HEALTH-CARE DECISION MAKING AT THE LATTER END OF THE LIFESPAN

A Dissertation in
Communication Arts and Sciences

by
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ABSTRACT

Decisions involving health care in later life entail consideration of a complex and diverse set of issues, making the process of decision-making a challenging and uncertain one for an older adult. The social relationships that are pertinent to the decision situation and significant in the lives of older adults can serve to support or further complicate their decision-making. As health care decisions have far reaching effects for the well-being and survival of older adults (Park, 1999) and the decision-making process is fundamentally a communicative activity (Street, 2007), understanding the communicative influences on the health care decision-making processes for older adults is essential. Guided by the Theory of Motivated Information Management (TMIM) (Afifi & Weiner, 2004) and an ecological perspective (Street, 2007), this study examined the personal decision-making networks of older adults faced with a major health care decision.

Interview and survey methods were utilized to gather information about older adults’ information-seeking behavior during the decision-making process as well as regarding the influence of numerous communication contexts on the process and outcome of the decision-making. Personal decision-making networks (n=62) were developed from the data gathered that illustrated communication properties of interest, such as frequency of decision contact, relational quality, and influence on the decision process and outcome. The ties between and influence of the members (targets) in each participant’s decision-making network (n=279) were also analyzed according to participants’ perception of frequency of decision contact, relational quality, and direction of influence between the members of the network.

Personal social network analysis of the decision-making networks revealed that networks fall along a continuum of influence ranging from dominance of organizational influence on the process and outcome of decision-making to dominance of interpersonal influence. The type of
health care decision mediates the influence of organizational and interpersonal contexts in networks. Analyses of the interactions reported by participants among network members demonstrated that older adults who reported reciprocal interactions with their adult children over the course of their decision-making experienced a decrease in their anxiety with the process of decision-making, where older adults who reported that their adult children attempted to influence their decision-making reported an increase in anxiety. Further, a decision-maker’s propensity for involvement in their health care decision predicted use of media sources for information during the decision-making process. Additionally, older-adult decision-makers’ communication efficacy predicted their information-seeking behavior during the decision-making process, demonstrating partial support for the TMIM. The implications of the findings for medical professionals involved in the health care decisions of older adults and families who seek to support older adults facing a major health care decision are discussed, as well as considerations for advancing information-seeking theory.
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At my parents’ 25th wedding anniversary dinner, my godfather, Mr. Dan Groom, told me, “You know, you can learn something from every person you talk to.” “Really?” I must have responded. “Every person you talk to,” I remember him repeating. In the smile and chuckle that followed, Mr. Groom communicated that, like most wise teachers, he had a hopeful, yet realistic expectation that his student may or may not take his lesson to heart. He may be surprised to learn that I remember this conversation, but like most wise students, I thought upon his lesson for more than a fleeting moment.

Indeed, this dissertation is a compilation of what I have learned by talking with people. The focus, of course, is on my learning associated with the investigation of communication and health-care decision making in later life. Naturally, the professors under whom I studied during my graduate experience at The Pennsylvania State University shaped this dissertation, as did the voice of each person I formally surveyed and interviewed for the project. However, although the years I spent as a graduate student provided the most specific and thorough learning experience I have engaged thus far, some of the most meaningful conversations that influenced my research and ensured a successful completion of this project and my graduate education were unrelated to my formal education at The Pennsylvania State University. I have been listening to people talk about aging, health, and decision-making since before my conversation with Mr. Dan Groom. I think that after my conversation with him, I began to listen more attentively to these conversations, if only to discern whether his was right. I discovered he was. I have learned something from each person with whom I have spoken. Certainly, the quality of information learned from any given source has varied. Some contributions to my learning have been meaningful and positive. Sometimes the information is useful. Sometimes…not so much.
Sometimes I have been able to distinguish what is useful and constructive with ease. Other times, I have not. Not until my career as a doctoral student was I introduced to the formal study of ways to knowing and developed my own episteme. Meanwhile, I had accumulated a wealth of knowledge from talking with, listening to and observing a variety of people who have been influential to this work and to my graduate career. I also found myself with more support for my collegiate experience than I could have imagined. As such, my heart is filled with gratitude for many individuals who have taken the time to talk with me.

First, I am thankful to God, who has become my primary conversation partner and source of strength. I have not always been able to “see” God working in my life, as a graduate student or otherwise, yet, “Beckoned or not beckoned, God is present.” He has blessed me with a multitude of individuals and circumstances that over the course of my life that moved me to the place I find myself today. Sometimes the only way to “see” God and His love is through the individuals he places in one’s path, which has certainly been the case with me many times.

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Chapter 1: Introduction and Literature Review

Introduction

Adult life is wrought with major decisions. From the time that individuals step into adulthood by making their first major decision, independently from a parent or guardian, to the time they complete their advanced care directives, life is punctuated and subsequently shaped by the major decisions they make along the way. Some major decisions may be clear and simple; others will be complicated and stressful. Most significant decisions will present challenges that require serious thought and consideration and will involve other important individuals in one’s life. All of these decisions have the ability to change one’s life for the better or worse.

Making decisions related to one’s health and medical care can be an intensely challenging experience. When faced with a major health-care decision, such as choosing between various treatment regimens or selecting a living arrangement after encountering a disability, one is confronted with a new reality about one’s health. An individual’s need for predictability and consistency in life (Schutz, 1970) is inherently threatened in such situations. The uncertainty associated with illness (e.g., Babrow, Kasch, & Ford, 1998) can intensify an already stressful situation (Babrow, Hines, & Kasch, 2000). In addition to coping with the stress related to their condition, those faced with illness or disability must also process complicated medical information and a myriad of available treatment alternatives (Park, 1999). Any major health-care decision will have important effects on one’s quality and quantity of life, which render the process of decision-making an important and difficult endeavor.

In addition to managing the uncertainty and stress associated with a health condition, individuals facing a decision about their health care must simultaneously cope with a variety of social relationships. Naturally, the relationship between a physician and patient has important
implications for health-care decisions. Provider-patient interaction has been researched extensively and found to have important implications for various outcomes, such as patient satisfaction, adherence to treatment, and health outcomes, such as patient anxiety, symptom resolution, and health status (for review, see Brown, Stewart, & Ryan, 2003). Further, research suggests that the interaction and information exchange between providers and patients is critical to informed decision-making (Street, 1992). Yet, the relationship and interaction between patients and providers presents challenges for both the clinician and patient. The clinician must decide how much, what, and when to give information to the patient in light of patient needs, as well as current ethical and legal standards (Gillotti, 2003). Meanwhile, the patient must process the information given to them by physicians (Park, 1999) in light of their own beliefs, values, and need to weigh difficult and uncertain outcomes of their situation (Gillotti, 2003). Clearly, the provider-patient relationship is crucial to the decision-making process and important implications for decision outcomes.

Although discussions with organizational figures, such as doctors and nurses, are commonly the starting point for individuals facing health related decisions, research also suggests that one taps into one’s informal, interpersonal social network when faced with decisions regarding one’s health (Tardy & Hale, 1998). Family members and friends are important sources of information and support in understanding health experiences (e.g., Cline, 2003). Although the informational and emotional support gleaned from the various players in one’s social network may be beneficial to individuals, the content and delivery of support can vary in its effectiveness (e.g., Albrecht & Goldsmith, 2003). Family members and friends are essential in providing support and information for a person facing a major health-care decision. Nonetheless, due to the variation within their helpfulness, other figures could potentially add an
additional layer of stress and complexity to the process of decision-making for an individual facing a major health care decision.

Decisions involving health care at the later end of the life span frequently entail consideration of an especially complex and diverse set of medical issues (Pfieffer, 1998). Older adults often fall victim to multiple chronic health problems concurrently, which require them to manage numerous treatments regimens (Nussbaum, Ragan, & Whaley, 2003). Assessing the risk and benefits associated with a given course of action can be especially complicated in light of competing medical treatments. The fact that older adults can experience some degree of cognitive compromise due to the effects of aging on information processing, working memory capacity, and long term memory (Park et al., 2002), as a result of the illness or pain associated with a condition (Park & Meade, 2007), or because of the stress, fatigue, and pressure to learn new medical information (Chan, Ybarra, Park, Rodriguez, & Garcia, 2007) only further serves to complicate the decision-making process for older adults.

In addition to the complications associated with medical care in the latter stages of the lifespan, older adults also encounter complexities when managing the social relationships associated with making major health care decisions. The relationship between an older adult and a health care provider is of particular significance and can be complicated by the unique medical and interpersonal needs of older adults during their interaction with their health care providers (Nussbaum, Ragan, & Whaley, 2003). For example, although there is a current trend of shared decision-making between patients and providers stem from the positive effects of provider-patient collaboration on patient adherence to treatment regimens (e.g., DiMatteo, Rieter, & Gambone, 1994; Ong, de Haes, Hoos, & Lammes, 1995), improved health (e.g., Brody, Miller, Lerman, Smith, & Caputo, 1989), and decreases in decisional conflict or a person’s state of
uncertainty about the decision (Kremer, Ironson, Schneiderman, & Hautzinger, 2007), less joint decision making occurs between older patients and their physicians than between younger patients and their providers (Greene, 1987). Nonetheless, even for those older adults who desire greater involvement in their medical decisions (Belcher, Fried, Agostini, & Tinetti, 2006), some researchers see the shift in medical decisions from doctor to patient as having the potential to affect the health care of older adults negatively because they could have more difficulties comprehending and remembering medical information than younger adults (Liu & Gonzalez, 2007). Older adults clearly have unique needs in their encounters with physicians that affect and complicate their decision-making processes and outcomes.

In addition to clinicians, a person may consult numerous other relevant individuals during the decision-making process. This is especially true of older adults, who are often accompanied by a family member or friend when visiting a physician (Nussbaum, Ragan, & Whaley, 2003). Older adults’ relationships with their adult children has been noted as particularly significant in the decision-making process, especially as older adults find that they may need to rely on their children for support or help after a decision is made (Hummert & Morgan, 2001). The social support and opinions of friends who have faced similar situations can also play an important role during the decision-making process for older adults. Essentially, “Friendship can provide a very secure context in which declining health can be managed” (Nussbaum, 1994, p. 214). Certainly, friendship at the latter end of the lifespan becomes of vital importance in coping with the stresses of making a major decision about one’s health care.

Health-care decisions for older individuals can have far reaching effects for their well-being and survival (Park, 1999), which makes the significance of these decisions enormous. The pressures associated with health-care decisions create a difficult and demanding decision-
making process for older adults. The social relationships that are significant to older adults faced with a major health-care decision can serve to support or further complicate their decision-making. Despite the importance of sound medical decision-making, research focusing on decisions involving health care in later adulthood is sparse; even less has examined the decision-making process as an inherently communicative one that involves connections between the decision makers and the various relations important to them and their decisions. As Street (2007) emphasized, medical decision-making is fundamentally a communicative activity. As the landscape of health care continues to evolve and the communication contexts in which health care decisions are situated become more complicated, presenting consumers with an increase in the amount of health-related information available on the Internet and related media sources (Korp, 2006), and number of choices available for them (e.g., U.S. Department of Health and Human Services, 2004), and as the current cohort of older adults have aged along with these changes, revived attention to the communicative influences on their health-care decisions is warranted.

The overarching purpose of the research reported in this dissertation was to examine the process of health-care decision making for older adults and the communicative influences involved. After proposing communication and uncertainty management theory as a framework that can help explain older adults’ communicative choices during the decision-making process, an ecological perspective, which emphasizes that the interactions involved in an older adult’s health-care decision are positioned within and affected by a variety of social contexts, is offered as a means for situating interactions involved in the health-care decision-making process of older adults and as a guide for reviewing scholarship associated with the phenomenon. Research questions and hypothesis are offered and later analyzed through personal social network analysis,
leading to conclusions and discussion of the importance of future research in decision-making and health care.

Information Processing and Health-Care Decision Making:
The Cognitive and Communicative Challenges for Older Adults

One of the most important contributions to the understanding of how older adults make decisions related to their health care, which is largely absent in social science investigations on the topic, grows out of the field of cognitive psychology. Research addressing how older patients actually process medical information has emerged in hope of determining how physicians can better assist their older patients in making their decisions (see Park, Morrell, & Shiffren, 1999). Age-related changes in cognitive functioning, memory, and information processing can affect older adults’ medical decision-making processes (Liu & Gonzalez, 2007). Although automatic processing of information among older adults rarely becomes impaired with age, effortful processing, such as is involved in studying medical instructions, may be slowed (Park, 1999). Decreases in effortful processing ostensibly results in reduced decision quality, as older patients may make decisions with less information and deliberate consideration (Meyer, Russo, & Talbot, 1995). Older adults also show decreases in working memory (e.g., Park 2000). When working memory diminishes, an individual’s ability to store and simultaneously manipulate multiple pieces of information is compromised (Liu & Gonzalez, 2007). As older adults facing medical decisions may be called upon to process various pieces of information they need to make their decisions, age-related declines in working memory have the potential to affect negatively older adults’ capacity to make optimal medical decisions. Additionally, age related declines in long-term memory can also present challenges for older adults in making health related decisions. As Liu and Gonzalez (2007) observed, “Individuals who are presented with a
great amount of information may lose details of information they receive, leading to systematic distortions in the information they recall and leaving them only a general positive or negative affective impression” (p. 206). Although Liu and Gonzalez’s review of the age-related changes in cognitive function that can present challenges for older adults making medical decisions was applied in the specific case of compliance with medical regimens, the importance of considering the effect of age-related decline in cognitive function on medical decisions in a broader sense is clear, even from the cursory discussion offered here.

Considering the changes in cognitive functioning and information processing associated with advanced age, not only do physicians have compelling reasons to work with older adults in discussing health care options to ensure satisfying and high quality health-care decisions, as Liu and Gonzalez (2007) and Park and Meade (2007) suggest, but so do other social actors that may be of influence during the decision-making process. For example, recognizing that older adults may need more time to process information associated with their decisions (Park, 2000) is important for adult children and friends to know as they aid older adults with their health care decisions. After all, in their examination of the underlying influences in older adults’ medical decisions, Roberto, Weeks, and Matheis-Kraft (2001) discovered that medical considerations, quality of life, age, past experiences, and personal relationships were all prominent guiding factors for older adults’ decision-making. Clearly, older adults are not alone in managing information associated with medical decisions. This evidence suggests that the information management is complicated beyond the cognitive level for older adults engaged in a health-related decision. Communication scholarship utilizing an uncertainty management perspective offers a means of untangling the various influences that can affect the health-care decision-
making process for older adults. As such, the Theory of Motivated Information Management is proposed to help explain older adults’ communicative choices during the decision-making.

Theoretical Framework: The Theory of Motivated Information Management

Introduction

The theoretical framework that underlies this investigation grew from the body of communication research focusing on communication and uncertainty management (e.g., Afifi & Weiner, 2004; Babrow, 1992, 1995; Brashers, 2001). The underlying assumption of many of the theories in this body of literature is that life is uncertain and that people cope communicatively with the uncertainty they face (e.g., Babrow, 1992, 1995). Uncertainty is widely recognized as a central feature of illness (e.g., Atkinson, 1984, 1995; Babrow, Hines, & Kasch, 2000; Babrow, Kasch, & Ford, 1998; Katz, 1984). Babrow, Hines, and Kasch (2000) identified various facets of uncertainty in the illness experience. Uncertainty is often a result of the complexity of illness in terms of the causes of a disease or condition, the contingent nature of symptoms, and presence of reciprocal causal processes of an illness. Another component of uncertainty in illness involves the quality of available information about a disease or illness. For example, the sufficiency and clarity of information, as well as its reliability and validity, can produce a variety of uncertainties for a person facing an illness. As such, application of theory focused on uncertainty management and communication is appropriate in an investigation of decisions involving health care. Although not all decisions involving health care stem from a disease or illness, as in the case of decisions involving care after an accident or major surgical procedure (i.e., whether to move to an assisted living residence following an injury) or decisions that extend from the normal process of aging (i.e., whether to change health insurance providers because one anticipates needing more coverage after age 65), any major health-care decision likely involves
complexities and uncertainties similar to those associated with an illness. As discussed previously, major health-care decisions, especially those in the latter stages of the lifespan, have the potential for complexities associated with the various social contexts posited by an ecological perspective of decision-making. As such, theory focused on communication, uncertainty, and information management serves as an appropriate guide for investigation of the process of decision-making and its associated outcomes for older adults.

Theory focused on the process of information-seeking and management would lend a particular insight to the process of decision-making for older adults considering a major health care decision. There is research regarding how older adults cognitively process information about their health care decisions (e.g., Liu & Gonzalez, 2007; Park, 1999). However, how older adults actually seek and manage information they receive during the process of decision-making is not clear. Further, their willingness to engage in discussions about their health care with relevant others, such as physicians and family members, has yet to be examined. Part of Afifi and Weiner’s (2004) Theory of Motivated Information Management specifically addresses individuals’ likelihood of seeking information as a function of their assessment of their ability to cope with and communicate about an important situation, as well as their assessment of relevant others’ ability and willingness to provide information about the situation. Thus, the present investigation applied the Theory of Motivated Information Management to illuminate older adults’ communication with members of their decision-making network about their major health care decisions.

Overview

Afifi and Weiner (2004) proposed TMIM as a framework that accounts for active information management efforts occurring through interpersonal channels (Afifi & Weiner,
2006). Like the other theories of uncertainty management and communication with which it shares assumptions and from which it extends, such as Efficacy Theory (Bandura, 1997), the Theory of Uncertainty Management (Brashers, 2001), Problematic Integration Theory (Babrow, 2001), and the Comprehensive Model of Information Seeking (Johnson & Meischke, 1993), TMIM rests on the assumption that people communicatively manage the uncertainty they face in important situations. One of the unique qualities of TMIM that made it well-suited to this research endeavor is that it focuses on the information seeker’s assessment of an interpersonal situation and how his/her assessments affect a decision to engage in an interpersonal exchange.

In short, Afifi and Weiner (2004) proposed a three-phase process of information management. The first phase, interpretation, is characterized by an awareness of a discrepancy between the desired amount of uncertainty about an important issue and the actual amount of uncertainty about the issue. The awareness of discrepancy purportedly produces anxiety. The second phase posited by TMIM, evaluation, results from the anxiety associated with the discrepancy. As a result, Afifi and Weiner propose that a person will assess the outcomes of an information search and his/her perceived ability to gain the sought-after information. A person’s perception of his/her ability to seek information presumably depends on three assessments of efficacy. Afifi and Weiner (2004) utilized Bandura’s (1997) definition of efficacy, an individual’s perception of the ability of a target person to successfully enact a behavior or produce an outcome, to ground their conception of efficacy, but extend the conceptualization by specifying three types of efficacy. First, coping efficacy refers to as the extent to which individuals believe they have the resources (instrumental, emotional, or otherwise) they need to manage the process and outcomes they expect from the information management. Second, Afifi and Weiner (2004) also considered communication efficacy, or a person’s belief that he or she
possess the skills to complete the communication tasks involved in the information-management process successfully, as part of an individual’s self-efficacy. Finally, target efficacy has two dimensions: the target’s ability and the target’s honesty. In combination, these concepts reflect an individual’s belief that an information target is able and willing to provide complete information. Afifi and Weiner felt that both parts are important in that individuals are not likely to seek information from those who do not have access to information or who are not willing to provide it. Essentially, the TMIM predicts that efficacy assessments are a function of a person’s outcome assessment and serve as a partial mediator of the outcome assessments on the chosen information management strategy. Essentially, these strategies feed into the final phase of the information-seeking process: the decision of information management strategies.

**Rationale and Hypotheses**

Tests of TMIM as a model for information-seeking have shown had partial success in predicting search for relational information (Afifi, Dillow, & Morse, 2004) and sexual health information (Afifi and Weiner, 2006), as well as in illuminating the decision to talk with family members about organ donation (Afifi, Morgan, Stephenson, Morse, Harrison, Reichert, & Long, 2006). The purpose of this investigation was not to model the process of decision-making about health care for older adults, but rather to investigate the communicative influences during the decision-making process and on the outcome of the decision. The communicative choices involved in the decision-making process were important in fulfilling the purpose of this investigation and establishing TMIM’s potential utility in furthering knowledge of the predictors of information-seeking behaviors of older adults. The fourth proposition of the TMIM, “The likelihood of seeking information is a function of the weighted combination of the three efficacy assessments (coping, communication, and target efficacy)” (Afifi & Weiner, 2004, p 179),
involves an essential construct in the investigation of an older adult’s health care decision-making process. TMIM posits that an individual’s coping efficacy, communication efficacy, and assessment of target efficacy serve important functions in the communication choices a person makes during the information management process. In applying the TMIM to the specific situation of older adults making a major health care decision, TMIM would predict that an older adult’s perceived efficacy in the health care decision-making process, as well as assessment of others’ ability to aid in the process, should affect their network of decision-making. For example, a person who has confidence in his or her ability to process information associated with their health care decision and in their ability to successfully communicate about his/her decision may be more likely to seek out information about their decision than someone who does not have such confidences. Further, a person’s expectations regarding the efficacy of a doctor or adult child in aiding them with the process of decision-making will likely predict their choice to engage in discussions with them during the decision-making process. Given the complexities associated with the various interpersonal relationships relevant to the decision-making process of an older adult, the self-efficacy of the decision-maker and his/her assessment of the efficacy of the individuals in his/her decision-making network will likely impact the decision-making. Hence:

H1: Older adults’ evaluation of their communication efficacy is predictive of their information-seeking behaviors in their health care decision-making network.

H2: Older adults’ assessment of the efficacy of targets in their health care decision-making networks is correlated with their information-seeking behavior involving the targets.
Health-Care Decision Making: An Ecological Perspective

In addition to considering the health-care decision-making process through the lens of information and uncertainty management, an ecological perspective on the process has the potential to link scholarship from a variety of academic disciplines, especially in the case of decision-making in older adulthood. Although a modest amount of scholarly research has addressed medical, health care, or health-related decisions, research dedicated specifically to the unique concerns of older adults and their decisions is not as prevalent.

Research focusing on health-related decisions occurs in various academic disciplines, which demonstrates the multidisciplinary nature of the subject. A starting place for most research in the social sciences involving health-care decision making is physician-patient interactions. A wealth of research in communication, psychology, and health sciences has examined patient involvement in decisions (e.g., Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Flynn, Smith, & Vanness, 2006; Frankel & McGraw, 2007; Kremer, Ironson, Schneiderman, & Hautzinger, 2007), especially as it relates to provider-patient collaboration in decision-making (e.g., Belcher, Fried, Agostini, & Tinetti, 2006; Jahng, Martin, Golin, & DiMatteo, 2005) or decision aids aimed to help providers and patients make informed medical decisions that take into account patients’ values (e.g., Street, 2007). Further research relating to provider-patient interactions and decision making has examined the disclosure of information by providers, with the purpose of helping patients in making medical decisions (see Gillotti, 2003 for a review). At a general level, findings from research concerning patient-provider interaction and decision-making indicate that patients vary in their desire for involvement in their medical decisions and their desire for partnership with their physician during the process. Some research also indicates that physicians are challenged in ascertaining the patient’s desire for participation
in the decision-making process, as well as determining how to disclose and discuss complex medical information with and break bad news to patients. Utilizing decision aids to assist providers and patients in their decision-making interactions could serve to simplify the complexity of such discussions, but the current state of research dealing with decision aids has indicated that most aids are developed and implemented without attention to communication and decision theory and, as a result, have not been shown to improve health outcomes (e.g., McCaffery, Irwig, & Bossuyt, 2007; Street, 2007). Clearly, additional research that integrates the work of the various disciplines that seek to address the complexities involved in provider-patient interactions regarding medical decisions could improve efforts to aid providers and patients in their discussions.

In addition to examining provider-patient interactions and health decisions, scholars have addressed the impact of emotion on a patient’s health decisions (e.g., Lockenhoff & Carstensen, 2007; Redelmeier, Rozin, & Kahneman, 1993; Shapiro & Muskin, 1993), risk assessment in health-care decision making (e.g., Amsterlaw, Zikmund-Fisher, Fagerlin, & Ubel, 2006), uncertainty management involved in health-care decisions (e.g., Babrow 1992, 1995), and the effect of media resources and the Internet in aiding individuals in their medical decisions (Ybarra & Suman, 2008). Further, research endeavors have addressed decision-making involved with specific health decisions, such as end-of-life care (e.g., Kuczewski & DeVita, 1998; Sprung & Oppenheim, 1998) or cancer (e.g., Czaja, Manfredi, & Price, 2003; Luce, 2005). Research in the area of medical decision making has certainly diversified throughout fields and topics related to decision making involving health. One would hope that in the midst of the striking multi-disciplinary nature of research examining health-care decision processes and outcomes that
interdisciplinary research endeavors would abound. Unfortunately, little research has bridged
the various pockets of research that have sprung up in this area.

Not only have few interdisciplinary efforts attempted to build coherence to scholarly
literature in the area of decision making and health care, but scholars have been inconsistent in
their terminology of the core concepts of research. The terminology varies from “medical
decision-making,” “health-care” or “healthcare” decision-making, and “health-related decisions.”
Research focusing on “medical decision-making” seems to encompass decisions situated in a
formal medical setting and involving a medical professional. For example, Liu and Gonzalez’s
(2007) reviewed judgment and decision processes in older adults’ compliance with medical
regimens. They discussed the impact of cognitive aging on older adults’ ability to make
“medical” decisions, or decisions related to medical treatment prescribed by a physician. Not all
research that focuses on “medical decision-making” shares the same definition of “medical
decision” as a choice that involves physician care. In fact, the journal *Medical Decision Making*
works under a broader view of medical decisions as those choices regarding health (*Medical
Decision Making*, 2008). Such a definition is attractive, if only because decisions that seem to be
situated in a formal medical setting clearly involve social actors outside that context (e.g., Tardy
& Hale, 1998).

Other publications refer to “health care decisions” (e.g., Carr & Khodyakov, 2007; Karel,
Moye, Bank, & Azar, 2007) or “healthcare decisions” (e.g., Amsterlaw, Zikmund-Fisher,
Fagerlin, & Ubel, 2006; Flynn, Smith, & Vanness, 2006). Research using the former phrasing
seems to focus more on general health-care arrangements, such as changes in living
arrangements as a result of a health condition, than the latter, which concerns decisions that have
a care component associated with a formal medical dimension, such as choosing a course of care.
for rehabilitation services. However, research utilizing these phrases does not consistently follow this distinction. Finally, some research examines “health-related decisions” (e.g., Happ, Swigart, Tate, Hoffman, & Arnold, 2007; Rimal, Ratzen, Arnston, & Freimuth, 1997), which typically, but not always, address decisions related to health in a very general sense. In fact, Rimal, Ratzen, Arnston, and Freimuth (1997) refer to decisions that are so far removed from a formal medical setting that the decision-maker is not referred to as “patient” but “health citizen.” For the purpose of this investigation, the variance and possible spectrum of definitions associated with decisions in this area of research was acknowledged. However, as definitions in this area of research are inconsistent, the phrases are used interchangeably throughout the dissertation unless specifically noted.

The overview of research thus far indicates that to further knowledge of the process of health-care decision making for older adults, a comprehensive exploration of the area may serve to unite the various facets of the decision-making process. An ecological perspective on decision-making may function more effectively to position the interactions involved with decision-making about health care. Similar to Street’s (2003) proposal of the ecological perspective on communication in medical consultations, which portrays the interaction between health-care providers and patients as affected by a variety of social contexts, a person’s medical decision-making can be placed in a reciprocal model of influence involving an interpersonal context, cultural context, spiritual/religious context, political-legal context, organizational context, and a media context (see Figure 1). Patient medical decision-making is, without a doubt, situated within a highly complex ecology. All the factors in question deserve attention in understanding the processes involved in patient decision-making and outcomes associated with particular influences.
When faced with complex health-related decisions, most people draw on their social networks to provide advice, confirmation, and support (e.g., Pescolido, 1992; Strain, 1990). Individuals who assist a person in interpreting bodily changes and choosing a course of action constitute a person’s lay referral system (Friedson, 1960). Activating social ties that comprise a person’s lay referral system can teach and reinforce patterns of self-care, validate or contradict a person’s interpretation of symptoms, provide a basis for social comparisons, encourage or discourage professional consultation, suggest pathways to complementary or alternative healers, provide reassurance, or simply affirm a person’s importance and self-esteem by listening to complaints and concerns (Stoller, 1998). Lay referrals can come from a spouse, an adult child, a sibling, a friend, or any other person in an individual’s social network. In older age, spouses
and adult children are the most likely people to inhabit the lay referral system for an individual (Schoenberg, Amey, Stoller, & Muldoon, 2003). However, it should be noted that Schoenberg, Amey, Stoller, and Muldoon have indicated that older individuals have a complex social network in which all social actors may play important roles when it comes to decisions involving health care. Thus, kin and nonkin are considered as potentially influential members in the interpersonal context of older adults’ health care decision-making networks.

Family members are particularly important figures in the interpersonal context associated with an older adult’s decision about health care. Major decisions about the care of an older adult typically occur within a family (High, 1988), and how families approach decisions about health care can have profound implications for the psychological and physical health of older individuals (Lieberman & Fisher, 1999). At a more general level, family members serve as a source of instrumental support for older adults by providing services or financial assistance (Crohan & Antonucci, 1989). As major health-care decisions, such as determining whether to have a surgical procedure, may necessitate financial management and arrangement of care following the procedure, instrumental support from family members may be an important factor in considering them. Provision of instrumental support is specific to the role of a family member as opposed to nonkin. Like friends, however, family members are also seen as important sources of emotional support (Felton & Berry, 1992) and as confidants (Connidis & Davies, 1990, 1992). Presence of instrumental, emotional support, and trustworthy companionship are important dimensions of an older adult’s social support network that may become particularly significant in the face of a major health-care decision. Such support could potentially affect the stress and anxiety associated with a major health-care decision, if not help to determine the outcome of such decisions. Family members certainly have the potential to be critical sources of influence.
during the process of decision-making for older adults faced with major health-care decisions, and, thus, are of vital importance for consideration.

Although evidence suggests that family members serve important functions in older adults’ decisions concerning health care, little research has examined individual family roles in health-related decision-making. If an older adult is married at the time of a major health-care decision, one would assume that the spouse plays an important role in the decision-making process. Substantive research has addressed marital relationships in older age, especially in contrast to those in younger age (e.g., Levenson, Carstensen, & Gottman, 1993, 1994) and the role of a spouse as caregiver of a partner in later adulthood (e.g., Johnson, 1985), especially in the case of a spouse caring for a partner with dementia (e.g., Zarit, Todd, & Zarit, 1986) and the burn-out associated with spousal caregiving (e.g., Fitting, Rabins, Lucas, & Eastham, 1986). Far less research has addressed the role that a spouse specifically plays in the major health-care decisions of their partners. At best, research tends to group the role of a spouse in a health care decision as part “family” involvement (e.g., Hummert & Morgan, 2001).

The lack of focus on spouses in the health-care decision-making processes of older adults is notable, in view of the fact that those over the age of 65 are more likely to be living with a spouse than without one. According to the U.S. Census Bureau (2007), 55.3% of those aged 65 and older are married and the spouse is present in the household (as opposed to absent, separated, divorced, or deceased). The percentage of males over 65 who are living with a spouse is higher than for females (72.8% and 42.5% respectively), but the percentage decreases with age. Although over 50% of individuals aged 75 to 84 still live with a spouse, the percentage for that age 85 and older is 28.6%. Despite the reduction in marriage rates for those 85 and older, the role of a spouse is likely to be of consequence in a health-care decision at some point in a
married person’s older adulthood, as individuals over 65 are more likely to have multiple,
chronic, and acute medical problems than younger adults (e.g., Greene & Adelman, 2001).
Generally, partners are the primary source of comfort and safety when a person encounters a
physical and/or psychological threat (Helgeson & Cohen, 1996). In fact, spouses reportedly
provide a distinct and important source of social support to their partners that is not associated
with friends or other family members (Coyne & DeLongis, 1986). Older adults may be more
reliant on their marital partners for support following decreases in their social network resulting
from the retirement, relocation, and/or death of other interpersonal contacts, such as adult
children or friends (Gagnon, Hersen, Kabacoff, & Van Hasselt, 1999). In light of the importance
of the spousal relationship for individuals at the later end of the lifespan and the distinct role of a
partner in providing support, especially in the face of illness, the spousal relationship certainly
deserves consideration when examining the health care decision-making processes of older
adults.

As research shows that marital relationships in older adulthood differ significantly from
those in younger adulthood, understanding what makes older marriages unique may shed light on
the role of a spouse in a medical decision. The degree of marital quality in a relationship may
be an important factor in the influence of a spouse in a health-care decision, if only because a
spouse’s perception of support from a partner ostensibly, in part, in determines marital
satisfaction (Fincham & Bradbury, 1990). Mares and Fitzpatrick (2004), in a review of
communication in the close relationships of older adults, noted that recent cohorts of older adults
typically report high levels of marital satisfaction, declines in the severity of their marital
problems, and high levels of control over their marital situation. However, they also noted that
the cross-sectional design of most of the research in this area may indicate that such findings are
attributable to cohort effects rather than improvement of marital quality over time. Nonetheless, increases in marital quality in older age suggest that older couples may experience greater levels of support within their marriages than younger and middle aged couples (Gagnon, Hersen, Kabacoff, & Van Hasselt, 1999).

Marital quality, conjugal support, and health are linked in important ways in older marriages. Social support from a spouse in making a major health-care decision could be a critical factor. After all, older adults depend on their spouses for support in older age (Gagnon, Hersen, Kabacoff, & Van Hasselt, 1999), and higher levels of social support often offset the detrimental impact stress has on older adults’ mental health (Cutrona, Russell, and Rose, 1986). Acitelli and Antonucci (1994) found the connection between conjugal support and health to be particularly strong for older wives. Specifically, older wives’ perceptions of support from their husbands (not actual support) had important implications for their emotional health and marital satisfaction (Acitelli & Antonucci, 1994). The authors speculated that emotionally supportive behavior of husbands is closely linked to the marital and life satisfaction among older women.

Despite the connection between conjugal support and health, some evidence suggests that conjugal support generally diminishes with age. Depner and Ingersoll-Dayton (1985) studied the responses of 412 married individuals who were interviewed about the provision and receipt of social support at the later end of the lifespan. The sample was split into three age groups: 50-64, 65-74, and over 75. The three different types of social support of interest were emotional support (such as confiding and reassuring), respect, and health support (such as caring when ill and talking about one’s health). The authors determined that receipt of health support and provision of health and emotional support declined with age, but no significant age differences in the category of emotional support surfaced.
These results are especially interesting since illness adversely affects the marriages of many older adults (Booth & Johnson, 1994). Illness erodes satisfaction in a marital relationship (e.g., Booth & Johnson, 1994; Levenson, Carstensen, & Gottman, 1993; Wright, 1991) with the healthy being at greater risk of decline in marital satisfaction (Adamson, Feinauer, Lund, & Casrta, 1992; Booth & Johnson, 1994). Part of the reason for the decline is that spouses often take the role of a primary caregiver of a partner in the case of illness or disability, can be a burden and source of stress (e.g., Fitting, Rabins, Lucas, & Eastham, 1986; Zarit, Todd, & Zarit, 1986). Another reason for the decline in marital satisfaction during a partner’s illness relates to emotional patterns initiated by the ill spouse. In a study examining older-adult marital partners seeking treatment for marital or familial difficulties, some wives reported that during a husband’s illness, the husband made excessive demands for care and attention, harbored anger toward the wife, felt depressed and frustrated, and as a result withheld affection, which, in turn, left the wife feel rejected, resentful, and confused (Kosberg & Garcia, 1987). Illness can certainly have an effect on the degree of conjugal support in a marriage and marital quality in important ways that may be relevant in considering the role of a spouse in the major health-care decisions that older adults face.

The purpose of this review is not to disentangle the complexities associated with marital satisfaction and social support in the face of a major health care decision. Rather, it serves as a signal of the serious positive or negative influence a spouse could have in the health-care decision-making process of a partner. Conjugal support and marital quality appear to be inextricably linked in ways relevant to medical decisions. For example, if a person is confronted with a major medical decision in which one decision outcome would require the aid and care from a spouse, partnership in a marriage described as “high quality” would likely dictate the
outcome of the decision, as high quality marriages are also characterized by conjugal support. However, the idea of having to provide more support to a partner in a marriage that is already suffering could have direct negative consequences on the outcome of a major medical decision. Clearly, more research needs to address the role of a spouse on older adults’ decisions concerning health care. Further, the research cited above does not differentiate between long-term marriages in older adults versus marriages that occur in older adulthood. As research suggests that the dynamics of marital relationships may be cohort-specific, one might also deduce that other forms of romantic partnership, such as heterosexual cohabitation and same-sex partnership, that are more frequent in younger generations may also be seen as more salient in the social networks of older adults as new cohorts of adults age or a spouse passes away. Overall, the influence of romantic partners in the health care decisions of older adults is an important area of inquiry and consideration.

Family members other than spouses also appear to play a significant role in the decision-making processes of older adults. Of the research focusing on the role of families in health-care decisions, the influence of adult children on the decision-making process has received the most attention in scholarly research. The most common family members involved in the medical decision-making of an older person are adult children (Hagestad, 1984; Keith, 1983) and they have been found to be highly influential in their parents’ decision-making (Cicirelli, 1992a). In fact, a majority of elderly persons depend on help from their children more than on any other source (Cicirelli, 1992a). Some research has revealed that adult children are important and positive influences in the decision-making of their parents. In one study, Coulton, Dunkle, Chow, Haug, and Vielhaber (1988) determined that families play a vital, supportive role in elderly patients’ decision-making concerning hospital discharge planning. Participants in the
study reported that family members can either support the patient’s own decision-making efforts or make decisions on behalf of their family members, both of which can positively influence the decision-making. In another study, Pratt, Jones, Shin, and Walker (1989) investigated how involved elderly, single women are in decision-making relating to their care, as well as to how influential their daughters are in the process. Over 80% of the mothers and daughters in the study reported that the daughter was “always” or “usually” influential in major health care decisions or decisions about their mothers’ housing. Further, over 90% of the mothers and daughters also reported that they were satisfied or very satisfied with the decision-making process. Research, then, suggests the potential for adult children to have a positive effect in aiding their elderly parents in health care decision-making processes.

Although adult children can play a positive role in a parent’s health care decision-making process, adult child-parent communication about a parent’s health-care decision may be complicated by challenges that stem from issues of dependence and independence in their relationships. Negotiations of dependence and independence across a lifespan of a family are well documented (e.g., Baltes, 1996; Cicirelli, 1992a). Baltes (1996) asserted that humans in Western cultures learn to value independence and self-reliance as youth, whereas dependence is seen as a negative part of older adulthood. Families negotiate the move of children from dependence to independence, as well as the shift from independence to dependence, in response to the challenges of aging (Cicirelli, 1992a). Adult children play a central role in the negotiation of the latter case (Hummert & Morgan, 2001), if only because they are frequently in contact with their parents and provide assistance to them in their older age (e.g., Norris & Tindale, 1994; Rossi & Rossi, 1990). The negotiation between adult children and their parents in respect to independence versus dependence may be problematic because different family members have
different and potentially conflicting attitudes about autonomy and paternalism (Cicirelli, 1992a). Adult children may feel a strong concern and responsibility for the welfare of their parents that could manifest itself in interventions in a parent’s life in order to protect the parent (Cicirelli, 1992a). In exhibiting such paternalism toward a parent, an adult child signals that he or she is more competent than the parent (Hummert & Morgan, 2001). Paternalistic behavior can infringe on an older adults’ personal autonomy, or their capacity to make and execute their own decisions (Cicirelli, 1992a). A major health-care decision, then, provides a ripe situation for negotiations of independence and dependence between adult children and their parents. Such decisions may be a sign that an older adult is moving into a state of dependency, or, as defined by Cicirelli (1992a), a state of not being able to satisfy one’s own needs and wants by oneself. The stress associated with a major health-care decision, coupled with the perception that the ominous state of dependency associated with older age looms ahead, does not set the stage for effective discussions concerning health-related decisions, especially if adult-children exhibit paternalistic behavior. Indeed, the interactions that constitute the decision-making process between an adult-child and parent are characterized as problematic (Coupland, Weimann, & Giles, 1991).

Although adult children have the potential to be a positive influence in the health care decision-making of their parents, more research is needed to address how older adults actually can successfully use their family members, particularly adult children, to achieve satisfying decision outcomes.

Because of the difficulties associated with communication between older adults and their adult children in regard to their health-care decisions, older adults may be more willing to accept advice and help from persons closer to their age. For this reason, siblings and friends may be attractive interpersonal contacts in an older adult’s health care decisions. Elderly siblings,
researchers have shown, care be valuable sources of help in older age (e.g., Cicirelli, 1992b), even though systematic investigation of their role in health care decision-making has not yet occurred. Research suggests that sibling-support in older age is less prevalent than support from spouses and adult children, but that siblings, nonetheless, play an important role in supplementing the efforts of other family members (Cicirelli, 1992b). In the case that support is not available from adult children and spouses, for example, as a result of geographic distance or widowhood, sibling support is typically greater (e.g., O’Bryant, 1988). Dykstra (1993) discovered that the proportion of siblings active in an older adult’s social network is higher in cases in which a person had not married, which again lends support to the notion that sibling support is less critical in instances in which a spouse is present. Nonetheless, because sibling dyads tend to have a high degree of closeness in older age (e.g., Avioli, 1989; Cicirelli, 1982) and stand ready to assist each other in times of need (e.g., Cicirelli, 1992b), the potential for siblings to be significant in the health care decision-making processes of older adults should not be overlooked.

Friends may also play an important role in the health decisions of older adults. The positive influence of friends and acquaintances on older adults’ psychological well-being is well documented (e.g., Litwin, 1998; Powers, 1996; Reinhardt, 1996). As mentioned previously, friends provide emotional support (Felton & Berry, 1992) and serve as confidants (Connidis & Davies, 1990, 1992), just as family members do. Friendships also serve unique purposes that family members do not. Older adults’ friends more often are companions for social activities than adult children and other kin (Crohan & Antonucci, 1989). Additionally, friendships can be more important to psychological well-being than family contacts (e.g., O’Connor, 1995; Pecchioni, Wright, & Nussbaum, 2005).
Although research examining the role of friends in the health-care decisions of older adults is limited, older adults do report that they rely on their friends for counsel (e.g., Shea, Thompson, and Blieszner, 1988) and depend on friends to assist them in their judgments, decisions and dealings with others (Sukowsky, 1977). Calling on friends for advice and counsel in matters involving major health-care decisions may be attractive for older individuals, as friendships later adulthood provide a secure environment in which to manage declines in health (Nussbaum, 1994). On the whole, such findings suggest that older adults may be inclined to discuss their health-care decisions with friends not only because they expect friends can provide social support during the process, but also because they may seek advice from friends about the decision at hand.

Friendships in later life may be particularly important when considering major health-care decisions since friendships in later life are not wrought with the same challenges of power and control that are common in familial relationships. Friendships in later adulthood are characterized by nonobligatory provision of social support and equality (Nussbaum, 1994). Support is given and received between friends in a more balanced fashion than, for example, in the case with parent-adult child dyads, in which support is associated with dependency (Nussbaum, 1994). This notion received support in a study in which interviews with older adults focused on social support, social control, and companionship in the close relationships of older adults. Rook and Ituarte (1999), for instance, determined that friends served more often as sources of companionship, whereas family members as a whole were sources of social control, as well for both social and instrumental support. The fact that older adults appear to seek friends more for companionship than they do other family members in the context of health-related behavior context lends support to the notion that older adults need friendships to buffer the
effects of less egalitarian relational patterns, particularly in the parent-adult child relationship. Older adults, presumably, need friends to discuss difficulties with their adult children (Francis, 1981). Moreover, friendship in later life inhibits demoralization (e.g., Lowenthal & Haven, 1968).

Reviewing the potential influence of the figures associated with the interpersonal context of an older adult’s health-care decision certainly echoes Schoenberg, Amey, Stoller, and Muldoon (2003)’s assertion that the social network associated with such decisions is complex. Considering the roles of each potential interpersonal influence and their relationships to an older adult decision maker can bring to light the distinctive elements associated with each figure.

*The Cultural Context*

Of all of the social contexts that serve to situate the interactions involved with decisions about health care, the cultural context of communication is the most intangible. The influence of culture on decision-making, because of the symbolic and subconscious nature of its influence in human life, may be more indeterminate than the influence of other social contexts in the ecology of health care decision-making. Chen and Starosta (1998) define culture as “a set of fundamental ideas, practices, and experiences of a group of people that are symbolically transmitted generation to generation through a learning process” (p. 25). Culture, then, can include a group’s collected values, beliefs, norms, rules, communicative behavior, social institutions, and media channels (Pecchioni, Ota, & Sparks, 2004). Culture is inextricably and reciprocally linked to communication (Chen & Sarosta, 1998; Gundykunst, 1998, Williams & Nussbaum, 2001). Culture also is bound to definitions of health and illness and the causes of disease (Witte & Morrsion, 1995). Thus, naturally, culture as a factor in health communication is an important concern.
Street (2003) situates the context of culture in health communication by explaining three ways in which ethnicity appears to have a predispositional influence on communication. First, race and ethnicity affect how providers and patients interact. For example, how patients convey their symptoms may not be understood by providers if they do not share ethnic background. Second, preferred styles of communicating in terms of assertiveness and expressiveness differ across ethnic groups. People from individualistically oriented cultures, like The United States and Northern Europe, may be more direct and assertive in their communication with physicians and about their health than persons from collectivist countries. Moreover, individuals from collectivistic countries may be less willing to communicate about their health and more apprehensive in talking with a health professional. Finally, as Street (2003) noted, those of different ethnic background may have different explanatory models of disease and illness. He explained that a person’s understanding of health includes beliefs about the cause of an illness, the degree of personal control over health, and the best ways to manage health problems. These considerations are drenched in one’s cultural upbringing and have a predispositional influence on communication about health. Clearly, culture has significant consequences for health communication.

Cultural factors in health communication are particularly relevant for older adults. To begin, cultural background appears to have effects on the biological aging of the human body (e.g., Kontos, 1999), as well as the cognitive performance of older persons (e.g., Levy & Langer, 1994). Culture also helps individuals to make sense of mortality, suffering, and death, (e.g., Greenberg, Solomon, & Pyszczynski, 1997), which become increasingly salient in the lives of older adults.
In addition to ways in which cultural background can affect issues related to health in older adults, age may also be considered a culture in and of itself. Pechionni, Ota, and Sparks (2004) note that definitions of and meanings assigned to the aging process vary as a function of culture and that age may be treated as a co-culture. Like other cultures, such as those marginalized on the basis of gender, race, ethnicity (e.g., Gutierrez & Lewis, 1997), social class (e.g., Marshall & McKeon, 1996), disability (e.g., Braithwaite, 1996), and sexual orientation (e.g., Yep & Pietri, 1999), people are often marginalized on the basis of age (e.g., Hummert, Garstka, Shaner, & Strahm, 1994). Marginalization is a serious concern for health communication, as negative effects on individuals’ ability to maintain good health result from it (see Ford & Yep, 2004). Moreover, evidence suggests that marginalization could specifically affect decisions involving medical care. For example, one study revealed that those marginalized on the basis of ethnicity were less likely to self-express their own healthcare choices (Hornung, Eleazer, Strothers, Wieland, Eng, McCann, et al., 1998). Hornung et al. concluded that the possibility exists that ethnic minorities run a risk of being subjected to treatment regimens that are at odds with their personal preferences. In turn, such choices could negatively affect the quality of life of such marginalized individuals and have an impact on their medical care costs.

Although the effect of culture specifically on decision-making processes involving health care has yet to be addressed in scholarly research from a communication standpoint, one can deduce that cultural factors likely have an important influence on medical decisions. Further, evidence certainly suggests that culture is particularly influential in making decisions about health care at the later end of the lifespan. Culture may be particularly relevant in health-care decisions in the later stages of life with respect to sense-making about illness and end-of-life
issues. Nonetheless, cultural factors, as the definition of culture would imply, are often so
fundamental and symbolic that articulating or identifying the impact of such factors may be
elusive. If one takes those of advanced age as a marginalized culture in and of itself, the
influence of culture may be more concrete in the context of health-care decision making. As
mentioned in reference to the interpersonal context of communication, older adults sometimes
feel vulnerable to, demoralized by, and dependent on others in face of health-care decisions.
Connecting this to the notion of older age as a culture and as subject to the effects of
marginalization, one can see how culture may have a significant effect on the medical decision-
making processes of older adults.

The Religious/Spiritual Context

Relevant to the notion that examining decision-making about health care for older adults
with reference to culture could provide greater insight to the process is the potential impact of an
individual’s religion and/or spirituality in a similar regard. In fact, some research has indicated
that for some, race, ethnicity, religion, and health are inextricably linked, particularly among
older adults (e.g., Taylor, Chatters, & Levin, 2004). For example, various researchers have
examined aging, religion, and health among older African Americans and has determined that
religious involvement of African Americans has a beneficial effect on psychological well-being
(e.g., Levin & Taylor, 1998). Other studies have suggested that African American’s interactions
with clergy are significant for their self-esteem, but that such interactions may be unrelated in the
comprehensive review of research focusing on racial differences in religious involvement and
effects of religious factors on physical and mental health suggests that religion may be
differentially important for health and well-being, particularly among African Americans.
Additional research has addressed religion/spirituality and health in elderly Hispanic/Latino populations. For example, Levin and Markides (1985) identified links between religious factors and physical health and psychological health in three generations of Mexican Americans. Although scholars continue to explore religion and health associations in Mexican American populations with cross-sectional and longitudinal studies (see, for example, Levin, Markides, & Ray, 1996) that lend evidence to the importance of culture and religion/spirituality in health related contexts for Mexican Americans, many questions regarding the nature of the relationships at hand remain unanswered (Chatters, 2004). Still, such investigations are important as they explore religious experience within particular cultural groups that can aid in understanding how cultural and religious/spiritual factors function in other domains of interest, such as health-related decisions at the later end of the lifespan. Generally, one can conclude that one’s cultural and religious/spiritual background can come together in meaningful ways that can affect health and decisions related to health.

Aside from how religion and culture are intertwined affecting health and health care decisions, religion in and of itself is an important factor in the health considerations of individuals in later life. Generally, religious beliefs seem to affect how individuals view life, death, and health care (Grodin, 1993). As a result, religiosity and spirituality stand out as important elements in a biopsychosocial approach to medical care (Sloan, Bagiella, & Powell, 1999), which stresses the incorporation of the physical, mental and spiritual in order to ensure quality health care. After all, religion has been shown to shape how patients understand and enact medical directives and advice (Barnard, Dayringer, & Cassel, 1995), which suggests the importance of considering a person’s religious/spiritual background during medical encounters.
The integration of religion and spirituality as considerations in health care may be especially important for adults at the later end of the lifespan for several reasons. First, religious beliefs and motivation tend to increase in older age (Koenig, Kvale, & Ferrel, 1988). Additionally, older adults who were not previously active in religion revert to their religious roots when faced with issues of death and dying (Klessig, 1992). As major health-care decisions at the later end of the lifespan frequently involve consideration of end-of-life issues, religion and spirituality may prove to be important in such decisions. Some research supports this possibility. For example, Ejaz’s (2000) investigation of the influence of religious and personal values on older adult’s attitudes toward life sustaining treatments revealed that older adults who were of Catholic, Jewish, or Protestant faith, generally reported that their religious beliefs influenced their decisions concerning life-prolonging treatments. Additionally, religion and spirituality reportedly affect how patients make medical decisions, especially as they pertain to chronic and terminal illness (Wennberg, 1989). Further, a study examining decisions to continue dialysis indicated that a majority of respondents wanted their religious beliefs to be considered a great deal in the decision-making (Sehgal, Galbraith, Chesney, Schoenfeld, Charles, & Lo, 1992).

Clearly, older adults tap into their religious and spiritual backgrounds when making end-of-life medical decisions. The extent of the influence of religion and spirituality for major medical decisions that are not readily identified as involving end-of-life issues, however, is unclear. For example, an older adult making a decision to have a hip replacement may be less influenced by his/her religious background than someone deciding whether to continue dialysis because the latter would presumably be perceived as a more life-threatening situation. The seriousness of the decision and the severity of the associated consequences would likely mediate the influence of religion and spirituality in the decision-making.
The impact of religion and spirituality on end-of-life treatment choices is clear, as religious belief systems often speak directly to such issues. A myriad of religious traditions have specific doctrine and ethical standards for end-of-life medical decision-making, not only in matters of high controversy, such as physician-assisted suicide or euthanasia, but also in matters involving advanced care planning, palliative care, withdrawal of life-support, and life-extending treatments (O’Connell, 1995). For example, Judaism, especially in orthodox sects, upholds preservation of life at all costs (Dubler & Nimmons, 1992), whereas Catholicism teaches that discontinuation of medical procedures that are “burdensome, dangerous, extraordinary, or disproportionate to the expected outcome” (p. 550) is acceptable (Catechism of the Catholic Church, 2000).

Religious and spiritual belief systems have additional characteristics that may make them relevant in health care decision-making processes, even if they do not involve end-of-life issues. First, religion and spirituality can be a resource for coping with the stress of a major medical decision. Religion has been acknowledged as an important factor for individuals in times of crisis or stress (e.g., Pargament & Ano, 2004). Religion and spirituality contribute to the way people orient to times of trouble or threat (McFadden, 2004). Thus, religion can play an important role in coping with threats, such as those that accompany a major medical decision. For example, Koenig, George, and Siegler (1988) conducted a study in which they explored the emotion-regulating coping strategies adults aged 55 to 80 used in response to stressful experiences. As part of semi-structured interviews, participants answered questions concerning how they coped with their most stressful experiences. Their spontaneous responses fell into 25 distinct categories of emotion-regulating coping strategies. Almost half of the respondents mentioned a religious coping behavior as a response to at least one of the three stressful
experiences about which they talked during the interviews. The most frequently mentioned coping strategies were religious in nature. The authors speculated that during experiences when people feel little control and for which problem-focused coping strategies have little value, religious coping strategies can be a particularly effective in dealing with stress (Koenig, George, & Siegler, 1988). The physical illnesses or disabilities that form the basis of a major health-care decision may be instances in which a person feels little control. Indeed, individuals depend heavily on religious/spiritual beliefs as resources to cope when they are physically or psychologically ill (e.g., Koenig, 1998). As a result, religious coping strategies may be an important part of the decision-making process for older adults faced with a major medical decision. The impact on physical health could be positive or negative, however. As Pargament and Ano (2004) observed, religious coping strategies can be beneficial in that persons are comforted by their knowledge of the love of their higher power and thus experience a decrease in anxiety. On the other hand, religious coping may prevent persons from seeking medical treatment for curable diseases because seeking such help would demonstrate a lack of faith in God. Religion and spirituality could most certainly influence an individual’s ability to cope with the process of decision-making regarding a major health care decision, and could potentially impact the decision outcome in meaningful ways as well.

Another characteristic of religion and spirituality that may be relevant in the process of making decisions related to health in older adulthood is that religious practice links an individual to a network of positive social support. Individuals who report high levels of also typically have higher levels of social support than those who are not religious (e.g., Krause 2002; Krause, Ellison, Shaw, Marcum, & Boardman, 2001). As discussed in relation to the interpersonal context of communication, social support may be of critical importance in the decision-making
of older adults faced with a major health-care decision. Beyond the general importance of social support in making major medical decisions in later adulthood, social support in a religious or spiritual context seems to have unique effects. Social support related to religion and spirituality can provide particularly potent support for one’s values and beliefs (Krause & Wulff, 2005). For example, social integration that results from prolonged involvement with one’s congregation or religious sect may increase one’s sense of belonging and identity with a particular religious group, making the support and advice from other members particularly meaningful and influential.

Social support associated with one’s religion and spirituality can also serve as an additional source of healthy religious coping. Religion and spirituality connect people to congregations, which can serve as coping mechanisms in and of themselves by communicating support through formal and informal means, including worship services, opportunities for fellowship, prayers, hymns, and symbols, such as pastors shaking hands and the presence of flowers in church (McFadden, 2004). McFadden (2004) specifically connected congregation to religious coping. She noted that religious congregations provide support for public rituals and private behavior that enables people to cope with health related tribulations. Further, congregations can support others by providing aid to those who are frail or otherwise mentally incapacitated. In a sense, religious coping necessarily becomes even more communal as people advance in age and frailty (McFadden, 2004).

Unfortunately, the positive effects of religious social support and contact with a religious congregation may have on the health care decision-making processes of older adults could be compromised by the fact that health often prohibits older adults from participation in religion.
Alas, active participation in church services tends to decline in older age, even though religious belief and motivation tends to increase (Koenig, Kvale, & Ferrel, 1988).

Although research in communication has only recently taken up examination of spiritual and religious factors in health-related study, such attention to the religion and spirituality as an influential social context on health-related decisions is certainly warranted. As Parrott (2004) asserted in introducing a special issue of *Health Communication* dedicated to integrating the study of religious faith and spirituality in health communication research and practice, “Individual predisposition to think, feel, or act based on belief in a spiritual power greater than humans affecting the course of nature and the role of humans within that realm has far-reaching health effects. Knowledge about lay discourse associated with religious faith and spirituality, therefore, is likely to reveal insights about lay theories associated with health, which may be used to facilitate health education, promotion, and counseling efforts across disciplinary boundaries associated with health communication” (p. 1). Given what is known about the significant influence religion/spirituality on health, the effect of religious coping on stress and health issues, the link between religion/spirituality on social support, and the unique contribution of support from individuals in religious/spiritual context, religion and spirituality likely play a more significant role in major medical decision-making than is currently understood.

*The Political-Legal Context*

Numerous factors comprise the political-legal context of health care. For example, a socialized system of health care has a very different influence on patient decision-making than does a pay-for-service system. Although the impact of the federal government on the inner workings of a nation’s health care system is certainly an important consideration for an individual’s medical decision-making, discussion here focuses on the factors associated with
managed care and insurance, which are both immediate and salient in an older person’s experience of a major health care decision.

Managed care is a broad term describing the current, dominant way in which health care providers negotiate payment levels for a defined patient population with health insurance providers for the purpose of keeping health care costs low (Nussbaum, Pecchioni, & Crowell, 2001). A variety of changes have come with the advent of managed care, especially for older patients whose experience with the health care system predates it. An older patient may not be able to choose a specific physician or health-care provider, spend as much time with a particular physician as he or she would like, or be completely aware of the payment structure of a visit or procedure (e.g., Farmer, 1994; Serafini, 1990; Ward, 1990). As health-care providers try to manage declining revenues as a result of managed care, primary-care physicians often must spend less time with each patient and redefine their professions in the health-care system (for example, becoming gatekeepers to specialists) (e.g., Farmer, 1994; Serafini, 1990; Ward, 1990). In short, managed care directly affects the way health-care providers interact with patients in regards to services (Greene & Adelman, 1996).

Another political-legal factor that may directly affect decisions about health care is a person’s medical insurance. At a general level, continuous insurance coverage has been associated with improved health (Hadley & Waidmann, 2006), even though this claim has been contested (Kronick, 2006). Nevertheless, research offers plausible reasons to believe that insurance status has an effect on one’s health decisions and, in turn, one’s overall health. For example, Medicare health maintenance organizations are allegedly superior to Medicare fee-for-service plans in delivering preventative care (Landon, Zaslavsky, Bernard, Cioffi, & Cleary, 2004). One study revealed that elderly individuals who had dual Medicare-Medicaid enrollment
were significantly less likely to have colorectal cancer screening than those who were not dually enrolled (Koroukian, Xu, Dor, & Cooper, 2006). Further, research has indicated that veterans receiving health care through the Veterans Health Administration are more likely to report having an influenza vaccine, a pneumococcal vaccine, and prostate cancer screening than those veterans receiving care through a Medicare HMO (Keyhani, Ross, Herbert, Dellenbaugh, Penrod, & Siu, 2007). Health insurance status seems to affect decisions related to health care prevention. The extent to which insurance type and socioeconomic status affect a health related decisions of a greater magnitude is not clear. Overall, however, the political-legal context offers various concerns for older adults’ decisions about health care. Perhaps the implications are most evident through the effects of managed care on physicians, as seen in the subsequent discussion of the influence of the organizational context older patient decision-making.

The Organizational Context

The organizational context of health care is complex and consists of a variety of features that affect a person’s health care, including the physical health-care facilities in which a person receives care, the system of financing and insurance for care, and the people associated with these systems (Street, 2003). Physicians are the most direct resource for information and source of influence on decision-making about health care at the latter end of the lifespan. A wealth of scholarly work has examined physician-patient interactions (see Part II, Thompson, Dorsey, Miller, & Parrott, 2003). A concise summary of research concerning physician-older patient interactions can serve as a suitable starting point for examining the organizational influence on decision-making for older adults. After all, the stakes associated with physician-patient interaction in informing health decisions are particularly significant for older adults, as the risks and benefits of any given intervention are great. The potential for medical interventions to help
older adults is major, but high risks of mortality and morbidity are also associated with
treatments for older adults (Halter, 1999). Certainly, the role of a physician in decision-making
related to health care is of critical importance to an older patient. Unfortunately, a variety of
complications can arise in physician-older patient interactions that can affect the decision-
making process.

Many of the complications in physician-older patient interactions stem from complexities
associated with the current trend in patient care that encourages adults to exercise autonomy in
their medical decisions and share the decision-making process with their health-care providers
(Liu & Gonzalez, 2007). In the past, a physician was primarily responsible for selecting patient
treatments (Altman, Parmlee, & Smyer, 1992). Thus, medical decision-making rested mostly
with one’s physician. As a result of movements in ethics to ensure that physicians by law must
present information to a patient regarding “the nature of the disorder and of the proposed
intervention, the likely benefits, risks, and discomforts, and possible alternatives” (Appelbaum &
Grisso, 1988, p.1637), the notion of patient involvement, participation, and control has become
an important one in research.

Patients are increasingly doing their own research and collaborating with their physicians
to improve their quality and length of life (Lindberg, 2002). In contrast to the traditional,
paternalistic approaches to health care in which the physician was primarily responsible for
selecting treatments and making decisions about medical interventions (as was the case when the
current cohort of older adults began using medical services), today’s physician and patient now
commonly share the responsibility (Altman, Parmlee, & Smyer, 1992). However, older adults
often do not assert their right to participate actively in the decisions for medical treatment
selection. Biesecker and Thompson (1995) observed that the current cohort of older adults do
not want as much involvement in medical decision-making as do younger adults, which, by implication, suggests that older patients want physicians to be in control of the medical decision-making. In addition, a study by Curley, Eraker, and Yates (1984) that investigated patients’ treatment choices relative to their uncertainty revealed that one-third of the sample deferred to the physician in making decisions concerning health care. The study also showed that as people advance in age, they are more likely to commission others to make decisions for them. Overall, research suggests that despite the fact that individuals of sound mind have a right to participate in determine decisions about proposed medical care under the doctrine of informed consent (Altman, Parmlee, & Smyer, 1992), older adults may hesitate to assert their right to be actively involved in treatment selection (Zwahr, 1999).

There are many reasons why older adults may not want as much involvement in medical decision-making as their younger counterparts. Yates and Patalano (1999) noted that the “age-agency” association may be a cohort artifact. Participative health-care decision-making is simply more popular now than when older adults first came in conscious contact with the health-care system. Another reason that older adults may be less participative in decision-making is that they believe their decision-making capability has diminished with advancing age. Older adults may also commission others to make decisions for them because they find that making complex decisions takes more energy and effort than they want to expend. Yates and Patalano suggest that commissioning the services of an external decision maker is not necessarily an admission of diminished capabilities, but an economic, intelligent exercise in executive action. The experience of older adults has taught them that delegating certain undertakings is just as effective as and less time-consuming than doing things for themselves. Finally, Yates and
Patalano concluded that older adults may also adopt the attitude toward health related decision-making as simply “not that important” and would rather be engaging with other aspects of life.

Other reasons for a lack of involvement in medical decision-making relate to the idea that active involvement of a patient in medical decision-making processes may place additional burden on an individual who is already distressed (Pierce, 1996). Sometimes, the severity of a decision may create difficulties in coping. Older adults are more likely than younger individuals to be dealing with chronic conditions complicated by co-morbidities (Adelman, Greene, & Charon, 1991; Biesecker, 1996; Nussbaum, Ragan, & Whaley, 2003). Commissioning the decision may be a way for older adults to manage the uncertainty and severity of their health condition(s).

A final area of research that helps explain older adults’ low desire for participation in medical decisions involves cognitive factors. Zwahr (1999) posited and uncovered evidence that older individuals may take a hands-off approach to medical decision-making because their informational needs have not been satisfied and therefore, do not feel comfortable in health decision-making.

The possible reasons for older adults’ hesitation to participate in health-care decision-making are numerous and varied. Nonetheless, research has established that patient involvement and control in health decisions are important. Research by Ballard-Reisch (1990) stressed the importance of a patient’s participation in medical decision-making and the importance of open communication to allow for negotiation of roles and outcomes during the decision-making process. Ratzan (1993) also emphasized the importance of negotiation during medical encounters and argued that effective communication and building trust during patient-physician interactions is necessary for both sides achieve their goals. Further, exercising personal
autonomy and control has proved to be significant in maintaining one’s psychological health at all ages (Heckhausen & Schulz, 1995). Active participation has many beneficial outcomes. For example, according to Wallace (1986), active participation in medical decisions leads to more rapid recovery. Brody, Miller, Lerman, Smith, and Caputo (1989) determined that active involvement in health-related decision making contributed to improved treatment effectiveness, as well as greater control of and improvement in actual health. If physicians offer more information and control to patients, they may enhance their physical and mental health and reinvest patients with a sense of control (Taylor, 1976). Finally, doctors’ sharing responsibility in decision-making with their patients fosters increased outpatient responsibility, perceptions of control, and positive therapeutic outcomes (Pendleton, Schofield, Tate, & Havelock, 1984). Active patient involvement in health-care decision-making can certainly have important implications in the process and outcomes of coping with the uncertainty involved in the decisions of older adults.

Despite the purported positive effects of patient involvement in health care decisions, older adults do not seem to reap the benefits of a health care system characterized by patient participation in their decisions. As mentioned previously, Liu and Gonzalez (2007) emphasized that when older adults are expected to take an active role in their medical decisions, the potential for suboptimal decision-making increases. Two reasons emerge from current scholarship that can explain why this may be the case. First, there are characteristics associated with health care professionals and the current system of managed care that pose challenges for older patient involvement in their health care decisions. Second, characteristics of older adult decision makers are not conducive with such a system. Considering these two complications in detail may shed
new light on the potential impact of physicians on the medical decision-making process of older adults.

The competency in the communication of medical information during the physician-older patient encounter is key in a physician’s ability to provide therapeutic intervention and a basis for patient adherence (Halter, 1999). At a very basic level, effective communication in physician-patient encounters is characterized by successful inquiry and information-sharing by both parties (e.g., Hall, Roter, & Katz, 1988; Thompson, Robinson, & Beisecker, 2004). Physicians must seek information from patients about their health and provide information about health conditions and treatments. Patients must provide information about their health and be able to ask questions relevant to understanding their condition and treatment options.

Unfortunately, research suggests that the process of inquiry and information sharing between older patients and their physicians is less than optimal. Researchers have noted that that older adults typically ask fewer questions, need longer interactions to ask important questions, give less information to a health-care provider, and are much less assertive than their younger counterparts (Nussbaum, Ragan, & Whaley, 2003). Some studies have shown that older patients may ask more questions during a medical encounter, but only if the encounter is lengthy (Beisecker & Beisecker, 1990). Physicians are more likely to raise medical issues than older patients, although older patients are more likely to raise psychological matters (Adelman, Greene, Charon, & Friedman, 1990). Further, physicians do not tend to respond with as much information if older patients raise an issue and generally respond with less information relative to the information they provide to younger adults (Street, 1991). Physicians tend to spend less time with older people that younger ones (Adelman, Greene, & Charon, 1991), even if older patients take more time in providing information about their conditions (Haug & Ory, 1987). A
physician’s time is often constrained by the current system of managed care in that physicians are often required to limit appointment length, which adds an extra layer of complexity to the physician-older patient interaction (Nussbaum, Pecchioni, & Crowell, 2001). Finally, research has suggested that physicians have not received formal training in effectively communicating medical information to elderly patients in order to aid them in making their medical decisions (Halter, 1999). The nature of communication between physicians and their older patients is wrought with complications that can inhibit effective health care decision-making.

Williams and Nussbaum (2001) attribute communicative complications of physician-older patient interactions to ageism and stereotyping. Moreover, the Communication Predicament of Aging Model (Ryan, Giles, Bartoluci, & Henwood, 1986) posits that when a young individual approaches an older person to interact, such is the most likely case in a physician-older patient medical encounter, the younger person notices certain physical cues that trigger intergroup categorization and associated age stereotypes. So despite the fact that outward physical cues of aging (such as grey hair or wrinkles) are not correlated with cognitive impairment or slowed mental capacity (Sprott & Roth, 1992), when interacting with older adults, younger individuals communicate such stereotypic assumptions through their speech patterns (Ryan, Giles, Bartoluci, & Henwood, 1986). One would assume that physicians would be above allowing stereotypic expectations based on physical cues that are not related to the mental capacity of an individual to guide their interactions with older adult patients and thus would have less problematic interactions during their medical encounters than other younger adults. However, the communicative problems as a result of ageist stereotypes are most pronounced in medical encounters (Nussbaum, Pecchioni, Grant, & Folwell, 2000).
Although tapping into stereotypes that associate older age with dementia is inappropriate, changes in information processing do occur as part of the normal process of aging and can affect how older adults obtain and use information from an encounter with a medical professional. Older adults are slower at processing information, have less capacity with which to process new information, and experience more difficulty focusing attention on most relevant and important information in their environment than younger adults (Park, 1999). Automatic processing (the processes that effortlessly guide everyday behavior), on the other hand, are, at worst, only slightly age-impaired (Park, 1999). Accordingly, older adults are adept at understanding speech, and some evidence suggests that they have little difficulty comprehending written materials, except in cases in which inferences are required or grammatical structure places a high load on working memory (Kemper & Kemtes, 1999). Hence, although older adults may initially understand the information presented to them by a health professional, they may have trouble remembering the information presented to them, especially if it is novel or does not build on existing knowledge (Park, 1999).

Older adults may be slow to process information that is rapidly presented in verbal interactions with health-care providers and may not have the cognitive resources required to make appropriate inferences about the information presented to them verbally. As a result, older adults may have difficulty comprehending medical information at both a simple level in terms of understanding instructions concerning medications and at more complex levels, such as what is required to make important medical decisions (Park, 1999). Older patients often must make decisions on the basis of less information and less effortful, controlled processes, which, in turn, may lead to a decrease in decision quality (Meyer, Russo, & Talbot, 1995).
The characteristics associated with health-care providers and the system of managed care coupled with characteristics of older adult decision makers certainly complicates the process of medical decision-making for older adults. The problems that arise in information sharing in older adult-physician interactions can have far-reaching consequences for older adults. The quality of diagnosis depends, in part, on the information shared by the patient (Thompson, Robinson, & Beisecker, 2004), and information-giving on the part of the physician is associated with increased compliance, patient recall and understanding, and patient satisfaction (Hall, Roter, & Katz, 1988), decreased levels of concern in patients (Arnston, Makoul, Pendleton, & Schofield, 1989), and improved health status (Kaplan, Greenfield, & Ware, 1989). Although older patients reportedly do not receive as much information as younger patients, they do desire it (Beisecker, 1988; Haug & Ory, 1987; Rogers, Addington-Hall, Aberly, McCoy, Bulpitt, Coats, & Gibbs, 2000), which can have a significant impact on their health-related decision-making.

Although the physician-patient interaction is the most commonly researched organizational factor influencing health-related decision making, other organizational influences have impact as well. For example, health-care teams and professional health associations (such as the American Diabetes Association or American Cancer Society) may be important resources. As established previously, health care for individuals later in the life span can involve decisions regarding a complex and diverse set of medical issues (Pfeiffer, 1998). Older individuals and their caregivers frequently experience a high degree of uncertainty regarding medical care treatment options as a result of the variety of medical, psychological, social, and religious/spiritual concerns pertinent to health care decisions (e.g., Hines, Babrow, Badzek, & Moss, 1997).
Given their ability to draw expertise from a variety of relevant professionals, health-care teams (HCTs) may provide an effective means of dealing with the complexity, diversity, and uncertainty surrounding medical decisions (e.g., Pfeiffer, 1998). The ability for HCTs to aid older adults in the health decision-making may be an important area of research. However, research regarding the effectiveness of HCTs has been inconsistent at best (see Poole & Real, 2003). The reasons for these inconsistencies may stem from theoretical and definitional issues in current research regarding HCTs. The current political-legal context of health care is not conducive to the development of health-care teams to aid in the decision-making process for older individuals; thus, research involving naturally occurring HCTs is challenging. Nonetheless, the impact of HCTs as a potentially positive organizational influence in the decision-making process for older adults should not be underestimated. Various investigators have advanced the notion that HCTs are a feasible and effective means of managing the diverse needs of older patients (e.g., Hogan & Fox, 1990; Hogan, Fox, Badley, & Mann, 1987; Pfeiffer, 1998; Poulin, Walter, & Walker, 1994; Rubenstein, Josephson, Wieland, English, Sayre, & Kane, 1984; Silliman, McGarrey, Raymond, & Fretwell, 1990; Tierney & Vallis, 1999). Although professional health associations are not as heavily researched as forms of health decision-making support, their impact as an organizational influence should not be overlooked.

Clearly, the organizational context of communication in the ecology of health-related decision making in older adulthood can have far-reaching impacts for decision-makers. The complexities associated with physician-older patient interactions run deep, and extant scholarly literature provides no easy answers for dealing with the challenges, especially given the current political-legal climate of the health care system in the United States which is biased against longer appointment times and health care teams which could assist in the medical decisions of
older adults. The influence of figures in the organizational context on the decision-making process and outcome of a major health care decision from the perspective of the decision-maker has yet to be accomplished. Given what is known about the complexities in communication associated with the political-legal and organizational contexts in regard to the state of health care for the current cohort of older adults, such research would be enlightening.

The Media Context

Media technologies are an essential component of the health care system (Street, 2003). Technologies, such as telephone, fax, printing, and Internet, have become highly integrated into Western medical systems and serve a variety of purposes in the delivery of health care. Television and radio are also relevant sources for health-related information, for example, in that they can expose people to news coverage and public service announcements about health. As Street (2003) noted, however, the medium that has received the most attention in recent years with reference to health care is the Internet. For the purpose of this review, the Internet also serves as the foundation for considering the influence of the media context on decisions about health care for older adults, as it is an important source of health information.

Older individuals are more and more frequently using the Internet (McMellon & Schiffman, 2002), which has made age a less significant predictor of Internet use (Morrell, Mayhorn, & Bennett, 2000). Increasing numbers of older adults are enthusiastic users, particularly for self-initiated access to health information. A recent study indicated that about 46% of adults over 60 use the Internet and that about 26% use the Internet to search for health information (Ybarra & Suman, 2008). Indeed, the Internet has become a necessary tool for older adults in making health-care decisions. The Internet could very well serve as an alternative or supplementary source to more traditional sources of health information (Morell, Mayhorn, &
Bennett 2000). Older individuals are doing research concerning health and medical care independently, and as a result, the Internet is having a considerable impact on people’s health as they are using online resources to learn about wellness issues and research about diseases (Lindberg, 2002).

Although information is available online specifically for the purposes of older adults’ search for health information and takes into consideration some normal concerns about aging, such as font and color designs for older eyes (Morell, Mayhorn, & Bennett, 2002), the Internet is limited, in that most Web page designs do not consider age-related declines in vision and motor skills (Echt, 2002). Another limitation of the Internet as a viable source for older adults to learn about health related issues is that access to Internet technology remains a problem for some older adults. Despite such restrictions, the use of the Internet by older adults for locating health information is likely to increase and to continue having a positive impact on their health-related decision making (Morell, Mayhorn, & Bennett, 2002) even though the lack of quality of information found on health websites could be disconcerting (e.g., Eysenbach, Powell, Kuss, & Sa, 2002). Internet usage certainly seems to be a relevant factor in considering the process of health decision-making for older adults and may have important implications in the outcomes of their decisions.

A final way in which the Internet may be relevant to the health care decision-making processes of older adults is in its relation to provider-patient communication. Street (2003) observed that the Internet could facilitate greater patient participation in medical care through expanding a patient’s knowledge base and increasing communication with physicians through e-mail. Increasing shared decision-making between physicians and patients may result (Bauer, 2000; Winker et al., 2000), which, as discussed previously, has shown to be beneficial in many
regards for the average adult, but not so much with older adult populations as a result of age-related declines in information processing. The possibility that Internet technology could serve to aid older adults in processing information was an essential area of research for cognitive scholars. For the purpose of this investigation, the possible connection of Internet serving to aid or impede interactions between individuals and physicians is important. Although Internet technology may serve to facilitate physician-patient interaction, research suggests that it could also have the opposite effect. In a recent study, 49% of individuals reported that the Internet is their first line of inquiry for health information in, contrast to 11% who seek their physician first (Hesse et al., 2005). Further, Aspden and Katz (2001) determined that of patients who used the Internet to find health information, only 37% discussed their findings with their doctors.

Although these statistics are not specific to older adult populations or the health concerns of those at the later end of the lifespan, they may serve as a signal that the Internet has the potential to supersede the influence of a physician in decisions about health, at least in respect to whether or not to seek the advice of a physician.

The Internet clearly has consequences for the health-care decisions of older adults. The current cohort of older adults has shown increased utilization of the Internet for health information from their predecessors, and cohorts close behind are likely to follow suit. Sensitivity to the influence of the Internet as an influential factor in the medical decisions of those at the latter end of the lifespan is prudent, especially given the potential for the Internet to affect the interaction between decision-makers and their physicians.

**Rationale, Research Questions, and Hypotheses**

The social ecology of decisions involving health care at the later end of the lifespan, in light of what is known about how the communication situated in the interpersonal, cultural,
religious/spiritual, organizational, political-legal, and media contexts affect the processes and outcomes associated with health related decisions, is certainly rich and complex. What is clear from this review is that although each context has distinct elements that affect the health care decision-making of older adults, these contexts are overlapping and interdependent. For example, the cultural context and religious/spiritual context are intertwined in meaningful ways, as are the organizational and media, and organizational and political-legal. Moreover, although research endeavors have examined the effect of actors in each context, little is known about how contexts come together in the process of decision-making to determine the outcomes of the process. For example, some researchers have examined the complexities associated with interpersonal relationships, such as the adult child-parent dyad, on the decision-making process. Others have studied organizational influences on the decision-making process, such as in the case of examinations of the influence of a physician on decision-making in older adulthood. How older adults faced with a major health-care decision perceive influences from members of these contexts and how the influences come together to produce a health-care decision at the later end of the lifespan has yet to be explored. Understanding how these contexts influence decisions relating to health care at the later end of the lifespan is important for understanding the health care decision-making process for older adults and the outcomes associated with the process. Given the highly complex ecology within which a decision about health care is situated for older adults and the social network associated with their decisions, the overarching research question for investigation was as follows:

RQI: What patterns emerge in decision-making networks for older adults considering a major health-care decision?
Examining the different types of personal decision-making networks that emerge for older adults faced with a major health care decision, as well as identifying the different patterns of influence that surface from investigating the decision-making process from an ecological perspective, can offer insight into how communication between older-adult decision-makers and the members of their decision-making networks impact the decision-making process and outcomes associated with the decisions.

Beyond the overarching research question, evidence points to particular relationships within older adults’ decision-making networks that may serve as a particular function during the process of a major decision about health care. First, as established previously, family and friends have important roles in health related decision-making of older adults. Family members are particularly influential in the decision-making networks of older adults (Townsend & Poushock, 1986) with the most commonly researched relationship in regard to health-care decision making being the parent-adult child dyad. Adult children tend to give a significant amount of advice to their parents (Hagestad, 1984; Keith, 1983); thus, how adult children approach advice giving and assistance in the health-care decisions of their parents can have significant implications for the psychological and physical health of the parents and the children’s quality of their relationship with them (Lieberman & Fisher, 1999).

As discussed previously, the way in which families negotiate dependence and independence can prove to be problematic during the process of decision making. Increased dependence of an older adult on an adult child creates a need for families to negotiate independence and dependence and make decisions in response to the challenges of the older adult (Cicirelli, 1992a). Older adults strive to maintain their autonomy, independence, and capacity to make and execute decisions, but adult children may communicate with them in
paternalistic ways that threaten their independence and self-image (Hummert & Morgan, 2001). Adult children are often willing to provide support to help maintain parents’ independence, but the interactional process associated with provision of support can affect communication patterns in the family in ways that create greater dependence of the older parent on the adult child. In short, as a result of the interplay between older adults’ simultaneous needs for independence and assistance coupled with adult children’s desire to help/protect their parents by adopting a paternalistic role (Cicrelli, 1992a; Morgan & Hummert, 2000), the interactions between adult children and their aging parents that constitute part of the decision-making process may be problematic (Coupland, Wiemann, & Giles, 1991).

Clearly, the parent-adult child interaction during a major health care decision can serve a positive or negative role during a major health-care decision. A logical outcome of the parent-child interaction is the parent’s satisfaction with the decision-making process. As discussed previously, the health-care decision-making process of an older adult can be a complicated and stressful endeavor. Interactions during the process may serve to ease the process of decision-making and make it more satisfying or increase decision-related stress and make the process dissatisfying. Consistent with interpersonal communication scholarship, which conceptualizes satisfaction as “need gratification” and “reinforcement” (e.g., Keyton, 1991) and as influenced by internal state and environment, along with affect (e.g., Hecht, 1978), and group decision-making scholarship, which examines satisfaction with decision-making processes and outcomes (e.g., Gouran, 1973; Hecht & Riley, 1985), satisfaction may be connected to interactions associated with older adults’ decision-making processes. If an adult child and parent are successful in negotiating issues of dependence and independence during their interactions concerning a major health-care decision, the interaction will likely serve to make the decision-
making process more satisfying for the decision maker. However, if an adult child asserts his or her influence on the decision to an extent that the decision-maker perceives the interaction to be dependency inducing, the older adult decision maker will likely experience less satisfaction with the decision-making process. In other words, reciprocal interactions between an adult child and parent about a major health care decision will likely yield a more satisfying decision-making process for older adults. Hence:

H3: Older adults who report reciprocal interactions with their adult children concerning a major health-care decision will be more satisfied with the decision-making process than older adults who report non-reciprocal interactions with adult children concerning their health-care decisions (with influence direction from adult child to parent).

H4: Older adults who report reciprocal interactions with their adult children concerning a major health-care decision will experience less anxiety with the decision-making process than older adults who report non-reciprocal interactions with adult children concerning their health-care decisions (with influence direction from adult child to parent).

The next social context associated with health care decision-making at the latter end of the lifespan is the cultural context. Culture is so pervasive that individuals are generally unaware of the role it plays in everyday occurrences and relationships (Gundykunst, 1998, Hofstede, 1984; Schein, 1985). Although important for understanding health care decision-making processes, as established previously, the nature of its influence is quite unclear. However, the influence of one’s culture on a major decision about health care would likely be significant for a decision-maker. The following research question is a starting point for understanding the influence of the cultural context:
RQII: How does culture influence the decision-making process and outcomes for older adults who utilize cultural contacts as part of their decision-making networks?

The next context of interest is the religious/spiritual context. As established previously, religion and spirituality reportedly affect how patients make medical decisions, especially as they pertain to serious and advanced illness (Wennberg, 1989). When making decisions about life sustaining or life-prolonging treatments, individuals tend to tap into their religious and spiritual beliefs (e.g., Ejaz, 2000; Sehgal et al., 1992). Thus, the seriousness of the decision and the severity of the associated consequences likely mediate the influence of religion and spirituality in the decision-making. Therefore:

H5: Individuals who rate their health-care decisions as serious and severe will report more influence from the religious/spiritual context of influence than those who do not rate their health-care decisions as serious and severe.

As reviewed previously, a considerable amount of research has addressed the role of religion and spirituality in coping with stress and anxiety (e.g., Paragment & Ano, 2004) and physical and psychological illness (e.g., Koenig, 1998). In that religion and spirituality can be a resource for coping with the stress of a major medical decision (Koenig, George, & Siegler, 1988), the existence of religious coping strategies in a health-care decision-making process will likely serve to affect the process positively. Especially given that dimensions of positive religious/spiritual coping involve knowledge of love and other positive affect associated with ones higher power (Pargament & Ano, 2004), satisfaction with the decision-making process associated with a major health-care decision may prove to be a relevant outcome of utilization of such coping strategies. As mentioned previously, satisfaction has been conceptually associated
with “need gratification” and “reinforcement” (e.g., Keyton, 1991) and affect (e.g., Hecht, 1978). Thus:

H6: Older adults who report positive religious coping strategies will experience greater satisfaction with the health-care decision-making process than individuals who report use of negative religious coping strategies or no religious coping strategies.

H7: Older adults who report positive religious coping strategies will experience less anxiety in the health care decision-making process than individuals who report use of negative religious coping strategies or no religious coping strategies.

The political-legal context surrounding health care and health-care decision making in The United States has changed substantially over the past several decades as a result of managed care, and the political-legal context continues to change. Many agree that reform of the United States health-care system is necessary (Fuchs & Emmanuel, 2005), as one of every six Americans has no health insurance, health-care spending is escalating rapidly, administrative costs are excessive, and medical errors (including overuse and underuse of medications and procedures) are rampant (Wachter & Shojania, 2004). If current trends continue, U.S. health insurance costs could consume the average household's annual income by 2025 (Devoe, Dodoo, Phillips, & Green, 2005). Where an individual is situated in the political-legal context of the health-care system can have significant implications for their health decision-making. For example, Lesser et al. (2005) reported that patients in their study were more likely to make use of primary care clinics if they had public insurance (46 percent) than were those with private insurance (34 percent) or no insurance (30 percent). Further, compared to patients with private insurance, those with public or no insurance had greater severity of depression, more co-morbid psychiatric symptoms, lower life satisfaction scores, and greater functional impairment, all of
which could have profound impacts on health-care decision-making. Although the effect of the political-legal context on individual health-care decision-making may be difficult given the ever-changing nature of the political landscape in the United States, simply examining where individuals are situated in the political-legal context in terms of their health insurance situation may offer new insights as to the extent to which the political-legal arena limits decision-making. Thus:

RQIII: Are different types of decision-making networks mediated by insurance type?

The next set of question derives from research involving the organizational context. As mentioned previously, the current trend in health care is toward more personal involvement and control of health care decisions by patients. The notion of patient involvement, participation, and control has become an important one in research relating to physician-patient interaction in light of the growing trend labeled a “consumeristic” attitude on the part of patients (e.g., Biesecker, 1988). Increasingly, patients are doing their own research and collaborating with their physicians to improve their quality and length of life (Lindberg, 2002). In contrast to the traditional, paternalistic approach to health care in which the physician has been primarily responsible for selecting treatments and making decisions concerning medical interventions (as was the case when the current cohort of older adults began using medical services), today’s physician and patient now commonly share the responsibility (Altman, Parmlee, & Smyer, 1992). However, older adults often do not assert their right to participate actively in the decisions for medical treatment selection (e.g., Biesecker & Thompson, 1995); however, some evidence has suggested that they desire information about their decisions (e.g., Beisecker, 1988) and that older adults vary in their desire for involvement in their medical decisions (e.g., Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Belcher, Fried, Agostini, & Tinetti,
Understanding how older adult decision-makers’ propensity for involvement in their health care decisions affects their process of decision-making is important, especially in light of research that suggests that involvement of older adults in their decisions can have negative consequences for the outcome (e.g., Liu & Gonzalez, 2007). Consequently:

**RQIV:** How does an older adult’s propensity for involvement in health-care decision-making affect their decision-making networks?

A final area of consideration related to the influence of a particular social context in the ecology of major health-care decisions extends from the media context. As noted previously, older adults have reported that they desire information about their health-care decisions (e.g., Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Beisecker, 1988). For individuals who desire more information about their health concerns and conditions to make their decisions, media sources may serve as an important means of self-educating. Thus, generally, a person who has a high propensity for involvement in their health care decisions will likely seek information from the media in some form, whether the sources are books, pamphlets, seminars, or Internet websites.

Also discussed previously, the Internet is becoming progressively more important for older adults faced with major health-care decisions. Increasing numbers of older adults are enthusiastic users of computers and the World Wide Web, particularly for self-initiated access to health information (Morell, Mayhorn, & Bennett, 2000). Indeed, the Internet has become a necessary tool for some older adults to acquire health information. The number of older adults is rapidly growing in The United States society, and the need for reliable health information to be available online is likely to increase their numbers (Morell, Mayhorn, & Bennett, 2002). The Internet can serve as an alternative or supplementary source to more traditional sources of health
information. Individuals are doing research related to health and medical care independently. As a result, the Internet is having a tremendous impact on people’s health as they use online resources to learn about issues of wellness, as well as various diseases and disorders (Lindberg, 2002). Older adults are similar to their younger counterparts in this regard. Older adults are increasingly interested in using the Internet for health information. Further, information is available on the Internet directly for the purpose of older adults’ search for health information (Morell, Mayhorn, & Bennett, 2002). Thus, the Internet has potential as a tool for empowering older adults in their health-related decision-making. Older individuals who use the Internet to search for health information are empowering themselves and regaining part of the lost control over their lives that they experience as a result of health related concerns (McMellon & Schiffman, 2002). The Internet has positive impact on their lives, especially in respect to the power of information provided by the Internet. Thus, for older adults who have a strong propensity for involvement in their medical decisions, the Internet may serve as a viable way for them to satisfy their needs for involvement and information. In the event, however, that utilizing the Internet is not an option for an older adults who have a high propensity for involvement in medical decisions, whether they are able to satisfy their needs for involvement through other media, organizational, or interpersonal sources is unknown. The following hypothesis and research question follow logically from such considerations:

H8: An older adult's propensity for involvement in health-care decision making will be positively related to their use of media sources during their process of decision-making.

RQV: For older adults facing a major health-care decision who have a high propensity for involvement in their health care decisions, how does utilization of the Internet impact their satisfaction with the decision-making process?
Chapter 2. Methods

Overview

The overarching purpose of this study was to investigate the decision-making process and decision-making networks involved in major health care-decisions of older adults. The questions and hypotheses posed in the study were addressed through interview and survey methods, which yielded both qualitative and quantitative data pertaining to the health-care decisions faced by older adults, the process of decision making, the factors involved in the decisions as situated in the social contexts of decision-making and the influence of each on the process, the personal social network involved in the health-care decisions, and the influence of network members.

Participants

Individuals aged 60 years and above who were considering a major health care decision were recruited for the study. Individuals with Alzheimer’s disease or a related form of dementia that would preclude them from legal responsibility for a health-care decision were excluded from participation. The participants self-defined “major health care decision.” In other words, any decision considered “major” and involving “health care” by a participant met the criteria for inclusion in the study. Those in the process of making a major health care decision or who had made a major health-care decision no more than one month prior to the initial interview were accepted in the study. Only the participants who reported significant motivation for decision-making in the past month were considered. So, for example, a person considering a move into an assisted-living residence for the past year, but had not been actively considering options for living arrangements in the past month, was not enrolled in the study.
Participants were from central Pennsylvania, the greater Saint Louis, Missouri area, south central Illinois, and the south Chicago area. Some were recruited through participant referral. Area physicians and medical specialists, long-term care/rehabilitation center directors, human resource consultants, physical/occupational therapists, and directors of senior centers and centers for aging assisted in the recruitment. After explaining the purpose of the study and receiving written permission from the relevant individuals and relevant organizational review boards, the health-care professionals distributed recruitment fliers to potential participants and displayed them in appropriate locations within their respective organizations. An on-site sign-up sheet was available for interested participants to provide contact information. The researcher also recruited participants by means of notices in public places and word of mouth. Sixty-five individuals agreed to take part. However, two individuals passed away before completing the tasks and one withdrew because of poor health. Sixty-two participants remained in the study. Of these, 18 were males (29%), and 44 were females (71%). The age of the participants ranged from 60 to 86 years, $(M=70.71, SD=7.95)$. Figure 2 shows the age distribution of the participants.
Figure 2. Distribution of age among study participants.

Over half of the participants reported that they were married. Figure 3 shows the distribution of participants according to marital status.
The majority of participants in the study identified themselves as Caucasian. Two respondents indicated African-American, one American Indian, and two other respondents choose the “Other” option. The ethnic-racial identities of participants are summarized in Figure 4.
Participants were also asked to report the highest level of education they received. A summary of participant education level appears in Figure 5.
Data pertaining to annual income levels appears in Figure 6. Nine participants declined to provide annual income information.

Figure 6. Summary of participants' annual income level.

All but one of the participants had some form of medical insurance, and approximately one-third of the participants had more than one type of medical policy. Three participants were unsure of exactly what type of medical insurance policy they owned. A summary of participant medical insurance appears in Figure 7.
Figure 7. Summary of participants' type of medical insurance.

Participants were asked to identify their religious preference/affiliation. The responses were tabulated and appear in Figure 8.
Figure 8. Summary of participants' religious preference/affiliation.

Internet usage among the participants is summarized in Figure 9. The majority of participants in this study reported common use of the Internet (61%). Common reasons for not using the internet appear in Figure 10.
Figure 9. Internet usage among participants.

Figure 10. Reasons for not using the Internet.
The participants reported a variety of types of health-care decisions. One distinct type involved choices concerning care providers. Decisions of this type manifested themselves in three ways. First, participants facing a new condition reported deliberating with two or more potential doctors, surgeons, or specialists to treat the new condition. Other decisions surfaced when participants were dissatisfied with some aspect of a provider’s care and considered changing providers as a result. Finally, there were decisions concerning whether to seek a second (or third) opinion after a diagnosis.

A second group of decisions involved surgical procedures. Participants fit into this category if faced with the possibility of having a major surgical procedure. For example, those who were considering sinus surgery or a knee replacement fell into this category.

The third category of decisions involved general treatment decisions. If participants were considering a course of action for treating a condition that did not involve a major surgical procedure or a change in medication, their decisions were considered as involving general treatment decisions. For example, the decisions involving diabetes management and fibromyalgia were in this category. Decisions concerning treatment in the “general” category ranged in their degree of gravity. However, because all participants considered their decisions “major” when enrolling in the study, the “general treatment” category proved to be an appropriate category for consideration.

The fourth category of decisions consisted of those that involved medication only. For example, the decisions of participants who reported that they were working with their physician to determine a complex medication regimen, such as in the case of myasthenia gravis or depression, fit into this category. In some cases, changes in medication also accompanied
surgical procedures and other treatment options, but the change in medication was not the central concern. In such cases, the decisions fell into the second or third category.

A fifth category of decisions involved decisions about health insurance. In this category fell all decisions involving purchasing or changing health insurance.

Decisions relating to living arrangements as a result of a health condition or health related concerns comprised a sixth distinct category. Participants considering a change in residence because of an immediate health concern fell into this category. The degree of immediacy in these decisions also ranged. In some instances, participants fluctuated in their perceptions of when the change in residence would happen. Nonetheless, all participants, upon enrolling in the study, considered themselves to be in a position of making a health-care decision. Thus, decisions about living arrangements, even in the event that no decision had been made six weeks after the initial interview, were considered in the study and fell into this category of decisions.

One participant in this study reported that she was deciding whether or not to quit working because of health problems. This decision was unique and not amenable to inclusion in any of the other categories.

Finally, some decision-makers reported that they were deciding whether or not to seek professional medical help. In several cases, the researcher fortuitously sough volunteers at “the right place at the right time” and caught the decision makers literally in the process of making a major decision to seek medical attention as a result of pain or complications with a pre-existing condition. Other participants entered the study shortly after deciding to seek medical help (for example, at a follow-up appointment at the doctor’s office following the decision for go to the emergency room three days prior). Their retrospective accounts of their decision-making
process germane and appropriate for inclusion in the data set. Figure 11 shows the decision types uncovered in the study.

Figure 11. Summary of decisions considered by participants.

Procedures, Instrumentation, and Measures

After contacting potential participants and determining that they were eligible for participation in the study, the researcher explained to them what the study entailed and invited them to be part of it. If the individual agreed, the researcher set a time and place convenient for an interview and survey. Interviews were conducted in the participant’s home, at local restaurant or coffee shop, or via telephone. If participants indicated at the time of recruitment a preference
for a telephone interview, the researcher went over the informed consent document (see Appendix B) in detail at the time of recruitment and emphasized that the responses would be confidential, as well as one could choose not to respond to questions or withdraw at any time. After explaining the consent form in detail, the investigator sent two copies of the document and a self-addressed stamped envelope to the participant in the mail with an accompanying note explaining that the participant should keep one copy of the consent form for his or her records and return one to the researcher in the enclosed, self-addressed stamped envelope. In the case that a participant preferred to meet face-to-face, the researcher brought two copies of the consent form to the initial interview. The investigator again emphasized the key points mentioned above and then asked the participants to read the consent form, sign one copy and return it to the researcher, and keep one for his or her records.

Upon receipt of the consent form, the researcher began the initial interview. The initial interview/survey served to elicit information about the decision-making process before a decision was made. Most initial interview/surveys were completed before participants reached a decision about their health care. However, several retrospective accounts were included in the study. Four participants had emergencies that prevented the researcher from collecting data at the time of the decision, but she was able to meet with the participants shortly there after for fresh accounts of the decision-making process. Four other retrospective accounts were included because the participants had recently made the decision and were able to provide detailed accounts of their communications relating to the decisions. Initial survey/interview sessions varied in length, but usually lasted between two and four hours. Initial survey/interview sessions were typically split into two or more meetings due to length. The final interview/survey took
place immediately following the decision or six-weeks after the initial interview. Final
interview/surveys lasted between one and two hours.

Interviews took place face-to-face or via telephone. However, several participants
preferred to complete sections of the survey individually on paper. All participants had the
opportunity to use paper prompts to guide their interview and survey sessions, but no one used
them consistently. Interviews unfolded as conversations in which the participants responded to
survey items either by a) assigning a numerical value followed by an example to illustrate the
response or explaining their reasoning behind the answer or b) expressing uncertainty about how
to quantify the response followed by talking through their reasoning or offering an example to
illustrate their thoughts on the subject. If participants engaged in the latter, the researcher led
them back to the original question and scale and asked again for assignment of a numerical value
for the survey item.

Instrumentation

The initial survey had six sections. The complete instrument appears in Appendix C.
The first section, Section A, focused on general information concerning the health-care decision
of interest. Participants were to describe the health-care decision and the decision-making
process to date. To gauge the starting point in the decision-making process, participants were
also to indicate the degree of severity and seriousness of the decision, as well as the anxiety they
associated with the decision.

The next section of the initial interview/survey related to information management. The
section contained items pertaining to participants’ motivation, coping efficacy, communication
efficacy, and propensity for involvement in health-care decisions.
Section C required participants to provide a self-report of their physical and psychological health.

Section D called for demographic information, including racial/ethnic identification and health insurance type, as directed by the study’s research questions.

Religious and spiritual considerations for the study were assessed by the items in Section E. Following the identification of a religious affiliation were items tapping the participants’ subjective religiosity, religious coping and religious commitment/orientation.

Section F of the initial interview addressed participants’ usage, comfort, and confidence in using the Internet.

The final section of the initial interview, Section G, asked participants to identify their decision-making networks. First, participants were asked to think about the individuals they knew personally and to whom they might talk to or had already talked about the health-care decision. They were to provide an exhaustive list of all those with whom they might speak and were given examples of the types of individuals that may be relevant in their decision-making process, including physicians, psychologist/psychiatrists, insurance representatives, pastors/spiritual advisors, spouses, adult children, friends, and siblings. The interviewer recorded the initials of each person respondents identified. These individuals comprised the interpersonal contacts in the participant’s decision-making network. The participants were next asked to think about other sources they might consult or had already consulted about the decision. They were again to develop an exhaustive list. Examples of types of sources they might consult, including Internet websites, books, magazines, and insurance information, and informational pamphlets. The interviewer recorded each source. These sources constituted the non-interpersonal contacts in the participants’ decision-making networks. Once identified as a
member of a decision-making network, both interpersonal and non-interpersonal nodes are referred to as targets.

For each interpersonal and non-interpersonal contact in the decision-making networks, participants answered a series of questions. In the case of interpersonal contacts, the participant provided information about the target’s relationship to the participant, the target’s gender, age, occupation, religion, the length of relationship with the participant, frequency of communication between the target and participant, the target’s geographic distance from the participant, the target’s knowledge of the participant’s financial situation and health insurance, the quality of the relationship with the participant, the target’s status of equality relative to the participant, the number of times the two had spoken about the decision prior to the initial interview, and the target’s efficacy.

For each non-interpersonal source of information, participants responded to a different series of questions, including whether they had consulted the source before the initial interview, how often they normally consulted the source, how they came in contact with the source, how critical/important they thought the information they would receive from this source would be in making the decision, and how much they trusted the source.

If a member of a participant’s decision-making networks was a physician, there were three additional questions relating to one’s satisfaction with the physician.

After the initial interview, the researcher talked with participants to determine an appropriate time for the final interview. If participants anticipated making a decision within a week of the initial interview, the investigator immediately set up a time for the final interview. If participants were unsure of the time frame in which they would make a decision, the investigator asked permission to call one week after the initial interview to set up an appointment.
The investigator also asked participants to keep track of the individuals with whom they spoke about the health-care decision in the interim time between the initial and final interview. Originally, participants were to complete a decision-making journal during the time between the initial and final interview. For each person or source participants contacted, they were to individually fill out a survey that included the items following Section G of the initial interview. However, the participants did not usually complete the surveys from week to week. Consequently, the investigator simply asked them to keep a record of those with whom they spoke about the decision. Then the investigator called participants on a weekly basis (for six weeks or until a decision was made) to ask participants whether or not they had talked to or consulted additional sources about their decision. If yes, the investigator had them respond to the survey items that corresponded to their contacts. One day before the each final interview, the investigator called the participant to confirm the final interview time, check on whether he or she had any additional contacts, and to complete any additional survey items that might be needed.

At the end of the six week period (or upon making the health-related decision), a final face-to-face interview/survey took place (see Appendix C). The first part of the final interview, Section A, focused on the participants’ overall satisfaction with the decision-making process and outcome, if possible, as well as the anxiety relating to the process. They were rated the decision severity and seriousness once again. In the next section, the participants indicate how much each context of communication influenced their decision-making, as well as how much their financial state influenced their decision-making. The next section of the final interview, Section C, included four open-ended items relating to the participants’ decision-making process in respect to what could have made the decision-making process easier and more satisfying for them, what they would have done differently, and what advice they would give others in a similar situation.
After finishing the summary questions, the participants addressed a series of questions involving their interpersonal contacts during the decision-making process. First, the participants provided a count of the conversations that they had with each target. They also reported the usual form of contact with the target (e.g., face-to-face, via telephone), who usually initiated the conversation, the typical duration of the conversation, the length of the longest conversation, the usual atmosphere of the conversations, and the degree of familiarity the target had with the participant’s health care situation before and after conversations with him/her. Finally, the participants rated the overall influence of the target on the decision-making, how critical the target was in the process of decision-making, how helpful the target was in terms of coping with the process of decision-making, and how helpful the target was in providing information the participant needed to make the decision.

Participants also responded to questions concerning their consultation of non-interpersonal sources, including the number of contacts they made with each, the typical amount of time they spent consulting the source, and the longest amount of time they spent consulting the source. They also indicated how influential the source was in general, how critical or important the source was in the decision-making process, and how helpful the source was in terms of coping with the process and providing necessary information for making the decision.

The participants next ranked each interpersonal and non-interpersonal source in terms of their influence on the process and outcome, respectively. At this time, they also assigned each person or source of information to one or more contexts of communication.

In the final part of the interview, the participants provided information about the relationships and contacts between each dyad in their decision-making networks. First, they indicated how often each interpersonal contact talked with each other interpersonal contact.
They then noted the number of times they thought each interpersonal target discussed the participant’s health-care decision with each other interpersonal contact. Finally, the investigator asked the participants to take the perspective of each interpersonal contact to answer six questions about the contact’s relationship or interaction with each of the other members of the network, including the participant. The questions assessed the quality of the relationship between network members and the perception of equality in the relationships from the participant’s perception of each decision-making network member’s perspective of the relationship. Finally, the participants reported who initiated the conversation about their decision and who had tried to influence who during the conversations about the decision, if the participants thought one had occurred. The investigator recorded the answers on a matrix sheet.

Measures

*Decision Gravity*

It was important to have participants indicate the gravity of the decision because of its potential impact on their decision-making network and its predicted relationship with participants’ reports of spirituality/religiosity (as discussed previously). Two survey items constituted the measure of the gravity of the decision in both the initial and final interview. The first item asked, “How serious is the decision you are considering for you?” and participants responded on a scale of one to five. A response of one indicated that the participant viewed the decision as “very serious”, whereas five indicated that the participant considered the decision to be “not very serious.” The second survey item was: “How severe are the consequences of the decision you are considering?” The participants again responded on a scale of one to five, with one indicating that the consequences of the decision were very severe. The questions associated
with the gravity of the decision for participants were designed to have high face validity and appear to do so.

**Anxiety with Decision**

Two items served as the measure of participants’ anxiety. During the initial interview, the participants indicated the degree of nervousness/anxiety that they associated with the decision they were considering. They responded on a scale of one to five, with one indicating that they were “very nervous” and five indicating that they were “not very nervous.” In the final interview, they responded to the question, “Overall, how much anxiety have you experienced with the decision-making process?” Participants responded on a scale of one to five, with a response of one indicating a considerable amount of anxiety with the decision-making process and a five indicating “not much” anxiety with the process.

**Efficacy**

Three types of efficacy were of interest in the study. The first two were coping efficacy and communication efficacy as assessed during the initial interview. Survey items were adaptations of ones in Afifi, Morgan, Stephenson, Morse, Harrison, Reichert, and Long’s (2006) investigation of family decision talk about organ donation and examples from Afifi and Weiner’s (2006) study of information-seeking about sexual health. The items relating to communication efficacy showed high reliability in Afifi et al.’s (2006) investigation (Cronbach’s $\alpha = .74$, $M = 5.14$, $SD = 1.42$) and in Afifi and Weiner’s (2006) study (Cronbach’s $\alpha = .84$, $M = 5.91$, $SD = 1.26$). Similarly, items measuring coping efficacy revealed high reliability in Afifi et al.’s (2006) investigation (Cronbach’s $\alpha = .73$, $M = 5.67$, $SD = 1.42$) and in Afifi and Weiner’s (2006) study (Cronbach’s $\alpha = .91$, $M = 3.62$, $SD = 1.56$).
A measure of each target’s efficacy was assessed during the initial interview as well. The measure were adapted from Afifi et al.’s (2006) study examining decisions to talk about organ donation and Afifi and Weiner’s (2006) investigation of talk about sexual health. The measures of target efficacy failed to meet minimum standards for reliability in Afifi et al.’s (2006) investigation. In Afifi and Weiner’s (2006) study, target efficacy was operationalized as a participant’s ability to provide information and the participant’s perception of the target’s completeness of information. Target ability was demonstrated as moderately reliable (Cronbach’s $\alpha = .71$, $M = 5.99$, $SD = 1.14$) while the dimension of information completeness achieved high reliability (Cronbach’s $\alpha = .87$, $M = 5.97$, $SD = 1.19$).

The items for communication, coping, and target efficacy and respondent scale are presented in Appendix D.

**Propensity for Involvement in Health-Care Decision-Making**

A person’s propensity for involvement in the health-care decision was measured with items adapted from Brashers, Haas, and Neidig’s (1999) Patient Self-Advocacy Scale (PSAS) (see Appendix E). This scale was developed as a measure of patient involvement in health-care decision-making. The dimensions of the scale are illness education, assertiveness, and potential for nonadherence to treatments prescribed by physicians. The reliability and validity of the scale were demonstrated through tests administered to a sample of adults from an HIV-AIDS population and a sample of adults from the general population (Brashers, Haas, and Neidig’s, 1999), which established that the PSAS was a reliable and valid measure of patient involvement in health-care decision-making. For education, a Cronbach’s $\alpha = .64$, for assertiveness, Cronbach’s $\alpha = .70$, and for nonadherence, Cronbach’s $\alpha = .79$. Overall, the scale for PSA returned a Cronbach’s $\alpha = .78$. 
Religious Coping

A measure of religious coping was utilized in this investigation because of the potential utility of religious/spiritual resources on the decision-making process likely depend on the positive or negative coping strategies that accompany an individual’s religion. Pargament, Smith, Koenig, and Perez (1998) developed the Brief RCOPE to test for positive religious/spiritual coping that reflects benevolent religious involvement in the search for significance and a negative factor that reflects religious struggle in coping. A sample of patients over age 55 who were recruited from a hospital were used to assess the reliability of the Brief RCOPE and tests demonstrated a high reliability for the positive religious coping (Cronbach’s \( \alpha = .87 \)) and acceptable reliability for negative religious coping (Cronbach’s \( \alpha = .69 \)). The items used to assess positive and religious coping and the accompanying scale are reported in Appendix F.

Internet Usage

The items measuring Internet usage were adapted from Vuori and Holmlund-Rytkonen’s (2005) survey of Internet users over the age of 55. The items, which have high face validity, ask individuals about their overall Internet usage as well as utilization of specific Internet functions and their attitudes toward the Internet. The items used in this analysis to gather information about Internet usage asked participants about general Internet usage and the degree to which they use the Internet specifically for health related information. The items used to determine Internet usage are reported in Appendix F: Measure of Internet Usage. Further, participants’ use of the Internet during their decision-making process was determined by how many Internet sources they reported in their non-interpersonal decision-making network.
Usage of Media Sources

Participants’ propensity for involvement in their health-care decisions was expected to be related to their use of media sources for information about their particular health-care decision. Thus, the number of media sources participants reported as part of their non-interpersonal decision-making network in the process of their decision-making were counted.

Satisfaction with Decision-Making Process and Outcome

One survey item served as the measure of how satisfied a participant was with the process of decision-making: “Overall, how satisfying has the decision-making process been for you?” The item capturing a participant’s satisfaction with the outcome of the decision was: “How satisfied are you with the decision you have made?” Participants responded to both questions on a scale of one to five, with a response of one indicating high satisfaction.

Frequency of Contact.

To determine types of decision-making networks involved in the health-care decisions of older adults and the patterns of influence associated with such networks, a variety of social network measures were included in the study. The first was overall frequency of contact between participants and interpersonal targets. During the initial interview, participants were asked, “Usually, how often do you speak to this person?” Participants responded on the following scale:

1. Each day
2. More than once a week
3. Once a week
4. Every other week
5. About once a month
6. About once every three or four months
7. About once every six months
8. Once a year
9. Less than once a year
10. I do not usually speak with this person.

Similarly, participants indicated their frequency of contact with non-interpersonal sources in response to the question, “How often do you normally consult this source?,” on the following scale:

1. Each day
2. More than once a week
3. Once a week
4. Every other week
5. About once a month
6. About once every three or four months
7. About once every six months
8. Once a year
9. Less than once a year
10. I have never consulted this source before.

The frequency of contact between targets in the participants’ social networks was measured during the final interview with the question, “How often do you think that these people usually speak to each other?” Participants responded on the following scale.

0 These people do not know each other.
Each day
More than once a week
Once a week
Every other week
About once a month or every other month
About once every three or four months
About once every six months
Once a year
Less than once a year
These people know each other, but are not normally in contact.

Frequency of Contact about Decision

The next social network measure was the frequency of contact in the network that occurred about the participant’s health-care decision. Participants indicated frequency of communication with interpersonal targets in response to the question, “Throughout the course of your health-care decision-making process, how many times were you in contact with this person about your decision?,” to which participants responded with the number of times they had spoken to the person over the course of the decision-making process. The participants kept a record of the persons with whom they spoke about their decisions after the initial interview and referred to their record to answer the question. Participants who had spoken to a target before the initial interview added the number of times they reported speaking to the target at the initial interview with the number of times they had recorded speaking to the target between the time of the initial interview and the final interview.
The participants also kept a record of their consultations with non-interpersonal sources during the decision-making process. During the final interview, they responded to the question, “Throughout the course of your health-care decision-making process, how many times did you consult this source about your decision?” and responded with a number of times they had consulted the source.

The participants also reported on their perception of how often they thought the members of their interpersonal decision-making network discussed their health-care decisions. During the final interview, they responded to the question, “How many times do you think these people discussed your health-care decision?,” with one of the following choices:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>These people do not know each other.</td>
</tr>
<tr>
<td>1</td>
<td>1 time</td>
</tr>
<tr>
<td>2</td>
<td>2-3 times</td>
</tr>
<tr>
<td>3</td>
<td>4-5 times</td>
</tr>
<tr>
<td>4</td>
<td>6-7 times</td>
</tr>
<tr>
<td>5</td>
<td>8 or more times</td>
</tr>
<tr>
<td>6</td>
<td>I do not think these people discussed my decision.</td>
</tr>
</tbody>
</table>

**Length/Duration of Decision Contact**

The length or duration of decision contact between a participant and a target was measured in addition to the frequency of the decision contact to take into account the potential salience a particular contact might have had in the decision-making process. The length/duration of an interpersonal contact was measured by two survey items that took two different forms. If the main form of contact between the participant and an interpersonal target was verbal, the participant answered the following two survey items:
“What was the usual duration of the contacts you had with this person about your health-care decision?”

1. 5 minutes or less
2. 5 – 30 minutes
3. 30 – 60 minutes
4. 60 minutes or longer
5. Not sure

“What is the longest conversation that you had with this person regarding your health-care decision?”

1. 5 minutes or less
2. 5 – 30 minutes
3. 30 – 60 minutes
4. 60 minutes or longer
5. Not sure

If the major form of contact between the participant and the target about the health-care decision took place through post, e-mail, or online chatting, the participant answered the following questions:

“How would you describe the usual length of the writing/contact?”

1. Very brief – a short mention
2. Brief, but more than a passing thought
3. A good amount
4. At length
5. Not sure
“What was the longest length of the writing/contact about your health-care decision?”

1. Very brief – a short mention
2. Brief, but more than a passing thought
3. A good amount
4. At length
5. Not sure

The item capturing the length/duration of a participant’s contact with a non-interpersonal source were: a) “How would you describe the usual length of time you consulted this source?” and b) “What was the longest length of time you consulted the source?” The participants responded to the questions on a four point scale, with one indicating very brief contact and four indicating lengthy contact. Participants also had the option of indicating that they were not sure about their duration of contact with a source.

Relational Quality

Relational quality, or the bond between a participant and a target in his or her network, was measured as a potential factor in the influence of a target in a participant’s decision-making network. The measure tapped closeness, stability, and trust.

Relational quality between each participant and target was measured with six questions. During the initial interview, the participants responded to the following questions about their relationships with each interpersonal contact: a) “How stable do you consider your relationship to be?”; b) “How close do you consider your relationship with this person?”; and c) “How much do you trust this person?” Responses were on a scale of one to five, with one indicating the highest degree for each dimension of relational quality. Relational quality between the participant and each target was also assessed during the final interview when the participant took
the perspective of each target and reported on the target’s perception of the relational quality
between the target and the participant. The participant was asked, “How stable do you think that
(target) would report on his/her relationship with you?”; “How close to you think (target) would
consider his/her relationship with you?”; and “How much do you think (target) trusts you?”
Responses were again on a scale of one to five, with one indicating the highest degree of each
dimension of relational quality. Assessing the participants’ perceptions of relational quality from
each perspective allowed for consideration of nonsymmetric relational quality to be taken into
consideration in the personal social network analysis.

Similarly, the relational quality between every member of the interpersonal social
network was measured during the final interview when the participant took the perspective of
each person in the network and answered the following questions: “How stable do you think
(target) would report his/her relationship with each other person?”; “How close do you think
(target) would consider his/her relationship each other person?”; and “How much do you think
(target) trusts each other person?” Participants responded on a scale of one to five, with one
indicating a high degree of the construct of interest. Participants also had the option of
responding with a “0” to indicate that the targets did not know each other.

**Target Influence**

The influence of a target was measured in terms of influence on the process of decision-
making and on the outcome of the decision. The participants answered the following survey
questions about each interpersonal target’s influence on the process of decision-making: a)
“Overall, how critical or important do you think this person was in your decision-making
process?” and b)”Overall, how helpful were the conversations you had with this person in terms
of coping with the process of decision-making?” Participants responded on a scale of one to five, with one indicating the highest degree of influence on the process.

During the final interview, participants were also instructed to “Please rank the people and sources you consulted in terms of their overall influence in the decision-making process (1 being the most influential).” Participants ranked all of the contacts in their decision-making network (interpersonal and non-interpersonal) from 1 (most influential) to N (least influential), where N was the total number of target’s in a participant’s decision-making network. The rankings provided a means for differentiating among targets’ influence because the participants ordered all of the targets. Thus, the ranking of the targets in terms of their influence on the process also served as a partial index of the two items constituting the measure of each interpersonal target’s overall influence on the process of decision-making.

The influence of non-interpersonal targets on the decision-making process was measured during the final interview with two survey items: a) “Overall, how critical or important do you think this source was in your decision-making process?” and b) “Overall, how helpful was consulting this source in terms of coping with the process of decision-making?” Participants responded on a scale of one to five, with one indicating the highest degree of influence on the process. As non-interpersonal sources were also ranked in terms of their overall influence in the decision-making process as part of the final interview, the rankings served as partial index of the influence of non-interpersonal sources in the process of decision-making.

The influence of targets on the outcome of the decision-making process was also of interest. Even if participants had not made a certain decision about the health-care decision at hand, they were asked to respond to questions about the influence they perceived each interpersonal and non-interpersonal source likely would have on the anticipated outcome.
Participants answered the following questions about interpersonal members of their decision-making networks to measure their influence on the outcome of their decision: a) “Overall, how influential was this person on your decision-making?” and b) “Overall, how helpful were the conversations you had with this person in terms of providing information you needed to make your decision?” Responses to each question were on a five-point scale, with one representing the most influence. During the final interview, the participants ranked the people and sources they consulted in terms of their overall on the decision outcome, with one being the most influential and N being the least influential, where N was the number of contacts in the decision-making network. Again, the rankings served as a partial index of the targets’ influence on the outcome of the decision-making process.

Participants further indicated the influence of non-interpersonal sources on the outcome of the decision-making process in respect to two items: a) “Overall, how influential was this source on your decision-making?” and b) “Overall, how helpful was consulting this source in terms of providing information you needed to make your decision?” Each question was on a five-point scale, with one signifying the most influence. As non-interpersonal sources were also ranked according to their degree of influence on the outcome of the decision-making process, the rankings served as partial index of the non-interpersonal targets’ influence on the outcome of the decision-making process.

*Direction of Target Influence*

To determine whether or not a participant perceived that a particular members of a his or her decision-making network were attempting to influence other targets in their thinking about the participant’s decision entailed assessment of the direction of target’s influence. For each target in a decision-making network, the participants were to note, in the case the target spoke to
another person in the network about the health-care decision, whether they thought the target tried to influence the thinking of the other person on the issue of the decision.

The response options were as follows:

0  These two people do not know each other.
1  I do not think these two people spoke about my health-care decision.
2  I'm not sure if these two people spoke about my health-care decision.
3  I think (target) would have been the influencing person during the contact.
4  I think the other person would have been the influencing person during the contact.
5  Neither person would have influenced the other during the contact.
6  I'm not sure if one person would have influenced the other.
7  Both parties probably would have influenced each other

Target Knowledge of the Decision Situation

Each participant reported his/her perception of each target’s knowledge of his/her decision-situation. During the initial interviews with the first five participants, the investigator noticed that all mentioned that particular targets who were giving them advice about their health-care decisions did not know about a major factor in their decision-making, such as whether their insurance would cover a procedure or medication the participant was considering. As a result, the investigator added the following items to the survey protocol to determine whether a target’s knowledge of factors associated with major health-care decisions correlated with the target’s influence on the decision. After the additional survey items were approved by the Institutional Review Board, the primary investigator went back to the participants from whose interviews the questions were developed and asked the questions in survey format.
The first two items pertained to each target’s knowledge of the participant’s health insurance and financial situation, to which participants could respond that the target had full knowledge, some knowledge, no knowledge, or the participant was unsure if the target had this knowledge. The participants also responded to the following questions to determine the target’s knowledge of the health-care decision situation before and after conversations with the participants: a) “Before speaking to you about this health-care decision, what degree of familiarity did this person have with health care situation at hand?” and b) “After speaking to you, what degree of familiarity did this person have with the health-care decision at hand?” The participants responded on a scale of one to five, with one indicating the target was very familiar with the situation and five indicating that the target was very unfamiliar with the situation.

*Contextual Influence*

Two measures served to capture the influence of each context. During the final interview, participants responded to a single question assessing the overall influence of each context: a) “How much do you think your cultural background or contacts influenced your decision-making?”; b) “How much do you think your religion/spirituality influenced your decision-making?”; c) “How much do you think your interpersonal contacts (friends and family members) influenced your decision-making?”; d) “How much do you think political-legal factors (such as health insurance type) had on your decision-making?”; e) “How much do you think media resources (Internet, books, magazines) influenced your decision-making?”; and f) “How much do you think organizational resources (doctors, nurses) influenced your decision-making?” Responses were on a scale of one to five, with one representing “very much” influence and five representing “not very much” influence.
During the final interview, the participants also assigned each interpersonal and non-interpersonal contact to one or more of the contexts put forth by an ecological perspective. The combined influence measure for each target within a context were summed to compiling a total influence measure for each context.

Qualitative Assessment

In addition to the quantitative data collected in the study, there was qualitative data that entered into various analyses. The information participants shared with the investigator in response to open ended questions during the initial interview (“Please describe the health-care decision that you are considering.” and “Please describe your decision-making process thus far.”) and the final interview (“Overall, what could have made the decision-making process easier and more satisfying for you?”; “Is there anything that could have made the decision more satisfying?”; “In retrospect, is there anything you would’ve done differently?”; and “What advice would you give someone who is in a similar situation as you are making a similar decision?”) were recorded in detail. Further, because interview/surveys were conducted orally, the participants also offered information about their decision-making throughout the process, which was recorded by the investigator also. All of the information offered during the interview/survey provided a means for creating a profile of the decision-making process for each participant. The objective in writing the profiles was to tell the “story” of the health-care decision from the participant’s perspective. Thus, the goal of the investigator was to characterize the decision-making process as objectively as possible on the basis of what the participant said when asked to describe the health-care decision and the process of decision-making. The investigator simply reported the opinions or deductions of the participant as opposed to including the analysis within the profile. The basic format for each profile was as follows:
**Participant alias**

**Decision**

The basic decision was noted. For example, “Whether to have surgery” could constitute the overarching decision faced by a participant.

**Decision Situation**

A short paragraph explained the decision in a bit more detail and the general factors surrounding the decision. For example, “Following a car accident that occurred 6 months prior to the initial interview, Justine still experienced problems with her right shoulder which had not subsided with physical therapy. Thus, Justine was in the process of deciding whether to have surgery to correct the problems she was having.”

**Process of Decision-making and Influencing Factors**

This section included expansion of the decision-making process. In some cases, the investigator wrote this as a story detailing how the decision situation unfolded, as that is how some participants approached the interview. In the case of deciding about surgery, this approach usually made logical sense because the process could be detailed almost incident by incident or conversation by conversation about the decision. In some cases, the “story” approach did not serve as an appropriate means for detailing the decision-making process. For example, sometimes, decision situations came upon a participant as a number of factors simultaneously presented themselves, as in the case of making a decision about future living arrangements. In such cases, including subheadings like, “Health Declines,” and “Family Pressures” proved to be a practical approach to expanding upon the decision situation.

**Final Decision**
In this section, there was a paragraph explaining the participant’s final decision and reasons for that decision.

Data Analysis

*Hypothesis I*

Analyzing the first hypothesis, that older adults’ evaluation of their communication efficacy is predictive of their information-seeking behaviors in their health-care decision-making networks, involved determining the number of targets with whom decision-makers initiated contact and correlating this value with the decision-makers’ self-reported communication efficacy using a Pearson’s $r$.

*Hypothesis II*

The second hypothesis predicted older adults’ assessment of the efficacy of a target in their health care decision-making networks would be correlated with their information-seeking behavior involving the target. Pearson’s $r$ indicated the strength of relationship between the participant’s information-seeking behavior with a target and his or her assessment of the target’s efficacy. Participants were identified as either actively seeking information from a target by reporting an intention to initiate the contact with them, or they were identified as not exhibiting information-seeking behavior. The index of target’s perceived efficacy was the average of ten survey relating to his or her honesty and ability to help the participant with the health-care decision of interest.

*Research Question I*

The first research question concerned patterns that emerge in decision-making networks for older adults considering a major health-care decision. In order to answer this research
question, personal social network analysis was utilized. Personal social network analysis is a specific type of social network analysis that views the connections within a social network from the perspective of one identity (i.e., person, organization) (Wellman, 2007). It differs from whole network analysis in that it “views relationships among all network members in a bounded population” (Wellman, 2007, p. 111). Personal social network analysis, then, is ideally suited to studying decision-making networks, as the individuals with whom the decision-maker consults bound a person’s decision-making network.

The questions addressed by personal social network analysts frequently center on the relationships that constitute a particular bounded network and the effects of those relationships on individual behavior. As Wellman (2007) summarizes:

In personal network analysis, scholars are standing in the center of a person’s world and analyzing who he or she is connected to and with what consequences…Personal network analysts are also well positioned to study the fundamental sociological question of the relative effects of ties and networks on behavior. Is it the relationships themselves that are the keys to support or the networks in which they are embedded?…Personal network analysts usually want to know which types of people are in an ego’s network (is it composed mostly of kin or friends?) and what kinds of resources flow through different kinds of networks (do kin provide more emotional support than friends?) (pp. 111-112).

Personal social network analysis, then, is well suited to studying decision-making networks, as the individuals with whom the decision-maker consults provide boundaries for a person’s decision-making network. The first research question in the present investigation calls for examination of the communication patterns among the individuals with whom an older adult decision-maker consults during a major health-care decision. Keeping in mind an ecological
perspective on decision making, one can see how the examination of communication patterns for older adults in the process of health-care decision making could benefit from the use of personal social network analysis, as it is an analytic tool that enables researchers to represent relational data and explore the nature and properties of those relations. Just as network analysis can serve to represent relational ties among a set of organizational nodes, it can serve to represent nodes important to an older adults’ health-care decision making. A personal social network analysis can also be applied to the sources of information an older individual may consult when making a health care decision. A typical information network for health-care decision making could be comprised of medical insurance providers, hospital staff or other personnel, physicians, friends, and religious figures. Within the network, each of these targets constitutes a node. The exchange of information defines the links among those nodes. The communication between an older adult and, for instance, medical insurance representative, can be characterized as directional, with the majority of information coming from the representative. In contrast, the exchange between an individual and his or her family and friends can be much more bi-directional, with an exchange of ideas and information from both nodes. Directionality is only one of the many communicative descriptors that can be modeled and analyzed using personal social network analysis. A variety of communicative descriptors can constitute a network pattern. Additionally, the nodes of a decision-maker’s network can be arranged according to the communication contexts set forth by an ecological perspective in order to examine the influences and interactions between the members of each context.

Consequently, answering the first research question in this investigation required the development of nine decision-making network figures for each participant to illustrate their decision-making networks. Each network figure was composed of nodes representing the targets
that participants reported consulting during the process of decision making. The lines or ties between each participant and target (and in some cases between targets) in the network figures were constructed from the relational data gathered during the interviews. Networks were drawn with Netdraw 2.081.

The network figures reflect the communication context (e.g., interpersonal, religious/spiritual) or contexts to which each target was assigned by the participant. The node of the participant occupied the space in the middle of the network. Each target node’s shape and location in the network figure reflects the primary communication context. In other words, targets belonging to the same communication context were grouped together in a particular sector of the figure, and the shapes of those nodes are the same. Targets assigned to the media context are found from 0° to 72°, the religious/spiritual context from 72° to 108°, the political-legal context from 108° to 126°, the interpersonal context from 126° to 270°, the cultural context from 270° to 288°, and the organizational context from 288° to 360°. Media nodes are square, religious spiritual nodes are upward-pointing triangles, political-legal nodes are shaped like an hourglass, interpersonal nodes are circles, cultural nodes are downward-pointing triangles, and organizational nodes are diamonds. Table 1 summarizes the primary context identification in network figures. Figure 12 illustrates the node locations by sector.
Table 1. Node location and shape in network diagrams according to primary context assignment.

<table>
<thead>
<tr>
<th>Context</th>
<th>Sector</th>
<th>Node Shape</th>
</tr>
</thead>
<tbody>
<tr>
<td>Media</td>
<td>0° to 72°</td>
<td>Square</td>
</tr>
<tr>
<td>Religious/Spiritual</td>
<td>72° to 108°</td>
<td>Triangle (point up)</td>
</tr>
<tr>
<td>Political/Legal</td>
<td>108° to 126°</td>
<td>Hourglass</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>126° to 270°</td>
<td>Circle</td>
</tr>
<tr>
<td>Cultural</td>
<td>270° to 288°</td>
<td>Triangle (point down)</td>
</tr>
<tr>
<td>Organizational</td>
<td>288° to 360°</td>
<td>Diamond</td>
</tr>
</tbody>
</table>
The participants could assign targets to more than one communication context. Thus, secondary and tertiary context identifications are also represented in network figures. Secondary contexts are distinguished by the color of the target’s node and tertiary context assignments are
distinguished by color of a target’s label. Table 2 and Table 3 indicate the color scheme for secondary and tertiary context assignment.

Table 2. Node color based on secondary context assignment.

<table>
<thead>
<tr>
<th>Context</th>
<th>Node Color</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organizational</td>
<td>Green</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Pink</td>
</tr>
<tr>
<td>Media</td>
<td>Blue</td>
</tr>
<tr>
<td>Religious/Spiritual</td>
<td>Lavender</td>
</tr>
<tr>
<td>Cultural</td>
<td>Orange</td>
</tr>
<tr>
<td>Political/Legal</td>
<td>Red</td>
</tr>
</tbody>
</table>

Table 3. Node label color based on tertiary context assignment.

<table>
<thead>
<tr>
<th>Context</th>
<th>Label Color</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organizational</td>
<td>Green</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Pink</td>
</tr>
<tr>
<td>Media</td>
<td>Blue</td>
</tr>
<tr>
<td>Religious/Spiritual</td>
<td>Lavender</td>
</tr>
<tr>
<td>Cultural</td>
<td>Orange</td>
</tr>
<tr>
<td>Political/Legal</td>
<td>Red</td>
</tr>
</tbody>
</table>

The first network figure, “Communication Frequency Between Interpersonal Nodes” provides a representation of the usual frequency of communication between the interpersonal
targets in a participant’s decision-making network. As mentioned previously, the frequency of contact between nodes was determined by two survey items. The participants indicated how often they spoke to each person whom they identified as part of their decision-making network on a scale of 1 to 10. A response of 1 indicated that the participant was in contact with the target daily. At the other end of the scale was contact with a target less than once a year (9). A respondent could also indicate that he or she was not normally in contact with the target (10). In this case, the participant was only in contact with the target during the process of decision-making and did not know the target otherwise. The participants also noted their perception of the frequency of contact among all of the other members of the decision-making network on the same scale, with the additional possibility of a “0”, which indicated that the network members did not know each other.

The survey items were reverse-coded. The frequency measure was then multiplied by 5/9 to change the scale from a 9 point scale to a 5 point scale. A value of 5 indicated high frequency of contact, whereas a value of 1 indicated low frequency. These values translated to the thickness of the tie between two nodes. A frequency value of 1 is represented by a 1-point line, a value of 2 is represented by a 2-point line, and so on. If targets were not connected (having a value of 0), no line is represented between the two. The color of the tie between the nodes also represents the frequency of communication and exists on a grey scale defined by the line’s red, green, and blue settings. A value of 5 is represented by black color (r=0, g=0, b=0), a value of 4 is represented by a dark grey color (r=80, g=80, b=80), a value of 3 is represented by a medium grey color (r=120, g=120, b=120), a value of 2 is represented by a light grey color (r=160, g=160, b=160), and a value of 1 is represented by a very light grey color (r=200, g=200, b=200). Thus, a dark, thick line indicates more frequent contact than a light grey, thin line.
A five-point scale was chosen for pragmatic reasons. Viewing the ties between participants on a scale of 1 to 5 allows for distinct color assignment. Any finer color assignment would present difficulties in distinguishing between two adjacent colors. In other words, subtle distinctions on a scale of 1 to 9 would be difficult for the naked eye to discern.

The second figure, “Frequency of Decision Contact Between Interpersonal Nodes,” provides a representation of the frequency of communication among all of the interpersonal targets in the decision-making network about the participant’s decision. The participants reported the number of times they spoke with each interpersonal target about their health-care decisions. They also reported the number of times they thought each target spoke to each other target about the decision on a scale of one to five (1 = 1 time, 2 = 2-3 times, 3 = 4-5 times, 4 = 6-7 times, 5 = 8 or more times). The participants recorded a “6” if they did not think the targets discussed his or her decision. Participants’ reports of their frequency of communication with each target were recoded on the same five-point scale as used to measure target-to-target contact concerning the decision. If targets did not discuss the health-care decision, no line is represented between the two. As in the first network figure, the thickness and color of a tie between nodes exists on a grey scale. Black color and a 5-point line represented the highest point of the scale noted above and light grey color and a 1-point line represented one discussion about a decision. Thus, a dark, thick line indicates more frequent communication about the participant’s health-care decision than a light grey, thin line.

The third network figure, “Participant’s Frequency of Decision Contact with Interpersonal and Non-interpersonal Targets” provides a representation of the frequency and duration of contact between the participant and each interpersonal and non-interpersonal node. A participant’s response to questions concerning the frequency and duration of contact between
himself/herself and each interpersonal and non-interpersonal target provided the basis for determining the tie between them. The tie between the participant and the targets was calculated by multiplying the average of the usual length/duration of contact between the participant and the target and the longest length/duration of contact between the participant and the target with the frequency of contacts between the two. The equation is:

\[
\text{Frequency of decision contact} \times \frac{\text{usual length/duration} + \text{longest length/duration}}{2}
\]

This calculation gives an estimate of the overall duration of time the participant was in contact with the target. Thus, the salience of one particular contact was accounted for in the measure, as well as the frequency of contact overall about the decision. The maximum calculated value within a particular decision-making network was then used to normalize the other values within that network. So, for instance, if the largest value of a tie was 35, every other value was divided by 35. Then each normalized value was multiplied by 5 so that the line thickness and coloring used in the first two figures could be applied to this figure as well, allowing for clear distinctions between ties.

An average ranging from 4.5 to 5 is represented by a 5-point line, an average ranging from 3.5 to 4.4 is represented by a 4-point line, an average of 2.5 to 3.4 is represented by a 3-point line, an average of 1.5 to 2.4 is represented by a 2-point line, and an average of 1.5 or less is represented by a 1-point line.

Similarly, an average ranging from 4.5 to 5 is represented by black color (r=0, g=0, b=0), an average ranging from 3.5 to 4.4 is represented by a dark grey color (r=80, g=80, b=80), an average of 2.5 to 3.4 is represented by a medium grey color (r=120, g=120, b=120), an average of 1.5 to 2.4 is represented by a light grey color (r=160, g=160, b=160), and an average of 1.5 or less is represented by a very light grey color (r=200, g=200, and b=200).
Thus, a thicker, darker line indicates more frequent contact about the participant’s decision than a thin, light grey line.

The fourth network figure, “Average Relational Quality Between Interpersonal Nodes,” provides a representation of the average relational quality between each interpersonal node. As explained previously the measures of relational quality were from the participants’ report of their own perception of stability, trust, and closeness between the members of their interpersonal decision-making network and themselves, as well as their perception of the stability, trust, and closeness among all interpersonal members of the decision-making network when taking the perspective of each interpersonal contact. For this network figure, an average of the relational quality reported from the perspective of each node (all of the targets and the participant) was calculated to provide a single value of relational quality that constituted the tie between the nodes.

The six survey items that measured relational quality were reverse-coded such that 5 indicated a high relational quality and 1 indicated a low relational quality. The tie thickness and color for this figure were assigned in the same manner as in figure three, with no tie indicating no relationship between targets and a dark, thick line indicating a higher quality relationship that a light, thin line.

The fifth figure, “Relational Quality Between Interpersonal Nodes – Nonsymmetric,” is a representation of the relational quality among the interpersonal nodes in the decision-making network which considers the participant’s perception of relational quality among the nodes when taking the perspective of each node. The participants indicated relational quality from the perspective of each node in the decision-making network in terms of stability, closeness, and trust on a five-point scale, with one indicating the highest degree for each dimension of relational
quality. The values for the items that measured relational quality were reverse coded so that five indicated that highest degree of relational quality. The values reported from the perspective of each node were then averaged. Thus, each tie in the decision-making network carries two values. One value represents the perception of relational quality from the perspective of one target in the dyad, and the other value represents the perception of the other target. These values are illustrated by the size and color of the arrowheads on each line. The size and color of the arrowhead is directly proportional to the relational quality. A relational quality average from 4.5 to 5 is represented by a 20-point arrowhead, an average of 3.5 to 4.4 is represented by a 16-point arrowhead, an average of 2.5 to 3.4 is represented by a 12-point arrowhead, an average of 1.5 to 2.4 is represented by an 8-point arrowhead, and an average relational quality of 1.5 or less is represented by a 4-point arrowhead. If a participant was unsure of a target’s perception of relational quality, no tie was indicated between the targets. Similarly, an average ranging from 4.5 to 5 is represented by black color (r=0, g=0, b=0), an average ranging from 3.5 to 4.4 is represented by a dark grey color (r=80, g=80, b=80), an average of 2.5 to 3.4 is represented by a medium grey color (r=120, g=120, b=120), an average of 1.5 to 2.4 is represented by a light grey color (r=160, g=160, b=160), and an average of 1.5 or less is represented by a very light grey color (r=200, g=200, and b=200).

An arrowhead pointing toward a node represents the alternate node’s perception of the relational quality between the nodes. If the arrowheads on one line are the same size, the participant perceives that the targets would perceive the relational quality between them to be the same. In other words, the tie is symmetric. If two different sized arrowheads appear on a line, the tie is considered nonsymmetric.
The sixth network figure, “Influence of Interpersonal and Non-interpersonal Targets on the Process of Decision-making,” represents a participant’s perception of the influence of each interpersonal and non-interpersonal target on the process of decision-making. The influence of each target on the process of decision-making was determined by the participant’s response to two survey items and the ranking of targets concerning the process of decision-making.

The responses to the survey items were reverse-coded, with five (on a scale of one to five) indicating a high degree of influence. The rankings were also reversed. A “1” indicates the lowest influence in the decision-making network, and N, where N indicates the number of targets in the decision-making network, indicates the highest influence in the decision-making network. The rankings were normalized by dividing each rank by N and then multiplied by 5 to reduce them to the same scale as the other measures of influence.

The reverse-coded values from the survey items reported about a target and the recoded ranking of the target were averaged to provide a numerical value of the target’s influence on the process of decision-making. This value was represented by the thickness and color of the tie. An average ranging from 4.5 to 5 is represented by a 5-point line, an average ranging from 3.5 to 4.4 is represented by a 4-point line, an average of 2.5 to 3.4 is represented by a 3-point line, an average of 1.5 to 2.4 is represented by a 2-point line, and an average of 1.5 or less is represented by a 1-point line. Similarly, average influence ranging from 4.5 to 5 is represented by black color (r=0, g=0, b=0), an average ranging from 3.5 to 4.4 is represented by a dark grey color (r=80, g=80, b=80), an average of 2.5 to 3.4 is represented by a medium grey color (r=120, g=120, b=120), an average of 1.5 to 2.4 is represented by a light grey color (r=160, g=160, b=160), and 1.5 or less is represented by a very light grey color (r=200, g=200, and b=200). Thus, a dark, thick line, then, indicates more influence than a light, thin line.
The seventh network figure, “Influence of Interpersonal and Non-interpersonal Targets on the Decision Outcome,” represents a participant’s perception of the influence of each interpersonal and non-interpersonal target on the outcome of decision-making. The influence score for each target on the outcome of decision-making was derived from a participant’s response to two survey items and the ranking of targets on the outcome of decision-making.

The responses to the survey items were reverse-coded so that five (on a scale of one to five) indicated a high degree of influence. The rankings were also reversed so that 1 indicated the lowest influence in the decision-making network and N (where N indicates the number of targets in the decision-making network) indicated the highest influence in the decision-making network. The rankings were normalized by dividing each rank by N and then multiplied by 5 to create comparable values.

The reverse-coded values from the survey items and the recoded ranking of the target were averaged to provide a numerical value measuring the target’s influence on the outcome of decision-making. This value was represented by the thickness and color of the tie in the same manner as in the sixth network figure. In short, a dark, thick line indicates more influence than a light, thin line.

The eighth network figure, “Frequency and Influence of Interpersonal and Non-interpersonal Targets on the Decision-making Process and Outcome,” is indicative of a participant’s perception of each interpersonal and non-interpersonal target’s influence on the process and outcome of the decision-making. The frequency of decision-making contact is also represented in the figure.

The influence of each target on the process and outcome of decision-making was determined by the participant’s response to two survey items indicating the influence of a target.
on the process of decision-making, two survey items indicating the influence of a target on the outcome of decision-making, and the ranking of targets on the process and outcome of decision-making.

The responses to the survey items were reverse-coded so that five, on a scale of one to five, indicated a high degree of influence. The rankings were reversed so that 1 was considered the lowest influence in the decision-making network and N (where N indicates the number of targets in the decision-making network) was considered the highest influence in the decision-making network. The rankings were normalized by dividing each rank by N and then multiplied by 5 to bring them to the same scale as the other measures of influence.

The reverse-coded values from all of the survey items relating to a target’s influence on the process and outcome and the recoded ranking of the target on the process and outcome were averaged to provide a numerical value of the target’s influence on the outcome of decision-making. This value is reflected in the color of the tie between two nodes. An average influence ranging from 4.5 to 5 is represented by black (r=0, g=0, b=0), an average ranging from 3.5 to 4.4 is represented by dark grey (r=80, g=80, b=80), an average of 2.5 to 3.4 is represented by a medium grey (r=120, g=120, b=120), an average of 1.5 to 2.4 is represented by light grey (r=160, g=160, b=160), and 1.5 or less is represented by a light grey (r=200, g=200, and b=200). The darker the line appears, the more influential the target on the process and outcome of the decision-making.

The frequency of decision contact between two nodes is illustrated by the thickness of the tie between them. The frequency value was calculated from the survey item measuring the number of contacts between the participant and each target in the decision-making network. This value was coded on a five-point scale (1 = 1 time, 2 = 2-3 times, 3 = 4-5 times, 4 = 6-7
times, 5 = 8 or more times) and the thickness of the line was represented accordingly. A thick
line indicates more frequent communication about a participant’s health-care decision than a thin
line.

The ninth and final network figure, “Frequency of Decision Contact, Direction of
Influence, Relational Quality, and Decision Knowledge, and Influence of Interpersonal Targets
on the Decision-making Process and Outcome,” relates to participants’ perceptions of the
influence of each interpersonal target on the process and outcome of decision-making. The
direction of influence between nodes is included, as is the frequency of decision contact,
relational quality between ego and targets, and targets’ knowledge of the decision situation.

The participants’ reports of each target’s knowledge of the decision situation were
measured by four survey items with five-point scales, with one indicating a high familiarity with
situation. The values were reverse-coded so that five indicated that a target was very familiar
with the decision situation. The reverse-coded values from the four survey items were averaged,
and used to determine the size of a target’s node in the figure. In order to make distinct size
differences, the average value of a target’s knowledge of the decision situation was multiplied by
three and added to 15. Thus, a value of 1 (low knowledge) produced a node size of 18 and a
value of 5 produced a node size of 30, and intermediate values between one and 5 would be sized
accordingly. The units of the size of each node are not specified in Netdraw, but this range
produced values that were visually distinct. The node of the participant in the network figure is
sized at 30 to help a viewer to gauge a node with “full knowledge” of the decision situation.

The thickness of a line represents the frequency of a target’s decision contact, in exactly
the same manner as reported regarding network figure 8.
The color of a tie represents the combined influence of a target, also in the same manner as reported for network figure 8. The length of the tie between only between the participant and the target was set by the average quality of relationship. The average relational quality was calculated in the same manner as seen in network figure 4. For average relational quality greater than 4.5, the length of the line was set to 100 pixels, an average relational quality between 3.5 and 4.4 was represented by a line of 150 pixels, an average relational quality between 2.5 and 3.4 was represented by a line of 200 pixels, an average relational quality between 1.5 and 2.4 was represented by a line of 250 pixels, and an averaged relational quality under 1.5 was represented by a line of 300 pixels. Thus, the shorter the line or the closer a target node is to the participant node, the higher the relational quality.

The participants indicated their perception of the direction of influence between each interpersonal node. The direction of influence was represented by the presence of an arrow on the tie between two nodes. If the participant reported that one person would have tried to influence the other during interaction about the decision, an arrow appears on the tie between the targets with the arrow pointing to the target who was reportedly influenced. If the participant thought that both parties would have tried to influence each other on the issue of the decision, two arrows appear on the tie, with one pointing to each target. If the participant indicated that neither person would have influenced the other or if the participant was unsure if one target would have influenced the other, no arrows were added to the tie. If the participant responded that the targets did not know each other or did not speak about the health-care decision, no tie was drawn between the targets.

These nine figures were examined along with a profile of each participant in order to determine different types of decision-making networks that emerge for older adults making a
major health care decision. Preliminary personal social network patterns were discerned through repeated examination of the each set of figures by the investigator. The figures were organized by patterns and then re-evaluated with participants’ profiles in each type in order to assess fit between the qualitative reports of the decision with the illustrations. Eight different examples of participants’ profiles and networks and included in appendices G, H, I, J, K, L, M, N, O, and P.

In addition to the personal social network diagrams, other structural properties commonly used in network analysis were investigated to see what information they might provide about the decision-making networks that emerged during the study. Because the networks are described only from the perspective of the participant, they share some unique characteristics. By their definition, the participant is always the center of the decision-making network and any target present in the decision-making network has a direct link to the participant. This characteristic makes some commonly used network analysis measures, such as notions of centrality or betweenness (Scott, 2000), not applicable to those considered in this study. Both centrality and betweenness measures for these personal social networks will always identify the participant as the central node, and therefore do not given any unique information from decision-making network to decision-making network.

Density is a network property describing the degree to which nodes in a network are connected. The density of any network graph with symmetric ties can be calculated from the following equation (Scott, 2000):

\[
density = \frac{l}{n(n-1)/2}
\]

where \( l \) is the number of lines in graph, and \( n \) is the number of nodes in the network. Density calculation range from 0 to 1, with 0 representing a network where none of the nodes are connected and 1 represent a network where each node is connected to every other node. Using
the density equation, two types of decision-making network density were calculated for each participant, the first being based on the normal frequency of contact between the participant and the targets referred to as normal density, and a second based on the contact specifically related to the health-care decision, referred to as decision density.

**Hypothesis III**

The third hypothesis was that older adults reporting reciprocal interactions with their adult children would also report a greater satisfaction with the overall decision-making process than older adults reporting non-reciprocal interactions. An independent sample \( t \)-test for unequal group sizes provided a test of the hypothesis.

**Hypothesis IV**

The fourth hypothesis was that older adults reporting reciprocal interactions with their adult children about a major health-care decision will experience less anxiety with the decision-making process than older adults reporting non-reciprocal interactions with adult children about their health care decisions (with influence direction from adult child to parent). An independent sample \( t \)-test for unequal group sizes again served as the test.

**Research Question II**

The second research question related to how culture influences the decision-making process and outcomes for older adults who utilize cultural contacts as part of their decision-making networks. Each participant who reported a cultural contact in their decision-making network or who rated culture as an important context of influence in survey responses was examined along with the participant’s profile of each participant to determine different types of decision-making networks that emerge for older adults making a major health care decision.
Because few participants indicated an influence of cultural context, hence only anecdotal evidence applied to this research question.

*Hypothesis V*

The fifth hypothesis predicted that participants rating their decisions as serious and severe would report a higher influence from the religious/spiritual communication context than those not seeing them as serious and severe. A composite measure was created by averaging the participants’ report of seriousness and severity of consequences of the health-care decision. Both seriousness and severity were rated on a scale of 1 to 5, with one being the most serious/severe and 5 being not very serious/severe. The participants were divided into two groups using a cutting point of 2.1 on the composite value, with those having a composite of less than 2.1 being classified as rating their decision as more serious and severe, and those having a composite of 2.1 or greater being classified as rating their decision as less serious and severe. The mean influence from the religious/spiritual context was compared for both groups using an independent sample t-test for unequal group sizes.

*Hypothesis VI*

In hypothesis VI, older adults noting use of positive religious coping strategies would experience greater satisfaction with the health-care decision-making process than individuals reporting use of negative religious coping strategies or no religious coping strategies. The survey contained five items relating to a participant’s positive religious coping strategies and five items related to negative religious coping strategies. Scores for both measures were averages of the responses to the five questions. The composite for positive religious coping strategies showed a relatively normal distribution over the range (M = 2.00, SD = 0.92), whereas the
composite for negative coping strategies indicated practically no participants using such strategies ($M = 3.68, SD = .036$). Both measures had a scale of 1 to 4. Because the negative coping strategy composite did not yield any significant variation, the population was divided on the basis of the positive coping strategy composite, with a cutting point of 2.1. Participants who had a composite value less than 2.1 were classified as reporting positive religious coping strategies, and those reporting a composite of 2.1 or greater were classified as using negative religious coping strategies or no religious coping strategies. The participants were divided in order to distinguish if a difference existed between religious coping strategies and satisfaction, and to isolate it. An independent sample $t$-test for unequal group sizes was then used to determine whether or not the difference in mean satisfaction with the decision-making process between the two groups was statistically significant.

*Hypothesis VII*

The seventh hypothesis held that older adults with positive religious coping strategies will report experiencing less anxiety with the decision-making process than individuals using negative religious coping strategies or no religious coping strategies. To test this hypothesis, the participants were grouped according to the same criteria as for Hypothesis IV. The mean value of each groups’ anxiety were compared using an independent sample $t$-test for unequal group sizes.

*Research Question III*

The third research question asked if different types of decision-making networks are mediated by insurance type. To examine this question, participants were divided into groups according to the insurance they held, and the mean of the dominant context measure (DCM) was
calculated for each group. A one-way ANOVA with the outcome variable as the mean of the DCM and the predictor as the insurance type was performed to identify if differences were statistically significant.

**Research Question IV**

The fourth research question addressed how older adults’ propensity for involvement in health-care decision-making relates to their decision-making networks. Pearson’s $r$ was the index of relationship in determining whether or not a participant’s propensity for involvement correlated significantly with the number of nodes in the participant’s decision-making network. Pearson’s $r$ also revealed whether or not there was an association between the participant’s propensity for non-adherence and the combined process and outcome influence of physicians in the participant’s decision-making network.

**Hypothesis VIII**

The eighth hypothesis was that an older adult’s propensity for involvement in health-care decision-making would be related positively to their use of media sources during their process of decision-making. Pearson’s $r$ was the indication of whether or not the data confirmed the hypothesis.

**Research Question V**

The fifth research question focused on whether or not older adults facing a major health care decision who also have a high propensity for involvement in their health-care decisions and use the Internet would express greater satisfaction with process of decision-making than older adults with a high propensity for involvement in their health care decisions who do not use the Internet. To answer this research question, participants were divided into two groups based on
their propensity for involvement in the health care decision-making process. Participants whose average propensity for involvement was less than 2.1 were in the high group, whereas those with a value greater than 2.1 were in the low group and were excluded from further consideration in this question. Among the 37 participants identified in the high propensity for involvement group, 24 regularly used the Internet, and 13 did not. An independent sample $t$-test for unequal group sizes served to reveal whether or not the mean difference for Internet usage between these groups was statistically significant.
Chapter 3: Results

Reliability of Measures

The estimates of reliability for the scales utilized in the study varied. The two-item measure for decision gravity, taken at the initial interview and final interview, yielded a Cronbach’s $\alpha = .629$. Anxiety related to the decision was measured with two items, one asked during the initial interview and the other during the final interview. The reliability for these two items was low, with Cronbach’s $\alpha = .585$. The low reliability of the measure taken at two different points in the decision-making process was not problematic in this case. In fact, one would expect that over time and as a result of one’s information-seeking and communication during the decision-making process that one’s anxiety might fluctuate.

The measures associated with the Theory of Motivated Information Management (TMIM) yielded satisfactory estimates of reliability for overall coping efficacy, Cronbach’s $\alpha$ was .762. When omitting the one item measuring coping efficacy related to the process of decision-making and considering only the three items for coping efficacy with the outcome of the decision, Cronbach’s $\alpha$ was .771. For communication efficacy, Cronbach’s $\alpha$ was .82. Cronbach’s $\alpha$ for the measure of target efficacy with regards to honesty was .781 and the measure of target efficacy with regards to ability yielded a Cronbach’s $\alpha$ of .893. Target efficacy overall had a Cronbach’s $\alpha$ of .807.

The measures of an individual’s propensity for involvement in the health-care decision yielded a Cronbach’s $\alpha$ of .646 for assertiveness, .606 for nonadherence, and .654 for education. In combination, these measures yielded a Cronbach’s $\alpha$ of .646.
Reliabilities for positive religious coping was high (Cronbach’s $\alpha = .88$). However, the measure for negative religious coping was very low (Cronbach’s $\alpha = .33$), which is substantially different from the estimated reliability for negative religious coping (Cronbach’s $\alpha = .69$) that Pargarment, Smith, Koenig, and Perez (1998) reported for their measure of negative religious coping.

The three-item measure of relational quality involving each person in his or her decision-making network, as well as his or her perception for all of the interpersonal members of the decision-making network, yielded a Cronbach’s $\alpha$ of .849.

Finally, for the four-item measure of a target’s knowledge of the participant’s decision situation had a Cronbach’s $\alpha$ of .677.

**Hypothesis I**

The first hypothesis posited older adults’ evaluation of their communication and efficacy would be predictive of their information-seeking behavior in respect to health-care decision-making networks. A correlation between the participants’ communication efficacy and the number of interpersonal targets with whom they initiated the conversation was significant, $r(61) = -.275$, $p = .032$, $r^2 = .076$. One participant’s decision-making network only contained media sources, and thus was not included in the analysis.

**Hypothesis II**

The second hypothesis was that older adults’ assessment of the efficacy of a target in their health care decision-making networks would correlate positively with their information-seeking behavior involving the target. Pearson’s $r$ yielded no evidence of a significant
relationship, \( r(279) = -.013, p = .83 \). The Pearson coefficient showed almost no effect. For \( r = .013, \alpha = .10 \), and \( n = 279 \) (the number of participant-to-target dyads), the power of the test is below the desired level of .80 (\( 1 - \beta = .078 \)). To reach a power level of 0.80 would require an \( r \) value of at least .15.

Research Question I

The first research question concerned patterns in decision-making networks for older adults considering a major health-care decision. The nine decision-making network figures, along with the corresponding participant profiles, were at the base of the answer. Preliminary examination of personal social network patterns yielded various descriptive and quantifiable conclusions.

First, target demographic information was compiled for all of the decision-making networks. A total of 279 interpersonal targets were identified by the study’s participants. One-hundred-fifty-one (54%) were males, and 125 (46%) were females. The participants identified a total of 70 non-interpersonal sources. The gender of one interpersonal target was not provided. The participants each identified their relationship with each interpersonal node. From the responses for targets identified as “Other”, three new categories were created: “medical professional”, “family member”, and “romantic partner”. “Medical professionals” included targets identified as nurses, dental assistants, and pharmacists. “Family members” included other biological relatives and individuals related to participants as a result of marriage, such as daughter-in-law and cousin. Separating these commonly reported classifications left the “Other” designation with such relationships as “long term care workshop facilitator”, “sales
representative”, and “support group director.” Figure 13 summarizes the types of interpersonal targets reported in the study.

Figure 13. Interpersonal targets relationship with participant.

Figure 14 summarizes the primary communication context assigned to each interpersonal node. A total of 104 targets had the “Organizational” context as their primary designation. Ninety-five of the targets assigned to this context were physicians or dentists. The rest were medical professionals in some respect (for example, nurse, physician’s assistant, dental assistant, or pharmacist).
The participants could also specify a secondary and tertiary communicative context for targets in their decision-making network if they deemed it necessary. Below is the number of designations only for interpersonal nodes of the participants’ decision-making networks.

Table 4. Communicative contexts of interpersonal target nodes.

<table>
<thead>
<tr>
<th>Context</th>
<th>Primary</th>
<th>Secondary</th>
<th>Tertiary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Media</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>166</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Cultural</td>
<td>3</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Religious/Spiritual</td>
<td>1</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Political/Legal</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Organizational</td>
<td>104</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>No Designation</td>
<td>0</td>
<td>250</td>
<td>275</td>
</tr>
<tr>
<td>Total</td>
<td>278</td>
<td>278</td>
<td>278</td>
</tr>
</tbody>
</table>

The participants also each identified a communication context for non-interpersonal target nodes in their decision-making network. Non-interpersonal targets refer to information sources other than people. Table 5 shows the context for the 70 non-interpersonal nodes the
participants identified. A clear and substantial majority of these nodes fell into the “Media”
context.

Table 5. Communicative contexts of non-interpersonal target nodes.

<table>
<thead>
<tr>
<th>Context</th>
<th>Primary</th>
<th>Secondary</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Designation</td>
<td>0</td>
<td>66</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Cultural</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Religious/Spiritual</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Political/Legal</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Organizational</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Media</td>
<td>63</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>70</strong></td>
<td><strong>70</strong></td>
</tr>
</tbody>
</table>

In addition to the demographic information compiled about the targets in the decision-
making network, demographic data yielded additional information about the entire collection of
decision-making networks. The decision-making network sizes for the 62 participants varied
greatly. There were three decision-making networks consisting of only the participant and a
single interpersonal target. The largest decision-making network was comprised of 17 targets
(15 interpersonal and 2 non-interpersonal sources). Table 6 presents a summary of the size of
participants’ decision-making networks. Distributions of the decision-making networks based on
the number of interpersonal and non-interpersonal targets and total number of targets appear in
Figure 15 and Figure 16, respectively. Although several of the decision-making networks had no
non-interpersonal targets, only one decision-making network did not contain any interpersonal
targets. This decision-making network solely consisted of 2 non-interpersonal targets.
Table 6. Decision-making network size.

<table>
<thead>
<tr>
<th></th>
<th>Min</th>
<th>Max</th>
<th>Average</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Target Nodes</td>
<td>0</td>
<td>15</td>
<td>4.50</td>
<td>2.88</td>
</tr>
<tr>
<td>Non-Interpersonal Target Nodes</td>
<td>0</td>
<td>4</td>
<td>1.13</td>
<td>1.26</td>
</tr>
<tr>
<td>Total Targets</td>
<td>1</td>
<td>17</td>
<td>5.63</td>
<td>3.42</td>
</tr>
</tbody>
</table>

Figure 15. Distribution of number of targets, interpersonal and non-interpersonal, contained in participants' decision-making networks.
In addition to the descriptive statistics above, examination of other personal social network data allowed for several inferences. As would be expected, participants reported greater frequency of contact overall with their interpersonal context than their organizational context. The more frequently participants reported that those in the interpersonal context were normally in contact with each other, the more likely the participants were to think such individuals would discuss their health-care decisions. The participants tended to report that even though they perceived that targets in the organizational context of communication were normally in contact, they did not think that these targets frequently spoke about their decisions. Most targets in the interpersonal context were not connected with targets in the organizational context, except in the case of spouses. Participants reported that their spouses often accompanied them to appointments with their physicians. Several mentioned that adult children, not normally in
contact with the participant’s physicians, were in contact about with the physician regarding the participant’s decision.

Network figure 4 illustrated the average relational quality among all of the interpersonal nodes, and network figure 5 illustrated the participants’ perceptions of nonsymmetric relational quality among interpersonal nodes. Nonsymmetries could arise as the participant considered how each target would rate the target’s relation quality with other member of the decision-making network. In addition, although differences between influence on the process, outcome, and combined influence (network figures 6, 7, and 8) were evident in individual networks, overarching patterns across decision-making networks were not.

In examining the ninth network figure, it is clear that the participants differed in their reports of influence coming from the organizational and interpersonal communication contexts. Some network illustrations were clearly dominated by organizational influence, whereas other decision-making networks were clearly dominated by interpersonal influence. In terms of the direction of influence, distinct differences emerged. Some participants saw members of the organizational context as trying to influence them, where other participants reported trying to influence the members of their organizational context. Decision-making networks usually exhibited one pattern or the other, but not both.

Many participants reported that their adult children tried to influence them more frequently than they tried to influence their adult children. They also reported that their spouses tried to influence them more frequently than they tried to influence their spouses about the decision.

The most interesting observations related to occurrences within the organizational and interpersonal contexts of communication, if only because most targets were assigned to these
contexts. The next most frequent context identification was the media. Media targets were less influential than interpersonal or organizational contexts, but were far more salient in the decision-making networks than were religious/spiritual, political-legal, or cultural contexts.

The most distinctive feature of influence seen in the decision-making network figures was that members of the organizational context seemed to be the predominant influence of one group of decision-making networks, while members of the interpersonal context seemed to be the predominant influence in another group. In light of this observation, each target’s influence, as calculated for network figure 8, was summed for the targets in each context. The influence of each target on the process and the outcome of the decision-making was combined and summed for each of the six communication contexts. The influence of the interpersonal and organizational contexts of communication was of particular interest, so the difference between the sum of the influence of the interpersonal context and the influence of the organizational context was computed to form a dominant context measure (DCM) that placed each decision-making network on a spectrum of influence ranging dominance of organizational influence to dominance of interpersonal influence. When the DCM was positive, interpersonal influence was dominant in the decision-making, whereas a negative DCM indicated that the organizational context influence is dominant. Figure 17 illustrates how, in fact, the decision-making networks fell along a spectrum from those dominated by organizational influence to those dominated by interpersonal influence.
A one-way ANOVA with the dependent variable being the difference between the combined interpersonal context influence and the combined organizational context and the predictor as the decision type revealed a significant difference in the means of the decision type groups, $F(7,54) = 3.55, p < 0.01$. The difference of the combined influence difference for each of the decision types appears in Table 7.
Table 7. Mean and standard deviation of difference between interpersonal and organizational context influence by decision type.

<table>
<thead>
<tr>
<th>Type of Decision</th>
<th>Difference in Context</th>
<th>Influence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Change Provider (n=5)</td>
<td>10.78</td>
<td>10.86</td>
</tr>
<tr>
<td>Surgery (n=23)</td>
<td>0.41</td>
<td>6.74</td>
</tr>
<tr>
<td>Medical Treatment (n=13)</td>
<td>0.68</td>
<td>5.16</td>
</tr>
<tr>
<td>Medication Change (n=5)</td>
<td>-4.29</td>
<td>6.26</td>
</tr>
<tr>
<td>Change Insurance (n=2)</td>
<td>-1.82</td>
<td>6.62</td>
</tr>
<tr>
<td>Living Arrangements (n=7)</td>
<td>11.77</td>
<td>11.67</td>
</tr>
<tr>
<td>Life/Work Activities (n = 3)</td>
<td>-2.00</td>
<td>-</td>
</tr>
<tr>
<td>Seek Medical Treatment (n = 6)</td>
<td>4.64</td>
<td>4.49</td>
</tr>
</tbody>
</table>

Participants who were making a health-care decision involving living arrangements, changing a health care provider or seeking medical treatment usually had decision-making networks clearly dominated by interpersonal influence. On the other hand, decisions involving changes in life/work activities, medication or insurance were clearly dominated by organizational
influences. Decisions concerning surgery and other medical treatments also tended to be
dominated more by interpersonal influence than organizational, but these decisions fell close to
the middle of the continuum, which indicated a closer balance of influence between
organizational and interpersonal than in the other decision types.

Decision-making network figures for ten different participants appear in Appendices G –
P to serve as examples and represent different findings throughout the manuscript. For the
purposes of illustrating networks at different points along the spectrum, network figures in
Appendices M, O, P, H are offered. As illustrated in the network figures in Appendix M,
“Mason’s” decision concerning heart surgery was dominated by organizational influence (DCM
= -6.547). “Scott’s” decision about treatment for prostate cancer, illustrated in Appendix O, was
also dominated by organizational influence (DCM = -2.84). The network figures in Appendix P
illustrate a balance between the influence of the organizational and interpersonal contexts (DCM
= .777) in “Margaret’s” decision about surgery for incontinence. As illustrated in Appendix H,
“Catherine’s” decision involving changing medications was dominated by interpersonal
influence (DCM = 5.750). Finally, “Lizzie’s” network figures in Appendix I illustrate her
decision relating to sinus surgery as clearly dominated by interpersonal influence (DCM =
11.627).

At times, interpersonal influence clearly trumped the organizational. For example (see
profile Appendix I), one participant reported that she decided not to have surgery as a result of
conversations she had with members of her interpersonal context. The adult children (nodes
JAD and JAJR) were the most influential members of her decision-making network, as
illustrated in Figure 42. Despite the fact that the participant reported that several people from the
organizational context were trying to convince her to have surgery, the explicit objection of one
adult child to the surgery, JAJR (as illustrated in Figure 44), as well as the less overt influence of her friend, AMZ, acquaintance, D, spouse JA, and another adult child who was unable to assist with the aftercare of the surgery (as reported by the participant and demonstrated in the profile) carried more weight in her decision. This was not an isolated case. Participants making decisions that involved members of their organizational and interpersonal contexts frequently decided not to follow the advice of a physician. Other participants reported seeking professional medical help as a result of referrals from their interpersonal context and made decisions about providers based on information from their family members and friends.

In other cases, the influence of the members of the organizational context clearly dictated the decision. For example, one participant, whose friends encouraged her to see a specialist about incontinence and having surgery for her condition, was set on having the procedure before her appointment with the specialist. However, when the specialist told her that she was not a candidate for surgery, she accepted the diagnosis and did not seek further opinions on the subject. Similarly, a woman who was diagnosed with fibromyalgia noted that she very much wanted to try a new medication to treat her condition. However, her physician would not prescribe the medicine to her and thus had the final say regarding her decision for treatment. Although this participant noted that she would later try to convince her primary care physician to prescribe the medicine during her next visit, she accepted his opinion for the time being.

Two personal social network density measures, one based on normal frequency of contact between network nodes (overall personal social network density), and the other based on communication specifically related to the health-care decision (decision-making contact density) were calculated. The means and standard deviations of both densities appear in Table 8.
Table 8. Mean and standard deviation of overall personal social network density and decision-making contact density.

<table>
<thead>
<tr>
<th>Density</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Personal Social Network</td>
<td>.681</td>
<td>.226</td>
</tr>
<tr>
<td>Density (n=62)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decision-Making Contact Density</td>
<td>.604</td>
<td>.245</td>
</tr>
<tr>
<td>(n=62)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The overall personal social network density tended to be higher than the decision-making contact density because although many members of a participant’s decision-making network may regularly communicate with one another, participants did not always think targets were discussing their health-care decisions.

The overall personal social network density measure captures the degree to which nodes within a decision-making network are connected and therefore it serves to describe one aspect of the decision-making network’s structure. In the course of investigating the patterns of influence that emerge from the decision-making networks, the density measures were correlated with influence from interpersonal, organizational, religious/spiritual, political/legal, and media context. Table 9 summarizes Pearson’s $r$ for each context correlated with both personal social network density and decision-making contact density.
Table 9. Pearson's $r$ values for density measures correlated with context influences.

<table>
<thead>
<tr>
<th>Context Influence</th>
<th>Personal Social Network Density</th>
<th>Decision-Making Contact Density</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$r$</td>
<td>$p$</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>-.360</td>
<td>-.004</td>
</tr>
<tr>
<td>Cultural</td>
<td>-.241</td>
<td>.059</td>
</tr>
<tr>
<td>Religious/Spiritual</td>
<td>-.241</td>
<td>.059</td>
</tr>
<tr>
<td>Political/Legal</td>
<td>-.259</td>
<td>.042</td>
</tr>
<tr>
<td>Organizational</td>
<td>-.188</td>
<td>.142</td>
</tr>
<tr>
<td>Media</td>
<td>-.271</td>
<td>.033</td>
</tr>
</tbody>
</table>

Statistically significant correlations exist between a personal social network density and the interpersonal, political/legal, and media context. For decision-making contact density, significant correlations appear for the interpersonal, political/legal, and media context. All $r$ values are negative and examination indicates that as the personal social network density and the decision-making contact density increases, the influence from any context tends to decrease. At first this observation might appear contradictory. However, participants with smaller decision-making networks tended to have higher density measures. In decision-making networks containing a large number of targets, the likelihood that links exist between targets decreased, yielding smaller density measures. In fact, a Pearson’s $r$ correlating the number of targets to the density measures showed a strong inverse relationship between the density measures and the
number of targets within a decision-making network. Table 10 presents the values for the correlation.

Table 10. Pearson correlation between number of targets and density measures.

<table>
<thead>
<tr>
<th></th>
<th>Personal Social Network Density</th>
<th>Decision-Making Contact Density</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pearson’s Correlation</strong></td>
<td>$r$</td>
<td>$p$</td>
</tr>
<tr>
<td><strong>Number of Targets</strong></td>
<td>-.517</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

As the number of targets in a participant’s decision-making network increases, the influence from each context also increases, but each target is less likely to be connected to other targets overall and with regards to decision-making contact. Taking this into consideration, overall personal social network density and decision-making contact density are more related to the network size than any pattern of context influence.

Finally, the relationship between decision-making contact density and satisfaction was analyzed using a Pearson’s correlation. Decision-making contact density and satisfaction with the decision-making process revealed no significant correlation, $r = -.024, p = 0.853$. Similarly, a Pearson’s $r$ did not show any significant correlation between decision-making contact density and satisfaction, $r = -.022, p = .866$. 
Hypothesis III

The third hypothesis predicted older adults reporting reciprocal interactions with their adult children about a major health care decision would be more satisfied with the decision-making process than those reporting that their adult children tried to influence their health care decisions (with influence direction from adult child to parent). An independent sample t-test for unequal group sizes revealed no significant difference, \( t(46) = .533, p = .597 \).

The Cohen’s effect size (1988) for the difference between the two means shows the observed difference between the means can be classified as a small effect \( (d = 0.16) \). Using the effect size, \( \alpha = .10 \), and the sizes of the groups \( (n1 = 32, n2 = 16) \), the power of the test was below the desired level of 0.8 \( (1-\beta = 0.13) \). With group sizes of 32 and 16, the test does reach a power level of 0.8 for effect sizes of .78 or larger. This test had sufficient power to detect a difference of 1.22 between the means the groups of older adults reporting that their adult children tried to influence their decision and those whose adult children did not with regard to satisfaction with the process of decision-making. As Table 11 shows, the mean satisfaction for adults reporting reciprocal interactions with an adult child show a difference between the two groups in the appropriate direction.
Table 11. Means and standard deviations for satisfaction by reciprocity with adult child.

<table>
<thead>
<tr>
<th>Relationship with Adult Child</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reciprocal (n=32)</td>
<td>2.75</td>
<td>1.46</td>
</tr>
<tr>
<td>Non-Reciprocal (n=16)</td>
<td>3.00</td>
<td>1.67</td>
</tr>
</tbody>
</table>

Hypothesis IV

The fourth hypothesis held that participants who report reciprocal relationships with an adult child experience less anxiety associated with the health-care decision-making process than those who report the adult child as attempting to influence the participant. A $t$-test for an independent sample of unequal size involving means of reported anxiety for participants with reciprocal relations with an adult child ($n1=32$) to participants with the adult children attempting to influence the process ($n2=16$) supported the hypothesis, $t(46) = -1.919, p = .061, \eta^2=.074$. 
Table 12. Means and standard deviations for anxiety by reciprocity with adult child.

<table>
<thead>
<tr>
<th>Relationship with Adult Child</th>
<th>Anxiety M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reciprocal (n=32)</td>
<td>3.25</td>
<td>1.32</td>
</tr>
<tr>
<td>Non-Reciprocal (n=16)</td>
<td>2.44</td>
<td>1.50</td>
</tr>
</tbody>
</table>

The level of anxiety many participants reported changed from the initial interview to the final interview. Those who reported reciprocal interactions with an adult child experienced a greater, but not statistically significant, decrease in anxiety level than those whose adult children attempted to influence them during the course of the decision-making process, $p = .0841$, $t(46) = 1.76$.

Qualitative data supports this conclusion. For example, “Theresa” depended on her son, MV, to determine living arrangements for her following an emergency surgical procedure. As illustrated in Appendix L: Decision-Making Network Example 6 – “Theresa”, in Figure 70, the positive influence of her son on the decision process and outcome was obvious, if only because he was the only member of her decision-making network. Nonetheless, the strong relational quality between them (as illustrated in Figure 66 and Figure 67) and the low frequency of communication between the two relating to the decision (as seen in Figure 64) suggest that the trust the participant placed in her son likely contributed to her relatively low anxiety with the decision-making process. In this case, the participant indicated that she felt little need to talk
with her son frequently about the decision because she trusted that he took care of the arrangements to her liking. This was not an isolated case in the study.

Table 13. Means and standard deviations for change in anxiety by reciprocity with adult child.

<table>
<thead>
<tr>
<th>Relationship with Adult Child</th>
<th>Change in Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship with Adult Child</td>
<td></td>
</tr>
<tr>
<td>Reciprocal (n=32)</td>
<td>-0.47  2.00</td>
</tr>
<tr>
<td>Non-Reciprocal (n=16)</td>
<td>0.50  1.27</td>
</tr>
</tbody>
</table>

Research Question II

The second research question focused on how culture influences the decision-making process and outcomes for older adults who utilize cultural contacts as part of their decision-making networks. As mentioned previously, few participants reported the influence from the cultural context. Thus, only anecdotal evidence apply in answering this question.

Two participants reported cultural contacts and for both, the cultural contact was influential in their decision-making. Several other participants who did not identify specific cultural contacts indicated that culture was at least “somewhat” influential in their overall decision-making. Qualitative evidence from the interviews suggested that in these cases, some aspect of culture affected their decisions, but not in the form of a target. For example, two noted that the culture of a location to which they were considering relocating affected the decision.
Others noted that the cultural background of a physician came into play when making their decisions in that a physician might not really understand where they were “coming from” with respect to some aspect of their care-related decisions. Although anecdotal, the influence of cultural factors on the health-related decisions of older adults seemed to be deeply embedded in their decision-making processes. For example, “Valerie” (Appendix J) noted cultural factors as an important part of her decision-making. She identified one of her decision-making contacts in discussing both the interpersonal and cultural contexts of communication. Perhaps more indicative of the importance of her culture in her decision-making is that in her responses to questions during the initial and final interviews, Valerie frequently referred to the cultural identity she formed as an English woman from South Africa without prompt from the researcher. As Valerie explained the decision-making process, she pointed to important cultural factors through stories in which her cultural identity was salient. She noted that her good friend Hannah, with whom she shares cultural background, understood her in ways that others could not because of their common cultural experience. As a result, Valerie said that she felt comfortable disclosing information to Hannah about her health care decision-making process. Further, Valerie connected her cultural background to political-legal factors as well in remarking that her decision-making would be easier if she were able to obtain medical care in her continent of origin where her adult children live.
Hypothesis V

The fifth hypotheses was that participants who rated their decision as serious and severe would report a higher influence from the religious/spiritual communication context than those who do not report their decision as serious and severe. A \( t \)-test without assuming equal variances, failed to support the hypothesis, \( t(60) = -1.019, p = .313 \). Cohen’s effect size for the difference between the two means indicated that the observed difference between the means can be classified as a small effect (d=0.26). Using the effect size, \( \alpha = .10 \), and the sizes of the groups \( (n1=37, n2=25) \), the power of the test was below the desired level of .8 (1-\( \beta = .26 \)). With group sizes of 37 and 25, for a power level of .8, effect sizes of .66 or larger would be necessary. This would also require a minimum mean difference of .66.

Table 14. Means and Standard Deviations for Influence from the Religious/Spiritual communication context by decision seriousness/severity.

<table>
<thead>
<tr>
<th>Seriousness/Severity</th>
<th>Religious/Spiritual Influence</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>More Serious/Severe (n=37)</td>
<td>3.32</td>
<td>1.81</td>
<td></td>
</tr>
<tr>
<td>Less Serious/Severe (n=25)</td>
<td>3.76</td>
<td>1.53</td>
<td></td>
</tr>
</tbody>
</table>
Hypothesis VI

The sixth hypothesis posited that older adults who report positive religious coping strategies would experience greater satisfaction with the health care decision-making process than individuals reporting use of negative religious coping strategies or no religious coping strategies. An independent sample $t$-test for unequal groups sizes with the mean of satisfaction with the decision-making process as the criterion variable showed no significant difference, $t(60) = .775, p = .442$. The Cohen’s effect size for the difference between the two means shows the observed difference between the means could be classified as a small effect ($d=0.20$). Using the effect size, $\alpha = .10$, and the sizes of the groups ($n_1=38, n_2=24$), the power of the test fell below the desired level of .8 ($1-\beta = .19$). With group sizes of 38 and 24 or a mean difference of .91, the test reaches a power level of .8 for effect sizes of .66 or larger.

Table 15. Means and standard deviations for satisfaction by religious coping strategy.

<table>
<thead>
<tr>
<th>Religion Coping Strategy</th>
<th>Satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>More Positive (n=38)</td>
<td>$M=2.16$, $SD=1.46$</td>
</tr>
<tr>
<td>Less Positive (n=24)</td>
<td>$M=1.88$, $SD=1.30$</td>
</tr>
</tbody>
</table>
Hypothesis VII

The seventh hypothesis predicted that older adults relying on positive religious coping strategies would report less anxiety with the decision-making process than individuals resorting to negative religious coping strategies or having no religious coping strategies. A t-test showed no significant difference between the two groups mean anxiety, \( t(60) = .104, p = .92 \) Cohen’s effect size for the difference between the two means shows the observed difference between the means could be considered as a small effect \((d = .03)\). Using the effect size, \( \alpha = .10 \), and the sizes of the groups \((n_1 = 38, n_2 = 24)\), the power of the test was found to be below the desired level of .8 \((1-\beta = .06)\). For sample sizes of 38 and 24, the test would reach a power level of .8 for effect sizes of .66 or larger, or a minimum difference of .96 between the means of those reporting positive religious coping strategies and those reporting negative religious coping strategies.

Table 16. Means and standard deviations for anxiety by religious coping strategy.

<table>
<thead>
<tr>
<th>Religion Coping Strategy</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>More Positive (n=38)</td>
<td>3.29</td>
<td>1.45</td>
</tr>
<tr>
<td>Less Positive (n=24)</td>
<td>3.25</td>
<td>1.45</td>
</tr>
</tbody>
</table>

Although the fifth, sixth, and seventh hypotheses received no support, religion and spirituality seemed to affect the decision-making process of individuals who reported that religion and spirituality were important to them and considered themselves to be religious and
spiritual. In fact, subjective religiosity was positively correlated with influence from the religious/spiritual context of communication. Two items measured participants’ subjective religiosity (“How important is religion to you? How religious do you consider yourself to be?”). A Pearson’s $r$ was used to investigate the relationship between subjective religiosity and the influence of the religious/spiritual context reported by the participant. The test showed a significant positive relationship between subjective religiosity and influence from the religious/spiritual context, $r(62) = .439, p < .001$.

The qualitative data collected during the study also supported the notion that for those who are religious and/or spiritual, religiosity and spirituality played an important role in the decision-making process. Participants frequently revealed that their faith aided them in coping with complicated and serious health conditions and eased their anxieties about their health-care decisions. For example, “Lizzie” (whose profile and network figures are offered in Appendix I), who needed to make a decision about having sinus surgery which was complicated by a complex health background and a distrust of the surgeon who would perform the surgery, expressed throughout her interviews that her faith played a significant role in helping her cope with her serious condition and make decisions about her health care. Lizzie, who reported intense suffering from sinus pain and from the effects of Lyme disease, said that some days she had trouble getting out of bed because she was in so much agony. However, her alarm clock was set to a religious radio station. She said that after hearing the prayers and commentary on the station and praying, she found strength to get out of bed. Lizzie also noted that she prays when making major decisions by asking, “What’s going on? What’s your plan here God?” and that she always knows what to do or “things just fall into place the way they should.” In the case of making a decision concerning sinus surgery, she said she prayed about the decision and had confidence
that she had made the right one. Although prayer and faith permeated the way Lizzie talked about how she coped with her poor health and health-related decisions, when examining Lizzie’s decision-making network profiles, such as in Figure 44, the influence of religion and spirituality fall secondary compared to the interpersonal influence. The ties between Lizzie and the members of her religious/spiritual context of communication are clearly weaker than those ties in the interpersonal context.

Similarly, “Diana,” a participant with multiple chronic and serious health conditions who was facing a decision about seeking a second opinion after receiving discouraging news from a specialist, spoke at length about how she was able to cope with what, at times, seemed like a hopeless situation through her strong faith. “How many months I’ve been suffering… I wonder if I will lose my leg. There seems like there is so little I can do and I may have to suffer like this the rest of my life. I don’t know, except that God help me, he (God) is there,” she said. Diana expressed that she felt fortunate that her husband and two of her close friends shared her deep religious convictions and were able to support her through their faith as well. However, as in Lizzie’s case, the measure of the influence of the religious/spiritual context was lower than the influence of the interpersonal context, if only because all of the members of the religious/spiritual context were also placed in the interpersonal context.

Research Question III

The third research question concerned whether or not insurance mediated the different types of decision-making networks. The results of an ANOVA were not statistically significant, \( F(7,54) = .48, p = .84 \). The type of medical insurance one had was not one of the major factors predictive of the type of decision-making network one formed. Although presented in Table 17,
insurance groups containing only one participant were excluded from the calculation. For the ANOVA, the \( f \) statistic classifies the observed effect size. For an \( f = .48 \), \( \alpha = .10 \), and the group sizes shown in Table 17, the predicted power of the test was below the desired level of .80 (1-\( \beta = .73 \)). To have a probability of rejecting the null hypothesis of 0.80, with the present group quantities, the \( f \) statistic would have to be equal to or greater than 0.52.

Table 17. Means and standard deviation for decision-making network type by insurance type.

<table>
<thead>
<tr>
<th>Decision-Making Network Types</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Medical Insurance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No insurance (n=1)</td>
<td>2.83</td>
<td>-</td>
</tr>
<tr>
<td>Fee-for-Service/Traditional Health Insurance (n=3)</td>
<td>3.52</td>
<td>11.30</td>
</tr>
<tr>
<td>Health Maintenance Organization (HMO) (n=8)</td>
<td>4.32</td>
<td>9.32</td>
</tr>
<tr>
<td>Preferred Provider Organization (n=11)</td>
<td>1.47</td>
<td>7.33</td>
</tr>
<tr>
<td>Medicare (n=15)</td>
<td>2.46</td>
<td>6.54</td>
</tr>
<tr>
<td>Medicaid (n=1)</td>
<td>-6.55</td>
<td>-</td>
</tr>
<tr>
<td>Uncertain (n = 3)</td>
<td>-3.11</td>
<td>3.26</td>
</tr>
<tr>
<td>Multiple Policies (n = 20)</td>
<td>3.76</td>
<td>10.21</td>
</tr>
</tbody>
</table>
Although most of the participants interviewed had some sort of insurance, the qualitative data gathered during the interviews of several participants illustrated the challenges that individuals with little or no health insurance may face during the decision-making process. For example, “Jeff,” who was self-employed most of his life and had never had health insurance, developed a hernia and needed to decide on a course of action for treating his condition. At the time of the initial interview, Jeff discussed a number of options for coping with the hernia. He said that he spoke to his wife’s doctor about his condition during one of her appointments and that the doctor gave him some guidelines to help him “live with the discomfort.” Jeff also spoke to friends who had had hernias and tried to look up information on the Internet about the condition. However, he said he had trouble finding information. Jeff noted that he was primarily concerned with finding out what symptoms indicated a need for immediate medical attention. During the initial interview, he said that he thought he would be eligible for Medicare “in a year or two” and was wondering if he could live with the condition until that time.

During the final interview, Jeff said that he had come to the conclusion that he needed to have surgery as soon as possible. He said he had also researched his eligibility for Medicare. He discovered that he could enroll in Medicare, but will not be eligible for benefits for 10 months. As a result, Jeff decided to adjust his work and personal activities so that they were less physically taxing. Further, he said that he is coping with the hernia by “pushing the bulge back into place” and “sometimes using a tight ace bandage for support.” Additionally, he was exploring ways to save extra money in case surgery should become necessary before he became eligible for Medicare benefits.

In a similar case, “Lillian,” who had consistently needed prescription drugs for over 20 years following the removal of her pituitary gland, was faced with a decision to find alternatives
for prescription drugs when she found out that she was unable to receive her medications at an affordable cost through a state sponsored program. The program, which she reported works with pharmaceutical companies to lower the cost of prescriptions for consumers, had always been a reliable way for her to obtain her medications. At the time of the initial interview, however, Lillian said that she had had difficulties receiving her medications. She reported that the companies would not respond to the forms that she sent, were slow in sending the medications, or would reject an application that she had sent which had previously been approved. As a result, she was not sure what to do. She said she was not able to afford the medications and could not take them regularly with the delays in the prescription program.

Over the course of her decision-making process, Lillian called the pharmaceutical companies that carry the drugs she needed to request the medicines. She said that one company required that she have three blood tests from her doctor before it would fill the prescription. She had the blood tests and filled out the paperwork, but she never received the medications. Another company required that she fill out new forms so it could renew her qualifications. Months later, she had not yet received word from the company on whether or not she qualified.

Lillian decided not to tell her family about her problem with paying prescription costs. She said that she knows that her father and daughter would be willing to help her financially, but neither is in a stable financial situation. She said that she knows that helping her pay for the prescriptions would put a burden on them.

During her interview, Lillian reported that she had discovered that she would qualify for Medicare benefits in seven months. She was unsure whether she should pursue her efforts to obtain the medicines. Even if her applications for the prescriptions were approved immediately, she figured she would probably not receive them for several months. On the other hand, if she
“gave up the fight,” she would be without the medicines for over six months. She said she was worried about how living without medications would affect her overall health. She thought that she might be able to survive on samples from her doctor for the next few months until she could receive benefits from Medicare, but she was not certain. She said her doctor had “been more careful about handing out drug samples lately” and she was not sure why. She hoped the pharmaceutical companies come through; otherwise, she said would have to make use of what she had.

Lillian and Jeff’s stories illustrate the complexities associated with making decisions about health-care in the case that one does not have medical insurance. The information seeking strategies exhibited by both participants focused on figuring out what each could do to “get by.” Neither party spoke extensively with friends or family members about the decision. Rather, both participants indicated that they did not want to burden or trouble anyone with their situation, if only because so little could be done given that they did not have medical insurance. Although Research Question III could not be answered by examining patterns in decision-making networks, qualitative data demonstrated that the presence of health insurance may have important implications for the communication involved in a health care decision and, in turn, the outcome of the decision.

Research Question IV

The fourth research question concerned how older adults’ propensity for involvement in health-care decision making correlates with the size of their decision-making networks. A Pearson $r$ for the participant’s propensity for involvement in health-care decisions and the number of nodes in his or her decision-making network revealed no significant association, $r(62)$
For correlations, \( r \) serves as an index of the magnitude of the observed effect. For \( r = .104 \), \( \alpha = .10 \), and \( n = 97 \), the power of the test was below the desired level of .80 (\( 1-\beta = .21 \)). For this number of data points, the test would reach a power level of .80 for \( r \) values of .32 or greater.

Pearson’s \( r \) for the participants’ propensity for non-adherence and influence their doctors had on the process and outcome of the health care decision was not significant \( r(97) = -.023, p = .827 \), which suggests almost no effect. The power of the test is below the desired level of .80 (\( 1-\beta = .74 \)). The test would reach a power level of .80 for \( r \) values of .25 or greater.

Hypothesis VIII

The eighth hypothesis suggested older adults’ propensity for involvement in health-care decision making would be positively related to their use of media sources in the process of decision making. A correlation for propensity for involvement and the number of media nodes in decision-making networks was significant, \( r(62) = -.27, p = .035, r^2 = .073 \).

Research Question V

The fifth research question related to whether or not older adults facing a major health-care decision who also have a high propensity in such and use the Internet report greater satisfaction with process of decision-making than their high propensity counterparts who do not use the Internet. A \( t \)-test for samples of unequal size, with reported satisfaction as the dependent measure, revealed no statistically significant difference, \( t(35) = -.654, p = .518 \). The mean satisfaction and standard deviations appear in Table 18. Cohen’s estimate of effect size for the
difference between the two means indicated that the observed difference between the means could be classified as a small effect \(d = .21\). Using the effect size, \(\alpha = .10\), and the sizes of the groups \(n_1 = 24, n_2 = 13\), the power of the test was below the desired level of .8 \((1-\beta = .15)\). With group sizes of 24 and 13, the test would have a probability of 0.80 of rejecting the null hypothesis for effect sizes of .88 or larger or a difference of 1.29 in the means of the two groups.

Table 18. Means and standard deviations for satisfaction for participants with a high propensity for involvement by Internet usage.

<table>
<thead>
<tr>
<th>Internet Usage</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use the Internet (n=24)</td>
<td>1.92</td>
<td>1.21</td>
</tr>
<tr>
<td>Do not Use the Internet (n=13)</td>
<td>2.23</td>
<td>1.69</td>
</tr>
</tbody>
</table>

Additional Analysis: Exclusion of Male Participants

Of the 62 participants enrolled in this study, only 18 were male. As a result of the small percentage of males in the sample, the statistical tests were performed excluding the males to determine if their presence in the sample was adversely affecting the outcomes of the data analysis. The results are summarized in Table 21, and Table 22. Reexamining the research questions and hypotheses using only the females in the sample did not result in any changes in the outcomes of the statistical tests.
Table 19. Comparison of statistical tests results excluding male participants for Hypothesis I and Hypothesis II.

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Males and Females</th>
<th>Females Only</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hypothesis I</strong></td>
<td>Patient information-seeking behavior correlated with communication efficacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$r(61)=-.275$</td>
<td>$r(43)=-.277$</td>
</tr>
<tr>
<td></td>
<td>$P=.032$</td>
<td>$p=.077$</td>
</tr>
<tr>
<td><strong>Hypothesis II</strong></td>
<td>Patient information-seeking behavior correlated with target efficacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$r(279)=-.013$</td>
<td>$r(208)=-.073$</td>
</tr>
<tr>
<td></td>
<td>$P=.828$</td>
<td>$p=.295$</td>
</tr>
</tbody>
</table>
Table 20. Comparison of statistical test results excluding male participants for Hypothesis III, Hypothesis VI, and Hypothesis V.

<table>
<thead>
<tr>
<th>Hypothesis III</th>
<th>Males and Females (62)</th>
<th>Females Only (44)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Satisfaction</td>
<td>Satisfaction</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>Reciprocal</td>
<td>32</td>
<td>2.75</td>
</tr>
<tr>
<td>Non-Reciprocal</td>
<td>16</td>
<td>3.00</td>
</tr>
<tr>
<td>(t(46)=.533)</td>
<td>(p=.597)</td>
<td>(t(36)=1.165)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hypothesis IV</th>
<th>Anxiety</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>Reciprocal</td>
<td>32</td>
<td>3.25</td>
</tr>
<tr>
<td>Non-Reciprocal</td>
<td>16</td>
<td>2.44</td>
</tr>
<tr>
<td>(t(46)=-1.919)</td>
<td>(p=.061)</td>
<td>(t(36)=-1.200)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Change in Anxiety</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>n</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reciprocal</td>
<td>32</td>
<td>-0.47</td>
<td>2.00</td>
<td>25</td>
<td>-0.52</td>
<td>2.18</td>
</tr>
<tr>
<td>Non-Reciprocal</td>
<td>16</td>
<td>0.50</td>
<td>1.27</td>
<td>13</td>
<td>0.85</td>
<td>1.14</td>
</tr>
<tr>
<td>(t(46)=1.764)</td>
<td>(p=.084)</td>
<td>(T(35.975)=2.533^*)</td>
<td>(p=.016)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(^*Equal:variances:not:assumed.)</td>
<td>(^*Equal:variances:not:assumed.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hypothesis V</th>
<th>Religious/Spiritual Influence</th>
<th>Religious/Spiritual Influence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seriousness/Severity</td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>More Serious/Severe</td>
<td>37</td>
<td>3.32</td>
</tr>
<tr>
<td>Less Serious/Severe</td>
<td>25</td>
<td>3.76</td>
</tr>
<tr>
<td>(t(56.851)=1.019^*)</td>
<td>(p=.313)</td>
<td>(t(36)=-.470^*)</td>
</tr>
<tr>
<td>(^*Equal:variances:not:assumed.)</td>
<td>(^*Equal:variances:not:assumed.)</td>
<td></td>
</tr>
</tbody>
</table>
Table 21. Comparison of statistical tests results excluding male participants for Hypothesis VI, Hypothesis VII, and Research Question III.

<table>
<thead>
<tr>
<th>Hypothesis VI</th>
<th>Satisfaction</th>
<th>Females Only (44)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious Coping Strategy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More Positive</td>
<td>N: 38 M: 2.16 SD: 1.46</td>
<td>N: 29 M: 2.18 SD: 1.89</td>
</tr>
<tr>
<td>Less Positive</td>
<td>N: 24 M: 1.88 SD: 1.30</td>
<td>N: 15 M: 2.00 SD: 1.68</td>
</tr>
<tr>
<td>t(60) = .775</td>
<td>p = .442</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hypothesis VII</th>
<th>Anxiety</th>
<th>Females Only (44)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious Coping Strategy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More Positive</td>
<td>N: 38 M: 3.29 SD: 1.45</td>
<td>N: 29 M: 3.18 SD: 1.46</td>
</tr>
<tr>
<td>Less Positive</td>
<td>N: 24 M: 3.25 SD: 1.45</td>
<td>N: 15 M: 3.06 SD: 1.39</td>
</tr>
<tr>
<td>t(60) = .104</td>
<td>p = .920</td>
<td></td>
</tr>
<tr>
<td>t(42) = .257</td>
<td>P = .798</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research Question III</th>
<th>No Insurance</th>
<th>Fee-for-service/Traditional Health Insurance</th>
<th>Health Maintenance Organization (HMO)</th>
<th>Preferred Provider Organization (PPO)</th>
<th>Medicare</th>
<th>Medicaid</th>
<th>Uncertain</th>
<th>Multiple Policies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision-Making Network Type</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>F(7,54) = .480</td>
<td>F(5,38) = .279</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>p = .840</td>
<td>P = .922</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 22. Comparison of statistical tests results excluding male participants for Research Question IV, Hypothesis VIII, and Research Question V.

<table>
<thead>
<tr>
<th></th>
<th>Males and Females (62)</th>
<th>Females Only (44)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research Question IV</strong></td>
<td>Patient Self Advocacy correlated number of decision-making network nodes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$R(62)=-.104$</td>
<td>$r(44)=-.101$</td>
</tr>
<tr>
<td></td>
<td>$p=.420$</td>
<td>$p=.515$</td>
</tr>
<tr>
<td>Propensity for non-adherence correlated with doctor's influence on process and outcome</td>
<td>$R(97)=-.023$</td>
<td>$r(62)=-.005$</td>
</tr>
<tr>
<td></td>
<td>$p=.827$</td>
<td>$p=.970$</td>
</tr>
<tr>
<td><strong>Hypothesis VIII</strong></td>
<td>Patient Self Advocacy correlated with number of decision-making network nodes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$R(62)=-.271$</td>
<td>$r(42)=-.308$</td>
</tr>
<tr>
<td></td>
<td>$p=.035$</td>
<td>$p=.048$</td>
</tr>
<tr>
<td><strong>Research Question V</strong></td>
<td>Internet Usage</td>
<td>Satisfaction</td>
</tr>
<tr>
<td></td>
<td>Use the Internet</td>
<td>$N$  $M$  $SD$</td>
</tr>
<tr>
<td></td>
<td>24  1.92  1.21</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15  2.20  1.27</td>
<td></td>
</tr>
<tr>
<td>Additional Analysis: Multiple Linear Regression Model</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In fitting with an ecological perspective which considers the interactions among various communication contexts, a multiple linear regression analysis was conducted to identify the factors with the most salient effect on a participant’s satisfaction with the decision-making process. The regression analysis included all of the factors in Table 23 and was performed...
without the addition of a constant term. The regression includes effect on satisfaction from participant characteristics, demographic information, personal social network properties, personal social network structures, and influence of communication contexts. In addition, interactions between communication contexts were included in the analysis.
Table 23. Variable used in the multiple linear regression analysis.

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Independent Variables</th>
<th>Context Influences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td><strong>Participant Qualities</strong></td>
<td><strong>Context Influences</strong></td>
</tr>
<tr>
<td></td>
<td>Type of Medical Decision</td>
<td>Total Combined Interpersonal Influence</td>
</tr>
<tr>
<td></td>
<td>Decision Anxiety</td>
<td>Total Combined Cultural Influence</td>
</tr>
<tr>
<td></td>
<td>Decision Gravity</td>
<td>Total Combined Religious-Spiritual Influence</td>
</tr>
<tr>
<td></td>
<td>Positive Religious Coping Strategies</td>
<td>Total Combined Political Influence</td>
</tr>
<tr>
<td></td>
<td>Negative Religious Coping Strategies</td>
<td>Total Combined Organizational Influence</td>
</tr>
<tr>
<td></td>
<td>Communication Efficacy</td>
<td>Total Combined Media Influence</td>
</tr>
<tr>
<td></td>
<td>Coping Efficacy</td>
<td>Interpersonal – Cultural</td>
</tr>
<tr>
<td></td>
<td>Patient Self Advocacy Measure</td>
<td>Interpersonal – Religious/Spiritual Interaction</td>
</tr>
<tr>
<td></td>
<td>Patient Self Education Measure</td>
<td>Interpersonal – Political/Legal Interaction</td>
</tr>
<tr>
<td></td>
<td>Patient Non-Adherence Measure</td>
<td>Interpersonal – Organizational Interaction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interpersonal – Media Interaction</td>
</tr>
<tr>
<td></td>
<td><strong>Personal Social Network Properties</strong></td>
<td>Cultural – Religious/Spiritual Interaction</td>
</tr>
<tr>
<td></td>
<td>Decision-Making Contact Density</td>
<td>Cultural – Political/Legal Interaction</td>
</tr>
<tr>
<td></td>
<td>Total Number of Target Nodes in each Participant’s Decision-Making Network</td>
<td>Cultural – Organizational Interaction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cultural – Media Interaction</td>
</tr>
<tr>
<td></td>
<td><strong>Demographic</strong></td>
<td>Cultural – Media Interaction</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>Religious/Spiritual – Political/Legal Interaction</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>Religious/Spiritual – Organizational Interaction</td>
</tr>
<tr>
<td></td>
<td>Race</td>
<td>Religious/Spiritual – Media Interaction</td>
</tr>
<tr>
<td></td>
<td>Income</td>
<td>Political/Legal – Organizational Interaction</td>
</tr>
<tr>
<td></td>
<td>Martial Status</td>
<td>Political/Legal – Media Interaction</td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>Organizational – Media Interaction</td>
</tr>
<tr>
<td></td>
<td>Insurance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Internet Usage</td>
<td></td>
</tr>
</tbody>
</table>
The resulting regression model was statistically significant, $F(28,49)=7.189$, $p<.001$. To identify the most influential predictors of satisfaction with the decision making process, variables with small influence on the participant’s satisfaction removed from the model using a backward-elimination method. The reduced model was statistically significant with $F(8,49)=29.925$, $p<.001$, $R=.924$, $R^2=.854$, adjusted $R^2 = 0.825$. Details of the reduced model are presented in Table 24.

Table 24. Reduced regression model prediction participant satisfaction with the decision-making process.

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>$\beta$</th>
<th>$\beta_o$</th>
<th>$T$</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decision Anxiety</td>
<td>-.245</td>
<td>-.389</td>
<td>-2.919</td>
<td>.006</td>
</tr>
<tr>
<td>Communication Efficacy</td>
<td>1.227</td>
<td>.952</td>
<td>6.244</td>
<td>.000</td>
</tr>
<tr>
<td><strong>Decision-Making Network</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Number of Nodes</td>
<td>0.229</td>
<td>.646</td>
<td>2.714</td>
<td>.010</td>
</tr>
<tr>
<td><strong>Context Influences</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Combined Organizational Influence</td>
<td>-.182</td>
<td>-.658</td>
<td>-3.808</td>
<td>.000</td>
</tr>
<tr>
<td>Combined Media Influence</td>
<td>-.252</td>
<td>-.533</td>
<td>-3.023</td>
<td>.004</td>
</tr>
<tr>
<td>Interpersonal-Organizational Interaction</td>
<td>-.007</td>
<td>-.347</td>
<td>-1.763</td>
<td>.085</td>
</tr>
<tr>
<td>Organizational – Media Interaction</td>
<td>.026</td>
<td>.468</td>
<td>2.586</td>
<td>.013</td>
</tr>
<tr>
<td><strong>Demographic</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>.458</td>
<td>.602</td>
<td>3.581</td>
<td>.001</td>
</tr>
</tbody>
</table>

Reduced model: $F(8,49)=29.925$, $p<.001$, $R=.924$, $R^2=.854$, adjusted $R^2 = 0.825$; $\beta$-Unstandardized regression coefficient; $\beta_o$-Standardized regression coefficient.
The reduced linear regression model shows that participants who experience less anxiety during the decision making process will experience a higher level of satisfaction with the decision making process. Also, participants with higher communication efficacy behaviors will experience a greater level of satisfaction. As the number of nodes in a participant’s decision-making network increases, satisfaction decreases. Further, participants tended to report higher satisfaction with more influence from the organizational context and similarly with the media context. The interaction between the interpersonal context and the organizational context was present in the final model. Satisfaction of participants tended to increase with this interaction, although only reaching a significance level of .085. Alternatively, a higher level of interaction between the media and organizational context tended to lead to lower satisfaction.

The multiple linear regression identified communication efficacy as the most the leading predictor of satisfaction with the decision-making process. In essence, a person’s belief that he or she possess the skills to complete the communication tasks involved in the information-management process successfully predicted satisfaction with the decision-making process.
Chapter 4: Discussion

Overview

The purpose of this investigation was to examine the process of health-care decision making among older adults and the communicative influences on the process. The hope was that this endeavor would provide information that would increase understanding of how older adults manage the complexities and challenges associated with their major health-care decisions so as to assist other adults in similar situations. The information could also be of value to those in older adults’ decision-making networks in discerning how to be supportive during the decision-making process and make it easier, more satisfying, and potentially of higher quality for older adults. The time that participants spent talking through their decision-making processes through systematic interview/surveys, detailing the influence of the various contexts of communication relevant to their decisions, providing information about the people and sources with whom, as well as that, they consulted about their decisions, and offering their perceptions of the interactions and relationships in respect to their influence and impact offered insights into how they managed the challenges. Having such insights can advance practical and theoretical knowledge in the area of communication and health-care decision making at the latter end of the lifespan.

Summary of Results

The first hypothesis posited that older adults’ evaluation of their communication efficacy would be predictive of their information-seeking behavior in their health-care decision-making network. The pertinent data supported the hypothesis. Specifically, older adults with a high
communication efficacy were more likely to initiate contact with targets than those individuals who reported low communication efficacy.

The second hypothesis proposed that older adults’ assessment of the efficacy of a target in their health care decision-making networks will be correlated with their information-seeking behavior involving the targets. The findings did not support the hypothesis. The power of the test, moreover, was only slightly below .8. These findings suggest for this sample of older adults making decisions about their health care, assessment of target’s efficacy may not be related to their information-seeking behavior.

The first research question focused on patterns in decision-making networks for older adults considering major health-care decisions. To answer the question involved the construction of nine network figures to illustrate each participant’s health care decision-making network. In brief, the first two network figures illustrate communication frequency overall and frequency of decision-related communication among interpersonal nodes. The ties in the third network figure illustrated the frequency of decision contact and the duration of contact between the participant and each interpersonal and non-interpersonal target. These three network illustrations, in combination, summarize the quantity of communication and contact in each decision-making network. The next two network figures illustrate the participants’ perceptions of relational quality among the interpersonal nodes in the decision-making network. One offers a symmetric view of relational quality that averages the participants’ assessment of each node’s perception of relational quality, whereas the other offers a non-symmetric illustration accounting for the participants’ assessments that interpersonal dyads may report on the relational quality between them differently. The sixth and seventh networks respectively illustrate the influence of each target on the process and outcome of the decision-making. The eighth network figure
illustrates targets’ influence on the process and outcome combined. Analyzing these three network figures served as an important comparison of targets’ influence on the process and outcome of decision-making. The ninth network captures a number of relational properties important to decision-making in a single network figure. The frequency of decision contact, the direction of a target’s influence, relational quality, a target’s knowledge of the decision situation, and target influence are illustrated.

The clearest pattern that emerged from analysis is that decision-making networks tended to be dominated by interpersonal or organizational influence. The total influence for each context was calculated by summing the individual contributions of each member of the decision-making network assigned to a particular context. Because the interpersonal and organizational contexts were of particular interest, the total interpersonal influence for each participant was subtracted from the total organizational influence, with the remainder representing the dominant context of influence for each person in the study. A negative value for the dominant context measure (DCM) indicated a dominant organizational influence, whereas a positive DCM value indicated that interpersonal influences dominated the decision-making. Decision-making networks distinctly fell along a continuum with organizational influence on one end and interpersonal influence on the other.

Although particular decisions were not isolated at one end of the organizational-interpersonal spectrum, different types of decisions were associated with interpersonal and organizational influence. Decisions involving living arrangements, changing health-care providers or seeking medical treatment were clearly associated with decision-making networks dominated by interpersonal influence, whereas decisions involving changes in life/work activities, medication, and insurance were dominated by organizational influences. Decisions
regarding surgery and other medical treatments also tended to be dominated more by interpersonal rather than organizational influence, but fell closer to the middle range of the spectrum, which indicates more balance between organizational and interpersonal influence for these decisions than the other types.

These findings have important implications for health care professionals, inasmuch as that the majority of the individuals comprising the organizational context of communication were health professionals. Members of older adults’ interpersonal context have the potential to exert powerful influence on their health-care decisions. Decisions for which professional health-care providers’ influence may be critical in the quality of health and life of an older adult have the potential to be overridden or reinforced by persons in an older adult’s interpersonal context with whom older adults tend to have more frequent contact and stronger relational quality.

The third hypothesis posited that older adults who report reciprocal interactions with their adult children about a major health care decision will be more satisfied with the decision-making process than older adults who report non-reciprocal interactions with adult children about their health-care decisions (with influence direction from adult child to parent). Although this hypothesis received no support, the older adults reporting reciprocal interactions with an adult child experienced a slightly higher satisfaction with the process of decision-making than older adults whose adult children tried to influence their decisions. Although the difference was not statistically significant, power analysis of the test was below the accepted .8, which warrants further investigation of the relationship with larger samples.

The fourth hypothesis proposed that older adults who report reciprocal interactions with their adult children about a major health-care decision will experience less anxiety with the decision-making process than older adults who report non-reciprocal interactions with adult
children concerning such decisions (with influence direction from adult child to parent). This hypothesis received support. Further, participants who reported reciprocal interactions with an adult child experienced a greater decrease in anxiety than those whose adult child attempted to influence them during the course of the decision-making process. These findings suggest the importance of adult children’s respecting the autonomy of their parents in the health-care decision-making process, as Hummert and Morgan (2001) emphasized, because exerting influence may be viewed as unnecessarily paternalistic (Cicirelli, 1992a) and produce anxiety for the parent. Though the reason that efforts to influence a parent are associated with an increase in anxiety is unclear, attempts by adult children to influence the decision-making of their parents may be reinforcing the notion that the parent is moving from a state of independence to a state of dependence, as noted by Cicirelli (1992a), which may be a cause of anxiety.

The focus of the second research question was how culture influences the decision-making process and outcomes for older adults who utilize cultural contacts as part of their decision-making networks. So few participants reported influence from the cultural context that no conclusion relating to this question was probable. Qualitative data gathered from those participants who did mention such influence, however, indicate that the influence of cultural factors on the decisions of older adults may be deeply embedded in their decision-making processes. Further, those individuals who indicated that culture affected their decisions, the source of influence appears to be very important.

The fifth hypothesis was that individuals who rate their decisions as serious and severe would report more influence from the religious/spiritual context of influence than those who do not. This hypothesis was not supported. The sixth hypothesis proposed that older adults who report positive religious coping strategies would experience greater satisfaction with the health-
care decision-making process than those reporting the use of negative religious coping strategies or no religious coping strategies, and the seventh hypothesis posited that older adults in the first group would experience less anxiety than those in the second group. Neither hypothesis received support. However, because power analyses did not reach the desired level of .8 for rejecting a false null hypothesis, further research with larger samples is warranted in studying the relationship between religion and spirituality and decision-making for older adults. Qualitative data indicated that religion and spirituality were important to many participants’ coping. However, the quantitative measures utilized in this study did not capture the effect. Part of the reason for this may be the lack of variance in the sample with regard to religion and spirituality. Further, most participants reported positive religious coping strategies. Additionally, the measure for negative religious coping strategies, reliable in other studies, was not in the present study (Cronbach’s $\alpha = .33$). Prior research in this area coupled with qualitative reports of participants in the study is discrepant with the quantitative results associated with these hypotheses. Thus, to conclude that religion and spirituality have little influence on the health care decision-making process for older adults is probably premature.

The third research question focused on whether or not insurance type mediates different types of decision-making networks. This hypothesis was not supported. However, given that the variability in the sample was low since most of those in the sample held some form of insurance and the power analysis did not reach .8, further research in this area would be appropriate. Type of insurance likely has effects on the makeup of an individual’s decision-making network, and understanding those effects could have important implications for public-health endeavors.

The fourth research question addressed the relationship of older adults’ propensity for involvement in health-care decision-making and their decision-making networks; however, no
relationship between either an individual’s propensity for involvement in their health-care decisions and the size of their decision-making network or the influence of doctors emerged. On the other hand, the eighth hypothesis, which proposed that older adults’ propensity for involvement in health-care decision-making would relate positively to their use of media sources during their process of decision-making, received support. Older adults who had a high propensity for involvement in their health decisions tended to gather information from various media sources. The results pertaining to the fifth research question, which focused on whether or not older adults facing a major health-care decision who have a high propensity for involvement in their health care decisions and use the Internet experience greater satisfaction with process of decision making than their counterparts not using the Internet, showed no significant difference on the measure of satisfaction. Thus, it appears that at least the current cohort of older adults who have a high propensity for involvement in their health-care decisions satisfy their needs for information through traditional media sources, such as books and pamphlets, as opposed to Internet resources.

Additional analyses of the factors influencing the process of decision-making were examined through a multiple linear regression. The model identified the eight most influential factors affecting satisfaction with the decision-making process. The independent variables in the reduced model were a decision-maker’s communication efficacy, anxiety with the process, and level of education, the number of nodes in a decision-making network, and influence from communication contexts (organizational, media, organizational-media interaction, and interpersonal-organizational interaction). A closer examination of each independent variable can aid in understanding the complexity of the health-care decision-making process for older adults.
Ranking the independent variables using the standardized regression coefficients, communication efficacy emerged as the single most influential factor predicting satisfaction. Communication efficacy refers to a person’s belief that he or she possesses the skills needed to complete the communication tasks involved in the information-management process successfully (Afifi & Weiner, 2004). Thus, individuals with high communication efficacy believe they can successfully manage the communication tasks associated with making a major decision about their health care, whereas individuals with lower reported communication efficacy may find the very act of seeking out information stressful and difficult, thus decreasing their satisfaction with the process of decision-making. The majority of participants filled their need for information by consulting physicians, media sources, adult-children, and friends. As discussed previously, each one of these sources has the potential for complicating the decision-making process. A decision-maker’s self-efficacy for managing communicatively the potential complications appears to be related to their satisfaction with the process of decision-making.

Combined influence from the organizational nodes ranked second among the independent variables. As organizational influence increased, participants tended to report a higher satisfaction with the process. Simply put, when the organizational context of communication was most influential in a decision, the decision-makers tended to be satisfied with the decision-making process. As the most common members of the organizational context of communication were physicians, one might deduce that if decision-makers feel they can place trust in their physicians to aid in their decision-making, the process is more satisfying.

An interesting finding was the inverse relationship between the number of nodes in a decision-making network and satisfaction with the process. As the number of nodes in the decision-making network increased, participants’ satisfaction tended to decrease. This
relationship ranked third in the regression model. A logical explanation may be that as sources of information increase during the decision-making process, the more complicated the information management becomes. Although the sources in the decision-making network may be helpful to decision-makers, the efforts involved in managing numerous sources of information may affect their satisfaction with the process.

A surprising finding from the regression was the relationship between the participant’s level of education and their satisfaction with the process. Generally, a higher level of education accompanied a lower satisfaction with the process. The non-standardized regression coefficient for education ranked fourth among the eight independent variables. The literature associated with this investigation does not explain the relationship and further study is warranted.

Influence from the media context along with the interaction of media and organizational influence were the fifth and sixth ranked variables, respectively. Satisfaction tended to be higher when the media context influenced the decision. When the media context interacted with the organizational context, satisfaction was lower. Information gleaned from the media context most likely provided participants with information specific to their decisions, thereby aiding them and raising their satisfaction with the process. The reduction in satisfaction that accompanied the interaction of the organizational and media contexts was unexpected. From this study, the reason for this relationship is unclear. Media sources are often produced by organizational entities, and might simply reinforce organizational opinions. Alternatively, media sources could provide a decision-maker with an opposing viewpoint to the course of action prescribed by organizational member, thereby causing confusion and decision-related anxiety. This finding warrants further investigation.
The anxiety associated with the process of decision-making was the seventh ranked independent variable in the regression. As a participants’ anxiety levels increased, satisfaction with the process of decision-making tended to decrease. This finding makes sense. A higher level of anxiety during the decision-making process should affect satisfaction with the process. What is surprising is that this variable did not have a higher correlation in the regression model.

Finally, the regression model predicted that as the interaction between the interpersonal and organizational communication contexts increased, satisfaction also tended to increase. In other words, as the influence from organizational and interpersonal contexts of communication increases, satisfaction with the process of decision-making also increases. A large influence in the organizational and interpersonal contexts may imply that sources in these contexts are in agreement with regards to the decision, which may increase satisfaction. However, a t-test showed the coefficient did not reach statistical significance, p=.085. As such, this evidence is inconclusive.

Practical Implications

Several important implications emerged from this study that reinforce the value of examining the decision-making process for older adults as influenced by various communication contexts rather than one that is simply influence by members of, for example, health organizations. An ecological perspective (Street, 2007) on the health care decision-making process of older adults served as a fruitful foundation for examining the various potential influences on the decision. Examining the decision-making network in light of the different communication contexts provided a means for examining each context in turn, as well as viewing the influences of the context as a whole.
Members of older adults’ interpersonal context clearly affected their decision-making. Members of the interpersonal context were the most frequently noted ones in the decision-making network and were, as a group, the most influential. The decision-makers of interest have more ready access to these members than they do media or organizational targets, and thus in this study they served a particularly important role. Qualitative accounts provided by the participants indicated that they viewed those in the interpersonal context of communication as sources of information and social support. The participants indicated that the members of their interpersonal context often served as “sounding boards.” At other times, they sought information from members of their interpersonal context that aided them in making decisions. At times, the participants sought information concerning whether or not help from the target could be provided if the participant needed it following a decision (for example, instrumental support following surgery). Additionally, many participants reported that they sought information from those persons in their interpersonal context who had faced similar decisions. Thus, qualitative accounts imply that friends and family members served not only to aid in health-care decision making in terms of coping with the process, but also in objectively arriving at decision. The rankings of the targets in respect to the process and outcome of decision-making supported this notion. For participants whose interpersonal targets were more influential than the organizational targets, the influence of the interpersonal targets on the process was similar to their influence on the decision outcome. Qualitative data served to demonstrate more fully the power an interpersonal target can have in the decision-making process, as in the case of “Lizzie” detailed previously and illustrated in Appendix I. Indeed, members of an older adult’s interpersonal context frequently served as a compelling force in their decision-making processes and outcomes.
This investigation also yielded results specific to relationship between the parent-adult child dyad and its impact on the decision-making process. Older adults who reported reciprocal interactions with their adult children about a major health care decision experienced less anxiety with the decision-making process than older adults who reported non-reciprocal interactions with adult children about their health care decisions in which the adult child tried to influence the parent. Specifically, if participants reported reciprocal interactions with adult children in the decision-making process, their level of anxiety about the process of decision-making decreased reportedly decreased between the initial and the final interviews. Older adults who reported non-reciprocal interactions with their adult children indicated that their anxiety increased. As mentioned previously, this finding is consistent with research suggesting that paternalistic behavior on the part of an adult child infringes on an older adult’s personal autonomy, or capacity to make and execute his or her own decisions (Cicirelli, 1992a) and indicates that adult-children play a large role in increasing or decreasing the amount of anxiety a parent has in the process of making a major health care decision. In fact, the positive role adult children served their parents’ decision-making was illustrated in decision-making networks, such as in Appendix L, as discussed previously. Clearly, adult children can have a significant and positive impact on the decision-making of their parents.

In addition to yielding important information concerning the role of members of an older adult’s interpersonal context on decisions, this investigation also led to new insight in the role of media sources during the decision-making process of older adults faced with a major health-care decision. Older adults’ propensity for self-educating in making their health-care decisions was positively related to their overall use of media sources during their process of decision-making. However, a person’s overall usage of Internet did not predict frequency of use of the Internet in
reaching health-care decisions. A person’s propensity for self-educating was correlated to use of media resources, but not specifically for Internet resources. This finding suggests that the current cohort of older adults having high propensity for self-educating satisfy their needs for information by traditional media sources, even when access to Internet resources is available to them.

The impact of culture, religion and spirituality, and political-legal factors on the decision-making processes of older adults facing major health-care decisions is still unclear. Cultural factors are implicated in the health care decisions of older adults. For those individuals who reported that culture influenced their decision, the impact appears to be very significant for them, as in the case of “Valerie” exemplified previously. Such qualitative data suggests that the influence of culture on a person’s health-care decision making is significantly embedded in the process of decision-making and may be inextricably embedded with other factors, such as political-legal and spiritual, as has been suggested elsewhere (e.g., Taylor, Chatters, & Levin, 2004). However, as relatively few participants in this study reported that cultural factors influenced their decision-making, the impact of culture on major health-care decisions awaits further attention and illumination.

Similarly, political-legal factors did not appear to be highly influential. Further, the type of medical insurance participants had was not apparently one of the major factors affecting their decision-making networks, in that did not mediate whether those in the organizational or interpersonal contexts were more influential in the decision. However, this conclusion is limited by the fact that the sample for the study comprised mostly individuals having some form of insurance.
In respects to religious/spiritual influences on the decision-making process of older adults, the findings raised more questions than they answered. When responding to the first two open-ended questions during the initial interview (“Please describe the health care decision that you are considering. Please describe your decision-making process thus far.”), more than half of the participants in the study mentioned they were coping with the process of decision-making by tapping into their religious/spiritual beliefs and resources, which provided evidence, unprompted by the researcher or the research protocol, of the impact of religion and spirituality on the decision-making process. However, reliance on religious and spiritual contacts and resources was not manifest in quantifiable ways in this study. Individuals who rated their decisions as serious and severe did not report more influence from the religious/spiritual context of influence than those who rated their decisions as relatively less serious and severe. Moreover, older adults who reported using positive religious coping strategies did not experience greater satisfaction with the health-related decision making than individuals using negative religious coping strategies or no religious coping strategies. Finally, older adults who reported using positive religious coping strategies experienced no less anxiety than individuals who relied on negative religious coping strategies or no religious coping strategies. Although religion and spirituality have been found to impact end-of-life issues and decision-making (e.g., Wennberg, 1989), religion and spirituality appear to be less influential in non-end-of-life health decisions. As with the influence of cultural factors on the decisions of older adults, religion and spirituality may be so deeply embedded in their decision-making processes for those individuals for whom religion and spirituality are important that the measures utilized in this investigation failed to tangibly reveal much of an overt level about their impact.
The organizational context of communication, as with the interpersonal context of communication, proved to be particularly influential in the decision-making of participants. Those in the organizational context, who were all medical professionals and a majority of whom were physicians, were very influential in the participants’ decision-making. In the instances which the organizational context was the dominating influence in the decision-making network, physicians were often more influential in the face of competing advice from members of the interpersonal context or despite the feelings or opinions of the participant. In many cases in which the organizational context of communication was the most dominant source of influence in the decision-making network, some participants felt they had no choice because they were in situations in which the doctor’s wishes and/or health circumstances precluded a lot of discussion and examination. In such cases, participants even frequently deferred to the doctor without any discussion. In emergency situations, the participants reported that they did not have the chance to discuss other options.

In addition to the qualitative evidence that speaks to physicians’ influence on health-care decisions is often nonnegotiable, there was no correlation between a participant’s propensity for non-adherence and influence of the physician. This is surprising, as one would expect that if a person has a propensity for non-adherence a physician would be less influential in the decision-making. Nonetheless, most participants reported having high satisfaction with their physicians and also indicated during their interviews that they were very particular about their choice of physician, as exemplified in “Roger’s” profile (Appendix K). Participants in larger geographic locales that offered more choices for medical care frequently reported “shopping” for a physicians, which they said was the reason why they were satisfied with the physician. In some cases, changing care providers constituted the participant’s decision. Participants in rural areas
did not frequently report “physician shopping.” Perhaps this behavior would be less in evidence among a sample of participants who reflect the general population in terms of their insurance status.

A large body of scholarship has recently addressed medical adherence and aging from a social and cognitive perspective (Park & Liu, 2007), specifically the cognitive processing of issues involved in adhering to a medical regimen. The concern that older adults do not always follow the advice of medical professionals is validated by the present study. Park’s (1999, 2007) work indicates that following the advice of medical professionals is important for the well-being and survival of older adults. The research in this dissertation demonstrates that individuals are seriously questioning whether to trust medical professionals and buy into a “consumeristic” view of medical care (Beisecker, 1988). The sample in the present study was possibly biased toward individuals who are more inclined to following the instructions of their health care providers because individuals were recruited through medical institutions. (In fact, the primary investigator received numerous calls from concerned adult children and spouses of individuals who were facing a medical decision and reportedly would not follow the prescribed advice of their physician with regards to having a major medical procedure. In all cases, the potential participant declined to be interviewed.) As a result, the potential for disregard of the advice of medical professionals in making major decisions about one’s health is greater than for which this investigation could account.

When discussing how older adults make judgments in medical situations, Chan, Ybarra, Park, Rodriguez, and Garcia (2007) discussed the factors of morality and competence in social information processing. Morality factors were defined as characteristics relevant to ethics and a sense of right and wrong in interpersonal relationships, as exemplified by traits related to
honesty, helpfulness, and sincerity, or lack thereof. On the other hand, competence issues were defined as characteristics relevant to achievement and the accomplishment of tasks and goals, as exemplified by intelligence, knowledge, and diligence. Participants in the study exemplified making decisions about the opinions of their physicians on characteristics of morality or social attractiveness in a variety of ways. They questioned their doctors on the basis of their social attractiveness (or morality) and noted consistently that it was especially important in their relationships with their primary-care physicians. Lack of social attractiveness was reportedly enough of a good reason to disregard the advice or instructions of a primary-care physician. Further, participants consistently noted that if a physician did not exhibit good listening skills, participants’ trust of the physician went down. One said that she needs a doctor with a “good bedside manner” and said that if a doctor does not take the time to listen, she did not trust him to diagnose a complicated medical condition. The participants did not seem to apply the same standards to specialists. They indicated that they questioned the ability of specialists on the basis of their social attractiveness. In fact, several of the decisions in the study were motivated by a participant’s questioning the ability of the specialist on the basis of their social attractiveness characteristics. In some instances, the participant chose to disregard treatment options the specialist provided. Others, after performing conducting additional research on a specialist and talking with people about the specialist, such as in Appendix G, deferred to the advice or recommendation of the specialist. Figure 20 – Figure 25 illustrate this occurrence in “Jim’s” tie with Dr. C, a specialist whose disagreeable bedside manner caused him to reconsider having Dr. C perform a surgical procedure. Despite low relational quality with Dr. C and Dr. C’s relatively low influence on Jim’s decision-making process (as seen in Figure 22), Dr. C’s expertise significantly influenced the outcome of Jim’s decision (as seen in Figure 23). In the end, Jim
decided to have Dr. C perform the surgical procedure. As illustrated in Figure 25, however, Dr. C’s influence on the decision was less than the influence of other interpersonal context members who reinforced Dr. C’s advice.

The most important finding of this study was that older adults predominantly seek the input of members of interpersonal and organizational contexts to make decisions about their health care. Neglecting to consider the impact of both organizational and interpersonal communication contexts in research or practice is injudicious in light of the findings here. Applying Street’s (2003) ecological perspective provided an important framework for arriving at this conclusion. This dissertation lends support for the value of utilizing an ecological perspective for advancing understanding of health related decisions. How different communicative contexts work together to impact and influence the decision-making processes and outcomes is essential in furthering research in this area.

**Theoretical Implications**

In addition to the implications for practice stemming from this investigation, other implications more theoretical in nature are offered by this work. Among other things, this study provided a test for the fourth proposition of the Theory of Motivated Information Management (TMIM), which holds that the likelihood of seeking information is a function of the weighted combination of coping, communication, and target efficacy (Afifi & Weiner, 2004). Specifically, older adults’ evaluation of their communication and coping efficacy is predictive of their information-seeking behavior in their health-care decision-making network. Further, older adults’ assessment of the efficacy of a target in their health-care decision-making networks is correlated with their information-seeking behavior. Participants’ assessments of efficacy were collected at the beginning of the decision-making process, in most cases, before interactions
about the decision were complete and before a decision was made. The few retrospective accounts that were accepted for consideration in the study occurred shortly after the decision was made. The interviews with such participants specifically required them to think back to their assessment of efficacy before the decisions were made. In the cases in which participants were recalling decisions in emergency situations, the difference between one’s current assessment of target efficacy was likely very closely related to their assessment at the time of the emergency decision. Thus, evidence in this study that tests the TMIM is particularly useful.

Communication efficacy was a strong predictor of whether or not an older adult sought interaction with interpersonal target members. However, coping efficacy, although not a strong predictor of seeking information about the health-care decision, was moderately correlated with communication efficacy, \( r(62)=0.51, p<0.001 \). Participants’ assessments of the efficacy of targets in their health-care decision-making networks did not correlate significantly with their information-seeking behavior involving the targets. Although the dimensions of target ability and target honesty presumably have an impact on a person’s information-seeking behavior, they do not seem to be strong predictors.

The findings reported here call into question a person’s assessment of a target’s efficacy during the information-seeking process. This is in direct contrast with Afifi and Weiner’s (2006) discovery that adolescents’ information-seeking concerning a partner’s sexual health showed the strongest connections to assessments of target efficacy. In light of the previous scholarship involving the complexities associated with members of older adults’ interpersonal and organizational contexts of communication, one might infer that an older adult’s assessment of target efficacy is tainted in a variety of ways. For example, an assessment might be attributable to age differences in information processing. As discussed previously with reference to older
adults’ communication with physicians, older adults might also be more inclined to make decisions about communication on the basis of “morality” and considerations such as social attractiveness or relational quality, rather than assessing potential targets on the basis of Afifi and Weiner’s (2004) constructs of honesty or ability, which are more likened to the “competency” factors discussed by Chan, Rodriguez, and Garcia (2007). Given the issues of dependence and independence in the relationship between adult children and their aging parents (e.g., Cicerelli, 1992a), an older adult’s perception of the social unattractiveness connected to dependency could affect his or her choice to speak with an adult child about a health-care decision more than his or her assessment of the adult child’s efficacy in the decision situation.

An additional explanation for the findings regarding target efficacy and information-seeking stems from the qualitative reports of participants in the study that members of their interpersonal context served as sources of social support as well as information. The TMIM predicts that target ability and target honesty have a specific impact on a person’s information-seeking behavior. An older adult’s motivation for speaking to an interpersonal contact in the health-care decision-making process may not have been to seek information, but rather to seek social support, regardless of the information gained. Indeed, the influence of interpersonal contacts on the process of decision-making was not significantly different from their influence on the outcome of the decision. This could indicate that conversations with interpersonal contacts resulted in information that affected the outcome of the decision. Nonetheless, participants’ assessments of interpersonal targets’ ability and honesty may not have been strong predictors of the communication with the targets because they did not enter the conversations with the intent to seek information. That conversations not intended as information-seeking endeavors can yield influential information in reaching a major health-care decision is an
important consideration for theories of information management. Further, research examining the role of target efficacy in information-seeking across the lifespan would be desirable in light of the evidence that changes in information processing in older age can affect assessments of target efficacy.

Limitations and Future Research

Although several important findings emerged in this study, it was limited in several respects. First, although the data suggested many interesting possibilities, the small sample size did not allow for strong conclusions to be made in many instances. Specifically, in the case of Hypotheses II, VI, VI, and VII, power analyses revealed that the data were possibly too few to detect any target effects. Further, in respect to Research Questions III, IV, and V, power analyses indicated that additional data would be needed to reach firm conclusions. Increasing the sample size has the potential to yield significant results where none emerged and provide additional insight to the influence of the cultural, political-legal, and religious/spiritual contexts. Further, obtaining a more diverse sample that more closely reflects the demographics of the general population would allow for more ecologically valid conclusions to be drawn, especially with regard to political-legal factors, such as insurance type.

In one of the cases in which a statistically significant result surfaced, a concern exists that the assumption of independence between cases may have been violated. Hypothesis IV, which predicted that participants reporting reciprocal relationships with an adult child would experience less anxiety in the decision-making process than those indicating that an adult child attempted to influence them, involved the use of parent-child dyads. Those who had multiple adult children in their decision-making networks were present in the sample multiple times. Thus, the statistical tests are interpreted knowing that a violation of independence may have occurred.
Additional methodological limitations present challenges that will need to be addressed in future research. Although this study involved the impact of the interactions within an older adult’s decision-making network, actual communication was not observed. To assess the ties between decision-making network members and to determine more precisely the influence of various aspects of the communication contexts, examination of actual conversations between participants and others in their decision-making networks is necessary in order to encourage modifications in conversational behavior that could potentially affect the decision-making process for older adults. For example, results from this study indicate that when adult children attempt to influence their parents’ decisions, the parents experience an increase in process-associated anxiety. How adult children actually attempt to influence the parent’s decision is, however, yet unclear, as well as why, more precisely, their attempts at influence are associated with increases in anxiety in their parents. Future research is necessary to discern these issues.

This research represented only the participant’s view of a decision. While the perspective of the older adult decision-maker is most important and justifiable in view of the fact that the investigation examined the decisions of older adults who were legally responsible for their decisions, the viewpoints of others relevant to the decision is critical to obtaining a more complete understanding the decision-making process and outcomes. This is especially true for analyzing the quality of the decision, which also was not assessed in this investigation. Future research investigating how significant conversations during the decision-making process affect decision quality could lead to useful insights into health care decision-making. Further, research endeavors examining the quality of decision from the perspective of relevant others in the decision-making network would potentially yield consequential findings for communication, as well as cognitive psychology.
A final set of limitations involves the role of the researcher in the process of decision-making. Although the researcher’s role in the decision-making process was subject to very careful management, the researcher essentially became part of the decision-making network as a consequence of interviewing participants in the middle of or shortly after they were faced with a major health-care decision. The researcher took care to ask the questions on the protocol and pose follow-up questions only when necessary for clarification. Nevertheless, following completion of the interviews, many participants observed that the researcher’s questions motivated them to think carefully about issues that they may not have normally considered. Although the researcher did not offer advice when asked (or otherwise) and refrained from asking leading questions, several indicated that engaging in the interview caused them to think more seriously about the decision and motivated them to take steps toward an outcome. This was especially the case with individuals who were engaged in decisions about future planning for living arrangements. The people in the study reported that the long-term nature of these decisions gave them and the other members of their decision-making network an excuse to avoid talking about them. Participants noted that they knew that moving was inevitable, but that they did not want to talk about the decision with others or take action about it until they absolutely had to. They frequently reported that talking with the researcher required them to consider the decision in a time frame when they would have normally avoided it. In a sense, the investigator became part of the decision-making network in these cases and potentially affected the decision-making process and outcome in a manner that was not accounted for during the study.

The findings that the study uncovered about the decision-making process despite the limitations, are encouraging and justify future research on the health care decision-making of older adults. Among other contributions, it confirmed the value of examining the complexities
of the health care decision-making process from an ecological perspective, which revealed aspects of the decision-making process that deserve further attention. Health-care decisions seem to vary along the lines of complexity and immediacy, as well as severity and seriousness. Complexity of the issue seems to be influential in that some decisions, such as planning for future living arrangements, which seem to involve not only health complexities, but relational complexities between the participant and other family members, as well as emotional complexities associated with moving. These complexities did not seem to be present in decisions, for example, involving knee replacement surgery. Nonetheless, emotional complexity was present in some instances of surgical procedures when considered in light of the surgery’s effect on other members of the participants’ interpersonal context, as in the case illustrated in Appendix M. As Figure 80 shows, the participant perceived that members of the organizational context were trying to convince him to have heart surgery. He perceived that only one member of his interpersonal context was trying to influence his decision. Yet, qualitative information gathered about the participant’s decision situation revealed that the emotional complexities associated with his decision and those individuals in his interpersonal context affected his decision in meaningful ways. Emotional complexity of a decision may have an important influence on the decision-making process not captured quantitatively in this dissertation. Further, the length of the decision-making process or how immediate is the decision was for participants seemed to have an effect on the decision-making, as illustrated by the dramatic differences in emergency decisions versus decisions about changing residences. For example, emergency decisions tended to have fewer decision contacts and resembled decision-making networks more similar to “Theresa’s” decision network, exemplified in Appendix L (Figure 63 through Figure 71). The network figures in Appendix N, on the other hand, illustrate decision-
making networks that are more representative of longer-term decisions associated with planning for future living arrangements. In Figure 88, the size of the decision-making network is larger, with the number of network nodes at 16. As Figure 84 illustrates, the members of the interpersonal context are densely connected. In Figure 86 and Figure 87 show that individuals involved tended to have more influence on the process of decision-making than on the outcome. Perhaps part of the reason for this is that most individuals in the study who reported that they were making a decision about living arrangements usually had not arrived at a decision after six-weeks of consideration. In general, participants tended to avoid making a decision about their health-care if at all possible, which was particularly the case in decisions involving living arrangements. Although much was gained from this investigation of decisions self-defined as major and not limiting the investigation to a specific kind of health care decision, future inquires would benefit from the examination of decisions based on different types of health care decisions. In short, utilizing an ecological perspective to guide this research offered insight to the various influences on the communication processes involved in making a major health-care decision in later stages of life. This knowledge paves the way for a program of research that explores the communicative influences involved major health care decisions along the dimensions of different decision types.

Utilizing personal social network analysis to examine the decision-making networks of older adults faced with a health care decision proved to be a unique and fruitful method of uncovering patterns of influence on the decision-making. Although utilized in communication research examining organizational communication (e.g., Monge & Contractor, 2003) and in understanding issues for health communication and contagion (e.g., Valente, Gallaher, & Mouttapa, 2004), using personal social network analysis to build understanding about decision-
making and bridge various social contexts is less frequent. This investigation demonstrated the utility of personal social network analysis in examining the health care decision-making process, even though it hardly scratched the surface of the potential power that such analysis has in this realm. Further application of network theory and analysis to explain patterns of relationships and influence would likely lead to better understanding of the health care decision-making processes of older adults.

Conclusions

Despite its limitations, the purpose of this investigation in examining the process of health-care decision making for older adults and the communicative influences on the process was accomplished that is advancing knowledge concerning how older adults manage complexities and challenges associated with making major health care decisions. The investigation also provided information relevant to advancing theories of information management that can be applied to the health care decision-making processes of older adults. These advancements have implications for members of older adults’ decision-making networks who seek to provide meaningful support during the decision-making process to make the process easier, more satisfying, and potentially of higher quality for older adults. The findings presented here also have important implications for medical professionals who assist old adults in making their major health care decisions. Finally, this inquiry paves the way for the way for future research that can assist older adults in managing the challenges, uncertainties, and complexities of making major health-care decisions at the later end of life.
References


Coyne, J. C., & DeLongis, A. (1986). Going beyond social support: The role of social


Halter, J. B. (1999). The challenge of communicating health information to elderly patients: A
view from geriatric medicine. In D. C. Park, R. W. Morrell, & K. Shifren (Eds.),


Society, 19, 677-689.


In J. F. Nussbaum & J. Coupland (Eds.), *Handbook of communication and aging research* (pp. 231-249), Mahwah, NJ: Erlbaum.


Poole, M. S., & Real, K. (2003). Groups and teams in health care: Communication and
effectiveness. In T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Eds.),


Roberto (Ed.), Relationships between women in later life (pp. 179-198). New York:
Haworth.

between single older women and their caregiving daughters. Gerontologist, 29, 792-797.

C. Ratzan (Ed.), AIDS: Effective health communication for the 90s (pp. 37-51).

Cognitive and emotional perspectives. Journal of the American Medical Association,
270, 72-76.

Reinhardt, J. P. (1996). The importance of friendship and family support in adaptation to

‘patient’: Health care promotion as increasing citizens’ decision-making competencies.
Health Communication, 9, 61-74.


Mahwah, NJ: Erlbaum.


Appendix A: Informed Consent Form

Informed Consent Form
for Social Science Research
Saint Louis University
The Pennsylvania State University

Participant: __________________________________    IRB# __________
Title of Project: Health Care Decision-making at the Later End of the Life Span
Principal Investigator: Jennifer E. Ohs
Address: 306 Xavier Hall
Saint Louis University
St. Louis, Missouri 63108
Telephone: (314)977-3508
(814)571-7461
E-mail: ohs@slu.edu

Advisor: Jon F. Nussbaum
Address: 238 Sparks Building
University Park, PA 16801
Telephone: (814)863-3619
E-mail: jfn5@psu.edu

“You” refers to the person who takes part in the research study.

You are being asked to take part in a research study conducted by Jennifer E. Ohs because you are a person over the age of 60 who is faced with a major health care decision.
1. **Purpose of Research:**
   **Why is this research being done?**

The purpose of this research is to examine decision-making involving health care in later life.

2. **Procedures to be followed:**
   **What am I Being Asked to do?**

First, you will be asked to complete a survey. You will answer questions in the form of a face-to-face interview. Due to the length of the survey, you may complete it in two different sessions. If you feel more comfortable completing the survey part of the study in a paper and pencil format, the materials will be provided for you.

Next, you will be asked to keep a record of the persons or sources you consult about your health care decision for six weeks or until you make a decision. You will complete a short survey for each person or source you consult.

At the end of the six week period or when you have made a decision, you will be asked to complete a final survey. You will answer the questions in the form of a face-to-face interview.

3. **Duration/Time:**
   **HOW LONG WILL I BE IN THE RESEARCH STUDY?**

The initial survey/interview will take about two hours and will be conducted in two sessions on different days (unless you would like to complete the survey/interview in one session). Depending on how much information you have to share, the interviews could take longer or shorter than two hours.

You will keep a record of the persons or sources you consult about your health care decision for six weeks or until you make a decision.

The final survey/interview will take about an hour. Depending on how much information you have to share, the interviews could take longer or shorter than an hour.

4. **Discomforts and Risks:**
   **WHAT ARE THE RISKS?**

There are certain risks and discomforts that may occur if you take part in this research study. You may experience some stress in talking about the health care decision you are making. Some of the questions are personal and might cause some discomfort. You do not have to answer any questions that make you feel uncomfortable.
If by participating in this research, you realize that you need physical, mental, or social assistance to help with coping, please contact one of the following agencies:

**In Saint Louis, MO:**
The Mental Health Association of Greater St. Louis  
314-773-1399

County Older Resident Program (CORP)  
(314)615-4516

**In State College, PA:**
Centre County Office of Mental Health/Mental Retardation–Drug and Alcohol  
(814)355-6782

Centre County Office of Aging  
(814) 355-6716

If you think you need assistance from one of the agencies but need help getting in contact with them, Jennifer Ohs, the primary researcher, will direct you.

There is also a slight risk that your information may become known outside of the research study. The investigator has taken precautions to prevent this from occurring. Please see section 7 of this document for more information. The investigator is willing to discuss any questions you might have about these risks and discomforts.

5. **Benefits:**

ARE THERE BENEFITS TO BEING IN THIS RESEARCH STUDY?

You will have the opportunity to discuss and journal about your decision-making processes in a systematic and meaningful manner. Discussing your decision may help you to make a better decision.

Your responses will provide invaluable information for physicians, researchers, therapists, counselors, and ultimately any older adult facing a major health care decision about managing the influences that others can have on the health care decision-making of older adults. Understanding the communicative influences on the decision-making can better help other older adults cope with the stresses of health care decisions. In addition, your responses will provide information about communication and decision-making in general as well as how communication in decision-making can affect the physical and psychological well-being of older adults.
6. Alternatives:
   WHAT OTHER OPTIONS ARE THERE?

   You may choose not to be in this research study.

7. Statement of Confidentiality:
   WILL MY INFORMATION BE KEPT PRIVATE?

   Your participation in this research is confidential.

   All research materials will be securely stored. A random code and first name will be assigned to each participant. Interview, survey, and contact log responses will be stored separately from the consent forms and the code list. All data recorded on the tablet laptop computer will be password protected. No data will be recorded while the tablet laptop computer is connected to the Internet and the information collected on the computer will be moved from the machine promptly after collection.

   Data will be kept until all possible uses of information are exhausted or up to 20 years, whichever comes first.

   The primary investigator and her assistants will have access to confidential data. The primary investigator’s advisor, Dr. Jon F. Nussbaum (The Pennsylvania State University) will have access to coded information.

   The following may review and copy records related to this research:
   - The Saint Louis University Institutional Review Board (the Board that is responsible for protecting the welfare of persons who take part in research studies)
   - The Pennsylvania State University’s Social Science Institutional Review Board
   - The Pennsylvania State University’s Office for Research Protections
   - The Office of Human Research Protections in the U.S. Department of Health and Human Services

8. WHAT ARE THE COSTS AND PAYMENTS?

   The primary investigator is responsible for the costs and procedures associated with the research activity. There will be no additional costs to you for taking part in this research study. All research study procedures are provided to you by the researcher. Participants in the study do not receive any incentive for their participation.
9. WHAT HAPPENS IF I AM INJURED BECAUSE I TOOK PART IN THIS RESEARCH STUDY?

If you believe that you are injured as a result of your participation in this research study, please contact the researcher and/or the Institutional Review Board as stated in section 10.

10. Right to Ask Questions: WHO CAN I CALL IF I HAVE QUESTIONS?

You can ask questions about this research. Contact Jennifer Ohs at (314)977-3508 or (814)571-7461 with questions, complaints or concerns about this research. You can also call this number if you feel this study has harmed you.

If you have questions about your rights as a research participant, or you have concerns or general questions about the research, please contact:

- The Saint Louis University Behavioral and Social Sciences Institutional Review Board at (314)977-2029
- The Pennsylvania State University’s Office for Research Protections at (814) 865-1775.

At these numbers, you will reach someone who will discuss your questions with you or will be able to refer you to someone else who will review the matter with you, identify other resources that may be available to you, and provide further information as how to proceed.

11. Voluntary Participation: WHAT ARE MY RIGHTS AND WHAT ELSE SHOULD I KNOW AS A RESEARCH STUDY VOLUNTEER?

Your decision to be in this research is voluntary. You can stop at any time. You do not have to answer any questions you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty or loss of benefits you would receive otherwise. The researcher will let you know of any new information that may affect whether you want to continue to take part in the research study.

If you agree to take part in this research study and the information outlined above, please sign your name and indicate the date below.
Statement of Consent
I give my informed and voluntary consent to take part in this research study. I will be given a copy of this consent document for my records.

_________  ____________
Participant Signature      Date

_________
Print Name of Participant

SAINT LOUIS UNIVERSITY – INSTITUTIONAL REVIEW BOARD – APPROVAL STAMP

This form is valid only if the IRB’s approval stamp is shown below.

I certify that I have explained to the above individual the nature and purpose of the research study and the possible benefit and risks associated with participation. I have answered any questions that have been raised and the participant has received a copy of this signed consent document.

_________  ____________
Signature of Principal Investigator      Date

_________
Print Name of Principal Investigator or Research Team Member
Appendix B: Research Instrument

Initial Interview
Section A: Decision Information

Please describe the health care decision that you are considering.

Please describe your decision-making process thus far.

How serious is the decision you are considering for you?
1 Very serious 2 Somewhat serious 3 Not very serious

How severe are the consequences of the decision you are considering?
1 Very severe 2 Somewhat severe 3 Not very severe

Please rate the degree of nervousness/anxiety that you associate with the decision you are considering.
1 Very nervous 2 Somewhat nervous 3 Not very nervous
Initial Interview
Section B: Information Management

How much information do you want to know about the factors surrounding your health care decision?

1  2  3  4  5
Very little  A little  Some  Quite a lot  A lot - as much as I can find

How much information do you have about your health care decision?

1  2  3  4  5
Very little  A little  Some  Quite a lot  A lot

To what extent do you agree or disagree with the following statements?

I am comfortable with the amount of information I have about my health care decision. I do not have too much or too little information.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Agree

I know less than I’d like to know about the factors surrounding my health care decision.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Agree

I want to know more than I currently know about the factors surrounding my health care decision.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Agree

I wish I knew more about the factors surrounding my health care decision.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Agree
I know more than I need to know about the factors surrounding my health care decision.

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I know more than I'd like to know about the factors surrounding my health care decision.

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When I do not have very much information about my major health care decisions, I am nervous.

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When I do not know very much about the factors surrounding my health care decisions, I am anxious.

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Thinking about the details of my health care decisions makes me anxious.

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I am nervous about finding out information regarding my health care decision.

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Having too much information about the factors surrounding my health care decision may overwhelm me.

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Thinking about the difference between how much I know and how much I want to know about my health care decision makes me nervous.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

It makes me anxious to think about what I know compared to how much I want to know about my health care decision.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

Making the decision about my health care will have positive outcomes.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

There are a lot more benefits than there are problems associated with making my health care decision.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

I expect that my health care decision-making process will be positive.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

I expect that the outcome of my health care decision-making process will be positive.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

My health care decision-making process will likely be a positive experience.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree
The benefits associated with making my health care decision are important.

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The benefits associated with making my health care decision are major.

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I know who I need to talk to in order to make a good health care decision.

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I know what sources I need to consult in order to make a good health care decision.

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I know how to access the information I need to make a good health care decision.

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I know how to talk to people in order to gain information I need to make a good health care decision.

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I have no trouble coping with the process of the health care decision-making.

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I am certain that I can handle my health care decision-making process, whether it is positive or negative experience.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Disagree

I have no trouble coping with the outcome of my health care decision, no matter what it is.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Disagree

I am certain I will be able to handle the outcome of my health care decision, whatever the outcome is.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Disagree

I am more assertive about my health care needs than most U.S. citizens.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Disagree

I frequently make suggestions to my physician about my health care needs.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Disagree

If my physician prescribes something I do not understand or agree with, I question it.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Disagree

Sometimes there are good reasons not to follow the advice of a physician.

1  2  3  4  5
Strongly Agree  Not Sure  Disagree  Strongly Disagree
Sometimes I think I have a better grasp of what I need medically than my doctor does.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree

If I am given a treatment by my physician I do not agree with, I am likely not to take it.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree

I don’t always do what my physician or health care worker has asked me to do.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree

I believe it is important for people to learn as much as they can about their illnesses and treatments.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree

I actively seek out information on my illness or condition.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree

I am more educated about my health than most US citizens.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree
Initial Interview
Section C: Assessment of Health

In general, would you say your health is:

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor

The following items are about activities that you might do during a typical day.

Does your current health limit you in moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

Does your current health limit you in climbing a flight of stairs?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

During the past four weeks, have you had any of the following problems with your work or other daily activities as a result of your physical health?

Have you accomplished less than you would like?

1. Yes
2. No

Have you been limited in the kind or type of work or other activities that you do?

1. Yes
2. No

During the past four weeks, how much did pain interfere with your normal work (including both work outside and inside your home)?

1. Not at all
2. A little bit
3. Moderately
4. Quite a bit
5. Extremely
During the past four weeks, how much of the time has your **physical health** interfered with your social activities (for example, visiting with family, friends, neighbors, or groups?  

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<tr>
<td>All of the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
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</table>

During the past four weeks, have you had any of the following problems with your work or regular daily activities as a result of any **emotional issues**, such as feeling depressed or anxious?  

Have you accomplished less than you would like?  

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<tr>
<td>Yes</td>
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Were you unable to do work or activities as carefully as usual?  

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<tr>
<td>Yes</td>
<td>No</td>
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The following questions are about **how you feel and how things have been with you** during the past four weeks. For each question, indicate the answer that comes closest to the way you have been feeling.  

**How much of the time during the past four weeks have you felt calm and peaceful?**  

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**Did you have a lot of energy?**  

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<td>A little of the time</td>
<td>None of the time</td>
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</table>

**Have you felt downhearted and blue?**  

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<td>6</td>
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<tr>
<td>All of the time</td>
<td>Most of the time</td>
<td>A good bit of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
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</table>
During the past four weeks, how much of the time has your *emotional health* interfered with your social activities (for example, visiting with family, friends, neighbors, or groups)?

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<tbody>
<tr>
<td></td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>None of the time</td>
</tr>
</tbody>
</table>
Initial Interview
Section D: Demographics

What year were you born? ____________

So on your last birthday you were ____________

What is your gender?

1. Male
2. Female
3. Other ____________

What is your marital status?

1. Married
2. Single
3. Divorced
4. Widowed

What is your racial/ethnic identification?

1. Caucasian
2. African American
3. Hispanic
4. American Indian or Alaskan
5. Asian/Pacific Islander
6. Other (please specify) ____________

What is your occupation? _________________________________

What is the highest level of education you have completed?

1. Elementary School
2. High School
3. University or College Bachelor’s Degree (e.g. B.A., B.S.)
4. Master’s Degree of equivalent (e.g., M.A., M.S., M.B.A.)
5. Ph.D. or equivalent (e.g. M.D.)
What was your **total household** income before taxes, last year? This includes **all** income from **all** household members who live with you (e.g., you, your husband/wife, etc.)?

1. $4,999 or less  
2. $5,000 - $9,999  
3. $10,000 - $14,999  
4. $15,000 - $19,999  
5. $20,000 - $29,999  
6. $30,000 - $39,999  
7. $40,000 - $49,999  
8. $50,000 - $59,999  
9. $60,000 - $69,999  
10. $70,000 - $79,999  
11. $80,000 - $89,999  
12. $90,000 - $99,999  
13. $100,000 - $129,999  
14. $130,000 - $159,999  
15. $160,000 or more

Please indicate the type of health insurance you have.

1. No insurance  
2. Fee-for-Service/Traditional Health Insurance  
3. Health Maintenance Organization (HMO)  
4. Preferred Provider Organization (PPO)  
5. Medicare  
6. Medicaid  
7. Uncertain

Do you have an insurance supplement?

1. Yes  
2. No

If yes, please indicate the provider: ___________________________
Initial Interview
Section E: Assessment of Religiosity/Spirituality

Religion and spirituality vary in their degrees of importance and influence in people’s lives. The following questions will address the importance of religion and spirituality for you.

At the present time, what is your religious preference/affiliation?

What specific denomination (if relevant)?

How important is religion to you?

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</thead>
<tbody>
<tr>
<td></td>
<td>Very important</td>
<td>Somewhat important</td>
<td>Not very important</td>
<td></td>
<td></td>
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</tbody>
</table>

How religious do you consider yourself to be?

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</thead>
<tbody>
<tr>
<td></td>
<td>Very religious</td>
<td>Somewhat religious</td>
<td>Not very religious</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Think about how you try to understand and deal with major problems in your life.
To what extent do each of the following statements reflect how the way you cope?

I think about how my life is part of a larger spiritual force.

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</thead>
<tbody>
<tr>
<td></td>
<td>A great deal</td>
<td>Quite a bit</td>
<td>Somewhat</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

I work together with God as partners to get through hard times.

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<tr>
<td></td>
<td>A great deal</td>
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</table>

I look to God for strength, support, and guidance in crises.

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<tbody>
<tr>
<td></td>
<td>A great deal</td>
<td>Quite a bit</td>
<td>Somewhat</td>
<td>Not at all</td>
</tr>
</tbody>
</table>
I try to find the lesson from God in crises.
1 2 3 4
A great deal  Quite a bit  Somewhat  Not at all

I confess my sins and ask for God’s forgiveness.
1 2 3 4
A great deal  Quite a bit  Somewhat  Not at all

I feel that stressful situations are God’s way of punishing me for my sins or lack of spirituality.
1 2 3 4
A great deal  Quite a bit  Somewhat  Not at all

I wonder whether God has abandoned me.
1 2 3 4
A great deal  Quite a bit  Somewhat  Not at all

I try to make sense of the situation and decide what to do without relying on God.
1 2 3 4
A great deal  Quite a bit  Somewhat  Not at all

I question whether God really exists.
1 2 3 4
A great deal  Quite a bit  Somewhat  Not at all

I express anger at God for letting terrible things happen.
1 2 3 4
A great deal  Quite a bit  Somewhat  Not at all

To what extent is your religion involved in understanding or dealing with stressful situations in any way?
1 2 3 4
Very involved  Somewhat involved  Not very involved  Not involved at all
Please indicate the extent to which you agree or disagree with the following statements. If a statement does not apply to your religious values, please indicate that it is “Not Applicable.”

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>I try hard to carry my religion over into all my other dealings in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Quite often I have been keenly aware of the presence of God or the Divine</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>The prayers I say when I am alone carry as much meaning and personal</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>It is important to me to spend periods of time in private religious</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>My religious beliefs are what really lie behind my whole approach to</td>
<td>1</td>
<td>2</td>
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<td>5</td>
<td></td>
</tr>
<tr>
<td>Religion is especially important to me because it answers many questions</td>
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<td>2</td>
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<td>4</td>
<td>5</td>
<td></td>
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</tbody>
</table>
I read literature about faith (or church).
1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Not Applicable
Disagree

If I were to join a church group, I would prefer to join a Bible study group.
1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Not Applicable
Disagree

If I were to join a church group, I would prefer to join a social fellowship.
1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Not Applicable
Disagree

If not prevented by unavoidable circumstances, I attend church.
1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Not Applicable
Disagree

The church is most important as a place to formulate good social relationships.
1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Not Applicable
Disagree

The purpose of prayer is to secure a happy and peaceful life.
1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Not Applicable
Disagree

What religion offers me is comfort when sorrows and misfortune strike.
1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Not Applicable
Disagree

It doesn’t matter so much what I believe so long as I lead a moral life.
1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Not Applicable
Disagree
Although I am a religious person, I refuse to let religious considerations influence my everyday affairs.

1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Agree Not Applicable

I pray chiefly because I have been taught to pray.

1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Agree Not Applicable

A primary reason for my interest in religion is that my church is a congenial social activity.

1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Agree Not Applicable

Occasionally I find it necessary to compromise my religious beliefs in order to protect my social and economic well-being.

1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Agree Not Applicable

The primary purpose of prayer is to gain relief and protection.

1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Agree Not Applicable

I feel there are many more important things in my life other than my religion.

1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Agree Not Applicable

Religion helps to keep my life balanced and steady in exactly the same way my citizenship, friendships, and other memberships do.

1 2 3 4 5
Strongly Disagree Neutral Agree Strongly Agree Not Applicable
One reason for my being a church member is that such membership helps to establish a person in the community.

<table>
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<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Not Applicable</th>
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</table>

I was not very interested in religion until I began to ask questions about the meaning and purpose of my life.

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<tr>
<th>Strongly Disagree</th>
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<th>Neutral</th>
<th>Agree</th>
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I have been driven to ask religious questions out of a growing awareness of the tensions in my world and in my relation to my world.

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<tr>
<th>Strongly Disagree</th>
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<th>Agree</th>
<th>Strongly Agree</th>
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My life experiences have led me to rethink my religious convictions.

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<th>Strongly Disagree</th>
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God wasn’t very important for me until I began to ask questions about the meaning of my own life.

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<th>Strongly Disagree</th>
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<th>Agree</th>
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</table>

It might be said that I value my religious doubts and uncertainties.

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<tr>
<th>Strongly Disagree</th>
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<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
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For me, doubting is an important part of what it means to be religious.

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<thead>
<tr>
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<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
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I find religious doubts upsetting.

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<td>Agree</td>
<td>Strongly Agree</td>
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Questions are far more central to my religious experience than are answers.

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<td>Agree</td>
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As I grow and change, I expect my religion also to grow and change.

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<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
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</table>

I am constantly questioning my religious beliefs.

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<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
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I do not expect my religious convictions to change in the next few years.

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<td>Neutral</td>
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<td>Strongly Agree</td>
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There are many religious issues on which my views are still changing.

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</table>
Initial Interview
Section F: Internet Usage/Comfort/Confidence

The Internet is often a source of information for people making health care decisions. The following questions are about your use of the Internet.

Which statement best applies to you?

1. I have never heard of the Internet.
2. I have heard of the Internet, but I don’t really know what it is.
3. I know what the Internet is, but I have never used it.
4. I have used the Internet, but I do not use it very often or have stopped using it.
5. I have used the Internet and I still use it.

If you haven’t used or don’t use the Internet, please indicate your reason why. Please check as many responses as appropriate.

_____ The Internet doesn’t interest me.
_____ I don’t believe I need the Internet.
_____ I don’t know how to use the Internet.
_____ I don’t have access to a public or private Internet connection.
_____ My vision/arthritis/other physical reason prevents me from using the computer.
_____ Other reason (please specify) _________________________________________________

If you have used or still use the Internet, please answer the questions in the following section.

How often do you use the Internet?
1. Daily or almost daily
2. 3-4 times a week
3. Once a week
4. Once every two weeks
5. Once a month or less
How long do you usually visit the Internet at a particular time?
1  1 – 15 minutes
2  15 – 30 minutes
3  30 minutes – 1 hour
4  1 – 2 hours
5  2 – 3 hours
6  3 – 4 hours
7  more than 4 hours

Please indicate your opinion on the basis of your use and interest of the following Internet functions with regards to importance. If you do not use a particular function, please indicate, “Not applicable.”

Browsing websites/surfing
1  2  3  4   5
Very Important Somewhat Interesting, but not important Not at all Not applicable
Important

E-mailing
1  2  3  4   5
Very Important Somewhat Interesting, but not important Not at all Not applicable
Important

Searching for information – general
1  2  3  4   5
Very Important Somewhat Interesting, but not important Not at all Not applicable
Important

Searching for health and medical information
1  2  3  4   5
Very Important Somewhat Interesting, but not important Not at all Not applicable
Important

Searching for product information
1  2  3  4   5
Very Important Somewhat Interesting, but not important Not at all Not applicable
Important
Please indicate to what extent you agree with the following statements.

**Searching for medication information**

<table>
<thead>
<tr>
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<th>3</th>
<th>4</th>
<th>5</th>
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</thead>
<tbody>
<tr>
<td>Very Important</td>
<td>Somewhat Important</td>
<td>Interesting, but not important</td>
<td>Not at all important</td>
<td>Not applicable</td>
</tr>
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</table>

**Price information search/comparison**

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**Chatting with friends**

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<td>Very Important</td>
<td>Somewhat Important</td>
<td>Interesting, but not important</td>
<td>Not at all important</td>
<td>Not applicable</td>
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**Searching for information about doctors and health institutions**

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<td>Very Important</td>
<td>Somewhat Important</td>
<td>Interesting, but not important</td>
<td>Not at all important</td>
<td>Not applicable</td>
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**Please indicate to what extent you agree with the following statements.**

**It’s easy to use the Internet.**

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<tr>
<td>Strongly agree</td>
<td>Somewhat agree</td>
<td>Somewhat disagree</td>
<td>Strongly disagree</td>
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**I easily find what I’m looking for online.**

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<td>Strongly agree</td>
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**Web pages are clear and logical.**

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<td>Strongly agree</td>
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**It’s easy to read webpages.**

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<tr>
<td>Strongly agree</td>
<td>Somewhat agree</td>
<td>Somewhat disagree</td>
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<tr>
<td>Statement</td>
<td>Scale</td>
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<td>--------------------------------------------------------------------------</td>
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<tr>
<td>I’m satisfied with information I find on the Internet.</td>
<td></td>
<td>1</td>
<td>2</td>
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<tr>
<td>I trust information offered on the Internet.</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>One can easily learn to use the Internet without outside help.</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>I know where to search for information online.</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>I can trust the information I find online.</td>
<td></td>
<td>1</td>
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</table>

1: Strongly agree  2: Somewhat agree  3: Somewhat disagree  4: Strongly disagree
Initial Interview
Section G: Network Identification

Please take a moment to think about the *individuals you know personally* that you may talk to (or have already talked to) about your health care decision. For example, you may talk with your physician, psychologist/psychiatrist, insurance representatives, pastor/spiritual advisor, spouse, son or daughter, friends, or sibling(s). Please record the initials of each person you may speak to (or have already spoken to) about the health care decision you are considering.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Please take a moment to think about *other sources* you may consult (or have already consulted) about your health care decision. Examples could be Internet websites, books, magazines, and insurance information found in booklets/pamphlets. Please record potential sources other than individuals you know personally that you may consult (or have already consulted) regarding the health care decision you are considering.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Initial Survey
Target Information - Interpersonal Social Network

To be completed about each interpersonal contact.

What are the initials of a person that you identified that you may talk to (or have already spoken to) about your health care decision? ________________

What is this person’s relationship to you?
1. Spouse
2. Adult child
3. Sibling
4. Friend
5. Physician
6. Psychiatrist/Psychologist
7. Pastor or Religious/Spiritual Advisor
8. Financial Advisor
9. Other (please specify) _______________________________________

What is the gender of this person?
1. Male
2. Female
3. Other

Do you know what year was this person born? __________

So on this person’s last birthday he/she was (approximately) how old? __________

So relative to your age, this person is
1. Significantly younger than me
2. A bit younger than me
3. Close to my age
4. A bit older than me
5. Significantly older than me

What is this person’s occupation? __________

What is the religion of this person? ________________________________
The religious views of this person, relative to yours, are:
1. The same as my own
2. Similar to my own
3. A bit different than my own
4. Very different than my own
5. I’m not sure of this person’s religious views.

How long have you known this person?
1. Less than a year
2. 1-4 years
3. 5-19 years
4. 20 or more years
5. Not sure

Usually, how often do you speak to this person?
11. Each day
12. More than once a week
13. Once a week
14. Every other week
15. About once a month
16. About once every three or four months
17. About once every six months
18. Once a year
19. Less than once a year
20. I do not usually speak with this person.

Approximately how far does this person live from you in terms of miles? ________________

Does this person know what kind of health insurance you have?
1. Yes, this person has full knowledge of my health insurance policy.
2. This person has some knowledge of my health insurance situation.
3. No, this person has no knowledge of my health insurance information.
4. I’m not sure.
Does this person know about your financial situation?

1. Yes, this person has **full knowledge** of my financial situation.
2. This person has **some knowledge** of my financial situation.
3. No, this person has **no knowledge** of my financial situation.
4. I’m not sure.

How stable do you consider your relationship to be?

1 2 3 4 5  
Very stable Somewhat stable Not very stable

How close do you consider your relationship with this person?

1 2 3 4 5  
Very close Somewhat close Not very close

How much do you trust this person?

1 2 3 4 5  
Very much Somewhat Not very much

Do you consider this person to be your equal?

1 Yes, definitely.
2 Yes, in most regards, though in some ways this person is **superior to me**.
3 Yes, in most regards, though in some ways this person is **my subordinate**.
4 Not really – I consider this person to be **superior to me**.
5 Not really – I consider this person **my subordinate**.

Does this person treat you as an equal?

1 Yes, definitely.
2 Yes, in most regards, though in some ways this person treats me as a **superior**.
3 Yes, in most regards, though in some ways this person treats me as a **subordinate**.
4 Not really – this person treats me as a **superior**.
5 Not really – this person treats me as a **subordinate**.
Have you spoken to this person about your health care decision already?

1. Yes
2. No
3. Unsure

About how many times have you spoken to this person about your health care decision?

_____

The following questions are about how you anticipate your communication with this person to be when discussing your health care decision. If you have already spoken to this person about your health care decision with this person, please answer the questions based how you remember feeling about this person before talking with them about your health care decision. For each statement, please indicate the extent to which you agree or disagree with the following statements.

I expect that this person will be upfront about what he/she thinks about the health care decision at hand.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

I expect that this person can give me useful insights regarding my health care decision.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

I expect that this person may hide his/her true feelings about the health care decision.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree

This person would be very willing to offer his/her opinion about the health care decision.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Agree
Not Sure Disagree
This person will likely be honest about his/her opinion on my health care decision.

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<tr>
<td></td>
<td>Strongly Agree</td>
<td>Not Sure</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
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I expect that this person can aid me in my health care decision-making process.

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<td></td>
<td>Strongly Agree</td>
<td>Not Sure</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
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When I have a talk with this person about my health care decision, I’ll directly ask him/her about his/her opinions and attitudes about it.

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<td>Strongly Agree</td>
<td>Not Sure</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
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I expect that this person can give me useful information on my health care decision.

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<td></td>
<td>Strongly Agree</td>
<td>Not Sure</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
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In having a talk with this person about the health care decision, I’ll probably be completely upfront about my opinion and attitudes about it.

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<tr>
<td></td>
<td>Strongly Agree</td>
<td>Not Sure</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
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In general, how direct do you plan to be in discussing your health care decision with this person?

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<tr>
<td></td>
<td>Extremely Direct</td>
<td>Not Sure</td>
<td>Not Very</td>
<td>Not at all</td>
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**Initial Interview**

**Target Information - Non-Interpersonal Sources**

To be completed about each source outside of the participant’s interpersonal social network.

What is a source outside of your personal network that you plan to consult?

Have you consulted this source health care decision already?

1. Yes
2. No
3. Unsure

If so, about how many times have you consulted this source?  _____________

How often do you normally consult this source?

1. Each day
2. More than once a week
3. Once a week
4. Every other week
5. About once a month
6. About once every three or four months
7. About once every six months
8. Once a year
9. Less than once a year
10. I have never consulted this source before.

How did you come in contact with this source?

1. I sought out this source myself.
2. Someone *suggested* that I consult this source.
3. Someone *told* me to consult this source.
4. I came across this source by coincidence.
5. Not sure
How critical/important do you think the information you receive from this source will be in making your decision?

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<tr>
<td></td>
<td>Very important</td>
<td>Somewhat important</td>
<td>Not very important</td>
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How much do you trust this source?

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<tr>
<td></td>
<td>Very much</td>
<td>Somewhat</td>
<td>Not very much</td>
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</table>
Initial Interview
Target Background - Physicians

To be completed about each member of the network who is serving as your physician.

You mentioned that one (or more) of the individuals in your decision-making network was your physician. What are the initials the physician?
_________________

To what extent do you agree or disagree with the following statements?

I’m very satisfied with the medical care I receive from this physician.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree

I am very satisfied with the quality of interaction I have with my physician.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree

I trust my physician to give me the guidance and information I need to make appropriate health care decisions.

1  2  3  4  5
Strongly Agree Not Sure Disagree Strongly Disagree
**Final Interview**

**Participant Summary: Section A – Decision Summary**

Overall, how satisfying has the decision-making process been for you?

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<tr>
<td></td>
<td>Very satisfying</td>
<td>Somewhat satisfying</td>
<td>Not very satisfying</td>
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Overall, how much anxiety have you experienced with the decision-making process?

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<tr>
<td></td>
<td>A considerable amount</td>
<td>Some</td>
<td>Not much</td>
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Overall, how serious do you consider this decision?

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<tr>
<td></td>
<td>Very serious</td>
<td>Somewhat serious</td>
<td>Not very serious</td>
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How severe do you consider the consequences of the decision?

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<tr>
<td></td>
<td>Very severe</td>
<td>Somewhat severe</td>
<td>Not very severe</td>
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*If participant has arrived at a decision:*

How satisfied are you with the decision you have made?

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<tr>
<td></td>
<td>Very satisfied</td>
<td>Somewhat satisfied</td>
<td>Not very satisfied</td>
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</table>
Final Interview  
Participant Summary: Section B - Contextual Influences  

I am now going to ask you about your general perceptions of how much some different factors may have influenced your decision-making.

How much do you think your **overall financial state** influenced your decision-making?  
1  2  3  4  5  
Very much  Somewhat  Not very much

How much do you think your **cultural background or contacts** influenced your decision-making?  
1  2  3  4  5  
Very much  Somewhat  Not very much

How much do you think your **religion/spirituality** influenced your decision-making?  
1  2  3  4  5  
Very much  Somewhat  Not very much

How much do you think your **interpersonal contacts** (friends and family members) influenced your decision-making?  
1  2  3  4  5  
Very much  Somewhat  Not very much

How much do you think **political-legal factors** (such as health insurance type) had on your decision-making?  
1  2  3  4  5  
Very much  Somewhat  Not very much

How much do you think **media resources** (Internet, books, magazines) influenced your decision-making?  
1  2  3  4  5  
Very much  Somewhat  Not very much
How much do you think organizational resources (doctors, nurses) influenced your decision-making?

1. Very much
2. Somewhat
3. Not very much
Final Interview
Participant Summary: Section C - Final Questions

Overall, what could have made the decision-making process easier and more satisfying for you?

Is there anything that could have made the decision more satisfying?

In retrospect, is there anything you would’ve done differently?

What advice would you give someone who is in a similar situation as you are making a similar decision?
Final Interview
Target Information - Interpersonal Social Network

For each person that you spoke to about your health care decision, please answer the following questions.

Throughout the course of your health care decision-making process, how many times were you in contact with this person about your decision?

________________

What is the usual form of contact you had with this person about your health care decision?
1. Face-to-face
2. Over the phone
3. E-mail
4. Internet chatting
5. Postal mail
6. Other

Who usually initiated the contact about your decision?
1. I initiated.
2. This other person initiated.
3. Neither initiated – we initiated the conversation equally or the conversation about the decision flowed from another topic.
4. A third party initiated the contact between us.
5. I’m not sure who usually initiated the contact(s).

What was the usual duration of the contacts you had with this person about your health care decision?
6. 5 minutes or less
7. 5 – 30 minutes
8. 30 – 60 minutes
9. 60 minutes or longer
10. Not sure

What is the longest conversation that you had with this person regarding your health care decision?
6. 5 minutes or less
7. 5 – 30 minutes
8. 30 – 60 minutes
9. 60 minutes or longer
10. Not sure
(If the major form of contact with this person about your health care decision took place through post, e-mail, or online chatting, how would you describe the usual length of the writing/contact?)

6. Very brief – a short mention
7. Brief, but more than a passing thought
8. A good amount
9. At length
10. Not sure

(If you consulted through post, e-mail, or online chatting, what was the longest length of the writing/contact about your health care decision?)

6. Very brief – a short mention
7. Brief, but more than a passing thought
8. A good amount
9. At length
10. Not sure

What was the usual atmosphere of the conversation/contact?

1. Very pleasant and relaxed
2. Somewhat pleasant and relaxed.
3. Somewhat unpleasant and not very relaxed.
4. Very unpleasant and stressful
5. Not sure
6. Other (please describe)

Did one (or some minority) of the contacts stand out as having a different atmosphere? If so, please describe the atmosphere.

1. Very pleasant and relaxed
2. Somewhat pleasant and relaxed.
3. Somewhat unpleasant and not very relaxed.
4. Very unpleasant and stressful
5. Not sure
6. Other (please describe)

Before speaking to you about this health care decision, what degree of familiarity did this person have with health care situation at hand?

1. Very familiar
2. Familiar
3. Not sure
4. Unfamiliar
5. Very Unfamiliar
After speaking to you, what degree of familiarity did this person have with the health care decision at hand?

1. Very familiar
2. Familiar
3. Not sure
4. Unfamiliar
5. Very Unfamiliar

Overall, how influential was this person on your decision-making?

1   2   3   4   5
Very influential Neutral Not very influential

Overall, how critical or important do you think this person was in your decision-making process?

1   2   3   4   5
Very important Somewhat important Not very important

Overall, how helpful were the conversations you had with this person in terms of coping with the process of decision-making?

1   2   3   4   5
Very helpful Neutral Not very helpful

Overall, how helpful were the conversations you had with this person in terms of providing information you needed to make your decision?

1   2   3   4   5
Very helpful Neutral Not very helpful
Final Interview
Target Information – Non-interpersonal Network

For each “other” source of information you consulted during your decision-making process, please respond to the following questions.

Throughout the course of your health care decision-making process, how many times did you consult this source about your decision?

________________

How would you describe the usual length of time you consulted this source?

1  2  3  4  5
Very brief    Brief    A good amount    At length    Not sure

What was the longest length of time you consulted the source?

1  2  3  4  5
Very brief    Brief    A good amount    At length    Not sure

Overall, how influential was this source on your decision-making?

1  2  3  4  5
Very influential    Neutral    Not very influential

Overall, how critical or important do you think this source was in your decision-making process?

1  2  3  4  5
Very important    Somewhat important    Not very important

Overall, how helpful was consulting this source in terms of coping with the process of decision-making?

1  2  3  4  5
Very helpful    Neutral    Not very helpful

Overall, how helpful was consulting this source in terms of providing information you needed to make your decision?

1  2  3  4  5
Very helpful    Neutral    Not very helpful
Final Interview: Ranking Sheet

Listed in the first column on the chart below is each person (indicated by initials) and information source that you consulted during the course of your decision-making process for the study.

In the 2nd column, please rank the people and sources you consulted in terms of their overall influence in the decision-making process (1 being the most influential).

In the 3rd column, please rank the people and sources you consulted in terms of their overall on the decision outcome (1 being the most influential).

In the 4th column, please assign each person to a particular context (or contexts) of influence:

- **Interpersonal** (for example, family members, friends)
- **Cultural** (for example, friends related through culture, such as persons you know through the Polish Heritage Foundation)
- **Religious or Spiritual** (for example, spiritual advisors, pastors)
- **Political-Legal** (for example, a health insurance representative)
- **Organizational** (for example, a doctor, nurse, or representative at the Alzheimer’s Association)
- **Media** (for example, Internet websites, magazines)

<table>
<thead>
<tr>
<th>Person/Source</th>
<th>Influence on Process</th>
<th>Influence on Outcome</th>
<th>Context(s)</th>
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...
**Final Interview**  
**Network Questions**

How often do you think that these people usually speak to each other?

0  These people do not know each other.  
1  Each day  
2  More than once a week  
3  Once a week  
4  Every other week  
5  About once a month or every other month  
6  About once every three or four months  
7  About once every six months  
8  Once a year  
9  Less than once a year  
10  These people know each other, but are not normally in contact.

How many times do you think these people discussed your health care decision?

0  These people do not know each other.  
1  1 time  
2  2-3 times  
3  4-5 times  
4  6-7 times  
5  8 or more times  
6  I do not think these people discussed my decision.

How stable do you think (target) would report his/her relationship with each other person?

0  These two people do not know each other.  
1  Very Stable  
2  
3  Somewhat stable  
4  
5  Not very stable  
6  Not sure
How close do you think (target) would consider his/her relationship each other person?

0 These two people do not know each other.
1 Very close
2
3 Somewhat close
4
5 Not very close
Not sure

How much do you think (target) trusts each other person?

0 These two people do not know each other.
1 Very much
2
3 Somewhat
4
5 Not very much
Not sure

Does (target) think he/she is equal to each other person?

0 These two people do not know each other.
1 Yes, definitely.
2 Yes, in most regards, though in some ways (target) would consider this person superior.
3 Yes, in most regards, though in some ways (target) would consider this person subordinate.
4 Not really – (target) would consider this person superior.
5 Not really – (target) would consider this person subordinate.
Not sure
If you think (target) spoke with the other persons about your decision, who do you think initiated the conversation?

0   These two people do not know each other.
1   I do not think these two people spoke about my health care decision.
2   I'm not sure if these two people spoke about my health care decision.
3   I think (target) initiated the contact.
4   I think the other person initiated the contact.
5   I initiated the contact between these two people.
6   A third party, other than myself, probably initiated the contact.
7   I'm not sure who initiated the contact.
8   Neither – they initiated equally or the talk about the decision flowed from another topic.

If you think (target) spoke to another person on this list about your health care decision, do you think (target) tried to influence the thinking of the other person on the issue of your decision?

0   These two people do not know each other.
1   I do not think these two people spoke about my health care decision.
2   I'm not sure if these two people spoke about my health care decision.
3   I think (target) would have been the influencing person during the contact.
4   I think the other person would have been the influencing person during the contact.
5   Neither person would have influenced the other during the contact.
6   I'm not sure if one person would have influenced the other.
7   Both parties probably would have influenced each other.
Appendix C: Measure of Efficacy

Scale

1  2  3  4  5
Strongly Agree  Agree  Not Sure  Disagree  Strongly Disagree

Communication Efficacy
I know who I need to talk to in order to make a good health care decision.
I know what sources I need to consult in order to make a good health care decision.
I know how to access the information I need to make a good health care decision.
I know how to talk to people in order to gain information I need to make a good health care decision.

Coping Efficacy
I have no trouble coping with the process of the health care decision-making.
I am certain that I can handle my health care decision-making process, whether it is positive or negative experience.
I have no trouble coping with the outcome of my health care decision, no matter what it is.
I am certain I will be able to handle the outcome of my health care decision, whatever the outcome is.

Target Efficacy - Honesty
I expect that this person will be upfront about what he/she thinks about the health care decision at hand.
I expect that this person may hide their true feelings about the health care decision.
This person would be very willing to offer his/her opinion about the health care decision.
This person will likely be honest about his/her opinion on my health care decision.

Target Efficacy – Ability
I expect that this person can aid me in my health care decision-making process.
I expect that this person can give me useful information on my health care decision.
I expect that this person can give me useful insights regarding my health care decision.
Appendix D: Measure of Propensity for Involvement in Health Care Decisions

Scale

<table>
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<th></th>
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<th>3</th>
<th>4</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Not Sure</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
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**Patient Self-Advocacy Scale**

*Assertiveness*
I am more assertive about my health care needs than most U.S. citizens.
I frequently make suggestions to my physician about my health care needs.
If my physician prescribes something I do not understand or agree with, I question it.

*Nonadherence*
Sometimes there are good reasons not to follow the advice of a physician.
Sometimes I think I have a better grasp of what I need medically than my doctor does.
If I am given a treatment by my physician I do not agree with, I am likely not to take it.
I don’t always do what my physician or health care worker has asked me to do.

*Education*
I believe it is important for people to learn as much as they can about their illnesses and treatments.
I actively seek out information on my illness or condition.
I am more educated about my health than most US citizens.
Appendix E: Measure of Religious Coping

Scale:

1  2  3  4
A great deal Quite a bit Somewhat Not at all

Positive Religious Coping
I think about how my life is part of a larger spiritual force.
I work together with God as partners to get through hard times.
I look to God for strength, support, and guidance in crises.
I try to find the lesson from God in crises.
I confess my sins and ask for God’s forgiveness.

Negative Coping
I feel that stressful situations are God’s way of punishing me for my sins or lack of spirituality.
I wonder whether God has abandoned me.
I try to make sense of the situation and decide what to do without relying on God.
I question whether God really exists.
I express anger at God for letting terrible things happen.
Appendix F: Measure of Internet Usage

Which statement best applies to you?

1 I have never heard of the Internet.
2 I have heard of the Internet, but I don’t really know what it is.
3 I know what the Internet is, but I have never used it.
4 I have used the Internet, but I do not use it very often or have stopped using it.
5 I have used the Internet and I still use it.

If you haven’t used or don’t use the Internet, please indicate your reason why. Please check as many responses as appropriate.

_____ The Internet doesn’t interest me.
_____ I don’t believe I need the Internet.
_____ I don’t know how to use the Internet.
_____ I don’t have access to a public or private Internet connection.
_____ My vision/arthritis/other physical reason prevents me from using the computer.
_____ Other reason (please specify)

Please indicate your opinion on the basis of your use and interest of the following Internet functions with regards to importance. If you do not use a particular function, please indicate, “Not applicable.”

<table>
<thead>
<tr>
<th>Scale</th>
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<th>3</th>
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<td>4</td>
<td>3</td>
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<td>1</td>
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<tr>
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<td>3</td>
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<tr>
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<td>4</td>
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<td>2</td>
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<td>4</td>
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</table>

Searching for health and medical information
Searching for medication information
Searching for information about doctors and health institutions
Appendix G: Decision-Making Network Example 1 – “Jim”

Decision: Surgeon for Hernia Operation

Decision Situation

Jim was facing a hernia operation. Originally, he had decided to see a surgeon who was skilled at performing laparoscopic surgery, unlike other surgeons in his area. However, Jim found the surgeon to have a “condescending” and “disappointing” demeanor. As a result, Jim considered finding a different surgeon to perform the operation.

Process of Decision-making and Influencing Factors

Jim, 64, reported that he had his first hernia operation 16 years ago. According to Jim, this surgery involved making a three to four inch incision in his abdominal cavity. He described this surgery as “somewhat invasive.”

At the time of the initial interview, Jim said that he suspected that he had been developing another hernia for about six months. As time passed, he said the need to have a hernia operation became clearer. He went to his primary physician, Dr. W, and mentioned his symptoms. The physician examined him and confirmed that he had a hernia and would need surgery. Dr. W recommended that he see a specialist and mentioned three possible surgeons for the procedure.

Jim said that he considered his options for a surgeon carefully and purposefully chose Dr. C. Jim said Dr. C was a newer surgeon in the health system in his area. He learned from Dr. W that Dr. C had recently come to his area (which he described as a smaller area with few options for medical care) from a more sophisticated health system. Jim appreciated that Dr. C’s technique for surgery was less invasive. He chose Dr. C over the two other surgeons because the
others were not skilled at laparoscopic surgery. “The first surgery I had laid me out for three or four days,” he said. “I was interested in having a faster recovery time.”

Jim went to see Dr. C to determine if he was a candidate for a less invasive surgery for the hernia. Dr. C confirmed that Jim had a hernia. “He told me I could leave it alone and it would get worse or have it corrected,” Jim said. Dr. C also confirmed that he was a good candidate for the laparoscopic procedure, which Jim knew would be less invasive. Jim said that he knew he wanted to have it corrected. “I knew it would only get worse. I had experienced it getting worse for six months already,” he said. However, Jim reported that he wasn’t sure that he wanted to have Dr. C perform the surgery. “Dr. C’s bedside manner was not good. I found him to be insensitive,” he said.

As a result, Jim called a friend, “Patty,” who worked in the quality assurance department at the managed care site. Jim told Patty about his experience and asked for her opinion. He reported that he trusted Patty to give him good advice. Patty told him that Dr. C was a fine surgeon.

Final Decision

Despite his hesitancy Jim decided to have Dr. C perform the surgery. He said that Patty’s assessment of Dr. C was important in his decision. “She assured me that (Dr. C’s) expertise was sound. So I swallowed my feelings and went through with it. I almost made the decision that I wasn’t going to let this guy touch my body, but someone I trust said he knew his stuff,” Jim said.

Decision-Making Network Nodes:

Dr. W – Physician
Dr. C – Physician
PJ – Friend
DL - Spouse

IT - Website with information about laparoscopy

PA - Pamphlet

Figure 18. Decision-making network example 1: Communication frequency between interpersonal nodes.
Figure 19. Decision-making network example 1: Frequency of decision contact between interpersonal nodes.
Figure 20. Decision-making network example 1: Frequency of decision contact with interpersonal and non-interpersonal nodes.
Figure 21. Decision-making network example 1: Average relational quality between interpersonal nodes.

Figure 22. Decision-making network example 1: Relational quality between interpersonal nodes - nonsymmetric.
Figure 23. Decision-making network example 1: Influence of interpersonal and non-interpersonal targets on process of decision-making.
Figure 24. Decision-making network example 1: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 25. Decision-making network example 1: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 26. Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix H: Decision-Making Network Example 2 – “Catherine”

Decision: Medication Change

Decision Situation

Catherine, who has Myasthenia Gravis (MG), was making a decision about the treatment for her disease. She was working with her doctors to discern an appropriate course of treatment to achieve remission from the disease when she experienced possible side effects from a new medication. She needed to decide whether to continue on the course.

Process of Decision-making

Almost four years prior to the initial interview, Catherine was diagnosed with (MG). Catherine described the condition as an autoimmune neuromuscular disorder that makes her muscles weak. Specifically, persons with MG tend to experience fluctuations of weakness of their voluntary muscle groups. Catherine further explained that her immune system fights the message sent from her muscles to her nerve. Catherine developed MG in her 60s, which she said is highly unusual, as the disease usually presents in infancy or symptoms develop in a person’s 20s. She described her condition as mild overall, especially in comparison to others who are completely immobilized by the disease.

Catherine said that her symptoms developed during a stressful time of her life and she thinks that stress aggravated the condition. She recalled having double vision one night and that the muscles in her face sagged. She made an appointment to have her eyes lifted, thinking that the issues she was having had to do with aging. However, the ophthalmolic surgeon she saw informed her that the symptoms she was experiencing could be due to Myasthenia Gravis and he would not perform any kind of procedure until MG was confirmed or denied.
Catherine went to a specialist at a prominent medical center to be tested and she was diagnosed with MG. Catherine decided to see a neurologist at the same medical center’s muscular dystrophy center for treatment because she did not want to be treated by a local neurologist. She said that she trusted the center’s neurologist to be “up on cutting edge treatment and technology” and she was confident that she was getting the best care possible.

Through the neurologist and with her own research, Catherine said that she learned that there was a “whole litany of things” one can do to treat MG, so that “if one thing doesn’t work, they try another and another.” She said her neurologist began a course of treatments and Catherine spent six months on the regime “without much of a response.” She reported that after several different drug therapies, she was settled on two main drugs: Mestinon and Imuran.

Catherine described Mestinon as her “base drug” and explained that as cholinesterase inhibitor, it promoted electro chemical impulses to aid her muscle functioning. Catherine reported that she takes Mestinon every four hours and she understands that she will be on this medication forever. Catherine also takes Imuran as an immunosuppressant. She said that her neurologist believes that a person can be put into remission, so he suggested weaning her off of Imuran and replacing with a different immunosuppressive agent, CellCept. The initial plan was for Catherine to take both Imuran and CellCept for some time and then to wean off of Imuran. Catherine said that eventually, she was to wean off of CellCept as well and would then be considered in remission from MG.

After taking CellCept with Imuran for seven days, Catherine said she developed symptoms of numbing and tingling. She thought that these could be side effects of the new drug, but the symptoms mimicked those of a stroke. She said that as a result, she went in to see her internist. The internist admitted her to the hospital as a potential stroke victim so that she could
be tested. At the hospital, Catherine said a series of tests were run, including an MRI, a sonogram of her arteries, and an echocardiogram. She was told that all of her test results were normal for an “aging, Caucasian female.” However, during the hospital visit, Catherine became convinced that she had not had a stroke, but that her symptoms were side effects of the drug. She said that the doctor said that the results of the tests could not rule out the possibility that she had had a Transient Ischemic Attack (TIA) or “mini-stroke.” In short, her symptoms could indicate that she had a TIA or could indicate that she experienced side effects of the medication. Catherine said that she was discharged as a having had a TIA, but that the doctor recommended that she stop taking CellCept. When I asked what the side effects of the drug meant for her health, Catherine thought a moment and said, “Why, I don’t know. The tingling and numbness must indicate something pretty serious if I was sent to the hospital to find out if I had had a stroke.”

After returning from the hospital, Catherine got a phone call from her neurologist. She said he told her to go back on CellCept at the initial recommended dosage, but to cut her dosage of Imuran in half. She explained that she negotiated with her neurologist and decided to at least postpone taking CellCept again until after she returned from a short trip. Catherine said that it was important to her not to worry about the potential side effects while on her trip.

During the time of the initial interview (the first session out of two), Catherine admitted that she was not certain she wanted to go back on CellCept. She questioned, “Do I respect (my neurologist’s) instructions and go back on the drug? Or do I ask for a new one? Practically, the only option left for me is to go on steroids, and I’ve been against that from the beginning.” She said that the way she saw it is that she had four options:
1. Stay on Imuran and risk that her body could get used to this immunosuppressant or that her body could revert.

2. Wean off Imuran and try CellCept, as the neurologist recommended.

3. Ask for a new immunosuppressant.

4. Try steroids.

At the second session of the initial interview, which occurred after Catherine’s trip, she reported that she decided to follow her neurologist’s instructions to take a smaller dose of Imuran and begin taking CellCept again.

**Influencing Factors**

*Family and Friends*

Catherine’s husband died seven years prior to the interview. About three years ago, Catherine connected with a person in her life, “Colin,” that she described as, “A friend. Well, more than a friend. We are in a committed relationship. He is a partner.” Colin currently lives about a thousand miles from Catherine. In the 1970s, Colin and his wife lived in the same geographic region as Catherine and her husband and the two couples were friends. Catherine said that in the 1980s, she and her husband moved. However, the couples remained friends well through the 1990s. Early in the 2000s, Catherine said that she and Colin each lost their spouses. After grieving, Catherine said that she and Colin, “found a relationship on a new level.” Catherine said they reconnected because she was invited to the baptism of his grandchildren. At that time, “The conversation flowed and the life between us was different,” Catherine explained.

Catherine said that although she spoke to Colin about her medical issues and decisions, the conversations are “more clinical than emotional. If I give him the pros and cons, and tell him what I think I should do, he listens. He won’t confirm or deny what I’ve said. This is helpful,
but he does not give advice…. Males do not do investigating as much as women. Men are warriors. So (Colin) expects me to bring the decision to him and he will support me. I ask him to understand what I’m going through. He supports me in whatever is happening.”

Catherine has one adult child. Her son “Eric” lives across the country. She speaks to him on the phone about three times each week. She said that she is upfront with him about her condition and her decisions, but is not sure how he feels about what she says. “I try to hear things in his voice, but because we are on the phone and I do not see his nonverbals, so it’s hard to tell what’s going through his head,” she explained. She said that she can gather a lot from his voice about his true feelings, so she suspects he is not always upfront with her about how he feels about her condition. Catherine commented that she knew that even when Eric was not always direct with her on the phone about his feelings, she understood that the two of them never took each other for granted.

Catherine noted two other people in her decision-making network who were very influential in her decision: her brother, “Bill,” and her best friend, “April.” She said that both are very protective of her. Catherine said that Bill has educated himself about MG and she can count on him for emotional and objective support. She explained that she depends on April, who worked for the Department of Public Welfare for 30 years and has a background with the aging and medical services, for emotional and objective support as well. According to Catherine, April is not only an instrumental friend who she trusts to tell her the truth, but that April never hesitates to access information for Catherine about MG and other services to which she does not otherwise have access.

Final Decision
As planned, Catherine began taking a smaller dose of Imuran with a CellCept just before returning from vacation. Catherine said that after being on this regime for one week, she had not experienced any side effects. She figured that if she had not experienced the side effects within a week, as she had the first time she took CellCept, that all was well with the treatment regime. However, about 20 days later, Catherine said that she began to experience side effects. Not only did she develop symptoms of tingling and numbness, but she had insomnia for three days. “I was wide awake for three days! I felt like I could run a marthon!” she said. “I had never felt so good!” She said that while she felt terrific, that by the third day she thought, “This can’t be good.” The tingling and numbness increased so she called her neurologist who told her to stop taking the CellCept.

Catherine said she felt disappointed. She wondered if she could take a smaller dosage of the CellCept instead of ceasing the medication entirely, but her neurologist said not to and that they would discuss it at her next appointment. She repeated that had never felt so good and had hoped that she could be put into remission through a similar treatment regimen.

During the final interview, Catherine also mentioned that she had seen a local neurologist to see about the possibility of having a local doctor to ease the health care process and decrease the travel difficulties. The local neurologist told her that if she had been a new patient of his just diagnosed, he would have recommended her to the more renowned muscular dystrophy center for treatment. “Doctor’s around here just don’t see many cases of MG,” she said. She said that the doctor agreed to be her adjunct in case she needed local treatment, but that she would get the cutting edge care with her other doctor. Catherine also said that the local doctor told her not to expect to be in remission from MG. She explained, “I’m very disappointed. (My other doctor) was very optimistic about going into remission. I know I’m lucky to have a mild case of MG,
But I’m still a bit disappointed. I’m trying very hard to keep a positive outlook... I want to be one of the success stories."

Despite the fact that she experienced side effects from taking CellCept again, Catherine said she was glad she made the decision to go back on it. “I’m glad I took it again. I felt better than I had in three years! I don’t want to take it again. Unless something else changes, like I could take a smaller dosage and not experience the side effects. But I don’t know enough about the drugs to know if that would be a good idea,” she said.

**Decision-Making Network Nodes:**

PT – Friend

BB – Adult child

DrK – Physician

DrP – Physician

DH – Sibling

TS – Romantic partner

MDN – Medical Newsletter

MDAW - MDA Website

MB - Medical reference books

GW - Government website - NIH
Figure 27. Decision-making network example 2: Communication frequency between interpersonal nodes.
Figure 28. Decision-making network example 2: Frequency of decision contact between interpersonal nodes.
Figure 29. Decision-making network example 2: Frequency of decision contact with interpersonal and non-interpersonal nodes.
Figure 30. Decision-making network example 2: Average relational quality between interpersonal nodes.
Figure 31. Decision-making network example 2: Relational quality between interpersonal nodes - nonsymmetric.
Figure 32. Decision-making network example 2: Influence of interpersonal and non-interpersonal targets on process of decision-making.
Figure 33. Decision-making network example 2: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 34. Decision-making network example 2: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 35. Decision-making network example 2: Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix I: Decision-Making Network Example 3 – “Lizzie”

Decision: Whether to have sinus surgery

Decision Situation

Lizzie needed to make a decision about having sinus surgery. Her decision was complicated by a complex health background and a distrust of the surgeon who would perform the surgery.

Process of Decision-making

“Lizzie” was diagnosed with Lyme Disease about a year and a half prior to the initial interview. She recalled that it took nine months for the doctors to diagnose her. She said her first symptoms began almost a year prior to diagnosis, just months before her mother passed away. “There was just so much stress at that time and my health just hit rock bottom. The symptoms I had seemed like they could’ve just been related to stress,” she said.

Lizzie described Lyme disease as a condition that weakens the immune system. “If you suffer from a cold or flu, or you’re stressed, the adrenal glands are already weakened, and you can’t fight anything off,” she said of the disease. She reported that she had a lot of fatigue, which lead her to feel depressed for quite some time. However, about six months after she was diagnosed with the disease, she said that she began to feel “considerably better” and that the doctor said she was, “85% cured of Lyme.”

Lizzie said that she remained in “good condition” for about seven months. At this time (about 3 months prior to the initial interview), Lizzie said that she began to experience “typical head stuffiness and a cold.” The head cold moved into her upper respiratory system and so she called her physician. She said she was treated, but received little relief. Lizzie mentioned that she had sinus surgery almost 30 years prior and had not had sinus trouble since then. She figured
that the Lyme disease was complicating her sinuses, so her physician treated her for the symptoms, given that she had Lyme disease. A few weeks passed and Lizzie said she felt no better, so her physician referred her to an ear, nose, and throat specialist. Lizzie said that the specialist told her that she needed sinus surgery and that she was sent to the local hospital to have a CAT scan to confirm that need.

After having the scan, Lizzie said she saw the specialist again and that he told her the scan confirmed the need for surgery “to remove whatever had coagulated back in 1979” when she had her first sinus surgery. The specialist scheduled her for the procedure to occur in about a month. After the specialist left the room and Lizzie was waiting for the nurse to come back with instructions for her surgery, Lizzie said that she heard the specialist talking in another examination room. She said that the patient was a man who “obviously had Alzheimer’s disease or something” and was having trouble talking about his symptoms, so his wife was talking to the doctor for him. Lizzie reported, “I heard (the doctor) tell her, ‘I love to cut! I love to do surgery! But I don’t think that surgery will really help him (your husband). Believe me, if I thought it would help, I would do it because I love to cut!’ and then (the doctor) laughed. It didn’t seem funny to me. He sounded disgusting. And it made me uncomfortable.”

As Lizzie was leaving the examination room with her pre-surgical instructions, she said she saw the doctor in the hall with two patients of his who were also leaving the building. Lizzie said he told her that she wouldn’t be sorry she decided to have surgery and assured her that she would feel much better after it was over. Lizzie said that he stopped the two other patients who were leaving and used them as testimonials to the surgery. The patients, one woman Lizzie described as “around her age” and the other as “significantly younger,” both told her that the
surgery was “great.” Lizzie said she left the office feeling uncomfortable and like the doctor was trying to sell her a surgery and it “didn’t sit right.”

Lizzie said that nevertheless, she prepared for her pre-operation meeting with the anesthesiologist. She prepared her medical history chart for the appointment and updated a list of the medications she was on and the ones to which she had had a negative reaction. She said that as she was going over her list, she realized whenever she went on a medicine or had a new treatment, she had experienced some sort of reaction or complication and had to try something else. Further, Lizzie said that as she went through the pre-surgery material the nurse had given her, she noticed that one of the “side effects” listed about the procedure was blindness. Lizzie said that at this point, she began to seriously wonder if she should have the surgery. She contemplated if the potential complications would outweigh any benefit to having the surgery, especially given that she had Lyme disease and a medical history of complications with the different kinds of anesthetics and medications.

Influencing Factors

Personality

Lizzie described herself as, “The lady who crosses bridges that may never need to be built.” She pointed to her forward thinking and exceptional organization. As evidence, she produced a system of files that incorporated her medical history and future care planning. She recounted that she began her filing system years ago to keep track of information that may be important as she and her husband aged. About a month prior to the initial interview, Lizzie said she saw an advertisement on television for a program that was intended to help older adults prepare for their future care. She explained that she was interested to learn about “the experts’ recommendations” and looked forward to learning how to fill in “any details” she may have
forgotten. Lizzie laughed as she said, “And wouldn’t you know it! They suggested a filing system just like mine!”

*Family and Friends*

Lizzie has been married to “William” for 46 years. She described her relationship with William as close and devoted. She said that William was a very loving husband and a very good listener. His gift of listening was his best form of support for her. However, she said that if she was to have the surgery, she did not think he would be eager to spend time with her at the hospital. She laughed as she recalled how unsettled he was when she birthed their three children.

Lizzie described her relationship with each of her children, two sons and a daughter, as close and stable. She expressed that she loved each one very much. She said that she did not plan on speaking to one of her sons about the sinus surgery because he was not in a position to provide support to her due to his personal life circumstances. She expressed that she did not want to bother her other son or her daughter about the sinus trouble or the possibility of having surgery, but nonetheless would mention it to each of them.

*Religion and Spirituality*

Lizzie reported that she has only been able to remain as positive as she is because of her faith. She explained that throughout her journey with Lyme disease and in considering having sinus surgery, that she has called upon God to guide her and strengthen her. She said that most mornings, she has trouble “getting out of bed and getting going” until she hears a religious radio program by Mike Kellog, a man from the Moody Bible School. Lizzie said that each morning, like a “loving grandfather,” Mike Kellogg gives her much needed “pearls of wisdom” to encourage her to get up and live her life with joy. She said that she listens to his program as she gets ready and after it concludes, she turns it off and prays the rosary. She said that the time she
has in the morning helps her to move forward with her day and gives her the strength and guidance she needs to live fully and make hard decisions.

When asked how she prays and how she listens for guidance, Lizzie replied that she found strength in ritualistic and routine prayers, “like the rosary and going to mass.” She smiled and then said, “And I pray…I always thank God frequently throughout the day. Like on a snowy day if the garage door works, I say, ‘Thank you, God!’ Or if a friend calls when I just needed to hear another voice, I smile and say, ‘Thank you, God!’” After a few moments, Lizzie continued that she prays throughout the day to find out from God, “What’s going on? What’s your plan here God?” and that she always knows what to do or “things just fall into place the way they should.”

Lizzie reported that in the past three months, she has had “a lot of things on (her) mind.” She said that she has had a lot of temptations. “I hear, ‘You don’t really believe that do you?’ and I put it down. Yes, I believe. Sometimes I read that only weak-minded people believe. Well, I guess that’s who I am,” she said.

She repeated that each morning she comes back to hear the program by Mike Kellogg and to say the rosary. She said that each morning she prays, “Come Holy Spirit, fill our hearts.” She explained that prayer is her crutch and that after saying that, she can “get it together. I swear to God it works,” she said. “That’s how I listen. Neat things happen.”

Final Decision

Lizzie decided not to have sinus surgery. The decision was based on many factors, she said. She reported that it began when she felt uncomfortable at the specialist’s office and that the risks associated with the surgery, especially given her specific health background, also gave her
reason to doubt. However, she noted three main reasons that she decided not to have the operation.

First, Lizzie realized that some of the potential complications of the surgery could prevent her from going on a short trip to visit her granddaughter for her birthday. Her granddaughter, she said, had experienced some depression in the past year. Lizzie mentioned that she and her granddaughter had a special connection and that both of them would have been deeply disappointed if Lizzie was unable to be with her on her birthday.

Missing the trip, Lizzie said, would have given her enough reason to postpone the surgery, if not cancel it all together. She said that her conversations with her adult children were most influential. The first conversation was with her son “George.” Lizzie said that when she called George to tell him about the upcoming procedure, he reminded her that she had sinus surgery a few years ago. Lizzie said that she had forgotten about it and asked him how he felt about it now. She said that George told her that his sinuses did not get any better and he was sorry he ever had it. Lizzie figured, “Why bother? The worst case scenario for what they find in there (her sinuses) is cancer and quite frankly, with Lyme disease, I figure that I would die of that before I die of untreated cancer.”

Lizzie said that the fact that her son had the surgery and regretted having it was very convincing. However, she said that her deciding moment not to have the operation was after she spoke with her daughter. “When I told my kids about this, I expected my daughter to come and be with me,” she said. “I would have had the surgery had she come. But she didn’t offer. ‘Keep me posted,’ was what she said. I really would have needed her here to get through it,” Lizzie said. She mentioned that she knew that her son, who lives closer than her daughter, would likely drive down after the surgery if she needed him. She also mentioned that her husband would be
there for her, that, “he’s not fond of medical stuff…he’s just not comfortable with that kind of support and I need support.” She said that she felt isolated without her daughter, but would never tell her that because she did not want her to feel badly. Nonetheless, Lizzie said, “Had she (her daughter) offered to come out, I would’ve had the surgery.”

In the end, Lizzie said it was “a good thing. I’m glad I didn’t go through with it.” In fact, at the time of the final interview Lizzie said that her sinuses had not been bothering her. She reported that she went to have one of her teeth filled at the dentist and that after the Novocain wore off, she had no sinus pain. She said that her sinus trouble was not over then, but that she had not experienced the same kind of pain and pressure after her visit to the dentist. A few weeks later, Lizzie said that she went in for an appointment with her general practitioner about adjusting her medications for Lyme disease. After being put back on a former drug she had been taking for Lyme disease, Lizzie said that her sinuses completely cleared up. She said that all of this reaffirmed that the surgery was not necessary. She reported, “If it is cancer (in my sinuses), it is not a death sentence. I think (the specialist) was overdramatic and I do not think that my old (ear, nose, and throat) doctor would have decided so quickly that I needed surgery.”

When asked what could have made the process of decision-making easier, Lizzie mentioned that she wished that her ear, nose and throat doctor had not retired so early and lamented that there was no other specialist in town except the one she saw. “I would’ve loved (old doctor’s) opinion – the opinion of someone I had an established relationship with… I just would have liked to get a second opinion,” she said.

**Decision-Making Network Nodes:**

DrP – Physician

DrK – Physician
JA – Spouse
JA Jr – Adult child
JAD – Adult child
DA – Granddaughter
AMZ – Friend
MLC – Friend
JH – Friend
PACB – Physician assistant
DL – Acquaintance
LFC – Acquaintance
P1 – Patient at DrK’s office
P2 – Patient at DrK’s office
LR – Support group director
MK – Radio Show Program
MC – Mayo Clinic Website
Figure 36. Decision-making network example 3: Communication frequency between interpersonal nodes.
Figure 37. Decision-making network example 3: Frequency of decision contact between interpersonal nodes.
Figure 38. Decision-making network example 3: Frequency of decision contact with interpersonal and non-interpersonal nodes.
Figure 39. Decision-making network example 3: Average relational quality between interpersonal nodes.
Figure 40. Decision-making network example 3: Relational quality between interpersonal nodes - nonsymmetric.
Figure 41. Decision-making network example 3: Influence of interpersonal and non-interpersonal targets on process of decision-making.
Figure 42. Decision-making network example 3: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 43. Decision-making network example 3: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 44. Decision-making network example 3: Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix J: Decision-Making Network Example 4 – “Valerie”

Decision: Planning for Future Living Arrangements

Decision Situation

Valerie summarized her decision as preparing for her future care and living arrangements. She currently lives in an independent condominium with her husband, but she is not sure what she would do if her health condition worsened or if her husband was unable to take care of her. She mentioned the possibility of moving into a continued care retirement community (CCRC), but that he husband was not interested in inquiring about such arrangements. She noted a myriad of factors that complicate her situation. “I haven’t faced the worse case scenario,” she said.

Decision Process and Influencing Factors

Health Factors

Valerie was diagnosed with Parkinson’s disease nine and a half years ago. As a result, she has experienced much macular degeneration. “The Parkinson’s is moving quickly,” she said and explained that she had experienced considerable weakening of her eyes. In order to see the television, she said she must be within four feet of it. “Soon I will not be able to drive,” she added. Further, many activities of daily living are compromised as a result of Parkinson’s and the macular degeneration. She said that she depends on her husband for help.

Family

Valerie said that her husband of 20 years, “Thomas,” takes very good care of her. She said that with Parkinson’s, she can become “agitated” in daily activities. “Like putting on an earring,” she said. “The atrophy in my hands prevents me from being able to work the clasp.”
Valerie also mentioned that she has edema. She said that her feet and ankles swell and that she must wear stockings that put 20-30 pounds of pressure on her legs. “I do not have much strength in my hands and I cannot put on the stockings. My husband has to do it each morning,” she explained.

Valerie described Thomas as supportive, loving, and very goodhearted. She mentioned that he is not particularly conversational and that it can be difficult to draw him into a conversation about future living arrangements. She said that he did not engage in serious discussion about future planning and that she does not pressure him.

Valerie said that she feared being a burden to her husband. She mentioned that as time goes by, she finds she is winding down and she does not want to be a nuisance. “How, as a person, will I be able to cope without feeling sorry for myself? I do not tell my husband my feelings. He will worry. In my daily life, I am already so dependent (on him). I do not tell him how much I fear the future,” she said.

Thomas is Valerie’s second husband. Her first husband passed away unexpectedly over 20 years ago. She and her first husband had two children – a son and a daughter. Both live in South Africa.

Her son and his wife live in Johannesburg and have two children. Valerie described her relationship with him with a smile saying, “He is such a personality!” She recalled a time when her son, who is a popular television personality in South Africa, came to the United States for his television program and was able to stay with her for five days. “His visit was a turning point for me. He is always so funny,” she said. She mentioned that before his visit, she was beginning to feel down. “His visit helped me to see a purpose in living. He was sheer joy,” she said, smiling.
Although Valerie expressed that she loved her son and being with him very much, she would not depend on him to take care of her. “I know if the chips were down, they (her son and his wife) would take care of me, but they have their own lives. We do not live in each other’s pockets. I do not expect to,” she explained.

Valerie’s second husband has three sons and a daughter. She said that she does not feel comfortable asking her step-children for help.

**Hannah – A Friend and Cultural Connection**

Valerie said that she had a friend, “Hannah,” to whom she was close. Valerie said that Hannah was a supportive friend, but Hannah’s battle with cancer kept Valerie from soliciting too much from her. She said that if she needed to talk with Hannah, she knew she could rely on her, but that she did not implore too much from her friend, as Hannah’s health condition was delicate. “She suffers so much,” Valerie said.

Valerie described Hannah as a particularly cherished friend. When Valerie, who described herself as, “English, from South Africa,” moved to the United States after marrying Thomas, she felt a bit isolated from her familiar culture. She said she was glad to meet Hannah, who is also English. Valerie explained that her friendship with Hannah eased the transition into her new life in the United States and that they have been close ever since.

**Financial Situation**

Valerie reported that her financial situation is “ok,” but that with Parkinson’s disease she cannot get extended medical coverage in a hospital. If she needed to spend time in a hospital, she said that she and her husband could not afford it. She said that she hoped that the money they had would hold out if Thomas passed away and she had to depend on an alternative living situation for care.
Political-Legal Arena

Valerie also reported that living with her son is not a viable option, if only because he resides in South Africa. “I must stay in this country for medical reasons,” she explained. As a United States citizen, Valerie said she would not qualify for medical care in South Africa that would be comparable to Medicare in the United States.

Faith

Valerie is a Roman Catholic. She said her faith is her support and she would never change her religion. Her husband is Lutheran. When they got married, Valerie told Thomas that she would do anything for him except change her religion. “Religion is the one constant thing for me,” she said. “It is deep rooted in me, not acquired. It just is for me.”

When asked how she prayed, Valerie responded that she prayed “little prayers” during the day. She said that throughout the day she thanked God and asked Him for help. “I do not kneel and pray unless I am at church,” she said, “but I pray throughout the day.”

When asked how she listened she replied, “I listen when I get the message.” She smiled and said, “It’s amazing.” She said that even if she did not know or understand something at one time, God proved later that “He knew what he was talking about.” She offered two stories of when she specifically heard a message.

First, Valerie described the time when she and Thomas were in the process of moving into their current home. She said that Thomas was very excited and a “ball of energy” about moving, but that she did not want to move. One day when she and Thomas were outside of the potential new home, Thomas asked Valerie to help her measure the garden area. As she was doing so, she said she was praying and telling God that she did not want to move. Valerie said
that as clear as could be, she heard “But I want you to.” Valerie said that, “God knew. It was all in the scheme of things.”

The second story that Valerie told began when she was in South Africa. She said that she had gone to church and a friend had given her a prayer booklet. The book promised that if said the prescribed prayers for a year that twelve people close to the prayer would go straight to heaven without spending time in purgatory. Valerie said that she tossed the booklet in a drawer for a while, but then at some point was motivated to dig it out and pray the prayers in the booklet. “I said the prayers each day, missing a day or so on occasion, but always going back to say the prayers,” she reported.

Valerie continued the story by saying that she needed to take a plane to England from South Africa. After saying goodbye to her (first) husband and beginning the flight, she took out the booklet and said the last prayer and completed the year of prayer for twelve souls to be taken directly to heaven. Soon after her flight landed in England, Valerie learned that her husband had passed away unexpectedly in his sleep that night.

Valerie said that on her flight back to South Africa after learning of his passing, Valerie was trying to sleep. She said that as she was drifting off to sleep, she heard a female voice laughing and the voice said to her, “I am to tell you he didn’t believe it, but now he knows he was wrong.”

Valerie smiled and explained that her first husband thought that going to church was only for old people and women. Valerie said that one time he mentioned that “maybe there was something to church going,” but he never went to church. Valerie mentioned that he was always full of laughter, and that comparatively, mass was always serious. She said that they used to joke that at the gates of heaven, that he would have them all full of laughter.
Valerie wondered if she had really heard a voice when she was on the plane and began to pray to the Holy Mother Mary for the “sign of the roses” to confirm that she had really heard the voice. Valerie explained, “That’s what Catholics do – to ask for a sign of the roses through the Holy Mother.” However, Valerie took the prayer back. “I realized that the voice was real and I didn’t need a sign,” she said.

Valerie reported that later, at her first husband’s funeral service, her daughter dropped a hymnal. Valerie bent down to pick it up and out of the hymnal dropped a prayer card with a picture of Our Lady of Roses. Valerie explained, “I have never seen a prayer card like that in a hymnal. I had gotten proof that the voice I heard was correct.”

After recounting these stories, Valerie explained that her faith was a major form of support for her in any decision. She said she trusted God to take care of her. “Don’t worry until you have to,” she explained. “Worry is payment due before things go pass.” She said that she has hope and believes that all will be taken care of and that she does not have to worry about her future living arrangements.

Final Decision

At the time of the final interview, Valerie had not made a decision about her future care planning, but reported that the act of speaking about it during the initial interview had motivated her to be more proactive about planning. She explained that she had realized during the initial interview how important Hannah was to her. She said that she called Hannah and that Hannah confirmed that she was analytical and very intelligent and that she would be able to make appropriate plans. As a result, “I’ve opened up about it. Planning hasn’t been as good as I’d hope, but I predict that it will be better in future months. I’m asserting myself more, which will improve the situation and my satisfaction with this process,” she said.
When asked what could have made the decision-making process easier and more satisfying, Valerie replied, “My husband’s attitude. I wish he would listen more and participate more.” She mentioned that seeking marriage counseling would likely help her and Thomas to communicate more, but that engaging in such counseling “isn’t in his nature.”

In summarizing the impact that Hannah and Thomas have on her planning for future care, she said, “I’ve known them more than 20 years. If (Hannah) died, I would be devastated. But if (Thomas) died, I would be completely lost. His loss would be immensely more difficult.”

Valerie closed the final interview by answering the question, “In retrospect, is there anything you would have done differently?” Valerie sighed and summarized the enormous impact that living in the United States has had on her decision. “When (Thomas) and I got married, I told him there was one thing I could never change for him. I told him I would never change my religion. Subsequently, he told me that he thought I was going to say that I would never leave South Africa. He said that if I would’ve told him that, he would’ve done it. He would’ve left his job in the United States and lived there with me,” she explained. She shook her head and said that if she would have known that, she would have liked to stay in South Africa. She explained that as a woman at that time, she felt it was her duty to follow her husband and would have never suggested staying in South Africa. “But I would have liked to be closer to my children. I miss them and he isn’t as close to his children here in the U.S. anyway,” she said. However, she said that she knows he would not have been as happy in South Africa. But it would have made her health care planning easier now. She said in closing, “Just wish for good health and the courage to cope when you cannot deal with things.”

**Decision-Making Network Nodes:**

E – Friend
Figure 45. Decision-making network example 4: Communication frequency between interpersonal nodes.

Figure 46. Decision-making network example 4: Frequency of decision contact between interpersonal nodes.
Figure 47. Decision-making network example 4: Frequency of decision contact with interpersonal and non-interpersonal nodes.

Figure 48. Decision-making network example 4: Average relational quality between interpersonal nodes.
Figure 49. Decision-making network example 4: Relational quality between interpersonal nodes - nonsymmetric.

Figure 50. Decision-making network example 4: Influence of interpersonal and non-interpersonal targets on process of decision-making.
Figure 51. Decision-making network example 4: Influence of interpersonal and non-interpersonal targets on the decision outcome.

Figure 52. Decision-making network example 4: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 53. Decision-making network example 4: Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix K: Decision-Making Network Example 5 - “Roger”

**Decision:** Course of action for dealing with respiratory problems

**Decision Situation**

After moving to a different geographic location about a year prior to the initial interview, Roger faced a series of respiratory-related problems. After his primary care physician treated him for the issues to no avail, Roger needed to make a decision about an appropriate course of action to deal with the problems. He knew he had the option of seeing an allergist or a pulmonary specialist, but he had little faith that a specialist could aid him. He also knew that the problems were brought on by the new environment he lived in and thus he had the option moving out of the area. He also could choose to live with the problems.

**Process of Decision-making and Influencing Factors**

According to Roger having serious medical problems in his youth and seeing doctors for minor ailments for over his lifetime in various medical systems taught him how to navigate the health care system. At 16 years of age, Roger had polio and lost the use of his legs. Then at 22, Roger was involved in a serious car accident and spent 5 months in rehabilitation. “I learned early to negotiate institutions so I could get my way,” he said.

Roger reported that despite the serious health problems he had as a young man, he has been able to enjoy excellent health for most of his adult life. During the times that he was treated for minor ailments, such as having his gall bladder removed, his experiences with health care providers and health care institutions were wholly positive. Roger said that he has always had “fabulous doctors and world-class insurance,” which “gives a person a lot of power in the medical system” in the United States. Having lived in Spain, Germany, and Norway, Roger said that he has an appreciation of the variance in the quality of health care that exists throughout the
world and what kind of excellence is possible. As a result, he said he knows how to work within
the health care system to obtain high quality care. For example, he recalled that he has never had
to wait for care in during his adult life and he always finds the best doctors. “I don’t end up like
a lot of people. I get what I want when I want it. I get connected with the best doctors. I get
appointments when I need them. I can e-mail my doctor and I get a personal response within 24
hours,” he said. He laughed as he said that having good medical care is all about who you know.
“I’m shameless about my connections,” he said. He explained that he wants the best in all areas
of the health care system and uses his connections to get it. “I know hospitals are not customer
driven, so I use my connections to get what I want,” he said.

About a year prior to his initial interview, Roger moved to a new city. He said that after
he moved he was suddenly attacked with various respiratory issues. He reported that asthma,
thrush, sleep apnea, and general bronchial troubles came upon him very suddenly. He sought
help from his primary care physician, but the various treatments the doctor prescribed failed to
bring about lasting results. His physician suggested that the problem might be some sort of
allergen in his environment that was not present in his prior locations. Roger said he was faced
with a serious decision of how to cope with his condition. He was not certain if he should see an
allergist, a pulmonary specialist, or if he could consider other options, such as moving.

During the course of the decision, Roger discovered that his new home had mold. The
manager of the building agreed to move him to a new floor, but Roger knew that this would not
solve the problems entirely. He had lived in the new city for over a year and had noticed that the
severity of his condition varied greatly with the weather and humidity. He concluded that the
mold was certainly a complicating factor, but that moving to a new home in the same city would
not solve the problems.
Roger said that his adult children, N, C, JMJ, and L, were concerned about him, especially when they realized how seriously his respiratory issues had worsened and they found out about the mold in his home. N, his son, was especially vocal and was insistent on him moving out of his current home. Roger said that N called his sisters to inform them of the health issues that his father was having. N asked JMJ, who is perceived by the siblings to have greater pull with their father, to “talk some sense” into him. Roger laughed as he remembered that JMJ’s response to N was to question what she could do about it. According to Roger, JMJ knows that he will take care of himself and that his adult children can do nothing to persuade him. “They all know that,” said Roger.

The option of moving again surfaced during this time as well, but Roger said that leaving the area was not an option. “I like it in (new city) too much,” he said. As a result, Roger was left with the option of seeking a second opinion or doing nothing. Roger did not have high hopes for an appointment with a specialist. He said was considering going to an allergist, but was not committed. “Many people think doctors are gods. Most are just average,” he said. Roger said that he was not optimistic that a specialist would tell him that anything else could be done. “I may end up being told that it wouldn’t get better. That’s okay. That’s what it is. My feelings are irrelevant,” he said. He went on to explain that not feeling well is part of life. He quoted Winston Churchill as saying, “Much of the world's work is done by people who don't feel well.” He explained that he may just have to learn to live and work with the respiratory issues.

At the time of the final interview, Roger said that during his decision-making process, a friend introduced him to D, another person who had suffered from polio in his youth. D mentioned that he saw a pulmanologist who specialized in post-polio care. D suggested that
Roger see him, implying that there may be a connection between Roger’s bronchial issues and polio.

**Final Decision**

Roger decided to have an appointment with the pulmonary specialist D recommended to him. After seeing the doctor, Roger reported that he was very impressed with his appointment with “the reining post-polio expert in the United States, if not in the world!” He said that he discovered that all of the respiratory problems he had been experiencing could be a direct consequence of polio. He explained that a small group of muscles in his chest above his collar bone were probably affected during the treatment he had for polio. Roger said his other doctors had not asked about how he was treated for polio, but the pulmonary specialist had made the connection immediately. Roger said that the pulmanologist would be running more tests. At the time of the final interview, he was very pleased with the second opinion. “I’d been tested for post-polio syndrome,” he said, “But I was told I don’t have it. This guy may be able to shed some light on all of this.” Roger said that he had faith that this doctor could be able to help him. “I expect that my quality of life to improve significantly,” he said, “and I will negotiate every step of the way.”

**Decision-Making Network Nodes:**

Dr. O - Physician

PC - Dating partner

D - Friend/Acquaintance

JMJ - Adult child

C - Adult child

N - Adult child
Figure 54. Decision-making network example 5: Communication frequency between interpersonal nodes.
Figure 55. Decision-making network example 5: Frequency of decision contact between interpersonal nodes.
Figure 56. Decision-making network example 5: Frequency of decision contact with interpersonal and non-interpersonal nodes.
Figure 57. Decision-making network example 5: Average relational quality between interpersonal nodes.
Figure 58. Decision-making network example 5: Relational quality between interpersonal nodes - nonsymmetric.
Figure 59. Decision-making network example 5: Influence of interpersonal and non-interpersonal targets on process of decision-making.
Figure 60. Decision-making network example 5: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 61. Decision-making network example 5: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 62. Decision-making network example 5: Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix L: Decision-Making Network Example 6 – “Theresa”

Decision: Care Following Surgery

Decision Situation

Theresa was faced with the decision of choosing a form of care giving after an emergency operation.

Process of Decision-making and Influencing Factors

Theresa reported that she had always had very good health when she faced an emergency health situation. She had not been on any medication or had any ailments. “All of this hit me very suddenly. I watch what I eat. I thought I was in good shape. I go to the gym almost every day. I thought I was in good health,” she said.

She explained that right before visiting her brother, who lives in a different state, she had gone to a Pilates class at her gym. She was in pain and thought that she had pulled an abdominal muscle during class. She left for the 7 hour bus ride in a bit of pain and when she returned four days later, she was in a great deal of pain. When her son picked her up from the bus station, she asked him to take her immediately to the emergency room.

Theresa does not remember very much about the time after she arrived at the hospital. She figured that she must have been put on heavy pain killers and lost two days of memory while she was there. She remembers waking up and being told that she had an appendectomy. The burst in her appendix was so severe that the doctors had to remove part of her colon. “I was disoriented when I came around. By the third day, I was in so much pain, I asked God to take me. He wasn’t ready,” she explained.

Theresa said she that during the time in the hospital, she was on an IV that pumped glucose into her body. When she was released from the hospital, she was 45 pounds heavier than
when she entered. She was told that she needed to stay at a rehabilitation center in order to get up and moving again and drain all of the fluid. She was in the rehabilitation center for 9 days. “They finally got a lot of the liquid out of me and I had to learn how to walk up steps. I could not leave until I was able to walk up the steps again,” she explained. During the time at the rehabilitation center, it became clear that she would need extensive care after she left. She developed a condition she called “weeping legs” and explained that all of the fluid that her body retained would gush through blisters in her legs. Her condition needed to be attended to regularly. She said she knew she had a choice of several options for care after finishing rehab. She said she asked her son to take care of the arrangements.

Final Decision

After talking with her son, she decided that having homecare was the best option because her son recommended it. Theresa said she talked to her son about the arrangements and trusted his decision. “I’m glad he chose homecare so I could be in my own apartment,” she said.

Theresa said that the homecare specialists came in three days a week for ten weeks. “They kept adding time to it because the blisters weren’t looking good with all of the fluid coming through. At first, they gave me six weeks of care, then added on 4 weeks.” During this time, she reported that the homecare specialists dressed legs and gave her exercise that helped. All of the liquid put pressure on lungs and heart, which gave her challenges in terms of breathing and walking.

Theresa attributed the decision-making mostly to her son. She said she trusted her son to tell her everything that she needed to know. Her son is her only survivor. She lost her husband a year prior to the appendectomy and her younger son had passed away 18 years prior. Of her older son she said, “He is my rock. I put all my trust and faith in my son.”
Decision-Making Network Nodes:

MV – Adult child

Figure 63. Decision-making network example 6: Communication frequency between interpersonal nodes.

Figure 64. Decision-making network example 6: Frequency of decision contact between interpersonal nodes.

Figure 65. Decision-making network example 6: Frequency of decision contact with interpersonal and non-interpersonal nodes.
Figure 66. Decision-making network example 6: Average relational quality between interpersonal nodes.

Figure 67. Decision-making network example 6: Relational quality between interpersonal nodes - nonsymmetric.

Figure 68. Decision-making network example 6: Influence of interpersonal and non-interpersonal targets on process of decision-making.

Figure 69. Decision-making network example 6: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 70. Decision-making network example 6: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.

Figure 71. Decision-making network example 6: Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix M: Decision-Making Network Example 7 – “Mason”

“Mason”

Decision: Heart Surgery

Decision Situation

Mason has a history of kidney and heart problems. Treatment for his heart condition is affected by his kidney condition. Although his doctors have recommended a course of action to treat his kidney condition in a way that would allow him to have heart surgery, Mason is unsure if he wants to engage in the treatment because the treatment for his kidneys would affect his quality of life. Further, he is hesitant to have heart surgery because of the inherent risk in the procedure; his wife, who also has health problems, loses health insurance benefits upon his death.

Process of Decision-making and Influencing Factors

At the time of the entail interview, Mason had recently been hospitalized for heart problems. He said that his cardiologist ordered an EKG. Mason said that after receiving the results of the test, the cardiologist prepared him for invasive heart surgery to “put in stints” in his heart. However, the cardiologist who ordered the surgery was not aware that Mason had a kidney condition which would disqualify him for the surgery. Mason emphasized that after the cardiologist found out that he had kidney problems, the cardiologist cancelled plans for the surgery because the dye used to trace the blood flow for placement of the stints can stop kidney functioning.

Mason said that he had been seeing a kidney specialist because his kidneys function at only 15%. Mason explained that dialysis would be a consideration, making heart surgery feasible and increasing kidney function. However, he said he would rather not go on dialysis
because it would impair the quality of his life. He noted that he is more afraid of dialysis than death. Mason said that his kidney specialist has recommended that he have dialysis and has told him that he needs to take care of his heart. Mason explained that his kidney specialist told him that if his heart goes, he goes. Mason, however, said that he feels that if his kidneys go, “there’s no use living.”

An Active Lifestyle

At the time of the initial interview, Mason reported that he was putting off making a decision about his treatment by taking blood thinners, which increase the chances of severe bruising and bleeding from minor injuries. Several weeks ago, Mason said he spent a “guy weekend” with his sons and grandsons. They traveled out into the wilderness staying in a cabin and spending time together hiking and fishing. During their weekend, Mason said he slipped on a stairway and fell into a pile of rocks. He bled profusely and his leg, side, and face were badly bruised. “I was pretty colorful,” he said. Fortunately, he and his family were not too far from a hospital. He went to the emergency room and spent several house having tests and being bandaged up.

Insurance and Family

Another factor Mason noted as part of his decision-making process is insurance coverage for his wife. Mason considers his insurance through his former employer as excellent. Mason said that his wife is covered under his insurance as long as he is alive. His wife is 81 and has serious health problems.

Mason reported that his family has mixed feelings about his decision. Most importantly, his family wants him to live. He said that they do not agree about whether his quality of life
would decrease if he underwent dialysis. He said that one of his sons feels strongly that he should choose dialysis.

Quality of Life

Although Mason felt that his decision is serious, he said, “I’m not worried about it. No pressure on me. I think what will happen will happen.” He considers the quality of his life at the time of the initial interview to be good. He said that the heavy doses of medication he is taking make him tired and that he sleeps for twelve to fourteen hours each day. Nevertheless, he still enjoys his computer and his books and his interest in aircrafts. He and his wife still travel. He said he is not ready to make a life-changing or life-threatening decision.

Final Decision

Six weeks after the initial interview, Mason said he had not made a decision as to whether to have heart surgery and he was not certain when he would make the decision.

Decision-Making Network Nodes:

RB – Daughter-in-law
BB – Adult child
AR – Nurse
FGB – Physician
HAM – Physician
SMH – Physician
EB – Spouse
Figure 72. Decision-making network example 7: Communication frequency between interpersonal nodes.
Figure 73. Decision-making network example 7: Frequency of decision contact between interpersonal nodes.

Figure 74. Decision-making network example 7: Frequency of decision contact with interpersonal and non-interpersonal nodes.
Figure 75. Decision-making network example 7: Average relational quality between interpersonal nodes.

Figure 76. Decision-making network example 7: Relational quality between interpersonal nodes - nonsymmetric.
Figure 77. Decision-making network example 7: Influence of interpersonal and non-interpersonal targets on process of decision-making.

Figure 78. Decision-making network example 7: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 79. Decision-making network example 7: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 80. Decision-making network example 7: Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix N: Decision-Making Network Example 8 – “Julia”

Decision: Plans for future living arrangements

Decision Situation

Julia’s husband passed away five years prior to the initial interview. Her husband’s passing caused her to consider the reality that she would not be able to live independently in her own home. Although she reported that her health is good overall, she has diabetes and reported concerns about living alone because of her health and age. As a result, since her husband’s passing, she has looked into Long Term Care (LTC) insurance and other types of living arrangements. About nine months before the initial interview, Julia said that her dog died and that “although it probably sounds silly, I’ve felt more alone since he died and I’ve been thinking about my living arrangements more seriously.” At the time of the initial interview, Julia said that her upcoming 74th birthday had motivated her to look at LTC insurance policies, as she knew that her insurable age would be changing upon her birthday and would affect her premium rates.

Process of Decision-making and Influencing Factors

Continuing Care Communities in Her Daughter’s Town

Julia said that shortly after her husband died, she began to think about her future living arrangements. She began talking to people and gathering information on LTC insurance and the kinds of retirement communities she might have to move into. She said that she did not seriously consider any specific course of action. Three years later, Julia said her brother passed away after residing in a senior living home, which caused her to start thinking about future planning once again. Her daughter “Janine” had recently accepted a job in a new town, so when Julia went to visit her for the first time, they dropped by a Continuing Care Retirement Community (CCRC) in her daughter’s new town. Julia said that she was interested in seeing this particular CCRC
because her brother had been impressed with a similar “Quaker” community in a different state. Julia said that was able to see the basic facilities and the kind of living space that she would have there and described it as “nice.”

A few months later, Julia and her other three daughters visited Janine for the holidays. They made an appointment to tour the same CCRC and everyone agreed it was a “nice place,” according to Julia. However, she said that she was not ready to make a decision about moving.

Another nine months passed without much serious consideration of her living arrangements, when Julia’s dog passed away. With her pet’s passing, Julia said that she was more open to the possibility of moving, so she went to visit Janine again. During this visit, Julia said that she and Janine drove through a different CCRC. Julia said that at this time, she still was not ready to make the decision to move to her daughter’s town and into a CCRC.

*Julia’s Home and the Possibility of Investing in Land in Her Town*

Julia said that after visiting the various CCRC’s in her daughter’s town, “I was torn. I love my house and the people I live around. It’s an 1850’s farmhouse overlooking a lake and I like it here a lot.” Julia described how much she enjoyed living in her area and her neighbors. She mentioned that a friend of hers was selling a nearby waterfront and that she had considered buying the land and staying to manage the property. “It would be a good investment,” Julia said. “The waterfront is beautiful and it would be possible to sell it for more someday if I needed the money. Or if I just live here forever, my daughters could have the money,” she said.

*The Possibility of Long Term Care Insurance*

Several months after visiting the third CCRC in her daughter’s town (two months prior to the initial interview) Julia said that she attended a workshop on LTC insurance through a local university. Julia said that she received important information at the workshop and began to more
seriously consider the option of LTC insurance. The following month, Julia said that she went to her back to make some changes with the placement of her finances and that while she was there, she spoke to the bank’s LTC specialist. Julia said that she decided to consider some of the programs offered at the bank, but made not commitments at that time.

The following month (one month prior to the initial interview), she visited her daughter Janine and toured a third CCRC in her daughter’s town. Julia said that the third CCRC was “fine,” but she was not sold on the idea of moving into a CCRC in the town where Janine lived. She said that she wondered what would happen if Janine’s work would move her to a different geographic location and did not want to live in a CCRC in an area where she did not know anyone.

Two months later (the same month as the two sessions of the initial interview), Julia visited with the LTC insurance sales representative. With her 74th birthday approaching, Julia has decided to proceed with drawing up a policy for LTC insurance. At the time of the initial interview (second session), Julia had described the process as complicated and she was still trying to figure out the effect that differing state laws and policies played in the distribution of benefits. At the time of the initial interview, Julia said, “I’m still not sure what points to put in the policy and what states I could potentially reside in if I needed long term care. That’s important because I would like to live close to my daughters if I am not going to be able to live at home. I’m not really sure how all this will turn out, but I know I need to make a decision because the policy will be more expensive once I turn 74. Oh my, is it expensive.”

Health
Julia has diabetes. Overall, she considers her health to be very good and she said that her diabetes was “not bad, but could get expensive.” She said she can take care of her home, although she has “a cleaning lady to come in and help and someone do the lawn care.”

**Final Decision**

Julia decided to take out a Long Term Care insurance policy. At the time of the final interview (first session), her insurance salesperson had written the policy and Julia had already had a phone interview with the underwriting company. “It was demeaning,” Julia said. “They were asking me questions about what year it was and who was the president.” Julia said that she got off the phone feeling badly about her age and thought how awful it would be to be disqualified, given the questions that were asked. Subsequently, Julia was qualified for the insurance and made the cutoff date of her 74th birthday. At the time of the first session of the final interview, she was waiting for the policy to be delivered.

Julia noted several major reasons that she chose to take out the LTC policy instead of moving to a CCRC. The main reason is that taking out the policy allows her to maximize her time residing in her own home. “I want to stay in my home as long as possible,” she said. “The policy allows me to have in-home care and that would be best. It also covers for community day care. And if I become completely incapacitated, I will be covered for assisted living,” she said. “Living at home is best for now. My home is older. I know I still have things I need to do for it. As long as I can have people do some of those things for me, I think I am okay living here.”

Although she said she is confident that LTC insurance meets her needs in terms of maximizing the length of time she will be able to stay in her own home and minimize the time she spends in assisted living, at the time of the first session of the final interview, she said that she is having second thoughts. “I would have liked to take a step back and had a chance to
further process and look at things, but I had the time pressure of my birthday,” Julia said. She mentioned that since the policy was written she had seen a television program and read a booklet published by AARP that covered important considerations for taking out a LTC insurance policy. One consideration that she said she became aware of is that in-home care may only be provided if the insured is living in the same home he or she was living in at the time the policy was written. “So I’m not sure if the policy would cover my care if I decided to move in with my daughter or something,” Julia said. She also mentioned that she learned that if one wants in-home care, one must choose a person associated with a particular agency and not someone chosen independently. “My friend has a really good person come to take care of her in her home and I know she’s independent – not part of an agency. If I had my choice, I would choose her and now I’m not sure if my policy will cover her,” Julia explained.

Julia said that she has 30 days from the time the policy is delivered to make changes or cancel the policy. At the time of the first session of the final interview, Julia said she intended to speak to her representative to modify the policy. “I’ve been thinking about it and I may have to tweak the policy a bit,” she said.

Julia described the process as complicated. She mentioned that it was difficult to find the right policy for the right price. “It is expensive,” she said, “and it appears that it will be even more expensive to tweak the policy to allow me to be covered for in-home care even if I move in with my daughter.”

When asked what advice she would give someone who is in a similar situation making a similar decision, Julia said that it is important to be educated and to talk to family a lot. “I did a lot of homework,” she said. “I went to the LTC workshop, which was very good. I looked into a lot of places and read a lot. I really did my homework. I should have done more.”
**Decision-Making Network Nodes:**

GT – Adult child

ST – Adult child

JT – Adult child

JOE – Sibling

JHT – Brother-in-law

MAT – Mother-in-law

MC – Friend

LT – Friend

AT – Friend

BT - Friend

PC – Long term care workshop facilitator

SS – Long term care association agent

LTC – Book about long term care

NY – Booklet about long term care

AARP – AARP publication on long term care insurance

CA – A publication by a department of aging on long term care insurance
Figure 81. Decision-making network example 8: Communication frequency between interpersonal nodes.
Figure 82. Decision-making network example 8: Frequency of decision contact between interpersonal nodes.
Figure 83. Decision-making network example 8: Frequency of decision contact with interpersonal and non-interpersonal nodes.
Figure 84. Decision-making network example 8: Average relational quality between interpersonal nodes.
Figure 85. Decision-making network example 8: Relational quality between interpersonal nodes - nonsymmetric.
Figure 86. Decision-making network example 8: Influence of interpersonal and non-interpersonal targets on process of decision-making.
Figure 87. Decision-making network example 8: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 88. Decision-making network example 8: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 89. Decision-making network example 8: Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix O: Decision-Making Network Example 9 - “Scott”

Decision: Treatment for Prostate Cancer

Decision Situation:

After Scott’s primary care physician diagnosed him with prostate cancer, Scott needed to make a decision about his treatment. He was aware of the various treatment options for his condition and reported a deliberate process of information gathering and decision-making about his treatment.

Process of Decision-making and Influencing Factors

Scott, who at the time of the initial interview had recently turned 60, said that he knew that as he aged he would be more susceptible to health issues. He said that his age and his upcoming retirement, which would change his health care insurance benefits, motivated him to make an appointment with his primary care physician (PCP) to have a full physical examination. After his appointment, Scott was diagnosed with prostate cancer. At the time of his diagnosis, his PCP noted various options for treatment. Scott said that out of the options presented by his PCP, he considered the following: do nothing, have a surgical operation, receive radiation treatment, or have an implant. Scott said that his PCP suggested that he visit an urologist in order to gather information to make his decision. Scott said he met with an urologist, who ordered additional tests. The urologist also recommended that he see an oncologist, which Scott did. Based on the results of the tests the urologist ordered, the oncologist helped Scott to narrow down his treatment choices to having a surgical operation or undergoing radiation therapy. The oncologist gave him a short book to read on his condition that outlined his treatment options. Subsequently, Scott saw a radiologist to find out more information about radiation therapy. After the visit, Scott went back to seek advice from the oncologist. “The oncologist was a
neutral party,” Scott reported. The urologist would be doing the surgical operation and the radiologist would have been doing the radiation, so Scott said he trusted the oncologist to give him unbiased advice about which treatment would be best for him.

During the process of decision-making, several of Scott’s friends heard about his diagnosis. Two of them, BRK and BRB, who also had prostate cancer, spoke with him about their experiences and how they went about their treatment procedures. Scott said that he appreciated their concern and support during his decision-making process.

**Final Decision**

Scott decided to have a surgical operation. He explained that he made the decision the way he had been trained to make decisions as an engineer. He explained his thought process: “If you go in and have an operation, they will take everything out. If you just have radiation, there’s a chance that not everything will be removed and you may have to go back and do more. I wanted to just have one thing done and know that the problem was taken care of.” He said he knew that the surgical procedure might result in other “side effects,” but that he did not want to go through the radiation procedure only to have to do the surgical removal later anyway.

He said that his physicians, particularly his oncologist, were most important in his decision-making process. He noted that the book his oncologist gave him was important as well. He said that having references to consult about his health care is important to him, but he wants his physicians to approve the information. He said he muddles through some of the information, as he is not a medical expert, but that he consults his physicians if he has questions about the information. He expressed discomfort about using the Internet for information. “I trust my physician and specialists to give me appropriate information, not the Internet. The book (given
by the urologist) helped me get comfortable with the uncertainty I had about the (prostate) cancer.”

**Decision-Making Network Nodes:**

DrUR – Physician  
DrRAD – Physician  
DrONC – Physician  
BRK – Friend  
BRB – Friend  
BK - Book  

Figure 90. Decision-making network example 9: Communication frequency between interpersonal nodes.
Figure 91. Decision-making network example 9: Frequency of decision contact between interpersonal nodes.

Figure 92. Decision-making network example 9: Frequency of decision contact with interpersonal and non-interpersonal nodes.
Figure 93. Decision-making network example 9: Average relational quality between interpersonal nodes.

Figure 94. Decision-making network example 9: Relational quality between interpersonal nodes - nonsymmetric.
Figure 95. Decision-making network example 9: Influence of interpersonal and non-interpersonal targets on process of decision-making.
Figure 96. Decision-making network example 9: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 97. Decision-making network example 9: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 98. Decision-making network example 9: Frequency of decision contact, direction of influence, relational quality, target decision knowledge, and influence of interpersonal targets on the decision-making process and outcome.
Appendix P: Decision-Making Network Example 10 - “Margaret”
Decision: Surgery for Incontinence

Decision Situation

Margaret said she began experiencing “slight incontinence” for about a year and a half prior to the initial interview. “I’m not incontinent, but when I have to go, I have to go right away,” she said. Margaret explained that about a year ago, she began to wonder if there was anything that could be done for the problem. She spoke to her primary physician, who prescribed medicine for her. At the time, the physician mentioned that if the problems continued or worsened, that there may be other procedures that could help. Since speaking with her primary physician, Margaret said that she had spoken to two individuals that made her seriously consider having surgery for incontinence.

Process of Decision-making and Influencing Factors

Conversations with Two Friends

Margaret said that quite randomly, the subject of incontinence and surgery occurred in two conversations. First, Margaret had a conversation with her friend, “Dana,” on the phone. Dana mentioned to Margaret that she had surgery for incontinence. Margaret said that she was surprised and then asked how it went. Margaret reported that Dana was “so, so glad” that she had the surgery. Margaret said that after her phone conversation with Dana, she was seriously considering requesting a surgical procedure to help her incontinence.

Margaret reported that not long after her conversation with Dana, she called her brother. When she told him that she was considering having a surgical procedure for the incontinence, she told her that his wife, “Jillian,” has just had a similar procedure. Her brother passed the
phone to Jillian and Margaret said she learned that Jillian was also very glad that she had the procedure. “She told me that she only wished she had done it sooner,” Margaret said.

Margaret said that after her conversation with Jillian, she thought about what she had told her and subsequently called to talk to her again about the surgery. “(Jillian) is very reserved, so we didn’t talk very long, but she said that she was still very glad she had the surgery,” Margaret reported.

As a result of the conversations, Margaret decided to see a doctor at a well-known clinic in a city nearby to talk about having a surgical procedure. She said she called her primary physician to get a referral, which she got, and made the appointment.

**Family**

As mentioned previously, Margaret has a brother. She reported that she talks to him frequently, but did not use him for advice in making the decision about having surgery. “He was helpful to refer me to his wife, but otherwise I didn’t talk to him about the incontinence. I don’t like to talk about it much,” Margaret said.

Margaret also has four children. Only one daughter, “Caroline” lives in the same town as her. Margaret mentioned that she did not see Caroline as frequently as she would like. According to Margaret, Caroline was often overburdened with work. “She’s overworked and a perfectionist. Not a good combination. Anyway, I don’t want to burden her, so I try not to bother her too much,” she explained. Nonetheless, Margaret said that because she could not drive due to cataracts, she asked Caroline to take her. Her daughter said that she would, but the day before the appointment, Caroline was busy and could no longer take her. Margaret said that she was so intent on making it to the appointment that she hired a car and driver from a limousine
service to take her. “It was actually pretty fun,” Margaret said. “The driver said that the price included two passengers, so I invited a friend to come with me!”

Religion and Spirituality

Margaret, a Roman Catholic, mentioned that she prayed before she went to the appointment with the specialist. “I pray for guidance and to go the right direction, to make a good decision,” she said. “I pray for what I want, but that no matter what happens, He will give me the grace to cope.” When asked how she prayed, Margaret talked about how she didn’t enjoy repetitious prayer or praying to saints “like other Catholics do a lot. I go right to the top. I speak to God as a friend,” she explained.

When asked how she listens and understands direction from her prayer life she replied, “Things seem to evolve. You know someone’s listening. He guides me gently and fills me with peace. God just takes care of things. He lifts me up and fills me with peace.”

Final Decision

Via a limousine service, Margaret made it to her appointment with doctor at the well-known clinic. After evaluating her at her appointment, he concluded that she did not need to have surgery for the incontinence. According to Margaret, her condition was different from that of her friends and that having a surgical procedure would likely aggravate the condition instead of helping.

Margaret said that the doctor gave her a different medication, but that she was not sure that she would take it. “The side effects were constipation and blurred vision. I’m not interested in that. But I have diabetes and one of the side effects of the medicine I take for that is diarrhea, so maybe the new medicine will even out my system,” she said. As a former nurse, Margaret said that she tends to “evaluate much” on her own. “But my own research cannot match what a
specialists knows,” she admitted. In fact, when asked advice she would give someone in a similar situation making a similar decision, her response was, “Go to a doctor who is a specialist in the field.” She said that she wished there was a local specialist because transportation was a problem.

Although she is satisfied with the decision not to have surgery, she concluded, “It’s an awkward situation. Incontinence limits where you can go and what you can do. I wish there was something more I could do.”

**Decision-Making Network Nodes:**

AD – Friend

GM – Sister-in-law

DrR – Physician

DrK – Physician

W – Physician practice website

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Figure 99. Decision-making network example 10: Communication frequency between interpersonal nodes.
Figure 100. Decision-making network example 10: Frequency of decision contact between interpersonal nodes.
Figure 101. Decision-making network example 10: Frequency of decision contact with interpersonal and non-interpersonal nodes.

Figure 102. Decision-making network example 10: Average relational quality between interpersonal nodes.
Figure 103. Decision-making network example 9: Relational quality between interpersonal nodes - nonsymmetric.

Figure 104. Decision-making network example 10: Influence of interpersonal and non-interpersonal targets on process of decision-making.
Figure 105. Decision-making network example 10: Influence of interpersonal and non-interpersonal targets on the decision outcome.
Figure 106. Decision-making network example 10: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
Figure 107. Decision-making network example 10: Frequency and influence on interpersonal and non-interpersonal targets on the decision-making process and outcome.
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Abbreviated Curriculum Vitae

Educational History

Ph.D.  Communication Arts and Sciences
The Pennsylvania State University, Expected December 2008
Committee:  Jon F. Nussbaum (Chair)
            Dennis Gouran, Roxanne Parrott, Rachel Smith, and Roger Finke
Dissertation:  Health Care Decision Making at the Latter End of the Life Span

M.A.  Speech Communication
The University of Illinois, Urbana-Champaign, January 2001
Committee:  Ruth Anne Clark (Chair), Noshir Contractor, and Robert Husband

B.A.  Speech Communication
The University of Illinois, Urbana-Champaign, January 2000

Publications


Convention Presentations/Panels


