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Decision Making among Older Adults with a Limited Prognosis

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Decision Making Among Older Adults with a Limited Prognosis

by

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DISSERTATION

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Dedication

I dedicate this work to my parents, Joanne and Rafael Romo. Though they did not live to see me achieve this goal, they were instrumental to setting me on the path to a career in nursing and to seeking an answer to the question: “How can we help older adults receive the palliative care they need and deserve at the end of their lives?”

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I need to acknowledge the influence of Cicely Saunders, the founder of the modern hospice and palliative care movement, on both my personal and professional life. She had vision to see that dying patients deserved better and the courage to make it a reality. She once exhorted healthcare professionals to impart this message to dying patients: “You matter until the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.” I take this as a motto for my own work.

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Note

Some of the content of this dissertation has been presented at national conferences. An early draft of Chapter 2 was presented as a poster at the Leadership Conference of National Centers of Gerontological Nursing Excellence, San Diego, CA, November 2012. An early draft of Chapter 4 was presented as a poster at the Scientific Meeting of the Gerontological Society of America, New Orleans, LA, November, 2013.

Abstract

Decision Making among Older Adults with a Limited Prognosis

Rafael Diaz Romo

Decisions near the end of life must be made at a time of great emotional upheaval and rely on knowledge that few people possess outside of healthcare. Complicating this is that choices appear to change as older adults become more ill and approach death. Thus, healthcare providers must help older patients navigate this complexity to make decisions that are consistent with their priorities and wishes. Research examining end-of-life decisions has been descriptive in nature, looked at decisions from among younger adults, or examined decision making among those with cancer diagnoses. In addition, the research often focused on prospective decisions among healthy elders. Much less is known about decision-making processes used by older adults with a limited prognosis.

The aim of this dissertation was to examine decision-making processes among older adults with a limited prognosis who were in the midst of making significant healthcare decisions. The goal was to explore the phenomenon from within the context of the end of life to bring forth the missing voice of these elders.

Twenty community-based adults (13 men, 7 women, ages 67-97) with a prognosis of less than 12 months were recruited through the San Francisco Veterans' Administration Medical Center and the University of California, San Francisco, Division of Geriatrics. One-on-one interviews were conducted in participants' homes using a semi-structured interview guide. Interviews were recorded and transcribed verbatim. Grounded theory was used to analyze the interviews to allow themes and concepts to emerge organically from the data.

Two main themes emerged: *maintaining a sense of control* and *decision making in the* *context of ambiguity*. Participants rarely discussed actual decisions and preferred to delegate end-of-life decisions. By using different approaches to express their priorities and goals, they maintained the *sense* of control without being *in* control. The actual context of decisions could not be understood a priori, which resulted in uncertainty and ambivalence that influenced how decisions were made.

By understanding how older adults approach late-life decisions, healthcare providers can better support their patients as they make different choices and help guide patients to choices that are consistent with their stated preferences and priorities.

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CHAPTER ONE

INTRODUCTION

Background

Those who provide care to older adults are keenly aware of the importance of patient decision making. As older adults approach the end of their lives, they experience many ups and downs in their health that lead to uncertainty and decisional conflict regarding their care (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Mishel, 1990; Song & Sereika, 2006; Teno, Weitzen, Fennell, & Mor, 2001). Clinical circumstances change resulting in the evaluation of past decisions and the need for new ones that can lead to changes in preferences for care over time (Fried et al., 2006; Janssen et al., 2012; Kievit et al., 2010; Winter & Parker, 2007). Along with clinical circumstances, personal, psychosocial, cultural, religious, and environmental issues influence decision making (Bullock, 2011; Carr, 2011; Chen, Haley, Robinson, & Schonwetter, 2003). Thus, decision making is a complex process that evolves over time and includes more than just an understanding of patients' clinical circumstances: it also involves the full contextual environment within which decisions are made.

Healthcare providers need to navigate this complexity when supporting the decision making among their most ill patients because they are responsible for ensuring that patients have the information needed to make informed decisions (Beauchamp & Childress, 2009). The principle of respect for personal autonomy – the right of patients to make choices (i.e. to make decisions) that reflect their personal values – is a cornerstone of biomedical ethics (Beauchamp & Childress, 2009), and though considered equal to the other principles of beneficence, non-malfeasance, and justice, autonomy receives more emphasis in clinical practice. The Patient Self-Determination Act reflects this emphasis by codifying autonomy as a legal – not just a moral – right of patients, extending a protection for research participants to patients in general. Consequently, there is great interest in how to support patient decisions.

Shared decision making is widely seen as the optimum approach to supporting decision making in clinical practice (Charles, Gafni, & Whelan, 1999; Kon, 2010). In this approach, providers and patients work collaboratively to reach a mutual decision. Information is shared in both directions, with providers and patients being equal partners in the process. Shared decision making aims for a decision that both parties believe is appropriate and desirable; however, while evidence indicates that shared decision making often results in greater patient satisfaction with decisions, the model is difficult to implement (Joosten et al., 2008; Legare, Ratte, Gravel, & Graham, 2008). Other models aim to identify the conflict and uncertainty around end-of-life decisions but look at decision outcomes, rather than the underlying processes leading up to a decision being made (Janis & Mann, 1982; Mishel, 1990).

In addition to developing decision-making models, significant research has been undertaken to explore the many different factors influencing end-of-life decisions. As noted above, researchers have explored the influence of physical decline and changes in preferences at the end of life. Other areas have been studied as well, including patients' preferences for care at the end-of-life (Gott, Small, Barnes, Payne, & Seamark, 2008; McKechnie, MacLeod, & Keeling, 2007; Steinhauser et al., 2000), characteristics of those who have made choices for or against various interventions (Casarett, Van Ness, O'Leary, & Fried, 2006; Gauthier & Swigart, 2003; Hakim et al., 1996; Thomas, O'Leary, & Fried, 2009), and the preferred and actual role patients play in decision making (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Heyland, Tranmer, O'Callaghan, & Gafni, 2003; Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis, 2005; Moorman, 2011).

There is one other important area of research: the use of hospice (Casarett et al., 2006; Huskamp et al., 2009; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2010; Waldrop & Meeker, 2012). Hospice provides high-quality, patient/family-centered palliative care to those in the final months of life that focuses on managing pain and symptoms while maximizing quality of life; consequently, as older adults approach death and experience more decline, hospice is likely to become an appropriate option (Medicare Payment Advisory Committee, 2008; National Hospice and Palliative Care Organization, 2012). Hospice is also important because it specifically addresses issues that older adults report are of greatest importance at the end of life; however, many experts consider the service underutilized (Brickner, Scannell, Marquet, & Ackerson, 2004; Carlson, Morrison, & Bradley, 2008; Schockett, Teno, Miller, & Stuart, 2005; Vig et al., 2010). Despite rapid growth in recent years, most eligible patients either do not access hospice or only enroll within three weeks of dying (National Hospice and Palliative Care Organization, 2012). While hospice will never be appropriate for all people who die, it is an important option that should be considered and made available to older adults. But like other decisions, a hospice decision evolves over time and results from a process that starts well before the actual decision to enroll is made.

Problem Statement

The extant literature has significantly informed end-of-life and hospice decision making; however, the perspective of the literature is limited. Methods often used hypothetical scenarios and asked participants to prospectively consider abstract decisions. Research has often excluded older adults with advanced illness and drew heavily from patients with cancer, rather than those with co-morbidities as is common among older adults. Consequently, the perspective of older adults who are in the midst of making actual decisions that directly impact their end-of-life care is limited in our current knowledge. The decision-making process, its impact on the resulting decisions (or non-decisions), and its influence on the care older adults receive at the end of life need to be better understood.

Significance

The ultimate consequence of birth is death. This may seem very cynical; however, the statement highlights an important aspect of aging: death is a natural part of the process. Not surprisingly, the majority of deaths occur among older adults, who are apt to experience a period of decline in which hospice becomes appropriate (Xu, Kochanek, Murphy, & Tejada-Vera, 2010). But whether or not older adults utilize hospice, they deserve high-quality palliative care. Understanding how older adults who have a limited prognosis and are approaching the end of life make healthcare decisions, including whether to use hospice or not, and the consequences of the decisions will allow providers to address patients' concerns, mitigate barriers to care, ensure that appropriate care is provided in accordance with patients' desires, and influence future policy decisions regarding palliative care for the elderly.

For this dissertation study, I specifically recruited participants from models of care outside of hospice. The aim was to understand how older adults make decisions in the period leading up to when hospice may be appropriate. By recruiting older adults with a limited prognosis, I aimed to expand current knowledge to include a population that is often not included in research. In a discussion regarding the state of current knowledge, Prigerson and Maciejewski (2012) noted that if we are to fully understand how patients come to receive the end-of-life care they do, we need more data from "actual, not hypothetical, terminally ill patients, their family members, and providers" (p 26). While significant quantitative research has described the characteristics of those who do and do not enroll in hospice and has found statistically significant relationships between different variables, minimal research has been undertaken to understand the how and why that underlie these associations. Prigerson and Maciejewski (2012) also noted this in their commentary saying that researchers need to “zoom in” and “fill in missing details and enhance the resolution of the overall EOL care picture” (p. 27). This qualitative research study aims to be one step toward creating this knowledge.

This study has implications for policy makers. People over 65 years of age account for over 70% of deaths in the United States and over 85% of all hospice patients; thus, end-of-life and hospice care are significant issues for Medicare (National Hospice and Palliative Care Organization, 2012; Xu et al., 2010). Twenty-five percent (25%) of all Medicare expenditures cover the costs in the last 12 months of a recipient’s life (Calfo, Smith, & Zezza, 2008), and the hospice benefit was introduced to, in part, reduce these costs while improving care (Medicare Payment Advisory Committee, 2008). However, the prevalence of short enrollments (less than 3 weeks) is seen as encumbering these goals, with patients seeking curative measures that preclude hospice and declining hospice services when offered (Casarett et al., 2006). Thus the role of older adults in this decision influences the use of hospice and needs to be understood.

Research exploring end-of-life decision making among older adults focuses primarily on the decision outcome – whether or not patients want life-sustaining treatments and/or chose to enroll in hospice. In that research, there is an implication that the decisions are clinically “wrong” and that changing patients’ behavior would result in “better” choices. At one level, I concur with this assessment: older adults often receive aggressive care that significantly diminishes their quality of life at the end of life (Earle et al., 2004; Smith et al., 2012), and this care appears contrary to their stated wishes (Fried, Bradley, Towle, & Allore, 2002). Further, older adults appear to be making these choices themselves, at least to some degree (Huskamp et al., 2009; Thomas et al., 2009). However, before providers can change behavior, they must understand what the current behavior is and why it exists. There are few models that aim to understand the underlying decision-making processes, particularly in healthcare. Such a model would help further research and provide the basis on which to design and develop clinical interventions. This dissertation study was designed to begin filling in this gap in knowledge.

Theoretical Perspectives

Theoretical perspectives were used to inform this dissertation in two different ways. First, the methodological approach to this study was grounded theory that is based on the theoretical perspective of symbolic interactionism (Charmaz, 2006; Corbin & Strauss, 2008). Consequently, symbolic interactionism influenced and guided the design, implementation, and analysis of this study. Second, as discussed below, I used other theoretical perspectives to (a) frame the existing literature prior to starting the study and (b) use as a lens through which to view the study's findings after the analysis was complete.

Symbolic Interactionism

According to symbolic interactionism (Blumer, 1969), human behavior is understood through analyzing the meanings individuals give to the things and people in their environment, not simply by analyzing the direct responses to them. People bring meaning to their experiences through their social interaction with others and their environment; consequently, individuals respond to a social reality that they define. Each situation is unique to the individuals involved and the circumstances of the interaction. Symbolic interaction is an excellent perspective to use when studying end-of-life and hospice decision making. When considering these decisions, older adults do not merely respond to the reality that their providers believe they are dying, they respond to the meaning that hospice, death, and dying have for them from within the context of their social world.

The influence of symbolic interactionism on grounded theory is quite apparent. Grounded theory aims to understand the meanings behind the social processes in a phenomenon, so the symbolic interaction is the focus of analysis (Charmaz, 2006; Corbin & Strauss, 2008). Grounded theory provides a flexible set of techniques that are used to explicate and understand the social processes constituting a phenomenon. With end-of-life decisions, older adults come not just with their sense of self, but also the meaning these decisions have for them. End-of-life decision making is done through the interactions patients have with their providers, families, friends, and other social players. Through symbolic interactionism, grounded theory is well suited to elucidate these processes.

Theoretical Frameworks

To frame the literature review and as a post-hoc lens for the study findings, I used a formal decision-making theory and two supplemental theories: prospect theory, socioemotional selectivity theory, and perceived control. Prospect theory (Kahneman & Tversky, 1979) is an economic theory that has been adapted to healthcare decisions, including end-of-life decisions (Kievit et al., 2010; Winter, Lawton, & Ruckdeschel, 2003; Winter & Parker, 2007). According to prospect theory, people make decisions based on how they value different options relative to a neutral reference point and whether choices are framed as positive or negative. Differences between choices are seen as small when the choices are further "away" as compared to "close" to the reference point. This perceptual difference results in different choices being made based on the relative proximity to the reference. This theory is discussed in more detail in Chapter 4.

Socioemotional selectivity theory (Carstensen, Isaacowitz, & Charles, 1999; Lockenhoff & Carstensen, 2004) was used to account for the differences seen in how younger versus older adults make decisions. This theory states that people's future time perspective changes emotional salience and leads to different priorities and choices. Aging inherently brings a limited (vs. open) future time perspective that influences the decisions older adults make. Socioemotional selectivity did not turn out to be a helpful perspective for this study, as will be discussed in Chapter 5.

An aspect of decision making that is not captured in either prospect or socioemotional selectivity theory is that decision makers must (a) want to make a decision and (b) believe they are able to do so. The theory of perceived control (Wallhagen, 1998) brought in this perspective. This theory posits that people continually appraise the environmental demands placed on them against the resources they have available. An imbalance between the two creates dis-equilibrium and a loss of control. By adjusting their circumstances, people seek to regain a balance between demands and resources, thereby achieving a sense of control. Part of this process may be changing priorities/goals or delegating decisions to others. At the end of life, older adults are asked to make significant healthcare decisions that have tremendous ramifications and do so in the face of a great deal of uncertainty. This can result in demands exceeding resources and require older adults to attempt to re-establish balance. How the data of this study informed and was informed by perceived control is discussed in Chapters 3 and 5.

Central to these theories is that people are situated and act within unique contexts. These contexts are best understood by examining the processes within them, which can be done through symbolic interactionism. A conceptual diagram of the relationship between prospect theory, socioemotional selectivity theory, and perceived control is shown in Figure 1.

Dissertation Aims

This dissertation study examined the decision-making process of older adults with a limited prognosis who were in the midst of making significant decisions about their care. This was done by exploring the social processes involved in patients' decision making to understand how these processes influence patients’ perceptions of their disease, prognosis, and care. Specific aims were:

1. To examine the human factors (providers, family, friends, etc.) and non-human factors (culture, race/ethnicity, religion, etc.) that are significant to older adults’ end-of-life decisions and how these factors influence the use of hospice.
2. To explore older adults’ experiences and perceptions of their health, illness, and prognosis, and how their experiences influence their decisions.
3. To understand the conditions under which hospice and other end-of-life options are perceived as choices and the influence this perception has on using hospice or not.
4. To gain insight into possible theoretical perspectives that will facilitate future study.

While I specifically sought to understand how participants’ decision-making processes influenced their access to hospice, I was not able to do so directly. None of the participants had discussed hospice care with their providers and few knew what the service was. As a result, there was insufficient data with which to explore hospice decisions. The implications of this will be discussed in Chapter 5.

Organization of the Dissertation

This dissertation has five chapters. This introduction forms the first chapter and identifies the research problem, its significance, and need for study. Chapters 2, 3, and 4 are written as independent manuscripts for publication. Each was written with the guidelines of a specific peer-reviewed journal in mind, including the journal’s aims, target audience, and words limits. Though target journals have been identified, at the time of this writing, none of the chapters have been submitted for publication.

Chapter 2 synthesizes the extant literature on end-of-life and hospice decision making and argues for a new conceptual framework that can be used to understand the underlying processes at work. In this way, Chapter 2 sets up the background for the overall study, but also yields a framework that begins to address Aim 4.

Chapter 3 uses grounded theory to bring forth the process of interest and reveals the ways participants achieved and maintained a sense of control without having to actively make decisions. Chapter 3 further informs Aim 4, but also explicates issues related to Aims 1, 2, and 3.

Chapter 4 uses prospect theory (Kahneman & Tversky, 1979) as a priori framework to guide a qualitative analysis of the data. The aim was to see how perceived prognosis and health status influence participants' decision-making processes. In addition, I sought to understand how prospect theory informed and was informed by the findings. Chapter 4 looks specifically at Aim 2 and furthers the goals of Aims 3 and 4.

Chapter 5 is the final discussion and summary of the dissertation study. In that chapter, I summarize the findings of the study across manuscripts and discuss their relevance to the theoretical perspectives used in the study. I also discuss the study's implications on hospice decision making and its strengths and limitations. I conclude the chapter with a discussion of the implications on clinical practice and future research.

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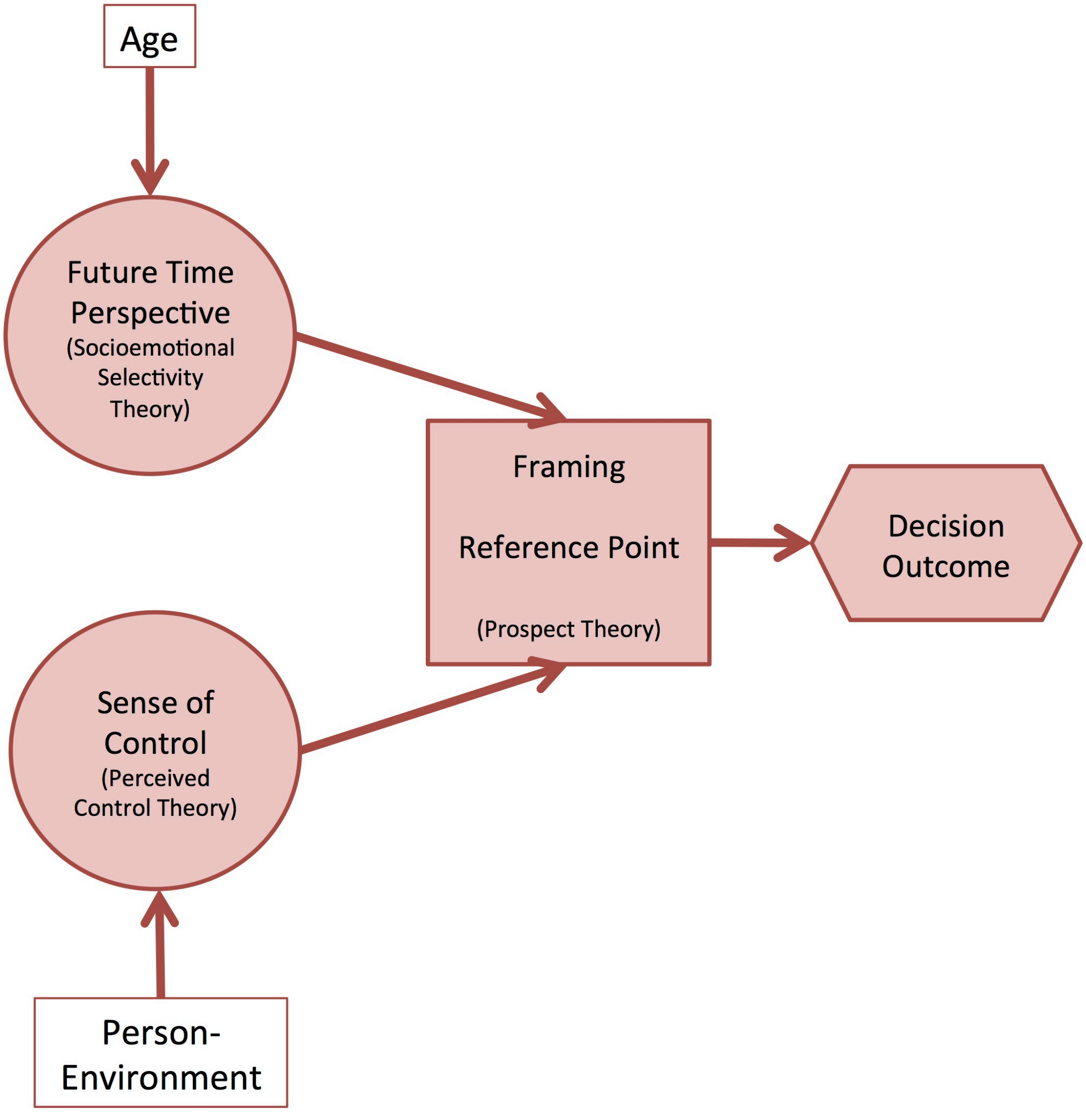

Figure 1. The Relationship between Prospect Theory, Socioemotional Theory, and Perceived Control

CHAPTER TWO

DECISION MAKING AT THE END OF LIFE: A PROCESS PERSPECTIVE

Though hospice aims to provide end-of-life care consistent with older adults' stated priorities (Steinhauser et al., 2000), most decedents do not received its services, and among hospice patients, the majority dies within weeks of enrolling (National Hospice and Palliative Care Organization, 2013). Consequently, hospice may not be used as widely as would be anticipated. Significant research has been undertaken to understand the characteristics of those who do and do not use hospice; however, less is known about how patients come to make the actual decisions, especially among those who decline to use hospice (Gauthier & Swigart, 2003; Szirony, Sopko, Masiulaniec, & Binder, 2011; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2010). The aim of this article is to explore the extant literature regarding hospice decision making among older adults. Because limited research has focused specifically on hospice decisions, we include relevant literature related to end-of-life decisions in general. We first discuss four factors that we see as directly influencing the decision outcome. We then discuss the decision-making context, including our view of a "decision-making triad" consisting of the patient, clinical providers, and patients' social network. Next, we present a conceptual framework that views decision making as a process, rather than an isolated act. Finally, the implications for clinical practice and future research are discussed.

Factors Influencing Hospice Decision-Making Behavior

Understanding Prognosis

A hospice decision is influenced by both providers' and older adults' understanding of prognosis. At a minimum, referring physicians must determine that patients have less than six months to live (Medicare Payment Advisory Committee, 2008). Further, because hospice patients must forgo curative treatments, they must at least tacitly acknowledge that they are approaching death, even if they are not aware of the six-month criteria. Providers are more likely to discuss hospice with patients' they believe have a limited prognosis, and patients who understand this prognosis are more likely to forgo life-sustaining treatments (Casarett, Van Ness, O'Leary, & Fried, 2006; Huskamp et al., 2009; Thomas, O'Leary, & Fried, 2009).

When prognosis was limited, researchers have found that older adults often state they prefer low-burden treatments to invasive, high-burden ones (Coppola et al., 1999; Rosenfeld, Wenger, & Kagawa-Singer, 2000; Waldrop & Meeker, 2012). In other studies, when participants believed they would survive longer than six months, they were more likely to want life sustaining treatments, including chemotherapy (Temel et al., 2010; Weeks et al., 1998). Older adults appear to use treatment outcome, not burden, as a factor in making decisions, with some studies noting that participants would forgo invasive, burdensome treatments when minimal hope for recovery is expected (Cosgriff, Pisani, Bradley, O'Leary, & Fried, 2007; Fried, Bradley, Towle, & Allore, 2002; Hakim et al., 1996).

However, despite poor clinical prognoses, patients often have optimistic perceptions of how long they have to live (Casarett et al., 2006; Huskamp et al., 2009; Temel et al., 2011). This perception complicates decisions and leads to choices based on unlikely clinical outcomes and a desire for treatments inconsistent with hospice. But even when patients know their prognosis, many still will not enroll in hospice – as many as 30% of eligible patients decline after the option is presented (Huskamp et al., 2009; Thomas et al., 2009). Consequently, prognosis is one but not the only factor influencing decisions to utilize hospice.

Illness/Health Experience

Another factor influencing decision making is an individual's experience with his/her illness and health. Compared to non-hospice patients, those in hospice have more co-morbidity and functional decline, leading to less desire for want life-sustaining interventions (Chen, Haley, Robinson, & Schonwetter, 2003). Other researchers note that these factors alone increased the likelihood that patients and providers discuss hospice (Casarett et al., 2006; Thomas et al., 2009). Huskamp et al. (2009) also found that participants who experienced poorer health than others (as measured in the EuroQoL EQ-5D) were more likely to have discussed hospice with providers. Patients have identified "pivotal events" that led them to re-evaluate their circumstances and begin the transition to accepting hospice, such as significant changes in their health, indications that their disease was progressing, or a need to stop treatments such as chemotherapy (Gauthier, 2005). Among African Americans, Campbell, Williams, and Orr (2010) found that participants used changes in their health as a trigger for decision making but only if the changes resulted in physical symptoms. Thus older adults rely on their experience with illness to help guide their end-of-life choices.

When deciding to discuss options with patients near the end of life, providers use their own perception of patients' experiences and changes in condition. Using a hypothetical patient meeting national guidelines for prognositic disclosure, Keating et al. (2010) found that most physicians would discuss prognosis; however, they would only discuss hospice and end-of-life care options if patients were symptomatic and had no non-palliative options available.

Different diagnoses result in different experiences that influence decision making. Patients with heart failure, obstructive pulmonary disease, and renal failure have lived with their conditions for years; consequently, they do not necessarily see the disease as progressive or life limiting (Curtis, Engelberg, Nielsen, Au, & Patrick, 2004; Pinnock et al., 2011). Consequently, patients with non-cancer diagnoses are more likely to want interventions that would preclude hospice and to focus on factors unrelated to their underlying condition (Cosgriff et al., 2007; Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis, 2005). They also often view hospice as a service only for cancer patients or consider hospice only when they no longer want to be hospitalized, while cancer patients viewed hospice as appropriate but only when close to death (Waldrop & Meeker, 2012).

Thus, the decision to accept hospice is based on understanding one's disease and prognosis, as well as seeing a contextual need for the services. Patients, families, and providers often do not see hospice services as necessary or valuable until patients are very close to death and actively dying (Vig et al., 2010; Waldrop & Meeker, 2012). This finding is reflected in the high level of satisfaction with the timing of hospice referrals, even among those who enroll within days or weeks of death (Kapo, Harrold, Carroll, Rickerson, & Casarett, 2005; Teno et al., 2007).

These factors likely contribute to the prevalence of short stays in hospice (less than three weeks) – patients must perceive themselves as "sick and dying" before they seek to change the focus of their care. However, significant interplay between prognosis and illness/health experience appears to exist. While patients often have overly optimistic views of their prognosis, they become more realistic as their health declines (Temel et al., 2011). In addition, patients who discuss prognosis with their providers may change their perception of their health and consequently find hospice more acceptable.

Decisional Control

In addition to prognosis and illness/health experience, personal autonomy is an important factor in decision making. In countries like the U.S., strong emphasis is placed on patients' making independent, informed decisions about their care; yet, the actual and preferred roles older adults wish to take vary greatly. Not all patients make the decision to enroll in hospice (Casarett, Crowley, Stevenson, Xie, & Teno, 2005). For some patients, they can no longer make decisions for themselves due to their medical condition; however, many patients chose to delegate hospice decisions to others (Casarett et al., 2005; Hirschman, Corcoran, Straton, & Kapo, 2010). Consequently, many older adults may prefer a more passive approach to autonomy.

Patients' preferences range from wanting to be fully independent to completely delegating decisions to others. In between lies some degree of collaborative decision making where patients want to share decisional responsibility (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Heyland, Tranmer, O'Callaghan, & Gafni, 2003; Laakkonen et al., 2005). The extent to which patients wish to share, delegate, or maintain control over decisions varies from one study to the next, ranging from 20 – 40% for those who want to maintain or delegate decisional control. The differences may be related to sample differences and survey construction. Butow et al. (1997) recruited only cancer patients, included significantly more men than women, and asked who "should" make decisions. Heyland et al. (2003) recruited patients with cancer, COPD, HF, and end-stage cirrhosis, had an equal number of men and women, and asked what role participants "preferred." Laakkonen et al. (2005) recruited participants with cardiovascular disease and also asked who "should" make decisions, but they added a "close relative" into the mix of decision makers. The word-choice may be subtle but significant, as "should" has paternalistic connotations while "prefer" implies a degree of control.

In contrast to other researchers, Moorman (2011) found that 80% of her participants (*N*=4477) wanted to maintain autonomy in their end-of-life decision making. However, she further notes that the expression of autonomy does not necessarily equate to independent decision making because "patients may value the notion of autonomy but not its practice" (p. 151). This observation is supported by a study among women with breast cancer that found yielding decisions to and relying on a trusted person enabled some participants to maintain a sense of control and autonomy (Swainston, Campbell, van Wersch, & Durning, 2012).

Decisional control is also related to illness experience and prognostic awareness. Studies have found that physical decline is significantly related to wanting less involvement in decision making (Butow et al., 1997; Heyland et al., 2003; Laakkonen et al., 2005). Though the relationship between prognostic awareness and decision-making role has not been a focus of most studies, taken as a whole, the body of literature implies that such a connection exists.

Open Communication

Good, open communication is a critical aspect of end-of-life decision making. To fully appreciate the benefits and barriers to hospice, patients and their families must understand prognosis and the severity of the patient's illness. This understanding comes from communication with providers (Casarett et al., 2006; Huskamp et al., 2009) – simply discussing hospice significantly increases the likelihood patients will utilize the service. However, these discussions do not appear to happen often (Fried, Bradley, & O'Leary, 2003), and when they do, they are frequently late in a disease process, leaving insufficient time for patients to adapt to their changing circumstances or adjust their healthcare priorities (Walczak et al., 2013).

Physicians and nurses often point out that patients and families neither wish to discuss nor acknowledge their prognosis and its implications, thereby creating barriers to hospice (Brickner, Scannell, Marquet, & Ackerson, 2004; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). However, researchers also found that most patients want to know their prognosis but also want to control how and when discussions happen (Ahalt et al., 2011; Fried et al., 2003; Hagerty et al., 2004; McDonald et al., 2003). Rather than having a long, detailed discussion during a single meeting, patients want frequent, short conversations regarding prognosis (Hagerty et al., 2004). Older adults also cite benefits to knowing prognosis, such as making preparations, getting the most out of life, and being informed (Ahalt et al., 2011). These benefits outweighed concerns for any distress related to knowing prognosis.

Still, a sizable minority did not want to know their prognosis and strongly opposed the idea of being told (Ahalt et al., 2011; Fried et al., 2003; Hagerty et al., 2004; McDonald et al., 2003). Along with weighing clinical circumstances, providers must navigate the ambivalence patients may experience, which can be challenging (Thai, Walter, Eng, & Smith, 2013). Providers may attempt to have initial conversations regarding prognosis and to re-evaluate treatment goals but find patients unreceptive. As a result, patients may sometimes believe a discussion of prognosis has not been held. The difficulty for providers is to recognize the appropriate time to begin the communication, as well as the fluid nature of patients' decisions and preferences.

Through discussing prognosis and clinical circumstances, providers help patients and families understand their prognosis and the progression of their conditions. Similarly, providers come to understand patients' values and priorities. Consequently, the relationship between prognosis, illness/health experience, and decisional control unfolds within this communication. Each influences the other and changes the perceptions patients have regarding available options and whether patients seek an active or passive role in decision making.

The Decision-Making Context

The decision-making behavior described above does not occur in an isolated manner. Many forces influence patients, including other people and the situational environment of the decision.

Decision-Making Triad

Research on patient decision making has focused primarily on the patient, the provider, or the relationship between the two. Providers are responsible for giving patients the information needed to make informed decisions, and patients are considered the ultimate decision maker (Beauchamp & Childress, 2009). But there is a third actor that has not been studied as much: patients' families and friends. Family members have been studied as surrogate decision-makers, owing to the role they assume if patients decisional capacity; however, their role as supportive players is evident.

Laakkonen et al. (2005) noted that more than 50% of all participants wanted a family member involved in end-of-life decisions, though they did not explore the degree of this involvement. Bullock (2011) and Campbell et al. (2010) found that participants spoke of wanting family involved in end-of-life/hospice discussions, even expressing anger when providers did not wait for family to be present. Among Latinos and Asian Americans, end-of-life decisions are often seen as family decisions, not individual ones, and patients are sometimes left out of the process entirely. This can occur even when patients still have the capacity to make decisions (Blackhall et al., 1999; Carr, 2011; Colclough & Young, 2007).

The importance of social relationships is also seen in other ways. The lack of social support may manifest a need for hospice, as those who are unmarried or live alone are more likely to use hospice (Chen et al., 2003; Huskamp et al., 2009). Fear of being a burden on family increases the likelihood that older adults will discuss end-of-life issues with their families, and positive experiences with hospice or experiencing the death of a loved one result in more favorable views of hospice (Blackhall et al., 1999; Carr, 2011). On the other hand, families may decrease the likelihood that hospice will be used. Vig et al. (2010) performed a small study (*N*=30) of patients who declined hospice and found that some family members were opposed to hospice because they feared losing control over the care of their loved ones.

Because family and friends play an important role in decision making, they cannot be excluded from the equation. By supporting and encouraging – or actively discouraging – hospice use, informal social partners can be either an enabling or an inhibiting force. Limited research has looked at the role of these players outside of surrogacy; consequently, the degree to which they influence older adults' decisions is not yet clear.

Contextual Environment

The decision-making triad exists within the same contextual environment; however, the environment influences the members differently. Policy analysts have long cited Medicare's hospice regulations as an impediment to hospice use. The need to forgo standard, curative care in favor of the purely palliative focus of hospice has been dubbed "the terrible choice" (Casarett et al., 2009) and is considered the major reason for patients to decline a hospice referral (Reb, 2003). Physicians often cite prognostic uncertainty as a primary reason to hesitate making a referral in the first place (Brickner et al., 2004; Ogle, Mavis, & Wyatt, 2002). Though Medicare sets general standards for admission, specific criteria vary from one hospice provider to another, with some accepting patients with IV fluids, antibiotics, tube feedings, etc. while others do not (Aldridge Carlson, Barry, Cherlin, McCorkle, & Bradley, 2012; Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004). Another issue may be the availability of services. While hospice services are readily available in urban and suburban areas, rural communities may have limited access to hospice services (Virnig, Ma, Hartman, Moscovice, & Carlin, 2006). Consequently, hospice organizations add an additional layer of complexity to the decision.

In addition to the policy and structural issues around hospice, sociocultural aspects and religion are important contextual components that have been extensively studied. Studies have found that compared to Whites, on average other racial and ethnic groups expressed stronger preferences for life-sustaining treatments and dying in a hospital, and less favorable views of hospice, all of which would decrease the likelihood of hospice use (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Blackhall et al., 1999; Carr, 2011; Johnson, Kuchibhatla, & Tulsky, 2008; Ludke & Smucker, 2007; True et al., 2005). Likewise, significant differences have been noted between groups based on religion and spirituality, with a greater degree of religiousness/spirituality associated with a greater desire for life-sustaining treatments and hospitalization at the end of life (Balboni et al., 2007; Blackhall et al., 1999; True et al., 2005; Van Ness, Towle, O'Leary, & Fried, 2008).

Race, ethnicity, and religion also influence patients' desire for decisional control. Many researchers have noted that on average White and African American participants value personal autonomy, while Latinos and Asian Americans prefer family-centered decision making (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Carr, 2011; Colclough & Young, 2007). Those with a belief in fate – that God controls the timing of death – are also less likely to be involved in decision making (Garrido, Idler, Leventhal, & Carr, 2013; True et al., 2005).

Generalizing the data on sociocultural influences is challenging. Focusing on group differences runs the risk of overlooking intra-group heterogeneity that must be understood. For example, Ludke and Smucker (2007) found that 71% of their African American participants were willing to use hospice, compared to 89% of Whites. Johnson et al. (2008) found that on average African American participants had a less favorable view of hospice than did Whites (26.2 vs. 29.4 on a scale of 8 to 40, with 8 being the least favorable score). Consequently, though hospice is favored in both groups, it is not a universally held view, with significant intra-group variability unexplained. In addition, the degree of influence religion has varied based on how the concept was assessed, reflecting the impact the different measurements may have had. Further, the relationship between the decision-making context, decision-making triad, and sociocultural and religious factors is not easily teased out. Balboni et al. (2013) provide an example in a recent study. They found that participants with a higher degree of spiritual support from their religious communities were more likely to want life-sustaining treatments and less likely to enroll in hospice. However, when participants felt they also received spiritual support from their providers, the opposite was true. Balboni and colleagues could not explore why this was the case, but it is reasonable to assume that the interaction between providers and patients gave rise to the perception of this support.

Hospice Decisions as a Process

Though choosing to enroll in hospice can be seen as an isolated, stand-alone decision, it is better seen as arising from the interaction of beliefs, attitudes, and behaviors that evolves over time. Hospice admission criteria lend support to the former view, as there is generally a unique point in time when patients' healthcare providers recommend hospice, and patients then "elect" the services (Medicare Payment Advisory Committee, 2008). This is a significant event and marks transition from a curative to palliative focus related to care (National Hospice and Palliative Care Organization, 2013). However, the discernment around enrolling in hospice begins earlier and involves considering patients' priorities for care. In the best-case scenario, as patients' conditions progress and their health declines, providers begin to explore clinical circumstances with their patients and re-evaluate the goals of treatment. Options are considered and re-examined. Choices get made and re-assessed.

Thus the decision-making process that has occurred over a disease trajectory influences whether or not a referral to hospice is made and how the referral is perceived. We represent this process in Figure 2 by synthesizing our review of the literature into a conceptual framework.

Decision making occurs within a contextual environment that consists of policy and environmental issues, psychosocial factors, and sociocultural and religious considerations. Further, the “decision maker” includes the patient as well as informal and professional social partners such as family, friends, and healthcare providers. These players are uniquely influenced by the contextual environment and bring their own perspectives to communication, understanding of prognosis, experience with illness/health, and preferred decision-making role. The result is a decision behavior that evolves and changes over time.

Understanding decision making as a process is particularly important for older adults because they often die after a long period of decline during which hospice is likely to become appropriate (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). However, pinpointing the timing of this transition can be challenging. Compared to younger adults, older ones are more likely to die from illnesses that are characterized by unpredictable trajectories of decline, such as cardiovascular disease, heart failure, renal failure, diabetes, and chronic obstructive pulmonary disease (Xu, Kochanek, Murphy, & Tejada-Vera, 2010). These trajectories can lead to temporal changes in decision making and explain the observations of many researchers, such as older adults often changing preferences for life-sustaining treatments as their health declines (Fried, O'Leary, Van Ness, & Fraenkel, 2007; Winter & Parker, 2007) and wanting less involvement in decision making as they become more ill (Butow et al., 1997). Further, the process of accepting and adjusting to the reality of the end of life unfolds gradually and involves recognizing both the decline in ones health and ineffectiveness of current treatments (Gauthier & Swigart, 2003; Walczak et al., 2013). The same process is true for coming to see the value of hospice.

Discussion

The complex, multifactorial nature of end-of-life decision making has many implications for both clinical practice and research. Healthcare providers must be mindful of the variability found among patients when it comes to decision making and treatment preferences. While biomedical ethics includes four equal principles of autonomy, non-maleficence, beneficence, and justice (Beauchamp & Childress, 2009), respect for autonomy frequently gets more emphasis, especially when one of the outcomes is death. Respect for personal autonomy can be difficult if patients rely heavily on others for guidance and delegate decision making, as may be true for older adults regarding emotionally-laden decisions (Lockenhoff & Carstensen, 2004). In these situations, providers may feel uncomfortable taking a more proactive role and prefer to mention every possible option, even if they are unlikely to improve clinical outcomes. However, offering patients choices simply because they are available may do a disservice, especially if outcomes are framed only as living-or-dying and not in the context of patients' priorities and goals. In Table 1, we provide suggested strategies that providers can use to optimize when and how to have hospice discussions with their patients.

Discussing end-of-life care with patients can be difficult but is a core aspect of caring for older adults. Some clinicians suggest routinely offering to discuss prognosis with patients who have a prognosis of less than 10 years or have reached the age of 85 (Smith, Williams, & Lo, 2011). By doing so, providers can begin to explore preferences when patients are in relatively good health, rather than during a crisis. Shared decision making (Charles, Gafni, & Whelan, 1999) is widely regarded as the model for patient-provider communication and calls for patients and providers to work collaboratively and make decisions jointly. However, shared decision making requires strong communication skills and significant time – providers often feel they have neither (Legare, Ratte, Gravel, & Graham, 2008). Palliative care programs are designed to facilitate these conversations and have been shown to improve satisfaction with care, reduce healthcare utilization, improve symptom management, and increase quality of life (Rabow et al., 2013).

Earlier and more frequent discussions would also facilitate recognizing clinically significant changes that result in hospice being an appropriate option. To date, limited research has been undertaken to explore hospice decision making specifically among older adults with a limited prognosis. Existing models of decision making focus on decision outcomes and identifying “better” ways of making decisions. However, before attempting to alter patients’ behavior, providers must first understand the origins of the current behavior. To this end, future research needs to focus on older adults’ decision-making processes within the full context of their situations.

To understand more fully the combined role of patients, families and friends, and providers, it is necessary to explore the perspectives of all the actors involved in decision making. Most studies have examined decisions from the perspective of patients and providers alone or within the dyad of patient-provider. However, the influence of informal social partners like family and friends needs to be understood beyond their role as surrogates. To varying degrees, hospice decisions arise from the interaction of all three actors, and each of these actors bring his or her unique perspective to the process of decision making. Research is also needed that explores what happens when patients are unwilling to exercise personal autonomy so that the implications on the type and quality of care received are better understood.

For researchers, the challenge will be to design studies that integrate the many different aspects of decision making and still yield meaningful findings. In order to simplify study questions, researchers often select specific aspects of the decision-making process to examine, but this frequently yields more questions than answers. In their critique of the Dartmouth Atlas, Prigerson and Maciejewski (2012) highlighted this issue by noting the lack of psychosocial details that would help to frame and understand the data generated by the project. Qualitative research can answer the "how" and "why" questions and begin to tie together the existing knowledge to yield a more complete picture of patient decision making.

Summary

Our review describes the complex and intricate nature of hospice decision making. By examining the contextual process used, we are able to identify key aspects of decision making that directly influence the behavior that results in different decisions. Exploring this process will not only enable us to further our understanding of the barriers to hospice that continue to persist but also help us to understand the unique needs of those who never utilize hospice. Our goal is not to identify ways to encourage and increase the use of hospice but to understand the needs of older adults at the end of life. Whether in hospice or not, all older adults should receive high quality palliative care.

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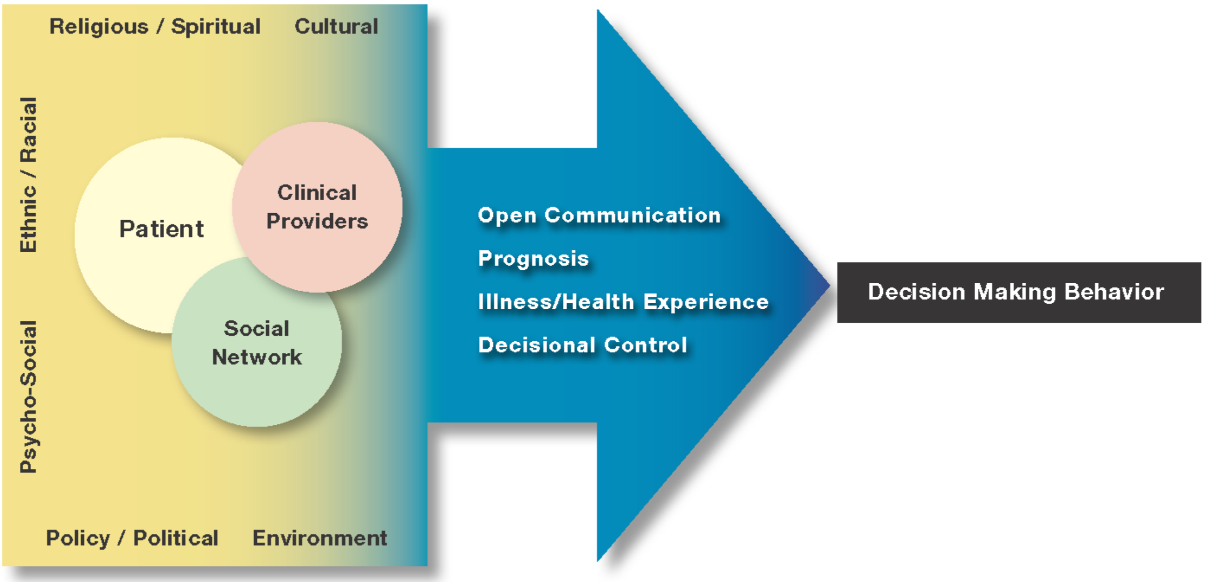

Figure 2. Decision-Making Process at the End-of-life

Table 1.

Strategies to Optimize Hospice and End-of-Life Discussions

- Focus on patients’ values and outcomes rather than treatment alternatives.
- Communicate about values, outcomes, and prognosis early in the illness trajectory.
- Use earlier communication to improve patients’ understanding of their conditions and help patients to adjust to changes over time.
- Continually assess patients’ circumstances and use significant changes in clinical circumstances as “triggering” events to re-evaluate goals of care.
- Encourage patients to include family or friends in the discussions of priorities so that these potential surrogates are better informed and feel more confident making substitute decisions.
- Consider prognosis when making recommendations and use online calculators to aid in estimating prognosis (for example, ePrognosis – http://eprognosis.ucsf.edu).
- Collaborate with palliative care programs to better understand patients’ priorities and decision making.

CHAPTER THREE

DECISION MAKING IN THE CONTEXT OF LIVING AT THE END OF LIFE: MAINTAINING A SENSE OF CONTROL

Background

How older adults come to make their healthcare decisions is of great interest to healthcare providers, particularly as it applies to end-of-life care, as understanding this process is critical for ensuring that patients make informed decisions and exercise personal autonomy – the biomedical ethic acknowledging patients' right to make choices (i.e. make decisions) based on their values and beliefs (Beauchamp & Childress, 2009). Patients maintain control over their healthcare via autonomy and informed consent, and providers are responsible for assuring patients have sufficient information to exercise this right (Field & Cassel, 1997).

Despite the importance placed on autonomy, many older adults do not want either full disclosure of their clinical situations or participation in decision making, with many delegating decision making outright (Ahalt et al., 2011; Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Heyland, Tranmer, O'Callaghan, & Gafni, 2003; Knauft, Nielsen, Engelberg, Patrick, & Curtis, 2005; Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis, 2005). Thus, providers – whether physicians, nurses, or social workers – may aim for the ideal of informed, autonomous consent but the patient prefers to not be informed and abdicate decision-making responsibility. In these cases, providers find themselves in an extremely challenging situation.

As older adults' experience declines in and changes in clinical circumstances, they often change preferences for end-of-life care, further complicating the decision-making process. When asked about their preferences for future end-of-life care, older adults consistently prioritize issues regarding quality of life, such as being free of pain, physical discomfort and anxiety; dying naturally; bringing their lives to a close; feeling respected, and interacting with loved ones (Fried, Bradley, Towle, & Allore, 2002; Heyland et al., 2006; Steinhauser et al., 2000; Vig, Davenport, & Pearlman, 2002). Yet in the last months of life, older adults often receive treatments and interventions that preclude their stated priorities, such as hospital admissions, stays in intensive care units, chemotherapy, and other life-sustaining treatments (Casarett, Van Ness, O'Leary, & Fried, 2006; Miesfeldt et al., 2012; Smith et al., 2012). Though many older adults lose decisional capacity at the end of life and must rely on surrogates (Shalowitz, Garrett-Mayer, & Wendler, 2006), most maintain the ability into the days and weeks before their deaths (Graham et al., 1997; Plassman et al., 2008). So, it appears that decisions near the end of life arise from a dynamic process and to some degree older adults are making decisions that lead to receiving care that is inconsistent with their priorities. Consequently, understanding older adults' perspectives and decision-making processes is important to understanding this phenomenon.

Different factors appear to influence treatment decisions among older adults, including physical health status (Fried, O'Leary, Van Ness, & Fraenkel, 2007; Winter & Parker, 2007), perception of health (Campbell, Williams, & Orr, 2010; Gauthier, 2005), prognosis awareness (Casarett et al., 2006; Huskamp et al., 2009), racial/ethnic variations (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Blackhall et al., 1999; Johnson, Kuchibhatla, & Tulsky, 2008), religion/spirituality (Balboni et al., 2007; Blackhall et al., 1999; True et al., 2005), and preferred roles in decision making (Butow et al., 1997; Casarett, Crowley, Stevenson, Xie, & Teno, 2005; Heyland et al., 2003; Hirschman, Corcoran, Straton, & Kapo, 2010). All of these studies have provided important information about patient characteristics and the relationships between different variables. However, much of this research comes from the perspective of healthcare providers or family members. Many of the studies only recruited patients with advanced cancer, did not specifically examine older adults near the end of life, or used hypothetical scenarios, not actual decisions. Also, the studies did not explore the underlying processes used by participants when making their decisions.

What is missing from the discourse is the voice of older adults who have a limited prognosis and are in the midst of making significant healthcare decisions. Further, knowledge about how older adults make their actual decisions during this time is not known. Because of this lacuna, healthcare providers may not fully appreciate their patients' needs, and filling this gap would allow providers to address patients' concerns and ensure that appropriate care is provided in accord with patients' desires.

The purpose of this qualitative study was to bring forth the voice of these older adults. The aim was to explore how older adults with a limited life expectancy made healthcare decisions near the end of their lives and to explicate their decision-making processes.

Methods

Grounded theory (Charmaz, 2006; Corbin & Strauss, 2008) guided the design, implementation, and analysis of this study. The study aimed to explore and understand the perspectives of older adults who are near the end of their lives and are in the midst of making significant healthcare. The University of California San Francisco (UCSF) Committee on Human Research and the San Francisco Veterans Administration Medical Center (SFVAMC) Research and Development Committee approved the study protocol.

Recruitment, Study Participants, and Setting

We recruited patients from four primary care programs: the SFVAMC Home-Based Primary Care, SFVAMC Geriatrics Medicine Clinic, UCSF Housecalls, and UCSF Center for Geriatrics Care. We met with primary care providers (physicians and nurse practitioners) to explain the purpose of the study and eligibility requirements, answer questions, and ask for potential participants to be referred. Eligible patients were those who were 65 years of age or older, had a life expectancy of less than one year, were capable of making their own decisions, resided in the community, and were English-speaking. Potential participants were not excluded based on a diagnosis, and we did not exclude those who willingly delegated their decisions to a surrogate, as we wished to investigate and understand the role of these factors in the decision-making process. We excluded patients residing in skilled nursing facilities.

Providers determined life expectancy by asking themselves the question: “Would I be surprised if this patient dies within the next 12 months?” If the answer was no, the patient met the prognostic eligibility criterion. The providers consulted with affiliated social workers and psychologists to exclude patients with significant cognitive impairment and those believed to be too physically or emotionally fragile to participate in a 45-minute interview.

Potential participants were first identified because they met the inclusion criteria and the referring provider believed the patients would be good informants. Working with the providers, we identified subsequent participants based on their ability to develop and expand emerging themes and concepts. Recruitment continued until theoretical saturation was achieved. Potential participants were mailed information about the study and asked to return a response card. A member of the research team (RDR) then screened interested patients over the telephone. The researcher explained the study and verified eligibility. A teach-back approach was used to ensure that potential participants were able to understand and explain the study. As a result of the teach-back, three people were excluded. We specifically sought out informants from different racial and ethnic groups; however, the number of interested respondents was small. Arrangements were then made for a face-to-face interview in participants’ homes.

Twenty participants were included in the analysis. Participant characteristics are given in Table 2. Thirteen participants were men and seven were women. Participants ranged in age from 67 to 97 years. Seventeen were white and three non-whites. Four participants were married or in domestic partnerships; eight were widowed; six were divorced; and two were never married. Half of the participants were recruited through the SFVAMC.

Data Collection

Data collection took place over a four-month period, and each participant was interviewed only once. At the start of the meeting, the study was explained and informed consent was received using a teach-back approach. No one was excluded at this stage. The interview guide focused on four general areas: (a) current health and healthcare; (b) recent decisions and communication with providers; (c) decisions made regarding end-of-life care; and (d) anticipation for future care. Participants' views on hospice were of interest; however, most participants had no experience with or understanding of the services, so the data gathered were not useful to the analysis. Probes were used to explore and clarify the ideas and concepts articulated by participants, and at the conclusion of the interview, participants completed a demographic survey and the Edmonton symptom assessment scale (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). With participants' permission, medical records were later examined to ascertain medical history and review providers' notes. The Edmonton symptom assessment scale was used to understand participants' perception of their symptom burden. Because of the sensitive nature of the interview, we were mindful of participants' responses and reactions to the questions; however, none of the participants expressed undue distress nor asked to end the interview. To ensure interviews ended on a positive tone, the final question asked participants to focus on positive aspects of their lives.

Interviews were digitally recorded and professionally transcribed. Transcripts were reviewed and verified for accuracy. The same researcher (RDR) conducted all interviews and verified the transcripts.

Data Analysis

The interview guide was initially developed based on extant literature and was reviewed by experts in aging, decision making, and end-of-life care. The guide was pilot tested for face validity and modified to clarify areas of ambiguity and confusion. In keeping with grounded theory methodology (Charmaz, 2006; Corbin & Strauss, 2008), the guide evolved over the study period as the ongoing analysis identified emerging themes and concepts that needed explication. Probes were used to refine and more deeply explore participants' responses and to relate these responses to existing themes and concepts. Initially, we attempted to have participants speak to the details of specific decisions they had made, including the content of conversations, who was involved, and their thinking at the time. However, participants did not do this; instead, they spoke about the context in which decisions came up and the outcomes of the choices that were made. Consequently, the focus of the interview shifted to explore this aspect of participants' decision making.

Through the analysis, we sought to gain an in-depth understanding of the underlying processes involved in participants' decision making from within the context of the participants' experiences. Throughout the study, field notes were taken and memos were written to capture methodological issues and theoretical perspectives as they arose. We explored the similarities and differences seen within and across interviews, and we identified negative cases to challenge and refine the emerging concepts. In accordance with constant comparative analysis, analysis and coding began with the first interview and continued iteratively with each subsequent interview. As new codes were generated, earlier transcripts were recoded. The data were coded and analyzed using NVivo qualitative analysis software (QRS International, 2013).

A single researcher (RDR) performed the coding and met with members of the research team to review interviews and discuss the emerging codes, concepts, and categories. When disagreements arose about the meaning of participants' interviews and the emerging codes, they were resolved by consensus. The research team represented expertise in geriatrics and gerontological nursing, palliative and end-of-life care, ethics, decision making, and qualitative methods. As the theme of *maintaining a sense of control* emerged, probes were added to the interviews to specifically explore this concept.

To further support the quality and rigor of the analysis, interim findings were discussed with experts outside of the research team. These experts included professionals in aging with expertise in medicine, nursing, social work, and sociology.

Results

Maintaining a Sense of Control

As described by these participants, decisions were generally not made in an intentional, deliberate manner; instead, the data reflect an organic process in which participants discussed surrounding events and circumstances. Participants did not always make active making decisions and often chose to delegate decision making outright; yet, they still felt comfortable with how decisions were being made. Thus, it was from within this context that the overarching theme of *maintaining a sense of control* emerged.

Whether delegating decisions or not, participants felt they retained control. Their perception of control arose out of their appraisal of their unique circumstances and belief that their decision making was manageable because it was in the hands of a trusted person. From the locus of control framework (Rotter, 1966), maintaining active control over decisions is presumed to be the most adaptive approach; however, our participants achieved a sense of control by deferring decisions and delegating the responsibility to others. Participant 110 said, "You know, with the decisions that my providers makes for me, you know, if feels like, you know, everything is in control. And that makes me feel good too, you know?"

Participants maintained a sense of control through different approaches to *expressing priorities and goals* that reflected how participants articulated their preferences, often through circumlocution. Further analysis identified four categories that describe the different processes used to articulate priorities and establish a sense of control: *engaged avoidance*, *adaptive denial*, *third-party analogies*, and *direct communication*. We present a model of the interrelationship of the different concepts in Figure 3. These are not meant to be mutually exclusive categories of behavior, as participants often expressed views reflective of more than one category; however, they generally relied on one category over the others.

Expressing priorities and goals

Expressing priorities and goals involves describing desired outcomes at the end of life and highlighting meaningful aspects of ones lives. Participants did this in ways that protected their experiences with and perceptions of their illnesses. They were articulating what they could without directly acknowledging the reality of their health. End-of-life care decisions revolved around maintaining these priorities and then accepting (or not accepting) treatments that would enable (or inhibit) their ability to maintain these priorities and values.

With these priorities in mind, participants expressed preferences to avoid "aggressive measures," forgo "heroic efforts," and not have their lives "artificially maintained." For example, Participant 105 said, "I wouldn't want to live if I was going to be a vegetable. Have them pull the plug." Participant 118 commented, "I'd want to live unless I was in very bad pain. You're not human when you're in a very bad pain." In contrast to using these priorities to identify unwanted care, other participants prioritized getting well, or at least better than they currently were.

Participant 103 anticipated his health would improve; as a result, he focused on extending his life and being willing to undergo significant burden to achieve that:

> I would probably try anything that would consequently not come to the end, and I would rather think about having the bypass put in, and if something happened, I died on the table, at least I went through as much as I could to get to that point, to preserve life.

This participant had complicated diabetes with significant cardiac and renal disease, so he probably would not be an ideal candidate for surgery. However, because his priority was extending his life, he was willing to consider it.

Participants also spoke of activities that brought meaning to their lives and a willingness to undergo burdensome treatments if they could return to doing these activities. Participant 114 talked about her quilting, writing, emailing with friends, and watching old Barbara Stanwyck movies. When asked if she would like to continue doing these activities, she responded, "Absolutely. I mean that's my life." She then describes a bad death as the opposite:

> My image of [a bad] death is being in a nursing home and watching the Shopping Channel and basketball on the television. … It means no quilting, no computer.

While she does not want to be kept alive "artificially," she is willing to undergo any treatment that would return her to her current health and enable her to participate in preferred activities:

> Give it a go if there's a chance I'm gonna come back and I'm gonna to be able to at least watch Turner Classic Movies and recount my theory of Lubitsch's third act in all his films in response to his early theatrical training.

These activities brought meaning to her life that would be lost if she can no longer participate. Consequently, a desire for future care and length of life depended on whether she would maintain her ability to participate in these activities.

From within the context of expressing priorities and goals, participants used one of four overlapping processes to articulate their desires for care.

Direct communication

Direct communication was used to clearly indicate what care was or was not desirable. By understanding their broader goals, some participants had already made significant choices regarding their care. Participant 108's goals are to be kept "painless and comfortable"; consequently, when his physician suggested cardiac surgery, he declined, preferring to manage his condition medically:

> I just said 'No, not at my age. I'm not interested in surgery and stuff like that. Let's treat it and keep it calm and that's it.' It's just the idea of being uncomfortable, and you know there's nothing comfortable about surgery.

By relying on his priority of being comfortable, he rejected an entire class of care: surgeries.

Similarly, Participant 113 prioritized staying home and dying in his house, leading him to reject the possibility of future hospitalizations and surgeries:

> I am opposed to surgery. I don't want to go to the hospital anymore. And there will be no more surgeries in my life. I will not do it. I'm just going to stay home. I'm going to die in this house.

After prioritizing dying in his home and making the decision to no longer have surgeries or to be hospitalized, Participant 113 said he would no longer think about these choices:

> I'm not going to think about anymore. I'm just going to – I've done what I've done and I'm going to go about my business and one day I'm awake and one day I won't. That's all.

This statement reflects the use of both active and deferred choice: having made and articulated this priority (an active choice), he now puts aside further thoughts of end-of-life care, anticipating that others will make the right choice for him (deferred choice).

Third-party analogies

Third-party analogies involve expressing one's values and preferences by rejecting the experience of someone else, thereby avoiding explicit decisions. Participant 116 related a story about intubated patients to express her discomfort with the idea for herself:

> I don’t know. I’ve seen other people on breathing machines when I worked as a volunteer at [hospital]. I saw other people for months would be on a breathing machine and I don’t know what the prospects were for recovery. Maybe the doctors were more optimistic in predicting recovery if they became ill enough to be on a breathing machine. I don’t know. I don’t know for sure. It doesn’t appeal to me, the fact I would be maybe months on a breathing machine.

Participant 119 also used his experience to describe a scenario he would not want for himself:

> … like so many people I saw when I was working in neuro that wanted every possible thing done for the patient just so they could have them around. I never saw the practicality of that.

In these exemplars, the participants alluded to the care as futile and not in the patients’ best interests, but rather than directly say, “I do not want this myself,” they used the indirect language of “it doesn’t appeal to me” and “I never saw the practicality of that.” However, by telling these stories, participants were able to express the priorities and values they hoped would one day guide their providers or surrogates without having to make decisions themselves.

Adaptive denial

Adaptive denial involves a tacit acknowledgement that one’s health will decline, taking steps to ensure priorities and values are met, and then putting further thoughts in the background. Participant 118, who had chronic obstructive pulmonary disease, acknowledged putting thoughts of death in the background as an act of denial:

> You know, I’ve denied death my whole life. I was always positive that things weren’t going to change, and I just didn’t think you were going to die, or my husband was ever going to die. But the denial is just like some of the psychiatrists say.

Despite saying this, she knew that her condition would get progressively worse and that one day she was likely to need help:

> I built a room downstairs a year and a half ago. I don’t want to go to assisted-living. I want to stay here. But eventually, I will need somebody, if I live long enough. I put a new bathroom and a room. And of course, there is laundry down there. I have a place to put somebody to take care of me.

Participant 115 also avoided thoughts of end-of-life care: “I have not yet reached that stage. I can answer you that if I had reached that stage.” Nevertheless, she demonstrated that she knew she was at the nadir of her life by pointing to the many boxes stacked around her apartment:

> These boxes. I have many boxes here. Little by little – I am the one doing it – I pack them up. Every time, every week I ship out these things. Especially now when people are suffering there [home country] from the ravages of typhoons and floods. So I say, “Give it out there.” I have many, you know, friends who will dispose of these to people really in need. So, I say – and my other son, I shipped this out to the school. That’s why my place is a place like a warehouse. You see? There’s many boxes.

Adaptive denial had a protective function, allowing these participants to background thoughts about end-of-life decisions but still proactively take steps to prepare in a manner that reflected their priorities and values. By removing the demand to directly make decisions, they could avoid the distressful aspect of contemplating their own death and still *live* their values. As a result, they were able to maintain a sense of control – their situations remained manageable.

Engaged avoidance

Engaged avoidance involves a more direct approach to backgrounding than *adaptive denial*. Here, participants actively put thoughts of the end of life in the background and avoided thinking about their choices. Though this may appear like a passive form of decision making, *engaged avoidance* is actually an active process. Participant 110 said:

> I can’t even think about anything I wouldn’t want [at the end of life] because if I didn’t want it, I would avoid it, and I’d try very hard to keep from making an objective decision, you know, and things that would be contrary to my thinking in what I want to do in my life.

This quote intimates that the participant had priorities and values regarding the care he received, but he also said he had not discussed his preferences with his provider. As noted above, he gained a sense of control by having his providers make decisions on his behalf, so he did not feel a need to discuss choices directly with his providers. However, he also specifically excluded his family because “they make me feel like I’m not capable of making my own decisions,” yet he expected his daughter to act appropriately as a surrogate: “I just take for granted that my daughter would know [what to do].” Similar to *adaptive denial*, there appears to be a protective aspect in this case, a sentiment echoed by Participant 112: “I just don’t, you know, think about it. It doesn’t sound like a very interesting subject.” By not thinking about these choices, participants can avoid focusing on a very negative, and possibly distressful, aspect of their lives in favor of more positive ones.

Engaged avoidance involves compartmentalizing one’s life to keep positive aspects in the foreground and negative aspects in the background. But the approach also reflected having a clear perception of one’s health status and prognosis even when this perception was not consistent with the clinical picture. Participant 110 acknowledged his physical decline on the one hand but set the goal “to get better” on the other. Participant 113 accepted his health was declining and, though he did not think he was “going to die soon,” he wasn’t going to “make any long appointments.” Thus, these participants have set priorities that they hope will guide their surrogates when the time comes, even without a direct discussion of their preferences.

Contextual Factors

Data analysis also revealed three contextual factors that play important roles in either supporting or threatening participants’ sense of control: trust, acute situations, and family. These are interrelated concepts that work together and are not easily teased apart, but they reflect aspects of participants’ unique situations that lead to having a sense of control.

Provider Trust

Trust in one’s healthcare provider emerged as a common factor across interviews, and participants frequently talked about how this trust led to a sense of control over decision making. Participant 105 said he does whatever his provider tells him to do, but when asked if he felt in control of his decisions, he replied:

> Yes. [Because] I have confidence in their decision over mine regarding health. I have confidence in his decision and skill, and his experience, that I can trust him. For the most part, I trust all of my doctors.

Participant 119 echoed this sentiment, saying: "I'm certainly going to go on the assumption that these people know what they're doing, and I don't have to involve myself with it."

Underlying this trust is a belief that the provider had skills and expertise that participants do not. Participant 108 said, "I do what I am told," and then explained:

> Let's put it this way. You want to know something about cabinet making? Carpentry I do great with it. But medically, no. I can't even pronounce the dang words.

These participants saw themselves as ill equipped to make healthcare choices. But by delegating decisions to trusted providers, participants eliminated the demand for making decisions and achieved a sense of control.

On the other hand, a non-trusting relationship with providers could threaten this sense of control. Participant 103 spoke of the difficult relationship he had with his provider. First, he didn't feel she spent enough time with him, but also she did not take his concerns into account:

> She's the type that comes back with, "Well, if you don't wanna do it, fine." She's very blunt sometimes and not necessarily the right way. I mean, it's like, "Okay, fine. You want to kill yourself, kill yourself. I don't have time for that."

This participant did not necessarily disagree with the advice he was getting, but having a provider he couldn't trust meant he could not comfortably rely on the advice he received or defer decisions to the provider. To resolve the issue, the participant changed providers. In doing so, he attempted to re-establish a trusting relationship and regain a sense of control.

While saying they relied on their providers to make choices for them, some participants also identified having a safety net of sorts – to be able to take back control whenever they needed it. Participant 108 said, “I do what I’m told” regarding his healthcare, but he held out “I think it is my right to make the decision.” This allowed him to challenge his providers in the past when he felt it was necessary and allowed him to change his mind.

By establishing a trusting relationship with healthcare providers, relying on their training and expertise, and knowing that they could take back an active role in making a choice, participants were able to maintain a sense of control. In turn, the sense of control allowed them to shift their focus away from life-and-death decisions and to valued aspects of their lives.

Acute Situations

Participants also spoke of recent acute situations that required emergent in-the-moment decisions. In these cases, participants were in physical distress, sought immediate relief, and ultimately underwent some type of medical intervention. Participants did not feel that choices were presented to them and deferred to healthcare providers to tell them what must be done. The procedure or treatment was not participants’ focus; rather, the outcome was, and participants trusted providers to present the best choice. Participant 119 talked about going to the emergency department and ultimately having a pacemaker inserted:

> [They said] the pacemaker would be the most practical way to do it, and that I was pretty much assured of feeling a lot better once I had the pacemaker inserted. So that’s as far as the feedback that I got as to how the whole thing was going. They didn’t really give me a set of options because it pretty much sounded to me like the whole thing was etched in stone.

Despite the decision being “etched in stone,” he was comfortable with what was happening: “They knew best, and obviously I thought they knew best.” By trusting his providers and deferring to their recommendations, he focused on the goal of alleviating his acute symptoms and returning to his baseline state of health.

Acute situations could also threaten a person’s sense of control if the patients’ expectations were inconsistent with their clinical situations. Participant 114 spoke of her distress during a recent hospitalization when she had emergent cardiac stents placed. She felt she was taken in for the procedure before she was ready and described her daughter as “running along after the gurney, saying, ‘Wait! I have to research this.’” The participant noted that “you succumb to the medical powers,” and she felt she was being told, “Do what I tell you, like a little girl” without being given time to consider the proposed plan of care. However, the clinical circumstances likely did not allow for a long discussion, and because of an apparent lack of communication, a happy medium was not found.

The situation described by Participant 114 highlights an important aspect of these acute situations: the health provider and patient are often unknown to each other. Participant 114 describes her current primary provider as “just a dream;” however, she established the relationship over time. The cardiologist in the hospital was a provider unknown to her and saw an immediate emergent condition that could be resolved. Given the participant’s desire to “research” recommendations before consenting, she was likely to never be comfortable with in these circumstances and would continue to feel like she “was just a number” when hospitalized.

The anxiety and stress that accompanies these situations can make it difficult to adequately process all the information that is being given and may result in care the participants’ stated they did not want. Participant 101 spoke of having a norovirus and needing emergency care. Though he said he would not want to be intubated, he acknowledged that he might have ultimately consented: “You know, when you’re in the midst of it, you become pretty anxious. So you never know. If it had come to that [needing to be intubated] for me, I don’t know what I would have done.”

The relationship between trust and acute situations is apparent. Having a trusting relationship with providers made delegating decisions much easier, even when the providers were not well known to the participants. On the other hand, because acute situations usually involved unknown providers, a loss of control could exist because there was not enough time to establish a trusting relationship.

Family

Family was an important part of the context that could support or hinder a sense of control. Two participants had delegated decisions outright to their daughters and noted the comfort this brought them. Participant 111 said:

> I'm more comfortable with my daughter [making decisions]. I mean, I know she wouldn't steer me wrong. She went to college, which I didn't do. I just went to high school and that was my education. So, she's pretty well up on this stuff.

Participant 114 noted:

> My poor daughter has to do all the heavy grunt work, and it's just a burden. I'm sorry, but God, I'm glad she's there. I can't cope, and it's so complex now. I don't know if I could've coped when I was 20.

In both these cases, the participants felt their daughters were better suited to making decisions and delegating this task to their children relieved the participant of the burden without reducing their sense of control.

Other participants specifically left family out of their decisions as a means of preserving control. Still, they would ultimately rely on family members to act as surrogate decision makers and trusted that their chosen surrogate would act appropriately. Participant 104 said:

> My children try to reverse the role. In other words, they are trying to be the parent. And I am the one they are taking care of, which is sometimes aggravating to me.

As a result, he filled out a Physicians Order for Life-Sustaining Treatment (POLST) and simply told his family what he expected: "And I told them this is what's going to happen. This is what I want." This participant was similar to Participant 110, who earlier noted that his children treat him like he is incapable of making his own decisions; however, Participant 110's concern for his children's behavior resulted in him not talking about his end-of-life priorities and goals. Even so, he maintained a sense of control because he trusted his daughter to make the "right decision" when the time comes.

Discussion

The data reported here suggest that rather than focusing on specific decisions, our participants considered the context in which choices arise and outcomes that would result. They reflected on their personal priorities and values related to living at the end of life and used these to exemplify their past and future preferences for care. Instead of making independent choices, participants had a predisposition to delegate decisions to another person, usually healthcare providers or family. Though they wished to rely on a trusted person to make decisions, participants did not always discuss their priorities with this person. Still, they were comfortable with the arrangement and were able to achieve and maintain a sense of control over their decisions. Four overlapping categories of behaviors emerged that reflected the various ways participants expressed their priorities and goals that enabled them to have this sense of control. The results of this qualitative analysis have important implications to the notion of personal autonomy and patient decision making, as well as practice and policy.

Perceived Control and Autonomy

These findings are consistent with Wallhagen's (1998) theory of perceived control. According to this theory, a person achieves a sense of control by maintaining a balance between environmental demands and resources. People strive to maintain equilibrium between these competing factors, and when they are not aligned, a sense of control is lost. New demands (end-of-life decisions) can disrupt the balance and lead people to take steps to regain equilibrium.

Consequently, perceived control is achieved through one's self-appraisal of their circumstances and comes from the experience of having a *sense* of control, not from being *in* control. This can occur whether or not a person makes his or her own decisions. Of importance to the current discussion, Wallhagen's theory contextualizes the experience: a sense of control evolves from within the individual's unique personal situation.

In the context of living at the end of life, end-of-life decisions may create an imbalance between demands and resources that is alleviated by delegating decisions to others. By indirectly speaking of their priorities and delegating these difficult decisions, participants made adaptations to re-establish equilibrium and a sense of control. The desire to avoid and/or delegate difficult decisions has been noted by other researchers. Delegating decisions to healthcare providers may allow older adults to offset the need for making negative, challenging decisions (Lockenhoff & Carstensen, 2004). By yielding control for decisions to a trusted person, some women with breast cancer were able to maintain a sense of control (Astin et al., 1999; Swainston, Campbell, van Wersch, & Durning, 2012). Our participants had the same experience.

These findings challenge conventional notions of autonomy that focus on having patients make independent decisions about their healthcare (Entwistle, Carter, Cribb, & McCaffery, 2010; Holstein, Parks, & Waymack, 2011). Allowing patients to make independent choices is important; however, the focus on choice ignores the context in which decisions are made and the fact that patients do not always want to make decisions. Some of our participants, those represented by *engaged avoidance* and *adaptive denial* in particular, would be disinclined to exercise autonomy in an active manner. Likewise, if pressed to speak directly about their preferences, those who used *third-person analogies* would also have difficulty. *Direct communication* provided the clearest sense of what a participant wanted. Even in this case, however, some participants stated that they would no longer discuss their choices, ultimately leaving end-of-life decisions to others.

Our participants knew they were delegating decisions but still felt they had control over their decisions. Consequently, delegating decisions was in and of itself an exercise of autonomy. The sense of control achieved seems to have arisen out of the relationships participants had with their providers and, to a lesser extent, families. Central to these relationships is the trust that enabled the older adults to feel secure with others making decisions on their behalf. This concept of trust in relationship with providers is central to the understanding of autonomy as articulated by Holstein et al. (2011), who note "autonomy is only and always practiced in relationship to other persons and to social institutions" (p. 27). Thus, autonomy is itself contextual.

Advance Directives and Supporting Patient Decision Making

As a way to respect patient autonomy, older adults are encouraged to use advance care planning and advance directives to communicate their end-of-life care preferences. However, widely used advance directive documents, such as living wills, *Five Wishes* (Aging with Dignity, 2013) and the Physician/Medical Orders for Life-Sustaining Treatments (National POLST Paradigm, 2013), focus specifically on interventions and treatments, not the values underlying the choices – the focus of our participants. Researchers have noted that older adults' prefer value-driven advance care planning (McMahan, Knight, Fried, & Sudore, 2013) and that such an approach can act as an effective proxy to a written advance directive (Winter, 2013). Still, providers may have a hard time adopting such an approach. In a recent study, Lakin, Isaacs, Harris, Sullivan, and Sudore (2014, March) found that emergency room physicians identified treatment-focused advance planning, such as a do-not-resuscitate order or a POLST, as the most useful, while value-focused planning were the least.

We join our voice to that of many others who criticize the treatment-focus of advance care planning for its lack of attention to context. Fagerlin and Schneider (2004) argued that advance directives fail in part because the outcome of future needs cannot be predicted and articulating these treatment preferences is difficult. Sudore and Fried (2010) echoed this sentiment and argued that planning should focus on preparing patients and families to make future, in-the-moment decisions rather than set down a list of do's and don'ts that lack context. Our participants reflected these concerns. They had advance care discussions with their providers and in general did not want "heroic" measures or artificial life-support; however, they qualified these preferences if they could return to their current health. The determination that a given intervention would result in this outcome was left to the healthcare provider.

Our findings suggest that providers need to be open to the nuanced nature of decision making among older adults and to be willing to take a more proactive role in the process. Because providers have the training and knowledge that support clinical judgment, they understand the likelihood of different outcomes and can thereby situate choices within the context of patients' lives. With this understanding, providers can take different approaches to discussing choices. Those patients who actively background thoughts of the end-of-life (*engaged avoidance* and *adaptive denial)* are the most challenging, but providers can be attuned either to key actions taken or statements made. For example, Participant 118 built a room for a future in-home caregiver in order to stay in her home. When the time should come, her provider could encourage the patient to avail herself of the room and position in-home services, like hospice, as a means to achieve that end. Providers can explore *third-party analogies* and use this information to frame different outcomes from patients' own perspectives and priorities. Patients who use *direct communication* give the best guidance to providers. Using strong statements like "there will be no more surgeries in my life" (Participant 113), providers can present choices in light of these statements and even choose to not present options they know are incongruent with patients' preferences.

Providers may be reticent to actively make decisions or to limit the options presented to patients because they do not see this as their role, but there are many times when they find this appropriate (Bremberg & Nilstun, 2005; Fried, Stein, O'Sullivan, Brock, & Novack, 1993). Alternatively, some providers turn to surrogates to make decisions (White, Malvar, Karr, Lo, & Curtis, 2010). As our data indicate, patients are not necessarily talking to their designated surrogates either. To improve potential surrogates' understanding, providers need to bring them into discussions with patients at earlier stages and not wait until patients can no longer speak for themselves. Including surrogates in discussions does not have to be seen as usurping patient autonomy but instead as a way to ensure surrogates and providers have a mutual understanding of patients' values and priorities.

Implications to Practice and Policy

In order for providers to support older adults in the context of living at the end of life, they must have an intimate understanding of their patients. Achieving this understanding takes time and may be difficult for many providers. Hospital-based providers generally have not met patients prior to admission and are focused on the presenting clinical situation. Primary care providers have a deeper understanding of patients' perspectives and may better serve hospitalized older adults with advanced illness, particularly when it comes to making important end-of-life decisions. This is not to challenge the role of the hospitalist, only to highlight a limitation in a specific population.

Yet within the constraints of an office visit, primary care providers may be challenged for time as well. Policy programs could help alleviate this issue by supporting the training of more palliative care specialist who could then be available as consultants. Palliative care programs have been shown to improved patient outcomes by increasing satisfaction with care, alleviating symptoms, and reducing hospitalizations just prior to death (Schwarz et al., 2012; Temel et al., 2010). These specialist need not be exclusively physicians, as nurses, social workers, and chaplains can effectively provide palliative care services (Black, 2005; Breier-Mackie, 2001; Glombicki & Jeuland, 2014; Reeves et al., 2009). In addition to enlisting other professionals, communication tools are emerging that show great promise in helping providers talk with their patients and patients to articulate their needs (Bernacki, Gawande, & Block, 2014, March; Sudore et al., 2014).

We call on healthcare providers to take proactive steps to understand patient preferences and to ensure decisions are consistent with these wishes. One can argue that providers cannot be responsible for forcing decisions from patients who do not wish to make them; however, decisions are being made, even if by default. Further, there are additional costs to including more professionals into the mix, though current changes in healthcare systems may make other approaches more cost-effective. Recent changes in Medicare reimbursements and the creation of accountable care organizations aim to pay for the appropriateness and efficiency of the care, which includes reducing the intensity of end-of-life care and the frequency of hospitalizations. These are admirable goals that are consistent with our participants' views. However, to achieve these goals we must better understand patients' perspectives and use their perspectives as a starting point for discussions.

Limitations

As a qualitative study, we cannot make predictive statements from our data; however, they are consistent with the findings of many other researchers, adding to its generalizability. Only one participant was under that age of 70, so we may have missed generational issues between aging baby boomers and other older adults. Half of our participants were recruited through the Veterans Administration; as a result, their military background may have influenced their views and propensity to defer to their healthcare providers. The data rich themes and concepts, however, were noted across all the interviews and so did not appear to reflect the specific feelings of veterans. On the other hand, 16 of our 20 participants were in a medical-home program and received care in their residence. Thus, their willingness to delegate decisions may reflect a closeness to their providers that doesn't exist in those who are only seen a clinic or hospital. We also could not explore racial and ethnic variations because so few participants were members of a minority group. Future research should target older adults who receive their care through community-based clinics, particularly ones that serve minority groups in larger numbers.

We asked participants to discuss past decisions, so recall bias may have effected their responses. We also did not explore the perspectives of providers or designated surrogates; consequently, there may be disagreement among the groups that we could not explore. Future research should include the perspective of these other key players in decision making so the full complexity of the decision-making process can be understood. The problem with recall is inherent to a retrospective study and argues research involving in-the-moment data collection when decisions are actually being made. Still, as one of the few studies to explore current decision making among older adults with a limited prognosis, we add valuable insight and information to this important growing body of knowledge.

Conclusion

Our study shows that older adults with a limited prognosis do not necessary desire or need active control over their decision making. Rather, they want to rely on healthcare providers and family to understand their priorities and goals and to make decisions on their behalf that are consistent with their preferences. By understanding the different approaches adopted by adults, healthcare providers can better support both patients and potential surrogates in making choices. The goal should not simply be to reduce hospitalizations or enroll patients in hospice but rather to ensure that older adults receive high-quality care, including palliative care, at the end of life, no matter where this care is provided. Taking proactive steps to elucidate patient desires will help providers address patients' concerns and mitigate barriers to appropriate care.

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Table 2.

Participant Characteristics

N=20	
Age Range (median)	67 – 98 (89)
Gender	
Female	7
Male	13
Race	
White	17
Non-white	3
Marital Status	
Married	4
Widowed	8
Divorced	6
Never married	2
Perceived Quality of Life	
Excellent	3
Very Good	9
Good	2
Average	6
Poor	0
Number of symptoms[1]	

1 or fewer	3
2 or more	17
Number of Co-Morbidities	
2-4	4
5-7	13
8 or more	3

[1] Symptoms on the Edmonton System Assessment System > 3, as reported by the participants.

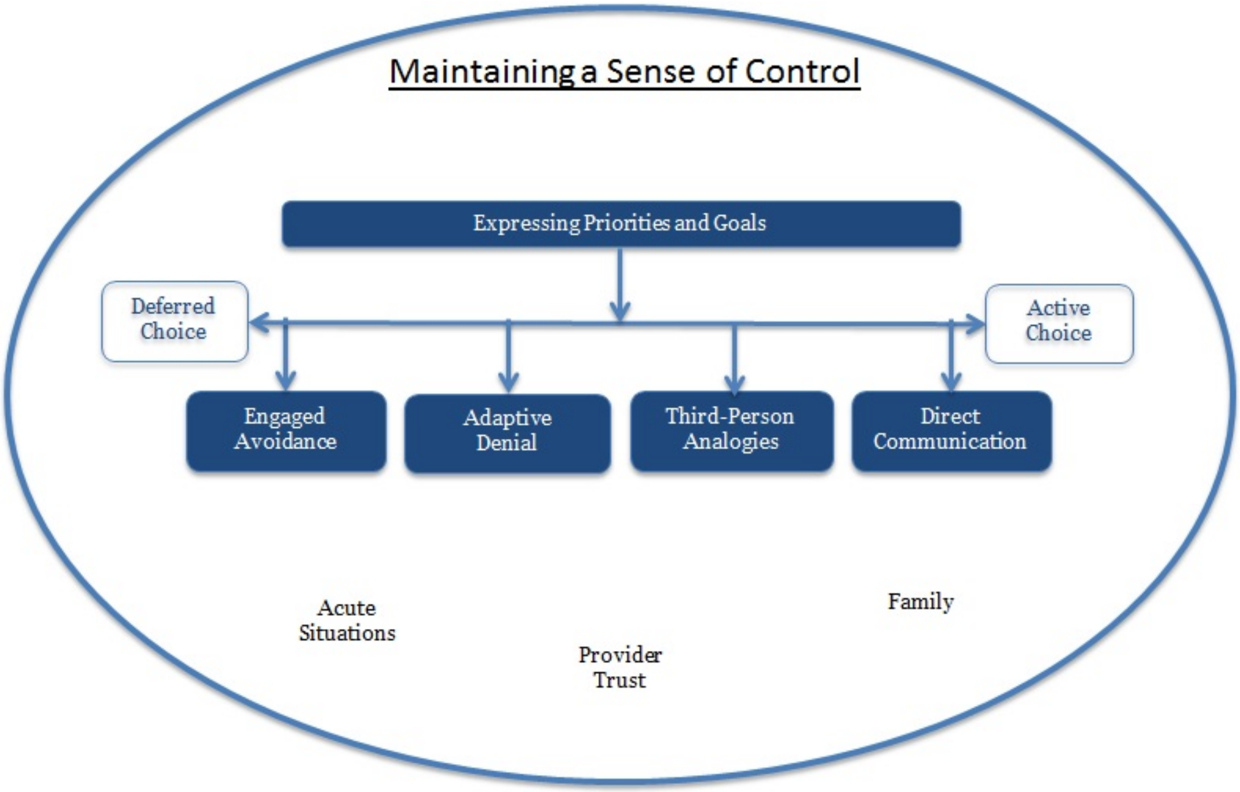

Figure 3. Maintaining a Sense of Control at the End of Life

Maintaining a sense of control does not necessarily come from actively making decisions. Instead, the sense of control arises from the ways participants found to express their priorities and goals, usually with the expectation that someone else will make an appropriate decision on their behalf. Decisions are made within a contextual environment that is influenced by provider trust, the acuity of the situation, and family. Participants achieved a sense of control by balancing the demand of making a decision with their environmental resources. The four ways of expressing goals and priorities (engaged avoidance, adaptive denial, third-party analogies, and direct communication) yield different degrees of participation with respect to making choices, either fully deferred to others or actively choosing. However, even within each approach, participants could reflect both deferred and active choice. For example, participants who utilized direct communication did so by clearly stating they did not want certain types of care, such as being hospitalized. However, they also state that once the decision had been articulated, they would no longer think about it, deferring to a delegate to make the actual decision.

CHAPTER FOUR

DECISION MAKING AMONG OLDER ADULTS WITH A LIMITED PROGNOSIS: A THEORETICAL PERSPECTIVE

Background

Older adults' preferences for end-of-life care are not static; rather they can change over time and need to be periodically revisited. Using life-sustaining treatments as a measure of end-of-life choices, researchers found that overall preferences largely stayed the same over time but individual variability existed: participants' preferences change from wanting more treatment to wanting less and vice versa (Barrio-Cantalejo et al., 2013; Carmel & Mutran, 1999; Danis, Garrett, Harris, & Patrick, 1994; Ditto et al., 2003; Fried et al., 2006). To complicate the issue further, these studies found different variables to be significantly associated with a desire for life-sustaining treatments, with only a decrease in physical functioning being seen across all. This variability may impede healthcare providers' efforts to support patients' decision making, especially as they get closer to death. Predicting when, and among whom, these changes will occur is difficult but could help healthcare providers anticipate and navigate difficult conversations.

Health status influences the type of care older adults find acceptable near the end of life. Compared to those in better health, older adults in poor health are more willing to accept life-sustaining treatments (Fried et al., 2006; Straton et al., 2004; Winter, Lawton, & Ruckdeschel, 2003; Winter & Parker, 2007). However, when looking at longitudinal data, conflicting results have been seen: preferences for life-sustaining treatment either increased or decreased with declining health, depending on the study (Fried et al., 2007; Janssen et al., 2012; Straton et al., 2004). In contrast, prognostic awareness may be a more consistent indicator of a desire for life-sustaining treatments. Participants who perceive their prognosis to be short were more likely to forgo treatments (Casarett, Van Ness, O'Leary, & Fried, 2006; Huskamp et al., 2009; Temel et al., 2011; Weeks et al., 1998). As older adults' health declines, their perception of prognosis may change; consequently, an interrelationship may exist between health status and prognostic awareness that influences older adults' preferences for care and is not captured in the current research.

Comparing studies in this field is challenging. Different measures for health status have been used, as well as different instruments to measure preferences for life-sustaining treatments. Measures also used hypothetical scenarios rather than focusing on actual decisions. Further, some studies focused on cancer patients while others used more broad samples of older adults. Finally, these are descriptive studies that did not explore the underlying motives for the choices articulated.

Though many theoretical frameworks have been proposed that aim to better support patients' decision making and improve satisfaction with decisions (Charles, Gafni, & Whelan, 1999; Janis & Mann, 1977; Mishel, 1990), few aim to explain the behavior that underlies the process. Prospect theory (Kahneman & Tversky, 1979; Tversky & Kahneman, 1981) has been gaining interest in healthcare, particularly regarding end-of-life decisions (Rasiel, Weinfurt, & Schulman, 2005; Verma, Razak, & Detsky, 2014). This is a robust economic theory and posits that people frame choices (prospects) as positive or negative relative to a reference point that lies on a continuum that has some value to the decision maker (commodity). The reference point is the point where a prospect would have a zero value; that is, it is seen as neither a gain nor a loss. In healthcare has often been health status (Dolan, 1996; Winter et al., 2003). We illustrate the properties of prospect theory in Figure 4a, where the commodity is health status and ranges from death in the loss domain to perfect health in the gain. The reference point could be a person's current health status, so a prospect that would not result in a change in health status has no value. A prospect that would result in a decline in health status would be considered a loss and have a negative value versus a gain and positive value for improved health status. End-of-life decisions typically involve choosing between options that result in some degree of decline, putting both prospects in the loss domain. Because of the non-linear nature of the value curve, the relative difference between two prospects will appear greater when one or both of the prospects lie close to the reference point ($d_1 > d_2$).

Researchers have empirically tested prospect theory and argue that it explains the variability in preferences related to health status (Dolan, 1996; Happich & Mazurek, 2002; Kievit et al., 2010; Winter et al., 2003; Winter & Parker, 2007). However, their findings do not explain those of other researchers who note the influence of prognostic awareness on the patients' willingness to forgo these same treatments. It appears when the reference changes to perceived time left to live (prognosis) from health status, the values of choices also change. The purpose of this qualitative study was to explore how the perception of prognosis and health influenced decision making among older adults with a limited life expectancy. The aim was to understand the phenomenon from the perspective of those in the midst of making important decisions related to their healthcare. We discuss the findings in light of prospect theory to explore how the findings inform the theory and explicate its limitations in the context of decision making near the end of life.

Methods

We report on a qualitative exploratory study designed to compare and contrast participants' experiences with decision making at the end of life within the context of their perceptions of health and prognosis. This analysis was part of a larger study that explored the overall decision-making processes among older adults with a limited prognosis and used grounded theory to guide its design, implementation, and analysis (Charmaz, 2006; Corbin &

Strauss, 2008). The University of California San Francisco (UCSF) Committee on Human Research and the San Francisco Veterans Administration Medical Center (SFVAMC) Research and Development Committee approved the study protocol.

Study Participants and Setting

Participants were recruited through the SFVAMC Home-Based Primary Care program, SFVAMC Geriatrics Medicine clinic, UCSF Housecalls program, and UCSF Center for Geriatrics Care. We met with primary care providers (physicians and nurse practitioners) to explain the purpose of the study and eligibility requirements and then asked them to refer appropriate patients. Eligible patients were those who were 65 years of age or older, had a life expectancy of less than one year, were capable of making their own decisions, resided in the community, and were English-speaking. Participants were not excluded based on a specific diagnosis or preference to delegate their decisions. We specifically excluded patients residing in skilled nursing facilities.

Providers determined life expectancy by asking themselves the question: “Would I be surprised if this patient dies within the next 12 months?” If the answer was no, the patient met the prognostic eligibility. The providers consulted with affiliated social workers and psychologists to exclude patients with significant cognitive impairment and patients they believed could not withstand a 45-minute interview. Potential participants were first identified because they met the inclusion criteria and the referring provider believed the patients would be good informants. Subsequent participants were identified and recruited based on their ability to develop and expand emerging themes and concepts. Recruitment continued until theoretical saturation was achieved.

Twenty participants were recruited. Detailed information about each participant is given in Table 3. Thirteen participants were men and seven were women. The ages ranged from 67 to 97. Seventeen were White and three were non-White. Four participants were married or in domestic partnerships. Half of the participants were recruited through the SFVAMC and were men. The Edmonton symptom assessment scale (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991) was used to understand participants' perception of their symptom burden, and all but one reported having some symptoms (rated as 3 or higher on a scale of 0 to 10).

Data Collection

Potential participants were mailed information about the study and asked to return a response card. A member of the research team (RDR) contacted respondents, explained the study, and verified eligibility. A teach-back approach was used to ensure that potential participants were able to understand and explain the study. As a result of the teach-back, three people were excluded. We specifically sought out informants from racial and ethnic groups; however, the number of respondents from these groups was small.

Arrangements were then made for a face-to-face interview in participants' homes. At the start of the meeting, the study was explained a second time and informed consent was received using a teach-back approach. No one was excluded at this stage. The interview guide focused on four general areas: (a) participant's current health and healthcare; (b) recent decisions and communication with providers; (c) decisions made regarding end-of-life care; and (d) participant's anticipation for future care. During interviews, probes were used to explore and clarify the ideas and concepts articulated by participants. All interviews took place over a four-month period, and each participant was interviewed only once. Participants' views on hospice were of interest; however, most participants had no experience with or understanding of the services, so the data were not useful to the analysis. After the interview was concluded, participants were asked to fill out a short demographic survey and the Edmonton symptom assessment scale (Bruera et al., 1991). Interviews were digitally recorded and professionally transcribed. A single researcher (RDR) conducted all interviews and verified all transcripts for accuracy.

Because of the sensitive nature of the interview, attention was paid to participants' responses and reactions to the questions; however, none of the participants expressed undue distress nor asked to end the interview. Further, the final question asked participants to focus on positive aspects of their lives, thereby ending the interview on a positive tone.

Data Analysis

The interview guide was developed based on extant literature and was reviewed by experts in aging, decision making, and end-of-life care. The guide was pilot tested for face validity and modified to clarify areas of ambiguity and confusion. In keeping with the constant comparative methodology (Charmaz, 2006; Corbin & Strauss, 2008), we modified the guide over the study period as the ongoing analysis identified emerging themes and concepts that needed explication. Probes were used to refine and explore participants' responses more deeply and to relate these responses to existing themes and concepts.

Participants' perception of their health and prognosis was determined by analyzing their responses to various questions. Positional maps (Clarke, 2005) were used to generate the findings reported here by laying out the various positions taken within the data related to participants' perceptions of prognosis and health. Throughout the study, field notes were taken and memos were written to capture methodological issues and theoretical perspectives as they arose. We explored the similarities and differences seen within and across interviews, and we identified negative cases to challenge and refine the emerging concepts. In accordance with constant comparative analysis, analysis and coding began with the first interview and continued iteratively with each subsequent interview. As new codes were generated, earlier transcripts were recoded. The data were coded and analyzed using NVivo qualitative analysis software (QRS International, 2013).

A single researcher (RDR) undertook the coding and met with members of the research team to review interviews and discuss the emerging codes, concepts, and categories. When disagreements arose about the meaning of participants' interviews and the emerging codes, they were resolved by consensus. The research team represented expertise in geriatrics, gerontological nursing, palliative and end-of-life care, ethics, decision making, and qualitative methods. To further support the quality and rigor of the analysis, interim findings were discussed with experts outside of the research team. These included professionals in aging with expertise in medicine, nursing, social work, and sociology.

Results

Decision Making in the Context of Ambiguity

Analysis revealed an overarching theme of *decision making in the context of ambiguity* that resulted from participants' feelings of uncertainty and ambivalence regarding future, end-of-life care. This care was seen from a contextual point of view but one that could not be accurately predicted. Thus, participants believed that the circumstances and outcomes of decisions could change and might be open to different interpretations. It was from within this ambiguity that they defined their priorities and goals at the end of life and articulated the challenges of making decisions. Using the possible circumstances and outcomes of decisions, all participants put limits on what they considered acceptable or unacceptable care. However, these limits were stated in very broad generic terms, such as not wanting to be maintained on artificial life support, lose cognitive abilities, or suffer physical discomfort.

Where participants drew the line and when it would be crossed varied. Even when talking in strong terms, they recognized that their stated preferences were not absolute because of the uncertainty inherent in any outcome. Participant 110 spoke of the challenges faced when considering end-of-life choices, saying, “I wouldn’t know which direction to go, you know. You might plan for this thing and something else happen, you know? So, I can’t really plan.”

Along with uncertainty, some spoke of seeing both good and bad aspects of a choice and noted how this ambivalence made decisions difficult. Participant 106 notes:

> She had me sign a DNR for – but I thought I’d think about it later. Well, I’m now to the point where something like that would help, but I certainly wouldn’t want people not to resuscitate me for some reason. If it were a temporary thing, you know? But if I had signed the DNR, well, they might not do that for me. But if there weren’t much of a chance for my recovery, I think it’d be okay to have the DNR. If it’s some little thing that I’m unconscious because of some little thing, I could get better anyway? If that DNR were signed and people would leave me alone and not even try to get me back, well that wouldn’t work so well. Only if I would – it were a matter of being bedridden from then on or maybe even wheelchair ridden from then on, then they could do it.

These two quotes exemplify how uncertainty of and ambivalence towards the possible outcomes creates ambiguity about choices: depending on the perspective taken, choices may be valued differently and result in different decisions. Consequently, participants hedged their decisions saying they would (or would not) make certain decisions “unless.”

The data also revealed that prognosis and health status were important factors that influenced how participants balanced different priorities. Participants appeared to be value choices based on their perceptions of their health status and prognosis, which led them to prioritize choices that would extend length of life or maximize quality of life. Some participants, however, used both health status and prognosis to value choices, looking for a happy medium that would satisfy all their priorities. Participants expressed what they believed their prognosis to be: short, long, or uncertain. Similarly, they articulated their perceptions of their health status as being good or poor. Given these variations, participants fell into one of six groups that represented their perception of their health (excellent/good or average/poor) and their prognosis (long, uncertain, or short), and the analysis of these groups gave rise to three categories that reflect how participants articulated their priorities and goals at the end of life based on their perception of health status and prognosis: *focusing on living*, *being comfortable*, and *using a sliding scale*. Though these categories are presented as distinct, participants articulated views that could be attributed to each of the categories but tended to be represented by one more than the others. Table 4 shows how the three categories that emerged are represented among the six groups identified. We present a model of the context of decision making in Figure 5.

Articulating and Balancing Priorities

Focusing on living

Focusing on living was seen primarily among those who perceived a long prognosis, whether their perception of health was good or bad. Indeed, among those who acknowledged health problems, they put these issues in the background and anticipated getting better. Participant 118 said, “I don’t consider myself sick,” while acknowledging her health will likely decline. But she also backgrounded the issue, saying, “I anticipate it [obstructive pulmonary disease] won’t – it will stay about the same if I keep up exercise. I don’t think [it will get worse] – well, it probably will get a little worse.” In this way, she demonstrated the idea of perceptional congruence, or the view that her prognosis (long) was inline with their view of their health (good or improving).

Focusing on living was accompanied by a willingness to undergo treatments to achieve the goal of living as long as possible, even if the treatments resulted in some physical decline.

However, these decisions were not always seen as choices, as Participant 114 explained: "It didn't seem like I had a choice – I mean I could've said, 'No, I'm just gonna die at home,' [but] I don't know that there are many choices." Because such participants' prioritized living longer, viewing the alternative outcome as dying meant it was not a choice and as such was not considered as an option.

Participant 118 had a slightly different perspective. She had a positive attitude that she felt would enable her to endure significant decline to continue living:

> I was positive that I could beat it, and I think – I know it has a lot to do with it, but I've always been positive. [So,] I think I'd want to live. … But no matter what the disability, if I were comfortable in a wheelchair, I'd take it.

Participant 118's comment "if I was comfortable" revealed her awareness that there are outcomes that would limit her desire for life-extending treatments. The priority to extend life ends "if I couldn't function mentally and I was in pain and I was on a ventilator, artificial feeding." Participant 103 said similarly, "I would probably try anything that would not come to the end. … If something came up that – to be in a vegetative state, then no." Consequently, if a treatment resulted in a significant enough decline in health, it would have less value.

A priority to live as long as possible was not exclusive to those who felt they had a long prognosis and were in good health. Participant 105 did not have a clear perception of his prognosis but said he wanted to focus on living as long as he could:

> I'd want to live longer, but I wouldn't want to live if I was gong to be a vegetable. … [But] if I were confined to a chair or something, I would make the best of it.

Though he was unsure of his prognosis, he believed he was recovering well from a recent illness and was hopeful for a recovery. So, in this way, he was similar to the participants quoted above, and his priority to live longer was consistent with his perception of his health.

Both Participants 105 and 118 illustrated the importance of adaptation. By adapting to declining health, they could focus on meaningful aspects of their lives. Participant 105 offered:

> I would make the best of it [increased disability and decline]. I'd look for the advantages. The good part. What is the good part of this? What's good? What could be good about this? … [If I am] able to enjoy my life.

As exemplified by these participants, adaptation increased their quality of life and likely mitigated a need to focus on comfort and physical decline. Consequently, they shifted their priorities to focus on living longer.

Being comfortable

Perceptional congruence was also seen among those who believed they had a short prognosis and poor or declining health. In this case, participants focused on comfort, including the ability to maintain valued activities, and rejected some types of care. Participant 108 said:

> To tell you the truth, I have no future, so why bother with it [life-extending treatments]. My doctor asked if I thought about surgery [for my heart], and I just said, "No." I'm not interested in surgery and stuff like that. Let's treat it and keep it calm. That's all. I want to sit back and enjoy my boys. I've got a beautiful set of boys [that] you ever wanted to see. I am the richest man in the world.

This participant considered himself close to the end of life and placed a great deal of value on the satisfaction he received from his family. Consequently, he prioritized his ability to continue this interaction over having a surgery to address his unspecified heart condition. Participant 113 likewise spoke of wanting avoid hospitalizations and to maintain certain pleasures:

> I have a cigar every night after supper and a cup of coffee. Always have. And as I told the doctor [when he recommended I quit smoking], there are some sacrifices I won't make or some things I won't do.

He then described an occasion when he fell and paramedics were called:

> By the time they [paramedics] got here, I was feeling better. I was in bed, and two of these guys came in, and I told them "Thank you, but I don't want to go to the hospital." He said, "You've got to." I said, "Oh [*explicative*] you! What do you mean I've got to? This is America, for Christ's sake. Look out the window!"

Participant 113 stayed true to his priority of avoiding hospitalizations. He understood that there could have been a serious underlying cause of his syncope, but because he could still speak for himself, he was adamant that he would not leave his house. This was also consistent with his desire to “die in this house.”

These participants valued comfort over length of life based on their perception of prognosis. Despite clear priorities, *being comfortable* did not involve an absolute rejection of all measures that might extend one’s life. Participant 113 held out, “I did say no heroic measures. But I want a shot. If there’s a shot at living, give it to me.” Thus, a tension remains between refusing interventions viewed as potentially painful or futile and a desire not to die. Like other participants, he did not say what “a shot” meant or whether hospitalization would be acceptable in this situation. As such, he demonstrated the struggle participants had expressing choices because of the ambiguous context of the outcome.

Using a sliding scale

Those who felt their prognosis was uncertain and, to a lesser extent, those who perceived themselves to have a short prognosis but to be in good health, did not have clear preferences for comfort over length of life. Instead, these participants spoke of balancing the two goals. What was or was not acceptable was nuanced and based on the circumstances and degree to which one would experience distressing symptoms. Participant 107 said he would “try everything to keep things going” but explained that end-of-life decisions were not so black-and-white:

> That would be dependent upon, at that point in time, my level of being able to take care of myself. How severe the deterioration is. If I’m gonna be bedridden for the rest of my life, or am I gonna be comatose. That would be a sliding scale on what I would do or decide to do. … I don’t have a roadmap for that.

This exemplar demonstrated that some degree of experiencing unwanted symptoms could be acceptable depending on other circumstances. Consequently, any treatment decision is a contextual one that cannot be easily anticipated, much less described. Instead, this participant would wait until the situation arose before making a decision on what treatment to receive. If he was unable to make decisions on his own, he trusted his provider or surrogate to make the best decision on his behalf.

Adaptation is also reflected in *using a sliding scale*. Part of the balance Participant 107 attempted to achieve arises from adapting and accepting decline:

> Well, [it's] how you deal with [it] – I don't dwell on it. I can't do – I can't play tennis. I can't play golf. I don't dwell on these things. I mean I accept them. There's nothing I can do about it. There are some things collectively with the docs I can do to maintain a reasonable standard of living as far as activities go. But I know my limitations, and I accept them.

Accepting and adapting to changes is good, as long as his threshold of acceptability was not crossed.

Discussion

Our study explored decision making among older adults with a limited prognosis who were in the midst of making significant decisions related to their healthcare. Unlike previous studies that described the statistical relationship of health status and prognostic awareness to end-of-life decisions (Casarett et al., 2006; Fried et al., 2006; Huskamp et al., 2009; Janssen et al., 2012; Straton et al., 2004; Temel et al., 2011), we used qualitative methods to understand the underlying processes that informed participants. Participants used different approaches to make decisions and relied on the context in which decision making occurred to frame and value options. Participants noted that this context could neither be fully understood nor appreciated until they were in the midst of it. Consequently, attempts to make decisions around end-of-life care were couched in ambiguity. Thus, decisions were conditional and subject to change as the context changed. Participants who articulated the clearest preferences (*focusing on living* and *being comfortable*) still hedged their decisions and indicated there were conditions under which their choices might be different. Those who had uncertain perceptions of their prognosis stated that all decisions were contextual and actively balanced competing priorities (*using a sliding scale*). Generally, participants did not specifically speak of quality of life; however, they did talk about the importance maintaining physical comfort, cognitive abilities, and meaningful activities. These factors, particularly physical comfort, are key elements in many measurements of the quality of life at the end of life (see systematic review by Mularski et al., 2007), so we can argue that the participants were balancing the competing priorities of length and quality of life.

Our findings reflect some aspects of prospect theory. *Focusing on living* used health status as the commodity and their perceived baseline health as the reference point. As a result, participants prioritized living longer and framed choices (prospects) relative to their health. Prospects that extended their lives were acceptable because participants anticipated a return to or near their baseline health. Conversely, *being comfortable* used perceived prognosis as the commodity, framing and valuing prospects in relationship to it. Options that would decrease comfort and ability to maintain important activities, and thereby impact their quality of life, were framed as greater losses compared to those that preserved these areas. *Focusing on living* reflected an often-overlooked aspect of prospect theory: the reference point need not be the status quo. From a clinical perspective, all the participants were in poor health, but the perception was quite different for many, who believed they were in good or improving health. For them, a prospect that promised a return to their perceived baseline health was viewed as a gain, not a loss, so the discomfort related to a particular choice was acceptable.

Our findings also lend support to the effect of framing on decision making. Researchers have found framing to be important, noting that changes in the wording of questions can change participants' answers even though the outcomes remain the same (Coppola et al., 1999; Winter, Parks, & Diamond, 2010). Our participants frequently used framing to articulate choices. "If there's a chance," "if I am comfortable," and "I want a shot" were prospects framed as gains. On the other hand, statements like "in a vegetative state," "couldn't function," and "weren't much of a chance" reflected negative framings. Through framing, participants noted the uncertainty in and ambivalence toward end-of-life decisions, attempting to illustrate the nuanced nature of their decisions. Framing also set limits on a particular choice, making a decision acceptable under certain circumstances.

A limitation to prospect theory is that only one commodity can be used to determine value. This is feasible when applied to economic situations where all prospects would have a monetary value. In that case, both objective and subjective aspects of assigning a value can be measured in monetary units. However, other types of commodities are valued very differently. Different commodities and reference points could explain why some studies found that older adults in poor health had preferences for life-sustaining treatments (Fried et al., 2006; Winter & Parker, 2007) while other studies found that those who perceive a short prognosis are inclined to forgo the same treatments (Casarett et al., 2006; Huskamp et al., 2009). *Using a sliding scale* illustrated how participants used both of health status and prognosis as a commodity. A model of prospect theory that allows the use of two commodities could provide a framework from which to view the balancing done by our participants. We illustrate what this might look like in Figure 4b. Prospects are valued not only based on framing and the reference point but also on how a person uses the two commodities.

Our model has limitations. By adding a second commodity, we have created a 3-dimensional framework that significantly complicates the theory. Prospect theory is rooted in robust, rigorous mathematical modeling that is beyond the scope of this analysis, and we acknowledge that our perspective simplifies that complexity. Researchers in healthcare decision making have empirically verified the shape and nature of the value curve (Verhoef, de Haan, & van Daal, 1994; Winter et al., 2003), and we are unable to say if or how that could be done with our extension. One could argue that there is a single commodity at play and that other factors are used to weight prospects. The weighting function is another aspect of the theory often overlooked but represents how perceived probabilities contribute to the value of prospects. Perceptional congruence may indicate that prognosis had a greater influence on our participants than health status. Participants may have valued choices based on how long they thought they might have to live, and health status was used to weight the prospects instead of being a competing commodity. Thus, a long prognosis meant length of life received more weight than quality of life and influenced the choices participants articulated. However, *using a sliding scale* indicated a more involved process was at play for many participants. Quantitative studies are needed that specifically explore the relationship between perception of health status and prognosis, particularly with large datasets that would allow for greater generalizability.

The act of balancing between length and quality of life has also been noted by other researchers among patients with various conditions, such as cancer, heart failure, and pulmonary disease (Chen, Haley, Robinson, & Schonwetter, 2003; Dev et al., 2012; Fried, Bradley, Towle, & Allore, 2002; Meropol et al., 2008). Consequently, despite its limitations, our model provides a good conceptual framework from which to view the variable and dynamic approaches used by patients to make decisions at the end of life, even if it cannot be tested empirically in the way prospect theory has.

The three approaches we identified in our analysis reflect the different ways participants try to value choices against competing goals. The contextual issues identified reflect the various factors that come to bear on the values placed on choices. By understanding that patients' reference points are variable, healthcare providers can better support their patients' decision making by identifying a common starting point for discussions. From there, providers can help patients reframe choices in a manner that reflects their values, minimize uncertainty and ambivalence, and facilitate patient-centered choices. For example, knowing that a patient prioritizes quality of life, providers can frame end-of-life care decisions from that perspective. Thus, a decision to be hospitalized or not results from the likely outcome of the stay. For patients who prioritize length of life because they believe they have a long prognosis, providers can gently and gradually bring these perceptions more in line with patients' clinical circumstances, resulting in a new reference point and different framing. Then conversations to elucidate the limits of patient preferences could be more fruitful. For patients who lay between these two goals, providers can work to minimize patients' uncertainty and ambivalence, thereby gaining a clearer understanding of patients' true values. Finally, since older adults often anticipate that end-of-life decisions will ultimately be made by someone else, our model can help providers make better judgments on patients' behalf and guide family members who are acting as surrogates.

As a qualitative study, we cannot make broad, general inferences from the data. The findings can only be used to understand that older adults use different approaches to end-of-life decisions that reflect how competing goals are balanced. A key component of our analysis was to understand participants' perceptions of their health and prognosis. However, we had to intuitively determine their views by analyzing the entire interview. Efforts to maintain the quality of data collection and analysis should have mitigated possible errors in coding. The fact that participants self-defined their health status and prognosis means our data reflect a different perspective than other studies and limits our ability to compare our findings. Half of our sample was recruited through the Veteran's Administration, and their military background may have influenced their views. However, the analysis did not reveal thematic differences between the groups. Similarly, most of the participants received their healthcare in their homes, thus their experience may have been much different than those who receive care through outpatient clinics. We were unable to explore racial and ethnic differences because so few of the participants were from these groups.

Conclusion

By examining participants' perception of health status and prognosis and exploring the ways these perceptions influenced older adults' decision making at the end of life, we have been able to examine how prospect theory can inform decision making – and how the theory is limited. Many aspects of prospect theory were seen in our data; however, the theory was unable to account for the manner in which our participants used both health status and prognosis when making decisions. We argue that extending prospect theory to include multiple commodities may be helpful, and we provided an illustration of what this might look like. As a conceptual framework from which to view how older adults used these commodities to achieve a balance between the competing goals of length versus quality of life, the model can be useful to both researchers and providers.

Our study has important implications for healthcare providers who are tasked with helping older adults make difficult decisions as they approach the end of life. By understanding that choices are valued based on patients reference points and that patients are frequently trying to balance between competing goals, providers can alleviate the conflict patients often feel when making decision and facilitate discussions about care from the patients' perspective. The starting point must be patients' perspective, even if not supported clinically. The result would be decisions consistent with patients’ priorities and goals, as well as increased satisfaction with the ones made.

It is quite possible that a radically different decision-making theory is needed to understand patients’ behavior at the end of life. The contextual environment in which a choice is made may change dramatically when death goes from being an abstract idea to a reality. This change may not be captured in existing theories on decision making but may explain why many researchers have contradictory findings. We propose a model that we hope will stimulate the dialog in both research and practice.

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Table 3.

Participant Characteristics

N=20	
Age Range (median)	67 – 98 (89)
Gender	
Female	7
Male	13
Race	
White	17
Non-white	3
Marital Status	
Married	4
Widowed	8
Divorced	6
Never married	2
Perceived Health	
Excellent	2
Very Good	4
Good	4
Average	6
Poor	4
Perceived Prognosis	
Long	6
Short	8
Unknown	6
Number of symptoms[1]	
1 or fewer	3
2 or more	17
Number of Co-Morbidities	
2-4	4
5-7	13
8 or more	3

[1] Symptoms on the Edmonton System Assessment System > 3, as reported by the participants.

Table 4.

Categories of Perception based on Health and Prognosis

		Perception of Health	
		Good Health	**Average/Poor Health**
Perception of Prognosis	**Long Prognosis**	*Focusing on Living* I've always been healthy. So, I don't, you know, think about it [care at the end of life]. (Participant 112)	Give it a go, if there's a chance I'm gonna come back. (Participant 114)
	Uncertain Prognosis	I don't even think about it, [but] I wouldn't want to be on life support. (Participant 111)	*Using a Sliding Scale* You say to yourself, "Where's the quality of life? Where's the enjoyment or how am I able to function the way I'd like?" I know that's a grey area, and it's a difficult thing to put into words. (Participant 119)
	Short Prognosis	That is not yet. I have not yet reached that stage. I couldn't answer that. I can answer you that if I had reached that stage. (Participant 115)	*Being Comfortable* Keep me comfortable. That's all. Painless and comfortable. (Participant 108)

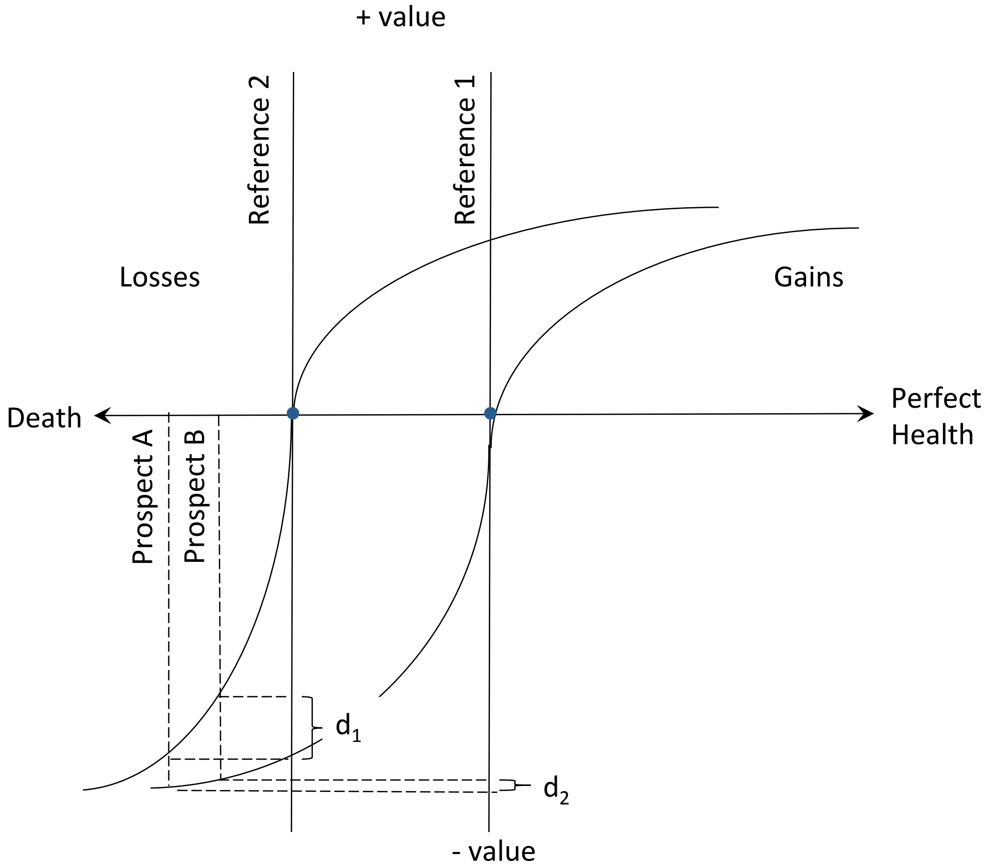

Figure 4a. Prospect theory Applied to Healthcare Decisions.

Prospects (choices) are valued positive (gains) or negative (losses) relative to a neutral reference point. The reference point and prospects lie on the continuum of a commodity (health status). In this example, health status ranges from death (the worse status) on the left to perfect health on the right. The value of a prospect changes in a non-linear manner as it becomes more “distant” to the reference point. The S-shaped nature of value curve the means that the value of a prospect changes the most when closest to the reference point; consequently, the relative difference between two prospects is greater when one or both prospects are close to the reference point ($d_1 > d_2$).

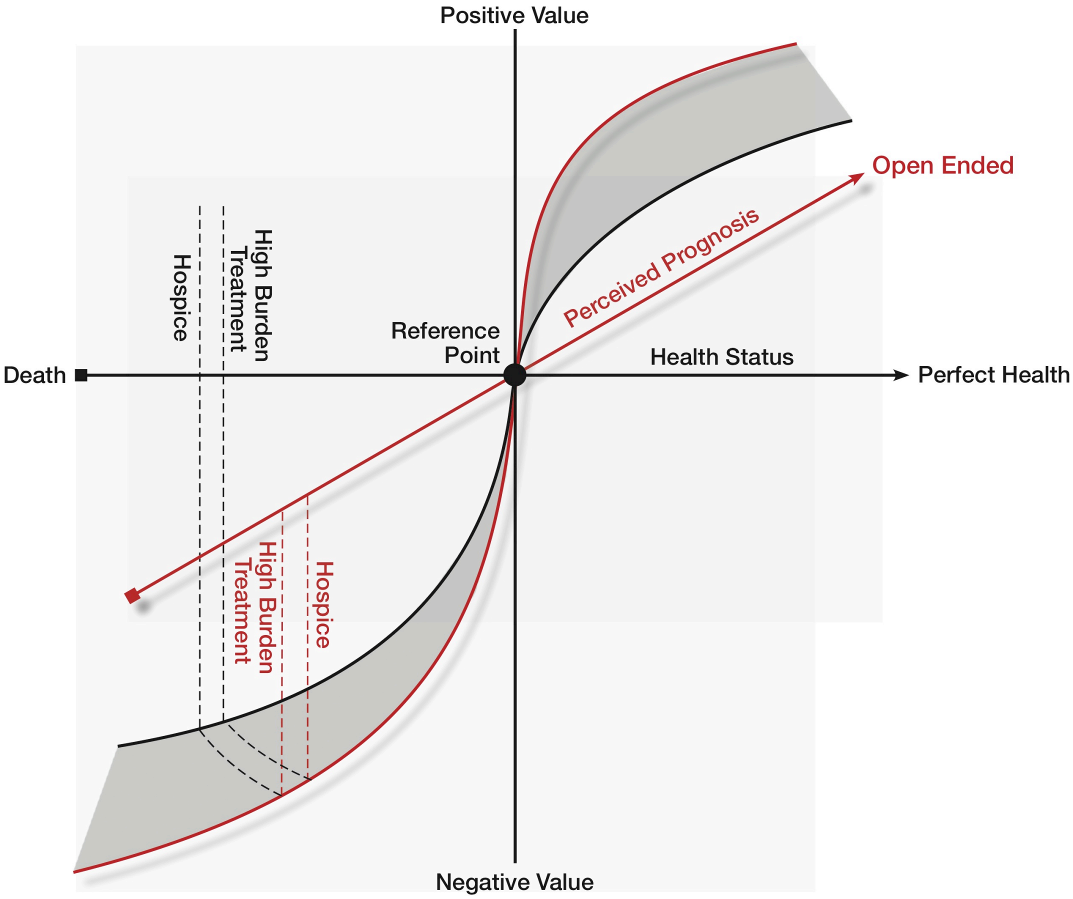

Figure 4b. An Extended Model of Prospect Theory Applied to Multiple Commodities.

This extended model introduces a second, competing commodity. Here, a prospect is valued, not just on framing and the reference point, but also on how decision makers use both commodities. If decision makers rely solely on one commodity or the other, then the model functions the same as the 2-dimensional model in Figure 1a (i.e. if health status is the commodity being used, then the example in Figure 1b applies). When competing commodities are used, the value of the prospect changes depending on how decision makers are balancing between the two. If they lean to one commodity over the other, then the value of the prospect will be influenced by the preferred priority. However, if they are using both commodities more equally, the value depends on where decision makers lie between the two.

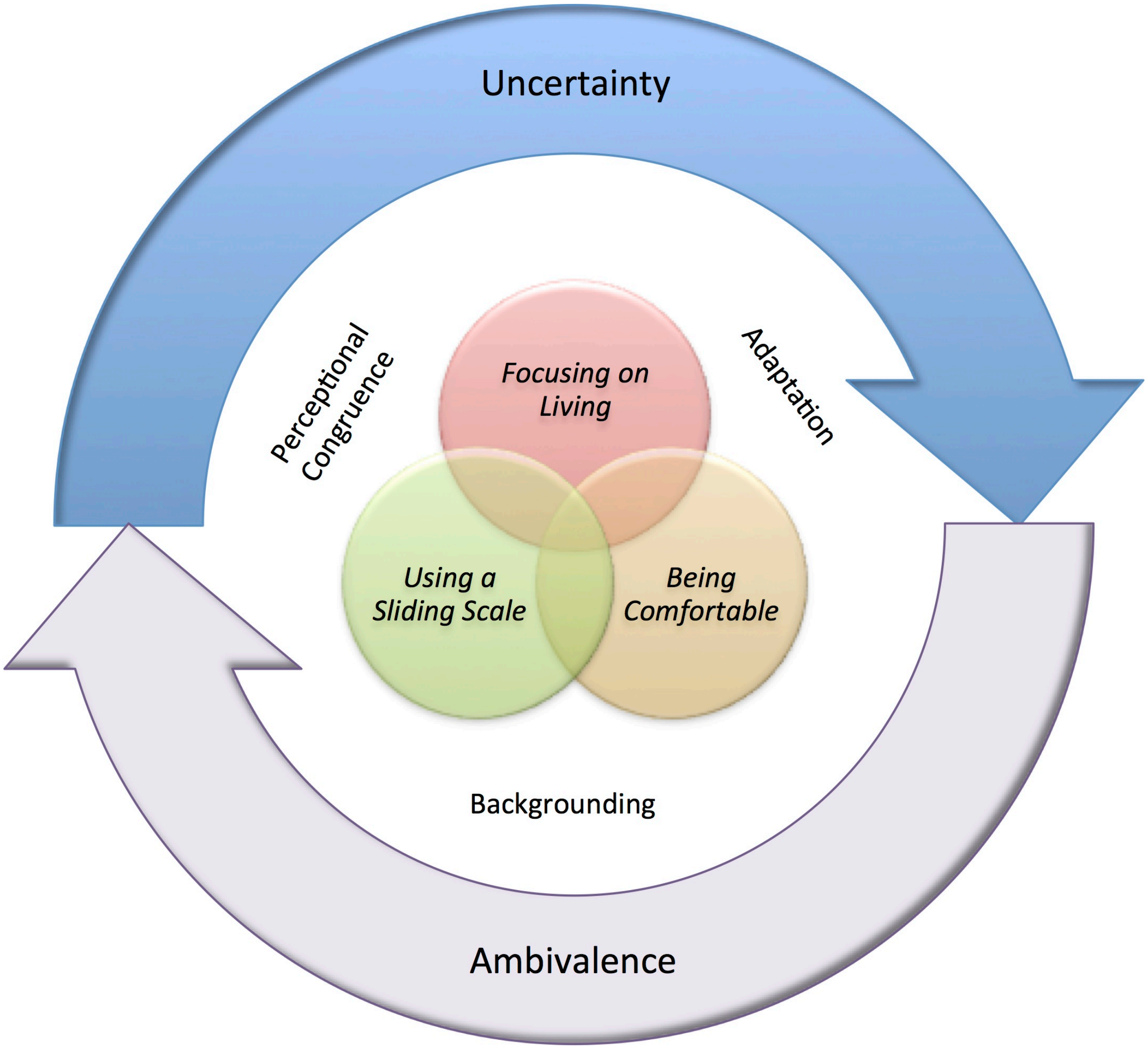

Figure 5. Decision Making in the Context of Ambiguity.

Three overlapping approaches were identified that reflected how participants balanced between issues related to quality of life with length of life in relationship to their perception of prognosis and health status. Decisions were made within a contextual environment that influenced how participants framed and valued different choices.

CHAPTER 5

DISCUSSION

The purpose of this dissertation was to explore the decision-making processes used by older adults with a limited prognosis in order to add their unique perspective to our current knowledge. The data from this study indicate that decisions are contextual, with older adults taking into account both their current and anticipated circumstances. In addition, because of the ambiguity inherent in the choices, many older adults delegate their decision making to others. In this chapter, I first discuss the literature review and overall study findings. Next, I examine the significance of the findings, exploring their relevance to the theoretical perspectives used to frame the study, and implications for hospice use, clinical practice, and policy. I end the chapter by discussing the study's limitations and future directions for research.

Summary of the Dissertation

The Review of Current Knowledge

I began the dissertation by synthesizing the extant literature to understand what is and is not known about patient decision making. I noted that missing in this body of literature is the specific perspective of older adults with a limited prognosis who are faced with significant healthcare decisions. In addition, only a small number of studies examined the underlying decision-making processes. I concluded there are four factors that directly influence the decision outcome and lead to an evolving decision behavior: decisional control, illness/health experience, prognosis, and open communication. But I also noted that the decision maker is not just the patient but also includes the provider and family (or other significant informal relation), forming a decision-making triad. The members of the triad act together by bringing their unique perspectives to the process and have varying degrees of influence on decision making.

This literature review led to the study that was undertaken, including the strategy to recruit community-based older adults with a limited prognosis. A key aspect was recruiting older adults who were capable of making their own decisions in order to understand patients' perspectives.

Dissertation Findings

The overarching finding from the data is that participants focused on their priorities and goals, not specific choices. Because the context of end-of-life decisions could not be known in advance, ambiguity existed when attempting to contemplate these choices in the present. As a result, participants felt they could not make these decisions themselves and relied on others to do so. I analyzed the data in two ways. First, I allowed themes to emerge organically from the data. I found that rather than discuss specific interventions or decisions, participants sought to maintain a sense of control over their decisions by using different approaches to expressing their priorities and goals. Participants anticipated a delegate would make decisions for them based on their priorities, and thus these older adults still felt in control of their decisions.

In the second analysis, I used participants' perception of prognosis and health status as a lens through which to view the data. The findings indicate that participants considered both prognosis and health status in order to balance between length and quality of life (or at least some aspect of it, like comfort, maintaining important activities and relationships, etc.). However, because end-of-life decisions were made in the context of ambiguity, they did not make absolute decisions and recognized that these decisions depended on future circumstances that could not fully appreciated today. Thus, participants hedged or bounded their decisions, saying they would or would not want certain types of care "unless …"

Other significant aspects of the context were trust and the urgency of the decision. Trust enabled participants to feel comfortable delegating decisions to others and maintain a sense of control. This trust arose from both the personal relationship with the delegate and the belief that the delegate had superior expertise and/or abilities to make these decisions. In addition, participants felt the delegate would be more likely to understand the context of these choices. Thus, by trusting a provider or family member, they were able to also manage the ambiguity they saw in the decisions. Trust was also reflected in acute situations when decisions had to be made quickly. In these circumstances, participants often accepted treatment they said they would not want because they trusted the advice of their providers. In these acute situations, participants relied on the providers to tell them how to resolve the symptoms and generally followed this advice without question.

Implications of the Research Findings

Relevance to the Theoretical Perspectives

The findings of this dissertation study are informed by and help inform the three theories I used as perceptional lenses. The primary theory was prospect theory (Kahneman & Tversky, 1979), and I anticipated the theory would help explain some aspects of the underlying decision-making processes. I augmented prospect theory with socioemotional selectivity theory (Carstensen, Isaacowitz, & Charles, 1999) and perceived control (Wallhagen, 1998). These theories are discussed in Chapter 1.

Of the three theories, perceived control (Wallhagen, 1998) had the most relevance to the data, with the findings both giving support to and being supported by the theory. Participants maintained a sense of control even in the absence of being actively involved in making their own decisions. By using different approaches to articulate their priorities and goals, they were able to adjust their perspectives to alleviate demands and achieve a balance with their perceived resources, thereby achieving and maintaining their *sense* of control while not being *in* control.

The findings also had some relevance to prospect theory (Kahneman & Tversky, 1979), but the data of this study reveal significant shortcomings of the theory with respect to decision making near the end of life. Namely, prospect theory uses one “commodity” on which to value prospects, but the findings show older adults balance competing priorities. This balancing is not easily reflected in a two-dimensional construct, so I expanded the model to use two commodities (health status and perceived prognosis). This model helped to give a visual framework for the phenomenon.

The results did not support socioemotional selectivity theory (Carstensen et al., 1999). I suspect this is because socioemotional selectivity is a life-span development theory, and its construct of future time perspective relates to an abstract view of aging as an implicit ending. This idea is quite different from the very real knowledge that one is near or approaching death due to their health. The difference in constructs could explain the differing findings of many researchers. A limited future time perspective has been found to be a significant indicator of engaging in advance care planning or a preference to forgo life-sustaining treatments among those in good, but not poor, health (Allen, Hilgeman, & Allen, 2011; Sims & Carstensen, 2013, November). But other research has found that decisions change as health declines (Fried, O'Leary, Van Ness, & Fraenkel, 2007; Winter, Lawton, & Ruckdeschel, 2003). This change does not appear to be captured by socioemotional selectivity, thus it appears that two different phenomena exist.

Hospice Use

An aim of this study was to explore decision making regarding hospice; however, few participants had experience with or knowledge of the service. As a result, I was unable to directly explore how participants’ decision-making processes impacted hospice decisions; however, the data have significant implications to hospice care. First, because participants were delegating end-of-life decisions to others, the decision to utilize hospice would likely fall to these delegates. So these delegates need to first understand older adults' priorities and goals and then determine if hospice is consistent with them. If it is, these delegates can then frame choices in a way that positions hospice as a means of achieving the goals.

A choice does not need to be framed as "do *x* or die," instead it can be viewed as "the best option to help you maintain your priorities" or "the best care possible." Because many participants did not have a clear understanding of their clinical circumstances, they may not have been receptive to the idea of hospice, discouraging providers from bringing up the topic. Physicians, nurses, and social workers that come in contact with patients near the end of life need to be mindful to not contribute to the misperception. Patients have a right to refuse to acknowledge the reality of their situation, but providers walk a thin ethical line if they actively contribute to the misunderstanding. The data of this study indicate that if patients understand their clinical circumstances, they would make different choices and hospice might be seen as appropriate.

Clinical Practice and Policy

Participants used different approaches to making decisions that are meaningful for healthcare providers. By understanding the approach generally used a patient, providers can tailor conversations and interactions to suit the patient's preferences and reflect their priorities. Family members need to be brought into end-of-life discussions much earlier in the decision-making process so that they also have a better understanding of their loved ones' preferences. Though this may be seen as an imposition on patients' autonomy, family are generally called upon to be surrogate decision makers in the final days of a patient's life (Silveira, Kim, & Langa, 2010). Including family into conversations can be framed as a means of ensuring patients' wishes are heard and respected.

The focus of these discussions also needs to be on patients’ values and priorities, not on specific interventions like do-not-resuscitate orders. Participants were ambivalent about making treatment-focused decisions because they could not know the context in which the decision would be made nor the outcome that would result. For every reason to not accept care, there were also reasons to accept it. The distinguishing factors were the context and outcome. Should patients prefer a passive role in decision making, providers may need to use indirect approaches to allow patients to state their preferences, while providing the opportunity to avoid actively making choices. The alternative is that “no” decision is made; however, not making a decision is a decision in and of itself because the status quo will be maintained. In situations where patients do not wish to make decisions, they may receive care that is inconsistent with their wishes, particularly if providers are unwilling to make decisions on their behalf or to work with family members to do so.

Providers also need to ensure patients understand their clinical situation and prognosis. These issues influenced participants’ decision making and their priorities for care. Without this information, older adults are making decisions based on outcomes that are unlikely to occur and may endure significant discomfort. But, as noted, older adults may not want to have these discussions, thus providers must again rely on understanding patients’ priorities and goals, and then make recommendations accordingly.

From a policy perspective, changes need to be made that encourage and support the needed communication between providers, patients, and their families. The rhetoric of “death panels” resulted in changes to the Patient Protection and Affordable Care Act that removed provisions to reimburse providers for having conversations about goals of care with older adults.

Such reimbursement would help mitigate the challenge of making time for these conversations during a standard clinical encounter, and though the conversation needs to occur more frequently than the law would have provided for, it would have been a good start.

Limitations of the Study

Though I attempted to explore hospice decisions directly, I was unable to do so. Consequently, a limitation of this study is the same as many of the studies I critiqued: actual hospice decisions were not explored and end-of-life decisions were discussed from a hypothetical perspective. Research is needed that explores these in-the-moment decisions; however, recruiting older adults and those at the end of life is difficult, and I encountered many of the obstacles noted by other researchers, including having limited relationships with primary providers (Ewing et al., 2004; McHenry et al., 2012; Steinhauser et al., 2006). Primary providers are key to gaining access to my population of interest. As I continue to expand my body of work, developing these relationships will be vital. Still, because all the participants were quite ill and had a limited prognosis, they were making decisions within the context of the end of life and the data were relevant to their decision-making processes. The sample was predominantly male and limited my ability to find differences based on gender; however, a predominantly male sample is itself unusual. Thus, considering these findings with those of other studies provides a unique perspective that counter balances the limitation noted.

I did not include the perspectives of providers and family, so I cannot speak to any incongruence between their views and that of participants. The impact of providers' perspectives is well known (Brickner, Scannell, Marquet, & Ackerson, 2004; Chinn, Liu, Klabunde, Kahn, & Keating, 2013; Keating et al., 2010; Ogle, Mavis, & Wang, 2003), so their role cannot be discounted. Very little research exists that explores the role informal social partners, such as family, during the early phases of end-of-life decision making, and this study provides limited information in that regard. Exploring the role of family beyond that of being surrogates is needed.

Future Directions

This dissertation represents the beginning of my research career, and the results provide ample support for the need for future research. The findings suggest that a relationship exists between health status and prognosis; however, this phenomenon is better understood among those with cancer (see Chen, Haley, Robinson, & Schonwetter, 2003; Huskamp et al., 2009; Meropol et al., 2008; Temel et al., 2011; Weeks et al., 1998) than those with other conditions (see Dev et al., 2012; Waldrop & Meeker, 2012). Research is needed to explore this relationship, particularly among older adults who are more likely to die from complications related to all their co-morbidities than to just a single disease.

The data indicate that informal social partners could play an important role, especially in light their anticipated role as delegates. I was unable to locate any research that looks at this relationship outside that of being a surrogate; consequently, research is needed that explores the place of family and friends prior to the need for surrogates. Further, a decision-maker triad exists but has not been explored. Future research is needed that recruits triads of patients, family members, and providers so that the relationship can be understood.

Finally, I argued that new theoretical models of decision making are needed that are unique to end-of-life decision making. Existing theories do not adequately explicate the true nature of the process in the final stage of life, and this study indicates that the process changes when the decisions are made relative to the abstract future idea versus the reality. Such a theory could be used to support both clinical practice and research efforts to ensure older adults receive high quality palliative care at the end of their lives.

Summary

My goal in undertaking this study was to understand the decision-making processes used by older adults with a limited prognosis, not to identify specific ways to encourage or increase hospice use. By understanding the processes used, healthcare providers can better support older adults in their decision-making efforts and to ensure they receive high quality palliative care that is consist with their wishes, no matter what clinical environment they are in. Despite the limitations of the study, it provides data that highlights important limitations to current approaches. The finding that participants did not necessarily want active control over their decisions challenges current notions of personal autonomy and the emphasis on advance care planning and written advance directives. It also raised many questions for future research that can expand on the findings reported here. As a dissertation study, this marks the beginning of a body of work that will continue to increase our understanding of older adults' decision-making processes.

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APPENDICES

Appendix A. Interview Guide

[Introduce study and consent participant]

Do you have any questions for me before I begin? [Begin recording]

Content Area	**Possible Probes**
1. *Understanding participant's current health and care.* How are things going health-wise?	What medical conditions do you have? How have you been managing [condition]? Tell me about the last time you met with your healthcare provider.
2. *Exploring past decisions.* You mentioned [choice that was discussed in Q1]. Can you tell me about that situation? [If nothing specific stated in Q1}: Tell me about the some of the different choices you made regarding your healthcare.	Who was involved? What did your provider say? What were the different things you considered when making these choices? How do you prefer to make your decisions? By yourself? With advice from your family/provider? Together with family/provider? Leave it to family/provider after they have talked with you? Let family/provider make decisions without involving you? Why is that? Do you ever feel overwhelmed by the choices you have to make? Have you ever *not* taken the advice your provider gave you? Tell me about that.
3. *Explore decisions made in the context of end-of-life care.* You mentioned [you don't have much time left/you wouldn't want to live a certain way/etc.], why is that? Have you discussed what kind of care you would like at the end of life with anyone?	With whom did you discuss this? In what ways were these discussions helpful or unhelpful when choosing different options? How long do you think you have left to live? Do you think about that [prognosis] when making healthcare choices?
3a. *Exploring hospice as an option. [Only if hospice has been brought up]* Tell me about your experience with hospice.	What were the factors that came to bear on your discussions regarding hospice. Have you had other discussions regarding around hospice? Could you see a time when you would (re)consider hospice? What would that situation look like?

4. *Exploring participants future-time perspective and its influence on decisions.* What to you anticipate in the future?	How has your thinking changed over time? Have you done anything differently having made the different decisions you've made? What kind of care do you want as you go forward?
5. *Wrapping up on a positive tone.* Tell me what is going well for you.	Explore positive aspects of the participant's life. What was it like to go through this interview?

Thank you for taking the time to speak with me. Do you have any questions for me?

[end recording]

[Fill out surveys]

Appendix B. Demographic Questionnaire

Study ID: ___________

Healthcare Decision Making Study

Participant Demographic Information

Age: ______________

Gender: ☐ male ☐ female

Race/ Ethnicity: ☐ White ☐ Asian ☐ Other ________________ ☐ African American ☐ Latino/ Hispanic ☐ American Indian/ Alaska Native ☐ Native Hawaiian/ Pacific Islander

Education: ☐ Grade School ☐ High School ☐ Some College ☐ College ☐ Graduate School

Income: ☐ <$10,000 ☐ $10 – 30,000 ☐ $30 – 60,000 ☐ > $60,000

Marital Status: ☐ Single ☐ Married/ DP ☐ Widowed ☐ Divorced

Religion: ☐ Catholic ☐ Protestant ☐ Jewish ☐ Muslim ☐ Other:_________________

Place of Residence: ☐ Home ☐ Board and Care ☐ Assisted Living

Who else lives with you? ____________________________

Do you have a paid in-home caregiver? ☐ No ☐ Yes

How many hours in the home? _________________

How would you rate your quality of life? ☐ Excellent ☐ Very good ☐ Good ☐ Average ☐ Poor

How would you rate your overall health? ☐ Excellent ☐ Very good ☐ Good ☐ Average ☐ Poor

Who is your primary healthcare provider? _______________________________

Name of primary caregiver/person involved in care? ____________________________

Phone number: ____________________________

Appendix C. Protocol Approval - UCSF Committee on Human Research

UCSF
University of California
San Francisco

Human Research Protection Program
Committee on Human Research

Notification of Expedited Review Approval

Principal Investigator
Margaret Wallhagen

Co-Principal Investigator
Rafael D Romo

Type of Submission: Submission Response for Continuing Review Submission Form
Study Title: Decision making among community-based older adults with advanced illness

IRB #: 10-01117
Reference #: 088340

Committee of Record: Laurel Heights Panel

Study Risk Assignment: Minimal

Approval Date: 06/30/2014 **Expiration Date:** 07/10/2015

Regulatory Determinations Pertaining to this Approval:

Individual Research HIPAA Authorization is required of all subjects. Use the Permission to Use Personal Health Information for Research form.

A waiver of HIPAA Authorization and consent is acceptable for the recruitment procedures to identify potential subjects. The recruitment procedures involve routine review of medical or other records, do not adversely affect the rights and welfare of the individuals, and pose minimal risk to subjects and their privacy, based on, at least, the presence of the following elements:
(1) an adequate plan to protect the identifiers from improper use and disclosure; (2) an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, or a health or research justification for retaining the identifiers was provided or such retention is otherwise required by law;
(3) adequate written assurances that the requested information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of the requested information would be permitted by the Privacy Rule;
(4) the research could not practicably be conducted without the waiver; and (5) study recruitment could not practicably be conducted without access to and use of the requested information. The research subjects will sign a consent form prior to participation in the study.

This submission was eligible for expedited review as:
Category 6: Collection of data from voice, video, digital, or image recordings made for research purposes
Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

IRB Comments (if applicable):

All changes to a study must receive CHR approval before they are implemented. Follow the modification request instructions. The only exception to the requirement for prior CHR review and approval is when the changes are necessary to eliminate apparent immediate hazards to the subject (45 CFR 46.103.b.4, 21 CFR 56.108.a). In such cases, report the actions taken by following these instructions.

Expiration Notice: The iRIS system will generate an email notification eight weeks prior to the expiration of this study's approval. However, it is your responsibility to ensure that an application for continuing review approval has been submitted by the required time. In addition, you are required to submit a study closeout report at the completion of the project.

Approved Documents: To obtain a list of documents that were approved with this submission, follow these steps: Go to My Studies and open the study – Click on Submissions History – Go to Completed Submissions – Locate this submission and click on the Details button to view a list of submitted documents and their outcomes.

For a list of all currently approved documents, follow these steps: Go to My Studies and open the study – Click on Informed Consent to obtain a list of approved consent documents and Other Study Documents for a list of other approved documents.

San Francisco Veterans Affairs Medical Center (SFVAMC): If the SFVAMC is engaged in this research, you must secure approval of the VA Research & Development Committee in addition to CHR approval and follow all applicable VA and other federal requirements. The CHR website has more information.

Appendix D. Protocol Approval - VA ACOS/Research & Development Committee

Department of Veterans Affairs

Memorandum

Date: 4/5/13

From: ACOS, Research and Development (151)

Title: Healthcare decision making among community-based older adults with advanced illness

To: Alexander Smith, M.D., MPH, M.S. Mail Code: 181G

1. This SFVAMC project has been reviewed and approved by the Research and Development Committee according to the VHA Handbook following approval by the relevant subcommittees. This project may now be initiated.

Date of Review / Approval: 4/4/13

2. A project update and expenditure report must be submitted annually and at the completion of the study.

3. **MODIFICATION:** Any modification to the research project must receive prior approval from the relevant subcommittees.

4. **ADVERSE EVENTS:** For Human studies, all serious unanticipated problems involving risks to subjects or others, local unanticipated serious adverse events, or apparent serious or continuing noncompliance (see VHA Handbook 1058.01) must be reported to the Clinical Research Office within five (5) days of the Principal Investigator having knowledge of the event. Submission of the report in iMedRIS® constitutes such notification.

5. All research personnel must have a VA appointment (Full Time Equivalent, Without Compensation or an Intergovernmental Personnel Agreement), must have completed all required training, and must be functioning under their appropriate approved scope of practice.

Carl Grunfeld

Digitally signed by Carl Grunfeld
DN: cn=Carl Grunfeld, o, ou,
email=carl.grunfeld@ucsf.edu,
c=US
Date: 2013.04.05 13:47:15 -07'00'

Carl Grunfeld, M.D., Ph.D

Approval to start this project is based on the following:

• BUA (Biological Use Approval) Number:	N/A
• ACORP (Animal Studies) Number:	N/A
• CHR (Human Studies) Number:	10-01117
• Radioisotope Protocol Number:	N/A
• Use Authorization for Chemicals of Extremely Acute Toxicity (UACEAT):	N/A

To be used in lieu of
VA FORM **2105**

SMIA-0002

Appendix E. UCSF Study Consent Form

IRB NUMBER: 10-01117
IRB APPROVAL DATE: 08/15/2014
IRB EXPIRATION DATE: 07/10/2015

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Healthcare decision making among community-based older adults with advanced illness

This is a research study about healthcare decision making among older adults with advance illness. The study co-principle investigator, Rafael D. Romo, RN, PHN, doctoral student, from the UCSF Department of Physiological Nursing will explain the study to you. The principle investigators are Margaret I. Wallhagen, PhD, GNP-BC, FAAN from the UCSF Department of Physiological Nursing and Alexander K. Smith, MD, MPH, MS from the SF VA Medical Center.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you have had to make important decisions regarding your healthcare.

Why is this study being done?

The purpose of this study is to learn more about how patients, such as you, make decisions regarding your healthcare.

The study is financially supported by a John A. Hartford Foundation/Building Academic Geriatric Nursing Capacity scholarship and an S. D. Bechtel Jr. Foundation grant through the UCSF Division of Geriatrics.

How many people will take part in this study?

About 70 people will take part in this study. Thirty participants will be patients, 20 will be informal caregivers, and 20 will be healthcare providers.

What will happen if I take part in this research study?

If you agree, the following procedures will occur:

- The researcher will ask you for some basic information about yourself and family.
- The researcher will interview you for about 45 minutes in a private place. The researcher will ask you to describe your experiences with your health and decision making.
- The researcher will make a sound recording of your conversation. After the interview, someone will type into a computer a transcription of what's on the tape and will remove any mention of names. The sound recording will then be destroyed
- You may be asked to participate in another interview at a later time, but this interview is voluntary and is up to you.

How long will I be in the study?

Participation in the study will take a total of 45 minutes to 2.25 hours over one to three interviews.

Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the study researcher or staff person right away if you wish to stop being in the study.

Also, the study researcher may stop you from taking part in this study at any time if he or she believes it is in your best interest, if you do not follow the study rules, or if the study is stopped.

What side effects or risks can I expect from being in the study?

Some of the interview questions may make you uncomfortable or upset. You are free to not answer any question you do not wish to answer. You may request a break at any time and are free to end the interview whenever you want.

Are there benefits to taking part in the study?

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals better understand how patients make their decisions and to provide better care as a result.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. You will not lose any of your regular benefits, and you can still get your care from our institution the way you usually do.

Will information about me be kept private?

Participation in research may involve a loss of privacy, but information about you will be handled as confidentially as possible. A medical record will be created because of your participation in this study. Your consent form will be included in this record. Therefore, your other doctors may become aware of your participation. Hospital regulations require that all health care providers treat information in medical records confidentially; however, your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

What are the costs of taking part in this study?

You will not be charged for any of the study treatments or procedures.

Will I be paid for taking part in this study?

In return for your time, you will receive a $25 prepaid debit card at the end of each interview. The maximum amount you would get is $75 in debit cards. We will give you separate instructions on how to use the card.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way. You will not lose any of your regular benefits and can still get your care from our institution the way you usually do.

Who can answer my questions about the study?

You can talk to the researcher(s) about any questions, concerns, or complaints you have about this study. Contact the researchers as follows: Rafael Romo at (408)472-6224, Margaret Wallhagen at (415)476-4965, or Alex Smith at (415)221-4810, x4684. If you wish to ask questions about the study or your rights as a research participant to someone other than the researchers or if you wish to voice any problems or concerns you may have about the study, please call the Office of the Committee on Human Research at 415-476-1814

CONSENT

You have been given a copy of this consent form to keep.

You will be asked to sign a separate form authorizing access, use, creation, or disclosure of health information about you.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

____________ ____

Date Participant's Signature for Consent

____________ ____

Date Person Obtaining Consent

Appendix F. VA Study Consent Form

IRB NUMBER: 10-01117
IRB APPROVAL DATE: 06/30/2014
IRB EXPIRATION DATE: 07/10/2015

Department of Veterans Affairs	INFORMED CONSENT FORM
Subject Name:	**Date:**
Title of Study: Healthcare decision making among community-based older adults with advanced illness	
Principal Investigator: Alexander K. Smith, MD	**San Francisco VAMC**

This is a research study about healthcare decision making among older adults with advance illness. The study co-principle investigator, Rafael D. Romo, RN, PHN, doctoral student, from the UCSF Department of Physiological Nursing will explain the study to you. The principle investigators are Margaret I. Wallhagen, PhD, GNP-BC, FAAN from the UCSF Department of Physiological Nursing and Alexander K. Smith, MD, MPH, MS from the SF VA Medical Center.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you have had to make important decisions regarding your healthcare.

Why is this study being done?

The purpose of this study is to learn more about how patients, such as you, make decisions regarding your healthcare.

The study is financially supported by a John A. Hartford Foundation/Building Academic Geriatric Nursing Capacity scholarship and an S. D. Bechtel Jr. Foundation grant through the UCSF Division of Geriatrics.

How many people will take part in this study?

About 70 people will take part in this study. Thirty participants will be patients, 20 will be informal caregivers, and 20 will be healthcare providers.

What will happen if I take part in this research study?

If you agree, the following procedures will occur:

- The researcher will askyou for some basic information about yourself and family.
- The researcher will interview you for about 45minutes in a private place. The researcher will ask you to describe your experiences with your health and decision making.
- The researcher will make a sound recording of your conversation. After the interview, someone will type into a computer a transcription of what's on the tape and will remove any mention of names.

- You may be asked to participate in another interview at a later time, but this interview is voluntary and is up to you.

How long will I be in the study?

Participation in the study will take a total of 45 minutes to 2.25 hours over one to three interviews.

Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the study researcher or staff person right away if you wish to stop being in the study.

Also, the study researcher may stop you from taking part in this study at any time if he or she believes it is in your best interest, if you do not follow the study rules, or if the study is stopped.

What side effects or risks can I expect from being in the study?

Some of the interview questions may make you uncomfortable or upset. You are free to not answer any question you do not wish to answer. You may request a break at any time and are free to end the interview whenever you want.

If you are injured as a result of being in this study, VA will ensure that treatment is made available at a VA medical facility. If you are eligible for veteran's benefits, the costs of such treatment will be covered by the Department of Veterans Affairs. If you are not eligible for veteran's benefits, the costs of treatment may be billed to you or your insurer just like any other medical costs, or covered by the Department of Veterans' Affairs or the University of California, depending on a number of factors. The Department of Veterans Affairs and the University do not normally provide any other form of compensation for injury. For further information about this, call the VA Regional Counsel at (415) 750-2288 or the office of the UCSF Committee on Human Research at (415) 476-1814.

Are there benefits to taking part in the study?

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals better understand how patients make their decisions and to provide better care as a result.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. You will not lose any of your regular benefits, and you can still get your care from our institution the way you usually do.

Will information about me be kept private?

Participation in research may involve a loss of privacy, but information about you will be handled as confidentially as possible. A medical record will be created because of your participation in this study. Your consent form will be included in this record. Therefore, your other doctors may become aware of your participation. Hospital regulations require that all health care providers treat information in medical records confidentially; however, your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

What are the costs of taking part in this study?

You will not be charged for any of the study treatments or procedures.

Will I be paid for taking part in this study?

In return for your time, you will receive a $25prepaid debit card at the end of each interview. The maximum amount you would get is $75 in debit cards. We will give you separate instructions on how to use the card.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way. You will not lose any of your regular benefits and can still get your care from our institution the way you usually do.

Who can answer my questions about the study?

You can talk to the researcher(s) about any questions, concerns, or complaints you have about this study. Contact the researchers as follows: Rafael Romo at (408)472-6224, Margaret Wallhagen at (415)476-4965, or Alex Smith at (415)221-4810, x4684. If you wish to ask questions about the study or your rights as a research participant to someone other than the researchers or if you wish to voice any problems or concerns you may have about the study, please call the Office of the Committee on Human Research at 415-476-1814

CONSENT

You have been given a copy of this consent form to keep.

You will be asked to sign a separate form authorizing access, use, creation, or disclosure of health information about you.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

____________ ____

Date Participant's Signature for Consent

____________ ____

Date Person Obtaining Consent

Appendix G. UCSF Permission to Use Personal Health Information Consent

IRB Approval Number 10-01117

University of California
Permission to Use Personal Health Information for Research

Study Title (or IRB Approval Number if study title may breach subject's privacy): Healthcare decision making among community-based older adults with advanced illness

Principal Investigator: Margaret I. Wallhagen, PhD, GNP-BC

Sponsor/Funding Agency (if funded): John A. Hartford Foundatin/J. D. Bechtel Jr. Foundation

A. What is the purpose of this form?

State and federal privacy laws protect the use and release of your health information. Under these laws, the University of California San Francisco (UCSF) or your health care provider cannot release your health information to the research team unless you give your permission. The research team includes the researchers and people hired by the University or the sponsor to do the research. If you decide to give your permission and to participate in the study, you must sign this form, as well as the Consent Form. This form describes the different ways that the researcher, research team and research sponsor may use your health information for the research study. The research team will use and protect your information as described in the attached Consent Form. Once your health information is released it may not be protected by these privacy laws and might be shared with others. However, other laws protecting your confidentiality may still apply. If you have questions, please ask a member of the research team.

B. What Personal Health Information will be released?

If you give your permission and sign this form, you are allowing SF VAMC to release the following medical records containing your Personal Health Information. Your Personal Health Information includes health information in your medical records and information that can identify you. For example, Personal Health Information may include your name, address, phone number or social security number.

☐ Entire Medical Record
☐ Outpatient Clinic Records
☒ Progress Notes
☐ Consultations
☒ History & Physical Exams
☐ EKG
☐ Other:

☐ Radiology Reports
☐ Radiology Images
☐ Diagnostic Imaging Reports
☐ Operative Reports
☐ Pathology Reports
☐ Emergency Medicine Center Reports

☐ Laboratory Reports
☐ Psychological Tests
☐ Dental Records
☒ Discharge Summaries
☐ Health Care Billing

C. Do I have to give my permission for certain specific uses?

Yes. The following information will only be released if you give your specific permission by putting your initials on the line(s).

____ I agree to the release of information pertaining to drug and alcohol abuse, diagnosis or treatment.

____ I agree to the release of HIV/AIDS testing information.

____ I agree to the release of genetic testing information.

____ I agree to the release of information pertaining to mental health diagnosis or treatment as follows:

____

D. How will my Personal Health Information be used?

Your Personal Health Information may be released to these people for the following purposes:

1. To the research team for the research described in the attached Consent Form;
2. To others at UC who are required by law to review the research;
3. To others who are required by law to review the quality and safety of the research, including: U.S. government agencies, such as the Food and Drug Administration, the research sponsor or the sponsor's representatives, or government agencies in other countries. These organizations and their representatives may see your Personal Health Information. They may not copy or take it from your medical records unless permitted or required by law.

E. How will my Personal Health Information be used in a research report?

If you agree to be in this study, the research team may fill out a research report. (This is sometimes called a "case report".) The research report will ***not*** include your name, address, or telephone or social security number. The research report may include your date of birth, initials, dates you received medical care, and a tracking code. The research report will also include information the research team collects in the study. The research team and the research sponsor may use the research report and share it with others in the following ways:

1. To perform more research;
2. Share it with researchers in the U.S. or other countries;
3. Place it into research databases;
4. Use it to improve the design of future studies;
5. Use it to publish articles or for presentations to other researchers;
6. Share it with business partners of the sponsor; or
7. File applications with U.S. or foreign government agencies to get approval for new drugs or health care products.

F. Does my permission expire?

This permission to release your Personal Health Information expires when the research ends and all required study monitoring is over. Research reports can be used forever.

G. Can I cancel my permission?

You can cancel your permission at any time. You can do this in two ways. You can write to the researcher or you can ask someone on the research team to give you a form to fill out to cancel your permission. If you cancel your permission, you may no longer be in the research study. You may want to ask someone on the research team if canceling will affect your medical treatment. If you cancel, information that was already collected and disclosed about you may continue to be used. Also, if the law requires it, the sponsor and government agencies may look at your medical records to review the quality or safety of the study.

H. Signature

If you agree to the release and use of your Personal Health Information, please sign below. You will be given a signed copy of this form**.**

____
Name of Subject (print)

____ __________________
Signature of Subject Date

Note: if the subject is a minor, an individual signing with an "X", an adult incapable of giving consent, or is unable to read the authorization, fill out and attach the "special signatures" page (sections "I" and "J").

University of California
Permission to Use Personal Health Information for Research

SPECIAL SIGNATURES PAGE

I. If the subject is a minor, or an individual signing with an "X", or an adult incapable of giving consent (where IRB approved), the legally authorized representative or witness signs here:

____	______________________
Name of Legally Authorized Representative or Witness to the "X" (print)	Relationship to the Subject
____	______________________
Signature of Representative or Witness	Date

J. If the subject is unable to read the authorization, the translator or reader and a witness sign here:

I have accurately and completely read this Authorization to ______________________ (subject's name) in _________________(language), the subject's primary language. **The subject has verbally affirmed his/her Authorization to me and to the witness.**

____
Name of Translator or Reader (print)

____	______________________
Signature of Translator or Reader	Date

____
Name of Witness (print)

____	______________________
Signature of Witness	Date

Appendix H. VA Authorization for Release of Protected Health Information

SAN FRANCISCO VETERANS AFFAIRS MEDICAL CENTER
AUTHORIZATION FOR RELEASE OF PROTECTED HEALTH INFORMATION FOR RESEARCH

Study Title: Healthcare decision making among community-based older adults with advanced illness

SFVAMC Principal Investigator: Alexander K. Smith, MD CHR No: 10 - 01117

Subject Name: ____________________________ SSN: ____________________

Beginning April 14, 2003, HIPAA (Health Insurance Portability & Accountability Act) allows you to control how your private health information is used. You have been asked to participate in the study listed above, this form provides an explanation about the use and disclosure of your health information for this research, and requests your permission to use and share your individual health information.

The purpose of this study is **<u>to learn more about how patients with advanced illness make decisions regarding their healthcare.</u>**

An informed consent to be a research subject may be presented and explained separately for some research and a separate signature will be requested before any research procedures are done.

Individual Health Information to be Used or Disclosed. By signing this document, you will authorize the parties listed below to provide the principal investigator and members of the research team access to the following information about you:

☒ History and Physical Examination
☒ Discharge Summary(ies)
☐ X-rays
☐ Diagnostic/Laboratory tests
☐ Drug Abuse Information
☐ Alcoholism or Alcohol Use
☐ Billing records
☐ Operative Report(s)

☒ Progress Notes
☐ Photographs, videotapes, other images
☐ HIV (testing or infection) records
☐ Sickle cell anemia
☐ Mental Health (not psychotherapy notes)

Other Records: _____

Only the following records of types of health information:

Parties Who May Disclose Your Individual Health Information. The researcher named above and his or her research staff may obtain your individual health information from the following hospitals clinics, providers, or other entities:

<u>San Francisco Veterans Administration Medical Center</u>

Parties Who May Receive or Use Your Individual Health Information. The research team may also need to disclose the information to others as part of the study process. This may include:

☒ UCSF Committee on Human Research
☐ US Food & Drug Administration (FDA)
☐ The study sponsor:
☐ Others:

☒ VA regulatory personnel

Duration of Investigator Access and Use of your Individual Health Information. Your health information cannot be used indefinitely without your knowledge. This authorization to access and use your individual health information will expire **at the end when data analysis is completed**.

Right to Refuse to Sign this Authorization. This authorization to release health information is voluntary. Treatment, payment, enrollment or eligibility for benefits may not be conditioned on signing or refusing to sign this Authorization. If you decide not to sign this authorization you will not participate in this research study or receive research related treatment.

Right to Revoke Your Authorization. You can revoke this authorization, in writing, at any time. To revoke your authorization, you must write to the Principal Investigator of this study or you can ask a member of the research team to give you a form to revoke the authorization. Your request will be valid when the research team receives it. If you revoke this authorization, you will not be able to continue to participate in the study. This will not affect your right as a VHA patient to treatment or benefits outside the study.

If you revoke this authorization, the investigator and the research team can continue to use information about you that was collected before receipt of the revocation. The research team will not collect information about you after you revoke the authorization.

If this is a study where you do not know if you will receive a placebo or the active agent, or the study is masked for some reason, you will not be allowed to see research-related medical records about you that are created or obtained by the research team. You will be able to see them again when the study is completed. This will not affect your doctor's ability to see your records as part of your normal health care.

Potential for Re-disclosure. The VHA complies with the requirements of the Health Insurance Portability and Accountability Act of 1996 and its privacy regulations and all other applicable laws that protect your privacy. We will protect your information according to these laws. However, once your information is disclosed outside the VHA, there is a possibility that your information could be used or disclosed in a way that it will no longer be protected. Our Notice of Privacy Practices (a separate document) provides more information on how we protect your information. If you do not have a copy of the Notice, the research team will provide one to you.

Signature. I have read this authorization form and have been given the opportunity to ask questions. If I have questions later, I understand I can contact the researcher or a member of the research team. I will be given a signed copy of this authorization form for my records. I authorize the use of my identifiable information as described in this form.

Print Name of Research Participant or Representative ______ Signature of Research Participant or Representative ______ Date ______

If signed by someone other than the research participant, state your authority to act for the subject:______

Signature of Person Obtaining the Authorization ______ Date ______

Translator (if applicable) ______ Date ______

The execution of this form does not authorize the release of information other than that specifically described. The information requested on this form is solicited under Title 38USC. The form authorizes release of information that you specify in accordance with Health Insurance Portability & Accountability Act, 45 CFR 160 and 164, 5 USC 552a and 38 USC 5701 and 7332. Your disclosure of information requested ion this form is voluntary. However if the information, including social security number (SSN) is not furnished completely and accurately the Department of Veterans Affairs will be unable to comply with the request.

Appendix I. VA Consent for Use of Picture or Voice

Department of Veterans Affairs

CONSENT FOR USE OF PICTURE AND/OR VOICE

CONSENT OF *(Name)*

NOTE: The information requested on this form is solicited under the authority of title 38, United States Code. The execution of this form does not authorize disclosure of the materials specified below except for the purpose(s) stated. The specified material may be used within the VA for authorized purposes, such as for education of VA personnel or for VA research activities. It may also be disclosed outside the VA as permitted by law. If the material is part of a VA system of records, it may be disclosed outside the VA as stated in the 'Routine Uses' in the "VA Privacy Act Systems of Records" published in the Federal Register. A copy of the 'Routine Uses' is available upon request to the administrative office of the VA facility involved. You do not have to consent to have your picture or voice taken, recorded, or used. Your refusal to grant your consent will have no effect on any VA benefits to which you may be entitled.

I hereby voluntarily and without compensation authorize pictures and/or voice recording(s) to be made of me *(or of the above-name individual if the individual is legally unable to give consent)* by *(specify the name of the VA facility, newspaper, magazine, television station, etc.)*

While I am *(describe the activity, if any to be photographed or recorded)*

I authorize disclosure of the picture and/or voice recording to *(specify name and address of the organization, agency, or individual(s) to whom the release is to be made)*

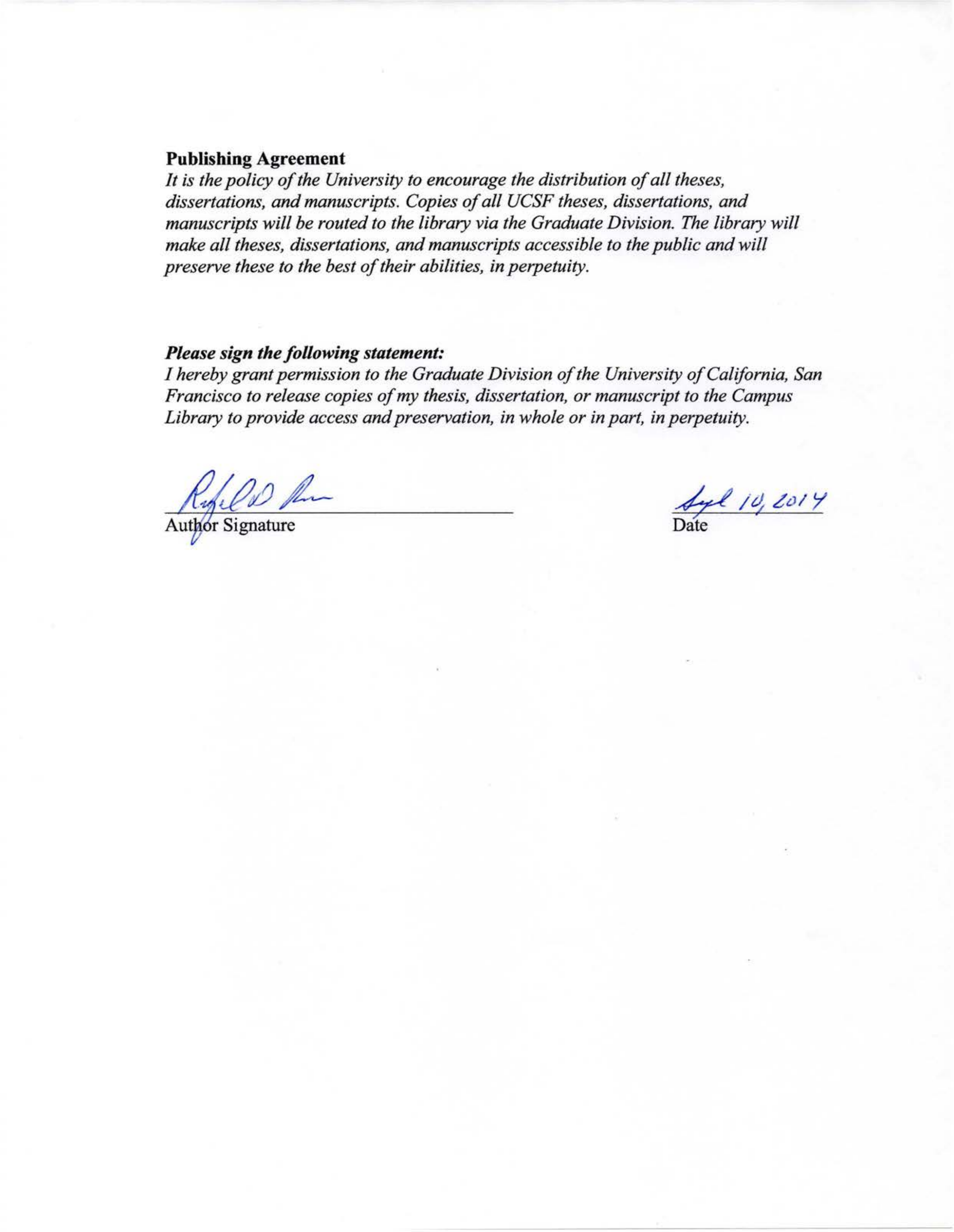
I understand that the said picture, video and/or voice recording is intended for the following purpose(s):

I have read and understand the foregoing and I consent to the use of my picture and/or voice as specified for the above-described purpose(s). I further understand that no royalty, fee or other compensation of any character shall become payable to me by the United States for such use. I understand that consent to use my picture, video and/or voice recording is voluntary and my refusal to grant consent will have no effect on any VA benefits to which I may be entitled. I further understand that I may at any time exercise the right to cease being filmed, photographed or recorded, and may rescind my consent for up to a reasonable time before the picture, video or voice recording is used.

SIGNATURE OF INDIVIDUAL OR OTHER LEGALLY AUTHORIZED PERSON	DATE
PERMISSION OBTAINED BY *(NAME - TITLE - ADDRESS)*	
SIGNATURE OF INTERVIEWER OR INDIVIDUAL OBTAINING CONSENT	DATE
PRODUCTION TITLE	PRODUCTION NUMBER
INDIVIDUAL' S NAME AND ADDRESS	IMPORTANT: This form must always be completed prior to the making or using pictures, video or voice recording(s) of any VA patient. If any patient health or demographic information is to be provided or released with the picture, video or voice recording, VA Form 10-5345, Request for and Authorization to Release Medical Records or Health Information is required prior to the release of such data to any source.

VA FORM
MAY 2005 **10-3203**

Publishing Agreement



Publishing Agreement
It is the policy of the University to encourage the distribution of all theses, dissertations, and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations, and manuscripts accessible to the public and will preserve these to the best of their abilities, in perpetuity.

Please sign the following statement:
I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Author Signature

Sept 10, 2014
Date