviors and outcomes (Rothert et al., 1997; Wills & Holmes-Rovner, 2006). Decisions are defined as choices between alternatives (Thompson & Dowding, 2002), that influence subsequent behaviors and outcomes.

Decision-making occurs within a decision-making context, which includes the decision, behaviors, outcomes and influences (internal and external) that shape the decisions people make (Wills & Holmes-Rovner, 2006). ACP decisions, for example, may be shaped by personal influences or decision factors (internal influences), broader socio-cultural community decision factors or interventions (external influences), or outcomes, such as initiated advance directives (AD) or congruence of decisions with preferred care goals. The ACP decision-making process is dynamic because it may be engaged in repeatedly, especially in response to changes within the decision-making context. Individuals' ACP preferences, however, may or may not change over time.

The goal of ACP is awareness of and respect for individuals' preferences for their future health care. The hope is that communication and consideration of preferences will prevent avoidable distress and suffering for patients, families, and caregivers by honoring individuals' expressed wishes. This type of communication helps to foster the often desired outcome of a "...good death—one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Field & Cassel, 1997). Based on these communication goals, ACP has been endorsed as a domain of quality care at the end of life (Field & Cassel; Stewart, Teno, Patrick, &

Lynn, 1999) by public and private organizations such as the Michigan Commission on End of Life Care (2001), the American Geriatrics Society (Lunney, Foley, Smith, & Gelband, 2003), and Last Acts (a program of the Robert Wood Johnson Foundation) (Kaplan & Peres, 2002).

Barriers to Engaging in Advance Care Planning

Although ACP has been encouraged and publicly supported, research summaries document that at least 50% of the American population does not engage in advance planning (Kaplan & Peres, 2002; Kass-Bartelmes et al., 2003; Lorenz et al., 2004; Lunney, Foley et al., 2003). These results have persisted despite intense efforts over the past 15 years to increase the prevalence of planning for end of life care. End of life researchers and their colleagues who study shared decision-making offer a variety of explanations, summarized by this investigator as four common barriers to ACP: reluctance, relevance, resources, and restraints.

The first barrier is reluctance. People are often reluctant to consider their end of life preferences. Weiner and Cole (2004) found this reluctance in both patients and health care providers, related to personal discomfort with the topic, concern that it will cause distress for others, or the perception that it will either take too much time or that it is not needed at this time.

The second barrier is relevance, which may arise from a variety of sources. Some people are not interested in participating in decision-making (Levinson, Kao, Kuby, & Thisted, 2005; Say, Murtagh, & Thomson, 2006). Others perceive it as culturally inappropriate (Makoul & Clayman, 2006). Still others may lack decisional capacity for such planning to be relevant (Hammes & Briggs, 2002b; Pierce & Hicks, 2001).

The third barrier is availability of resources. Individually, some people may lack the information, skills, or confidence to thoughtfully consider care options in light of their personal values and communicate their decisions effectively. Within communities, ACP is affected by the availability of ACP information and the perceived importance of ACP among community members (Pearlman, Cole, Patrick, Starks, & Cain, 1995). When people engage in ACP, their actual outcomes during end of life care often greatly depend on the resources of their community health care system. Positive outcomes may be realized in organizations that educate HCP's to initiate and honor ACP conversations as a part of routine adult health care (Ferrell et al., 2005; Robinson et al., 2004; Weissman et al., 2005). An organizational culture of respect for patient preferences supported by structures and processes to provide assistance with ACP has been reported as essential (Hammes & Rooney, 1998). If these community resources are not available, outcomes may be less optimal or nonexistent (Hammes & Briggs, 2002a).

The fourth barrier is perceived restraints—literally feeling held back by the complexities of constructing and communicating preferences and keeping preferences current. People who engage in ACP have much to consider: An array of choices, uncertainties, and consequences which need to be understood and evaluated on the basis of their preferences (which may be unclear) (Pierce & Hicks, 2001) so that future care (which may or may not be needed) is provided according to their wishes when they can no longer make or communicate their decisions (Pearlman et al., 1995). Once preferences are constructed, people then have to find a way to effectively communicate them to others who may someday be involved in decision-making. This can be

challenging, particularly if others feel reluctant to discuss end of life issues or find them irrelevant (Weiner & Cole, 2004).

Ideally, because ACP is a dynamic decision-making process—responsive to changes in the decision-making context—people should regularly return to the decision to engage in ACP. This provides the opportunity to validate or reconsider preferences in response to the decision process itself or changes in individual or community influences. However, re-engagement in ACP depends on peoples’ awareness of and willingness to acknowledge or adapt to such changes (Grounds, 2004) and their abilities to still make decisions, possibly under new constraints of physical or emotional stress or limited time (Pierce & Hicks, 2001). If new preferences are constructed, effective communication of those changes is also needed. In a review of the state of ACP research, Emanuel summarizes these restraints as the “... great difficulty in knowing one’s own preferences, articulating and recording them, and getting them understood and implemented...” (2003).

The Role of Advance Care Planning Research

Through ACP research, changes within the decision-making context of ACP can be examined and encouraged. For example, researchers may study how decisions lead to outcomes or how changes in internal influences affect decisions or how an external intervention affects peoples’ perceptions of reluctance, relevance, resources, and restraints. Although in the beginning ACP research was focused on advance planning as an intervention or an event, researchers are encouraged now to study ACP as a process (Emanuel, 2003).

Influences on End of Life Planning

Researchers have documented a variety of influences on end of life planning. First there are internal individual influences—such as knowledge, demographics, values, experiences, and self-efficacy (Cicirelli, 1997; Davison & Degner, 1998; Pearlman et al., 1995; Pierce & Hicks, 2001). Secondly, there are external community influences, such as access to ACP information and support of ACP processes within the health care community (Byock, Norris, Curtis, & Patrick, 2001; Hammes & Rooney, 1998). Thirdly, there are external interventions designed to influence and create a context in which advance planning becomes more prevalent (Kass-Bartelmes et al., 2003). All three types of influences have been studied by researchers using community-based educational interventions that inform and encourage people to engage in ACP (Byock et al., 2001; P. Clarke, Evans, Shook, & Johanson, 2005; Hamel, Guse, Hawranik, & Bond, 2002; Hammes & Rooney, 1998; Waters, 2000).

Community-based approaches to ACP have been recommended as a way to increase the number of people who engage in advance planning (Field & Cassel, 1997). Respecting Choices®—a whole-community approach to ACP that includes professional training, public education, and strategies for mobilizing organization and community support—is an example of an intervention that increased advance planning from 15 to 85% by residents in the LaCrosse, Wisconsin community (Hammes & Rooney, 1998). When people engage in ACP together, an environment of shared decision-making is created (Kass-Bartelmes et al., 2003) that encourages continued shared consideration and communication of end of life preferences.

This dissertation examines the impact of a structured ACP educational program intervention on selected personal influences on individuals' decisions to engage in ACP. The ACP program intervention, using the Respecting Choices® curriculum, was designed to address common barriers to ACP and foster an environment of shared decision-making to promote ongoing engagement in ACP. Programs were presented to established groups of individuals in communities. During the programs, individuals were encouraged to further engage in ACP; that is, to understand, reflect, identify and discuss their preferences to help them formulate and make available plans for end of life care (Hammes & Briggs, 2002b). Participants were given tools and strategies to continue these conversations beyond the program with their significant others and health care providers.

Studies of End of Life Planning

Previous ACP studies have not focused on ACP as a decision-making process. Instead, researchers have focused almost exclusively on only one outcome of ACP: an initiated advance directive (AD) that formally communicates an individual's preferences. Other features of the ACP decision-making process such as engaging in ACP behaviors or deciding to engage in ACP are almost non-existent in the literature. The decision to re-engage in ACP has also not been examined. Since the objectives of ACP are broader than an AD (Kolarik, Arnold, Fischer, & Tulsky, 2002) and are best studied as a process (Emanuel, 2003), this dissertation focuses on ACP as a dynamic decision-making process that may be engaged in repeatedly.

Purpose of Study

The purpose of this dissertation is to add to the understanding of ACP as a dynamic decision-making process by examining internal and external influences within the decision-making context that may affect individuals' decisions to engage and re-engage in ACP.

Research Questions

This pre-post survey study of ACP is designed to answer the following questions, as depicted in the Focused Model of the Decision to Engage in ACP in Chapter 2 (see Figure 2, p. 23).

Before participation in a community-based ACP program:

1. What are the self-reported Personal Influences on Decision and Personal Decision Factors of adults who have decided to engage in ACP?
2. Which variables from among the Personal Influences on Decision and Personal Decision Factors are associated with the Decision to Engage in ACP?
3. Do the Personal Influences on Decision and Personal Decision Factor variables that are associated with the Decision to Engage in ACP differ between participants with previous ACP experience compared to participants without previous ACP experience?

After participation in a community-based ACP program:

4. Are there changes from pre- to post-ACP program intervention in self-reported ratings of enough knowledge, importance, ability, and likelihood to have an ACP conversation?

5. Do the changes between participants' self-reported pre- and post-ACP program intervention ratings of enough knowledge, importance, ability, and likelihood differ between participants with previous ACP experience compared to participants without previous ACP experience?

Overview of Dissertation Study

Chapter 1 has presented the problems of approaching end of life without preferences being known, common barriers to ACP, and the lack of studies that examine ACP as a decision-making process. The purpose of this study is to add to the understanding of ACP as a dynamic decision-making process by examining internal and external influences on individuals' decisions to engage and re-engage in ACP within the decision-making context. Chapter 2 will introduce the *Decision Process Model for Advance Care Planning* as the conceptual framework for the study and define study concepts based on this model. Chapter 3 will review the ACP literature to describe the impetus for and key concepts of ACP as a dynamic decision-making process. Through a review of descriptive and intervention ACP studies, this chapter will describe current understanding of ACP, gaps in knowledge, and the significance of this study. Chapter 4 will describe the methods for the study: its context of the MMACPC Research Project, its design, subjects, instruments, procedures, protection for human subjects, and plan for data management and analysis. Chapter 5 will present the results of the study. Chapter 6 will provide a discussion of the results, including limitations and implications of the study for nursing practice, education, and research.

CHAPTER 2

CONCEPTUAL FRAMEWORK AND DEFINITIONS

The purpose of this chapter is to introduce a dynamic decision-making process model of Advance Care Planning (ACP). Through analysis of existing ACP and decision-making models, the *Decision Process Model for Advance Care Planning* has been synthesized by this investigator to provide a conceptual framework for ongoing ACP research and clinical practice.

A literature search was performed to identify published journal articles reporting research or a review of literature having a primary focus on ACP or end of life planning (advance directives) in an adult population which included a depicted or described conceptual model of ACP or decision-making. The Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, and PsychINFO databases were searched for peer-reviewed journal articles published from 1985-2006. Productive search terms included “advance directive + conceptual framework,” “advance care planning + conceptual framework,” “advance care planning + theoretical models,” “advance care planning + models,” and “advance care planning + decision-making + models.”

Conceptual Models of ACP

Interest in ACP gained momentum in the early 1990's as research began to demonstrate that a narrow focus on written advance directives was not effectively improving communication or decision-making at end of life (Field & Cassel, 1997; Hammes & Briggs, 2002b). In contrast, ACP emphasized the ongoing process of deliberation and communication of end of life preferences (Emanuel, 2003). Conceptual models of ACP began to appear in the literature around 1995.

Models from Qualitative Studies

The earliest work used grounded theory and ethnographic methodologies to describe the processes being used to make advance directive decisions. Hurley, Volicer, Rempusheski, and Fry (1995) described the process of achieving consensus between family members and health care providers related to treatment decisions for Alzheimer's patients. Rein et al. (1996) described the process used by inpatients to decide whether or not to initiate an advance directive. Shidler (1998) described a system-focused, interaction framework to honor individuals' treatment wishes that included all persons in the long-term care resident's treatment setting.

These qualitative studies were useful beginnings to describe components of the process and structure of ACP decision-making. They also introduced the shared decision-making context of ACP, in which individuals and others (such as invited family members or health care providers) exchange information about medical conditions and preferences to reach treatment decisions that are mutually agreeable (Frosch & Kaplan, 1999).

Models from Health Behavior Studies

The Health Belief Model (HBM), an example of a health behavior model, was used as the conceptual framework for two ACP studies. The HBM focuses on individuals' motivations and beliefs about a threat to their health that influences their likelihood of taking action to protect themselves. The hypothesis of the HBM is that health-related action is dependent on three simultaneous personal factors: 1) having sufficient motivation (or concern) so that the health issue becomes relevant; 2) believing that there is a threat of a serious health problem; and 3) believing that following a health

recommendation will be beneficial (Rosenstock, Strecher, & Becker, 1988). In the HBM, modifying factors such as cues to action or demographic, societal, or structural influences only affect the perceived threat and do not have a direct effect on the likelihood of taking action (Pender, 1996).

Using the HBM, Hamel, Guse, Hawranik, and Bond (2002) investigated older adults' perceptions of the likelihood and consequences of dying in a way that was contrary to their wishes contrasted with the perceived benefits and barriers to completing an advance directive. In an earlier study, VandeCreek and Frankowski (1996) examined barriers and benefits to initiating a living will in a population of outpatients with ongoing medical conditions. These studies found that perceived barriers were a significant influence on people's plans to complete an advance directive or living will. This concurs with findings from a systematic review of a decade of studies based on the HBM, that indicated that perceived barriers have been one of the HBM's most significant dimensions for prediction of health behaviors (Janz & Becker, 1984).

ACP studies using the HBM contribute to understanding the connection between individuals' perceptions—particularly of barriers—and their likelihood to take action. However, influencing factors such as personal, societal, or structural influences or cues to action—which are precursors to the concept of decision-making context—do not directly influence the likelihood of action. Nor is there a link between actions (behaviors) and outcomes.

Composite Model

Pearlman et al. (1995) proposed a composite conceptual model of ACP that combined the concepts of the HBM with the concepts of stages of change (Prochaska &

DiClemente, 1983), self-efficacy (Bandura, 1977), and human information processing (Newell & Simon, 1972). In this model, ACP is viewed as having both deliberative and communicative processes that lead to immediate and future outcomes. The environment also plays a role, influencing an individual's beliefs, information processing, behaviors, and outcomes.

Like the HBM, this model made the link between personal influences and subsequent behaviors. But it did much more:

- 1) It depicted ACP as a deliberative and communicative process, similar to the models from the qualitative studies.
- 2) It identified aspects of the decision-making context and the influence of stages of change on the process of ACP.
- 3) It introduced the role of beliefs about ACP, perceived self efficacy, deciding to do ACP, and processing of information as additional personal factors influencing the process.
- 4) It identified specific ACP behaviors of shared communication and documenting preferences.
- 5) It linked influences, behaviors, and outcomes.

Although this model integrates many essential concepts of ACP, it does not fully emphasize the decision-making focus of ACP.

Decision-Making Models

Decision-making assumptions and models were described in six ACP papers. Two additional models of generic decision-making contribute to further understanding of ACP as a decision-making process.

ACP Studies Based on Decision-Making Models

Hurley et al. (1995) examined the roles of health care professionals in the process of surrogates' decision-making. They described elements of the community context (such as the patient, the surrogate, the health care provider, and health care organization), preparation and catalysts for the interaction, and the outcomes and consequences of the resulting decisions. Rein et al. (1996) described an individual's process of evaluating an illness, establishing priorities, considering the implications of advance directives (ADs), and finally coming to a decision. The decision could be initiating an AD, choosing not to initiate an AD, or postponing making a decision about an AD.

In his paper describing individuals who may contemplate assisted suicide or active euthanasia, Cicirelli (1997) posited the assumption that the decision made would be related to the individual's psychosocial characteristics and deliberation about options and consequences. McAdam, Stotts, Padilla, and Puntillo (2005) modeled perceptual and ethnic factors that affect Filipino individuals' decisions to select or reject an AD. Decker and Reed (2005) explored the effects of developmental stage and context on older adults' plans for end-of-life treatment decisions.

These papers clearly acknowledge ACP as a decision-making process but also demonstrate features seen in the composite model. Similarities between these papers and the composite model include: 1) the role of the decision-making context; 2) the effect of influences on the decision, interaction, or behavior; and 3) outcomes of decision-making. These papers also add details about the steps of deliberation in ACP decision-making. However, they do not capture the concepts that ACP decision-making involves both construction and communication of preferences and that it is a dynamic process.

Interactive Decision-Making Framework

In 2001, Pierce and Hicks proposed an interactive decision-making framework, based on expected utility and information processing theories. They described decision-making as an interaction of patient and contextual factors that are catalyzed by the unique features of the decision problem. In this model, the decision problem is described as having alternatives (choices), complexity, probability, and outcomes or consequences. Contextual factors include actual risk, urgency, and time frames as well as patient-provider interaction, environmental stressors, cognitive demands and information. The patient is described as having values (utilities); preferences for participation and decision styles; expectations and perceptions of risk; and a physical and psychological state. Double-headed arrows linking the decision problem, context, and patient demonstrate the dynamic nature of decision-making. An assumption of the model is that the contextual factor of the interaction between patient and health care professional is crucial to the success of this shared decision-making process.

Briggs et al. (2004) used this interactive decision-making model to frame their pilot study of a patient-centered ACP intervention. Pairs of patients and their surrogate decision-makers were interviewed by health care professionals with the intent of increasing their knowledge of the decision problem, assessing their preferences for participation and decision style, and evaluating the congruence of preferences and levels of decisional conflict between patient and surrogate. This study also confirmed that the skill of the health care professional interviewer was a critical link to promoting effective interaction and successful shared decision-making.

The interactive decision-making framework is similar to the ACP qualitative studies in its recognition of the importance of shared decision-making. Like the composite model, it highlights the importance of patient and contextual factors throughout the decision-making process. It also clearly identifies the aspects of the problem which need to be deliberated during decision-making. This model adds an emphasis on interaction; that is, communicating preferences with all those involved in decision-making. It also recognizes the dynamic nature of such interaction. The pilot study by Briggs et al. (2004) demonstrates this model's fit with ACP concepts described from the literature and encountered in clinical practice. However, it does not clearly show the relationship of decision, behaviors, and outcomes in decision-making.

Decision Process Model

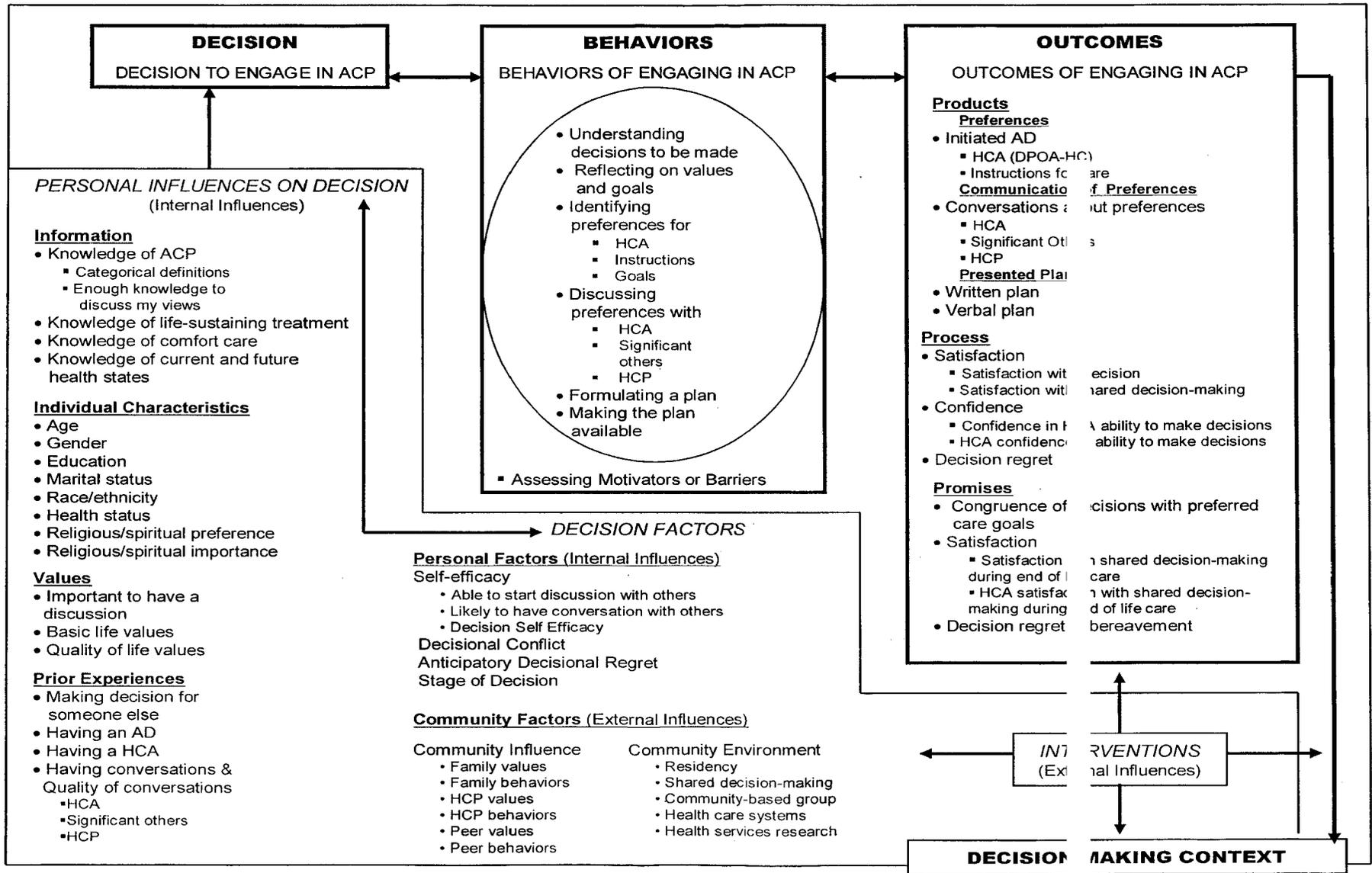
A decision process model (Rothert et al., 1997) with roots in the Lens Model (Brunswick, 1956), expected utility theory (Shoemaker, 1982), and social judgment theory (Hammond, Stewart, Brehmer, & Steinmann, 2002), examines how a patient's information and values combine to result in a decision that influences subsequent behaviors and outcomes. Wills and Holmes-Rovner (2006) offered a simplified model of patient decision-making based on the decision process model that shows how information and values interact to create preferences that dynamically inform the remaining decision-making steps: the decision, behaviors, and outcomes. These steps occur within a decision-making context that surrounds the entire decision-making process. This decision-making model is useful for guiding a study of ACP because it 1) demonstrates the relation of influences, decision, behaviors, and outcomes, 2) recognizes preferences as a key element, 3) captures the notion that decision-making is a dynamic process, and

4) acknowledges the decision-making context. Because the Decision Process Model provided the simplest decision-making framework, it was chosen as the basis of the conceptual model for this study.

In summary, each of the conceptual models reviewed in this chapter have some relevance for a comprehensive model of ACP as a dynamic decision-making process used to construct and communicate preferences. The structure and process of ACP decision-making was described in the qualitative studies; individuals' perceptions of barriers and their likelihood to take action in the health behavior model studies; and the connection between personal influences, behaviors, and outcomes from the composite model. The ACP studies using decision-making models added details about the steps of ACP decision-making while the ACP study based on the interactive decision-making model emphasized communication and the dynamic nature of such interactions. Finally, the Decision Process Model provided a useful framework to capture all of the elements of the decision-making process within the decision-making context.

The Decision Process Model for Advance Care Planning

The *Decision Process Model for Advance Care Planning* (see Figure 1) is an evolving adaptation of the decision process model applied to ACP. This conceptual model has been synthesized over the past three years from reviews of ACP conceptual models, decision-making models, and collective experiences in professional practice with patients, families, and health care providers encountering end of life decisions. Building on key concepts described for decision-making models, it depicts the breadth of how individuals decide to engage in ACP with resulting behaviors and outcomes.



Key: ACP = Advance Care Planning AD = Advance Directive HCA = Health Care Agent HCP = Health Care Provider

Figure 1. The Decision Process Model for Advance Care Planning

The major components of the model include: 1) the Decision to Engage in ACP, 2) the Behaviors of Engaging in ACP, 3) the Outcomes of Engaging in ACP, and 4) the Decision-Making Context. The decision-making context includes internal (e.g., personal influences on decision, personal decision factors) and external (e.g., community decision factors, interventions) influences on the Decision to Engage in ACP. The arrows linking the decision-making context influences, the decision to engage in ACP, the behaviors, the outcomes, and the decision-making context demonstrate that ACP is a dynamic decision-making process.

The Decision to Engage in ACP

For the purposes of this study, the Decision to Engage in ACP is defined as the choice people make to involve themselves in exploring their preferences for end of life care. This decision is shaped by internal and external influences of the decision-making context. Internal influences include Personal Influences on Decision and Personal Decision Factors. External influences include Community Decision Factors and Interventions.

Behaviors of Engaging in ACP

The behaviors of engaging in ACP are understanding (Briggs et al., 2004), reflecting (Pearlman et al., 1995; Pearlman, Starks, Cain, & Cole, 2005), identifying (Emanuel, 2000; Hammes & Briggs, 2002b), and discussing preferences (Barnard, 2002; Emanuel, 2000) to help in formulating (Briggs et al., 2004; Pearlman et al., 1995) and making a plan available for decision-making (Grimaldo et al., 2001; Richter et al., 1995; Schneiderman, Pearlman, Kaplan, Anderson, & Rosenberg, 1992; Sulmasy, Song, Marx, & Mitchell, 1996; J Teno et al., 1997).

In Figure 1, the behaviors of engaging in ACP are depicted inside a circle to reflect two observations from clinical practice. First, one behavior often leads to the next, but all seem to be necessary to fully engage in ACP. If any of the behaviors are missing, the resulting outcomes may be less optimal (Ditto et al., 2001; Hammes & Briggs, 2002b; Kolarik et al., 2002). Second, these behaviors do not necessarily happen sequentially. Instead, people engaging in ACP behaviors often move back and forth between the steps over time, refining their thoughts and plans as they gain more understanding, hear others' perceptions, and experience the outcomes of ACP. Assessing the motivators or barriers which affect these behaviors (Hamel et al., 2002; Rein et al., 1996; VandeCreek & Frankowski, 1996) can provide useful direction for the design of ACP educational program interventions which teach participants how to engage in ACP.

Outcomes of Engaging in ACP

In the composite model, Pearlman et al. (1995) described outcomes related to ACP in two timeframes: immediate and at the time of mental incapacity. Immediate outcomes included a coherent mental model, shared understanding, documents, sense of autonomy and well-being, and decreased burden on proxy (decision-maker) and family. Outcomes at the time of mental incapacity included a decreased burden on proxy, family, and health care providers; having future medical care matching patient wishes; and reduced health care expenditures. In Figure 1, the outcomes of engaging in ACP are classified by type rather than by timeframe. Because ACP is a dynamic decision-making process that may occur repeatedly over varied amounts of time, this model focuses on responses that result from engaging in ACP behaviors.

The first response or outcome is Products: these are the actual preferences and the method(s) used to communicate those preferences. Specific examples of such products include an initiated AD, conversations about preferences, and a presented plan in written or verbal form when health care is needed. In clinical practice, these products should be discoverable during an assessment of ACP decision-making. It is important to note that the initiated AD is not the only product of interest (Kolarik et al., 2002). Ideally, all of these products are present following engagement in ACP.

The second outcome type is Process, which is defined as the affective responses of involved individuals to the process of engaging in ACP decision-making. Such responses may include satisfaction, confidence, or regret.

The third outcome, Promises, refers both to effects of and affective responses to the products and process of engaging in ACP. A desired effect of ACP is that decisions about health care made after engagement in ACP are congruent with the goals of preferred care (Briggs et al., 2004; Gillick, 2001). Affective responses to these decisions, such as satisfaction or regret, provide an additional means of evaluation.

Decision-Making Context

The Decision-Making Context includes the decision, behaviors, outcomes and influences (internal and external) that shape the decisions people make (Wills & Holmes-Rovner, 2006). Personal Influences, internal to the individuals, include information (Davison & Degner, 1998; Pearlman et al., 1995), individual characteristics (Cicirelli, 1997), values (Pearlman et al., 1995; Pierce & Hicks, 2001), and prior experiences (Rein et al., 1996). Decision Factors, including internal personal and external community factors (Pierce & Hicks, 2001), also influence the Decision to Engage in ACP.

Interventions, which are external influences, may affect any of the other influences or the decision, behaviors, and outcomes. The *Decision Process Model for Advance Care Planning* includes the decision to engage in ACP, behaviors, outcomes, and influences (internal and external), all within the decision-making context.

Dynamic Decision-Making

Optimal ACP is not a one-time-only process. It is ongoing deliberation and communication that regularly reviews and possibly revises the plan in response to technological, developmental or health status changes (Hammes & Briggs, 2002b). Changes in the decision-making context influence the decision to engage again in ACP. Successful ACP results in a plan that enables effective decision-making, even as priorities or preferences change (Barnard, 2002; Emanuel, 2000; Pearlman et al., 1995).

The *Decision Process Model for Advance Care Planning* is ideal for guiding this dissertation study for the following reasons:

- 1) It demonstrates the relation of the decision, behaviors, outcomes, and decision-making context involved in ACP.
- 2) It identifies the modifying potential of personal influences and decision factors on the Decision to Engage in ACP.
- 3) It delineates the internal and external influences included in the decision-making context.
- 4) It demonstrates how ACP is an ongoing dynamic decision-making process.

A focused model of the Decision to Engage in ACP was created to depict the variables that are conceptually and operationally defined for this study (see Figure 2).

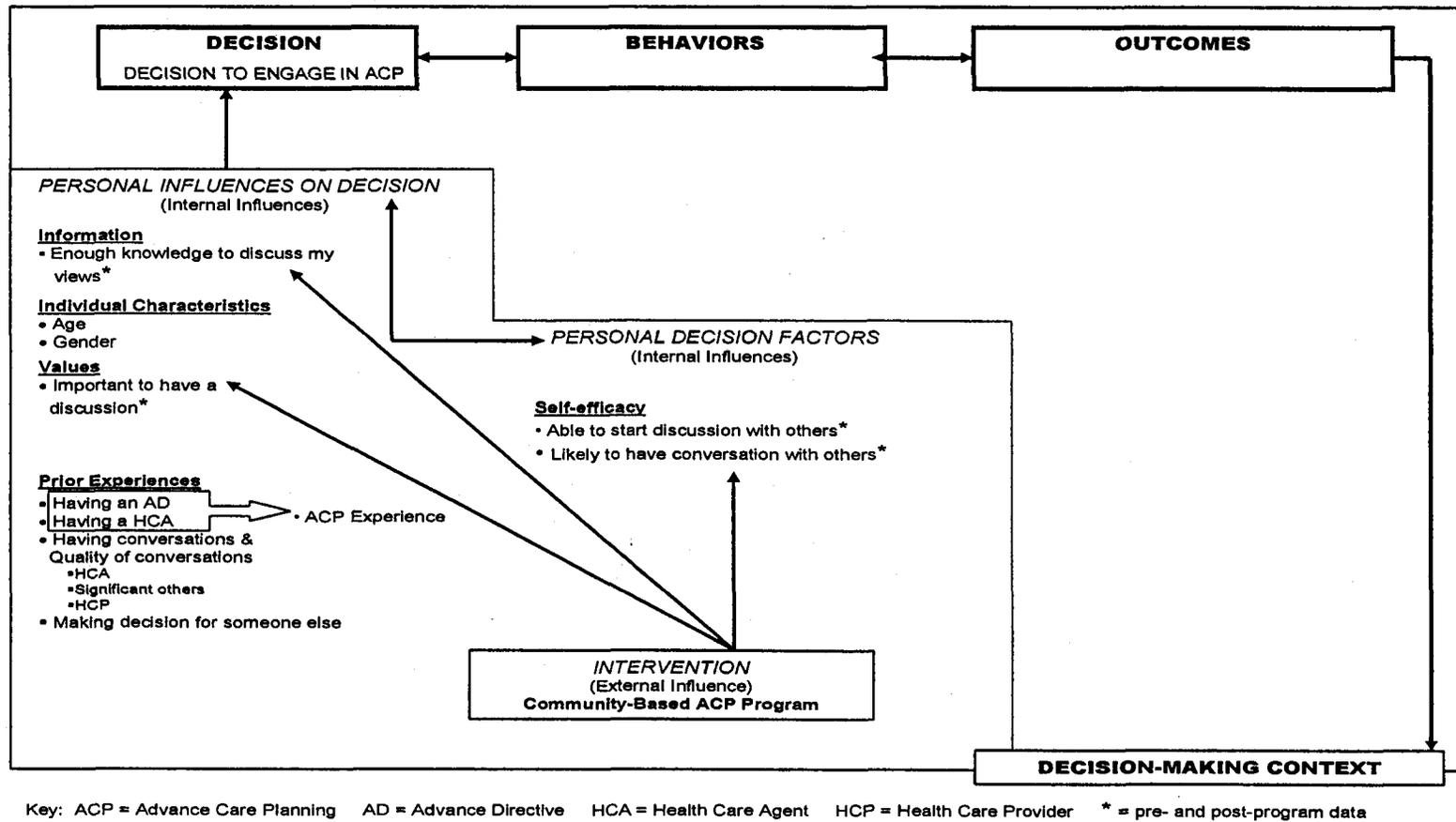


Figure 2. Focused model of the Decision to Engage in ACP.

Conceptual Definitions of Focused Model Concepts

Decision to Engage in ACP

The Decision to Engage in ACP is defined as individuals' willingness to involve themselves in exploring their preferences for end of life care through participation in a community-based, ACP education program. All participants in this study made the decision to engage in ACP by virtue of attending the ACP program intervention.

Behaviors and Outcomes

For the purposes of this study, neither the behaviors nor outcomes of engaging in ACP will be examined.

Decision-Making Context

The Decision-Making Context is defined as the decision, behaviors, outcomes and influences (internal and external) that shape the decisions people make (Wills & Holmes-Rovner, 2006). The influences of interest in this study include internal influences of Personal Influences on Decision and a Personal Decision Factor and the external influence of a Community-Based ACP Program intervention.

Personal Influences on Decision

Personal Influences on Decision are defined as variables relating to the individual that may act independently or interact with each other to modify the Decision to Engage in ACP. These variables include Information, Individual Characteristics, Values, and Prior Experiences.

Information. Information is defined as decision-relevant data inputs (Wills & Holmes-Rovner, 2006). Participants' information about ACP is measured as "Enough

knowledge,” which is defined as the participants’ self-report of whether or not they have sufficient information to discuss their preferences.

Individual characteristics. Individual characteristics of focus in this study include “Age” in years and “Gender,” male or female.

Values. Values reflect the importance individuals place on information, experience, and the context of decision-making (Wills & Holmes-Rovner, 2006). In this study, participants’ value of ACP is measured as “Important to have discussion,” which is defined as their self-report of their perception of the necessity of having conversations about preferences for end-of-life care.

Prior experiences. Prior experiences are defined as events, circumstances, or processes that have already occurred in individuals’ lifetimes. In ACP, relevant prior experiences may include having an AD (Advance Directive), having a HCA (Health Care Agent), participating in quality conversations about end-of-life care preferences, and making a decision about life-sustaining treatment for another person. Participants in this study will indicate the occurrences of these experiences prior to the time of their participation in the ACP program.

Having an AD is defined as the participant’s self-report of executing a statutory document for use at a future time when personal capacity to make informed health care decisions is lost.

Having a HCA is defined as the participant’s self-report of choosing and legally appointing a person to be the substitute health care decision-maker (Post, Blustein, & Dubler, 1999).

Having conversations is defined as the participant's self-report of discussing preferences for end-of-life care with others. The roles of these "others" may be a health care agent (HCA), significant others, and a health care provider (HCP).

Quality of conversations is defined as participants' self-reports of the thoroughness of their discussions of preferences with others.

HCA. As noted previously, the HCA is a person who has been chosen and legally appointed to be the substitute health care decision-maker (Post et al., 1999).

Significant others are defined as persons who play an important role in the life of an individual (O'Toole, 1997).

A HCP is defined as a licensed professional who provides health care to individuals within a health care setting. These licensed professionals may include physicians, mid-level providers (e.g., Advance Practice Nurses, Physician Assistants), registered nurses, dietitians, social workers, therapists, and chaplains.

Making decision for someone else is defined as the participant's self report of an event or process of communicating a choice related to life-sustaining treatment on behalf of another person who is incapable of making a choice.

Personal Decision Factors

Personal Decision Factors are defined as variables relating to the individual that modify an individuals' willingness or ability to make a choice between two or more alternatives.

Self-efficacy. Self efficacy is defined as an individual's perceived confidence to perform certain behaviors (Bandura, 1986). In this study, participants' self-efficacy will be measured by their self-ratings of their perceived confidence in their "Ability to start an ACP discussion" and the "Likelihood of having an ACP conversation."

Community-Based ACP Program Intervention

The Community-Based ACP Program Intervention is an example of a decision support intervention. Decision-support interventions are strategies used to promote informed, values-based decision-making (A. Clarke, Jacobsen, O'Connor, Stilwell, & Feldman-Stewart, 2005). This dissertation describes the impact of an ACP educational program intervention that was presented to established community groups.

Community-based. A community-based intervention is directed toward individuals and families within a community and designed to meet the needs of people where they live, work, worship, go to school, and receive healthcare (Calvin College Department of Nursing, 2003). The intervention used in this study was presented to people in established community groups, which are defined as organizations located in a community in which members naturally participate (P. Clarke et al., 2005). Participants in this study were from established community groups (faith, health-related layperson, or employee) in the Greater Lansing and Grand Rapids, Michigan communities.

ACP Program. Health education is defined as developing and providing instruction and learning experiences to facilitate voluntary adaptation of behavior conducive to health in individuals, families, groups, or communities (O'Toole, 1997). For this study, the ACP program is defined as a health education information sharing

session about ACP, presented by a certified Respecting Choices® ACP Facilitator to voluntary participants who were members of an established community group.

Dynamic Decision-Making

Dynamic Decision-Making is defined as a decision-making process that may be engaged in repeatedly in response to changes within the decision-making context. The arrows linking the decision-making context influences, the decision to engage in ACP, the behaviors, the outcomes, and the decision-making context depict ACP as a dynamic decision-making process. However, participants' reports of prior experiences with ACP can also be used to demonstrate that people are re-engaging in ACP.

For this study, the dynamics of ACP decision-making will be represented as participants' ACP experience. As noted in Chapter 1, previous studies of ACP have focused almost exclusively on initiation of an advance directive or appointment of a health care agent. Therefore, for this study ACP experience is defined as a participant's self-report of the prior experiences of having an Advance Directive (AD) or having a Health Care Agent (HCA) or both.

Chapter Summary

The conceptual framework for this dissertation study was synthesized from reviews of conceptual models of ACP, decision-making models, and professional practice experiences with patients, family members, and health care providers. The *Decision Process Model for Advance Care Planning* provides an ideal framework for this study because it depicts ACP as an ongoing dynamic decision-making process involving a decision, behaviors, outcomes, and internal and external influences within the decision-making context. The focused model of the Decision to Engage in ACP identifies the

Decision to Engage in ACP; the internal Personal Influences on Decision and Personal Decision Factor and external Community-Based ACP Program intervention influences within the Decision-Making Context; and the dynamics of decision-making represented by ACP Experience.

CHAPTER 3

LITERATURE REVIEW & SIGNIFICANCE OF STUDY

This chapter presents a brief overview of the literature related to the impetus for ACP and key features of ACP, followed by a review of studies of ACP, characterized by this investigator, that have laid the foundation for this dissertation. Results of ACP studies, organized by this study's research questions, will then be reviewed to demonstrate current understanding of influences on the decision to engage in ACP. The significance of this dissertation study to add to the knowledge base of ACP decision-making will be discussed throughout the chapter.

Advance planning for end of life preferences has been studied intensively over the past 15 years. ACP literature indexed in CINAHL and MEDLINE was reviewed to identify peer-reviewed journal articles that reported systematic reviews and clinical trials from 1985 to 2006. Governmental agency websites (e.g., the Department of Health and Human Services, the Center for Disease Control, the National Center for Health Statistics) were also searched for national survey studies which included items about advance directives (ADs) or ACP.

The Impetus for ACP

The impetus for ACP first came from public dissatisfaction with the quality of end of life care (Field & Cassel, 1997). Advances in technology and pharmacology have influenced societal attitudes and beliefs about death, dying, and health care at the end of life (Daly, 2006). While people hope for available treatments to cure their injuries or illnesses, they often simultaneously fear the prospect of needless suffering at the end of life, either from lack of care or from care that is ineffective or harmful (Field & Cassel,

1997). In America, with its predominant ethos of autonomy, these hopes and fears have translated into a desire for rights of self-determination and control of treatment choices.

Control of treatment choices is also important to good stewardship of health care resources. Americans fear the continuous increases in health care costs and the dire predictions of economic and health care provider shortages as the population ages. Because current treatments can prevent some immediate causes of death and effectively treat slower causes of death, the aging baby boomer generation is predicted to live much longer than previous generations (Field & Cassel, 1997). Costs related to end-of-life care will not only be borne by health care organizations but also by the general public through Medicare, Medicaid, the Veterans Administration, and other public programs (Field & Cassel, 1997). Thus, it was hoped that documentation of preferences would lead to reduced costs by preventing undesired treatments at the end of life.

In November 1991 the Patient Self Determination Act (PSDA) was implemented, requiring all hospitals, nursing homes, and health care programs that receive federal funding to ask patients about advance directives (ADs), make AD education available, and incorporate AD information into medical records (Crane, Wittink, & Doukas, 2005). ADs are statutory documents executed to communicate an individual's health care preferences for use at a future time when the individual's capacity to make informed health care decisions is lost (Post et al., 1999). Individuals, health care professionals, and policy makers hoped that ADs would be an effective strategy to address concerns about respect for individuals' rights and dissatisfaction with patient and family treatment at end of life (Galambos, 1998) as well as reduce resource use (Taylor, Heyland, & Taylor, 1999).

However, summary reports from Last Acts (Kaplan & Peres, 2002), the Institute of Medicine (Lunney, Foley et al., 2003), and the Agency for Healthcare Research and Quality (Kass-Bartelmes et al., 2003; Lorenz et al., 2004) confirm that, on average, ADs are unused by at least 50% of the population. Researchers have also provided evidence that the single outcome of a completed AD has not been effective to identify and honor most people's end of life preferences (Ditto et al., 2001; Hofmann et al., 1997; Kolarik et al., 2002; J Teno et al., 1997).

Advance Directives have also not been successful as a financial mechanism to reduce the costs of providing health care at the end of life. Although it was hoped that advance directives would be a more ethical alternative for decreasing cost than rationing, the actual relation of advance directives to cost savings has been mixed. In a systematic review, Taylor, Heyland and Taylor (1999) reported that although three retrospective studies showed some cost savings, prospective studies—with highly controlled experimental designs—demonstrated no evidence of cost savings attributable to advance directives. They concluded that little evidence exists to support the hypothesis that advance directives reduce resource use by hospitals.

These lackluster results provided an additional incentive to develop the concept of ACP. In contrast to a focus on completion of a static legal document (AD), ACP is a dynamic decision-making process with features of deliberation, communication, and shared decision-making focused on achieving several outcomes (Field & Cassel, 1997). In ACP, an AD can be a useful tool, but is only one of many means to achieve desired goals (Field & Cassel, 1997; Kolarik et al., 2002).

Key Features of ACP

The key features of ACP are the following: 1) a deliberative process, 2) a communicative process, 3) a shared decision-making process, and 4) a dynamic process.

A Deliberative Process

Engaging in ACP is a deliberative process. To understand decisions that may need to be made, people require information about likely future health conditions and the benefits and burdens of various treatments for those conditions (Briggs et al., 2004). Deliberation also includes personal reflection on values and goals to clarify which benefits and burdens are acceptable (Pearlman et al., 1995; Pearlman et al., 2005). Structured worksheets, such as living will or AD forms, can be helpful to identify preferences (Emanuel, 2000), such as selecting a decision-maker or specifying instructions (Hammes & Briggs, 2002b). The deliberative process, therefore, encompasses the ACP behaviors of understanding, reflecting, and identifying preferences.

A Communicative Process

Engaging in ACP is also a communicative process. People take the opportunity to talk about end of life issues (Emanuel, 2000) and build up relationships with others in the process (Barnard, 2002). In ACP, any form of communication (verbal, written, formal, informal) is acceptable as a plan, as long as it clearly communicates the results of the individual's deliberative process (Pearlman et al., 1995). However, formulating legal documents, such as an AD, does have a legitimate role (Emanuel, 2000). These documents serve to "memorialize the conversation" about end of life preferences (C. Thomason, personal communication, January 25, 2006). The goal of ACP

communication is shared understanding and a commitment to support the individual's preferences (Briggs et al., 2004). The communicative process of ACP includes the behaviors of discussing preferences, formulating a plan, and making the plan available.

Many researchers overlook the element of making the plan available; however, health care providers in professional practice readily identify this aspect of ACP communication as important. McAdam et al. (2005) noted that people's fears of not receiving adequate care once an AD is presented are a deterrent to engaging in ACP. In studies that do report a presented plan, the plan is usually located or documented in the patient's medical record or files (Grimaldo et al., 2001; Richter et al., 1995; Schneiderman et al., 1992; Sulmasy et al., 1996; J Teno et al., 1997).

A Shared Decision-Making Process

Effective ACP is a cooperative effort between the individual and selected others (Field & Cassel, 1997) to make decisions for which there are several available treatment options, no obvious right or wrong choices, and often uncertainty about the impact of the options on the well-being of those involved. Such decisions are defined by Frosch and Kaplan (1999) as ideal shared decision-making opportunities.

Shared engagement in ACP ideally includes all four of the essential characteristics of shared decision-making, as described by Charles, Gafni and Whelan (1997). First, it involves at least two parties: the person and their invited others—often family members and health care providers (Hurley et al., 1995). Secondly, the parties participate in the process of decision-making through discussing the person's preferences (Weiner & Cole, 2004) and formulating the plan. Thirdly, sharing of information must occur; not only of medical information, but also of the person's unique circumstances,

values, and life priorities (Lee, Back, Block, & Stewart, 2002). Finally, both parties agree to the decision by committing to support the plan, which is made available for decision-making.

Conversations that occur during shared engagement in ACP are especially important since advance planning decisions cannot be assumed to be clear, unambiguous, or “right” (Barnard, 2002). Conversations may clarify perspectives, values and goals so that decision makers have direction for situations not captured in a checklist or a contrived scenario. Some people choose not to prepare written instructions or leave instructions deliberately vague so that their appointed decision makers have permission to respond to the situations at hand (Hawkins, Ditto, Danks, & Smucker, 2005). In some cases ACP conversations reveal individuals who do not want to actively participate in decision-making about their personal situations (Field & Cassel, 1997).

Active participation in decision-making is not always desired (Hawkins et al., 2005). Lee et al. (2002) identify people for whom this may be true: 1) individuals who prefer less control over decision-making, perhaps because of culture, ethnicity, or age; 2) patients who have had no experience with a condition or treatment; 3) acutely ill patients without the physical or emotional resources to consider risks and benefits of choices; and 4) patients with fears of regret. In addition, Tilden et al. (2001) found that when decisions are burdensome, some people prefer to defer decision-making to others.

During shared engagement in ACP, the commitment is made to honor the best available “portrait” of the person’s desires (Emanuel, 2000), recognizing that it may evolve over the trajectory of the person’s illness, injury, or lifespan (Lunney, Foley et al.,

2003; Weiner & Cole, 2004). This includes respecting people's preferences to share and sometimes defer decision-making responsibilities.

A Dynamic Process

Because people's preferences and goals may change over time, ACP is a decision-making process that is best engaged in repeatedly (Field & Cassel, 1997). Effective ACP is thought to include ongoing deliberation and conversation that regularly reviews and possibly revises the plan in response to technological, developmental or health status changes. Successful ACP results in a plan that enables effective decision-making, even as priorities or preferences change (Barnard, 2002; Emanuel, 2000; Pearlman et al., 1995). However, studies of dynamic (repeated) ACP decision-making have not yet appeared in the ACP research literature.

Studies of Advance Care Planning

For the past 20 years the shortcomings and the efforts of America's health care system to provide quality care at the end of life have been publicized (B. A. Brown, 2003; Field & Cassel, 1997; Kaplan & Peres, 2002; Kass-Bartelmes et al., 2003; Lorenz et al., 2004). This has led researchers, especially since the 1991 federal Patient Self Determination Act (PSDA) was enacted, to study and report the impact and outcomes of efforts to promote ACP (Crane et al., 2005). The pre-PSDA five year Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) (Connors et al., 1995) is reviewed first because it represents a benchmark in end of life decision-making research.

The SUPPORT Study

In 1989, data collection began for Phase I of the SUPPORT study, a two-year prospective observational study to describe the process of decision-making and patient outcomes for seriously ill, hospitalized patients (Connors et al., 1995). This study, including 4301 patients from five teaching hospitals in the United States, documented deficiencies in physician-patient-family communication and in honoring end of life care preferences. Phase II, a two-year randomized controlled trial of an intensive intervention to improve communication and decision-making, began in 1992 and included 4804 patients. The intervention included 1) sophisticated patient prognostic reports provided to the patient's physicians and 2) a skilled nurse, the SUPPORT nurse, to elicit and document patient and family preferences for treatment. Surprisingly, although the Phase II intervention resulted in anecdotal positive outcomes, it did not significantly improve the primary outcomes related to physician-patient-family communication about end of life preferences. The SUPPORT study validated public and professionals' concerns that patients' preferences were not being communicated or honored and stimulated much research activity to more effectively accomplish this goal.

Studies related to the Patient Self-Determination Act (PSDA)

In 1993, the Department of Health and Human Services conducted an observational study of 72 randomly selected facilities in six states to evaluate implementation of the PSDA. It demonstrated that 21% of patients in hospitals, nursing facilities, and home health agencies had ADs. Two thirds of patients interviewed had some understanding of ADs and this understanding was influenced by receiving information about ADs. Hopp (2000) reported data from the Asset and Health Dynamics

of the Oldest Old (AHEAD) study, also conducted in 1993, which surveyed people born in 1923 or earlier. Of the 520 participants, 95% stated they had someone they trusted to make medical decisions but only 48.8% had talked with someone about their preferences for care. Just over 37% reported having an AD (20% having both a Living Will (LW) and Durable Power or Attorney for Health Care (DPOA-HC); 9% having a LW only; 8% having a DPOA-HC only).

J. Teno et al. (1997) analyzed the SUPPORT study data from Phase I (pre-PSDA) and Phase II (post-PSDA) and found no significant differences between patients' knowledge of a LW (62% pre; 67% post), knowledge of DPOA-HC (42% pre; 45% post), or having an AD (20% pre; 24% post). Documentation of the AD in the medical record, however, did increase significantly, particularly for Phase II patients who received the SUPPORT intervention (6% pre; 35% post; 77% post + intervention). In a related study, Bradley, Peiris, and Wetle (1998) examined the medical records of 600 randomly selected nursing home residents admitted during 1990 and 1994, finding an average of 28.5% to have had a discussion about their preferences with a HCP (20% pre-PSDA; 36.7% post-PSDA). These studies related to the PSDA demonstrate that legislated education cannot guarantee engagement in ACP.

Studies related to Special Populations

Next researchers targeted specific populations of patients who were hypothesized to have a vested interest in ACP. In 2001, Wenger et al. reported data from a cross-sectional survey of 2864 HIV patients in the United States (1996-1997) which showed that 50% had discussed their end of life preferences with their HCP and 38% had

completed an AD. This study found that patients were more likely to complete an AD after conversation with their HCP.

The Assessing Care of Vulnerable Elders (ACOVE) project was a quality assessment study conducted from 1998-1999 of 3207 randomly sampled community-dwelling adults, ages 65 or older, who were enrolled in two managed care organizations from 1998-1999. Five of the ACOVE End-of-Life Care quality indicators were specific to ACP (Wenger & Rosenfeld, 2001) and reported by percentage of adherence: 1) documentation of surrogate decision maker / AD in outpatient medical records (4%), 2) documentation of surrogate decision maker / AD in inpatient medical records (25%), 3) documentation of consideration of preferences for a patient with dementia (100%), 4) documentation of consideration of preferences for a patient admitted to ICU (17%), and 5) documentation of a patient's stated preferences or desire for an AD during the interview (12%). The mean adherence to all 14 indicators for end of life care was only 9% (Wenger et al., 2003).

In spite of Americans' apparent interest in improving end of life decision-making and health care providers' increased understanding of ACP, these national studies indicate that from 1989 – 1999 the knowledge, use, and outcomes of ACP were very limited. In response, researchers tried a variety of interventions to increase the prevalence of individuals' ADs or ACP. Studies of ACP interventions can be divided roughly into three time periods, each of which had studies using similar strategies.

Studies of Interventions

1990-1995: Randomized Controlled Trials Focused on Physicians and Patients

In addition to Part II of the SUPPORT study, seven other randomized controlled trials were conducted from 1990-1995 to increase patients' and health care providers' engagement with ACP. A common denominator of these seven studies was that the interventions were physician-driven. In the first three studies, physicians offered patients the opportunity to discuss or initiate an AD. These resulted in increased consideration of AD issues (Smucker et al., 1993), as well as 66% and 66.3% completed California DPOA-HC forms respectively (Anderson, Kaplan, & Schneidermann, 1994; Schneiderman et al., 1992).

In the next three studies, physicians initiated some sort of educational program to increase the number of completed ADs. Rubin et al. (1994) provided an explanatory pamphlet and DPOA-HC forms to 552 people with the result that 18.5% of the intervention group initiated a DPOA-HC form vs. a 0.4% response by the control group. However, Sachs, Stocking and Miles (1992) found that a 30-minute educational intervention, including written and follow-up materials, with older patients at an outpatient geriatric clinic did not result in a significant number of initiated ADs. Richter et al. (1995) provided AD written materials (control) plus a structured discussion and mailed follow-up reminder (intervention) to 176 patients with a result of 23% (intervention) vs. 3% (control) ADs returned for the patients' medical records within 6 months.

The final study in this group of seven was a comprehensive educational intervention on health promotion—including counseling about ADs—provided to

patients enrolled in a group health plan. Patrick et al. (1995) reported unexpected “excess mortality” in the intervention group of 2558 older adults who had received the intervention, which was thought to be related to the AD counseling.

In all of these studies, the physician-driven intervention produced an increase, though not always significant, in completion of ADs. These studies demonstrate that patients will respond to ACP interventions.

1996-2001: Randomized Controlled Trials Focused on Innovative Education Strategies

From 1996 to 2001, researchers intervened with a variety of innovative education strategies to try to increase patients’ engagement in ACP. Some researchers conducted ACP education through counseling with hospital patient representatives (Meier et al., 1996), nursing home admissions personnel (Molloy et al., 2000), or home health care visits with patients (Patterson et al., 1997). Others used interactive seminars with patients (Landry, Kroenke, Lucas, & Reeder, 1997); computer-generated reminders for health care providers (Dexter et al., 1998; Tierney et al., 2001); and multimedia presentations for patients (J. B. Brown, Beck, Boles, & Barrett, 1999; Siegert, Clipp, Mulhausen, & Kochersberger, 1996; Yamada, Galecki, Goold, & Hogikyan, 1999). Still other researchers targeted specific patient populations, e.g., hemodialysis (Singer et al., 1995), pulmonary rehabilitation (Heffner, Fahy, Hilling, & Barbieri, 1997), cardiac rehabilitation (Heffner & Barbieri, 2001), and preoperative patients (Grimaldo et al., 2001). All of these interventions demonstrated at least modest effectiveness; however, the prevalence of ACP or AD completion was no more than 15-40% in treatment or control groups.

2001-2004: Randomized Controlled Trials Focused on Resource Intense Strategies

From 2001 to 2004, researchers intervened in more complex ways, e.g., on a larger scale such as providing multimedia to 735 HMO members (Beck, Brown, Boles, & Barrett, 2002) or by means of consultations with highly trained facilitators such as Respecting Choices® nurses (Schwartz et al., 2002), home health social workers (Ratner, Norlander, & McSteen, 2001), or a palliative care team (Rabow, Petersen, Schanche, Dibble, & McPhee, 2003). These interventions demonstrated greater effects in the intervention groups on knowledge of ACP (effect size = 22%, Schwartz et al., 2002) and AD completion (46.2%, Beck et al., 2002; 83%, Ratner et al., 2001). However, such interventions have been criticized, as was the SUPPORT intervention, as being too costly for widespread use (Barnard, 2002).

In summary, ACP interventions—especially educational interventions—have mostly resulted in some level of increased engagement in ACP, particularly in the form of initiated ADs. A necessary prerequisite to engaging in ACP decision-making is knowledge: not only of what is involved in end of life conditions or treatments and the probabilities of different outcomes, but also self-awareness of preferences by the individual and those with whom decision-making will be shared (Briggs et al., 2004; Gillick, 2001; Weiner & Cole, 2004). Through focus group research and public discussions, Americans have reported that they value their rights of self-determination and control of treatment choices, but need understandable information to guide decision-making and planning (Lunney, Foley et al., 2003). Other studies have reported that, with guidance, individuals are willing to formulate plans for end of life care (Kass-Bartelmes et al., 2003).

Studies of Community-Based Approaches

In the past few years, some highly successful initiatives have focused on a “whole community” approach to ACP. Community-based approaches to ACP have been recommended by the Committee on Care at the End of Life (Field & Cassel, 1997) as a way to increase the number of people who decide to engage in ACP. Both the LaCrosse Advance Directive Study (LADS) (Hammes & Rooney, 1998) and the Missoula Demonstration Project (Byock et al., 2001) documented the impressive effects of extensive, whole-community ACP education. The LADS study documented a written advance directive prevalence change from 15% to 85% in response to extensive community advance directive education programs (now known as Respecting Choices®). The Missoula Demonstration Project incorporated an interdisciplinary community-based organization to both study and implement interventions to improve the quality of end of life experiences for Missoula, Montana residents.

More recently, Clarke et al. (2005) reported the benefit of approaching people through community-based organizations and groups in which they already participate. Because these community groups were already valued by their members, people’s unease toward engaging in ACP due to demographic, psychological, behavioral, or other barriers was diminished. Capitalizing on this mode of entry, the researchers were able to provide experts and resource materials to the community groups to encourage people to engage in ACP. About one third of the participants requested the education materials and 30-50% of each group’s participants subsequently completed an advance directive. In an exploratory study of 27 African Americans’ understanding and desire for a living will, Waters (2000) reported that 82% of the participants stated they would consider writing a

living will after an educational group discussion compared to the baseline of 89% who neither had nor wanted to consider a living will.

The ACP program intervention evaluated in this dissertation study was designed to provide information and strategies to individuals so they could learn how to construct and communicate their preferences for end of life care. This intervention incorporated four of the community-based strategies found effective in other studies: 1) the Respecting Choices® curriculum, 2) presentations offered to existing community groups, 3) certified Respecting Choices® ACP Facilitators (experts) conducting the ACP programs, and 4) standardized content and resource materials to encourage participants to continue their engagement in ACP.

Results of ACP Studies relating to Research Questions

Research Question 1

Research Question 1: Before participation in a community-based ACP program, what are the self-reported Personal Influences on Decision and Personal Decision Factors of adults who have decided to engage in ACP? To answer this question, ACP studies which reported baseline characteristics of their participants related to concepts in this proposed study were reviewed.

Personal Influences on Decision

The focused model of the Decision to Engage in ACP (Figure 2, p. 23) shows four Personal Influences on Decision: 1) Information, 2) Individual Characteristics, 3) Values, and 4) Prior Experiences. At least one study in the reviewed ACP literature reported baseline or other results for each variable included in the Personal Influences on Decision section of the Focused Model of the Decision to Engage in ACP. However,

none of the studies examined the prevalence of all these variables simultaneously. This dissertation study will contribute a more comprehensive picture of the variables included in personal influences on the decision to engage in ACP.

Information. Ten studies, conducted from 1992-2004, describe people's baseline information about ACP. The percentage of people who "knew of" a living will ranged from 25% (C. D. Moore & Sherman, 1999) to 62% (Singer et al., 1995; J Teno et al., 1997) to 80% (Landry et al., 1997; Siegert et al., 1996) to 96% (Waters, 2000). In Grimaldo et al.'s (2001) study, 80% stated they knew about DPOA-HC. Singer et al. (1997) reported that 88.7% of AIDS patients had "heard of" an AD, but in Waters' (2000) group of African Americans, 78% had not. Morrison et al. (1998) reported ethnic differences in knowledge of ACP ranging from 57% (White) to 39% (African American) to 20% (Hispanic). In addition to these studies, other researchers have tried to determine knowledge through true/false items (Ejaz, 2000; K. A. Moore et al., 1994) and asking for a simple definition of "advance directive" (Office of the Inspector General, 1993).

Two studies focused specifically on participants' knowledge. Silveira, DiPiero, Gerrity, and Feudtner (2000) used a series of vignettes and questions about state statutes to assess Oregon citizens' knowledge of options for end of life care. Siegert et al. (1996) measured comprehension of ACP concepts (living will, cardiopulmonary resuscitation) before and after an ACP intervention through open-ended and true/false interview questions during a randomized cohort trial of elderly residents of an extended care/rehabilitation center. Baseline comprehension of a "living will" was 75% in the cohort that received an AD video and, surprisingly, 90% in the cohort that received a general health-related video.

Baseline knowledge of ACP varied among participants in the ACP studies. None of the ACP studies reporting knowledge of ACP included participants' self-perception of having "enough knowledge" to engage in ACP. In this dissertation study, participants rated their perceptions of having "enough knowledge to discuss [their] views" using a single item on the Participant Survey.

Individual Characteristics. Individual characteristics considered in this proposed study include age and gender.

Age. In many studies, participants were of a specific age cohort (e.g., 65 or older) so differences in age were not reported (Blackhall et al., 1999; Bradley et al., 1998; Hamel et al., 2002; Hopp, 2000; Landry et al., 1997; Meier et al., 1996; Sulmasy et al., 1996). Other studies included adult participants of varied ages (B. A. Brown, 2003; Dexter et al., 1998; Hammes & Rooney, 1998; Morrison et al., 1998; Patterson et al., 1997; Reilly et al., 1995; N.S. Wenger et al., 2001).

Gender. Participants' gender was reported in most studies, with a mix of men and women participants. None of the studies were exclusively of women or men, but women were more prevalent in the majority of studies (Bradley et al., 2001; J. B. Brown et al., 1999; Ditto et al., 2001; Doorenbos & Nies, 2003; Landry et al., 1997; McKinley, Garrett, Evans, & Danis, 1996; Molloy et al., 2000; C. D. Moore & Sherman, 1999; K. A. Moore et al., 1994; Morrison & Meier, 2004; Patrick et al., 1995; Reilly et al., 1995; Sachs et al., 1992; Schneiderman et al., 1992; Silveira et al., 2000; Smucker et al., 1993; Sulmasy et al., 1996; Teno et al., 2004; Waters, 2000).

This dissertation study included men and women adult participants from young, middle, and older age groups. Similar to other studies, women participants were more prevalent.

Values. Only one study was found in which participants rated having plans for future care as important. Ditto et al. (2001), in a randomized controlled trial of 401 elderly (> 65 years old) outpatients and their designated surrogate decision-makers, reported on a 1-5 point scale a mean of 4.49 (SD = 0.04) for the outpatients and a mean of 4.55 (SD = 0.04) for the surrogates.

In this dissertation study, participants rated their perceptions of the perceived importance of ACP discussions using a single item, “Important to have discussions,” on the Participant Survey.

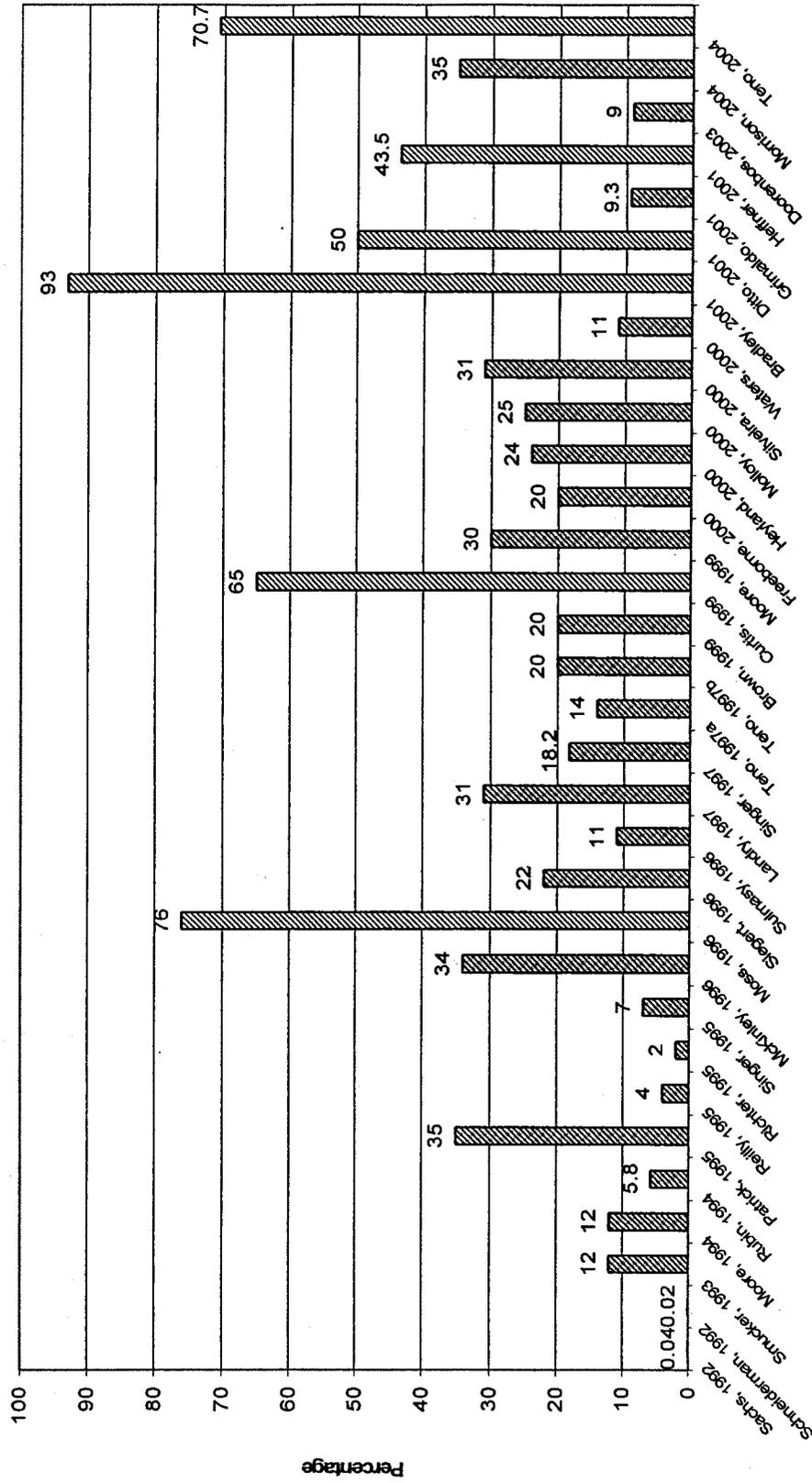
Prior Experiences. Prior experiences with ACP include having an AD, having a HCA, and having conversations about ACP (with HCA, significant others, and HCP), and making a decision about life-sustaining treatment for someone else. The category of having conversations includes both the indication that a conversation occurred as well as the perceived quality (or thoroughness) of that conversation.

Having an AD. Baseline percentages of participants with advance directives (ADs) were reported in 32 studies, ranging from < 10% to > 70%. The relatively large number of studies including these data reflects researchers’ predominant emphasis on initiated ADs as an outcome of ACP interventions. Wide variations in prevalence of ADs exist regardless of whether studies are organized by numbers and types of participants or by date of publication. A depiction of the

percentage of research study participants having an AD organized by date of study publication can be found in Figure 3.

In small exploratory studies ($n < 30$ participants), Moore and Sherman (1999) found that 6 (30%) of the minority and low-income seniors living in the community they interviewed reported having an AD, while Waters (2000) reported only 3 (11%) living wills (LW) in her interviews of community African Americans of varied ages. Six larger studies ($n = 30-100$) reported percentages in specific patient populations. Curtis et al. (1999) found 65% of 57 AIDS patients had LW while 60% had Durable Power of Attorney for Health Care (DPOA-HC). Doorenbos and Nies (2003) reported a 9% prevalence of LW or DPOA-HC in a survey of 45 Asian Indian Hindus. Heyland, Tranmer and Feldman-Stewart (2000) found 24% written ADs among 37 hospitalized patients with serious illnesses. Moss et al. (1996) reported that 76% of 50 patients with amyotrophic lateral sclerosis on long-term ventilation had written ADs. In a survey of 36 rehabilitation/extended care patients, Siegert et al. (1996) reported that 8 (22%) of them had an AD. Singer et al. (1995) surveyed 95 hemodialysis patients, finding only 7% with a LW.

Thirteen studies, with numbers of participants ranging from 101 to 500, documented percentages of ADs in various settings. Bradley et al. (2001) found 32.7% inpatients with cancer to have ADs while Schneiderman et al. (1992) found only 4 (0.02%) of 337 patients with life-threatening illness (primarily oncology,



First Author, Date

Figure 3. Percentage of research study participants having an AD, organized by date of study publication.

pulmonary, and autoimmune deficiency) to have ADs prior to their intervention. Grimaldo et al. (2001) found an average of 9% preoperative patients had an AD.

Reilly et al. (1995) surveyed recently discharged acute care internal medicine patients and found 4% having ADs. Patients from outpatient clinics were varied in their percentages of ADs: 1) urban family practice had 12% LW, 6% DPOA-HC, and 3% other AD (K. A. Moore et al., 1994; Smucker et al., 1993); 2) ambulatory cancer had LWs in 3% of their black and 34% of their White patients; 3) internal medicine had 31% (Landry et al., 1997), 2% (Richter et al., 1995), 11% (Sulmasy et al., 1996); 4) geriatric had 1% (Sachs et al., 1992); 5) HIV had an average of 18.6% (Singer et al., 1997); 6) cardiac rehabilitation had an average of 43.5% LW and 30.5% DPOA-HC (Heffner & Barbieri, 2001); and 7) mixed outpatient clinics had 46% AD or LW and 52% DPOA-HC (Ditto et al., 2001).

Three studies surveyed more than 700 people: an HMO group had an average of 20% ADs (J. B. Brown et al., 1999); senior citizens from New York City senior centers had an overall prevalence of 35% ADs with non-significant differences between White (41%), African American (30%), and Hispanic (35%) participants (Morrison & Meier, 2004); and Oregon adults at an internal medicine / family practice clinic reported 31% ADs (Silveira et al., 2000).

Seven research reports analyzed very large sets of data for AD prevalence. From the SUPPORT study data, Freebourne, Lynn and Desbiens (2000) found 618 (20.2%) ADs from 3058 patients with 11.7% LW, 13.4% DPOA-HC, and 4.9% both LW and DPOA-HC and Teno, Lynn et al. (1997) found 14% of 4804

patients with serious illness had an AD during their hospital admission but only 4.7% had this prior to the hospital admission. In a study of SUPPORT data pre- and post-Patient Self Determination Act (PSDA), Teno, Licks et al. (1997) found that 20% patients had ADs pre-PSDA and an average of 22% patients had ADs post-PSDA. In surveys of older adults, Molloy et al. (2000) found that < 25% of nursing home residents had an AD and Patrick et al. (1995) found an average of 35% prevalence in HMO participants. Rubin et al. (1994) found an AD prevalence of 5.8% in 1101 patients recently discharged from the hospital, with an average of 4.4% having a DPOA-HC. Finally, Teno et al.'s (2004) survey of relatives of deceased patients reported that 70.7% of the patients had a written AD at their last place of care before their deaths.

Having an HCA. Baseline percentages of participants with designated HCAs were reported in 7 studies, ranging from < 10% to > 40% (Figure 4). In randomized controlled trials of hospitalized or recently discharged patients, Rubin et al. (1994), Reilly et al. (1995), and Meier et al. (1996) documented HCA prevalences as 4.2-4.7%, 12.3%, and 6-26%, respectively. In studies of outpatients, HCAs were designated by 6% of elderly family practice patients (Smucker et al., 1993); 45.6-46.3% of internal medicine patients (Landry et al., 1997); 20% Hispanic, 31% African American, and 40% Non-Hispanic White of elderly geriatric and internal medicine patients; and 23% of hemodialysis patients (Hines et al., 1999).

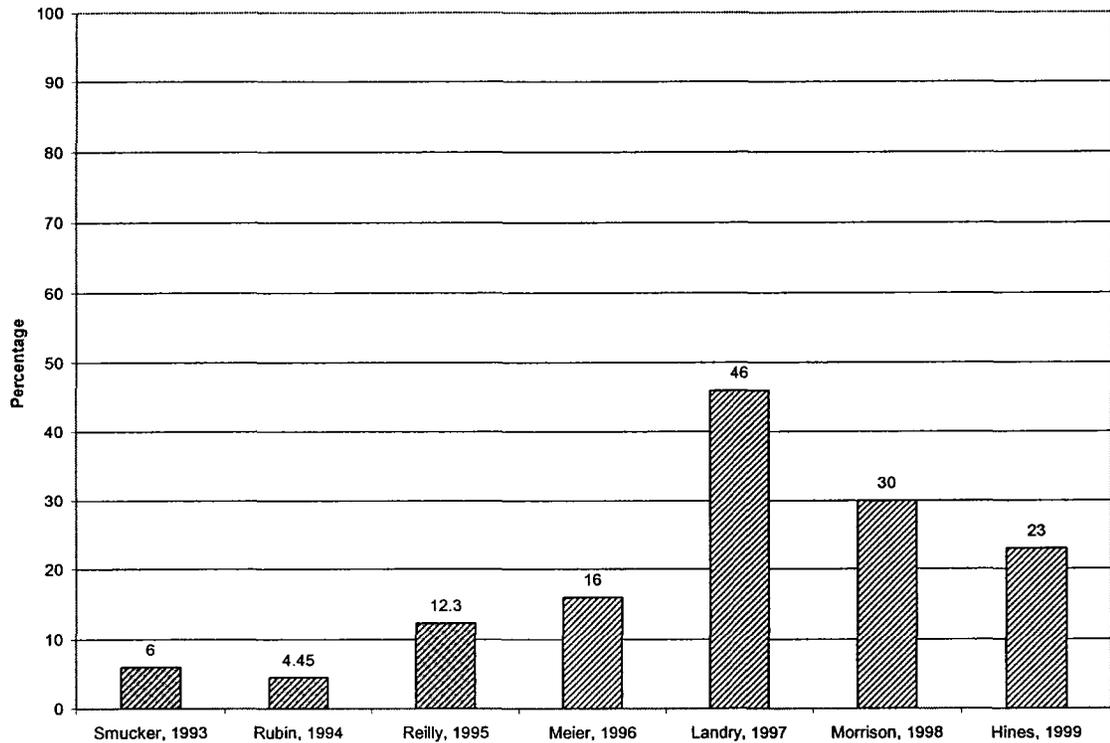


Figure 4. Percentage of research study participants having a HCA, organized by date of study publication.

Having Conversations. Baseline percentages of participants who have had conversations about ACP were reported in 14 studies. Figure 5 displays the percentages of conversations participants reported with their HCAs, significant others, or health care providers.

Not specified. Landry et al. (1997) reported that 50% of internal medicine outpatient participants in their study had previous discussions of end of life issues, but do not specify with whom.

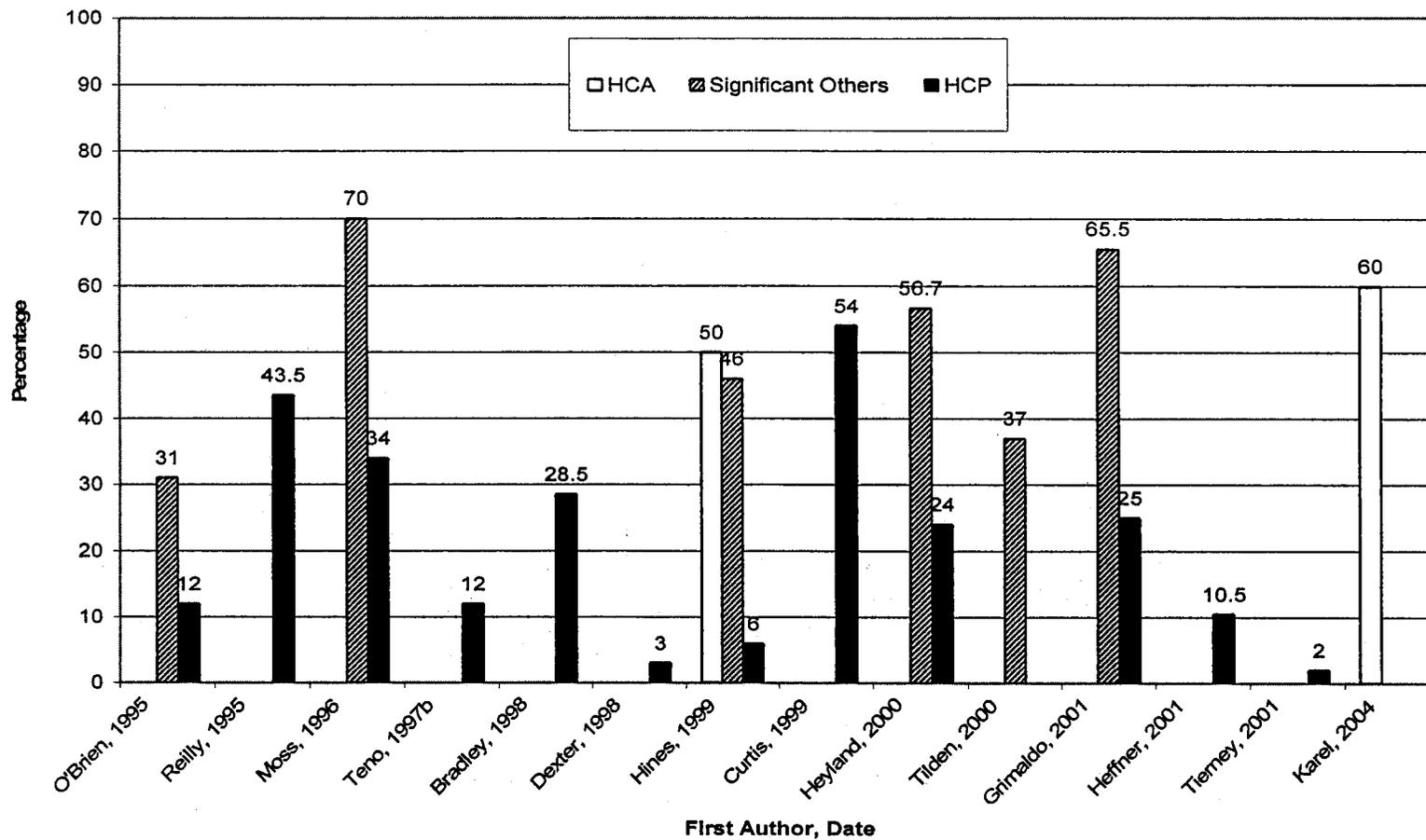


Figure 5. Percentage of research study participants having conversations, organized by date of study publication.

HCA. Two studies reported the percentage of participants who had conversations with their HCA, ranging from 50-60% (Hines et al., 1999; Karel, Powell, & Cantor, 2004).

Significant Others. Five studies reported conversations with family members, with percentages of participants that ranged from 30% to 70% (Grimaldo et al., 2001; Heyland et al., 2000; Hines et al., 1999; Moss et al., 1996; O'Brien et al., 1995). Only one study compared the percentage of conversations had with an HCA with conversations had with family members (Hines et al., 1999).

HCP. The percentage of participants who had conversations with their health care providers was reported in 13 studies, with a range of 2% to 40%. Bradley et al. (1998) found that the Patient Self Determination Act was positively associated with the likelihood of having a discussion with a HCP. Moore et al. (1994) found that the amount of time health care providers spent talking with patients about AD-related issues was related to overall comprehension of ADs. Morrison et al. (2004) noted that patients who were only comfortable discussing ADs when the HCP initiated the discussion were less likely to have a completed AD. Prior conversation with a HCP was a predictor for completion of ADs in two studies (Beck et al., 2002; N.S. Wenger et al., 2001). Again, only the Hines et al. study (1999) compared the percentage of conversations held with a HCP to the percentages of conversations with a HCA or significant others.

Quality conversations. None of the ACP studies reviewed reported participants' perceptions of the quality of conversations about ACP.

Making Decisions. Three studies reported the percentage of participants who had experience making decisions for someone else (Karel et al., 2004; Silveira et al., 2000; Waters, 2000); one additional study reports the experiences of patients with amyotrophic lateral sclerosis who made decisions for themselves (Moss et al., 1996).

Although numerous studies have reported the percentages of participants who have had prior experiences with some aspects of ACP—having an AD, having a HCA, and having conversations, making decisions for someone else—none of the studies examined all four aspects. This dissertation study examined all four aspects of the participants' prior experiences with ACP. This study also compared the prevalence of conversations with HCA, significant others, and HCP, which was only reported in one previous study (Hines et al., 1999). Finally, this study solicited participants' perceptions of the quality of their conversations, a finding not currently reported in the ACP literature.

Personal Decision Factors

Referring again to the Focused Model of the Decision to Engage in ACP (see Figure 2, p. 23), this dissertation study examined the Personal Decision Factor Self-Efficacy through participants' perceptions of their ability and likelihood of having ACP conversations with others. Only two studies examined self-efficacy or confidence related to ACP. Three additional studies discussed changes in participants' interest levels in ADs, which may be a reasonable proxy for likelihood. The focus on ADs may reflect a

greater emphasis in earlier advance planning studies on people's completion of AD forms (Kolarik et al., 2002) than on engaging in "caring conversations ... concerning their expectations and wishes for end of life care" (Michigan Commission on End of Life Care, 2001). None of these five studies specifically explored participants' perceptions of their ability or likelihood of having conversations related to ACP. By examining the variables of ability and likelihood, this dissertation will contribute to a beginning understanding of how prevalent self efficacy is among participants in an ACP program intervention.

Self Efficacy. Two studies reported participants' self-efficacy. Brown (2003) noted that providing an older adult with printed education materials and with personalized reinforcement of the content by a nurse may increase self-efficacy in deciding preferences for end of life care. Silveira et al. (2000) reported their survey participants' confidence in their knowledge of legal choices available for end of life decision-making in Oregon.

Able to start discussion with others. None of the studies reviewed for this proposal addressed the perception of confidence in the ability to start an ACP discussion with others. In this dissertation study, participants rated their perceptions of their ability to start a discussion with others using a single item on the Participant Survey.

Likely to have conversation with others. Three studies reported changes in participants' interest in ACP following interventions: an increase in thinking about an AD from the immediate post-program survey to the follow-up survey two weeks later (Smucker et al., 1993); a willingness to consider "getting an AD"

by 20.9% after hearing about them (Office of the Inspector Office of the Inspector General, 1993); and an intent to complete a living will that varied by age (McKinley et al., 1996). However, none of the studies reviewed for this study addressed the perception of being likely to have an ACP conversation with others. In this dissertation study, participants rated their perceptions of their likelihood to have a conversation with others using a single item on the Participant Survey.

Research Question 2

Research Question 2: Which variables from among the Personal Influences on Decision and Personal Decision Factors are associated with the Decision to Engage in ACP? This question is difficult to explore in the literature because none of the studies reviewed for this study specifically examined associations between internal influences and the decision to engage in ACP. Therefore, ACP studies which examined the associations of variables included in this dissertation study were reviewed.

In the Focused Model of the Decision to Engage in ACP (see Figure 2, p. 23), the Decision to Engage in ACP is thought to be associated with variables from “Personal Influences on Decision” (Information, Individual Characteristics, Values, and Prior Experiences) and the “Personal Decision Factor” self-efficacy (Ability and Likelihood). The Decision to Engage in ACP is thought to then influence the Behaviors of Engaging in ACP, which subsequently influence the Outcomes of Preferences and Communication of Preferences. Of the 21 studies examining associations between variables included in the model of ACP as a decision-making process, only nine included findings related to more than one of the personal influences on decision (information, individual characteristics, values, prior experiences). This dissertation study examined associations

among all four personal influences on decision and the personal decision factor self-efficacy with the decision to engage in ACP.

Personal Influences on Decision

Among variables in Personal Influences on Decision, associations were found between information, individual characteristics of age and gender, and of prior experiences of making decisions, having a HCA, and having discussions.

Information. Ejaz (2000) found that knowledge of an AD was associated with having an AD and the likelihood of implementing an AD. Morrison et al. (1998) found that knowledge gained through exposure to a friend or family member being on a ventilator influenced completion of an AD. In the same study, knowledge of a HCA was associated with designation of a HCA. Knowledge of advance directives was associated with experience making a decision (Silveira et al., 2000). Comprehension of an AD was increased when patients were younger and more educated but decreased if the HCP spent less time talking about AD issues (K. A. Moore et al., 1994). No studies examined “enough knowledge” as an associative variable.

Individual Characteristics. The associations of age and gender with other variables and outcomes were not consistent: some studies found them to be influences but others did not. When age and gender were influences, the findings were not consistent between younger and older ages or men and women.

Age. In two studies, age was associated with having a discussion (Dexter et al., 1998) and identifying preferences (B. A. Brown, 2003). In three studies, younger age was associated with an intent to complete an AD (McKinley et al., 1996) or completion of an AD (K. A. Moore et al., 1994; Patterson et al., 1997). However,

Hammes and Rooney (1998) found that younger age was associated with not completing a written AD. In contrast, four studies found older age to be associated with completing an AD (Dexter et al., 1998; Morrison et al., 1998; N.S. Wenger et al., 2001) or designating a HCA (Reilly et al., 1995). Age was not found to be associated in six studies: with the intent to complete an AD (Sulmasy et al., 1996); with the prior experiences of having an AD (Hopp, 2000) or having a discussion (Bradley et al., 1998; Hamel et al., 2002); with completing an AD (Hamel et al., 2002; Landry et al., 1997); or designating a HCA (Hopp, 2000; Meier et al., 1996).

Gender. In two studies gender was associated with completion of an AD: women in one (Doorenbos & Nies, 2003) and men in the other (N.S. Wenger et al., 2001). However, seven studies found no association of gender: with the intent to complete an AD (Sulmasy et al., 1996); the prior experience of having a discussion (Bradley et al., 1998; Hamel et al., 2002); completing an AD (Hamel et al., 2002; Landry et al., 1997; Molloy et al., 2000; Rubin et al., 1994); or designating a HCA (Meier et al., 1996).

Values. No studies reported testing the association of the perceived importance of ACP.

Prior Experiences. The prior experiences of having an AD, having a HCA, having discussions, and making decisions were found to be associated variables.

Having an AD. Ejaz (2000) found that knowledge of AD was associated with having an AD. Hopp (2000) found no relation between age and having an AD.

Having a HCA. Morrison et al (1998) found an association between having a HCA and completing an AD.

Having Discussions. Hamel et al. (2002) found an association between having discussions in general and completion of an AD; Wenger et al. (2001) found a similar association but more specifically with having discussions with a HCP. Morrison et al. (2004) found that people who were only comfortable having a HCP-initiated discussion were not likely to complete an AD. Bradley et al. (1998) found that the Patient Self Determination Act was associated with having a discussion about ADs but age and gender were not. Hamel et al. (2002) also found no association between age and gender and having a discussion about ADs. Dexter et al. (1998), however, did find that age was associated with having such a discussion.

Making decisions. Silveira et al. (2000) found an association between making a decision and knowledge of ADs, but no relation with completing an AD.

Personal Decision Factors

None of the reviewed studies mention associations with the decision factor self-efficacy or the perceptions of being able and likely to engage in ACP conversations.

Decision to Engage in ACP

No studies specifically examine associations with the Decision to Engage in ACP. However, the intent to complete an advance directive may be a reasonable parallel. The intent to complete an AD was not associated with age or gender in one study (Sulmasy et

al., 1996) but was associated with being younger, white, more educated, and having more income in another study (McKinley et al., 1996). Having no intention to complete an AD was associated with being black and having stronger religious beliefs (McKinley et al.).

Research Question 3

Research Question 3: Do the Personal Influences on Decision and Personal Decision Factor variables that are associated with the Decision to Engage in ACP differ between participants with previous ACP experience compared to participants without previous ACP experience? None of the studies reviewed for this dissertation have considered the role of the previous experiences of having an AD, having a HCA, or having both an AD and a HCA as a variable which may have an impact on other personal influences or decision factors associated with the Decision to Engage in ACP. However, studies with baseline percentages of participants who report prior experiences of having an AD or having a HCA are a reasonable substitute.

Referring once again to the Focused Model of the Decision to Engage in ACP (see Figure 2, p. 23), participants' prior experiences are considered to be Personal Influences on Decision that affect the Decision to Engage in ACP. Within a group of participants attending an ACP program, it is likely that some will have had prior experience engaging in ACP, while others may have decided to engage in ACP for the first time. The model depicts this dynamic as the variable "ACP experience." For the purposes of this dissertation study, ACP experience is defined as a participant's self-report of the prior experiences of having an AD, having a HCA, or having both an AD and a HCA. Using this definition, participants in ACP programs can be separated into those with and without prior ACP experience. Research is needed to describe the

potential influence of ACP Experience on participants' decisions to engage (again) in ACP. This dissertation study defines the variable ACP Experience and tests its association with other personal influence and decision factor variables and the decision to engage in ACP.

Personal Influences on Decision: Prior Experiences

Having an AD. As reviewed earlier in this proposal, researchers of 32 studies published the percentages of their participants who had an AD at baseline (see Figure 3, p. 48). Already having an AD was considered exclusion criteria for participants in four studies (Hamel et al., 2002; Landry et al., 1997; Sachs et al., 1992; Schneiderman et al., 1992). In a study of HIV positive patients, Singer et al. (1997) documented that 19.0% of the participants approached for the study already were satisfied with their previous ADs and declined participation in the study. Only Grimaldo et al. (2001) analyzed differences in the percentage of ADs found in the medical records of preoperative patients who declined participation in the study versus patients who participated in the randomized controlled trial. The refusal group had 8%, the control group 9%, and the intervention group 11% at baseline; these differences were not significant.

Having a HCA. As reviewed earlier in this proposal, seven groups of researchers published studies reporting baseline percentages of participants who had a HCA (see Figure 4, p. 51). Having a HCA was not an exclusion criteria for any of these studies.

Having Both an AD and a HCA. None of the studies reviewed indicated participants who had both an AD and a HCA.

Research Question 4

Research Question 4: After participation in a community-based ACP program, are there changes from pre- to post-ACP program intervention in self-reported ratings of enough knowledge, importance, ability and likelihood to have an ACP conversation? As a beginning answer to this question, 23 studies of ACP educational interventions, which included a pre- and post-intervention measure, were reviewed to determine which outcomes were being measured and the impact of the intervention on those outcomes.

The Focused Model of the Decision to Engage in ACP (see Figure 2, p. 23) depicts the Intervention as influencing the Personal Influences on Decision variables of “Enough Knowledge” and “Importance” as well as the Personal Decision Factor self-efficacy variables of “Ability” and “Likelihood.” These personal influence and decision factor variables are thought to influence the Decision to Engage in ACP which influences subsequent Behaviors and Outcomes of engaging in ACP. In more than 80% of the ACP educational intervention studies reviewed, the measured outcomes were from the Outcomes section of the model, which is not a focus of this dissertation study. Thus, only studies relating to the personal influences on decision and personal decision factor self-efficacy variables or the intervention will be discussed. This dissertation study evaluates the impact of a community-based ACP educational program on participants’ ratings of their perceived information, values, and self-efficacy related to ACP conversations.

Personal Influences on Decision

Only six studies reported an intervention’s impact on individuals’ information (n = 5) and value of ACP (n = 1).

Information. Five studies reported an impact on participants' knowledge of ADs, including Living Will (LW) and Durable Power of Attorney for Health Care (DPOA-HC) documents. Grimaldo et al. (2001), Schwartz et al. (2002), and Waters (2000) reported increases in participants' knowledge of ACP following a HCP-initiated conversation about ACP. Yamada et al. (1999) also noted increased knowledge of ACP after providing handouts and a video to participants. Teno, Lynn et al. (1997) reported a non-significant increase in knowledge of LW or DPOA-HC following implementation of the Patient Self-Determination Act (PSDA).

Values. Only the study by Waters (2000) reported a dramatic shift in perceived importance of ACP from 89% of the 27 African American participants having no LW and not wanting to consider one at the beginning of the program to 85% of the participants being willing to consider a LW at the end of the program. In addition, more than 85% of the participants stated that a community-based ACP discussion was valuable.

Personal Decision Factors

No studies discussed the impact of an intervention on self-efficacy or the variables of ability or likelihood to engage in ACP.

Research Question 5

Research Question 5: Do the changes between participants' self-reported pre- and post-ACP program intervention ratings of enough knowledge, importance, ability, and likelihood differ between participants with previous ACP experience compared to participants without previous ACP experience? Only one study could be found that describes the impact of an ACP intervention on participants who already had an AD. Brown et al. (1999) reported that a "substantial number" of subjects with previous ADs

added DPOA-HCs or made other changes to their ADs following ACP education. This is an example of re-engagement in ACP.

This final research question, using elements of Research Questions 3 and 4, evaluates the influence, if any, of the variable ACP Experience on the impact of the community-based ACP educational intervention on personal influences of knowledge and importance of ACP and the decision factor of being able and likely to engage in ACP. Since there is no literature discussing the role of ACP Experience on the impact of an ACP intervention, this dissertation study provides a comparison of the reports of community-based ACP program participants with and without ACP experience.

Significance of Study

This dissertation study intends to make five contributions to the knowledge base of ACP decision-making:

1. This study focuses on the Decision to Engage in ACP rather than behaviors or outcomes of engaging in ACP. The emphasis on this decision encourages investigation of ACP from a decision-making theoretical perspective.
2. This study examines the prevalence and association of an assortment of personal influence and decision variables among participants who have decided to engage in ACP. This contributes a more comprehensive picture of the internal influences on individuals' decisions to engage in ACP than is currently found in the literature.
3. This study measures the impact of a community-based ACP educational program intervention on selected personal influence and decision

variables related to having ACP conversations. The emphasis on information, values, and self-efficacy underscores the key features of ACP as a deliberative, communicative, shared decision-making, and dynamic process.

4. This study explores the association of an external intervention with changes in internal influences on a decision. This association provides a new target for the impact of an intervention that differs from the usual product outcome (AD).
5. This study provides a first look at ACP Experience as a variable that may modify other personal influences and decision variables as well as the impact of an ACP intervention. By examining the differences, if any, between participants with and without ACP experience, this study contributes to the understanding of individuals' decisions to engage in ACP for the first time or again. This promotes the understanding of ACP as a dynamic decision-making process.

CHAPTER 4

METHOD

This chapter reviews the methodology of the dissertation study. The context of the study—the Mid-Michigan Advance Care Planning Coalition (MMACPC) Research Project—will be described first as an example of a collaborative effort to promote ACP in communities. The method of this study, which was a secondary analysis of data collected during the MMACPC Research Project, follows.

Context of Study

Promotion of ACP

In 2003, a university-affiliated outreach program, the Capital Area Health Alliance – Advance Care Planning Coalition (CAHA-ACPC),² formed to promote ACP for Michigan residents. With funding from the Robert Wood Johnson Foundation Rallying Points Program (2002), CAHA-ACPC selected Respecting Choices®, a nationally recognized, comprehensive, community-based ACP program (Hammes & Briggs, 2002a), to provide professional training in the skills of ACP facilitation and community-based ACP strategic planning. Between March, 2004 and January, 2006, 52 ACP Facilitators were certified during CAHA-ACPC-sponsored ACP Facilitator training conferences. Each ACP Facilitator received Respecting Choices® training and resources to promote ACP. In return, CAHA-ACPC requested that the ACP Facilitators provide at least one ACP educational program for an established group of individuals in their communities.

² The Coalition was originally named the Mid-Michigan Advance Care Planning Coalition (MMACPC). It is a collaborative interdisciplinary group of health care providers and researchers from two local health care organizations (systems) and Michigan State University.

In April, 2004, CAHA-ACPC appointed a Research Subcommittee, the Mid-Michigan Advance Care Planning Coalition (MMACPC) Research Team, to measure the effectiveness of using ACP educational programs, conducted by ACP Facilitators in established community groups, to promote engagement in ACP. This investigator, as part of her doctoral studies, designed the MMACPC Research Project, acted as the Research Coordinator, and led Research Team meetings from June, 2004 to June, 2006. Funding for the MMACPC Research Project was awarded from the Blue Cross Blue Shield Foundation of Michigan Student Award Program (2004-2005) and the Marion Peterson Nursing Research Endowment (2005).

The MMACPC Research Project was a prospective descriptive quasi-experimental study that included an ACP program intervention with pre- and post-program surveys. Certified ACP Facilitators planned ACP programs, using Respecting Choices® resources, for established groups in their local communities. Approximately 400 people attended one of 25 ACP programs offered between July, 2004 and November, 2005, targeted to existing faith (n=16), health-related layperson (n=4), and employee (n=5) community groups in Greater Lansing and Grand Rapids, Michigan. A convenience sample of 347 adult men and women completed survey instruments (85% participation).

Development of Survey Instruments

The pre- and post-program survey instruments were developed by this investigator from Community Surveys provided in the Respecting Choices® Advance Care Planning Program Quality Improvement Toolkit³ (Briggs, Havlik, & Hammes,

³ While Respecting Choices® is a trade-marked name, the Community Surveys were made available in the public domain as tools to evaluate ACP programming.

2000; Hammes & Briggs, 2004). Items were selected and adapted based on a review of ACP decision-making literature and experiences from professional practice. The resulting Participant Survey included pre- and post-program surveys (see Appendix A). Content validity of the Participant Survey was confirmed through independent reviews by one of the Respecting Choices® founders (L. Briggs), CAHA-ACPC health care providers (L. Peterson, L. Harrison), and members of the MMACPC Research Team. Neither the Participant Survey nor the earlier Respecting Choices® Community Surveys have published psychometric reliability data. The Participant Survey was piloted in May, 2004 at an ACP Facilitator training conference and was deemed easy to comprehend and complete.

Survey Data Collection Procedure

When an ACP program was scheduled, the ACP Facilitator received survey materials for the expected number of participants from the Research Coordinator. At the beginning of the ACP program, the ACP Facilitator distributed a survey packet to each person in attendance and invited them to participate in the study. ACP Facilitators assured attendees that they could attend the ACP program whether or not they took part in the study. Participants completed a consent form (see Appendix B) and the pre-program survey before the planned ACP program content was begun. At the conclusion of the ACP program, participants completed a post-program survey. Following the ACP program, the ACP Facilitator returned the completed consents, pre-program surveys, and post-program surveys, along with a Program Identification form, to the Research Coordinator.

Data Management and Storage Procedures

To prepare for data entry, the Research Coordinator created 1) a tracking database to log sending and receiving of data collection packets; 2) a password-protected database for data entry; and 3) a set of data entry instructions and a codebook listing each variable from the survey. The Research Coordinator hired a student research assistant to assist with data entry and oriented her to procedures for data entry and how to safeguard the data and the privacy of participants' survey information. Participants' privacy was protected because the consent forms with identifying information were kept separate from the pre- and post-surveys. Only the pre- and post-survey data were exported into SPSS for analysis; therefore, the files used for data analysis contained no personal identifying information.

When a packet of research data arrived, the Research Coordinator logged the contents of the consent, pre-program survey, and post-program survey envelopes into a tracking database and assigned a program code (e.g., Faith 1, Employee 4). The collected data were entered into the secure database by the Research Coordinator (n = 8 programs) and the student research assistant (n = 17 programs). Analysis of the data was carried out by the Research Coordinator with direction from the Research Team.

MMACPC Research Project IRB Approval

The Michigan State University Committee on Research Involving Human Subjects (UCRIHS) approved the MMACPC Research Project in June, 2004, with renewals in June, 2005, May, 2006, and April, 2007. In addition, specific agency internal review board approval ("Reliance agreements") were obtained for Sparrow Health System (December, 2004) and Ingham Regional Medical Center (March, 2005) to cover

employee group programs offered in those health care organizations. An IRB Revision was approved in March, 2005 to add a personal identification number to the consent form and survey instruments. This number, while still protecting the participants' privacy, allowed comparison of individual participants' pre- and post-program ratings of knowledge, importance, ability, and likelihood of engaging in ACP. Copies of the IRB applications and approval letters are located in Appendix C.

Results Dissemination

Findings from the MMACPC Research Project have been presented regionally five times (Vander Laan, 2005a, 2005b; K.J. Vander Laan, P.B. Mullan, & G.K. Wyatt, 2005; Vander Laan, Mullan, Wyatt, McPhail, & Thomason, 2007; Wyatt, McPhail, Mullan, Thomason, & Vander Laan, 2005). National presentations have been made three times (K.J. Vander Laan, P.B. Mullan, & G.K. Wyatt, 2005; Vander Laan, Mullan, Wyatt, McPhail, & Thomason, 2006; Vander Laan & Wyatt, 2005).

Approval of Secondary Data Analysis

At its April, 2006 meeting, the MMACPC Research Team approved the use of the project data for this dissertation study. The planned data analyses of the matched pre-post survey data have not been previously done or reported.

Study Methods

Design

This dissertation study is a secondary analysis of a subset of data collected for the MMACPC Research Project. The MMACPC Research Project included pre- and post-program surveys of participants in an ACP program.

Subjects

The subjects for this study are a convenience sample of 147 men and women, ages 18 and older, who participated in one of 11 ACP programs offered by an ACP Facilitator to existing faith (n = 6), health-related layperson (n = 1), and employee (n = 4) community groups in Greater Lansing and Grand Rapids, Michigan.

The inclusion criteria for this study required participants who: 1) were 18 years or older because a potential product outcome of the ACP program is a legal document; i.e., an advance directive; 2) attended the entire ACP program (if only one session) or at least the first and last session of the ACP program (if more than one session); 3) were able to complete the surveys, which required the ability to read and write in English; 4) completed both the pre- and post-program surveys, and 5) created a personal identification number for use on both pre- and post-surveys. Participants were excluded from this study if they 1) did not complete both the pre- and post-program surveys or 2) did not write their personal identification number on both pre- and post-program surveys.

Measure – Pre- and Post-Program Survey Instruments

The data used for this study are a subset of items from the Participant Survey. Each item relates to a concept in the Focused Model of the Decision to Engage in ACP (see Figure 2, p. 23). Table C1 lists the Participant Survey items, related conceptual model variables, data collection timing, and item type (see Appendix C).

Human Subject Considerations

Since the MMACPC Research Project continues to have IRB approval, a revision form was submitted to the Community Research Institutional Review Board (CRIRB) to add personnel for data entry and analysis consultation and to outline data management

precautions for this study (see Appendix C). All personnel involved in conducting this study have current IRB training certification.

Data Management

Preparation for Data Entry. This investigator prepared the data to be used in this study to facilitate data entry and analysis. First, photocopies of the pre- and post-program surveys were made and the items from the Participant Survey to be used in this project were highlighted on the copies. The alphanumeric personal identification numbers were matched for pre- and post-surveys and given a common 4-digit identification number (PERSID). Then a codebook of survey questions, coding, and the corresponding SPSS template fields was created. Finally, an SPSS template was constructed with variables and the PERSID numbers for both pre- and post-surveys. The copies, codebook, and SPSS template were brought to CSTAT for actual data entry and preliminary analysis by student consultants.

Procedure for Verifying Data Integrity. The data used in this dissertation study were entered into the SPSS database by two students not previously associated with the MMACPC Research Project. This double data-entry procedure fully meets the best practice standard for data management prescribed by the National Institutes of Health (Stommel & Wills, 2004). Once both sets of data were entered into SPSS, the data were checked for discrepancies, illegal, and missing values. Correlations between the two data sets were checked for values of $r < 1.0000$; no errors were detected so no corrections were required. Had discrepancies or illegal values been found, the original surveys would have been checked to correct the data. Missing values were examined for patterns, such as skipping patterns related to preceding questions on the survey. Once all the data

were verified, the pre- and post-survey data files were merged by means of the unique personal ID, the number that was used to match each participant's pre- and post-survey data. These data comprise the master data set for this dissertation study.

Data Analysis

SPSS® version 12.0 statistical software was used for analysis of data in this study. The master data file was used to generate frequency distributions for each variable. Distributions were examined for symmetry and measures of central tendency and variability. The assumptions of normality were checked to determine whether parametric or non-parametric statistical tests would be used. The statistician provided guidance related to appropriate data transformations, significance levels, and statistical tests. Each research question was analyzed as discussed in the following sections.

Research Question 1. Prior to their participation in a community-based ACP program, what are the self-reported Personal Influences on Decision and Personal Decision Factors of adults who have decided to engage in ACP?

The frequency distributions of variables from the pre-program survey were reported for all of the participants (n = 147). Assumptions of independent samples and expected counts were checked and statistical significance adjustment, using Bonferroni's correction, was made when applicable. Then, using crosstabulation and chi-square analysis, the frequencies of the prior experiences of having an AD and having a HCA were compared with the frequencies of having conversations. Next, the reported conversation frequencies were compared between the HCA, significant others, and HCP conversation partners. Lastly, participants' perceptions of the quality of conversations were compared between the conversation partners (HCA, significant others, HCP).

Research Question 2. Which variables from among the Personal Influences on Decision and Personal Decision Factors are associated with the Decision to Engage in ACP?

The pre-program survey data was used for analysis. Correlations were calculated between each variable from the “Personal Influences on Decision” and the “Personal Decision Factor,” depicted in the focused model of the Decision to Engage in ACP (see Chapter 2, p. 25). Each pair of variables was examined for correlation strength and statistical significance. Since multiple comparisons were used for each variable, statistical significance was adjusted using Bonferroni’s correction.

Research Question 3. Do the Personal Influences on Decision and Personal Decision Factor variables that are associated with the Decision to Engage in ACP differ between participants with previous ACP experience compared to participants without previous ACP experience?

The pre-program survey data was analyzed in subgroups on the basis of the ACP Experience variable, which was derived from responses to the Having an AD and Having a HCA survey items. Data from participants who did not answer both of these items was excluded for this analysis. The frequency distributions of the interval level variables (enough knowledge, importance, ability, and likelihood) were checked for normality and homogeneity of variance and the non-parametric Mann-Whitney U-test was used to compare the groups. Next, correlations of all the personal influence and decision factor variables were calculated to determine correlation strength and statistical significance of the variable pairs. Statistical significance was set at $p < 0.05$, with Bonferroni’s correction for multiple comparisons.

Research Question 4. After participation in a community-based ACP program, are there changes from pre- to post-ACP program intervention in self-reported ratings of enough knowledge, importance, ability, and likelihood to have an ACP conversation?

A matched pre-program/post-program survey dataset was used for data analysis and each pre- and post-program rating of knowledge, importance, ability, and likelihood. After checking for assumptions of normality, each pre- and post-program variable was compared using the non-parametric Wilcoxon Matched Pair Signed-Ranks test.

Research Question 5. Do the changes between participants' self-reported pre- and post-ACP program intervention ratings of enough knowledge, importance, ability, and likelihood differ between participants with previous ACP experience compared to participants without previous ACP experience?

The matched pre-program/post-program dataset was then analyzed by subgroups on the basis of the ACP Participant Experience variable. The pre- and post-program ratings of knowledge, importance, ability, and likelihood were compared for each ACP Experience group using the Wilcoxon Matched Pairs Signed-Ranks test. Difference scores were calculated for each group of participants to examine the impact of the ACP education program intervention on each group's participants' perceptions of their knowledge, importance, ability, and likelihood of having ACP conversations. Difference score distributions were checked for normality and homogeneity of variance, then compared using the non-parametric Mann Whitney U test.

Chapter Summary

The purpose of this dissertation study is to add to the understanding of internal (e.g., self-efficacy) and external (e.g., ACP program) influences within the decision-making context that may affect individuals' decisions to engage and re-engage in ACP. A secondary analysis of matched pre- and post-program survey data will contribute to an understanding of associations between internal influences and the decision to engage in ACP, the impact of an ACP program intervention on internal influences, and the potential modifying effects of previous ACP experience.

Chapter 5

RESULTS

This secondary analysis of matched pre- and post-program survey data was designed to describe the frequency and associations between influences within the decision-making context that are present for participants who decided to engage or re-engage in ACP by attending an ACP program. The participants in this study were 147 adult men and women who attended an ACP program offered by an ACP Facilitator to an existing community group of which they were members. Following a brief overview of preliminary data analysis, the results for each research question will be presented.

Preliminary Analysis of Data

Frequencies and missing data

The data were examined with univariate descriptive statistics to determine frequencies of valid responses and patterns of missing data. For all but four variables, less than three percent of the frequency counts in the pre-program survey data were missing data. The valid responses for each variable were examined to identify appropriate statistical tests for determining associations between variables in later research questions.

Three patterns of missing data were found: 1) a survey item not answered which could be validly scored from a response elsewhere on the survey, 2) survey items which were answered with the possible response of “I’m not sure,” and 3) survey items which were contingent upon a previous item’s “Yes” response. In the first case, one participant who did not answer the gender survey item identified her gender in her personal identification number. Her gender was included in the valid reported results.

For the second case, all of the Prior Experiences variables included the possible response of “I’m not sure.” Except for basic reporting of frequencies, only the “Yes” and “No” responses are treated as valid data and the “I’m not sure” responses are treated as missing.

In the third case, four Prior Experience items—Having conversations with HCA and the three Quality of Conversations items—were designed to be contingent upon a “Yes” response to the items immediately preceding them, which explains the greater frequency of missing data for these items. However, three of the follow-up questions were answered by some participants even though they had answered “No” to the preceding items (see Table 1). The decision was made to include these participants’ responses as valid data.

Table 1

Comparison of Valid Data Percentages with and without Contingency Items

Focus Model Variable	Valid data if responses contingent on previous item %	Responses added if not contingent on previous item n	Valid data if all responses counted %
Having Conversations with HCA	61.9%	12	72.1%
Quality Conversations with Significant Others	61.2%	2	62.6%
Quality Conversations with HCP	15.0%	1	15.6%

Normality & Choice of Statistical Tests

The four ordinal/interval variables of Knowledge, Importance, Ability, and Likelihood were examined for normality of distribution in both pre- and post-program survey data. Because none of the variables meet the criteria for normality (based on

shape, skewness, or kurtosis), central tendency will be reported as the median and variance as the range. Bivariate analysis of variables in this study will be conducted using non-parametric (or “distribution-free”) statistic tests for four reasons: 1) Non-parametric tests do not depend on distributions meeting assumptions of normality. 2) Non-parametric tests can be used with small samples (although they tend to need a larger sample to detect statistical significance). 3) Non-parametric tests are able to used with data that is distorted from a restricted range of scores. 4) Non-parametric tests are able to test differences in central tendency without being affected by outliers (Howell, 2002).

When more than one relationship will be calculated for a variable, Bonferroni’s correction will be used to adjust the statistical significance to the number of comparisons being made. This prevents making a Type 1 error—declaring statistical significance to exist when it really does not—which may occur if multiple comparisons are being made, each at an alpha level of 0.05. For example, in Research Question 2, when Spearman rho correlations will be calculated for every pair of variables, statistical significance will be set at $p = 0.05 / \text{number of comparisons for each variable}$. Since there are 12 variables and each will be matched with all the others, the statistical significance will be set at $(0.05/11 = 0.004)$.

Recoding of Quality of Conversations Items

In the pre-program Participant Survey, the Quality of Conversations items were presented as 5-point ordinal/interval scales with descriptors of 1 = few comments only; 3 = good conversation; and 5 = complete and thorough conversation. Because this scale appeared to mix concepts of quantity (few comments only) with concepts of quality

(good, thorough), these items were recoded to two nominal/ordinal categories (1 and 2 = few comments; 3, 4, and 5 = thorough conversation).

Research Question 1

Prior to their participation in a community-based ACP program, what are the self-reported Personal Influences on Decision and Personal Decision Factors of adults who have decided to engage in ACP?

The frequencies of all variables from the pre-program survey data are presented in Table 2, in the sequence of the Focused Model of the Decision to Engage in ACP (see Figure 2, p. 25).

Results

Enough knowledge. The distribution of participants' ratings of having enough knowledge to discuss their views was examined using a histogram. The distribution was bimodal with modes of 3 and 5 and a kurtosis coefficient = - 2.32, which is too flat to be normal. The median score was 4.0 with a range of scores from 1 to 5. Thirty percent of the participants reported very much knowledge (5) and 30% reported knowledge at the midpoint (3). Less than 5% of the participants reported having no knowledge at all (1).

Age and gender. Crosstabulation was used to examine the age and gender of the study participants. There were participants from every age range; however, those in the 18-39 years range comprised only 1.4% of the total. Participants who were in the 31-59 years range were the most frequent with 58.8% of the men and 78.4% of the women participants included in this category. Participants who were > 75 years comprised 7.6%

Table 2

*Frequencies of Personal Influence on Decision and Personal Decision Factor Variables
in the Pre-Program Survey Data for the Total Sample*

Focus Model Variables	Responses	n	%
Enough knowledge to discuss my views	1 = not at all	6	4.1
	2	22	15.0
	3	44	29.9
	4	30	20.4
	5 = very much	44	29.9
	Missing	1	0.7
Age	18-30	2	1.4
	31-59	107	72.8
	60-75	25	17.0
	> 75	11	7.5
	Missing	2	1.4
Gender	Male	34	23.1
	Female	113	76.9
Important to have a discussion	1 = not at all	1	0.7
	2	3	2.0
	3	15	10.2
	4	23	15.6
	5 = very much	103	70.1
	Missing	2	1.4
Having an AD (Advance Directive)	No	81	55.1
	Yes	55	37.4
	I'm not sure	7	4.8
	Missing	4	7.5
Having a HCA (Health Care Agent)	No	52	35.4
	Yes	91	61.9
	I'm not sure	3	2.0
	Missing	1	0.7
Having Conversations with HCA	No	20	13.6
	Yes	83	56.5
	I'm not sure	3	2.0
	Missing	41	27.9

Table 2 (continued)

Focus Model Variables	Responses	n	%
Quality Conversations with HCA	Few comments	23	15.6
	Thorough conversation	60	40.8
	Missing	64	43.5
Having Conversations with Significant Others	No	51	34.7
	Yes	90	61.2
	I'm not sure	4	2.7
	Missing	2	1.4
Quality Conversations with Significant Others	Few comments	40	27.2
	Thorough conversation	52	35.4
	Missing	55	37.4
Having Conversations with HCP (Health Care Provider)	No	124	84.4
	Yes	22	15.0
	I'm not sure	0	0
	Missing	1	0.7
Quality Conversations with HCP	Few comments	4	2.7
	Thorough conversation	19	12.9
	Missing	124	84.4
Making decision for someone else	No	85	57.8
	Yes	59	40.1
	I'm not sure	1	0.7
	Missing	2	1.4
Able to start discussion with others	1 = not at all	4	2.7
	2	7	4.8
	3	35	23.8
	4	40	27.2
	5 = very much	60	40.8
	Missing	1	0.7
Likely to have conversation with others	1 = not at all	0	0
	2	8	5.4
	3	29	19.7
	4	30	20.4
	5 = very much	78	53.1
	Missing	2	1.4

of the total. Women comprised 76.6% of the participants and were the only gender represented in the 18-39 years range. Participants from the > 75 years category were almost equally divided between men and women.

Importance. The distribution of participants' ratings of feeling it is important to have a discussion was examined using a histogram. The median score for this distribution was 5.0 with a range of 1 to 5; however < 1% of participants rated importance as "not at all" (1) and only 2% of participants rated it as "2." On the basis of these four outlier scores, the distribution was skewed to the left (skewness coefficient = -9.228); it was also too peaked to be normal (kurtosis coefficient = 7.65). Seventy percent of participants reported feeling that having a discussion was very much important (5). Responses to this variable were the most homogenous of all the distributions.

Prior Experiences. Participants' reported prior experiences included having an AD (37%); having a HCA (62%); having conversations with HCAs (56.5%), significant others (61.2%), and HCPs (15%); and making a decision for someone else (40%). Sixteen of the study participants (10.9%) reported they were "not sure" whether they had had these prior experiences: Having an AD (n = 7); Having a HCA (n = 3); Having conversations with HCAs (n = 3), or significant others (n = 4); Making a decision for someone else (n = 1). One participant was "not sure" about three types of experiences, two participants about two types, and the remaining 13 about one type. These data indicate that some participants were unsure about these concepts prior to the ACP education program intervention.

Of the 53 participants who reported making a decision for someone else, 96% of the decisions were made for an adult, < 2% for a child, and < 2% for both an adult and

child. Fifty-six participants reported their feelings of preparedness to make a decision: 73.2% felt prepared, 17.9% did not feel prepared, and 8.9% were not sure.

Crosstabulation was used to further describe participants' prior experiences. Of the 134 participants who answered the Having an AD and Having a HCA items, 38.8% reported having both an AD and a HCA. Of the 100 participants who answered the Having a HCA and Having conversations with their HCA items, 77.0% reported having conversations with their HCA.

The quality of conversations with partners was reported by varying numbers of participants. Quality of Conversations with Health Care Agent was reported by 83 participants with 72.2% rating the quality as "thorough." Quality of Conversations with Significant Others was reported by 92 participants, almost equally divided between ratings of "few comments" (43.5%) and "thorough" (56.5%). Quality of Conversations with Health Care Provider was reported by 23 participants with 82.6% rating the quality as "thorough."

Ability. The distribution of participants' ratings of feeling able to start a discussion with others was examined using a histogram. This distribution was skewed to the left (skewness coefficient = -4.114), reflecting a few scores at the low end of the rating scale. The median score was 4.0 with a range of scores from 1 to 5. Only 2.7% of the participants felt not at all able (1), while 40.8% felt very much able (5) to start a discussion with others. Ratings of 3 and above were reported by 91.8% of the participants.

Likelihood. The distribution of participants' ratings of their likelihood to have a conversation with others was examined using a histogram. This distribution was skewed

to the left (skewness coefficient = - 4.274), with only 5.4% of the scores at the minimum of the range from 2 to 5. This range is the most restricted of the distributions, with a median score of 5.0. None of the participants rated themselves as “not at all” likely to have a conversation (1); more than half (53.1%) rated themselves as “very much” likely (5). Ratings of 3 and above were reported by 93.2% of the participants.

Further analyses

Relationships between Having an AD, Having a HCA, and Having Conversations.

Only two studies reviewed for this dissertation reported an association between the prior experiences of having an AD or having a HCA with conversations. Therefore, the prior experiences of Having an AD and Having a HCA were examined further individually for relationships with the Having Conversations variables using the Chi-Square test. Since three comparisons were being made for each variable, statistical significance was adjusted for each analysis using Bonferroni’s correction ($0.05/3 = 0.017$).

The data provide significant evidence ($p < 0.017$) to indicate there are relationships between having an AD and having conversations, in order of strength, with a HCP $\chi^2(1, N = 135) = 23.54, p < 0.001$; with significant others $\chi^2(1, N = 133) = 12.94, p < 0.001$; and with a HCA $\chi^2(1, N = 94) = 7.71, p = 0.007$. To further explore the degree to which Having an AD influences the Having Conversations variables, odds ratios were calculated for each relationship. For participants who reported having an AD, the odds of having conversations with a HCP were 14.11 times greater (95% CI 3.919, 50.829); with significant others, 4.42 times greater (95% CI 1.908, 10.253); and with a HCA, 4.80 times greater (95% CI 1.417, 16.260) than for participants who did not report having an AD.

Next the variable Having a HCA was examined for relationships with the Having Conversations variables using the Chi-Square test. A comparison between participants who reported Having a HCA and Having Conversations with HCA could not be done because the assumption of independence was not met (77.0% of the participants who answered “Yes” to having a HCA also reported having conversations with a HCA). The comparison of Having a HCA and Having Conversations with Significant Others could also be problematic since it is possible that some participants’ health care agents might also be their significant others. However, since the survey item did not explore this potential overlap, the comparison will be reported as if it is independent of the Having a HCA variable. Since two Conversation variables are being compared with the Having a HCA variable, Bonferroni’s correction will be used to adjust the value for statistical significance ($0.05/2 = 0.025$).

The data provided significant evidence ($p < 0.025$) to indicate there are relationships between having a HCA and Having Conversations, in order of strength, with Significant Others $\chi^2(1, N = 138) = 23.092, p < 0.001$ and with a HCP $\chi^2(1, N = 142) = 8.500, p = 0.004$. Odds ratios were also calculated for each relationship. For participants who reported having a HCA, the odds of having conversations with significant others were 6.03 times greater (95% CI 2.813, 12.917) and with a HCP, 7.14 times greater (95% CI 1.597, 31.953) than for participants who did not report having a HCA.

Participants’ Reported Conversation Partners. In the ACP literature reviewed for this study, there were relatively few studies that reported the experience of having conversations and only one that compared frequencies of conversations with three

different partners (HCA, significant others, and HCP). Thus, participants' reported conversations were examined by crosstabulation and are presented in Figure 3.

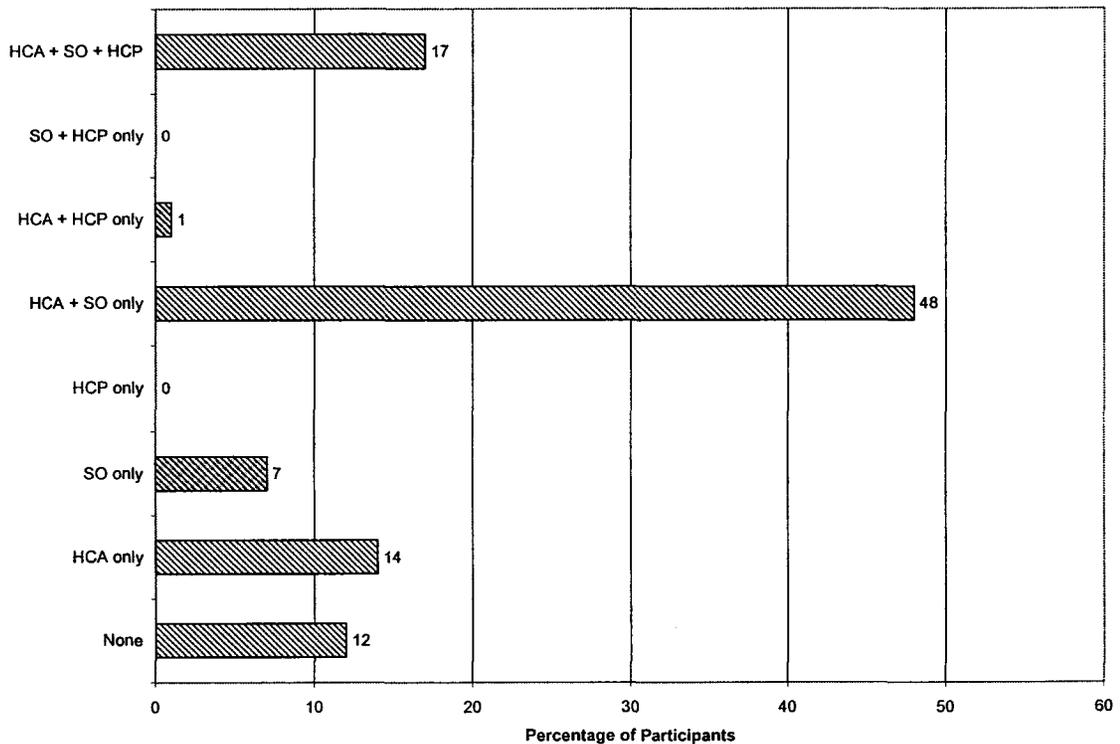


Figure 6. Percentage of participants who reported conversations with partners.

Note. HCA = Health Care Agent, SO = Significant Others, HCP = Health Care Provider

Ninety-eight participants answered the pre-program survey items about Having Conversations. About 50% reported having a conversation with their HCA and significant others. As discussed previously, there may be overlap between conversations with the HCA and the significant others. Another 17% reported having a conversation with their HCA, significant others, and HCP. However, 12% reported having no conversations at all; 14% reported conversations only with their HCAs; and 7% only with

their significant others. Except for the participants who reported having all three types of conversations, participants' conversations with Health care providers were almost non-existent.

Perceptions of Quality of Conversations. Perceptions of the quality of conversations have not been reported in the literature reviewed for this study. Figure 7 depicts participants' reports of the quality of conversations had with HCAs, significant others, and HCPs.

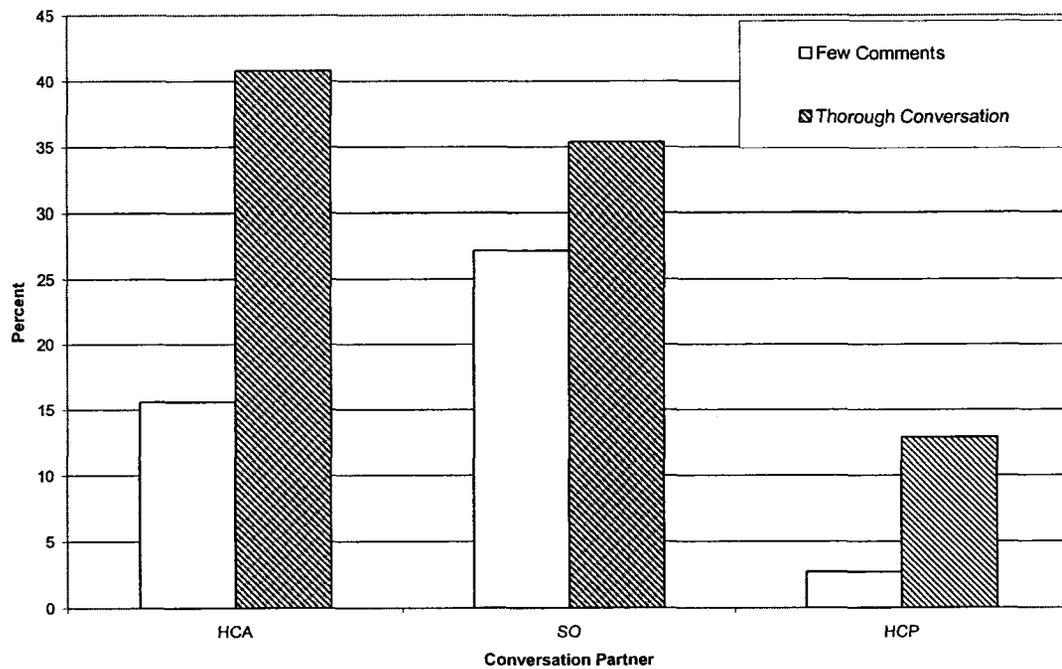


Figure 7. Percentage of participants reporting quality of conversations with conversation partners. *Note.* HCA = Health Care Agent, SO = Significant Others, HCP = Health Care Professional.

With all three conversation partners, participants reported the quality of their conversations more often as “thorough” than “few comments.” However, because the

actual frequencies of the conversations varied significantly, the magnitude of the reported quality for conversation types can be more accurately depicted using proportional percentages. Figure 8 shows that the few participants who had conversations with a HCP rated this conversation type to have the most thoroughness.

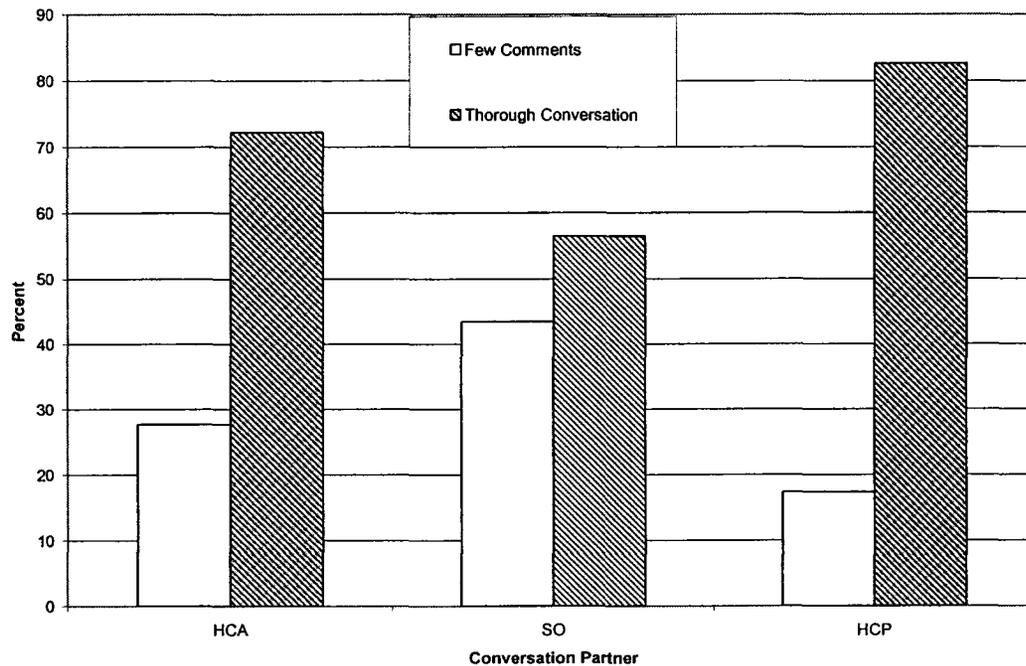


Figure 8. Proportional percentage of participants reporting quality of conversation with conversation partners. *Note.* HCA = Health Care Agent, SO = Significant Others, HCP = Health Care Professional.

Summary

All of the personal influences on decision and personal decision factor variables were present for at least some of the participants who completed the pre-program surveys. The distributions of Knowledge, Importance, Ability, and Likelihood were all significantly different than a normal distribution. Importance and Likelihood also demonstrated a restricted range of values. Statistically significant relationships were

found between the prior experiences of having an AD or having a HCA and having conversations with all partners. Conversations with partners vary significantly in frequency, with Conversations with health care providers being very minimal. The combination of Conversations with HCA and Significant Others is the most frequent but may not be independent. Conversation quality was also explored, with participants rating conversations with Health care providers to be proportionally the most thorough.

Research Question 2

Which variables from among the Personal Influences on Decision and Personal Decision Factors are associated with the Decision to Engage in ACP?

Correlations

All participants in this study have, by definition, decided to engage in ACP by attending the ACP program. Thus, the focus of this research question is on the relationships between the variables which are thought to influence this decision. These relationships were examined using the Spearman rank correlation coefficient (r_s), a non-parametric test for correlation (see Table 3). The Quality of Conversations variables were omitted from this analysis because for each a significant percent of the data was missing (with HCA = 43.5%; with Significant Others = 37.4%; with HCP = 84.4%). Because multiple comparisons will be made between each variable and the remaining 11 variables, statistical significance was adjusted using Bonferroni's correction ($0.05/11 = 0.004$).

Table 3

Spearman Rank Correlation Coefficients – Personal Influences on Decision and Personal Decision Factor Variables for Total Sample

	Know	Age	Gend	Imp	AD	HCA	C-HCA	C-SO	C-HCP	MDec	Able	Like
Know	1.000											
Age	0.019	1.000										
Gend	0.026	(0.229)	1.000									
Imp	0.361*	(0.126)	0.128	1.000								
AD	0.336*	0.362*	(0.193)	0.174	1.000							
HCA	0.373*	0.192	(0.081)	0.263*	0.571*	1.000						
C-HCA	0.257	0.049	0.180	0.285*	0.276	0.449*	1.000					
C-SO	0.285*	0.078	0.121	0.243*	0.313*	0.409*	0.412*	1.000				
C-HCP	0.363*	0.302*	(0.040)	0.168	0.418*	0.245*	0.182	0.235	1.000			
MDec	0.169	0.286*	(0.036)	0.094	0.238	0.070	0.009	0.052	0.358*	1.000		
Able	0.737*	(0.004)	(0.010)	0.497*	0.335*	0.325*	0.195	0.300*	0.340*	0.115	1.000	
Like	0.399*	(0.013)	0.163	0.744*	0.222	0.307*	0.326*	0.291*	0.291*	0.082	0.529*	1.000

Note. * $p \leq 0.004$; (x) = negative number; Know = Enough knowledge; Gend = Gender; Imp = Important; C-HCA = Conversation with HCA; C-SO = Conversation with Significant Other; C-HCP = Conversation with Health Care Professional; MDec = Making Decision for someone else; Able = Able to start discussion; Like = Likely to have conversation

Results

There were 32 pairs of variables with statistically significant correlations ($p \leq 0.004$) and 34 pairs of variables which were not statistically significant. Descriptions of correlation strength were drawn from Munro (2001). The results are discussed as relationships between variables, in the order of greatest to least strength.

Two pairs of variables, with a significance of $p < 0.001$, were categorized as “highly” correlated; that is, with a correlation value of 0.70 to 0.89. Both involve a personal influence on decision variable and a personal decision factor variable: Importance and Likelihood ($r_s = 0.744$) and Knowledge and Ability ($r_s = 0.737$). The strength of the first correlation is certainly influenced by the restricted ranges of values for both of the variables, Importance and Likelihood. However, it is still likely that there is a strong relationship between this pair of variables based on concepts from decision-making theory about values and intentions. The correlation suggests that participants’ intentions to have discussions are strongly related to the perceived value of having discussions. The correlation between knowledge and ability suggests that participants’ who report having enough knowledge to have discussions also report feeling confident that they will be able to start those conversations.

Three pairs of variables, all with a significance of $p < 0.001$, are categorized as “moderately” correlated ($r_s = 0.50-0.69$): Having an AD and Having a HCA ($r_s = 0.571$); Ability and Likelihood ($r_s = 0.529$); and Ability and Importance ($r_s = 0.497$). Since initiating an AD often includes designating a HCA, it is not surprising that these variables are associated. That the correlation is only “moderate” may be explained because the

percentage of participants reporting an AD was only 37% compared to 62% who reported having a HCA. The second pair—Ability and Likelihood—are the two variables in the personal decision factor Self-Efficacy, so association would be expected. However, since correlation is only moderate, they may each capture a distinct feature of self-efficacy. Finally, Importance and Ability represent another pairing of variables from the personal influences on decision and personal decision factors. The strength of a participant's value of having discussions may be tempered by the perception of one's ability to start these conversations.

Correlations are categorized as “low” if the correlation coefficient is between 0.26 and 0.49. Twenty-seven pairs of variables fall into this category. The four strongest associations, at significance levels of $p < 0.001$, all contain a Having Conversations variable: Having a HCA and Conversation with HCA ($r_s = 0.449$); Having an AD and Conversation with HCP ($r_s = 0.418$); Conversation with HCA and Conversation with Significant Others ($r_s = 0.412$); and Having a HCA and Conversation with Significant Others ($r_s = 0.409$). The first, second, and fourth correlations are supported by the earlier discussion of the odds ratio of having conversations when participants had either an AD or a HCA. The third correlation is supported by the earlier discussion of participants' reported conversations, where conversations with HCA and significant others accounted for 50% of the conversations.

Four of the next six correlations in close range, all at significance levels of $p < 0.001$, contain the variable Knowledge: Knowledge and Likelihood ($r_s = 0.399$), Knowledge and Having a HCA ($r_s = 0.373$), Knowledge and Conversation with HCP ($r_s = 0.363$), and Knowledge and Importance ($r_s = 0.361$). These may speak to the need for

knowledge to be able to construct and communicate preferences. Another correlation, Having an AD and Age ($r_s = 0.362$), demonstrates a directional association between initiating an AD and older age. Finally, Conversation with HCP and Making a Decision for someone else ($r_s = 0.358$) demonstrate an association between communicating with health care professionals for oneself or on behalf of someone else.

Three of the next four correlations, all with significance levels of $p < 0.001$, include the variable Ability: Conversations with HCP and Ability ($r_s = 0.340$), Having an AD and Ability ($r_s = 0.335$), and Having a HCA and Ability ($r_s = 0.325$). This may indicate the importance of having confidence in one's ability to be able to formally construct and communicate preferences. The other correlation in this range is Knowledge and Having an AD ($r_s = 0.336$), again supporting the idea that knowledge may be necessary to initiating a formal record of preferences.

The next four correlations, at significance levels of $p \leq 0.001$, include a Conversation variable: Conversation with HCA and Likelihood ($r_s = 0.326$), Conversation with Significant Other and Having an AD ($r_s = 0.313$), Conversation with HCP and Age ($r_s = 0.302$), and Conversation with Significant Other and Ability ($r_s = 0.300$). This may speak to the influence of feelings of self-efficacy, formal construction of preferences, and older age on communicating preferences to others. A fifth correlation in this range is Having a HCA and Likelihood ($r_s = 0.307$), which may indicate the influence that having formally designated someone to make decisions has on a person's intent to have discussions.

Of the last eight correlations, at significance levels of $p \leq 0.004$, six include conversation variables: Conversation with Significant Others ($r_s = 0.291$) and

Conversation with HCP ($r_s = 0.291$) are paired with Likelihood; Conversation with HCA is paired with Importance ($r_s = 0.285$); Conversation with HCA and Having an AD ($r_s = 0.276$); Conversation with HCA and Knowledge ($r_s = 0.257$); and Conversation with Significant Others and Knowledge ($r_s = 0.285$). These may speak to the influence of feelings of self-efficacy, value, and knowledge on people's willingness to communicate preferences to others. The relationship of Age and Making a Decision for someone else ($r_s = 0.286$) likely represents the directional association of growing older with the experience of needing to make decisions for others, such as one's parents or grandparents. Finally, there is a correlation between Importance and Having a HCA ($r_s = 0.263$). This may speak to the need for persons to value having a discussion and actually designating someone to speak for them.

The remaining 34 variable pairs fall into the "little, if any" category of correlation strength ($r_s = 0.00$ to 0.25), with none meeting statistical significance at the $p \leq 0.004$ level. Fifty-three percent of these non-significant pairs included the individual characteristic variables of gender ($n = 11$) or age ($n = 7$). This may suggest that these demographic variables are not likely to influence many of the other variables in the model. Prior experience variables, Making a Decision for someone else ($n = 8$) and Conversation variables ($n = 8$), accounted for another 47% of the non-significant pairs. The two remaining pairs included the variables Importance or Likelihood.

Summary

Forty-seven percent of the variable pairs demonstrated statistically significant correlations. The most highly correlated variables are participants' perceptions of 1) the importance and likelihood of having discussions and 2) having enough knowledge and

feeling able to start a discussion. Moderate correlations were found between the perception of being able to start a discussion and the perceptions of the importance and likelihood of the conversation. A moderate correlation was also found between the prior experiences of having an advance directive and having a health care agent. Low but significant correlations were found between 27 of the variables, with 63% of these including a Conversation variable (n = 17). More than 50% of the 34 non-significant correlations included the demographic variables gender (n = 11) or age (n = 7).

Research Question 3

Do the Personal Influences on Decision and Personal Decision Factor variables that are associated with the Decision to Engage in ACP differ between participants with previous ACP experience compared to participants without previous ACP experience?

Participants' answers to the Having an AD or Having a HCA survey items were examined to determine who had previous experience in constructing or communicating their preferences for end of life decision-making. Participants who reported having neither were classified as having No ACP Experience while those having an AD, having a HCA, or having both an AD and HCA were categorized as having ACP Experience. Participants with missing data for either of the AD or HCA items (n = 13) were excluded from analysis for this research question. The frequencies of all variables are presented in Table 4 for participants with (n = 85) or without (n = 49) ACP Experience.

Results

Enough knowledge. The distributions of participants' ratings of having enough knowledge to discuss their views were examined using histograms. For the ACP

Table 4

Frequencies of Personal Influence on Decision and Personal Decision Factor Variables in the Pre-Program Survey Data for Participants Classified by ACP Experience

Focus Model Variables	Responses	ACP Experience (n = 85)		No ACP Experience (n = 49)	
		n	%	n	%
Enough knowledge to discuss my views	1 = not at all	3	3.5	3	6.1
	2	10	11.8	12	24.5
	3	17	20.0	19	38.8
	4	21	24.7	8	16.3
	5 = very much	33	38.8	7	14.3
	Missing	1	1.2	0	0
Age	18-30	0	0	2	4.1
	31-59	59	69.4	41	83.7
	60-75	16	18.8	5	10.2
	> 75	8	9.4	1	2.0
	Missing	2	2.4	0	0
Gender	Male	20	23.5	9	18.4
	Female	65	76.5	40	81.6
Important to have a discussion	1 = not at all	1	1.2	0	0
	2	3	3.5	0	0
	3	3	3.5	11	22.4
	4	9	10.6	9	18.4
	5 = very much	67	78.8	29	59.2
	Missing	2	2.4	0	0
Having an AD (Advance Directive)	No	30	35.3	49	100
	Yes	55	64.7	0	0
Having a HCA (Health Care Agent)	No	3	3.5	49	100
	Yes	82	96.5	0	0
Having Conversations with HCA	No	8	9.4	7	14.3
	Yes	74	87.1	4	8.2
	I'm not sure	1	1.2	0	0
	Missing	2	2.4	38	77.6
Quality Conversations with HCA	Few comments	18	21.2	2	4.1
	Thorough conversation	56	65.9	2	4.1
	Missing	11	12.9	4	8.2

Table 4 (continued)

Focus Model Variables	Responses	ACP Experience (n = 85)		No ACP Experience (n = 49)	
		n	%	n	%
Having Conversations with Significant Others	No	17	20.0	30	61.2
	Yes	66	77.6	18	36.7
	I'm not sure	1	1.2	1	2.0
	Missing	1	1.2	0	0
Quality Conversations with Significant Others	Few comments	20	23.5	14	28.6
	Thorough conversation	46	54.1	5	10.2
	Missing	19	22.4	19	38.8
Having Conversations with HCP (Health Care Provider)	No	64	75.3	47	95.9
	Yes	20	23.5	2	4.1
	I'm not sure	1	1.2	0	0
	Missing	0	0	0	0
Quality Conversations with HCP	Few comments	4	4.7	0	0
	Thorough conversation	17	20.0	2	4.1
	Missing	64	75.3	47	95.9
Making decision for someone else	No	49	57.6	30	61.2
	Yes	34	40.0	19	38.8
	I'm not sure	1	1.2	0	0
	Missing	1	1.2	0	0
Able to start discussion with others	1 = not at all	2	2.4	2	4.1
	2	3	3.5	3	6.1
	3	14	16.5	18	36.7
	4	23	27.1	15	30.6
	5 = very much	42	49.4	11	22.4
	Missing	1	1.2	0	0
Likely to have conversation with others	1 = not at all	0	0	0	0
	2	5	5.9	2	4.1
	3	9	10.6	16	32.7
	4	12	14.1	14	28.6
	5 = very much	57	67.1	17	34.7
	Missing	2	2.4	0	0

Experience group, the median score was 4.0 with a range of scores from 1 to 5. The distribution was skewed to the left (skewness coefficient = - 2.627), with only 15.3% of the responses at a score of 1 or 2, but had a normal kurtosis. For the No ACP Experience group, the distribution was normal (skewness coefficient = 0.615; kurtosis coefficient = 0.095), with a median score of 3.00, and a range of scores from 1 to 5. Because the ACP Experience distribution was skewed, the distributions were compared between the groups using the Mann-Whitney test, which showed a significant difference in perceptions of knowledge between the Experience groups, $U(133) = 1305.5, p < 0.001$.

Age and gender. Crosstabulation was used to examine the ages and genders of the participants. There were men and women participants in both ACP Experience groups with women outnumbering men (ACP Experience: 75.9% women to 24.1% men; No ACP Experience: 81.6% women to 18.4% men). In the ACP Experience group, there were no participants in the 18-30 age range but the No ACP Experience group had two women participants (4.1%). In the > 75 age range, the ACP Experience group had four men and four women (9.6%) but the No ACP Experience group had none. In both groups, the 31-59 years range was the most frequent (ACP Experience = 71.1%; No ACP Experience = 83.7%). Because some of the crosstab cells had no values, a Likelihood Ratio was used to compare the groups in terms of age and there was a significant difference, $LR(3, n = 132) = 9.430, p = 0.041$. Since both experience groups had men and women participants, the Pearson Chi-Square test was used to compare the groups in terms of gender and there was no significant difference, $\chi^2(1, N = 134) = 0.488, p = 0.485$.

Importance. The distributions of participants' ratings of feeling it is important to have a discussion were examined using histograms. The median scores for both groups were 5.0 but the range of scores was 1 to 5 for the ACP Experience group and 3 to 5 for the No ACP Experience group. Although the range for the ACP Experience group appears to be less restricted than the No ACP Experience group, this was not the case. The ACP Experience group's distribution was severely skewed to the left (skewness coefficient = - 10.432), with only 8.2% of this group's participants rating Importance at a score ≤ 3 . The ACP Experience group's distribution was also very peaked (kurtosis coefficient = 14.243). The No ACP Experience group's distribution was also skewed to the left (skewness coefficient = - 2.338) but not as severely (22.4% of participants rated Importance as a 3) and kurtosis was normal. Ratings of "very much" (5) were given by 78.8% (ACP Experience) and 59.2% (No ACP Experience) of the participants. Because both distributions were skewed, the distributions were compared using the Mann Whitney test, which showed a significant difference in the perceptions of importance between the ACP Experience groups, $U(132) = 1599.5, p = 0.009$.

Prior Experiences. The last category of personal influences on decision variables includes the prior experiences of Having an AD, Having a HCA, Having conversations, Having quality conversations, and Making a decision for someone else. The first two variables, Having an AD and Having a HCA, were used to create the "ACP Experience" variable. Therefore, only the participants in the ACP Experience group reported prior experiences with having an AD (64.7%) and having a HCA (96.5%). Of the 85 participants who responded to these items, 61.2% reported having both. By definition,

none of the participants in the No ACP Experience group reported Having an AD or Having a HCA.

According to the survey item instructions, only the ACP Experience group participants should have indicated if they had conversations with their health care agents and 87.1% reported they had. However, 22.5% of the No ACP Experience group participants also answered this question with 8.2% reporting conversations with a health care agent. None of the participants in either group reported being unsure about whether they had had a conversation with a health care agent. As would be expected, a significant difference was found between the Experience groups related to the Conversation with HCA variable using Fisher's Exact test ($p < 0.001$).

In the ACP Experience group, 77.6% of the participants reported having a conversation with significant others, compared to only 36.7% of the No ACP Experience participants. One person from each Experience group reported they were not sure if they had a conversation with their significant others. Using the Pearson Chi-Square test, a significant difference was found between the Experience groups related to the Conversation with Significant Others variable, $\chi^2(1, N = 131) = 23.339, p < 0.001$.

As seen in the results for Research Question 1, conversations with Health care providers were very many fewer for both Experience groups: 23.5% for ACP Experience and 4.1% for No ACP Experience. Only one person from the ACP Experience group was unsure about this type of conversation. Using the Pearson Chi-Square test, a significant difference was found between the Experience groups related to the Conversation with HCP variable, $\chi^2(1, N = 133) = 8.725, p = 0.003$.

Participants from both groups reported having the prior experience of Making a Decision for someone else (40.0% ACP Experience; 38.8% No ACP Experience). In the ACP Experience group, 32 participants reported a type of decision with 96.9% being for an adult and 3.1% ($n = 1$) being for both an adult and a child. When these participants were asked about feeling prepared to make such a decision, 87.5% indicated they were, with one additional person (1.2%) who was unsure. In the No ACP Experience group, 18 participants reported making decisions, all for adults. Two thirds of these participants (66.7%) felt prepared but three participants (6.1%) were unsure. Using the Pearson Chi-Square test to compare the distributions, no significant difference was found between the groups related to Making a Decision for someone else, $\chi^2(1, N = 132) = 0.061, p = 0.804$.

Ability. The distributions of participants' ratings of feeling able to start a discussion with others were examined using histograms. For the ACP Experience group, the median score was 4.5 with a range of scores from 1 to 5. The distribution was skewed to the left (skewness coefficient = - 4.601), reflecting the 5.9% of participants who had rated Ability at a 1 or 2, and too peaked (kurtosis coefficient = 2.058) to be normal. For the No ACP Experience group, the median score was 4.0 with a range of scores from 1 to 5 and a normal distribution (skewness coefficient = - 1.265; kurtosis coefficient = 0.012). Because the ACP Experience distribution was skewed, the distributions were compared using the Mann-Whitney test, which showed a significant difference in perceptions of ability between the Experience groups, $U(133) = 2604.0, p = 0.001$.

Likelihood. The distributions of participants' ratings of their likelihood to have conversations with others were examined using histograms. For the ACP Experience

group, the median score was 5.0 with a range of scores from 2 to 5. The distribution was skewed to the left (skewness coefficient = - 5.826), reflecting the 5.9% of participants who had scored Likelihood at 2, and too peaked (kurtosis coefficient = 2.241) to be normal. For the No ACP Experience group, the median score was 4.0, also with a range of scores from 2 to 5, but the distribution was normal (skewness coefficient = - 0.612; kurtosis coefficient = - 1.744). Because the ACP Experience distribution was skewed, the distributions were compared using the Mann-Whitney test, which showed a significant difference in perceptions of likelihood to have conversations between the Experience groups, $U(132) = 1363.5, p < 0.001$.

Perceptions of Quality of Conversations

Figure 9 depicts the two groups of participants' reports of conversation quality with conversation partners. In the ACP Experience group, participants reported the quality of their conversations across all conversation partners more often as "thorough" than "few comments." However, in the No ACP Experience group, participants reported an equal quality for Conversations with HCA and a lesser quality for Conversations with Significant Others. For the two participants who reported a Conversation with HCP, both reported it as a "thorough conversation."

When the proportional percentages of conversations were graphed by conversation types (see Figure 10), the conversations with Health care providers are rated the most thorough regardless of Experience group. This is the same result as was seen in the total sample in Research Question 1.

The distributions of conversation quality by conversation partner were compared for the Experience groups. Since the No ACP Experience group was not expected to

report Conversation Quality with HCA's, no comparison of groups was performed related to this conversation partner. The comparison of distributions of Conversation Quality with Significant Others using the Pearson Chi-Square test demonstrated a significant difference between Experience groups, $\chi^2(1, N = 85) = 11.568, p = 0.001$. The Likelihood Ratio was used to compare the distributions of Conversation Quality with Health care providers because some cells had an expected count < 1 ; no significant difference was found between Experience groups, $LR(1, N = 23) = 0.803, p = 0.370$.

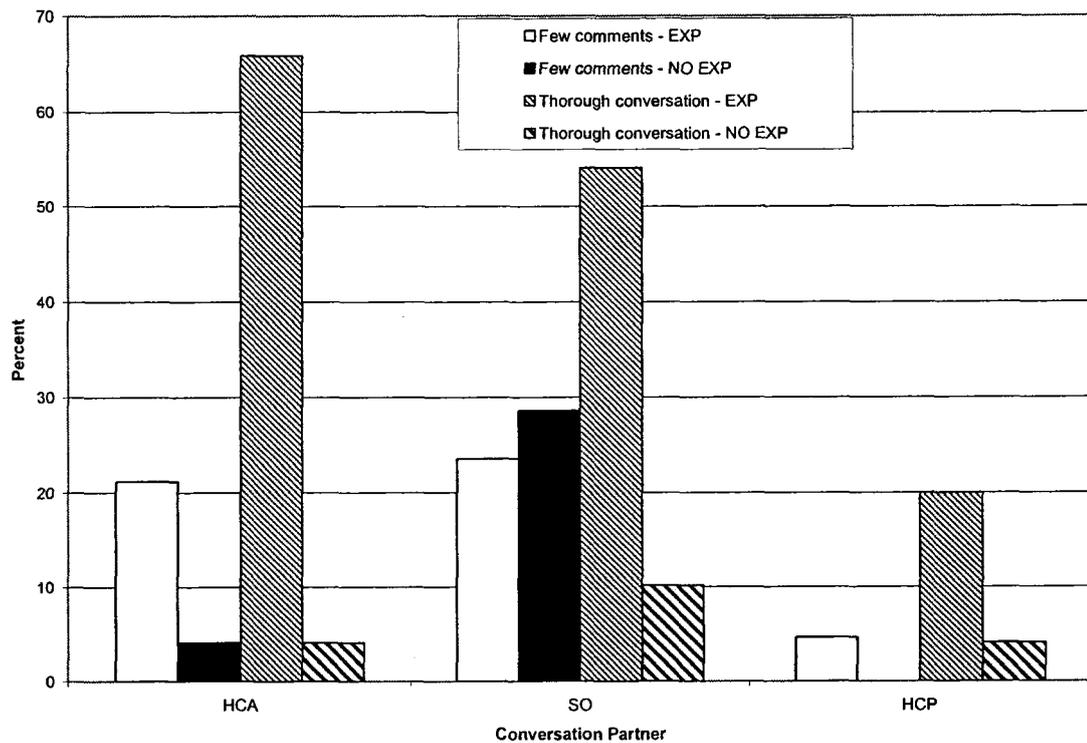


Figure 9. Percentages of participants from ACP Experience groups reporting quality of conversations with conversation partners. *Note.* HCA = Health Care Agent, SO = Significant Others, HCP = Health Care Professional.

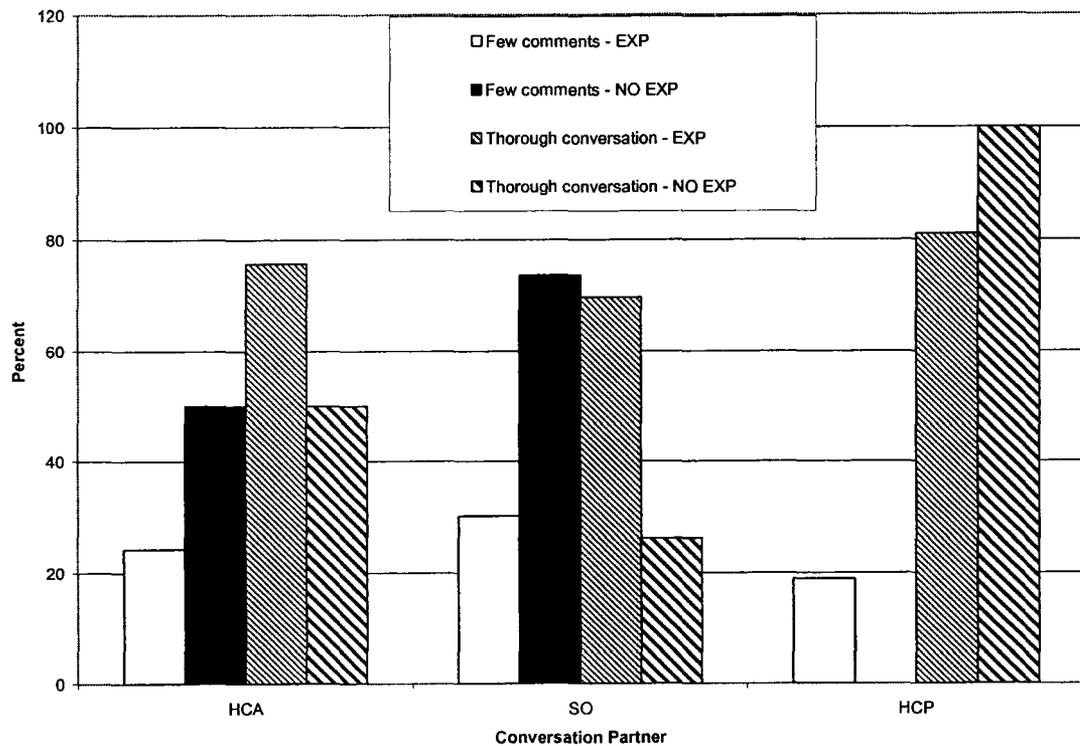


Figure 10. Proportional percentages of participants from ACP Experience groups reporting quality of conversations with conversation partners. *Note.* HCA = Health Care Agent, SO = Significant Others, HCP = Health Care Professional.

Correlations

Next the relationships between variables from the Personal Influences on Decision (Information, Individual Characteristics, Values, and Prior Experiences) and Personal Decision Factor Self-Efficacy were examined using the Spearman rank correlation coefficient (r_s) for each of the ACP Experience groups (see Tables 5 and 6). The prior experience variables Having an AD and Having a HCA were omitted because they are represented by the type of group. As in Research Question 2, the Quality of Conversations variables were omitted from this analysis because of the significant

Table 5

Spearman Rank Correlation Coefficients for Personal Influences on Decision and Personal Decision Factor Variables for Participants with ACP Experience

	Know	Age	Gend	Imp	C-HCA	C-SO	C-HCP	MDec	Able	Like
Know	1.000									
Age	0.043	1.000								
Gend	0.079	(0.160)	1.000							
Imp	0.466*	0.076	(0.021)	1.000						
C-HCA	0.221	0.012	0.124	0.227	1.000					
C-SO	0.178	0.043	0.079	0.155	0.267	1.000				
C-HCP	0.424*	0.341*	(0.016)	0.197	0.086	0.210	1.000			
MDec	0.309*	0.339*	0.011	0.278	0.170	0.106	0.518*	1.000		
Able	0.783*	0.074	(0.034)	0.558*	0.157	0.243	0.419*	0.274	1.000	
Like	0.496*	0.115	(0.042)	0.750*	0.332*	0.132	0.314*	0.255	0.580*	1.000

Note. * $p \leq 0.005$; (x) = negative number; Know = Enough knowledge; Gend = Gender; Imp = Important; C-HCA = Conversation with HCA; C-SO = Conversation with Significant Other; C-HCP = Conversation with Health Care Professional; MDec = Making Decision for someone else; Able = Able to start discussion; Like = Likely to have conversation

Table 6

Spearman Rank Correlation Coefficients for Personal Influences on Decision and Personal Decision Factor Variables for Participants with No ACP Experience

	Know	Age	Gend	Imp	C-HCA	C-SO	C-HCP	MDec	Able	Like
Know	1.000									
Age	(0.311)	1.000								
Gend	0.016	(0.180)	1.000							
Imp	0.044	(0.399)*	0.186	1.000						
C-HCA	0.061	0.134	0.039	0.070	1.000					
C-SO	0.246	0.057	0.041	0.067	0.134	1.000				
C-HCP	0.042	0.216	(0.169)	(0.075)	0.418	0.054	1.000			
MDec	(0.032)	0.355	(0.055)	(0.168)	(0.311)	0.077	0.048	1.000		
Able	0.645*	(0.376)	(0.027)	0.344	(0.222)	0.145	0.065	(0.113)	1.000	
Like	0.140	(0.265)	0.430*	0.728*	0.000	0.177	0.012	(0.178)	0.386	1.000

Note. * $p \leq 0.005$; (x) = negative number; Know = Enough knowledge; Gend = Gender; Imp = Important; C-HCA = Conversation with HCA; C-SO = Conversation with Significant Other; C-HCP = Conversation with Health Care Professional; MDec = Making Decision for someone else; Able = Able to start discussion; Like = Likely to have conversation

percentages of missing data in both Experience groups. Statistical significance was adjusted using Bonferroni's correction to adjust for multiple comparison between each variable and the remaining nine variables ($0.05/9 = 0.005$).

ACP Experience group. For participants in the ACP Experience group, there were 14 statistically significant pairs of variables and 31 non-significant pairs. Just as in Research Question 2, the variables of Knowledge and Able ($r_s = 0.783$) and Importance and Likely ($r_s = 0.750$) were "highly" correlated with statistical significance of $p < 0.001$. Four variables were "moderately" correlated, with statistical significance of $p < 0.001$: Able and Likely ($r_s = 0.580$), Important and Able ($r_s = 0.558$), Conversation with HCP and Making a Decision for someone else ($r_s = 0.518$), and Knowledge and Likely ($r_s = 0.496$). The first two pairs are similar to the moderately correlated pairs in the total sample, although with more strength in the ACP Experience sample. Compared to the total sample, in the ACP Experience sample the last two pairs increased in strength from "low" to "moderate."

Twelve pairs of variables were found in the "low" correlation category. The first two include Knowledge, first with Importance ($r_s = 0.466$) and then with Conversations with HCP ($r_s = 0.424$). The third pair is Conversations with HCP and Ability ($r_s = 0.419$); all three of these pairs have a statistical significance of $p < 0.001$. The next four pairs have a statistical significance of $p \leq 0.005$. Age is correlated first with Ability ($r_s = 0.341$) and then with Making a Decision for someone else ($r_s = 0.339$). These directional associations suggest that older participants feel more able to start discussions and have had to make decisions for others. Likelihood is paired with Conversations with HCA (r_s

= 0.332), then Conversations with HCP ($r_s = 0.314$). These associations suggest that participants who intend to have conversations do actually have conversations.

There are 31 pairs of non-significant variables ($p > 0.005$), but five of these pairs have a significance very close to $p = 0.005$. The first four of these pairs include Making a Decision for someone else with 1) Knowledge ($r_s = 0.309$), 2) Importance ($r_s = 0.278$), 3) Ability ($r_s = 0.274$), and 4) Likelihood ($r_s = 0.255$). This suggests that making a decision for someone else may contribute to participants' stronger feelings about their information, values, and self-efficacy related to engaging in ACP. The final pair of variables is Conversation with HCA and Conversation with Significant Others ($r_s = 0.267$), which was the most frequently reported combination of conversations in the total sample.

The following observations related to the 24 non-significant pairs of variables are of interest: 1) Gender was not significantly correlated with any other variable. 2) Age was not significantly correlated with any variables except Conversations with HCP and Making a Decision for someone else. 3) Conversations with Significant Others were not correlated with perceptions of Knowledge, Importance, or Likelihood or with Conversations with HCP or Making a Decision for someone else. 4) Conversations with HCA were not correlated with the prior experiences of Making a Decision or Conversations with HCP or with Ability. 5) Conversation with HCP was not correlated with Importance.

No ACP Experience group. For participants in the No ACP Experience group, there were just four statistically significant ($p \leq 0.005$) pairs of variables and 41 non-significant pairs. The most highly correlated pair was Important and Likely ($r_s = 0.728$),

which suggests that even participants without ACP Experience report a strong correlation between their value of and intention to have discussions. Knowledge and Ability are again correlated ($r_s = 0.645$), but this time only “moderately.” Both pairs have a statistical significance level of $p < 0.001$. The remaining two pairs are at a “low” level, with $p = 0.002$ and $p = 0.005$ respectively. The most surprising is Gender and Likelihood ($r_s = 0.430$) since gender has not had significant associations in either the total sample or the sample of experienced ACP participants. Age and Importance ($r_s = - 0.399$) is the second. These correlations suggest that there is a possibility that participants who have No ACP Experience may be younger and female and may value discussions more than their older counterparts.

Five variable pairs begin the non-significant correlations ($p > 0.005$). First is Able and Likely ($r_s = 0.386$), which has appeared in all three samples but is weaker in this sample. Second is Age and Ability ($r_s = - 0.376$), which suggests that younger people may have more confidence to engage in ACP. The last three variable pairs include 1) Age and Making a Decision for someone else ($r_s = 0.355$), 2) Importance and Ability ($r_s = 0.344$), and 3) Knowledge and Age ($r_s = 0.311$). It is notable that age this time appears in the direction of older age. Importance and Ability have appeared as “moderately” correlated variables in previous samples, but in this group are only correlated at a “low” level. The correlation category of “little if any” strength is not represented in this sample.

The majority of variable pairs, then, are not significant in this sample. Some observations that are similar to the ACP Experience group sample and total sample include 1) Except for the pair with Likelihood, Gender is not significantly associated with

any other variable. 2) The remaining combinations of age and other variables are not consistent in direction; older age is present with Likelihood but younger age is present with all types of conversations. 3) None of the conversation type variables are correlated with any other variable. 4) The remaining variable combinations with Making a Decision for someone else are all negative in direction. 5) Knowledge is not associated with either Importance or Likelihood in this participant group.

Summary

When participants with and without ACP Experience were compared, there were significant differences in most of the personal influences on decision and personal decision factor variables: Knowledge, Age, Importance, all types of Conversations, Ability, Likelihood, and Conversation Quality. Participants with ACP Experience had many more significant associations between variables than participants without ACP Experience. The variables of Importance to have Discussions and Likelihood of having Conversations are consistently highly correlated regardless of ACP Experience, but this may be related to the restricted ranges of these distributions.

Research Question 4

After participation in a community-based ACP program, are there changes from pre- to post-ACP program intervention in self-reported ratings of enough knowledge, importance, ability, and likelihood to have an ACP conversation?

The frequencies of the four pairs of variables that participants rated in the pre- and post-surveys are presented in Table 7.

Table 7

Frequencies and Measures of Centrality, Variance, and Normality of Variables Rated by Participants in Pre- and Post-Program Surveys

Focus Model Variables	Responses	Pre-Program		Post-Program	
		n	%	n	%
Enough knowledge to discuss my views	1 = not at all	6	4.1	0	0
	2	22	15.0	4	2.7
	3	44	29.9	19	12.9
	4	30	20.4	56	38.1
	5 = very much	44	29.9	65	44.2
	Missing	1	0.7	3	2.0
	Median / Range	4.00 / 1 to 5		4.00 / 2 to 5	
	Normality	Normal (- 1.591) Too flat (- 2.124)		Skewed (- 4.241) Normal (0.257)	
Important to have a discussion	1 = not at all	1	0.7	0	0
	2	3	2.0	0	0
	3	15	10.2	8	5.4
	4	23	15.6	28	19.0
	5 = very much	103	70.1	110	74.8
	Missing	2	1.4	1	0.7
	Median / Range	5.00 / 1 to 5		5.00 / 3 to 5	
	Normality	Skewed (- 9.315) Too peaked (8.213)		Skewed (- 8.828) Too peaked (5.646)	
Able to start discussion with others	1 = not at all	4	2.7	0	0
	2	7	4.8	4	2.7
	3	35	23.8	11	7.5
	4	40	27.2	45	30.6
	5 = very much	60	40.8	85	57.8
	Missing	1	0.7	2	1.4
	Median / Range	4.00 / 1 to 5		5.00 / 2 to 5	
	Normality	Skewed (- 4.128) Normal (0.277)		Skewed (- 6.700) Too peaked (3.577)	
Likely to have conversation with others	1 = not at all	0	0	0	0
	2	8	5.4	3	2.0
	3	29	19.7	9	6.1
	4	30	20.4	44	20.9
	5 = very much	78	53.1	89	60.5
	Missing	2	1.4	2	1.4
	Median / Range	5.00 / 2 to 5		5.00 / 2 to 5	
	Normality	Skewed (- 4.276) Normal (- 1.322)		Skewed (- 7.581) Too peaked (5.564)	

Results

Enough knowledge. The distributions of participants' ratings from pre- to post-program survey of having enough knowledge to discuss their views were examined using histograms. In the pre-program survey data, as described in Research Question 1, the distribution of enough knowledge was bimodal and too flat to be normal (kurtosis coefficient = - 2.124), with a median score of 4.00 and a range of scores from 1 to 5. In the post-program survey data, the median score was still 4.0 but the range was reduced to 2 to 5. This distribution was skewed to the left (skewness coefficient – 4.241), reflecting post-program scores of 2 by only 2.7% of the participants. Because neither the pre- or post-program distributions met the criteria for normality, the distributions were compared using the Wilcoxon Signed Ranks test. The data showed significant evidence that perceptions of having enough knowledge were greater in rank after the ACP program intervention than before ($z = - 6.642, p < 0.001$).

Important. The distributions of participants' ratings from pre- to post-program survey of feeling it is important to have a discussion were examined using histograms. In both the pre- and post-program survey data, the distributions were skewed to the left (skewness coefficient = - 9.315 [pre] and – 8.828 [post]) and were too peaked to be normal (kurtosis coefficient = 8.213 [pre] and 5.646 [post]). These non-normal distributions reflect the small number of participants who scored Importance at a level ≤ 3 (12.9% pre-program; 5.4% post-program). The medians were the same for both distributions (5.00) but the range decreased from 1 to 5 (pre) to 3 to 5 (post). Because the pre- and post-program distributions did not meet the criteria for normality, the distributions were compared using the Wilcoxon Signed Ranks test. Although the data

showed significant evidence that perceptions of feeling it is important to have discussions were not the same before and after the ACP program intervention ($z = -3.068$, $p = 0.002$), the ranks of importance were tied from pre- to post-program.

Ability. The distributions of participants' ratings from pre- to post-program survey of feeling able to start a discussion with others were examined using histograms. In both the pre- and post-program survey data, the distributions were skewed to the left (skewness coefficient = -4.128 [pre] and -6.700 [post]) and the post-program distribution was also too peaked to be normal (kurtosis coefficient = 3.577). This reflects the small number of participants who scored Ability at a level of ≤ 2 (7.5% pre-; 2.7% post-survey). The median scores increased from 4.0 to 5.0 from pre- to post-program with a decrease in range from 1-5 pre- to 2 to 5 post-program. Because the pre- and post-program distributions did not meet the criteria for normality, the distributions were compared using the Wilcoxon Signed Ranks test. The data showed significant evidence that perceptions of feeling able to start a discussion with others were not the same before and after the ACP program intervention ($z = -5.612$, $p < 0.001$); however, the ranks for ability were tied from pre- to post-program.

Likelihood. Finally, the distributions of participants' ratings of their likelihood to have a conversation with others were examined using histograms. In both the pre- and post-program survey data, the distributions were skewed to the left (skewness coefficient = -4.276 [pre] and -7.581 [post]), reflecting the small number of participants who rated Likelihood at a level ≤ 2 (5.4% pre-; 2.0% post-program). The post-program distribution was also too peaked to be normal (kurtosis coefficient = 5.564). The medians of 5.0 and the ranges of 2 to 5 were the same for both distributions. Because the pre- and post-

program distributions did not meet the criteria for normality, the distributions were compared using the Wilcoxon Signed Ranks test. The data showed significant evidence that perceptions of likelihood to have a conversation with others were not the same before and after the ACP program intervention ($z = -4.235, p < 0.001$). However, as with Importance and Ability, the ranks were tied from pre- to post-program.

Summary

The ACP education program intervention appears to have had a significant effect in changing participants' perceptions in all four areas: feelings of having enough knowledge, importance, ability, and likelihood to have ACP conversations. This suggests that an ACP education program intervention may impact both participants' personal influences on decision, such as Information and Values, and their personal decision factor, such as Self-Efficacy. However, only Knowledge actually increased in positive ranks from pre- to post-program. This suggests that Importance, Ability, and Likelihood may have had a ceiling effect, where pre-program scores are so high that it is hard to detect any difference in scores at post-program.

Research Question 5

Do the changes between participants' self-reported pre- and post-ACP program intervention ratings of enough knowledge, importance, ability, and likelihood differ between participants with previous ACP experience compared to participants without previous ACP experience?

The frequencies of the four pairs of variables that participants rated in the pre- and post-surveys are presented in Table 8 for participants with ($n = 85$) or without ($n = 49$) ACP experience.

Results

Enough knowledge. The distributions of participants' ratings from pre- to post-program surveys of having enough knowledge to discuss their views were examined using histograms. For the ACP Experience group, both pre- and post-program distributions were skewed to the left (skewness = - 2.627 [pre]; - 5.057 [post]) and the post-program distribution was too peaked to be normal (kurtosis = 3.867). This reflects that only 3.5% (pre) and 0% (post) of the participants rated their Knowledge at a level of 1 (not at all). The distributions for the No ACP Experience group were normal in shape for both pre- and post-program ratings. Both pre- and post-program medians were one point higher for the ACP Experience group (pre-EXP = 4.00; pre-NO EXP = 3.00; post-EXP = 5.00; post-NO EXP = 4.00), but the ranges were the same for both pre-program (1 to 5) and both post-program distributions (2 to 5).

Because the pre- and post-program distributions did not jointly meet the criteria for normality, the distributions were compared using the Wilcoxon Matched Pairs Signed-Ranks test. In both ACP Experience groups, the data showed significant evidence that perceptions of having enough knowledge were not the same before and after the ACP program intervention (ACP Experience [$z = -4.901, p < 0.001$]; No ACP Experience [$z = -4.543, p < 0.001$]).

Table 8

Frequencies and Measures of Centrality, Variance, and Normality of Variables Rated in Pre- and Post-Program Surveys by Participants Classified by ACP Experience

Focus Model Variables	Responses	ACP Experience (n = 85)				No ACP Experience (n = 49)			
		Pre-Program		Post-Program		Pre-Program		Post-Program	
		n	%	n	%	n	%	n	%
Enough knowledge to discuss my views	1 = not at all	3	3.5	0	0	3	6.1	0	0
	2	10	11.8	2	2.4	12	24.5	1	2.0
	3	17	20.0	1	4.7	19	38.8	13	26.5
	4	21	24.7	32	37.6	8	16.3	19	38.8
	5 = very much	33	38.8	46	54.1	7	14.3	15	30.6
	Missing	1	1.2	1	1.2	0	0	1	2.0
	Median / Range	4.00 / 1 to 5		5.00 / 2 to 5		3.00 / 1 to 5		4.00 / 2 to 5	
	Normality	Skewed to left		Skewed to left		Normal		Normal	
	Skew / Kurtosis	(- 2.627)		(- 5.057)		(0.615)		(- 0.691)	
			Normal kurtosis (- 1.054)		Leptokurtic (3.867)		Normal (- 0.825)		Normal (- 1.346)
Important to have a discussion	1 = not at all	1	1.2	0	0	0	0	0	0
	2	3	3.5	0	0	0	0	0	0
	3	3	3.5	4	4.7	11	22.4	3	6.1
	4	9	10.6	12	14.1	9	18.4	13	26.5
	5 = very much	67	78.8	69	81.2	29	59.2	32	65.3
	Missing	2	2.4	0	0	0	0	1	2.0
	Median / Range	5.00 / 1 to 5		5.00 / 3 to 5		5.00 / 3 to 5		5.00 / 3 to 5	
	Normality	Skewed to left		Skewed to left		Skewed to left		Skewed to left	
	Skew / Kurtosis	(- 10.432)		(- 8.460)		(- 2.338)		(- 3.787)	
			Leptokurtic (14.243)		Leptokurtic (7.847)		Normal (- 1.626)		Normal (1.055)

Table 8 (continued)

Focus Model Variables	Responses	ACP Experience (n = 85)				No ACP Experience (n = 49)			
		Pre-Program		Post-Program		Pre-Program		Post-Program	
		n	%	n	%	n	%	n	%
Able to start discussion with others	1 = not at all	2	2.4	0	0	2	4.1	0	0
	2	3	3.5	1	1.2	3	6.1	2	4.1
	3	14	16.5	5	5.9	18	36.7	5	10.2
	4	23	27.1	21	24.7	15	30.6	21	42.9
	5 = very much	42	49.4	58	68.2	11	22.4	20	40.8
	Missing	1	1.2	0	0	0	0	1	2.0
	Median / Range	4.50 / 1 to 5		5.00 / 2 to 5		4.00 / 1 to 5		4.00 / 2 to 5	
	Normality	Skewed to left		Skewed to left		Normal		Skewed to left	
	Skew / Kurtosis	(- 4.601) Leptokurtic (2.058)		(- 6.368) Leptokurtic (4.872)		(- 1.265) Normal (0.012)		(- 2.793) Normal (1.043)	
Likely to have conversation with others	1 = not at all	0	0	0	0	0	0	0	0
	2	5	5.9	0	0	2	4.1	2	4.1
	3	9	10.6	5	5.9	16	32.7	4	8.2
	4	12	14	19	22.4	14	28.6	20	40.8
	5 = very much	57	67.1	61	71.8	17	34.7	22	44.9
	Missing	2	2.4	0	0	0	0	1	2.0
	Median / Range	5.00 / 2 to 5		5.00 / 3 to 5		4.00 / 2 to 5		4.00 / 2 to 5	
	Normality	Skewed to left		Skewed to left		Normal		Skewed to left	
	Skew / Kurtosis	(- 5.826) Leptokurtic (2.241)		(- 5.916) Leptokurtic (2.691)		(- 0.612) Normal (- 1.744)		(- 3.233) Normal (1.622)	

For the ACP Experience group, the pre- and post-program ranks were tied, while for the No ACP Experience group, knowledge positively increased in ranks from pre- to post-program ratings. By comparing difference scores (pre-program rating subtracted from post-program rating) for the participants in each of the groups, the sources of the tied or changed ranks can be determined. In the ACP Experience group, 49.4% of the participants had no difference in their scores from pre- to post-program and another 12.0% had difference scores that cancelled each other (6.0% -1 and 6.0% +1). Thus, 61.4% of the ACP Experience group's scores were considered tied, while only 38.5% showed a positive difference. In the No ACP Experience group, 41.7% of the participants had no difference in their scores from pre- to post-program and another 4.2% had differences that cancelled each other (2.1% +1 and 2.1% -1). The No ACP Experience group had 45.9% tied scores but 53.7% showing a positive difference.

The difference score distributions for both ACP Experience groups were then examined to determine if there was a significant difference in the impact of the ACP education program intervention on Knowledge. This investigator hypothesized that the difference in pre- to post-program scores for all variables would be greater for participants with No ACP Experience than for those with ACP Experience.

For the ACP Experience group, the median difference score from pre- to post-survey rating of enough knowledge was 0.000 with a range of (-1) to 4, compared to a median difference score of 1.000 with a range of (-1) to 3 for the No ACP Experience group. The No ACP Experience group's distribution was normally distributed by the ACP Experience group's distribution was skewed to the right (skewness coefficient = 4.256), meaning more participants had a larger change in scores than would have been

expected, and too peaked to be normal (kurtosis coefficient = 3.357). Thus, the Mann Whitney U test was used to compare the difference scores between the Experience groups. There was no significant difference between the ACP Experience groups in their difference scores between pre- and post-program ratings of having enough knowledge to discuss their views, $U(131) = 1655.5, p = 0.085$.

Importance. The distributions of participants' ratings from pre- to post-program surveys of feeling it is important to have a discussion were examined using histograms. In both Experience groups for both pre- and post-program survey data, the median score was 5.0. For the ACP Experience group, the range of scores became smaller in the post-program ratings (Pre 1 to 5; Post 3 to 5), but for the No ACP Experience group, the range of scores was 3 to 5 for both pre- and post-programs. For both groups in both pre- and post-programs, the frequency distributions were skewed to the left, reflecting the very few participants who rated Importance at a level of ≤ 3 (ACP Exp pre = 8.2%; ACP Exp post = 4.7%; No ACP Exp pre = 22.4%; No ACP Exp post = 6.1%). For the ACP Experience group, both pre- and post-program distributions were also too peaked to be normal. Because the range of values in the distribution was significantly restricted and the median was at the ceiling for both Experience groups, significant differences were not expected in Importance from pre- to post-program.

Because none of the distributions for Importance met the criteria for normality, the distributions were compared using the Wilcoxon Matched Pairs Signed-Ranks test. In the ACP Experience group, the data did not provide significant evidence that the ratings of feeling it is important to have a discussion were different before and after the ACP education program ($z = -1.469, p = 0.142$) and, in fact, the ranks were tied.

However, in the No ACP Experience group, there was significant evidence that the ratings of importance had changed from pre- to post-program ($z = -2.676, p = 0.007$), even though these ranks were tied as well. Difference scores were then examined for each experience group to determine the source of the tied ranks. For the ACP Experience group, 79.5% of the participants had no change in their pre- to post-program score and 14.4% had scores that offset each other (7.2% -1; 7.2% +1) for a total of 93.9% ties. For the No ACP Experience group, 70.8% of the participants had no change in their pre- to post-program score and 8.4% had scores that offset each other (4.2% -1; 4.2% +1) for a total of 79.2% ties.

The difference score distributions for both ACP Experience groups were then examined to determine if there was a significant difference in the impact of the ACP education program intervention on Importance. For the ACP Experience group, the median difference score from pre- to post-survey rating of importance was 0.0 with a range of (-1) to 4, compared to a median difference score of 0.0 with a range of (-1) to 2 for the No ACP Experience group. Since both Experience groups' distributions were skewed to the right (skewness coefficients: ACP Experience = 11.628; No ACP Experience = 3.125), meaning there were more positive differences in scores than expected, and too peaked to be normal (kurtosis coefficients: ACP Experience = 33.006; No ACP Experience = 2.635), the Mann Whitney U test was used to compare the difference scores between the Experience groups. There was no significant difference in the difference scores between pre- and post-program ratings of the importance of having discussions between the ACP experience groups, $U(131) = 1724.0, p = 0.085$.

Ability. The distributions of participants' ratings from pre- to post-program surveys of feeling able to start a discussion with others were examined using histograms. The median score for the ACP Experience group was 4.5 with a range of 1 to 5 in the pre-survey and 5.0 with a range of 2 to 5 in the post-survey. The median score for the No ACP Experience group was 4.0 for both pre- and post-surveys but the range became smaller, from 1 to 5 (pre) to 2 to 5 (post). For the ACP Experience group, both pre- and post-program distributions were skewed to the left, reflecting the small number of participants who rated Ability at ≤ 2 (5.9% pre; 1.2% post) and too peaked to be normal. The distributions for the No ACP Experience group were normal in shape for the pre-program ratings and skewed to the left in the post-program ratings (only 4.1% of the participants rated at ≤ 2). Because the pre- and post-program distributions did not jointly meet the criteria for normality, the distributions were compared using the Wilcoxon Matched Pairs Signed-Ranks test. In both ACP Experience groups, the data showed significant evidence that perceptions of feeling able to start a discussion with others were not the same before and after the ACP program intervention (ACP Experience [$z = -4.302, p < 0.001$]; No ACP Experience [$z = -3.688, p < 0.001$]).

For the ACP Experience group, the pre- and post-program ranks were tied, while for the No ACP Experience group, Ability positively increased in ranks from pre- to post-program ratings. By comparing difference scores for the participants in each of the groups, the sources of the tied or changed ranks were determined. In the ACP Experience group, 60.7% of the participants had no difference in their scores from pre- to post-program and another 9.4% had difference scores that cancelled each other (4.7% +1 and 4.7% -1). Thus, 70.2% of the ACP Experience group's scores were considered tied,

while 29.8% showed a positive difference. In the No ACP Experience group, 39.6% of the participants had no difference in their scores from pre- to post-program and another 20.8% had differences that cancelled each other (10.4% +1 and 10.4% -1). This brought the No ACP Experience group to 60.4% tied scores and 39.6% showing a positive difference, which seems to contradict the positive ranks result.

To determine whether or not there was a difference in impact of the ACP education program intervention between the ACP Experience groups on perceptions of Ability, pre- to post-program difference scores were calculated and examined. For the ACP Experience group, the median difference score from pre- to post-survey rating of Ability was 0.0 with a range of (-1) to 4, compared to a median difference score of 0.5 with a range of (-1) to 4 for the No ACP Experience group. Since both Experience groups' distributions were skewed to the right (skewness coefficients: ACP Experience = 7.459; No ACP Experience = 2.399), meaning that positive differences were greater than expected in a normal distribution, and the ACP Experience distribution was too peaked to be normal (kurtosis coefficient = 11.426), the Mann Whitney U test was used to compare the difference scores between the ACP Experience groups. There was no significant difference in the difference scores between pre- and post-program ratings of feeling able to start a discussion between the ACP experience groups, $U(132) = 1745.0, p = 0.158$.

Likelihood. The distributions of participants' ratings from pre- to post-program surveys of the likelihood of having conversations with others were examined using histograms. The median score for the ACP Experience group for both pre- and post-surveys was 5.0 with a range of 2 to 5 in the pre-survey and 3 to 5 in the post-survey. The median score for the No ACP Experience group was 4.0 for both pre- and post-

survey ratings with a range of 2 to 5 at both times. In both experience groups, the range is restricted but there is a difference in median values. For the ACP Experience group, both pre- and post-program distributions were skewed to the left, reflecting a small number of participants who rated Likelihood ≤ 2 (5.9% pre; 0% post), and too peaked to be normal. The distributions for the No ACP Experience group were normal in shape for the pre-program ratings and skewed to the left in the post-program ratings (4.1% with score ≤ 2).

Because the pre- and post-program distributions did not jointly meet the criteria for normality, the distributions were compared using the Wilcoxon Matched Pairs Signed-Ranks test. In both ACP Experience groups, the data showed significant evidence that perceptions of likelihood to have conversations were not the same before and after the ACP program intervention (ACP Experience [$z = -2.827, p = 0.005$]; No ACP Experience [$z = -2.796, p = 0.005$]). However, both groups demonstrated ties in the ranks of likelihood from pre- to post-program.

Difference scores were then examined for each experience group to determine the source of the tied ranks. For the ACP Experience group, 72.3% of the participants had no change in their pre- to post-program score and 12.0% had scores that offset each other (6.0% +1; 6.0% -1) for a total of 84.3% ties and 15.7% positive differences. For the No ACP Experience group, 57.1% of the participants had no change in their pre- to post-program score and 12.2% had scores that offset each other (2.1% - 2; 4.1% - 1; 4.1% + 1; 2.1% +2) for a total of 70.8% ties and 29.2% positive differences.

To determine whether or not there was a difference in impact of the ACP education program intervention between the ACP Experience groups on perceptions of Likelihood, pre- to post-program difference scores were examined. For the ACP

Experience group, the median difference score from pre- to post-survey rating of ability was 0.0 with a range of (-1) to 3, compared to a median difference score of 0.0 with a range of (-2) to 2 for the No ACP Experience group. The No ACP Experience group scores were normally distributed both pre- and post-program. Since the ACP Experience group's distribution was skewed to the right (skewness coefficient = 7.261), meaning more positive differences than expected in a normal distribution, and too peaked to be normal (kurtosis coefficient = 11.583), the Mann Whitney U test was used to compare the difference scores between the Experience groups. There was no significant difference in the difference scores between pre- and post-program ratings of the likelihood to have conversations with others between the ACP experience groups, $U(131) = 1734.5, p = 0.138$.

Summary

In summary, the data suggest that for participants with No ACP Experience, the ACP education program intervention significantly impacts perceptions of Knowledge, Importance, Ability and Likelihood, with detectable positive changes in rank in Knowledge and Ability. For participants already having ACP Experience, the ACP education program intervention significantly impacts perceptions of Knowledge, Ability, and Likelihood, but without detectable changes in rank from pre- to post-program. This lack of sensitivity to statistically significant changes in participants' ratings is likely a result of the very high rating medians and the restricted ranges of variables.

Chapter 6

DISCUSSION

The focus of this dissertation study has been an examination of factors from the decision-making context that influence people's decisions to engage in ACP. In this chapter, interpretations of the study findings will be discussed by research question, with resulting implications for nursing practice, education, and research. Next the limitations of the study will be discussed. Then broader implications for practice, education, and research derived from this ACP study will be discussed, concluding with an overview of ideas for future research that build on this study.

Interpretation of Study Findings

Research Question 1

Prior to their participation in a community-based ACP program, what are the self-reported Personal Influences on Decision and Personal Decision Factors of adults who have decided to engage in ACP?

One of the intentions of this study was to contribute a more comprehensive picture of the internal influences on individuals' decisions to engage in ACP than is currently found in the literature. Thus, this study examined the prevalence and frequency of 15 variables included in personal influences on decision (Information (Knowledge), Individual Characteristics (Age and Gender), Values (Importance), and Prior Experiences (Having an AD, Having a HCA, Having Conversations [with HCA, Significant Others, or HCP], Having Quality Conversations [with HCA, Significant Others, or HCP], Making a Decision for someone else) and the personal decision factor Self-Efficacy (Ability and Likelihood). Of the literature reviewed for this study, at least one study reported a

baseline or post-intervention result of each of the personal influence or decision variables, but no study examined all of the variables simultaneously. All of the personal influence and decision variables were present to some extent in this convenience sample of adults who decided to engage in ACP through attendance at an ACP educational program.

Another intention of this study was to contribute to a better understanding of the communication aspects of ACP, rather than focusing primarily on the formal construction of preferences (such as through initiating an AD or designating a HCA). Thus, four of the survey questions asked participants for their perceptions of personal information, values, and self-efficacy related to having conversations with others; these aspects of ACP communication have not been studied extensively in the ACP literature.

Enough knowledge. Before the ACP program intervention began, there was quite a lot of variation in participants' reports of having enough knowledge to discuss their views. On the 1 to 5 scale, only 5% of the participants reported having "[none] at all" (1), while 30% of the participants rated their knowledge as the midpoint (3) and 30% as "very much" (5). In the literature reviewed for this study, participants were not asked to rate their knowledge related to having conversations, so no comparisons can be made. The variation in reported knowledge seems credible for a group of participants drawn from the community at large.

The implication of this result for both nursing practice and education is that, in general, most people have some information already about end of life decision-making. It is important to assess what knowledge they have and be able to clear up misunderstandings. At the same time, people may not have as much knowledge as they

perceive they need to be able to implement discussions. The implication for nursing research is that an investigator must try to determine participants' previous knowledge levels in order to measure the effect of an intervention. Soliciting the participants' appraisal of the level or usefulness of their knowledge (e.g., "having enough knowledge to...") has merit, particularly since a concept of interest in the *Decision Process Model for ACP* is self-efficacy. However, since there may be discrepancies in understanding of ACP terms (e.g., AD, HCA, living will, etc.), it also seems important to capture participants' more specific understanding of end of life decision-making elements. This could be done by asking participants to define key terms, as the Office of the Inspector General (1993) did, by having them answer true/false items, as Ejaz (2000) and Moore et al. (1994) did, or by analyzing the categorization of participants' definitions of ACP as the MMCAPC Research team did (Vander Laan, Mullan, Wyatt, McPhail, & Thomason, 2006). Measuring participants' knowledge with a combination of items will likely provide better comparative data.

Age and gender. In this study, adult participants from every age range attended the ACP education programs, with participants in the 31-59 years range being most frequent. This finding is different from most studies in the literature which either targeted a specific age cohort or had varied but usually older age participants. Participants in the 18-39 years range comprised < 2% of the total sample while participants > 75 years comprised 7.6% of the total. Women comprised 76.6% of the total sample of participants. Having a majority of women participants in this ACP study is similar to 19 studies of ACP reviewed previously.

There are three implications for nursing practice, education, and research that can be drawn from the age ranges and genders of this study's participants. First, the strategy of including existing community-based faith, health-related layperson, and employee groups was beneficial to acquiring a sample of participants who were of varied ages and gender. Secondly, very few participants were in the 18-39 years range. This is of concern because the goals of ACP—awareness of and respect for preferences—are not limited to any specific adult age group. The two participants who were in the 18-30 years range participated in an employee group ACP program. Targeting ACP education and research towards existing community-based groups of employees may be a strategy to engage younger adults in ACP. However, it is likely that additional strategies may be needed to address barriers of reluctance and relevance for younger adults in a community. Thirdly, the ratio of men to women participants was approximately 1:3. This may indicate the need to target existing community groups in which primarily men participate (e.g., Service Clubs such as Rotary, Kiwanis, Lions, etc.) or to target community groups where men and women participate equally. More research is needed to explore the potentially unique needs of younger adults and men related to engagement in ACP. The results of such research may more effectively target ACP interventions to promote whole community engagement in ACP (Field & Cassel, 1997).

Importance. In this study, prior to the ACP education program intervention, 70% of all participants reported feeling it is very important to have a discussion of future, potentially life-sustaining treatment with those close to them. This is similar to the findings of Ditto et al. (2001), in a randomized controlled trial of elderly outpatients and their surrogate decision-makers who rated having plans for future care as important. A

key feature of ACP is that it is a shared decision-making process, most often with significant others and health care professionals. It is interesting to note that of the approximately 100 participants who rated Importance as “very much,” 68.9% reported having a conversation with significant others and only 19.4% reported having a conversation with their health care provider.

The implications for nursing practice and education are two. First, people generally report feeling these types of end of life discussions are important (Lunney et al., 2003). This is a positive finding because when something is valued, people are likely to be receptive to more information about it. The second implication is that feelings of importance do not necessarily translate into discussions. This may be related to the barriers of resources and restraints described in Chapter 1. People may need resources such as decision-making supports or discussion guides to equip them for these discussions. In addition, they may need support and invitations to have these discussions on a regular basis. As health care professionals, nurses can be particularly helpful to alleviate perceived restraints by assessing barriers and offering resources to promote these shared conversations.

The implications for nursing research related to rating Importance involve the problems of a ceiling effect and possible group bias. In this study, only one item was used to detect participants’ value of ACP. This item included five responses, ranging from 1 = not at all to 5 = very much. The median score of this item in the pre-program survey was 5, indicating that at least 50% of the participants already valued Importance to the greatest extent possible. This ceiling effect prevents the researcher from being able to detect changes in participants’ perceptions of values in response to the ACP education

program intervention. From a statistical analysis perspective, this homogeneity of responses also restricts the types of statistical tests which can be used and how significant any findings really are. The second implication for nursing research relates to the setting—existing community groups—in which the surveys were completed. A potential problem of surveying a personal influence like values in such a group is the potential for group bias; that is, the assumption that everyone else probably believes the topic is important which then influences how the participant feels about the topic. Possible remedies for the problem of detecting values include 1) using more than one item to detect values, 2) increasing the number of points on the scale of value items, and 3) including items that may differentiate participants' personal values from the values they perceive others in the group to have.

Prior Experiences. This study examined four aspects of prior experiences with ACP simultaneously: Having an AD, Having a HCA, Having Conversations, and Making a Decision for someone else.

Having an AD & Having a HCA. Only 37% of the participants in this study reported having an AD; this finding is within the range of the baseline percentages of < 10 to > 70% reported in the literature reviewed for this study, but was lower than expected.⁴ However, 62% of the participants reported having a HCA, which was significantly greater than the baseline percentages of < 10 to > 40% reported in the reviewed literature. This finding is encouraging in that the majority of participants in this study recognized and acted on the importance of having a designated decision-maker.

⁴ In a previous analysis of the entire pre-program survey data set (n = 347), 42% of the participants had reported having an AD (Vander Laan et al., 2006).

These findings suggest two implications for nursing practice and education. First, approximately 40% of people who present themselves for health care services may have an initiated AD or a designated HCA. These formal products of engaging in ACP are important to communicate individuals' preferences so must be made available to all the health care professionals involved in the person's care. Secondly, in this study only 38.8% of participants reported having both an AD and a HCA. Although the designation of a HCA is often found within the AD, the results indicate that the presence or absence of a designated HCA cannot be assumed on the basis of having an AD. This implies that people seeking health care services should be asked both questions to assure that their preferences for decision-maker and any additional instructions are known.

In the same way, these findings have implications for nursing research related to ACP. First, researchers should anticipate that at least some participants in ACP studies may have prior experiences with initiating an AD or designating a HCA. Secondly, participants should be asked about both prior experiences since they may not equate Having an AD with Having a HCA.

Having Conversations. This study explored participants' prior experiences of having conversations with three different partners: their HCA, significant others, and HCP. Conversation prevalence was compared among the three partners and participants were also asked to rate the quality of conversations with each.

HCA. Of the 100 participants who answered the Having a HCA and Having Conversation with HCA items, 77% reported having conversations

with their HCA. This is a greater percentage than that reported by Hines et al. (1999) in a study of hemodialysis patients (50%) or Karel et al. (2004) in a study of male outpatient veterans prior to a discussion guide intervention (60%). However, this finding does raise an alert for nursing practice and education: Just because a HCA has been designated, it cannot be assumed that conversations have occurred between the individual and their HCA.

Significant others. Conversations with significant others were reported by 61% of this study's participants⁵, which is within the range of 30-70% reported in the literature reviewed for this study. Study participants in the comparative literature were outpatients who were preparing for surgery (Grimaldo et al., 2001), seriously ill hospitalized patients (Heyland, Tranmer, & Feldman-Stewart, 2000), hemodialysis patients (Hines et al., 1999), patients with amyotrophic lateral sclerosis (Moss et al., 1996), and nursing home residents (O'Brien et al., 1995).

In this dissertation study, 35% of the participants reported not having conversations with their significant others. This finding may reflect all four barriers to ACP: reluctance, relevance, resources, and restraints. The implication for nursing practice and education is that individuals' preferences for end of life care may not be communicated, even to the individuals' significant others. As professional nurses, we have the responsibility and often the opportunity to encourage people to

⁵ It must be noted that this study did not ask participants to specify if conversations with significant others included the conversation with their HCA, so the frequencies of conversations with these two partners may not be independent.

have these caring conversations (Field & Cassel, 1997) and to provide resources to help these conversations occur.

HCP. Only 15% of the participants reported having conversations with their health care provider. This finding, while within the range of 2 - 40% reported in the 13 studies reviewed for this dissertation, should cause great alarm, especially since health care providers may find themselves in a surrogate decision-maker role when an individual is no longer able to participate in decision-making at end of life (Daly, 2006; Hurley, Volicer, Rempusheski, & Fry, 1995). An implication for nursing practice and education is that it can almost be assumed that people have *not* communicated their preferences to their health care provider. Again it is likely that barriers of reluctance, relevance, resources, and restraints are responsible for these results, and probably perceived by both individuals and health care professionals. As professional nurses, we have a responsibility to not only encourage but also facilitate conversations between individuals and their health care providers (Field & Cassel, 1997). It may be most effective for the health care provider to initiate this conversation, as discussed by Morrison and Meier (2004), in their study of elderly residents of New York City.

Comparing Prevalences of Conversations. In the review of literature for this study, only Hines et al. (1999) reported the percentages of conversations with HCAs (50%), family members (46%), and HCPs (6%) for their study participants who were receiving hemodialysis. In this

dissertation study, 98 participants reported their prior experiences with Having Conversations. Only 12% reported having no conversations at all. Those who had conversations with only one partner included 14% with their HCA and 7% with their significant others. Of participants reporting conversations with two partners, about 50% reported having a conversation with their HCA and significant others⁶ but only 1% reported a conversation with both an HCA and HCP. About 17% reported having a conversation with all three partners (HCA, SO, and HCP). It is interesting to note that all of the participants who reported conversations with all three partners also reported Having an AD and Having a HCA. Since some people have not had any conversations and most people have not had conversations with all three partners, the implication for nursing practice and education is that conversations about end of life preferences must be promoted.

Quality of Conversations. None of the literature reviewed for this study reported participants' perceptions of the quality of their ACP conversations, so the results of this study provide a first glimpse of these variables. With all three conversation partners, participants reported the quality of their conversations more often as "thorough" than "few comments." Of the 83 participants who reported Conversation Quality with HCA, 72.3% rated these conversations as "thorough" compared to 27.7% who rated them as "few comments." Of the 92 participants who reported Conversation Quality with Significant Others, the ratings were

⁶ The variables Conversation with HCA and Conversation with SO may not be independent of each other.

56.5% “thorough” and 43.5% “few comments.” Of the 23 participants who reported Conversation Quality with HCP, 82.6% rated them “thorough” compared to 17.4% “few comments.”

There are three implications for nursing practice and education from these results. First, it appears that health care providers who are having conversations with individuals are perceived as doing it thoroughly. This may possibly be credited to the many education efforts focused on improving communication between health care providers and individuals about end of life preferences (Ferrell et al., 2005; Robinson et al., 2004; Weissman et al., 2005). Second, it appears that the majority of conversations between individuals and their designated HCAs are also perceived as thorough. Both of these results should be encouraging health care providers who are involved in education efforts about ACP communication. Third, the quality of conversations with significant others was reported as more evenly distributed between “thorough” and “few comments.” This may indicate that more or more effective resources are needed to facilitate conversations between individuals and their significant others.

The implication of these results for nursing research is that ACP conversations with all partners need more study. Based on a preliminary glimpse of participants’ perceptions of conversation quality, more study is also warranted to determine what the essential elements are of a quality conversation and how they might best be measured.

Making decisions. In this study, 40% of the participants reported making a decision for someone else (almost all adults) about life-sustaining treatment. Of those who reported their feelings of preparedness to make the decision, 73.2% felt prepared but 26.8% either did not or were not sure. In the literature reviewed for this dissertation, four studies reported the percentages of participants who had experience making decisions for someone else or themselves. Participants in these studies included male veterans (Karel et al., 2004), adult outpatients living in Oregon (Silveira, DiPiero, Gerrity, & Feudtner, 2000), community-dwelling African Americans (Waters, 2000), and patients with amyotrophic lateral sclerosis (Moss et al., 1996). An implication for nursing practice and education is that an assessment should be made of people's perceptions of preparedness when they are acting as the surrogate decision-maker for someone else. Again, by encouraging people to have conversations about end of life preferences, professional nurses can contribute to people's feelings of preparedness for this role. Proactive conversations can hopefully reduce the incidence of distress that may occur when people are unaware of others' preferences (Tilden, Tolle, Nelson, & Fields, 2001).

Self-Efficacy. This study asked participants to rate their perceived self-efficacy related to having conversations about life-sustaining treatment. None of the literature reviewed for this study included results for self-efficacy related to having conversations.

Ability. Before the ACP program intervention began, 40.8% of the participants rated their ability to start a discussion with others as 5 (very much). The median score for the sample was 4.0 and ratings of 3 or more were reported by 91.8% of the participants.

Likelihood. In a similar way, 53.1% of participants rated their likelihood of having a conversation with others as “very much” (5). The median score for the sample was 5.0 and ratings of 3 or more were reported by 93.1% of the participants.

The implication of these findings for nursing practice and education is that, even before receiving education, people may have some confidence to start and intention to have discussions about life-sustaining treatments with others. The key to promoting ACP is moving the person confidently and intentionally forward into the behaviors of engaging in ACP. Health care providers may be able to influence this through ACP interventions that increase participants’ resources for engaging in ACP.

The implication of these self-efficacy findings for nursing research is similar to the previous discussion of values. Both of the self-efficacy variables have high median values (Ability 4.0; Likelihood 5.0); likelihood has a restricted range; and the participants’ responses are very similar. Thus, it is likely that the limitations of ceiling effect and group response bias also apply to the measurement of these personal decision factors. In future studies, a more specific and sensitive instrument should be used to measure the concept of self-efficacy as a personal decision factor.

In summary, all of the personal influences on decision and decision factor variables specified in the Focused Model of the Decision to Engage in ACP were reported by at least some of the participants before the ACP education program began. Awareness of these internal influences from the decision-making context provides direction for health care professionals as they 1) assess people’s engagement in ACP;

2) promote people's engagement in ACP through supportive education resources; and 3) use multiple measures to detect participants' perceptions of their engagement in ACP.

Research Question 2

Which variables from among the Personal Influences on Decision and Personal Decision Factors are associated with the Decision to Engage in ACP?

This dissertation study examined associations among all four personal influences on decision (Information, Individual Characteristics, Values, and Prior Experiences) and the personal decision factor Self-Efficacy (Ability and Likelihood). Thirty-two pairs of variables were found to be correlated at a statistically significant level ($p \leq 0.004$). Table 9 depicts these variable pairs in groupings by correlation strength and statistical significance.

High correlation. For the two most highly correlated pairs—Importance and Likelihood, Knowledge and Ability—there are no comparative reports in the literature reviewed for this study. However, both make sense when considered from a decision process model perspective. In the simplified decision process model (Wills & Holmes-Rovner, 2006), information and values interact to influence the subsequent decision, behaviors, and outcomes. The Focused Model of the Decision to Engage in ACP shows the personal influences of information and values interacting with elements of the personal decision factor self-efficacy to influence the decision. In these highly correlated pairs, increased value is associated with an increased intention to act and increased information with increased confidence to act.

Moderate correlations. In the moderate strength correlation category, the first pair of variables, Having an AD and Having a HCA, was also reported by Morrison et al.

Table 9

Pairs of Influencing Variables in the Decision-Making Context Organized by Correlation Strength and Statistical Significance

High Correlation (p < 0.001)

Importance & Likelihood
 Knowledge & Ability

Moderate Correlation (p < 0.001)

Having an AD & Having a HCA
 Ability & Likelihood
 Ability & Importance

Low Correlation (p < 0.001)

Having a HCA & Conversation with HCA
 Having an AD & Conversation with HCP
 Conversation with HCA & Conversation with SO
 Having a HCA & Conversation with SO
 Knowledge & Likelihood
 Knowledge & Having a HCA
 Knowledge & Conversation with HCP
 Knowledge & Importance
 Having an AD & Age
 Conversation with HCP & Making Decision for Someone Else
 Conversation with HCP & Ability
 Having an AD & Ability
 Having a HCA & Ability
 Knowledge & Having an AD

Key: AD = Advance Directive HCA = Health Care Agent HCP = Health Care Professional SO = Significant Others

Table 9 (continued)

Low Correlation ($p \leq 0.004$)

Conversation with HCP & Likelihood
Conversation with SO & Having an AD
Conversation with HCP & Age
Conversation with SO & Ability
Having a HCA & Likelihood
Conversation with SO & Likelihood
Conversation with HCP & Likelihood
Conversation with HCA & Importance
Conversation with HCA & Having an AD
Conversation with HCA & Knowledge
Conversation with SO & Knowledge
Age & Making Decision for Someone Else
Importance & Having a HCA

Key: AD = Advance Directive HCA = Health Care Agent HCP = Health Care Professional SO = Significant Others

(1998) and is frequently noted in clinical practice. That the correlation is only moderate may be explained because the percentage of participants reporting an AD was only 37% compared to 62% who reported having a HCA. The second pair—Ability and Likelihood—are the two variables in the personal decision factor Self-Efficacy. Since the correlation is only moderate, they may each capture a distinct feature of self-efficacy. Finally, Importance and Ability are another pairing of variables from the personal influences on decision and personal decision factor. The strength of a person's value of having discussions may be tempered by the perception of one's ability to start those conversations. For the second and third pairs, there was no comparative literature found for this study.

An implication for nursing practice, education, and research from these high and moderate correlations is that a decision-making model, such as the Decision Process Model, helps conceptually in understanding the associations of personal influences and decision factors on the decision to engage in ACP.

Low correlations. In the low strength correlation category, there are 14 pairs with a statistical significance of $p < 0.001$ and 13 pairs with a significance of $p \leq 0.004$.

Low correlations with significance of $p < 0.001$. Each of the first four pairs contains a Having Conversation variable; three of these are paired with either Having an AD or Having a HCA. This is similar to the findings of Hamel et al. (2002) in their study of community-dwelling elders for Having an AD and Wenger et al. in their study of persons with HIV for Having a HCA. The next four pairs include the variable Knowledge. The first pair—Knowledge and Likelihood—are somewhat supported by Ejaz (2000) who found in their study of

institutionalized elderly that knowledge of an AD was associated not only with having an AD but also the likelihood of implementing an AD. In this dissertation study, the focus was on having knowledge and likelihood to have discussions rather than concern for initiating or implementing an AD. The second pair—Knowledge and Having a HCA—are somewhat supported by the Morrison et al. (1998) study which found that, in an older adult outpatient sample, knowledge of a HCA was associated with having a HCA. For the third and fourth pairs—Knowledge and Conversation with HCP, Knowledge and Importance—there is no comparative literature.

The next pair—Having an AD and Age—does have comparative literature, but the results are mixed. In this dissertation study, Having an AD was directionally associated with older age. This is similar to the results of Dexter et al. (1998), Morrison et al. (1998), Wenger et al. (2001) but not with the results of Moore et al. (1994) or Patterson et al. (1997) who found it associated with younger ages or with Hopp (2000) who found no relation between age and having an AD.

The next pair—Conversation with HCP and Making Decision for Someone Else—are not reported in the literature but make sense from a clinical perspective. Persons who have needed to communicate with health care providers while making decisions for others are also likely to be able to communicate with health care providers when making decisions for themselves.

The next three pairs all contain the variable Ability, which did not appear in the comparative literature reviewed for this study. These pairs suggest that

having confidence in one's ability to start discussions is related to formally constructing and communicating preferences.

The last pair in this grouping is Knowledge and Having an AD, which is somewhat supported by Ejaz (2000) who found that increased knowledge of an AD was associated with having an AD. Again, the difference in this study is the emphasis on knowledge for having discussions versus the outcome of an initiated AD.

Two patterns in these 14 pairs of variables were noticed that have implications for nursing practice and education. First, eight of the pairs included either the variable Having an AD or Having a HCA, which will be discussed more thoroughly later in this chapter. Three of these pairs included Conversations variables, each representing a different conversation partner (HCA, HCP, SO). Because these were only correlated at a low level, it is important to specifically ask people who report having an AD or HCA if they have had conversations about their preferences and identify with which partners.

The second pattern noted is that eight of the pairs include either the variable Knowledge (5 pairs) or Ability (3 pairs). This finding suggests that if people's knowledge or confidence in having discussions can be increased, other influences in the decision-making context, at least to a low level, may be affected as well. Thus, an implication for nursing practice and education is that health care providers who are planning interventions to promote ACP may want to include both information and possibly opportunities to practice discussions (e.g., role-playing). These teaching and learning strategies will provide people with

resources to guide their construction and communication of preferences (Lunney et al., 2003).

Low correlations with $p \leq 0.004$. Of the remaining 13 statistically significant variable pairs, 10 include a Conversation variable, with all three conversation partners represented (HCA, SO, HCP). Two of these conversation variables are associated with increased Knowledge, one with increased Importance, one with increased Ability, and three with increased Likelihood. This suggests that having conversations is related to people's perceptions of having enough information, value, confidence, and intention to actually engage in such discussions. Two of the remaining conversation variables were associated with having an AD, which was also reported by Hamel et al. (2002). The remaining conversation variable was associated with age, which was also reported by Dexter et al. (1998) but not by Bradley et al. (1998) or Hamel et al. (2002).

Two of the three remaining variable pairs include the variable Having a HCA, associated first with increased likelihood and then with increased importance. These may suggest that when people designate someone to make decisions for them, they perceive more personal intention and value in having conversations with others. The final variable pair is Age and Making a Decision for Someone Else. This represents the association of growing older with the experience of being asked to make decisions for others. In clinical practice, this phenomenon is seen frequently, as adult children are asked to make decisions for or with their parents or grandparents.

The implications for nursing practice and education from these 13 variable pairs are very similar to those discussed in the previous section. Although only at a low correlation level, the links between having conversations and perceiving enough knowledge, importance, ability, and likelihood to have these conversations were affirmed. This may lend support to assure that interventions designed to promote ACP not only provide information and opportunities to gain confidence, but also help participants clarify their values and encourage translation of intentions into actions.

In summary, just less than half of the personal influences on decision and decision factor variables specified in the Focused Model of the Decision to Engage in ACP were significantly correlated with each other, at least at a low level. Almost all of the variable pairs included 1) the self-reported ratings of enough knowledge, importance, ability, or likelihood to have an ACP conversation, 2) having an AD or HCA, or 3) Having conversations. These findings support the use of a decision-making theoretical perspective, such as the *Decision Process Model for ACP*, to help interpret the relationships between variables that may influence the Decision to Engage in ACP.

Research Question 3

Do the Personal Influences on Decision and Personal Decision Factor variables that are associated with the Decision to Engage in ACP differ between participants with previous ACP experience compared to participants without previous ACP experience?

Another objective of this dissertation study was to examine the dynamic nature of ACP as a decision-making process by comparing the personal influences and decision factor variables of participants who reported previous ACP experience with those of

participants who reported no previous ACP experience. There were no reports of this sort of comparison in the literature reviewed for this study.

Composite comparison. Table 10 provides a composite view of the personal influences on decision and personal decision factor variables for each group. As described in previous chapters, participants' reports of the variables Having an AD and Having a HCA were used to create subgroups of participants for comparison, so are not reported. Neither is the variable Conversation with HCA nor the three Quality Conversation variables, because each contained a significant frequency of missing data. Of the nine variables compared, seven were found to be significantly different between the groups.

The first implication for nursing practice and education is recognizing that in a group of participants who have decided to engage in ACP by attending an ACP education program intervention, there may be people who already have ACP Experience! This can be a mixed blessing to the ACP Facilitator presenting the program. On the positive side, participants who are willing to share their experiences often address how they personally overcame barriers to engaging in ACP, such as reluctance, relevance, resources, or restraints. Such "testimonials" can be empowering and encouraging to other participants. On the negative side, participants with experience may have misconceptions about ACP or may not have engaged in the entire decision-making process of ACP, so may be sharing a limited view.

Table 10

Composite Comparison of Selected Personal Influence on Decision and Personal Decision Factor Variables for Participants Classified by ACP Experience

Focus Model Variables	Significant difference	ACP Experience n = 85	No ACP Experience n = 49
Enough knowledge to discuss my views	Yes	Median 4.0 Range 1 – 5 38.8% rated as 5	Median 3.0 Range 1 – 5 14.3% rated as 5
Age	Yes	Older	Younger
Gender	No	23.5% Men 76.5% Women	18.4% Men 81.6% Women
Important to have a discussion	Yes	Median 5.0 Range 1 – 5 78.8% rated as 5	Median 5.0 Range 3 – 5 59.2% rated as 5
Having Conversations with Significant Others	Yes	77.6% had	36.7% had
Having Conversations with HCP (Health Care Provider)	Yes	23.5% had	4.1% had
Making decision for someone else	No	40.0% had	38.8% had
Able to start discussion with others	Yes	Median 4.5 Range 1 – 5 49.4% rated as 5	Median 4.00 Range 1 – 5 22.4% rated as 5
Likely to have conversation with others	Yes	Median 5.0 Range 2 – 5 67.1% rated as 5	Median 4.0 Range 2 – 5 34.7% rated as 5

Enough knowledge. Both groups of participants left room for growth in their pre-program ratings of having enough knowledge to discuss their views. Although the ACP Experience group reported more knowledge than the No ACP Experience group, only one third of the experienced participants felt they had

“very much” knowledge. The implication of this finding for nursing practice and education is that there are still many Americans who have limited knowledge of ACP as a dynamic decision-making process.

Age. The group of participants with ACP experience was older than the group with No ACP Experience. As mentioned in the previous discussion of correlated variables, the literature reviewed for this study was inconsistent in its findings of the relationship between age and having an AD or having a HCA. Because of the inconsistency of results across studies, no implications will be discussed.

Gender. There were no significant differences in gender between the groups. As with age, there are inconsistencies in findings of the relationship between gender and having an AD or having a HCA, so no implications will be discussed.

Importance. Both groups of participants rated their value for discussions very high in their pre-program ratings. Although more people in the ACP Experience group rated Importance very high (5), this finding indicates that people may value discussions of end of life preferences regardless of previous ACP experience.

The crucial question for nursing practice and education is whether or not people value discussing their *personal* preferences for end of life treatment or whether valuing discussion is just a general sentiment for all people or a biased response based on membership in a community group. An implication of this result may be the need to provide resources to help people clarify their personal values.

Conversations with Significant Others. There is a very significant difference between the groups in the reported frequency of conversations with significant others. Although the result for the ACP Experience group in contrast to the No

ACP Experience group looks significantly better, it must be noted that just under 25% of the participants did not report conversations with their significant others. This indicates that although preferences may have been formally constructed, communication of those preferences to others cannot be assumed. It is also significant that more than one third of the participants with No ACP Experience reported having a conversation with their significant others. This indicates that preferences may be communicated to others even if they may not have been formally (legally) constructed.

When the Quality Conversation with Significant Others data is examined between the groups, participants with ACP Experience report their conversations as being significantly more “thorough” than “few comments.” The result for participants with No ACP Experience is the opposite.

These results suggest two implications for nursing practice and education. First, all participants in ACP education programs, regardless of previous ACP experience, should be encouraged to engage in caring conversations with their significant others about their preferences for end of life treatment. Second, ACP education programs should provide resources to participants to help them have more thorough conversations with their significant others. Such resources should candidly address the barriers of reluctance, relevance, resources, and restraints and provide participants with strategies to start and carry on these conversations.

An implication for nursing research from these results is that an examination of ACP that looks only at the outcomes of having an AD or having a HCA will provide an incomplete picture of people’s engagement in ACP. As

Kolarik et al. (2002) and Emanuel (2003) assert, the objectives of ACP are broader than an AD and best studied as a process.

Conversations with Health Care Providers. The results of this study also demonstrate a significant difference in the frequencies of conversations with health care providers between ACP Experience groups of participants.

Frequencies of conversations that are less than 25% (23.5% ACP Experience group; 4.1% No ACP Experience group) should be of great concern to health care providers, particularly from a group that has already formally constructed their preferences for end of life treatment. Considering that barriers to ACP may be applicable to both individuals and their health care providers, the implication for nursing practice and education is that health care providers must be proactive in initiating and continuing conversations about their people's end of life preferences.

When the Quality Conversation with HCP data is examined between the groups, there is a potentially surprising finding: 100% of the participants with No ACP Experience report that their conversations with health care providers are "thorough" compared to 81% of the participants with ACP Experience. The implication this finding suggests for nursing practice and education is that the few people who have conversations with health care providers find these conversations to be mostly thorough. A second implication is that a casual conversation ("few comments") is unlikely to occur.

An implication for nursing research is the challenge to examine the idea of conversation quality and its effects on the behaviors and outcomes of engaging in

ACP. Presumably a “thorough” conversation is more effective than a “few comments,” but by what degree? Shared decision-making principles come into play here as well—are these conversations desired? What quality will be acceptable to the patient and health care provider?

Making decision for someone else. There was no significant difference between the ACP Experience groups in the frequency of making a decision for someone else. The literature reviewed for this study has nothing further to add so implications will not be discussed.

Able to start discussion. There was a significant difference in participants’ ratings of their abilities to start discussions, with the ACP Experience group rating its ability higher than the No ACP Experience group. The percentage of people rating their ability as “very much” was just less than 50% for the ACP Experience group and less than 25% for the No ACP Experience group. As in the knowledge variable, both groups leave room to increase their confidence in these pre-program survey ratings.

An implication of this finding for nursing practice and education is that participants’ confidence in their ability to start conversations about end of life preferences cannot be assumed, even if they report already having ACP Experience. This finding again reflects the need for more comprehensive study of ACP than simply formally constructing preferences.

Likelihood to have conversations. There was a significant difference between the groups in participants’ ratings of their likelihood to have conversations. Although both groups’ median rating was 5.0, the ACP Experience group had almost twice

as many people who rated their likelihood as “very much.” There were no participants in either group who reported not intending to have conversations at all. This result may imply that all participants intend to have ACP conversations and thus all may need resources to accomplish this. A second implication is that one third of the participants with No ACP Experience very much intend to have conversations even though they have not (yet) formally constructed their preferences.

Correlations. When correlations were calculated for variable pairs for each of the ACP Experience groups, the number of statistically significant pairs was greatly reduced in comparison to the total sample and significantly different between the groups. The ACP Experience group had 14 pairs of variables while the No ACP Experience group had only 4 significant pairs. It is interesting to note that the one highly correlated pair in both ACP Experience groups was Importance and Likelihood. Knowledge and Ability had the second strongest correlation—“high” in the ACP Experience group but only “moderate” in the No ACP Experience group. The remaining significant variable pairs in the ACP Experience group were similar to pairs found in the total sample, which is not surprising since two thirds of the study participants are in the ACP Experience group. The two remaining significant variable pairs in the No ACP Experience group are Gender and Likelihood, Age and Importance. It is likely that these two pairs of variables demonstrate significant relationships because the rating variables in each pair have a restricted range and the majority of participants in the No ACP Experience group were women in the 31-59 years range.

There are two implications of these findings for nursing practice and education. First, regardless of ACP Experience group, participants' value of discussions is highly associated with their intention to have discussions. Secondly, regardless of ACP Experience group, participants' knowledge is related to their confidence to be able to start such conversations. An implication for nursing research is to identify measures of Knowledge, Importance, Ability, and Likelihood that have more specificity and sensitivity. With such measures, the significance of the relationships between these variables can be better characterized.

In summary, when participants with and without ACP Experience are compared, there are significant differences in most of the personal influences on decision and personal decision factor variables. This finding has implications for the design and implementation of ACP education program interventions, since it is likely that participants at the same program may have different levels of ACP experience. Participants who have ACP Experience report more prior experiences with ACP and more positively perceive their levels of knowledge, importance, ability, and likelihood to engage in ACP conversations. However, there are significant numbers of participants with ACP Experience who have not communicated their preferences with significant others or health care providers, despite having formally constructed their preferences in AD or HCA documents. In the No ACP Experience group, there are fewer reported experiences with ACP and a less positive perception of knowledge, importance, ability, and likelihood to engage in ACP conversations. Yet, there are some participants who have communicated their preferences with significant others or health care providers even though they have not formally constructed their preferences. An implication for

nursing practice and education is that it can be expected that all participants in ACP education program interventions, regardless of previous ACP Experience, may need to be better informed and encouraged to have conversations with others about ACP.

Research Question 4

After participation in a community-based ACP program, are there changes from pre- to post-ACP program intervention in self-reported ratings of enough knowledge, importance, ability, and likelihood to have an ACP conversation?

Most studies of ACP interventions have examined outcomes—such as an initiated AD—as a measure of the intervention’s impact. In this dissertation study, however, the impact of the community-based ACP education program intervention is being measured by changes in two personal influences on decision variables (Knowledge, Importance) and two personal decision factor variables (Ability, Likelihood) that are thought to influence the Decision to Engage in ACP. In addition, all of these variables relate to conversations the participants may have about their preferences for end of life treatment.

Enough knowledge. Participants in the ACP education program intervention rated their knowledge as significantly increased from pre- to post-program. This change resulted in an increased number of positive ranks. In the literature reviewed for this study, the study by Yamada et al. (1999) contained the only report of an increase in knowledge following their intervention of information handouts and an ACP video.

Importance, Ability, and Likelihood. The changes in results of participants’ ratings of Importance, Ability, and Likelihood all were statistically significant from pre- to post-program surveys; however, for all the majority of the ranks were tied rather than

changing positively. There were no studies in the literature reviewed for this study that examined the impact of an ACP intervention on these variables.

In summary, the results of this study demonstrate that the ratings of all four variables changed from pre- to post-program surveys at a statistically significant level. Knowledge demonstrated a detectable change in positive ranks from pre- to post-program surveys, but the other variables only demonstrated ties in ranks. There are two implications for nursing practice and education from these results. First, the ACP education program intervention used in this study had a positive impact on participants' perceived knowledge. This may suggest that the strategies employed in this ACP program intervention (Respecting Choices® curriculum, presentations offered to existing community groups, certified ACP Facilitators conducting the programs, and standardized content and resource materials) are effective in promoting increased knowledge for participants who decide to attend. Secondly, the ACP educational program intervention did have an impact on each of the four variables. This suggests that an external ACP intervention can be used to impact internal influences within the decision-making context.

Detecting a change in participants' perceptions was impeded by ceiling effects and possibly group response biases. An implication for nursing research is the importance of evaluating the concepts included in the *Decision Process Model for ACP* with multiple measures that are able to detect change with specificity and sensitivity.

Research Question 5

Do the changes between participants' self-reported pre- and post-ACP program intervention ratings of enough knowledge, importance, ability, and likelihood differ

between participants with previous ACP experience compared to participants without previous ACP experience?

The final objective of this study was to investigate the dynamic nature of ACP as a decision-making process. The differences in ratings of Knowledge, Importance, Ability, and Likelihood reported by participants after an ACP educational program intervention, were examined after creating subgroups of the participants by their previous ACP Experience. This provided an opportunity to compare people who had made the decision to engage in ACP for the first time to people who were deciding to engage in ACP again. Table 11 provides a comparison of the variable ratings in pre- and post-program surveys by participants in ACP Experience group.

Comparisons. For participants with No ACP Experience, the ACP education program intervention significantly impacted perceptions of Knowledge, Importance, Ability, and Likelihood, with detectable positive changes in rank in Knowledge and Ability. For participants with ACP Experience, the ACP education program intervention significantly impacts perceptions of Knowledge, Ability, and Likelihood, but without detectable changes in rank from pre- to post-program. When difference scores are calculated for pre- to post-program ratings for each variable and compared between the ACP Experience groups, there is no significant difference detected between the two groups for any of the variables.

In summary, the implication of these findings for nursing practice and education is that the ACP education program intervention used in this study did have a significant impact on participants' ratings of their Knowledge, Ability, and Likelihood of having

Table 11

Comparison of Pre- to Post-Program Ratings of Knowledge, Importance, Ability, and Likelihood by Participants Classified by ACP Experience

Focus Model Variables	Significant Difference ACP Exp vs. No ACP Exp	ACP Experience		No ACP Experience	
		Pre-Program	Post-Program	Pre-Program	Post-Program
Enough knowledge to discuss my views	No	Median 4.0 Range 1 – 5 38.8% rated as 5	Median 5.0 Range 2 – 5 54.1% rated as 5	Median 3.0 Range 1 – 5 14.3% rated as 5	Median 4.0 Range 2 – 5 30.6% rated as 5
		Significant Difference Yes Pre-Post Ranks tied		Significant Difference Yes Pre-Post Ranks Positively Increased	
Important to have a discussion	No	Median 5.0 Range 1 – 5 78.8% rated as 5	Median 5.0 Range 3 – 5 81.2% rated as 5	Median 5.0 Range 3 – 5 59.2% rated as 5	Median 5.0 Range 3 – 5 65.3% rated as 5
		Significant Difference No Pre-Post Ranks tied		Significant Difference Yes Pre-Post Ranks tied	

Table 11 (continued)

Focus Model Variables	Significant Difference ACP Exp vs. No ACP Exp	ACP Experience		No ACP Experience	
		Pre-Program	Post-Program	Pre-Program	Post-Program
Able to start discussion with others	No	Median 4.5 Range 1 – 5 49.4% rated as 5	Median 5.0 Range 2 – 5 68.2% rated as 5	Median 4.0 Range 1 – 5 22.4% rated as 5	Median 4.0 Range 2 – 5 40.8% rated as 5
		Significant Difference Yes Pre-Post Ranks tied		Significant Difference Yes Pre-Post Ranks Positively Increased	
Likely to have conversation with others	No	Median 5.0 Range 2 – 5 67.1% rated as 5	Median 5.0 Range 3 – 5 71.8% rated as 5	Median 4.0 Range 2 – 5 34.7% rated as 5	Median 4.0 Range 2 – 5 44.9% rated as 5
		Significant Difference Yes Pre-Post Ranks tied		Significant Difference Yes Pre-Post Ranks tied	

conversations, regardless of previous ACP Experience. This lends support for offering ACP education program interventions broadly to participants, including those with and without previous ACP Experience, because all appear to receive some benefit. It is hoped that individuals' decisions to participate in an ACP education program intervention may trigger subsequent behaviors and outcomes of engaging in ACP because of new or increased perceptions of personal information, value, or self-efficacy.

The implication of these findings for nursing research in ACP is that the dynamic nature of participants' decisions to engage or re-engage in ACP can be studied and compared through a variable like ACP Experience. However, the measurement of changes in perceptions of personal influence on decision or personal decision factor variables must be both sensitive and specific enough to capture individuals' changes over time or in response to an intervention.

Limitations of the Study

While this study adds to the understanding of ACP as a dynamic decision-making process, the limitations of the study must be acknowledged. First, the participants in this study were not a random sample of individuals. Instead, they were a convenience sample of people who voluntarily attended an ACP education program, presented to an existing community group of which they were a member. Because the participants were from a convenience sample, the ability to generalize from the analysis of their responses is limited.

Secondly, some items on the Participant Survey were not specific or sensitive enough to detect changes in participants' perceptions from pre- to post-program. When the MMACPC Research Project was designed, the Research Team decided to use or

adapt survey items from existing measurement instruments offered as part of a Quality Improvement toolkit by Respecting Choices®. This decision offered the possibility of comparing the MMACPC Research Project data to data collected by other groups who were promoting ACP in communities using the Respecting Choices® curriculum and assessment tools. Unfortunately, the pre-post survey scaled items were prone to ceiling effects, which limited their usefulness to detect significant changes in participants' perceptions.

Thirdly, this study examined a small segment of time and activity related to individuals' ACP decision processes. Although this study's focus on the Decision to Engage in ACP rather than the behaviors or outcomes of engaging in ACP was intentional, it also limits the interpretation of the results to the timeframe of the ACP intervention.

Broader Implications

Implications for Practice

The results of this dissertation study demonstrated that 63% of the participants had ACP Experience, defined as initiating an AD or designating a HCA. Less than 40% had an AD or both an AD and HCA. These results are similar to the findings of studies reviewed for this dissertation which had a range of < 10% to > 70% ADs and < 10% to > 40% HCAs. It appears that the barriers toward engaging in ACP are still formidable for a large number of individuals. How can health care providers—not only nurses but also physicians, social workers, chaplains, and other interdisciplinary team members—respond to try to prevent the distress of not having preferences known or honored?

First, as interdisciplinary health care providers, we can initiate ACP conversations as a part of routine adult health care. Hammes and Briggs (2002) outline the advantages of this approach as having more professionals who can 1) identify the needs of patients (in any health care setting) for ACP conversations, 2) address the need for ACP conversations from different perspectives, and 3) share the responsibility for communicating, collaborating, coordinating, and connecting patients with resources, that can set the ACP process in motion. ACP should be viewed as a health promotion activity (Patrick et al., 1995) that provides resources to help people prevent undesired outcomes at a later time. It is important to know the resources available in community health care organizations to promote and support ACP; e.g., educational materials or ACP Facilitators.

Secondly, if an individual we are caring for has an AD or HCA, we can be sure this information is made available to all members of the health care team. An individual's preferences can only be honored if the health care team knows about them. This is not only the nurse's responsibility—it is a responsibility of all health care professionals and the health care organizations for which they work. Organizations need to adopt a culture of respecting individuals' preferences, supported by structures and processes that enable the health care team to know and honor those preferences. Organizational resources such as indicators in the electronic or paper medical record, automatic referrals from admission data profiles, continuing education on end of life decision-making or communication, and ethics committees are all evidences that advocacy for ACP is important to the organization.

Thirdly, if an individual has not had conversations with others—their designated HCA, significant others, or health care professionals—we need to encourage these caring conversations to occur. A variety of resources are available to help individuals start and maintain these conversations (see Appendix D). As in many other health promotion activities, the health care providers' abilities to speak from their own experiences with engagement in ACP can be both valuable and motivating to encourage other persons' behaviors.

Finally, if individuals have had conversations with others but have not chosen to initiate an advance directive, health care providers can encourage them to formulate a thoughtful plan (verbal or written, formal or informal) that communicates some values and basic preferences (Hammes & Briggs, 2002). Formulating a plan moves patients and their surrogate decision-makers toward being informed and willing to enter the decision-making process and enables them to make decisions in a timely way when needed.

Implications for Education

The results of this dissertation study also concurred with previous research reports that ACP interventions—especially educational interventions—have mostly resulted in increased preparation for engagement in ACP decision-making. A significant finding of this study is that individuals who participate in ACP interventions will likely have different levels of ACP experience. This has implications for the types of education programs and resource materials that may be needed. For example, it could be important to have resources that introduce the concept and terminology of ACP as well as resources that help individuals clarify their changing values and preferences or successfully

navigate the complexity of communicating their preferences to others who may be in conflict.

Another implication of this study is that individuals still need more knowledge about ACP as a decision-making process and about the types of decisions that may arise in the future. As health care providers, we have a professional responsibility to try to clearly communicate what is involved in end of life conditions and treatments and the probabilities of different outcomes (Davis et al., 2003; Moumjid, Bremond, & Carrere, 2003). This type of communication can support decision-making, particularly shared decision-making. At the same time, however, health care providers must be sensitive to those individuals who do not want to actively participate in decision-making about their personal situations (Charles, Gafni, & Whelan, 1997, 1999; Hawkins, Ditto, Danks, & Smucker, 2005; Lee, Back, Block, & Stewart, 2002). Knowledge of preferences—the individual's and others'—makes supporting and implementing an advance plan for end of life care much more achievable.

A third implication is that providing ACP education to existing community-based groups may promote access to a wider variety of participants at an earlier stage in the need for end of life decision-making than waiting for a health care encounter. An additional benefit is reduced barriers of reluctance and relevance and increased access to resources such as expert ACP facilitators and educational materials (Clarke, Evans, Shook, & Johanson, 2005).

Finally, this study's report of the perceived quality of conversations between individuals and their health care providers—though few in number—implies that education efforts aimed at improving health care providers' skills in initiating and

conducting ACP conversations are effective. End of life decision-making and communication are important topics to be included in the curriculum of professional health care education programs and in continuing education offerings (Ferrell et al., 2005; Field & Cassel, 1997; Weissman et al., 2005). Such educational efforts support development of competencies outlined by the Pew Health Professions Commission (1998) in their recommendations for the 21st century health care provider.

Implications for Research

The implications of this dissertation study for research can be organized by the key features of the ACP process. First, as a deliberative process, readiness to engage in ACP or the impact of interventions depends on an accurate appraisal of participants' knowledge of ACP. There must also be a way to differentiate individuals' personal values from their perceptions of others' values of ACP. Lastly, the process individuals use to identify their preferences—whether constructing, eliciting, or revealing them—needs to be examined.

Secondly, as a communicative process, strategies for promoting conversations with all decision-making partners need to be studied. The essential elements of a quality conversation need to be defined and measurement criteria created to determine what level of quality conversation is acceptable and effective for the individual and the decision partners. Next, creative formulations of advance plans should be examined for prevalence of use and effectiveness of guiding future end of life decision-making. Finally, individual, organizational, and community strategies to make plans available should be evaluated.

As a shared decision-making process, the method of presenting choices, probabilities, and condition-related decisions needs to be examined to determine whether it enhances the ability of individuals and their chosen others to share decision-making. ACP research should study decisional conflict as well as design and test strategies to navigate such conflict successfully. Further examination is also needed of the influences, both internal and external, that affect decision-making. In addition to exploring personal influences, studies should also assess influences from the community and the community environment that may affect decision-making. Future research should also attempt to identify unique ACP needs for groups of individuals; e.g., young adults, men, diverse race/ethnic groups, diverse religious/spiritual groups, diverse economic status, etc.

Finally, as a dynamic decision-making process, ACP research needs to examine the process of re-engaging in ACP. The results of this dissertation study indicate that a variable like ACP Experience is useful to create groups for comparison. Areas of further inquiry could include examining the impact of the frequency or regularity of re-engagement with ACP on product, process, and promise outcomes.

Implications for Future ACP Nursing Research

This dissertation study has laid the groundwork for this investigator's future ACP research. First, this study introduces a conceptual framework for studying ACP from a decision-making perspective, the *Decision Process Model for Advance Care Planning*. This model—with its attention to decision, behaviors, and outcomes occurring within a dynamic decision-making context—provides a wealth of opportunities for future study. It is hoped that in future studies, relationships between variables can be analyzed and modeled. It will be interesting to test variables within the decision-making context to

determine if they act as moderators or mediators of the decision, behaviors, or outcomes in the model.

Secondly, this study presents a more comprehensive picture of some internal influences on individuals' decisions to engage in ACP than is currently reported in the literature. In future studies it will be interesting to explore more internal influences and also external influences that may affect individuals' decisions to engage in ACP.

Thirdly, this study measured the impact of a community-based ACP educational program intervention on selected personal influence and decision variables related to having ACP conversations. Much more study is warranted to examine how people construct and *especially communicate* their preferences for end of life care. Given the disparity in frequencies of conversations with HCAs, significant others, and HCPs, it would be interesting to design and test interventions that target the prevalence and quality of conversations with each partner.

Finally, this study provided a first look at using ACP Experience as a variable to explore individuals' ongoing engagement in ACP. Since ACP has been defined in this study as a dynamic decision-making process, it will be interesting to design studies that specifically explore individuals' re-engagement in ACP.

Conclusion

This descriptive study has provided an in-depth examination of individuals who decided to engage in ACP by attending an ACP education program provided in existing community-based groups. For each participant, personal influences on decision and personal decision factor variables were identified within the decision-making context. The effectiveness of an external ACP educational program intervention was measured in

terms of its impact on selected internal personal and decision factors. ACP educational programs, provided by certified ACP Facilitators to existing community-based groups, were found to have statistically significant effects on the knowledge, importance, ability and likelihood of having conversations with others about end of life preferences.

Participants who decided to engage in ACP were compared with each other on the basis of previous ACP experience and significant differences were identified. All of this adds to the understanding of ACP as a dynamic decision-making process that assists people to construct and communicate their preferences for end of life care. Future research will continue to examine the internal and external influences within the decision-making context that affect individuals' decisions, behaviors and outcomes of engaging and re-engaging in ACP.

APPENDICES

Appendix A: Participant Survey

Appendix B: Information Letter / Consent Form

Appendix C: Dissertation Study Items from the Participant Survey

Appendix D: Resources for ACP Conversations

Appendix E: Glossary

Appendix A

Participant Survey

Pre-Program Participant Survey – Page 1

Your personal identifying number → _____
Birth month Birth day Gender Color

Mid-Michigan Advance Care Planning Coalition Research Project

Pre-Program Participant Survey

Please check the answer that best represents your opinion for each question. Please fill in the blanks where indicated. Additional comments are welcome at the end of the survey.

Date _____ Program Site _____

1. What do you think “Advance Care Planning” means? (please check all that apply)

- | | | |
|---|--|---|
| <input type="checkbox"/> Living Will | <input type="checkbox"/> Power of Attorney for health care | <input type="checkbox"/> Power of attorney for financial issues |
| <input type="checkbox"/> A Will | <input type="checkbox"/> A Patient Advocate | <input type="checkbox"/> A Legal Guardian |
| <input type="checkbox"/> A Trust | <input type="checkbox"/> Funeral planning | <input type="checkbox"/> A conversation about your wishes |
| <input type="checkbox"/> Instructions for use at a time when you are unable to make healthcare decisions for yourself | <input type="checkbox"/> Something else (specify) _____
_____ | <input type="checkbox"/> I’m not sure |

2. Do you have an Advance Directive?

- Yes No I’m not sure

→ 2a. If yes, what kind? _____

→ 2b. If yes, where is your Advance Directive currently located?

(please check all that apply)

- | | | |
|--|--|---|
| <input type="checkbox"/> At home | <input type="checkbox"/> At my attorney’s office | <input type="checkbox"/> In my medical record where I receive health care |
| <input type="checkbox"/> With my health care agent | <input type="checkbox"/> With other family members or significant others | <input type="checkbox"/> Safe deposit box |
| <input type="checkbox"/> Somewhere else (specify): _____ | | <input type="checkbox"/> I’m not sure |
-

3. Have you ever made medical decisions regarding the use of life-sustaining treatments for another person?

Yes No I'm not sure

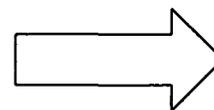
→ 3a. If yes, was this person an adult a child

→ 3b. If yes, did you feel prepared to make these medical decisions?

Yes No I'm not sure

4. Have you chosen a person (Patient Care Advocate) to make decisions for you if you ever become too ill to make decisions for yourself?

Yes No I'm not sure



Pre-Program Participant Survey – Page 2

Your personal identifying number → _____
Birth month Birth day Gender Color

→ 4a. If yes, have you had at least one conversation about your end-of-life wishes with that person (Patient Care Advocate)?

Yes No I'm not sure

→ 4b. If yes, please estimate the quality of that conversation (circle the number):

1	2	3	4	5
Few comments only		Good conversation		Complete and thorough conversation

5. Have you discussed your expectations for future medical care, including end-of-life decisions or wishes, with your physician or other primary health care provider?

Yes No I'm not sure

→ 5a. If yes, please estimate the quality of that conversation (circle the number):

1	2	3	4	5
Few comments only		Good conversation		Complete and thorough conversation

6. Have you discussed your expectations for future medical care, including end-of-life decisions or wishes, with other members of your family or significant others?

Yes No I'm not sure

Appendix B

Information Letter / Consent Form

Information Letter – Page 1

Mid-Michigan Advance Care Planning Coalition Research Project

Participant Survey – Pre-Program & Post-Program

Welcome to this program on Advanced Care Planning! We are very glad that you have come and we look forward to sharing information with you. While you are waiting for this program to begin, would you consider completing this **Participant Survey**?

This survey is being conducted by the Mid-Michigan Advance Care Planning Coalition to help us understand what advanced care planning you are already doing. This will help us plan future advance care planning educational programs for our community. The Pre-Program Participant Survey has eight questions about advance care planning and demographic data. It should take approximately five to ten minutes to complete. At the end of the program, the Facilitator will distribute a one question Post-Program Survey. This should take approximately two to five minutes to complete.

Your participation in this research project does not involve any cost. Your participation is voluntary. You may choose not to participate at all or you may choose not to answer certain questions. You may also discontinue your participation at any time without penalty. If you prefer not to complete the surveys, simply place the blank forms in the Participant Survey envelopes provided by the Facilitator. There are minimal risks involved in completing the survey; however you may experience strong feelings about the subject. If you do experience distressing feelings related to this survey, please talk to the Facilitator who will provide you with a community resource contact number.

Following this Advance Care Planning program, the Facilitator will send the surveys to our research team. The survey data from all participants will be entered into a database and analyzed as groups by the researchers. Your data will not be reported individually but only within a group. These group results will be shared with the Mid-Michigan Advance Care Planning Coalition and its collaborating organizations.

In the future, we may want to collect some follow-up data from participants in these programs. Please indicate if you would be willing to be contacted one additional time. Your contact information will be detached from your survey and filed in a separate place so that your name will not appear anywhere on the survey form. Your privacy will be protected to the maximum extent allowable by law.

<p>If you have any questions about this study, please contact the investigator:</p> <p>Gwen Wyatt RN, PhD B422 West Fee Hall Michigan State University East Lansing, MI 48824 Phone: [REDACTED] [REDACTED] Email: [REDACTED]</p>	<p>If you have any questions or concerns regarding your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact— anonymously if you wish—</p> <p>Peter Vasilenko PhD Chairperson of the University Committee on Research Involving Human Subjects (UCRIHS) 202 Olds Hall Michigan State University East Lansing, MI 48824 Phone: [REDACTED] [REDACTED] Email: [REDACTED]</p>
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(please turn the page)

Consent Form – Page 2

If you are willing to participate, please do the following:

- 1. Sign this consent form.**

You indicate your voluntary agreement to participate by completing and returning this consent form and the surveys.

Signature

Date

- 2. Create a personal identifying number by writing:**

The two digits of your birth month (e.g. January = 01, October = 10)	The two digits of your birth day (e.g. 06 or 13)	M for Male or F for Female	The first letter of your favorite color (e.g. Green = G)

Now write all these numbers and letters in a row onto the top of both the pre-program and post-program surveys. This will help us identify your surveys without having your name appear on them anywhere. (e.g. 0713FG for July 13 Female Green)

3. Are you willing to be contacted in the future for a follow-up to this program?

<input type="checkbox"/> YES	If yes, how may we contact you? Name: _____
<input type="checkbox"/> NO	Address: _____
	Phone: _____ Email: _____

4. **Please DO complete the pre-program survey now.
Please DO NOT complete the post-program survey yet!
Please put all of these papers in the appropriate envelopes the Facilitator will pass around.**

Thank you so much for participating in this survey!

8 Essential Talking Points for *Advance Care Planning*

- 1. Advance Care Planning (ACP) has 4 parts:**
 - 1. Selecting a decision maker who can make decisions for you if you are unable.**

This person may be called the Health Care Agent (HCA), the Durable Power of Attorney for Health Care (DPOA-HC), or, in Michigan, the Patient Advocate.
 - 2. Having conversations about your end of life care preferences.**

You should talk with your Patient Advocate, family or friends, and health care providers.
 - 3. Completing an Advance Directive.**

Although you can informally talk about your preferences, a written Advance Directive is the most legally reliable document. It may include designation of a Patient Advocate (DPOA-HC) and/or documentation of your instructions/preferences.
 - 4. Making your completed Advanced Directive readily available**

Keep your original in a safe place BUT be sure that you give key people copies that are readily available in a time of an unexpected emergency, (see Point # 7).

- 2. ACP is appropriate for adults of all ages and health conditions.**

At any time, you might not be able to participate in making medical treatment decisions; for example, you may be unconscious, or unable to communicate. Whether this is a temporary or permanent loss, you need someone (your Patient Advocate) who can communicate your instructions/preferences to the health care providers. It is appropriate to involve your school age and adolescent children in your conversations about your end of life preferences.

- 3. ACP is an opportunity to express your wishes about the kinds of end of life care you would like to have and not like to have.**

In your conversations and your Advance Directive, you should talk about the circumstances of the care you want or don't want. For example,

- you may want the health care providers to try a treatment at first to see if you can recover but discontinue it if it is not helping you improve your condition.
- you may always want comfort measures.
- you may never want an experimental treatment.

4. ACP is an ongoing process.

Your wishes may change as you grow older or if your health status changes. Perhaps there will be a treatment for a disease that is now available. Perhaps you have a change of heart about a treatment. It is a good idea to review your Advance Directive annually. It is also important to talk with your Patient Advocate, your family or friends, and your health care provider if your wishes have changed.

5. Your Patient Advocate only makes decisions for you if you are unable to make them.

Usually doctors decide if you are unable to make decisions for yourself based on your health condition. If you are unable, they will call in your Patient Advocate to make decisions for you.

- In Michigan, the Patient Advocate must sign the Advance Directive to show that s/he is willing to be your decision-maker.
- It is a good idea to appoint a back-up Patient Advocate in case the first person is not available when needed.
- Your Patient Advocate can make decisions for you about consenting to or refusing medical treatment. This includes decisions to withhold or withdraw life-sustaining treatment; these decisions could allow you to die of the illness or injury you have. It is very important that you have talked about these decisions ahead of time with your Patient Advocate and best if you leave instructions about them in your written Advance Directive.

6. An attorney is not needed to complete an Advance Directive.

There are many free or low-cost booklets and forms that can help you fill out your Advance Directive. However, some people find it convenient to create an Advance Directive with their lawyer when they are making out a will or doing estate planning.

- 7. Once you have created your Advance Directive, be sure everyone who needs to know about it has a copy.**
- Keep the original copy with your personal papers.
 - Give a copy to your Patient Advocate(s).
 - Let your family know you have an Advance Directive and/or give them copies.
 - Give a copy to your personal physician / health care provider.
 - Give a copy to your attorney (if you have one).
 - Always bring a copy with you to the hospital where you will receive treatment.
 - Keep a copy in your car.
 - Fill out a wallet card that lets people know you have an Advance Directive.
 - If desired, contact an organization that will keep a copy on record and send it to wherever it is needed.
- 8. ACP is a gift to yourself, your family, and your Patient Advocate.**
By talking about your wishes for end of life care, you can let your family and Patient Advocate know what is most important to you. This can make their decision-making less difficult.

Take time to personally reflect on your values and wishes for end of life care. You may wish to consider the following questions from “Caring Conversations:”

- What beliefs do you hold that influence your thoughts about life and your thinking about dying?

- With whom do you want to have a caring conversation about your values and wishes?

- What do you most want to say to them?

- When and where will you have your caring conversation?

- What concerns do you have about your health or future healthcare?

- What are your fears regarding the end of your life?

- What do you most value about your physical or mental well being?
(e.g. Do you love to be outdoors? Does being able to read or listen to music bring you pleasure? How important is it to be aware of your surroundings and the people with you? How important is seeing, tasting, touching?)

- Are there circumstances under which you would refuse or discontinue treatment that might prolong your life? If so, describe those circumstances.

- If you could plan it today, what would the last day of your life be like?
(e.g. Where would you be? What would you be doing? What would you eat? What music would you listen to? What would be your final words and your last acts?)

- How do you want to be remembered?

- What gives your life its purpose and meaning?

- What do you need for comfort and support as you journey near death?
(e.g. Do you want to pray with someone? Be read to from spiritual or religious texts? Listen to poetry or tapes? etc.)

- What does “very advanced age” mean to you?

- Do you wish to donate your organs and tissues?

- Do you wish to donate your body to science for health education?

- Would you agree to an autopsy? Do you prefer burial or cremation?

Compiled 2005 by John McPhail MA, CRC, LPC
Greater Lansing Health Ministries Consortium

What Should You Do With Your Advance Directive Now?

It is extremely important that this document, that specifies your wishes, is available. Therefore, you should:

- √ Let your family know you have completed this.
- √ Keep the original document with your personal papers.
- √ Give a copy to your doctors.
- √ Give a copy to your attorney.
- √ Give a copy to the person(s) designated as your Patient Advocate or Durable Power of Attorney for Health Care.
- √ Give a copy to the hospital where you will seek medical care. (Bring to the Medical Records Department.)
- √ Always bring a copy with you to the hospital.
- √ Keep a copy in your car.
- √ Complete a wallet card.
- √ Contact any organization that will keep a copy on record and send a copy to wherever it is needed.
- √ Other:

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Making Choices: Goals, Benefit & Burdens

How do you determine if a treatment is right for you? These questions may help you clarify the value of a treatment to you.

1. What is the goal of the treatment?
2. What are the benefits of the treatment?
3. What are the burdens of the treatment?
4. Are the benefits and burdens compatible with your individual goals?

<u>A treatment may be beneficial if it</u>	<u>A treatment may be burdensome if it</u>
<ul style="list-style-type: none"> • Is effective in prolonging life • Is effective in restoring / maintaining function • Is effective in relieving suffering • Promotes the goals / values of the person • Is consistent with the person's religious/cultural/spiritual beliefs 	<ul style="list-style-type: none"> • Results in more or intolerable pain • Is damaging to body image or function • Is psychologically harmful • Is physically restrictive • Carries an unacceptable cost for the person (financially, emotionally, spiritually)

Some more things to consider:

- Your preferences and goals may change as your health status changes. Some goals may become higher priorities or short-term goals may be balanced against long-term goals.
- You may need the assistance of others to determine your goals. Those who might provide assistance are your healthcare providers, pain-management specialists, hospice team, spiritual counselors, social workers, etc.

- In order for your goals to be honored, you must communicate them to your designated decision-maker (patient advocate or durable power of attorney for health care), family members and friends, and healthcare team members.
- Think about your goals and have these conversations as early as possible and in nonstressful situations with your family members and healthcare professionals.

Making Choices: Decisions & Definitions

Life-sustaining treatment: Any treatment that is used to sustain biological life

Choices about life-sustaining treatments:

- When to start
- When to forego or withhold
- When to withdraw
- How and when to maintain comfort
- When to mix management: making choices that extend life as well as choices that prepare for death and provide comfort

Cardiopulmonary Resuscitation (CPR)

- It is a standing order to start CPR in a hospital and most other healthcare organizations and by paramedics if a patient suffers a cardiac or respiratory arrest—unless there are clear orders not to start (e.g. a physician’s order that CPR not be attempted).
- Basic CPR involves pressing on the chest and blowing air into the lungs when breathing and heartbeat has stopped or has become ineffective. CPR typically lasts for 15 to 30 minutes. It may require administration of medications, the insertion of a tube to assist with breathing (intubation), and electrical stimulation of the heart.
- People who are at clear risk for requiring CPR include those with heart disease, those in long-term care facilities, or those with end-stage diseases.

Benefits:

- CPR is most beneficial for a healthy person whose heart has stopped suddenly from an accident or heart attack or in a person whose underlying condition can be effectively treated. CPR can prolong life with good functioning especially in patients who are healthy and younger, and if it is initiated within five minutes of the cardiac arrest.

Burdens:

- Less than 15% of hospitalized patients survive CPR and return to previous functional status. Only 1-4% of patients with multiple underlying medical conditions survive to leave the hospital. Rarely does a patient with an advanced cancer diagnosis leave the hospital after CPR.
- Pressing on the chest can cause soreness, broken ribs or collapsed lungs.
- Many people who survive CPR may require ventilator support for a period of time.

Artificial Ventilation

- Intubation involves the insertion of a tube through the mouth or nose into the lungs. This tube can then be connected to a breathing machine, or ventilator, to artificially support breathing.
- People with advanced lung disease, pulmonary infections, and neuromuscular disorders who could become ventilator-dependent should consider the type of medical interventions they would want if they went into respiratory failure.

Benefits:

- Adequate breathing or respiration (which is the process of providing oxygen to the body and removing carbon dioxide) can be interfered with by a variety of temporary and reversible conditions. These conditions include pneumonia and the need for breathing support after surgery or when a lung has collapsed after an accident. The breathing tube and artificial ventilator provide adequate respiration while the lung is healing or the body is recovering from another illness.
- For people with chronic pulmonary diseases, artificial ventilation can be used on a trial basis to see if they can improve enough to adequately breathe on their own. The benefits are to rest the lungs while other parts

of the person's health condition are being managed.

- In both situations, artificial ventilation may prolong life.

Burdens:

- The breathing tube produces discomfort from throat irritation, coughing and the need to suction secretions from the airway. The artificial ventilator may require some getting used to while the person learns to let the machine do part or all of the breathing. Psychologically, the person may be afraid or suffer sleep disturbances.
- To treat the discomfort, some people may require medications such as morphine and sedatives, which may alter level of consciousness.
- When using artificial ventilation for chronic pulmonary situations, it may be difficult or impossible to remove the ventilator. In these cases, persons are never able to resume breathing on their own and become ventilator-dependent for the rest of their lives.
- In addition, it may prolong dying.

Artificial Nutrition and Hydration

- Artificial nutrition and hydration involves the short-term or long-term administration of a balanced mix of nutrients and fluids via tubes (nasogastric, gastrostomy, and jejunostomy, intravenous) placed directly into the stomach, intestine, or vein.
- Short-term administration is needed to temporarily support a person while the cause of their inability to take nutrition is corrected (e.g. recovery from surgery).
- Long-term administration permanently sustains nutritional needs in persons who will never recover the ability to take nutrition on their own (e.g. persistent vegetative states, irreversible neurological disorders).

Benefits:

- Life may be prolonged.

- Person's personal and/or religious preferences are honored.
- Administration prevents weakness, dry mouth and thirst related to dehydration.

Burdens:

- Feeding tubes are often associated with aspiration of nutrients into the lungs, causing pneumonia (30% of cases) or throat, esophagus and stomach irritation and discomfort.
- Intravenous fluids increase the volume of secretions in the lungs, making breathing more labored and necessitating more frequent suctioning. Intravenous fluids increase congestion in other parts of the body, such as around tumors and organs, causing pain and discomfort as well as increased urination requiring frequent elimination needs and linen changes.
- For some confused persons who are in danger of self-harm from pulling at tubes, physical or chemical restraints may be required.

Antibiotics

- Infections used to be the way many people died, both young and old. Today we have sophisticated antibacterial agents that can prevent death in many cases, even with serious infections.

Benefits:

- Antibiotics eliminate the source of infection and, therefore, the accompanying side effects of an infectious process such as fever, chills, and discomfort.
- They may prolong life.

Burdens:

- Many antibiotics to treat infection need to be given intravenously, which requires starting and maintaining an IV site. There may be potential discomfort associated with starting the IV and keeping it patent.
- Antibiotics may delay the dying process by temporarily reversing a fatal event in an incurable illness (e.g. a person who has pneumonia due to end-stage lung cancer).

Dialysis

- Dialysis is a treatment provided to a person whose kidneys have stopped working. The kidneys take the waste out of the blood stream put there by the body's cells. If this waste is not removed, it will build up and ultimately cause death.

Benefits:

- Dialysis removes toxic waste products, allowing a person's other vital organs to function more normally.
- It may prolong life.

Burdens:

- Dialysis involves the insertion of catheters into the bloodstream and up to several hours of removing and filtering the person's blood several times a week.
- Once kidney function is gone, people are dependent on dialysis for the rest of their lives, or they may receive kidney transplants.
- Dialysis is expensive.
- It may prolong the dying process.

Making Choices: Withholding & Withdrawing Life-Sustaining Treatment

Many people fear that once a treatment is started, it will never be withdrawn. This may lead people to make statements such as, "I don't want to be hooked up to machines," or "I don't want any tubes."

Unfortunately, some of these fears may be translated into decisions that make it more difficult for health professionals and your decision-maker to attempt short-term trials of interventions that could be beneficial and consistent with your established goals.

If a trial of aggressive treatment is not serving the purpose for which it was started, it can be compassionately withdrawn without violating the rights of the person.

There is no moral or legal distinction between withholding treatment and withdrawing treatment. Both actions result in the same outcome: allowing the person to die of their underlying disease process.

The central moral question is whether or not there is justification to start or continue a treatment for a person given the circumstances of the situation (i.e., the person's diagnosis, prognosis, benefits and burdens of treatment, goals and values).

Making Choices: Comfort Care

What does “comfort care” mean to you? Choosing comfort care measures does not mean giving up or not providing potentially therapeutic treatment. Comfort care measures can and should be offered and provided at any stage of a person's health.

How do you feel about the control of symptoms during the dying process? Would you prefer to be as free as possible of your symptoms? Many interventions are available but some may have unintended effects (e.g. pain medicine may also cause sedation).

What other preferences do you have for comfort? Examples: music, selected people around you, spiritual counseling, massage, pets, environment, etc.

What present or future experiences are most important for you to live well at this time in your life?

In what way could you make this time especially meaningful for you and your loved ones? What legacy do you wish to leave?

Compiled from Respecting Choices® Advance Care Planning Facilitator's Manual (2002), Chapter 3
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Capital Area Health Alliance – Advance Care Planning Coalition

Appendix E

Glossary

Advance Care Planning (ACP)

A dynamic decision-making process (including decisions, behaviors, and outcomes) that helps people construct and communicate their preferences for end of life care.

Advance Care Planning (ACP) Experience

A participant's self-report of the prior experiences of having an Advance Directive (AD) or having a Health Care Agent (HCA) or both.

Advance Care Planning (ACP) Program

A health education information sharing session about ACP, presented by a certified Respecting Choices® ACP Facilitator to voluntary participants who were members of an established community group.

Advance Directive (AD)

A statutory document executed to communicate an individual's health care preferences for use at a future time when the individual's capacity to make informed health care decisions is lost. An AD may include designation of a health care agent and/or instructions for health care decisions.

Community

Both formal associations of people who are valued by one another and informal social structures and processes (e.g., discussions, activities, affiliations, responsiveness to one another) that reflect or advance some recognized commonality of history, culture, or perspective that is of value to the participants (Byock et al., 2001).

Community-Based Intervention

An intervention that is directed toward individuals and families within a community and designed to meet the needs of people where they live, work, worship, go to school, and receive healthcare (Calvin College Department of Nursing, 2003).

Culture

A set of attributes that collectively characterize a community: commonly held values, attitudes, assumptions, history, expectations, hopes, fears, and customary modes of professional, social, and personal interactions (Byock et al., 2001).

Decision

Choices between alternatives (Thompson & Dowding, 2002).

Decision Factors

Variables that modify an individuals' willingness or ability to make a decision.

Decision-Making

The evaluation of information about alternatives according to personal values (Mazur, 2003).

Decision-Making Context

The decision, behaviors, outcomes and influences (internal and external) that shape the decisions people make (Wills & Holmes-Rovner, 2006).

Decision Support Interventions

Strategies used by health care providers to promote informed, values-based decision-making (A. Clarke et al., 2005).

Decision to Engage in ACP

Individuals' willingness to involve themselves in exploring their preferences for end of life care.

Durable Power of Attorney – Health Care (DPOA-HC)

A person who has been chosen and legally appointed by a patient to be the substitute health care decision-maker. (Also known as Health Care Agent (HCA), Patient Advocate, and Proxy) (Post et al., 1999).

Dynamic Decision-Making

A decision-making process that may be engaged in repeatedly in response to changes within the decision-making context.

End of Life

The period during which an individual copes with declining health from an ultimately terminal illness, from a serious though perhaps chronic illness, or from the frailties associated with advanced age—even if death is not clearly imminent (Lunney, Foley et al., 2003).

End of Life Care

Both professional and informal care to treat medical conditions or meet basic human needs (such as bathing or eating) at the end of life (Byock et al., 2001).

Engaging in ACP

Understanding, reflecting, identifying, and discussing alternatives to help in formulating and making available plans for end of life care (adapted from Hammes & Briggs, 2002b).

Enough Knowledge

The participant's self-report of the perception whether or not they have sufficient information to discuss their preferences.

Established community groups

Organizations located in a community in which members naturally participate (P. Clarke et al., 2005).

Family

A set of relationships—established by blood or emotional bonds—in which individuals find identify and fulfill mutual obligations of domestic affairs, such as maintaining a household, raising a child, or providing care for each other (Byock et al., 2001).

Having an AD

The participant's self-report of executing a statutory document for use at a future time when personal capacity to make informed health care decisions is lost.

Having a HCA

The participant's self-report of choosing and legally appointing a person to be the substitute health care decision-maker (Post et al., 1999).

The participant's self-report of appointing an individual to make surrogate decisions at a future time when personal capacity to make informed health care decisions is lost.

Having conversations

The participant's self-report of discussing preferences for end-of-life care with others.

Health Care Agent (HCA)

A person who has been chosen and legally appointed to be the substitute health care decision-maker. (Also known as Durable Power of Attorney – Health Care, Patient Advocate, and Proxy) (Post et al., 1999).

Health Care Provider (HCP)

A licensed professional who provides health care to individuals within a health care setting. These licensed professionals may include physicians, mid-level providers (e.g., Advance Practice Nurses, Physician Assistants), registered nurses, dietitians, social workers, therapists, and chaplains.

Health Education

Developing and providing instruction and learning experiences to facilitate voluntary adaptation of behavior conducive to health in individuals, families, groups, or communities (O'Toole, 1997).

Important to have discussion

The participant's self-report of the perception of the necessity of having conversations about preferences for end-of-life care.

Informal Surrogate

A person who is asked by the medical team to help make treatment decisions because no one has been appointed by the patient or legally authorized (Post et al., 1999).

Information

Decision-relevant data inputs (Wills & Holmes-Rovner, 2006).

Initiated Advance Directive

Legal documents executed by persons while they are able to make personal decisions for use at a future time when they have lost the capacity to make informed decisions.

Making decision for someone else

The participant's self report of an event or process of communicating a choice related to life-sustaining treatment on behalf of another person who is incapable of making a choice.

Patient Advocate

A person who has been chosen and legally appointed by a patient to be the substitute health care decision-maker. (Also known as Durable Power of Attorney – Health Care, Health Care Agent (HCA), and Proxy) (Post et al., 1999).

Patient-Centered Care

Care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions (Committee on Quality of Health Care in America, 2001).

Patient Self Determination Act (PSDA)

The Patient Self-Determination Act requires hospitals, nursing homes, and health care programs to ask patients about advance directives and then to incorporate the information into medical records (Crane et al., 2005).

Personal Decision Factors

Variables relating to the individual that modify an individuals' willingness or ability to make a choice between two or more alternatives.

Personal Influences on Decision

Variables relating to the individual that may act independently or interact with each other to modify the Decision to Engage in ACP.

Preferences

A relatively greater liking of one alternative compared to another (Wills & Holmes-Rovner, 2006).

Prior experiences

Events, circumstances, or processes that have already occurred in an individual's lifetime.

Proxy

A person who has been chosen and legally appointed by a patient to be the substitute health care decision-maker. (Also known as Durable Power of Attorney – Health Care , Health Care Agent (HCA), and Patient Advocate) (Post et al., 1999).

Quality of Care

Care that meets recognized standards of professional service and that conforms to the values and preferences of the individuals, families, and professionals within the community (Byock et al., 2001).

Quality of Conversations

The participant's self-report of the thoroughness of discussions of preferences with others.

Self efficacy

An individual's perceived confidence to perform certain behaviors (Bandura, 1986).

Sense of Control in the Dying Process

A patient's internal feeling of being able to die in a way deemed acceptable and that any medical outcomes or states deemed unacceptable will be avoided (Kolarik et al., 2002)

Shared decision-making environment

A context in which individuals and others (such as invited family members or health care providers) exchange information about medical conditions and preferences to reach treatment decisions that are mutually agreeable (Frosch & Kaplan, 1999).

Significant others

Persons who play an important role in the life of an individual (O'Toole, 1997).

Surrogate

A person whose authority to make health care decisions for someone else is based on state statute or case law (Post et al., 1999).

Values

The importance individuals place on information, experience, and the context of decision-making (Wills & Holmes-Rovner, 2006).

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