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IMPACT OF CANCER-SPECIFIC ADVANCE CARE PLANNING ON PATIENT ANXIETY,
DECISIONAL CONFLICT, AND SURROGATE UNDERSTANDING OF
PATIENT TREATMENT PREFERENCES

by

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A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the College of Nursing
at the University of Central Florida
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ABSTRACT

Patients with life-limiting cancer and their families face unique challenges that interfere with their ability to make decisions or adequately express their health care preferences about end of life (EOL) treatment. As a result, patients at EOL often receive aggressive unwanted treatment that nationally costs billions of dollars and results in surrogate distress about not honoring patient wishes. Respecting Choices® DS-ACP is a disease-specific Advance Care Planning (ACP) intervention that is designed to overcome barriers associated with ACP and potentially decrease the incidence of unwanted, overly aggressive treatments at EOL. The intervention is delivered to patient-surrogate dyads by a trained facilitator who provides an opportunity for patients to identify values and goals that support their EOL choices and communicate these values and goals to their surrogates before they are in a medical crisis. Although Respecting Choices® DS-ACP has been effective with other populations, it has not been evaluated for patients with life-limiting cancer. Thus, the purpose of this study was to evaluate the Respecting Choices® DS-ACP intervention with patients with life-limiting cancer to determine if the intervention increases patient-surrogate congruence about the patient's EOL wishes and reduces decisional conflict without causing anxiety.

Study design was a Phase I clinical trial. A volunteer sample of 15 patients with a diagnosis of life limiting cancer and their matched surrogates participated in the study. The Statement of Treatment Preferences for Life-Limiting Cancer Form, the Spielberger State-anxiety Scale Form Y-1 (STAI) and the Decisional Conflict Scale (DCS) were administered pre- and post-intervention. The Quality of Communication about End of Life Care Form was administered at post test. Descriptive statistics were used to describe the sample. McNemar Chi-square and Binomial tests were conducted to investigate whether the intervention increased

congruence for five different situations on the Statement of Treatment Preferences for Life-Limiting Cancer Form. The Zar's Multiple Comparison Test of Differences was conducted to investigate the proportion of congruence observed across the five situations. A paired-sample t test was conducted to evaluate post-intervention changes in anxiety (STAI) and decisional conflict (DCS). Frequencies and percentages were conducted for the five items on the Quality of Communication about End of Life Care Form to evaluate patients' and surrogates' satisfaction with the intervention. Anecdotal comments about timing were content analyzed and summarized.

Congruence between patients and surrogates improved significantly in all five situations (range of $p = .001$ to $.031$), decisional conflict lessened significantly ($t(14) = 4.49, p < .001$), and anxiety did not change ($t(14) = 1.75, p = .102$) pre- and post-intervention. Participants reported satisfaction with the intervention, including its delivery and timing.

Findings from this study provide guidance on how to assist patients with life limiting cancer and their surrogates with EOL decision making. Study findings also support making the Respecting Choices ACP intervention part of usual care for patients with life limiting cancer and timing the intervention so that it is delivered before a medical crisis occurs. The lack of change in post-intervention anxiety scores suggests that ACP does not add to patient distress when ACP is conducted by a trained facilitator. This finding can be used to persuade health professionals to refer their patients for ACP. Additional research is needed to determine if increased patient-surrogate congruence leads to patients' wishes being followed and reduces surrogate decisional conflict and distress at EOL. Future research is also needed to determine if the Respecting Choices DS-ACP intervention is equally effective with racial and ethnic groups whose reluctance

to engage in EOL discussion has been documented in the literature or if the intervention needs to be culturally adapted.

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I dedicate my dissertation to my dear friend and colleague Melanie Culligan Schroeder, MSN, RN and to ALL the angels who guide, support, and comfort me daily. Our journey continues.

There is still much work to be done.

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CHAPTER 1: OVERVIEW

Introduction

The study was a Phase I clinical trial to evaluate an intervention to assist patients with life limiting cancer to formulate and express their end-of-life preferences to family members and health care professionals. An estimated 1.5 million Americans receive a diagnosis of cancer annually and more than 1,500 patients die every day from the disease (American Cancer Society [ACS], 2010). Patients with life-limiting cancer and their families face unique challenges that interfere with their ability to make decisions or adequately express their health care preferences about end of life (EOL). Life-limiting cancer patients typically maintain good functioning for a long period and then experience a rapid decline as the illness becomes overwhelming and leads to death (Lorenz et al., 2008; Lynn, 2005; Morita, Tei, & Inoug, 2003; Teno, Weitzen, Fennell & Mor, 2001). During their decline, these patients often endure intense symptoms that cause them to lose decision-making capacity. Very often, they have not communicated their preferences in advance to family members, leaving family members unprepared to make EOL decisions on their behalf. As a result, life-limiting cancer patients often receive care at the EOL that is inconsistent with their preferences (Goodman et al., 2010; McCarthy, Philips, Zhong, Drews & Lynn, 2000; Teno, Fisher, Hamel, Coppola, & Dawson, 2002).

Advance care planning (ACP) and advance directives (ADs) provide a general framework for decision making near the EOL by having patients identify their preferences for life-sustaining care ahead of time before they lose decision-making ability. Instructional ADs contain directives regarding what treatments patients want and the conditions under which they want treatments withheld. Proxy ADs enable patients to select surrogates, people they want to make decisions on their behalf if they are unable to do so. ACP is the process of identifying

goals, values, and beliefs about healthcare decisions that may need to be made in the future to assist patients and surrogates to prepare or enact instructional ADs.

Background of Problem

The Patient Self-Determination Act (PSDA) (42 U.S.C. 1395cc (a), 1990) specifies the need for instructional or proxy ADs to improve EOL experiences by communicating patients' wishes to family members and health professionals. The national guidelines for applying the PSDA to cancer is for patients diagnosed with life-limiting cancer and life expectancy of 1 year or less to have completed ACP and ADs (National Comprehensive Cancer Network [NCCN], 2010).

Despite these guidelines and two decades of legislation and studies, AD completion rates remain low. According to various reports they are between 18%-30% (Covinsky et al., 2000; Kish, Martin, & Price, 2000; Lo & Steinbrook, 2004; Wilkerson, Wenger, & Shugarman, 2007). Various ACP interventions aimed at increasing the completion of effective ADs have been tried (Coppola, Ditto, Danks, & Smucker, 2001; Ditto et.al., 2001; The SUPPORT Principal Investigators, 1995), but most interventions have not been effective. Even when ADs have been completed, they are often ineffective (Covinsky et al. 2000; Kish et al., 2000; Lo & Steinbrook, 2004; Wilkerson et al., 2007) leading to default medical care which often ends up being different and more aggressive than what patients want (Goodman et al., 2010; Wennberg, Fisher, Goodman, & Skinner, 2008).

There are a number of reasons for the lack of success with ACP and ADs. In actual practice, health care providers typically fail to initiate meaningful advance care discussions, perhaps because they lack the skills or time to do so (Baile, Lenzi, Parker, Buckman, & Cohen,

2002; Curtis, Patrick, Caldwell & Collier, 2000; Fischer, Tulskey, Rose, Siminoff, & Arnold, 1998; Tung, 2009; Yedidia, 2007). As a result, patient and surrogates often lack understanding of both the benefits and possible untoward consequences of EOL treatment options (Fried, Bradley, Towle, & Allore, 2002). Surrogates also may not know patients' values and decision choices because patients and surrogates avoid discussions of EOL in order to avoid upsetting one another (Briggs, 2003; Fried & O'Leary, 2008; Quill, 2000; Zhang & Siminoff, 2003). Additional problems pertain to timing: If advance planning occurs too early, it may rely on hypothetical situations. Patients cannot predict future decision choices for situations that they have not yet experienced (Fried et al., 2002; Fried, et al., 2007). On the other hand, if AD planning is delayed too long, ADs risk being formulated during stressful times when patients' decision making capacity is already compromised (Covinsky et al., 2000).

Statement of Problem

For patients with life-limiting cancer, planning for future health care decisions is more dynamic and complex than for patients with well managed illnesses. This dynamism and complexity poses additional ACP demands on professional facilitators, patients, and surrogates.

Respecting Choices® DS-ACP is a disease-specific ACP intervention that is designed to overcome barriers associated with ACP and ADs. The intervention is delivered by a trained health professional and includes both patients and surrogates. The facilitator explores the patient's understanding of his or her current illness, the likelihood of future complications, the benefits and burdens of treatment options, and the patient's values and goals (Briggs & Hammes, 2008/2010; Fried et al, 2006; Fried et al. 2002) and provides an opportunity for patients to communicate values and beliefs that support their EOL choices to their surrogates.

The Respecting Choices® intervention for patients and their surrogates has been successful in various populations, including patients with chronic illnesses (Briggs, 2003; Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Detering, Hancock, Reade, & Silvester, 2010; Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2010), patients undergoing cardiac surgery (Song, Kirchhoff, Douglas, Ward, & Hammes, 2005), geriatric patients (Schwartz et al., 2002), and adolescents living with HIV (Lyon et al., 2009). However, Respecting Choices® DS-ACP has not been evaluated for patients with life-limiting cancer.

Purpose of Study

The purpose of this study was to evaluate whether an ACP intervention using Respecting Choices® DS-ACP, delivered early in the cancer care continuum, increases patients and surrogates congruence and reduces patients' decisional conflict without causing anxiety. The general guidelines for Respecting Choices ACP were adapted in this study to be disease-specific for patients with life-limiting cancer.

Research Questions

The study answered the following research questions:

RQ1: Does the intervention increase congruence between patients and matched surrogates about patients' treatment preferences for life-limiting cancer?

RQ2: Are there significant differences in the proportion of congruence observed for different situations post-intervention?

RQ3: Does the intervention reduce patients' decisional conflict?

RQ4: Does the intervention increase patients' anxiety?

Hypotheses

Based on the proposed research questions, the following hypotheses were developed:

H_{A1}: The intervention will increase congruence of treatment preferences for life-limiting cancer questionnaire (pretest versus posttest) between patients and matched surrogates.

H_{A2}: There will be significant differences in the proportion of congruence observed for different situations post intervention.

H_{A3}: The intervention will reduce patients' decisional conflict.

H_{A4}: The intervention will not increase patients' anxiety.

Definition of Terms

The terms utilized throughout this proposal are defined as follows.

Advance care planning (ACP). A process of communication to assist individuals in understanding, reflecting upon, and discussing their goals, values, and beliefs about future health care decisions in the hypothetical event that individuals are no longer able to speak for themselves (Briggs & Hammes, 2008). ACP often culminates in the creation of an advance directive.

Advance care planning facilitator (ACP facilitator). A designated individual who has successfully completed an advance care planning facilitator skills training program to lead advance care planning discussions and related activities (Briggs & Hammes, 2008/2010).

Advance directives (ADs). A general term that describes two kinds of legal documents: living wills and medical power of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to

serious illness or incapacity. Each state regulates the use and application of advanced directives differently (National Hospice and Palliative Care Organization [NHPCO], n.d.).

Decisional conflict. Uncertainty about which course of action to take when the choice among competing actions involves risks, loss, regret, or challenges personal life values (NHPCO, n.d.).

End of life (EOL). A variable time prior to death when an individual experiences disability or worsening of a disease process (Briggs & Hammes, 2008/2010).

Health care provider. Any licensed professional who is responsible for delivering health care services, including physicians, nurses, nurse practitioners, social workers, pharmacists, respiratory therapists, and so on (Briggs & Hammes, 2008/2010).

Health care surrogate (surrogate). The person named in an advance directive or permitted under state law to make health care decisions on behalf of the person who is no longer able to make medical decisions (NHPCO, n.d.). “Any competent adult expressly designated by a principle to make healthcare decisions on behalf of the principle upon the principles incapacity” (Florida Statutes, 2009).

Life-limiting cancer. An initial or recurrent diagnosis of advanced cancer or invasive cancer. Advanced cancer is cancer that has grown beyond the organ in which it first started or affects a vital organ that cannot be removed. Invasive cancer is when cancer cells have penetrated the original layer of tissue (ACS, 2010).

Life-sustaining treatment. Any intervention that prolongs life, including technical and invasive treatment (e.g., ventilators, dialysis) or less aggressive treatments (e.g., antibiotics, IV fluids, and tube feedings; Briggs & Hammes, 2008).

Principle of nonabandonment. Reflects the healthcare providers' longitudinal commitment to care about patients and jointly seek solutions to problems with patients throughout their illness. This open-ended commitment to face the future together becomes more important as the future becomes less certain (Quill & Cassel, 1995).

Substituted judgment. The form of surrogate decision making regarding EOL care in which the surrogate attempts to establish with as much accuracy as possible what decision the patient would have made if the patient was competent to do so. This conclusion can be based on the patient's preference expressed in previous statements or the surrogate's knowledge of the patient's beliefs, values, personality, and prior lifestyle. This standard seeks to preserve the patient's right of self-determination by placing the patient's own preferences at the center of deliberation (Ascension Health Care Ethics, n.d.: Fl. Statutes, 2009).

Assumptions

The research was based on the following assumptions:

Patients with life-limiting cancer have pre-existing knowledge and ideas (representations) about their health problems.

Effective patient education is most likely to occur when patients' knowledge and beliefs (representations) are elicited before new information is provided.

Assessing patients' representation about a health problem provides a context in which ACP facilitators can give specific, highly relevant, individualized information that will have a greater chance of being accepted by the patient (Donovan & Ward, 2001).

Significance

Findings from this study provide information about how to assist patients with life limiting cancer and their surrogates with EOL decision making. Information about an intervention that clarifies patient wishes and increases surrogate understanding of those wishes has the potential to not only impact patient suffering from side effects of aggressive unwanted treatment and surrogate distress about honoring patient wishes at EOL but also reduce the billions of dollars of unwanted treatment currently spent at EOL for patients with life-limiting cancer (Smith & Hillner, 2011; Zhang et al., 2009). Findings from this study also answer questions about when in the patients' cancer trajectory is it appropriate to discuss EOL with patients with life limiting cancer and whether these discussions increase patient anxiety. Answering the latter question addresses provider concerns about possible negative effects of EOL discussions, thereby removing one barrier to EOL planning.

Outline of Remainder of Dissertation

Chapter 1 has served to provide an overview of why effective interventions are needed to improve patient-surrogate dyadic congruence and reduce patients' decisional conflict without causing anxiety. Chapter 2 is a review of the literature and discussion of the theoretical framework that organizes this research project. The specific focus is literature about barriers to completing ADs and studies that address strategies to improve EOL care so that is consistent with patients' preferences. These studies include a critical review of the Respecting Choices® DS-ACP intervention and how it has been implemented and evaluated to date. Chapter 2 also introduces the theory of the representational approach to patient education, which is the theoretical basis to the Respecting Choices intervention. The Respecting Choices DS-ACP

intervention, the study design and research procedures are described in Chapter 3. Chapter 4 reports the study findings. Chapter 5 discusses research questions and hypotheses supported or refuted by the findings

CHAPTER 2: REVIEW OF RELEVANT LITERATURE AND THEORETICAL FRAMEWORK

Overview

A review of the literature and theoretical framework for the research is presented in this chapter. The review of literature focuses on barriers to effective ACP, patient-surrogate dyadic congruence, and literature specific to patients with advanced cancer and ACP/EOL discussions. The Respecting Choices® DS-ACP intervention, the intervention evaluated in this study, is evaluated in terms of its implementations to date. The theory of representational approach to patient education, which served as the theoretical basis to the Respecting Choices DS-ACP intervention, is introduced.

Factors Considered Important at EOL

The literature about EOL has a number of foci, including factors considered most important to those people who are eminently approaching EOL, the people who care for them, and healthcare providers (Emanuel, Alpert, Baldwin, & Emanuel, 2000; Singer, Martin, & Kelner, 1999; Steinhauser et al., 2000). The overarching conclusions from all these studies are that support for decision making about EOL is essential and that this support must include explicit communication about the difficult decisions patients and their surrogates are likely to face and detailed information about patients' wishes. This support and communication is to help patients achieve a sense of control, thereby relieving burden on surrogates and strengthening relationships between patients and surrogates. Although these studies were about EOL in general, the same support requirements likely apply to ACP and EOL care for patients with life-limiting cancer.

EOL Treatment Decisions and Cancer Patients

Advance Directives

Written ADs in the form of living wills and appointments of health care surrogates allow patients to communicate their wishes before they reach decisional incapacity. These documents are intended to help patients with life-limiting illnesses avoid aggressive and futile life-sustaining treatments.

Hospice and patient rights advocates identified the need for written ADs in the 1990s. Since 1991, the federal Patient Self-Determination Act ([PSDA] 1990) requires Medicare and Medicaid providers to inform all adult patients of their rights to prepare an AD, participate in and direct their own health care decisions, accept or refuse treatment, and be informed of the health care facility's policy on the administration and application of these rights.

Despite widespread support for the concept of ADs, the potential benefits of written ADs have not been actualized. According to Fagerlin and Schneider (2004), a number of conditions must be satisfied for written ADs to function as intended. The first condition involves patients completing an AD. Second, those individuals charged with making decisions for the patient (i.e., surrogates) must understand and be willing to follow the instructions written in the ADs.

These two seemingly facile tasks are more complicated than they appear to be. People must decide in the present what treatment they would want in the future should they become incompetent. The ADs must accurately state patients' preferences in terms that are understandable by medical teams and surrogates. Completed ADs must be made available to individuals charged with making decisions for the patient. Concerns about the achievability of these conditions have been echoed by many experts in EOL decision making (see, for example, Ditto et al., 2001; Fagerlin & Schneider, 2004; Lo & Steinbrook, 2004; Perkins, 2007; Seckler,

Meier, Mulvihill, & Paris, 1991; Teno, Lynn & Phillips, 1994; Teno et al., 1997; Teno, Nelson, & Lynn, 1994). These concerns may account for why AD completion rates have remained low. For example, a study that evaluated the frequency of use of ADs by critically ill cancer patients at a tertiary cancer center found that this population of patients only had a 27% completion rate (Kish et al., 2000).

Scope of Advance Care Planning

Completing an AD is part of a broader process of advance care planning (ACP). ACP requires patients, surrogates, and providers to come together to develop a plan that meets the patients' goals, values, and preferences. Engaging in ACP early in the cancer care continuum is especially important because delirium and other forms of cognitive impairment are prevalent during treatment of advanced malignancies (Lynn, 2005; McCarthy et al. 2000; Morita, et al., 2003).

Early efforts to improve cancer care communication through ACP focused on ADs that primarily addressed resuscitation preferences. More recent efforts reflect the opinion that ACP must be expanded beyond simple ADs. Planning for EOL has evolved from the goal of having a patient complete ADs to engaging a patient in the process of thinking about what kind of life-prolonging medical care he or she would want should the need arise. Additional components include identifying a surrogate decision maker who will communicate the patient's wishes if the patient is unable to do so and helping the patient to communicate his or her wishes to the surrogate (Levi, Dellasega, Whitehead, & Green, 2010). In short, although ACP may lead to completion of ADs, its primary purpose is to facilitate the process of thinking about and communicating wishes so that more informed care can be delivered at EOL.

Role of Health Care Surrogates

One aspect of ACP involves delegating surrogates to make decisions on one's behalf in the event that one is no longer able to do so because of illness. Under the current U.S. model, surrogates are instructed to provide substituted judgment, choosing what the patient would have chosen based on the surrogate's knowledge of the patient's goals and values, the patient's prior behavior, or discussions with the patient about his or her preferences. If the patient never had the decisional capacity or the patients' preferences are unknown, a decision should be made in the patients best interests (The President's Council on Bioethics, 2005; Civil Rights Act, 2010). There is emerging consensus against relying solely on substituted judgment or best interests standards to judge the quality of a surrogate's decisions (see for example, Fagerlin, Ditto, Danks, Houts, & Smucker, 2001; Fagerlin & Schneider, 2004; Fins et al., 2005; Shalowitz, Garrett-Mayer, & Wendler, 2006; Smucker et al., 2000; Sulmasy et al., 1998). In fact, many experts challenge the ability of surrogates to use substituted judgment to accurately represent the treatment preferences of patients (see for example, Fagerlin et al., 2001 Rosenfeld, Wenger, & Kagawa-Singer, 2000; Shalowitz, Garrett-Mayer, & Wendler, 2006).

Inconsistency between ADs and Care Received

For patients with life-limiting cancer, the last six months of life are typically characterized by functional decline, severe pain and confusion that could have been controlled better by palliative care (Morita et al., 2003). Although patients increasingly prefer comfort care as they near death, many die in pain (McCarthy et al., 2000) receiving aggressive cancer treatment at EOL instead of palliation. In other words, they die receiving care that may actually be unnecessary or harmful. Findings from the landmark Study to Understand Prognoses and

Preferences for Outcomes and Risks of Treatments ([SUPPORT] The SUPPORT Principle Investigators, 1995) showed that, among patients with colon and lung cancer, 40% were in serious pain in the last days of life. More than 65% of these patients who died in serious pain had stated a preference for comfort care (McCarthy et al., 2000). Furthermore, one in 10 patients with lung and colon cancer received care that was incongruent with their preferences, as reported by family members (Lynn, Harrell, Cohn, Wagner, & Connors, 1997).

Aggressive treatment of cancer, even among patients with poor prognosis, continues to increase (Asola, Huhtala, & Holli, 2006; Earle et al., 2004; Goodman et al., 2010). The number of claims submitted to Medicare for patients with advanced cancer indicated the percentage of patients receiving chemotherapy within two weeks of death increased from 13.8% in 1993 to 18.5 % in 1996, and there were similar increases in numbers of emergency room visits and intensive care unit stays (Earle et al., 2004). It should not be assumed these statistics reflect a greater desire for aggressive care at EOL. In a study involving 335 patients with breast cancer, at 2 months before death, 64% of patients continued to receive endocrine therapy and 20% received chemotherapy, despite deterioration in their general condition. This situation is contrary to the medical standard of care, which specifies that at about two months prior to death, cancer-related treatment should be discontinued in favor of comfort measures (Asola et al., 2006).

There is some evidence that continuing to receive aggressive treatment at EOL when the AD states preferences for comfort measures may be particularly common in patients with life-limiting cancer. In a study that prospectively compared resuscitation status for patients with advanced cancer and patients with amyotrophic lateral sclerosis (ALS; Astrow et al., 2008), 6 of the 24 patients with cancer with DNR orders were found to have received CPR, whereas none of

the six patients with ALS with DNR orders received CPR. Because of the small numbers in the study, the differences between the two groups were not statistically significant. Even so, these numbers demonstrate the failure to honor cancer patients' EOL wishes.

Barriers to Effective Advance Care Planning

Ineffective or Delayed Communication

For patients with life-limiting cancer, relevant medical intervention options typically include short-term or terminal ventilator support, artificial nutrition and hydration, resuscitation, and hospice care (Martin, Emanuel, & Singer, 2000). Informed decisions about EOL care require a certain level of knowledge about these medical intervention options and their intended purpose.

Most cancer patients want to be informed if their illness is terminal and want information about treatment options tailored for their individual needs (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005). Yet, ACP discussions may occur less frequently with this population than with patients who have other life-limiting illnesses. A retrospective examination of charts of elderly patients with advanced cancer found that only 38% had ACP discussions documented (Bradley et al., 2001). A 2-year longitudinal study that involved reviewing medical records of 60 patients with advanced cancer and 32 patients with ALS found that the rate of ACP discussions differed in the two groups (Astrow et al., 2008). Although the patients with life-limiting cancer had significantly poorer survival prognoses than did the patients with ALS, medical records indicated that health care practitioners had far fewer ACP discussions with patients with life-limiting cancer than they had with patients with ALS. Regardless of the reasons for this disparity, patients with life-limiting cancer appear to be less adequately prepared for EOL decision making (Astrow et al., 2008).

The Astrow et al. (2008) study findings are consistent with a report that patients with life-limiting cancer are not fully informed about palliative care as an alternative or supplement to curative care (Gattellari, Voigt, Butow, & Tattersall, 2002). Similarly, a report on cancer care at EOL published by the Dartmouth Atlas Project (Goodman et al., 2010) found that one in three Medicare cancer patients spend their last days in hospitals and intensive care units. This finding suggests that many clinical teams administer aggressive treatment with curative attempts the patients may not want, negatively impacting their quality of their life in their last weeks and months (Goodman et al., 2010).

Responsibility for hesitancy to discuss EOL issues has been attributed to ambivalence of both the patient and the physician (Cherlin et al., 2005; Hagerty et al., 2005; Wright et al., 2008). Although there is evidence that patients with life-limiting cancer want their health care practitioners to initiate communications about ACP, providers rarely take the first step. Instead, these health care professionals wait for their patients to raise the topic or initiate the conversation (Baile, et al., 2002; Bradley et al., 2001; Walling et al., 2008).

Patient ambivalence is also reflected in a study by Lamont and Siegler (2000). They found that patients with life-limiting cancer were willing to endorse a policy whereby medical house staff discuss advance care preferences as part of the admission history. However, these same patients did not want to have ACP discussions with their oncologist. Perhaps patients are reluctant to initiate these discussions with their oncologists because of fears of being abandoned as their illness progresses (Back et al., 2008). Another study clarified that patients with cancer may be reluctant to discuss their advance care preferences with their oncologist but would do so if the discussion was initiated by their oncologist (Dow et al., 2010). It is possible that although patients with life-limiting cancer want to be involved in decisions about the care they will

receive at EOL, they equate these discussions with being abandoned, particularly if they occur at a time when the future becomes less certain (Quill & Cassel, 1995). Even if the evidence about patients' wanting these discussions with their oncologists is inconclusive, it is clear that patients with life-limiting cancer want to know that they will receive quality care and support even if curative treatments are ineffective (Evans, Tulsky, Back, & Arnold, 2006).

When advance care discussions do take place, studies suggest that clinicians do an inadequate job communicating with patients and families. One area of inadequacy involves providing relevant information in an understandable format (Bradley et al., 2001; Christakis & Lamont, 2000). For example, Fried, Bradley, and O'Leary (2003) examined agreement between patients or caregivers and providers regarding prognoses communication and found that, although providers reported having informed the patient and/or caregiver of a life-threatening condition, 46% of the patients and 34% of the caregivers reported no such discussion. In 23% of patient/provider and 30% of caregiver/provider pairs, the provider reported discussing an approximate life expectancy, whereas the patient or caregiver reported no such discussion.

Curtis, Patrick, Caldwell, and Collier (2000) found that one of the most frequently identified barriers to communication about EOL care identified by 57 physicians and their patients with AIDS was too little time during medical appointments. Lack of time is also a barrier for oncologists. Baile et al. (2002) examined the attitudes and practices of 167 oncologists regarding discussions of unfavorable medical information with their patients; the oncologists reported lack of time as the most common barrier to communicating matters about EOL care. Other commonly noted barriers included providers' limited formal training, feelings of unpreparedness, and the belief that conducting ACP discussions is complex (Tung, 2009; Yedidia, 2007). Topics related to the need for training to engage in the complexities of ACP

include fear of causing distress, helping patients make decisions for future treatment when treatment options are unpredictable, helping surrogates understand patient choices, and timing for ACP.

Fear of Causing Distress

ACP discussions require patients to confront the limitations of medical treatments and the reality that life is finite, which can cause psychological distress (Quill, 2000). Research suggests that both physicians and patients are ambivalent about talking about death and often avoid these conversations (Back et al., 2008; Baile et al., 2002; Bradley et al., 2001; Hancock et al., 2007; Kish et al., 2000). This ambivalence also extends to patients and their surrogates. Patients' and surrogates' fears and concerns of emotional distress, not wanting to upset loved ones, and a belief in positive thinking may prevent these dyads from discussing EOL issues with each other (Zhang & Siminoff, 2003).

On the other hand, a systematic review of 46 studies suggests that most of these reported fears are unfounded; patients and family members are capable of discussing EOL issues without experiencing undue anxiety (Hancock et al., 2007). This conclusion is further substantiated by a multisite, prospective, longitudinal cohort study of patients with advanced cancer and their caregivers (Wright et al., 2008); 300 dyads were interviewed periodically from enrollment to the patient's death, which occurred approximately four months after the first interview. Within 2-3 weeks of the patients' death, medical records were reviewed and caregivers were interviewed to assess the patients' quality of life near death. Bereaved caregivers' psychiatric illnesses and quality of life were assessed approximately six months after the patients' death. There were no group differences in patients' and caregivers' mental health among people who did and did not

discuss EOL issues with providers. In other words, there was no evidence EOL discussions were significantly associated with increased emotional distress or psychiatric disorders. Instead, patients that did not have EOL discussion received significantly more aggressive medical care in their final week of life, which was associated with worse patient quality of life near death (Wright et al.).

Similar to the findings reported by Wright et al. (2008), receiving a patient-surrogate ACP intervention (i.e., discussing and planning for EOL) did not result in increased anxiety for members of the intervention group (Song et al., 2005). More specifically, there was no significant difference in anxiety scores pre- and post intervention in the treatment and control groups. Findings from these studies suggest that talking about EOL is not associated with greater distress or anxiety (Hancock et al., 2007; Lyon et al., 2009; Song et al., 2005; Tang, Li, & Chen, 2008). In fact, EOL discussions may result in increased patient understanding of illness severity, fewer invasive procedures, lower rates of ICU admissions, and earlier hospice referrals at EOL (Wright et al., 2008). In other words, avoiding EOL care planning may not be in the patients' best interest.

Inability to Predict Treatment Choices

Another potential barrier to ADs and traditional ACP includes patients' inability to predict their future treatment preferences because of the difficulty anticipating all of the situations the patients may face (Fried et al., 2006; Fried & O'Leary, 2008; Teno et al., 1997; Winzelberg, Hanson, & Tulsky, 2005). Patients or their surrogates may discover an AD created during a period of relative health may not be applicable during a subsequent period of illness or incapacity (Fried et al., 2006).

Patients and surrogates often lack or misunderstand information about medical and treatment options, and/or have inaccurate preconceptions about the nature of the decisions at hand. For example, many people may be opposed to the notion of being placed on a ventilator, but whether patients may be willing to endure mechanical ventilation likely will depend on the reality of the circumstances (e.g., need for short- versus long-term mechanical ventilation, or overall prognosis for recovery). Health care practitioners not only lack the time, but also the skill needed to conduct in-depth discussions of EOL treatment decisions that consider key circumstances or qualifying conditions (Cherlin et al., 2005; Tung, 2009; Yedidia, 2007).

Another reason for patients' inability to predict future medical decisions is their over- or underestimation of the impact that specific disabilities will have on their lives (Fried et al., 2006). For example, patients may think they may be willing to accept losing the ability to walk or talk, but not the loss of cognition. Their willingness may change once they actually begin to lose the ability to walk or talk. In other words, patient preferences and the values underlying those preferences may change over time and with experience. Caregivers, surrogates, and patients' health care providers may be challenged to make decisions that run counter to patients' original AD, unless ACP addressed the possibility that preferences might change as the illness progresses.

Surrogates' Understanding of Preferences

Although patients may believe their ADs clearly express their preferences, these preferences may be less clear to surrogates. First, patients' expressed preferences for EOL often do not apply to complex situations associated with life-limiting cancer. Second, surrogates may also be challenged to make the "right" decision in cases where opposing goals and preferences

must be balanced (see for example, Fried et al., 2009). For example, patients may communicate conflicting information to the surrogate, stating they want to exhaust all possible measures to prolong life but also want to be kept comfortable at the EOL.

These complexities may explain why having access to the patient's AD or having a conversation with the patient regarding EOL preferences has not resulted in congruence between the patient wishes and the surrogate decision making (Coppola et al., 2001; Ditto et al., 2001; Hare, Pratt, & Nelson, 1992; Hines et al., 2001; Marbella, Desbiens, Mueller-Rizner, & Layde, 1998; Ouslander, Tymchuk, & Rahbar, 1989; Shalowitz, Garrett-Mayer, & Wendler, 2006; Uhlmann, Pearlman, & Cain, 1988; Zweibel & Cassel, 1989). For example, of the 250 patient-surrogate dyads interviewed by Hines et al. (2001), 63% of the patients and their surrogates agreed the patient had informed the surrogate of his or her preferences, and 33% of the patients reported having had more than five conversations with their surrogate. However, having more conversations about EOL issues did not increase surrogates' understanding of patients' specific preferences or values (Hines et al., 2001).

Timing

Patients with life-limiting illness and their caregivers and health practitioners have disparate views about how, with whom, and when discussions about EOL issues should be initiated (Clayton, Butow, Arnold, & Tattersall, 2005). Contrary to guidelines for providers to discuss prognoses and realistic expectations with patients and their families (NCCN, 2010), findings from a survey involving approximately 5,000 physicians indicated many physicians delayed having EOL discussions until all nonpalliative treatments were exhausted or the patient raised the subject (Keating et al., 2010).

Research To Improve Patient-Surrogate Dyadic Congruence

When patients cannot exercise their autonomy over medical care, decisions must be made for them on the basis of the substituted judgment standard. Most studies on this topic present hypothetical scenarios and estimate concordance or percent agreement between the patient's stated preference for EOL care and the surrogate's understanding of the patient preferences for each scenario. Percent agreement represents how closely surrogates can approximate patient decision making using substituted judgment.

Several studies have demonstrated that surrogate decision makers are not able to represent the patients' wishes accurately (Hare et al., 1992; Uhlmann et al., 1988; Zweibel & Cassel, 1989). For example, Uhlmann et al. (1988) studied elderly outpatients to determine spouses' awareness of patients' preferences for CPR or CPR plus ventilator following cardiac arrest in context with varying prognoses and health conditions. Although more than 75% of the spouses believed their predictions of patients' preferences were accurate, accuracy did not exceed that expected due to chance alone. Spouses significantly ($p < 0.05$) overestimated patients' preferences for resuscitation in the CPR and ventilation situations. These results suggest that spouses often do not understand patients' preferences and are unlikely to provide congruent substituted judgment when faced with decisions about life-sustaining treatments.

A study conducted by Zweibel and Cassel (1989) examined the ability of physician-selected surrogates to use substituted judgment for older single or widowed patients by examining a broader array of life-sustaining treatments than studied by Uhlmann and colleagues. (Physicians typically select a family member to act as a surrogate decision maker when a patient is older and single or widowed.) The study aims was to examine surrogates' ability to accurately reflect patient treatment choices when surrogates were not specifically directed to use substituted

judgment. Fifty-five patient-surrogate dyads were separately presented with five hypothetical case vignettes describing the following scenarios: CPR and mechanical ventilation for patients in coma, receiving chemotherapy in end-stage cancer, patients' inability to communicate with the health care practitioner, amputation in a demented elderly man, and tube feeding of a woman who refused to communicate with her doctors. For each scenario, surrogates were asked, "What would you tell the doctor to do?" Differences in patient - surrogate pairs revealed opposing decisions ranging from 24% for tube feedings up to 44% and 50 %, respectively, for resuscitation and chemotherapy (Zweibel & Cassel, 1989).

Hare et al. (1992) used a method similar to that used by Zweibel and Cassel (1989) to examine patients and their self-selected surrogates. However, they modified the vignettes used by Zweibel and Cassel to address the possibility that the vignettes about tube feeding and amputation were misinterpreted by study participants. The modifications included the following contextual information: Patients' current age was reported. Tube feeding was based a patient who was in a permanent coma. Amputation was presented as a life-extending treatment and not solely as a means of pain control. They also directed the surrogates participating in the study to use a substituted judgment standard, choosing a treatment the patients would choose. The sample included 50 patient-surrogate dyads with a range of ages, which allowed examination of possible age differences in patient-surrogate decisions. As measured by the kappa coefficient statistic, surrogates did not achieve statistically significant patient-surrogate dyadic congruence for any of the treatment decisions (Hare et al., 1992). Similarly, when the preferences of elderly patients in a nursing home facility were compared with their closest relative and nursing home staff (i.e., a nurse, social worker, and physician), surrogates were found to not be significantly better than chance at predicting patients' treatment preferences (Ouslander et al., 1989).

Seckler et al. (1991) assessed dyadic congruence of 70 patient-family surrogate pairs regarding the resuscitation preferences of competent elderly outpatients. They extended previous work (Ouslander et al., 1989; Uhlmann et al., 1988; Zweibel & Cassel, 1989) by including an assessment of the patients' comprehension of the meaning of the hypothetical interventions they were asked to consider. Patients were presented in person with three hypothetical CPR situations under two health status circumstances: current health and moderate dementia. Family surrogates were given the same situations and questionnaires over the phone. Though few pairs of patients and surrogates had previously discussed medical care preferences, 87% of the patients predicted that family members would accurately represent their wishes. Concordance between family members and patients was statistically significant, but the obtained kappas (0.27 and 0.30, respectively) indicated less than moderate strength of agreement (kappa > 0.4 is considered moderate; Cohen, 1960). Moderate agreement should be the minimum percent agreement required of surrogates when making serious EOL decisions on behalf of patients under the substitute judgment standard.

One criticism of these studies (Hare et al., 1992; Seckler et al., 1991; Uhlmann et al., 1988; Zweibel & Cassel, 1989) is that patients and surrogates were asked about patient preferences when the patients were not critically ill. Asking about preferences for hypothetical situations of deteriorating health that patients have yet to experience fails to characterize the decisions of patients and surrogates who are actually facing serious and complex choices. Research suggests that preferences for life-sustaining medical treatment can be unstable over time and highly dependent on the specific situation (Fried et al., 2006; Hawkins, Ditto, Danks, & Smucker, 2005). Because of the difficulty anticipating all of the situations patients may face (Winzelberg et al., 2005), EOL decisions expressed during a period of relative health may not be

applicable during a subsequent period of illness or incapacity (Fried et al., 2006). To investigate if difficulty imagining a decline in health was a limitation, Layde et al. (1995) evaluated the congruence of more than 1,000 patient-surrogate dyads when patients were hospitalized and seriously ill. Because of the severity of patients' illness and anticipated 6-month survival rate of 50%, Layde et al. were able to evaluate actual CPR preferences in light of the patients' current health status. Within pairs, the overall agreement rate with respect to CPR decisions was 74%. For patients who did not want to be resuscitated, however, 50% of the surrogates did not reflect the patient's wishes.

There is some evidence indicating that surrogates who discuss patient preferences beforehand have improved patient-surrogate dyadic congruence (Ouslander et al., 1989; Sulmasy, Haller, & Terry, 1994; Sulmasy et al., 1998). A pilot study of 50 general medical patients found that patient-surrogate dyadic congruence was positively associated with discussion between patient and surrogates (Sulmasy et al., 1994). Building on this connection, Sulmasy et al. (1998) conducted cross-sectional paired interviews with 250 patients with terminal diagnoses and their surrogates to determine what factors are associated with higher patient-surrogate dyadic congruence. On average, surrogates made correct predictions in only 66% of instances. Accuracy was higher for the permanent coma scenario than for scenarios of severe dementia or coma with small chance of recovery ($p = 0.001$). The accuracy of substituted judgments was positively associated with the patient having spoken with the surrogate about EOL issues. Age, ethnicity, marital status, religion, and ADs were not associated with accuracy.

Efforts to Improve Patient-Surrogate Communication

A number of intervention studies have evaluated how to increase patient-surrogate communication to promote congruence so that surrogates adequately understand patients' preferences to guide patients' EOL treatment preferences. Interventions to improve patient-surrogate communication have included educational interventions, conducting values histories, and having a trained facilitator engage both patients and surrogates in ACP.

Educational Interventions

Hare and Pratt (1993) evaluated the effectiveness of two educational programs: a workshop delivered in a classroom (instruction style) and a home study program (written materials). The objectives of the educational programs were to increase communication about EOL decisions and to increase patient-surrogate dyadic congruence. Fifty patient-surrogate dyads were presented with five hypothetical scenarios adapted from those used by Zweibel and Cassel (1989). Prior to receiving the intervention, patients and surrogates were asked to independently make treatment decisions based on what the patient would want for himself or herself. Study participants self-selected to participate in either the evening workshop or the home study. Participant reports about treatment decisions were obtained 6 weeks after each program was completed. Participants who elected to attend the workshop had significantly higher preintervention congruence scores compared to those who selected the home study program. When age and preintervention scores were held as covariates, no significant differences were found on the postintervention agreement scores according to form of educational intervention. In addition, no significant difference in pre- and postintervention agreement was found within groups. Overall, the educational workshop program appeared to

have a somewhat more positive impact than did the home study program. Neither program, however, significantly increased the agreement on difficult medical decisions (Hare & Pratt, 1993).

The SUPPORT initiative (The SUPPORT Principle Investigators, 1995) consisted of an intervention designed to improve communication and ultimately agreement between patients and their surrogates. A major hypothesis of SUPPORT was that accurate information and better communication would decrease the frequency of unwanted life-sustaining treatments. The study was conducted in two phases in five teaching hospitals. Phase I was a baseline observational study, and Phase II was a block-randomized clinical trial of an intervention intended to improve medical decision making and outcomes for seriously ill hospitalized patients (The SUPPORT Principle Investigators, 1995). Using information gathered during Phase I, the investigators developed an intervention to improve communication and understanding during the decision-making process and facilitate advance planning of treatment options. Nurses were trained to assist and facilitate communication with the 2,652 patients who received the intervention. The findings revealed a failure to honor patients' EOL preferences. The design of SUPPORT served as the baseline for several other investigations.

As an extension of SUPPORT (The SUPPORT Principal Investigators, 1995), Marbella et al. (1998) investigated whether nurses who spent extra time with patient-surrogate dyads to explain and answer questions about the patient's prognoses and potential treatment increased dyadic congruence about the patient's treatment preferences. The treatment group included 386 dyads, and the control group was comprised of 331 dyads. No significant differences in dyadic congruence were found between the two groups. Hiltunen, Medich, Chase, Peterson & Farrow (1999) analyzed narratives written by SUPPORT nurses describing the difficult decisions

seriously ill patients near the end of their lives face, and the experience of dealing with those decisions. The burden and complexity of family decision making emerged as a major theme. This analysis revealed that for successful ACP patients, families and providers should jointly discuss the patient's values and EOL wishes. Marbella et al.'s intervention may not have been effective because it did not include a values history.

Values History and Facilitated ACP

A *values history* is a specialized AD form that allows a patient to clarify their health-related values and goals and communicate these values and goals to their surrogates. The surrogate is then able to select treatment choices based on the patients' values and goals. This differs from a standard AD in that it asks patients to focus on clarifying their value-related reasons for specific treatment choices (Doukas & McCullough, 1991).

Patients and surrogates also seem to agree about the benefit of a values discussion. The utility of a values history is supported by a longitudinal study with 337 patient-surrogate dyads that completed interviews and questionnaires. Over half of patients (57%) and surrogates (67%) believed the best approach to documenting preferences was one that included both written requests and verbal communications with surrogates. Of those who did not choose both methods, more believed that verbal communication was the best approach. Most of the patients and surrogates who desired a written request, (50% and 44%, respectively) preferred one that contained only statements about values or goals (i.e., religious beliefs, importance of maintaining cognitive functioning) for care that patients would want guiding medical decisions. Fewer patients and surrogates desired an AD that included both value statements and precise treatment direction, and fewer still preferred one that omitted value statements and included only precise

directions regarding specific medical treatments (Hawkins et al., 2005). Similarly, in a qualitative study, patients and surrogates reported that facilitated discussions that identified values and discussions specific to health status or actual decisions that might need to be made were more effective than a discussion about hypothetical situations without facilitation (Karel, Powell, & Cantor, 2004).

Matheis-Kraft and Roberto (1997) conducted a randomized control trial to investigate whether prior discussions between elderly female patients and their family member surrogates were more effective if they included discussion of patients' personal values. A list of 23 value indicators and ten common EOL scenarios with three variations each (i.e., a total of 30 scenarios) were used to stimulate discussions and prioritize values. The three variations for each of the ten EOL scenarios were as follows: the patient's current state of cognitive functioning, the patient as permanently confused, and the patient in permanent coma. Patients in the experimental group were asked to choose from the list of value indicators (i.e., independence, burden, dignity, fear, comfort) that were most influential to her medical decision making and to discuss why the selected value was important to her. The surrogate was instructed to consider the values that his or her dyadic partner discussed. The experimental group did not have statistically higher agreement than the control group in 27 of the 30 situations using kappa. Using percent agreement, which is the best benchmark for assessing surrogates' understanding of patient preferences, the experimental group only had better patient-surrogate congruence in 11 of the 30 situations. Although the values history helped patients begin to communicate important information for EOL planning, it was not sufficient (Matheis-Kraft & Roberto).

Another trial evaluating the benefit of including a values history also yielded disappointing results. Ditto et al. (2001) tested various ADs with and without a values history as

part of an investigation to determine whether discussing the AD with the surrogate increased patient-surrogate dyadic congruence about patients' EOL preferences. None of the interventions produced significant improvement in congruence.

In contrast a study that included a trained facilitator in addition to a values history had more promising results. This study was conducted in Spain and evaluated patient-surrogate dyadic congruence in two intervention groups and in a control group; an AD containing a values history, two educational sessions guided by a trained nurse or a control group who had neither an AD nor participated in the educational sessions (Barrio-Cantalejo et al., 2009). Congruence in the control group and the group without facilitation was comparable. However, congruence between the dyads who received the facilitated educational sessions was significantly higher than it was in the control or AD groups. This finding underscores the benefit of having a trained ACP facilitator.

The promise of facilitated discussions between patients and surrogates that include patient values has led to the focus more on ACP as a process during which patients explore, discuss, articulate, and document their preferences rather than on ADs alone (Emanuel, von Gunten, & Ferris, 2000). This new focus is also consistent with evidence that suggests that EOL conversations should focus less on specific medical treatments a patient would or would not want and more on aspects of the patient's specific health status that are of particular importance to the patient. For example, patients may be more concerned about pain, mental deterioration, or physical dependency at EOL than whether they should be resuscitated (The President's Council on Bioethics, 2005). ACP that is customized to the patients' health condition and guides patients to express EOL wishes so that their surrogates are able to understand their values may be most

effective (Bingley et al., 2006; Fried, Bullock, Iannone, and O’Leary, 2009; Matheis-Kraft & Roberto, 1997; Rosenfeld et al., 2000).

In summary, if patients’ EOL wishes are to be honored, patient-surrogate dyadic congruence must be improved. The relatively high rate of discrepant decisions between patients and surrogates in the studies described above underscores the importance of effective patient-surrogate communication before the patient’s medical condition renders him or her unable to make their treatment preferences known. Conclusions across studies that have explored strategies to improve patient-surrogate dyadic congruence suggest that the most successful interventions include the following components: patients and surrogates engage in a process of exploring values and goals (Hawkins et al., 2005; Hiltunen et al., 1999; Sudore et al., 2008; Sulmasy et al., 1994; Sulmasy et al., 1998); patients’ values and goals are explicitly communicated to their surrogate (Barrio-Cantalego et al., 2009; Bingley et al., 2006; Hawkins et al., 2005; Karel et al., 2004; Levi et al., 2010; Mathies-Kraft & Roberto, 1997; Rosenfeld et al., 2000; Sulmasy et al., 1998), patient-surrogate discussions are facilitated by a trained professional and are specific to the health problems patients with a particular illness are likely to encounter (Barrio-Cantalego et al., 2009; Fried et al., 2009; Hagerty et al., 2005; Karel et al., 2004), and the process occurs early and is modified as the patients’ illness progresses (Hiltunen et al., 1999; Sulmasy et al., 1994; Sulmasy et al., 1998). The Respecting Choices® DS-ACP intervention encompasses these strategies.

Respecting Choices® Disease Specific Advance Care Planning

Respecting Choices® DS-ACP is an interventional interview conducted with patients and surrogates that is designed to promote the kind of in-depth dialogue central to ACP (Briggs &

Hammes, 2008). The method by which Respecting Choice DS-ACP generates the AD document (a Statement for Treatment Preferences) provides opportunities for accurate expression of the patient's wishes. Each element of the Respecting Choices DS-ACP interview is a venue for the patient and surrogate to reflect on the patient's goals and values and discuss how these goals and values can direct treatment decisions. The final AD document is not only intended to help patients communicate specific treatment preferences, but also to help surrogates understand patients' overarching priorities when unanticipated situations arise.

The Respecting Choices® DS-ACP has been evaluated for promoting patient-surrogate congruence of shared decision-making outcomes and decisional conflict with patients with chronic illnesses (Briggs et al., 2004), geriatric patients (Schwartz et al., 2002), and adolescents with HIV (Lyon et al., 2009). All of these studies found the Respecting Choices DS-ACP intervention significantly improved congruence between surrogates and patients in understanding the patients' preferences and reduced the surrogates' decisional conflict. Respecting Choices DS-ACP has also been evaluated in a multisite randomized controlled trial with outpatients diagnosed with congestive heart failure or congestive respiratory failure (Kirchhoff et al., 2010) and a randomized controlled trial study with 309 elderly hospitalized patients in Australia (Detering, Hancock, Reade, & Silvester, 2010). In both studies, surrogates in the intervention groups demonstrated a significantly higher degree of understanding of patients' goals than did surrogates in the control group (Detering et al., 2010; Kirchhoff et al., 2010). EOL wishes were also respected significantly more in those who had died in the intervention group (25 of 29) than those who had died in the control group (8 of 27; Detering et al., 2010).

A unique feature of Respecting Choices® DS-ACP is its focus on training professionals in the communications skills needed to facilitate a discussion that engages patients and

surrogates about the importance of ACP, the effects and meaning of the illness, and expectations for future care (Briggs & Hammes, 2008; Briggs et al., 2004; Westley & Briggs, 2004). The following components are included in the communication skill training: exploring past experiences, fears, and concerns; clarifying medical information and disease complications; assisting in weighing the benefits and burdens of life-sustaining interventions; and setting guidelines on what it would mean to live well as health conditions change.

Respecting Choices® DS-ACP has not been evaluated in patients with life-limiting cancer. Life-limiting cancer may present more complex EOL issues than the issues involved with chronic illness or congestive heart or respiratory failure. Although Respecting Choices® DS-ACP is tailored to complications and life sustaining treatments that are specific to a given disease, the same theoretical framework underlies every Respecting Choices® DS-ACP intervention.

Theoretical Framework

The Respecting Choices DS-ACP intervention is based on the social science theory of the representational approach to patient education (Donovan & Ward, 2001), which was derived from elements of the common-sense model (Diefenbach & Leventhal, 1996; Ward, 1993). The core tenet of the representational approach is that effective patient education is most likely to occur when patients' knowledge and beliefs are elicited before new information is provided (Donovan & Ward; Diefenbach & Leventhal).

Donovan and Ward (2001) proposed that patients be given a representation of their illness according to five dimensions: identity, cause, timeline, consequences, and cure/control. Identity pertains to how a person describes and experiences his or her symptoms or health

problem. Cause pertains to the individual's beliefs about the origin of their health problem. Timeline relates to beliefs about the length of the illness. Consequences are ideas about the short- and long-term outcomes of the problem. Cure or control are beliefs about the extent to which one can control or cure a health problem.

According to Donovan and Ward (2001), the representational approach is a fluid interview process that moves back and forth between these five dimensions. The goal of the approach is to maximize opportunities for patients to reflect and comment on their own ideas about their illness according to identity, cause, timeline, consequences and cure/control as well as to provide new information about these illness dimensions when patients are most ready to hear it. Opportunities for self-reflection provide conditions in which conceptual change can occur throughout the entire process and provide patients with a cognitive framework for interpreting and processing new information about their illness (Donovan et al., 2007).

Fins et al. (2005) and Maltby and Fins (2003) proposed a covenantal model of ACP whereby patients with life-limiting cancer and their surrogates can explore complex EOL situations that lack clear choices. A covenantal relationship between patient and surrogate is sustained by trust and understanding. Trust and understanding can be the greatest sources of guidance for surrogates facing EOL situations that are clinically and morally ambiguous and lack clear choices, (Maltby & Fins).

Respecting Choices is designed to offer guidance and trust. The Respecting Choices® DS-ACP requires developing or solidifying this covenantal relationship as part of helping both patients and surrogates understand that complex situations may arise and necessitate an interpretation of the patient's judgment by the surrogate. The underlying premise is that surrogates who have a reservoir of discretionary trust and receive adequate guidance from

patients are able to act ethically and effectively. An empowered surrogate is less likely to be burdened by guilt and emotional pain that can result when making life and death decisions (Fins et al., 2005).

CHAPTER 3: METHODS

Research Design

The design for this study was a Phase I clinical trial. A Phase I clinical trial was selected instead of a randomized control trial because of the risk of not providing an intervention that has demonstrated benefits with other study populations. A Phase I clinical trial design is appropriate for initial investigation of the impact of the Respecting Choices® ACP intervention with patients with life-limiting cancer and their surrogates. Measures were administered before and after the intervention. Anecdotal information was collected to evaluate patients' and surrogates' satisfaction with the intervention and its timing.

Independent and Dependent Variables

The independent variable in the study will be time (pre and post the Respecting Choices® DS-ACP intervention). Dependent variables in the study will be patient-surrogate congruence, patients' anxiety, and decisional conflict.

Population, Sample, and Setting

The sample included patients and their surrogate decision makers who have received a diagnosis of life-limiting cancer or whose previously treated cancer has progressed or reoccurred. For the purpose of this study the term life-limiting cancer is defined as an initial or recurrent diagnosis of advanced cancer or invasive cancer. Advanced cancer is cancer that has grown beyond the organ in which it first started or affects a vital organ that cannot be removed. Invasive cancer is when cancer cells have penetrated the original layer of tissue (ACS, 2010).

Sample Selection

Eligibility and Exclusion Criteria

To qualify for inclusion in the study, both the patients and their surrogate decision makers needed to be 21 years of age or older, speak and read English as their primary language and have the capacity to understand the information on the Statement of Treatment Preferences for Patients with Life-Limiting Cancer Form, a form which patients could choose to serve as their AD if they participated in the study (see Statement of Treatment Preferences for Life-Limiting Cancer in Appendix A). Silberfeld, Nash, and Singer's (1993) Verbal Assessment Questions (Appendix B) were used to screen for participants' capacity to understand the nature and purpose of the Statement of Treatment Preferences for Life-Limiting Cancer Form and the role of health care surrogates. The principal researcher administered the questions verbally prior to the intervention. The patients were required to assign a surrogate who would participate with the patient in the Respecting Choices® DS-ACP intervention. The surrogate could be a friend, a relative, or other known person who agreed to perform the role of surrogate. Participants were excluded from the study if they did not have a surrogate who was willing to participate in the intervention.

Recruitment

The initial intent was to recruit participants through partnership with area oncologists. However, consistent with the literature (see for example, Astrow et al., 2008; Baile, et al., 2002; Bradley et al., 2001; Curtis et al., 2000; Kish et al., 2000; Tung, 2009; Walling et al., 2008; Yedidia, 2007), it was difficult to gain consent from practicing health care professionals. More specifically, over fifteen local practices were contacted, including oncologists, primary care,

internal medicine, and hospice. Only one of these contacts led to a referral to potential study participants. Additional networking led to the Volunteers in Medicine Clinic (VIM), who eagerly embraced the opportunity to provide this ACP intervention to patients under their care who were dealing with life limiting cancer. The VIM clinic serves the health and wellness needs of community members who are not eligible for any government programs, are not covered by insurance and have income below 200 per cent of the poverty level. Medical care is provided by volunteer medical personnel working in concert with existing medical resources in the community, including oncologists and cancer centers.

The Health Insurance Portability and Accountability Act (HIPAA) precludes the researcher from screening or directly approaching potentially eligible patients. Therefore, the researcher presented selected VIM referral providers with inclusion and exclusion criteria and a verbal script to ask patients who met the eligibility criteria if they were interested in receiving additional information about the study. If a patient was interested in obtaining additional information, he or she was given a copy of an introductory letter written by the researcher that described the study (Appendix C). Interested patients who agreed to be contacted provided their preferred contact information on a card that accompanied the introductory letter.

The researcher contacted the potential participant(s) via their requested method, explained the study, confirmed that the patient had a surrogate decision maker, and explained the informed consent procedure. If the potential participant(s) agreed to participate, a meeting was scheduled to obtain informed consent (see *Informed Consent* and Appendix D), and enroll the patient and the surrogate. Study participation occurred at this same appointment, following consent. Special attention was given to ensure that participation was completely voluntary. In other words, that all contact with potential study participants was free of coercion and undue

influences (National Institutes of Health [NIH] 1979). Potential participants were assured that participation was completely their choice and that not participating would in no way affect their care. Potential participants who self-reported being uncomfortable with or not being ready to participate in the Respecting Choices intervention were provided with contact information in the event that they changed their mind or wanted more information.

Although 12 eligible participants from VIM initially agreed to participate in this ACP intervention, only five were able to do so due to the severity of their life limiting cancer. However, snowball recruitment provided an additional nine eligible recruits for the intervention. Three of the five participants who were recruited from VIM and received the intervention referred people with life-limiting cancer based on their satisfaction with the intervention. Participants referred by participants from VIM also provided referrals, including patients they met in cancer support groups or during treatment, for example during infusion therapy sessions. These potential participants were given the introductory letter (Appendix C) by the person referring them to the study. Interested individuals who agreed to be contacted gave verbal consent to their referral source and provided their preferred contact information on a card that accompanied the introductory letter. After receiving permission, the investigator contacted potential participants and followed the recruitment and informed consent sequence as previously described.

Sample Size, Power, and Significance

The initial plan was a sample size ranging from 15-34 depending on effect size. The upper number, 34 dyads, was based on detecting a medium effect size of .50, assuming a power of .80, and an α of .05 in analyses involving the paired t-test (Faul, Erdfelder, Buchner & Lang,

2009). However, analyses were conducted once data were obtained from 15 dyads to determine if the study effect sizes were large enough (.80) to be detected with a smaller sample.

Recruitment ceased once it was determined that 15 dyads provided sufficient power (.80) to detect a significant effect.

Setting

The setting for the proposed study was at the VIM clinic or the participant's home. Participant(s) were asked to select the time and location that they preferred.

Ethical Considerations

Based on findings from numerous studies with other study populations, (Briggs et al., 2004; Detering et al., 2010; Kirchhoff et al., 2010; Lyons et al., 2009; Schwartz et al., 2002; Song et al., 2005), there is strong evidence that the Respecting Choices® DS-ACP intervention is superior to traditional approaches for AD completion. Thus, all participants in this study received the intervention. Delivering the intervention to everyone was based on two principles--the wellbeing of each individual research participant taking precedence over all other interests and access to the best available standard of care (World Medical Association, 2008)--

In addition to following procedures for informed consent (see below), special attention was given to the sensitive nature of discussing EOL issues with patients and their surrogates. Extra attention was given to providing patients and surrogates with adequate study information to support making an informed decision about study participation. The guidelines outlined in *Eligibility and Exclusion Criteria* to assess the capacity to participate in the intervention and complete the AD were followed to decrease potential misunderstandings about the intervention and study procedures. Situations that might cause distress or burden were carefully considered

and managed during the intervention (NIH, 1979; McMillan & Weitzner, 2003). For example, the intervention includes a step to ensure that specific questions or concerns that arise during the intervention are discussed with the study participant and, if needed and with participant's permission, referred to the individual's health care provider (see Stage 6 of the intervention in *Respecting Choices*® *DS-ACP Interview* and Appendix E). Procedures were in place in the event additional resources were identified during the interview.

Additionally, data collection and the intervention were designed to minimize risks and burden. The intervention was scheduled to occur at a time and place that was most convenient for the participants. All data collection instruments were selected to collect only essential data and were administered at one visit by one researcher to ensure consistent application of the instruments.

Informed Consent

Participants were provided with a description of the study, its purpose, and why they were selected. The participants were given a description of what they would be asked to do, how long it would take, and information about the potential risks and benefits of participating. They were provided with a statement that participation was completely voluntary and that they could withdraw at any time without repercussions. Participants were provided with the researcher's contact information and instructed to contact her if any questions were to arise before or during the study. The participants were also provided with a name and contact information of another person they could call if they have any complaints or concerns about the research. A copy of the informed consent form and its explanatory text are included in Appendix D.

A copy of the Statement for Treatment Preference For Life-Limiting Cancer Form (see Appendix A) was given to the participants for their records. No names or identifying information were written on the data collection forms. Instead, the names of patients and surrogates were replaced by numbers randomly assigned to each dyad. Only one person, the researcher conducting the study, collected and stored the data. The participants were assured that all data would be kept confidential.

Permission to proceed was sought and secured from the Institutional Review Board (IRB) associated with the proposed research. The investigator first secured approval to proceed from the University of Central Florida's IRB before launching the study.

Intervention

Respecting Choices® DS-ACP Interview

The Respecting Choices intervention is delivered as a one-time interview that provides a structured approach for assessing the patient's and his or her surrogate's representation of the patient's illness, beliefs, goals, and values. The interview also explores experiences that may have an impact on health care decision making. The intended goal of this intervention is to help patients make informed choices that are understood by the surrogate. In the event there is a need for an additional meeting or follow-up discussion after the patient speaks with their healthcare provider, a follow up meeting is scheduled.

The six key stages of the Respecting Choices interview are as follows: (1) assess illness beliefs, goals, and values; (2) explore experiences; (3) explain the purpose of advance care planning; (4) clarify goals for life-sustaining preferences; (5) summarize what was learned; and (6) develop a follow-up plan. Details on these six stages are provided in *Respecting Choices®*

DS-ACP Interview (see Appendix E). The interview takes approximately 90 minutes. The researcher is a trained Respecting Choices ACP facilitator and delivered the intervention. The researcher took brief handwritten notes during the intervention to develop a follow-up plan for participants. The researcher documented anecdotal information as field notes after each interview.

Respecting Choices® DS ACP is a standard intervention with protocols that were applied consistently in a predetermined sequence. Fidelity to the intervention was maintained by its being administered by one trained facilitator. Any deviation to protocol that occurred was documented in a study log. The only deviation to protocol pertained to the recruitment method as described above (see *Recruitment*).

The Respecting Choices® DS ACP intervention uses disease specific scenarios and these scenarios are integrated into the Statement of Treatment Preferences Form (see Appendix A). Development of these scenarios was guided by the research of Fried et al. (2002), who noted that the treatment decisions of people with life-limiting illness are influenced by treatment burden, treatment outcome, and the likelihood of the outcome. Patients are asked to verbalize their goals for life sustaining treatments in clinical scenarios that include the following: low survival but high burden; high survival with functional disability; and high survival with cognitive disability specific to the illness trajectory of life-limiting cancer.

Respecting Choices Facilitator Training

Health care professionals who wish to administer the Respecting Choices® DS-ACP intervention materials are required to complete training. The training incorporates Weiner and Cole's (2004) conceptual approach, which addresses specialized skills of shared decision making

specific to advanced illness and EOL in addition to general patient-centered communication skills. Facilitators learn key communication techniques, such as exploring the meaning of words and phrases, listening, paraphrasing, clarifying, affirming and reaffirming, and displaying empathy. These communication techniques are integrated into the delivery of the Respecting Choices intervention and allow for the following: in-depth expression by the patient and surrogate; increasing patient and surrogate knowledge of the patient's illness; clarifying the patient's goals, values, and beliefs, thereby informing the surrogate; creating shared decision making as an approach; and creating an environment of trust and openness (Briggs & Hammes, 2008/2010).

The researcher completed the Respecting Choices facilitator training program in February, 2010. In addition to instruction in communication techniques, the 2-day competency-based training program included online learning modules, review of relevant literature, demonstrations, and practice scenarios to support the achievement of expected outcomes. The training also included the researcher demonstrating delivery of the Respecting Choices® DS-ACP interview via videotaping a role play and receiving constructive feedback from Respecting Choices faculty (Briggs & Hammes, 2008). As a final step in the ACP facilitator training protocol, the researcher completed and submitted a second video role-play for evaluation prior to administering the intervention for this proposed study. This final step culminated in certification and was completed prior to beginning recruitment of participants.

Instruments

Sociodemographic Form

Two versions of a sociodemographic questionnaire were administered: one for the patient and one for the surrogate (see Appendix F). Both versions include age, gender, marital status, education level, income, religious affiliation, and patient-surrogate relationship. The patient form also includes diagnosis, referral source (e.g., VIM Clinic, friend), housing status (where and with whom the patient lives), and a question about the patient's perceived prognosis. The surrogate form also includes a question about the surrogate's perception of the patient's perceived prognosis

Statement of Treatment Preferences for Life-limiting Cancer

The Statement of Treatment Preferences for Life-Limiting Cancer Form (see Appendix A) presents five clinical situations and clarifies goals for the patient's preferences and assesses the surrogate's understanding of the patient's preferences in each of the clinical situations. The first four clinical situations describe the following cancer outcomes after a trial of treatment: a prolonged hospital stay with little chance of survival; a worsening of the cancer with a 2-3 month survival; a good chance of survival with functional impairment requiring 24-hour nursing care; and a good chance of survival with permanent cognitive impairment requiring 24-hour nursing care, respectively. The fifth situation requires CPR and has a poor outcome. After discussion and clarification of the meaning of each situation, the patient is asked to choose 1 of 2 options for each situation: "continue all treatment," or "stop all treatment."

The Statement of Treatment Preferences was developed by Briggs & Hammes (2008/2010) and pilot tested with patients to assess participants' understanding of the form prior

to its use in research settings (Hammes, 2001). It has been used in research settings as a decision aid and documentation tool to promote understanding of likely situations that could occur in the future and express the patients' goals of treatment in light of acceptable and unacceptable burdens and outcomes (Briggs et al., 2004; Detering et al., 2010; Kirchhoff et al., 2010; Lyons et al., 2009; Schwartz et al., 2002; Song et al., 2005).

The Statement of Treatment Preferences is based on a modified version of the Emmanuel and Emmanuel Medical Directive, a reliable and valid means of both documenting patient wishes for EOL care and measuring the outcome of ACP interventions (Schwartz, Merriman, Reed & Hammes, 2004). Reliability assessment included internal consistency reliability across situations within and across treatments and situations and test-retest stability among patients with stable health (Schwartz et al., 2004). Both types of reliability were high.

Decisional Conflict Scale

The DCS (see Appendix G) measures perception of uncertainty in choosing medical treatment options and factors contributing to uncertainty, such as lack of information, lack of clarity regarding personal values, and lack of support in decision making (O'Connor, 1995, updated 2005). This instrument consists of 16 items and the following five subscales: Informed subscale (items 1-3), Values Clarity subscale (items 4-6), Support subscale (items 7-9), Uncertainty subscale (items 10-12), and Effective Decision subscale (items 13-16). Items in each subscale are scored on a 5-point Likert-type scale from 0 (*strongly agree*) to 4 (*strongly disagree*). The DCS was designed to be self-administered.

The DCS has been widely used to evaluate patients' decisions regarding types of health care treatment (O'Connor, 1995). Cronbach's alpha for the total DCS ranged from 0.78 to 0.92

(Meropol et al., 2003; O'Connor et al., 1999; O'Connor & Jacobsen, 2007). This instrument has been shown to have clinical utility, especially in situations in which patients are faced with complicated decisions. Sample size in most studies is usually based on detecting effect size of 0.30-0.40. Scores lower than 25 are associated with implementing decisions; scores exceeding 37.5 are associated with decisional delay or feeling unsure about implementation (Graham & O'Connor, 1995, updated 2005).

Song and Sereika (2006) examined the reliability and the validity of the DCS when the tool was used to measure patients' evaluations of the EOL decision-making process. This evaluation used a combined sample of patients who had participated in two previous studies (Briggs et al., 2004; Song et al., 2005). Song and Sereika, with one exception, found the DCS to have acceptable reliability and validity when used to assess EOL decision making. The exception pertained to the weak relationship between the uncertainty subscale and perceptions of the modifiable factors contributing to uncertainty, such as 'feeling the decision is easy to make'. They concluded that uncertainty is not a useful domain to measure when uncertainty is inevitable. Therefore, the original plan was not to use the uncertainty subscale (items 10, 11, and 12) in this study. However, most of the obtained inter-item correlation among the Uncertainty items was higher than .30. Thus the Uncertainty subscale was included in this study.

Spielberger State Anxiety Scale S-anxiety Scale

The STAI is comprised of two separate self-report scales for measuring state and trait anxiety, but only the scale for State anxiety was used in this study (see Appendix G). The State-anxiety Scale (STAI Form Y-1) consists of 20 statements that evaluate the respondent's feelings of apprehension, tension, nervousness, and worry right now—at the moment (Spielberger, 1983).

The STAI (Form Y-1 & Form Y-2) was designed to be self-administered and is reported to take approximately 6 minutes when used with college students and approximately 10 minutes when used with less-educated or emotionally disturbed persons (Spielberger, 1983).

The S-anxiety Scale has been found to be a sensitive indicator of change in transitory anxiety experienced by clients and patients in counseling, psychotherapy, and behavior modification programs. The scale has also been used extensively to assess S-anxiety induced by stressful experimental procedures and unavoidable real life stressors (Spielberger, 1983).

In studies conducted by Spielberger (1983), the stability coefficients for Form Y-1 were based on two groups of high school students tested in classroom settings. Test-retest intervals were 30 days (0.62 for males, 0.34 for females) and 60 days (0.51 for males, 0.36 for females). As would be expected for measures assessing change in anxiety resulting from situational stress, stability, as measured by test-retest coefficients, was low for the S-anxiety Scale. Internal consistency reliability ranged from 0.83-0.92 for S-Anxiety Scale (Weintraub & Hagopian, 1990).

Concurrent validity was supported by correlating the STAI with the Taylor Manifest Anxiety Scale and Institute for Personality and Ability Testing (IPAT) Anxiety Scale (0.79 to 0.83 and 0.75 to 0.76, respectively). Construct validity was determined by comparing like subjects under stressful and nonstressful situations (Derogatis & Wise, 1989). The STAI has been successfully used with high school and college students (Gaudry, Vagg & Spielberger, 1975; Spielberger, 1983), psychiatric patients (Spielberger 1983), medical and surgical patients (Cupples, 1991; Petersen, 1991; Weintraub & Hagopian, 1990; Wong & Bramwell, 1992; Zimmerman, Pierson, & Marker, 1988), obstetric patients (Annie & Groer, 1991; Pond & Kemp,

1992), the chronically ill (Gift, 1991), and the elderly (Fraser & Kerr, 1993). The STAI is written at a fifth-grade level.

Complete instructions are printed on the test form but may be modified to evaluate the intensity of the S-anxiety for any situation or time interval of interest. For research purposes, the researcher can alter instructions for the S-anxiety Scale to focus on a particular time period (Spielberger, 1983). In this study, the specified time period was “right now.”

To reduce response bias, such as the tendency to agree with positively worded items, half of the items are stated positively and half are stated negatively. The scoring weights for the anxiety-absent items are reversed (see Appendix H). Each STAI item is given a weighted score of 1 to 4. A rating of 4 indicates the presence of a high anxiety level for 10 items and a high rating indicates an absence of anxiety for the remaining 10 items. The scoring weights for the anxiety-absent items are reversed (for example, items marked 1, 2, 3, or 4 are scored 4, 3, 2, and 1, respectively). The anxiety-absent items for which scoring is reversed on the S-anxiety Scale are 1, 2, 5, 8, 10, 11, 15, 16, 19, and 20. To obtain scores, the weighted scores for 20 items are added together, taking into account the fact that scores are reversed for these items. Scores can vary from a minimum of 20 to a maximum of 80 (Spielberger, 1983).

Quality of Communication about End-of-life Care

The Quality of Communication about EOL Care Form (see Appendix I) assesses the fidelity of the intervention by asking about patient and surrogate satisfaction with the overall quality of the intervention and the facilitator. The form has been utilized to evaluate the quality of communication regarding EOL treatment in studies between the patient and his or her health care provider and the patient and nurse providing the Respecting Choices® ACP interview

(Briggs et al., 2004; Curtis, Patrick, Caldwell, Greenlee, & Collier, 1999; Lyons, et al., 2009; Song et al., 2005). This instrument consists of five questions: The first question asks if the patients' treatment preferences are known (congruence). Question 2, 3 and 4 pertain to whether participants felt the interviewer truly cared about them, listened, and gave them enough attention during the discussion (interviewer fidelity). These four questions are rated on a scale of 1 (no) to 3 (definitely yes). The fifth question asks participants to rate the overall quality of the discussion (interview fidelity) on a scale of 1 (poor) to 5 (excellent). Use of this questionnaire among AIDS patients has yielded good internal consistency with a Cronbach's alpha of 0.81 (Curtis et al., 1999). In a study using the Respecting Choices® ACP intervention, the internal consistency reliability was 0.87 (Song & Sereika, 2006).

Data Collection Procedure

After IRB approval was received from the researcher's university and referral sources, all eligible patient-surrogate dyads referred for study participation were provided with information about informed consent and requested to consent to participate (see Appendix D). Participants who agreed to participate signed the informed consent form, a copy of which was returned to both members of the dyad and the original retained by the researcher. Based on recommendations from prior studies (Ditto et al., 2001; Schwartz et al., 2002) in which transportation was a barrier to participating, participants were offered the choice of their home as the site of data collection. Each patient-surrogate dyad was scheduled for one 90-minute Respecting Choices® DS-ACP interview by the researcher. Prior to the interview, both the patient and surrogate were separated and requested to independently complete the appropriate Sociodemographic Data Form (see Appendix F), and Statement of Treatment Preferences for

Life-Limiting Cancer Form (see Appendix A). Patients also completed the DCS (see Appendix G) and STAI (see Appendix H). Participants were instructed to respond according to how they felt immediately before the intervention.

Next, the patient-surrogate dyads participated in the Respecting Choices® DS-ACP interview. The six stages (see *Respecting Choices DS- ACP Interview* in Appendix E) were addressed in one 90-minute interview session. Immediately after the interview, the patient and surrogate were separated. The patient completed the STAI second time (post test) but this time the directions were to respond based on how he or she felt immediately after the intervention. After completing the second administration of the STAI, the patient was also asked to complete the Statement of Treatment Preference for Life-Limiting Cancer Form, the DCS and the Quality of Communication about EOL Care Form. The surrogate also completed the Statement of Treatment for Life-Limiting Cancer Form and the Quality of Communication about EOL Care Form (see Table 1). Participants were asked to write in a response to an additional question about whether they thought this was a good time to have this discussion. Some participants chose to write qualifying information about the best possible time.

All forms were collected and stored by this researcher, as described in the section on *Ethical Considerations*. The patient's Statement of Treatment Preferences for Life-Limiting Cancer, as well as any written information about concerns or questions collected during the interview (e.g., questions the patient would like to discuss with his or her health care provider) were given to the patient.

Table 1. Data Collection Method by Time Pre-and Post- Intervention (Patients, Surrogate)

| | Pre Intervention | Post Intervention |
|-----------|---|--|
| Patient | Demographic Form (patient version) Statement of Treatment Preferences DCS STAI | STAI Statement of Treatment Preferences DCS Quality of Communication Form |
| Surrogate | Demographic Form (surrogate version) Statement of Treatment Preferences | Statement of Treatment Preferences Quality of Communication Form |

Data Analysis Plan

Data were entered into SPSS version 18.0 for Windows for analysis. Descriptive statistics were performed to describe the sample and included the frequencies and percentages, means, and standard deviations. For categorical or nominal data, frequencies and percentages were conducted. Means and standard deviations were calculated on interval/ratio data (Cronk, 2006; Salkind, 2005).

Research Question 1

RQ1: Does the intervention increase congruence on the Treatment Preferences for Life-Limiting Cancer Form (pretest versus posttest) between patient and matched surrogate?

To answer RQ 1, five 2x2 McNemar Chi-square tests were conducted to investigate whether the intervention increased congruence on the statement of treatment preferences for life-limiting cancer form (pretest versus posttest) between patient and matched surrogate. A pretest agree/disagree (0, 1) score and a posttest agree/disagree (0, 1) score were calculated for each patient-surrogate pair for each of the five situations. One McNemar Chi-square analysis was

conducted for each situation to compare changes in patient-surrogate agreement pre and post intervention. The rows correspond to pretest congruence (disagreement, agreement) and the columns correspond to posttest congruence (disagreement, agreement). A significant McNemar Chi-square test was interpreted as a significant change in the proportion of congruence over time.

Research Question 2

RQ2: Are there significant differences in the proportion of congruence observed for different situations at post test?

To answer RQ 2, the Zar's Multiple Comparison Test of Differences was conducted to investigate whether there are significant differences in the proportion of congruence observed for different situations on the Statement of Treatment Preferences for life-limiting cancer form at post test.

Research Questions 3 and 4

RQ3: Does the intervention reduce patients' decisional conflict?

RQ4: Does the intervention increase patients' anxiety?

A paired-sample *t* test was conducted to address both research questions 3 and 4. The independent or grouping variable in both analyses was time (pretest versus posttest). The paired-sample *t* test is an appropriate statistical analysis when the two scores are repeated measures, such as in situations when the assessment is used as a pretest before an intervention and as a posttest after the intervention (Field, 2005). The dependent variable in each analysis (decisional conflict, anxiety) was evaluated for presence of outliers and problems with normality prior to conducting the *t*-test. Descriptive statistics (skew, frequency) were inspected to evaluate normality. All appropriate assumptions were met for analysis using the paired-sample *t* test.

Analysis Assessing Fidelity and Timing of Intervention

Frequencies and percentages were conducted for the five items on the Quality of Communication about EOL Care Form to assess the fidelity of the intervention. “Yes” and “No” responses to the additional question about timing were tallied. Anecdotal comments about timing were content analyzed and summarized.

CHAPTER 4: RESULTS

Descriptive Statistics

Sample

Thirty people participated in the study, 15 patients and 15 paired surrogates. Although 12 eligible participants from VIM initially agreed to participate in this ACP intervention, only five were able to do so due to the severity of their cancer and/or reluctance to add to their surrogates' burden. As previously discussed (see **Recruitment**), snowball recruitment provided an additional nine eligible recruits for the intervention.

The demographic characteristics of the sample are presented in Table 2. All but three patients reported employment status as 'not currently working due to their current illness' or 'retired.' As can be seen in Table 2, slightly more than half of the participants were 55 years of age or older ($n = 8$, 53.3%) and the majority of surrogates were younger than the patients ($n = 9$, 60.0%). The majority of surrogates were spouses of married patients ($n=9$, 60%); a spouse was the surrogate for all but one of the nine married patients ($n = 8$, 90%). All patients reported some category of Christian as their religious background and almost half reported attending religious services at least once a month ($n=6$, 40%). Many participants were reluctant to report income but the five who were recruited from VIM were at least 200% below the poverty level.

Table 2. Socio-Demographic Characteristics

| Demographic | Patient | | Surrogate | |
|---|----------------|------|------------------|------|
| | <i>n</i> | % | <i>n</i> | % |
| Age | | | | |
| 54 years old or younger | 3 | 20.0 | 9 | 60.0 |
| 55-59 years old | 8 | 53.3 | 3 | 20.0 |
| 60 years old or older | 4 | 26.7 | 3 | 20.0 |
| Gender | | | | |
| Male | 6 | 40.0 | 3 | 20.0 |
| Female | 9 | 60.0 | 12 | 80.0 |
| Marital status | | | | |
| Single | - | - | 1 | 6.7 |
| Married | 9 | 60.0 | 13 | 86.7 |
| Divorced | 5 | 33.3 | - | - |
| Widowed | 1 | 6.7 | - | - |
| Domestic partnership | - | - | 1 | 6.7 |
| Religious Affiliation current | | | | |
| Non-denominational Christian | 10 | 66.7 | 8 | 53.3 |
| Catholic | 5 | 33.3 | 7 | 46.7 |
| How Often Attending Religious Services | | | | |
| Once a week or more | 4 | 26.7 | 1 | 7.1 |

| | Patient | | Surrogate | |
|--------------------------------------|----------------|------|------------------|------|
| Demographic | <i>n</i> | % | <i>n</i> | % |
| About once a month | 2 | 13.3 | 5 | 35.7 |
| Holy days and special occasions only | 2 | 13.3 | 6 | 42.9 |
| Never | 3 | 20.0 | 1 | 7.1 |
| Patient Housing Status | | | | |
| Home | 15 | 100 | - | - |
| Education Level | | | | |
| High school diploma/GED | 3 | 20.0 | 2 | 14.3 |
| Associates degree | 8 | 53.4 | 4 | 28.6 |
| Bachelor's degree | 2 | 13.3 | 5 | 35.7 |
| Graduate degree | 2 | 13.3 | 1 | 7.1 |
| Patient Cancer Diagnosis | | | | |
| Breast | 5 | 35.7 | - | - |
| Lung, Testicular | 1 | 7.1 | - | - |
| Multiple myeloma | 1 | 7.1 | - | - |
| Mouth, Tongue | 1 | 7.1 | - | - |
| Prostate | 2 | 14.2 | - | - |
| Nonhodgkins lymphoma | 1 | 7.1 | - | - |
| Ovarian | 1 | 7.1 | - | - |
| Kidney | 1 | 7.1 | - | - |

| | Patient | | Surrogate | |
|--|----------------|------|------------------|------|
| Demographic | <i>n</i> | % | <i>n</i> | % |
| Surrogate Relationship | | | | |
| Spouse | - | - | 8 | 53.3 |
| Child | - | - | 3 | 20.0 |
| Friend | - | - | 4 | 26.7 |
| How patients were referred to study | | | | |
| VIM | 5 | 33.3 | - | - |
| Urologist | 1 | 6.7 | - | - |
| From a Study Participant | 9 | 60.0 | - | - |
| Employment | | | | |
| Not Currently Employed | 12 | 80.0 | | |
| Currently Employed | 3 | 20.0 | | |

Research Question 1

RQ1: Does the intervention increase congruence in reported Treatment Preferences for Life-Limiting Cancer Form (pretest versus posttest) between patient and matched surrogate?

Congruence between patient and matched surrogate for treatment preferences for life-limiting cancer significantly increased from pretest to posttest in situations 1, 3 and 5, (low survival, high burden; high survival, functional disability; and CPR, high burden, respectively).

The remaining situations 2 and 4 (poor outcome, high burden and high survival, cognitive

disability, respectively) had complete agreement at the posttest so that the binomial test was required rather than the McNemar test. Table 3 presents the results by situation.

Table 3. Results for McNemar and Binomial Tests for Congruence at Pretest and Posttest

| Situation | Pretest Agreement | Posttest Agreement | <i>p</i> |
|--|--------------------------|---------------------------|-----------------|
| 1 – low survival, high burden | 53.3 (n=8) | 93.3 (n=14) | .031 |
| 2 – poor outcome, high burden | 60.0 (n=9) | 100.0 (n=15) | .001 a |
| 3 – high survival, functional disability | 26.7 (n=4) | 93.3 (n=14) | .002 |
| 4 – high survival, cognitive disability | 66.7 (n=10) | 100.0 (n=15) | .002 a |
| 5 – CPR, high burden | 40.0 (n=6) | 93.3 (n=14) | .008 |

Note. a Binomial tests used due to 100 % agreement at posttest.

Research Question 2

RQ2: Are there significant differences in the proportion of congruence observed for different situations at posttest?

The proportion of congruence observed after the intervention did not differ across the five situations ($p \geq 0.50$). These proportion ranged from 93 % - 100% (see Table 3)

Table 4. Zar’s Multiple Comparison Test of Differences in Proportions of Congruence across Situation at Post-test

| Situations | Proportions | p’ |
|--|--------------------|-----------|
| 1 – low survival, high burden | 14/15 | 77.47 |
| 2 – poor outcome, high burden | 15/15 | 84.85 |
| 3 – high survival, functional disability | 14/15 | 77.47 |
| 4 – high survival, cognitive disability | 15/15 | 84.85 |
| 5 – CPR, high burden | 14/15 | 77.47 |

Research Question 3

Does the intervention reduce patients’ decisional conflict?

To examine research question 3, a paired sample *t*-test was conducted to assess if there were significant differences in decisional conflict scale (DCS) over time (pretest vs. posttest). The results of the dependent sample *t* - test were significant, $t(14) = 4.49, p < .001$, suggesting that posttest decisional conflict was significantly reduced (see Table 5).

Table 5. Results of Paired Sample *t* Test for DCS Scores by Time (Pretest vs. Posttest)

| | Pretest <i>M</i> (<i>SD</i>) | Posttest <i>M</i> (<i>SD</i>) | <i>t</i> | <i>df</i> | <i>p</i> |
|-----|---|--|-----------------|------------------|-----------------|
| DCS | 25.52 (15.57) | 16.04 (15.41) | 4.49 | 14 | .001 |

Note: low score indicates less decisional conflict

Research Question 4

Does the intervention increase patient's anxiety?

To examine research question 4, a paired sample *t*-test was conducted to assess if there were significant differences in patients' anxiety over time (pretest vs. posttest). The results of the paired-sample *t* - test were not significant, $t(14) = 1.75, p = .102$, suggesting that there was not a significant difference in patients' anxiety/stress scores over time. As can be seen from the means reported in Table 6, moderate levels of anxiety were reported at both time points.

Table 6. Results of Paired Sample *t* Test for Anxiety/Stress Scores by Time (Pretest vs. Posttest)

| | <i>Pretest M</i> (<i>SD</i>) | <i>Posttest M</i> (<i>SD</i>) | <i>t</i> | <i>df</i> | <i>p</i> |
|----------------|-----------------------------------|------------------------------------|----------|-----------|----------|
| Anxiety/stress | 2.31 (0.33) | 2.21 (0.33) | 1.75 | 14 | .102 |

Additional Analyses Assessing Intervention Fidelity and Timing

Intervention Fidelity

After the intervention, the Quality of Communication about EOL Form (Appendix I) was used to ask participants to evaluate the interview and the interviewer and rate the overall quality of the discussion. As depicted in Table 7, the intervention was delivered as intended. All participants indicated they believed the patients' treatment preferences would be honored (congruence). All participants definitely felt the interviewer cared, listened, and gave

participants enough attention (Interviewer fidelity). All participants were definitely satisfied with the quality and effectiveness of communication (Interview fidelity).

Timing

All 10 patients and all seven surrogates who answered the question about timing answered yes, it was a good time to have a discussion about ACP. However, one patient specified that the best time would be one to two weeks after diagnosis because the discussion would mean more when she “was still going through it.” However, three patients explicitly stated that they liked the idea that the discussion occurred when they were not in crisis or heightened distress. These patients made comments like “Good lapse between treatment and [Respecting Choices] Interview,” “It is easier to let your feelings be known when you aren’t in a crisis”, and “I have no active cancer to cause stress and affect my decision making process.” One surrogate appreciated having the discussion before “it is too late” and two surrogates made comments like “there is never a bad time” and that the discussion would be “appropriate at any time.”

Table 7. Frequencies and Percentages for Analyses Assessing Intervention Fidelity and Timing

| | Patient | | Surrogate | |
|-------------------------------------|----------|-------|-----------|-------|
| | <i>n</i> | % | <i>n</i> | % |
| Question 1 – (Congruence) | | | | |
| Probably yes | 3 | 20.0 | 2 | 13.3 |
| Definitely yes | 12 | 80.0 | 13 | 86.7 |
| Question 2 – (Interviewer fidelity) | | | | |
| Probably yes | - | - | 1 | 6.7 |
| Definitely yes | 15 | 100.0 | 14 | 93.3 |
| Question 3 – (Interviewer fidelity) | | | | |
| Definitely yes | 15 | 100.0 | 15 | 100.0 |
| Question 4 – (Interviewer fidelity) | | | | |
| Probably yes | - | - | 1 | 6.7 |
| Definitely yes | 15 | 100.0 | 14 | 93.3 |
| Question 5- (Interview fidelity) | | | | |
| Very good | 4 | 26.7 | 4 | 26.7 |
| Excellent | 11 | 73.3 | 11 | 73.3 |

Note : questions 1-4 ratings: 1= 'no' 2=probably yes 3= 'definitely yes'. Question 5 ratings: 1=poor 2=fair 3=good 4= very good 5= excellent

CHAPTER 5: DISCUSSION

Implications

This study investigated the impact of the Respecting Choices® DS ACP intervention on patients with life-limiting cancer and their surrogates. Study findings were that participating in the intervention significantly improved congruence between patients and surrogates regarding EOL treatment preferences and reduced decisional conflict without causing anxiety. More specifically, congruence between patients and matched surrogates for patient treatment preferences significantly increased from pretest to posttest in all five situations. Feedback obtained from the participants indicated that everyone who participated in this study found the Respecting Choices® DS ACP intervention to be acceptable and beneficial.

Although it seems obvious that surrogates would have a greater understanding of patients' goals after an ACP discussion, most previous studies failed to show improved patient-surrogate dyadic congruence between patient and surrogate understanding after an ACP intervention (Ditto et al., 2001; Hare et al., 1992; Layde et al., 1995; Matheis-Kraft & Roberto, 1997; Seckler et al., 1991; SUPPORT, 1995; Uhlmann et al., 1988; Wilkinson et al., 2007; Zweibel & Cassel, 1989). The only studies that have found ACP to be effective in increasing patient-surrogate dyadic congruence have included the elements that are incorporated into the Respecting Choices DS ACP (Briggs, 2003; Briggs et al., 2005; Detering, et al., 2010; Kirchhoff, et al., 2010; Lyon et al., 2009; Schwartz et al., 2002; Song et al., 2005). Thus, findings from this study add to the body of literature that supports the essential elements of the Respecting Choices intervention.

One of these Respecting Choices DS ACP elements places importance on surrogate selection, specifically instructing patients to purposefully select a surrogate who is willing and

capable of making decisions consistent with their values and goals (Briggs et al., 2004; Singer et al. 1998, Schwartz et al., 2003). Consistent with this element, the researcher instructed patients who expressed an interest in study participation to select a surrogate whom they believed could best understand and support their wishes. Selected surrogates were required for study participation, as the intervention was designed for surrogates to be included in the ACP discussion. This requirement may have contributed to the success of the intervention because chosen surrogates may have been more open to and interested in engaging in EOL discussions than other people in the patients' interpersonal networks.

Another Respecting Choices DS ACP element places importance on having a trained facilitator guide the ACP discussion between the patient and surrogate. The requirement for facilitator training acknowledges that discussing EOL is difficult for health professionals and lay persons and additional communication skills are needed to help patients communicate their wishes to surrogates. One of the reasons for this study's success may be because the facilitator successfully completed a certified training program and had the skills to help patients have more effective EOL discussions with their surrogates.

The opportunity to discuss individual concerns is another key element in the Respecting Choices ACP intervention. Discussing individual concerns includes helping patients reflect on their goals and values and how these goals and values could direct treatment decisions. For example, most patients in this study said initially that they were willing to accept a trial of chemotherapy, regardless of their prognosis. With further discussion, the facilitator helped these patients understand the possible outcomes of a chemotherapy trial and adjust their expectations and clarify their wishes accordingly. In addition to reconsidering their general acceptance of chemotherapy, these patients were able to articulate possible outcomes that would make

acceptance of this treatment conditional. For example, patients identified loss of mental capacity or the inability to take care of themselves as conditions for not trying another trial of chemotherapy. Surrogates, by being present and engaged in the discussion, were better able to understand what would be unacceptable outcomes for the patient. Skilled ACP facilitation that included values clarification and included patient-surrogate communication about those values were absent from interventions that were evaluated in studies that found the interventions unsuccessful in improving patient-surrogate communication and congruence.

The perception that ACP discussions will raise anxiety and decrease hope in patients with life limiting cancer was not supported in this study. Consistent with findings reported by previous studies (see for example, Hancock et al., 2007; Lyon et al., 2009; Song et al., 2005; Tang, Li, & Chen, 2008; Wright et al., 2008), this study found that talking about EOL is not associated with greater distress or anxiety. More specifically, there were no significant differences between the pre- and post-test measure of state anxiety. Nonetheless, it important to note that anxiety was noted in patients when recruiting participants for this study. Not everyone who was approached for possible study participation was willing to discuss EOL. In fact, most participants reported that they were reluctant initially to discuss EOL issues. However, after participating most of participants' comments indicated that they were highly satisfied with the intervention and relieved by discussing their EOL concerns. The number of participants who actively recruited others to participate in the study is another testimony to participant satisfaction and the relief they obtained by receiving the intervention.

Study findings also mostly support earlier research that indicates the ACP process should occur early in the patient's illness before crises occur (Briggs & Hammes, 2008/2010; Hiltunen et al., 1999; Sulmasy et al., 1998). Patients participating in this study had either completed

treatment or were receiving treatment because of recurrence. All participants who responded to the question about Timing answered that after completing initial treatment was a good time period to have a discussion about ACP. Only one participant commented that the best time would be one to two weeks after diagnosis when she was still going through initial treatment.

The reasons for nonparticipation may also support the importance of having ACP discussions early in the illness. Seven eligible participants who were referred from VIM and initially expressed interest, were unable to participate because they were too ill from a recurrence of cancer. For example, one patient was admitted to an intensive care unit shortly after being referred to the study. Another reason for non-participation was that patients felt their loved ones had already assumed too much burden as a result of their cancer recurrence and asking them to participate in an EOL discussion would add to their burden. Perhaps these patients could have benefited from having this ACP discussion at a less stressful time in their illness, before another medical crisis occurred.

Limitations

There are a number of limitations that need to be considered when interpreting the study findings. First, for ethical reasons to not withhold a highly promising intervention, the design was not a randomized control trial (RCT). A RCT would provide the strongest evidence that it was the intervention that increased patient-surrogate congruence. Without this design, it could be argued that participants, by virtue of volunteering to take part in the intervention, were more open to and perhaps more reflective about EOL issues. This possible explanation is particularly applicable to one of the criteria for study participation, namely having a surrogate who was not only willing to participate but also willing and capable of making decisions consistent with

patient values and goals. However, it could also be argued that even people who are open and reflective need a trained facilitator to fully understand treatment consequences and use this understanding for clarifying and communicating EOL treatment preferences. These skills are beyond most lay people, particularly when they are personally dealing with a life limiting illness. As previously described, the facilitator in this study was a cancer expert with training in values clarification and communication.

Second, the sample was homogenous with regard to racial background (i.e., all of the participants were Caucasian). Racial and ethnic differences in ACP have been well documented and particular ethnic groups may be resistant to different aspects of planning (Smith et al, 2007). There is ample evidence that Caucasians are more likely to have ACP discussions than other racial/ethnic groups (Carr et al., 2012; Rhoades & Teno, 2010). Therefore, caution needs to be taken in generalizing results to racial or ethnic groups other than Caucasians.

Third, it is possible that reports of satisfaction with the intervention were biased by the presence of the researcher when participants completed the Quality of Communication form. The researcher delivered the intervention and, in part, was being evaluated by questions about the quality of communication. Response burden also deserves consideration. Participants completed the Quality of Communication form last, after an emotionally demanding discussion. They may have been fatigued, which could have decreased the accuracy of their responses. However, it is noteworthy that participants spontaneously offered positive comments about the intervention before they were asked formally. For example, most patients and surrogates expressed feeling relieved during the intervention when the facilitator assisted them to acknowledge and explore emotionally distressing concerns about EOL.

Fourth, the Respecting Choices DS ACP intervention was evaluated in its entirety rather than evaluating each of the specific elements mentioned above. Thus, there is no way of knowing if the success of the intervention can be attributed to any one element or a select configuration of elements, such as delivery by a trained facilitator, surrogate selection, or the focus on values and individual concerns. The strongest evidence for the conclusion that all of the elements are essential comes from omission; that is that the literature contains evidence interventions that were not successful in improving patient-surrogate congruence in EOL decision making lacks one or more of these elements.

Finally, the Respecting Choices DS ACP intervention is adapted to be disease specific. This adaptation requires that facilitators have some knowledge of the disease under consideration. Previous studies have used nurses or allied health workers such as social workers and chaplains (Briggs et al., 2004; Song et al., 2005) and (Detering et al., 2010; Kirchhoff et al., 2010; Lyons et al., 2009). However these studies were of patients suffering from other diseases, such as congestive heart, respiratory, or kidney failure. Life-limiting cancer may require more mastery of the subject matter than these other diseases because numerous and often controversial cancer treatment options are widely used. Allied health workers or nurses without a specialization in cancer may not understand the numerous cancer treatment options. Because the facilitator in this study was a nurse who has experience caring for patients diagnosed with cancer and in EOL situations, it is not clear if study findings can be generalized to facilitators who do not have this clinical training.

Implication for Practice and Policy

The study findings provide information for a number of policy and practice changes for ACP. First, participant reports of satisfaction with the intervention and the study finding that the Respecting Choices® DS-ACP intervention did not increase anxiety can be used to persuade oncologists and other health professionals that they need not be wary of referring patients for EOL discussions with trained facilitators. As evidenced by the literature, oncologists and other health professionals have often acted as gatekeepers who are reluctant to engage or refer patients for ACP because of their wish to protect their patients from stressful discussions about EOL. Their unsubstantiated concerns have limited referrals for ACP and are contributing to billions of dollars in unwanted health care.

The success of the intervention demonstrated in this study for improving patient-surrogate communication about EOL decisions can also be used to influence health policy. Given the relief and satisfaction expressed by participants, study findings support making the intervention part of usual care at facilities and practices that provide care for patients with life limiting cancer. Resources should be made available to train facilitators and make the intervention accessible at these facilities and practices. If future research documents that increased patient –surrogate congruence is indeed effective for respecting patient wishes at EOL, then policies about training and access should be mandated.

Delivering this intervention during different stages in the progression of a patient's illness or cancer progression was not compared in this study. This study did not make comparisons about different times in the patient's illness or cancer progression about when to deliver the intervention. However, participant satisfaction with when the intervention was delivered in this study supports delivering the intervention well before a medical crisis.

Implications for Future Research

Future research is needed to determine if increased patient-surrogate congruence does indeed lead to patients' wishes being followed at EOL and reduces decisional conflict and stress in surrogates. The recommended study design for this future research is a prospective one that follows patients and surrogates post intervention through to patients' EOL. As previously discussed, a Phase I clinical trial was chosen for the present study for ethical reasons to not withhold an intervention with promise. However, a comparative design that includes a naturally occurring comparison group (i.e., those who receive the standard approach) could be used in a future study to investigate the critical question of whether the intervention achieves these final outcomes (patient wishes being followed and less surrogate decisional conflict and distress) at EOL. For example, participants who receive the intervention could be followed prospectively to compare EOL care with those who did not receive the intervention. Patients and surrogates who did not receive the intervention could be recruited in the study at patients' EOL for comparison, thereby averting the ethical issue of withholding treatment.

Additional research is also needed with racial and ethnic groups whose reluctance to engage in EOL discussion has been documented in the literature. This research is needed to determine if the Respecting Choices DS ACP intervention is culturally appropriate or needs to be modified when used with certain racial or ethnic groups. A recommended approach would be to employ an exploratory qualitative design to understand group-specific values and perspectives about ACP. For example, conducting focus groups with members of specific racial or ethnic groups could generate informative discussions about within group similarities and difference in preferred ACP approaches. Approaching racial or ethnic groups through organizations that they trust, such as churches and matching the racial or ethnic background of

the focus group facilitator might increase their willingness to participate in focus groups about EOL values and perspectives.

Future research is also needed to determine which types of professionals are best suited for the role of ACP facilitator for patients with life-limiting cancer. Since implementation of the Respecting Choices DS ACP intervention is illness-specific and requires advanced knowledge of specific illness and related treatment outcomes, it may be that facilitators need to be health providers with a particular medical or nursing specialty. Since there are many types of cancer and different cancer- and patient-specific treatments, specialization may be even more important for intervening with patients with life limiting cancer. Thus future research is needed to determine the knowledge base needed to effectively facilitate ACP with this population. A comparative design is recommended to answer this research question. For example, professionals with differing degrees of clinical specialty expertise could be compared for participant satisfaction and patient-surrogate congruence as well as whether these intermediary outcomes lead to the final outcomes respecting patients' EOL wishes and decreasing surrogate decisional conflict and distress at end of life. In addition, certified training programs for preparing facilitators to deliver the Respecting Choices DS ACP intervention could contribute to evaluating the question about the best educational preparation for becoming a certified facilitator.

APPENDIX A: STATEMENT FOR TREATMENT PREFERENCES FOR LIFE-LIMITING CANCER

Statement of Treatment Preferences: Life-limiting Cancer

For _____ Date _____
(Signature of Patient)

Situation #1:

If I have a serious complication from my cancer (or treatment for my cancer) so that I was facing a prolonged hospital stay, requiring ongoing medical interventions AND my chance of living through this complication is low (for example, only 5 out of 100 patients will live), I would choose the following (Whatever my choice, I want treatment to keep me as comfortable as possible):

- To continue all medically appropriate treatment offered by my physician so I could live as long as possible ("Staying alive is most important to me no matter what.")
- To stop all efforts to keep me alive ("For me, quality of life is more important than length of life.")
- Unsure

Situation #2:

If I reach a point in the progression of my cancer where my cancer has spread and treatments will extend my life by no more than 2-3 months, and the side effects of treatment are serious, I would choose the following (Whatever my choice, I want treatment to keep me as comfortable as possible):

- To continue all medically appropriate treatment offered by my physician so I could live as long as possible ("Staying alive is most important to me no matter what.")
- To stop all efforts to keep me alive ("For me, quality of life is more important than length of life.")
- Unsure

Situation #3:

If I have a serious complication from my cancer (or treatment for my cancer) and had a good chance of living through this complication, but it was expected I would never either walk or talk (or both) and I would require 24 hour nursing care, I would choose the following. (Whatever my choice, I want treatment to keep me as comfortable as possible.)

- To continue all medically appropriate treatment offered by my physician so I could live as long as possible ("Staying alive is most important to me no matter what.")
- To stop all efforts to keep me alive ("For me, quality of life is more important than length of life.")
- Unsure

Statement of Treatment Preferences for Life-limiting Cancer
(continued)

Situation #4:

If I have a serious complication from my cancer (or treatment from my cancer) and had a good chance of living through this complication, but it was expected I would never know who I was or who I was with and would require 24 hour nursing care, I would choose the following. (Whatever my choice, I want treatment to keep me as comfortable as possible.)

- To continue all medically appropriate treatment offered by my physician so I could live as long as possible ("Staying alive is most important to me no matter what.")
- To stop all efforts to keep me alive ("For me, quality of life is more important than length of life.")
- Unsure

Situation #5:

If I have a sudden event that causes my heart and breathing to stop, I would choose the following:

- I want CPR attempted unless my physician determines any one of the following:
 - I have an incurable illness or injury and am dying; OR
 - I have no reasonable chance of survival if my heart stops; OR
 - I have little chance of long-term survival if my heart stops and the process of resuscitation would cause significant suffering
- I want CPR attempted if my heart stops
- I do not want CPR attempted if my heart stops, but rather, want to permit a natural death

Situation #6 (if applicable)

If I have an episode where I am unable to breathe on my own, I would choose the following:

- Attempt to use any appropriate noninvasive method to assist my breathing AND
 - Use mechanical ventilation if other methods fail
 - Do not use mechanical ventilation if other methods fail
- Do not attempt to assist my breathing by noninvasive methods or mechanical ventilation

If I have chosen to continue all treatments so that I could live as long as possible in ANY of the above situations, I would want treatment to stop for the following outcomes I find unacceptable (these could include length of time, more complications, discomfort, or burden on family). They include:

The person whom I have chosen to be my health care agent is:

_____ Phone: _____

I would want the person I have chosen to:

- Strictly follow my wishes
- Do what they think is best at the time, considering my wishes
- Don't know

APPENDIX B: VERBAL ASSESSMENT QUESTIONS

Do you understand that information in the advance directive contains choices that will be acted upon in the future, not the present?

Do you understand that the preferences in the advance directive will be honored only when you are no longer capable?

Do you understand the choice to select a surrogate decision maker and/or specify medical preferences?

Do you understand that the choices made can be changed at any time?

APPENDIX C: INTRODUCTORY LETTER

My name is Lynn Waser. I am a Registered Nurse, and a doctoral candidate at the University of Central Florida. I am also an Advanced Care Planning Facilitator. I am conducting a study on assisting patients diagnosed with cancer to make plans for future medical treatments and promoting respect for their choices.

The purpose of this study is to evaluate whether a specially designed advance care planning interview concerning a patient's medical care preferences and his/her chosen surrogate's preparation for future medical decision-making is beneficial. This study will address your wishes and preferences for medical treatment if you became unable to make such decisions in the future. You will need to select a surrogate, someone you might wish to make health care decisions for you, should you become unable to make such decisions in the future. If your surrogate and you agree I will interview you and your surrogate. The interview will provide an opportunity for you and your surrogate to think about your future medical treatment choices in the context of your current illness and promote your surrogate's understanding of your preferences for medical treatment. For this reason, your surrogate will be with you during the interview. The interview will be a 1 to 1½ hour discussion and will involve answering short questionnaires that should take no more than 30 minutes.

If you would be kind enough to write your name and phone number in the space below, I will contact you to answer any questions you have regarding this study. You can also call me at: (Phone Number)

Thank you

Lynn Waser MSN RN, Doctoral Candidate and Researcher

Your Name and Contact Phone Number or E-Mail: _____

APPENDIX D: INFORMED CONSENT



Impact of Disease-Specific Advance Care Planning on Anxiety, Decisional Conflict, and Surrogate Understanding of Patients with Life-Limiting Cancer

Informed Consent
- Patient Form -

Principal Investigator(s): Lynn A. Waser MSN, RN PhD Candidate.
Faculty Supervisor: Karen Aroian, PhD, RN, FAAN
Investigational Site(s): Volunteers in Medicine Clinic or the Participants' Home

Introduction: Researchers at the University of Central Florida (UCF) study many topics. To do this we need the help of people who agree to take part in a research study. You are being invited to take part in a research study which will include about 15-34 Dyads (30-68 people) from selected areas in your community. You have been asked to take part in this research study because you have a diagnosis of cancer and can contribute to this study by having a discussion with your surrogate decision maker about future medical decisions that you might choose. You must be 21 years of age or older to be included in the research study.

The person doing this research is Lynn A. Waser MSN, RN PhD Candidate of UCF College of Nursing. Because the researcher is a PhD candidate she is being guided by Karen Aroian, PhD, RN, and Lynn's UCF faculty supervisor in the College of Nursing.

What you should know about a research study:

- Someone will explain this research study to you.
- A research study is something you volunteer for.
- Whether or not you take part is up to you.
- You should take part in this study only because you want to.
- You can choose not to take part in the research study.
- You can agree to take part now and later change your mind.
- Whatever you decide it will not be held against you.
- Feel free to ask all the questions you want before you decide.

Purpose of the research study: I am conducting a study to assist patients diagnosed with cancer and their family members to make plans for future medical treatments and to promote respect for their choices. The purpose of this study is to evaluate whether a specially designed advance care planning interview concerning a patient's medical care preferences and his/her chosen surrogate's preparation for future medical decision-making is beneficial. This study will address your wishes and preferences for medical treatment if you became unable to make such decisions in the future.

What you will be asked to do in the study: First, you will need to select a surrogate, someone you might wish to make health care decisions for you, should you become unable to make such decisions in the future. If your surrogate and you agree, your surrogate and you will be interviewed by a trained nurse researcher. The interview will be a 1 to 1½ hour discussion and will involve answering short questionnaires that should take no more than 30 minutes. The interview will provide an opportunity for your surrogate and you to think about your future medical treatment choices in the context of your current illness and promote your surrogate's understanding of your preferences for medical treatment. For this reason, your surrogate will be with you during the interview.

The short questionnaires to complete include demographics, a document of your preferences for future medical treatment, a questionnaire about making decisions, a questionnaire about anxiety, your feelings or opinions about advance care planning discussions, and experiences of your surrogate in making decisions for you. A copy of the document of treatment preferences that you complete will be given to you for your records. In addition a copy of your treatment preferences will be given to your healthcare provider and kept in your medical record if you desire. A summary of the discussion and any questions raised for your healthcare provider will be given to you, and to your healthcare provider with your permission.

You do not have to answer every question or complete every task. Your decision to take part in this study is completely voluntary. You are free to withdraw from this study at any time. You have the right to refuse to answer any question that you would rather not respond to and may end the interview at any time. Your withdrawal or refusal will not affect any benefits or privileges to which you are entitled.

Permission for Future Contact: By signing my initials here, I agree that this investigator may contact me directly in the future for follow-up purposes or about other research opportunities. I understand that I can always decline participation in these future opportunities with no penalty. Initials: _____. In the future, I can be contacted directly at _____

Location: The researcher will go to the participants' home or meet with participants at the Volunteers in Medicine Clinic. Participants will be asked to select the time and location they prefer.

Time required: I expect that you will be in this research study for one session lasting 1 ½ -2 ½ hours

Risks: You may feel uncomfortable talking about your illness and about future medical care options for a situation when you are not able to speak for yourself. There is a risk that your participation in this study can bring up concerns about my illness and complications.

Benefits: You may not benefit directly from taking part in this study although sometimes sharing your beliefs about your illness, past experiences, and concerns about your health condition could be helpful to you. However, by participating in this study, you may benefit other people and their family members in the future.

Compensation or payment: There is no compensation or other payment to you for taking part in this study.

Confidentiality: Any records such as what was said during the interview or questionnaires that you completed from this study might be identifiable. For this reason, everything that you reveal will be kept completely confidential. Only the nurse researchers involved in this study will have access to the questionnaires that you complete. The information from this study will not be presented or published in any way that would allow the identification of any respondent.

Study contact for questions about the study or to report a problem: If you have questions, concerns, or complaints, or think the research has hurt you, talk to Lynn Waser, doctoral candidate in the College of Nursing, (772) 545-1132 or Dr. Karen Aroian, Faculty Supervisor, College of Nursing at (407) 823-4290 or by email at Karen.Aroian@ucf.edu .

IRB contact about your rights in the study or to report a complaint: Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been reviewed and approved by the IRB. For information about the rights of people who take part in research, please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901. You may also talk to them for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team
- You want to get information or provide input about this research

Your signature below indicates your permission to take part in this research.

DO NOT SIGN THIS FORM AFTER THE IRB EXPIRATION DATE BELOW

Name of participant

Signature of participant

Date



Impact of Disease-Specific Advance Care Planning on Anxiety, Decisional Conflict, and Surrogate Understanding of Patients with Life-Limiting Cancer

Informed Consent

- Surrogate Form -

Principal Investigator(s): Lynn A. Waser MSN, RN PhD Candidate.

Faculty Supervisor: Karen Aroian, PhD, RN, FAAN

Investigational Site(s): Volunteers in Medicine Clinic (VIM) or Participants Home

Introduction: Researchers at the University of Central Florida (UCF) study many topics. To do this we need the help of people who agree to take part in a research study. You are being invited to take part in a research study which will include about 15-34 dyads (30-68 people) from selected areas in your community. You have been asked to take part in this research study because your loved one has a diagnosis of cancer, and you can contribute to this study by discussing future medical decisions that your loved one might choose. You must be 21 years of age or older to be included in the research study.

The person doing this research is Lynn A. Waser MSN, RN PhD Candidate of UCF's College of Nursing. Because the researcher is a PhD candidate she is being guided by Karen Aroian, PhD, RN, and Lynn's UCF faculty supervisor in the College of Nursing.

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- You can agree to take part now and later change your mind.
- Whatever you decide it will not be held against you.
- Feel free to ask all the questions you want before you decide.

1 of 4



University of Central Florida IRB
IRB NUMBER: SBE-11-07718
IRB APPROVAL DATE: 7/5/2011
IRB EXPIRATION DATE: 7/4/2012

Purpose of the research study: I am conducting a study to assist patients diagnosed with cancer and their family members to make plans for future medical treatments and to promote respect for their choices. The purpose of this study is to evaluate whether a specially designed advance care planning interview concerning a patient's medical care preferences and his/her chosen surrogate's preparation for future medical decision-making is beneficial. This study will address your loved one's wishes and preferences for medical treatment if he/she became unable to make such decisions in the future.

What you will be asked to do in the study: If you and your loved one agree, you will be paired and your loved one and you will be interviewed by a trained nurse researcher. The interview will be a 1 to 1½ hour discussion and will involve answering short questionnaires that should take no more than 30 minutes. The interview will provide an opportunity for you to think about your loved one's future medical treatment choices in the context of his/her current illness and promote your understanding of his/her preferences for medical treatment. For this reason, you will be with your loved one during the interview.

The short questionnaires to complete include demographics, a document of your loved one's preferences for future medical treatment, your feelings or opinions about advance care planning discussions, and your experiences in making decisions for your loved one.

You do not have to answer every question or complete every task. Your decision to take part in this study is completely voluntary. You are free to withdraw from this study at any time. You have the right to refuse to answer any question that you would rather not respond to and may end the interview at any time. Your withdrawal or refusal will not affect any benefits or privileges to which you are entitled.

Permission for Future Contact: By signing my initials here, I agree that this investigator may contact me directly in the future for follow-up purposes or about other research opportunities. I understand that I can always decline participation in these future opportunities with no penalty. Initials: _____. In the future, I can be contacted directly at _____

Location: The researcher will meet with participants at the VIM clinic or go to the participants' home. Participants will be asked to select the time and location they prefer.

Time required: I expect that you will be in this research study for one session lasting 1 ½ -2 ½ hours.

Risks: You may feel uncomfortable talking about your loved one's illness and about future medical care options for a situation when your loved one is not able to speak for him/herself. There is a risk that your participation in this study can bring up concerns about your loved one's illness and complications.

Benefits: You may not benefit directly from taking part in this study although sometimes sharing your past experiences and concerns about your loved one's health condition could be helpful to you. However, by participating in this study, you may benefit other people and their family members in the future.

Purpose of the research study: I am conducting a study to assist patients diagnosed with cancer and their family members to make plans for future medical treatments and to promote respect for their choices. The purpose of this study is to evaluate whether a specially designed advance care planning interview concerning a patient's medical care preferences and his/her chosen surrogate's preparation for future medical decision-making is beneficial. This study will address your loved one's wishes and preferences for medical treatment if he/she became unable to make such decisions in the future.

What you will be asked to do in the study: If you and your loved one agree, you will be paired and your loved one and you will be interviewed by a trained nurse researcher. The interview will be a 1 to 1½ hour discussion and will involve answering short questionnaires that should take no more than 30 minutes. The interview will provide an opportunity for you to think about your loved one's future medical treatment choices in the context of his/her current illness and promote your understanding of his/her preferences for medical treatment. For this reason, you will be with your loved one during the interview.

The short questionnaires to complete include demographics, a document of your loved one's preferences for future medical treatment, your feelings or opinions about advance care planning discussions, and your experiences in making decisions for your loved one.

You do not have to answer every question or complete every task. Your decision to take part in this study is completely voluntary. You are free to withdraw from this study at any time. You have the right to refuse to answer any question that you would rather not respond to and may end the interview at any time. Your withdrawal or refusal will not affect any benefits or privileges to which you are entitled.

Permission for Future Contact: By signing my initials here, I agree that this investigator may contact me directly in the future for follow-up purposes or about other research opportunities. I understand that I can always decline participation in these future opportunities with no penalty. Initials: _____. In the future, I can be contacted directly at _____

Location: The researcher will meet with participants at the VIM clinic or go to the participants' home. Participants will be asked to select the time and location they prefer.

Time required: I expect that you will be in this research study for one session lasting 1 ½ -2 ½ hours.

Risks: You may feel uncomfortable talking about your loved one's illness and about future medical care options for a situation when your loved one is not able to speak for him/herself. There is a risk that your participation in this study can bring up concerns about your loved one's illness and complications.

Benefits: You may not benefit directly from taking part in this study although sometimes sharing your past experiences and concerns about your loved one's health condition could be helpful to you. However, by participating in this study, you may benefit other people and their family members in the future.

APPENDIX E: RESPECTING CHOICES ® DS-ACP INTERVIEW STAGES

Respecting Choices Disease Specific Advance Care Planning Interview

Stage 1: Assess Illness Beliefs, Goals, and Values

The Respecting Choices ACP begins with the facilitator explaining the purpose of the discussion as an opportunity for the patients and their surrogate to understand and think about the life-sustaining treatment choices the patient would want if unable to make his or her own decisions in the future. The ACP facilitator assesses patient and surrogate understandings of the patient's current medical condition, prognosis, and potential complications. The facilitator explores how patients' health conditions have affected their lives, what things are most meaningful to them, and expectations for their current plan of care. As the interview progresses, this information helps patients reflect on whether the burdens of particular life sustaining treatment match their goals for living well (Briggs & Hammes, 2008/2010).

Stage 2: Exploring Experiences

The facilitator explores the patient's experience with previous hospitalizations and with family and friends who have been seriously ill or died. These conversations help the facilitator assess what the patient learned and how those experiences may have helped or hindered the patient's ability to plan for the future. The facilitator also explores the quality of previous advance care planning discussions with loved ones because while patients often feel they have had enough discussion surrogates continue to lack understanding (Briggs & Hammes, 2008/2010).

Stage 3: Explaining the Purpose of Advance Care Planning

The facilitator weaves information gained from patients and surrogates during the first two stages of the interview to help them understand the purpose of more specific advance care planning. This discussion sets the stage for discussing specific medical decisions patients want their chosen surrogates to understand and to act upon in the future. The goal is to prepare the surrogates to be able to fully represent the patient's wishes (Briggs & Hammes, 2008/2010).

Stage 4: Clarifying Goals for Life Sustaining Treatment Preferences

During the fourth element, the facilitator uses the statement of treatment preferences for life-limiting cancer document to help patients express goals for life-sustaining treatment and

prepare surrogates for the role for future substitute decision-maker. The scenarios describe real situations, specific to life-limiting cancer that the patient may experience and types of treatment decisions the surrogate might be asked to make. The ACP facilitator explains the benefits and burdens of life-sustaining treatments and discusses the importance of choosing a healthcare surrogate that can represent the patients' decisions (Briggs & Hammes, 2008/2010).

Stage 5: Summary

During this element, the patient, surrogate, and ACP facilitator discuss the new information and the value of the discussion for the patient and surrogate. Any outstanding issues are raised. The need for future discussion as the situation and preferences change are reviewed (Briggs & Hammes, 2008/2010).

Stage 6: Follow-up Plan

A plan about ways to communicate the written plan to health care providers and other family members are developed. Referrals to appropriate resource, such as a social worker, will be provided to address any issues that may have occurred during the interview (Briggs & Hammes, 2008/2010).

APPENDIX F: SOCIODEMOGRAPHIC INSTRUMENTS

**Socio Demographic Form for Respecting Choices DS-ACP Study (Patient
Version)**

1) Age (please check one):

- 21-29
- 30-39
- 40-49
- 50-54
- 55-59
- 60-64
- 65-69
- 70-74
- 75-79
- 80 & up

2) Gender (please check one):

- Male
- Female

3) Marital Status (please check one):

- Single
- Married
- Separated
- Divorced
- Widowed
- Domestic Partnership

4) Religious Affiliation you were raised in (please check one):

- Christian
- Catholic
- Jewish
- Muslim
- Hindu
- Other

5) Religious affiliation that you currently practice (please check one):

- Christian
- Catholic
- Jewish
- Muslim
- Hindu
- Other

6) How often do you attend religious services (please check one):

- Once a week or more
- About once a month
- Holy Days and special occasions only
- Never
- Other (please specify):

7) Housing Status (please check one):

- Home
- Assisted Living Facility
- Other (please specify): _____

8) Education Level (please check one):

- Less than High School
- High School Diploma/GED
- Some College
- Associates Degree
- Bachelors Degree
- Masters Degree
- Doctorate

9) Occupation (please check one):

- Administrative Support
- Arts/Design/Entertainment
- Business
- Computer Technology
- Construction
- Education

- Engineers/Architects
- Forestry - Agriculture
- Food Service
- Graphic Design
- Healthcare
- Homemaker or Parenting
- Legal
- Maintenance
- Management
- Military
- Services
- Repair/Installation
- Sales
- Science
- Social Service
- Transportation
- Other (please specify) _____

10) Income Level (please check one):

- \$0-\$9,999
- \$10,000-\$19,999
- \$20,000-\$34,999
- \$35,000-\$44,999
- \$45,000-\$54,999
- \$55,000-\$64,999
- \$65,000-\$74,999
- \$75,000-\$99,999
- \$100,000 & up

11) Cancer Diagnosis (please check one):

- Breast
- Colon
- Lung
- Liver
- Bone
- Multiple Myeloma
- Leukemia
- Other (please specify): _____

12) Relationship to Health Care Surrogate (please check one):

- Spouse
- Parent
- Child
- Sibling
- Other Relative
- Friend
- Other (please specify): _____

13) Where and how did you hear about this study?

14) What is your understanding of your cancer diagnosis?

**Socio Demographic Form for Respecting Choices DS-ACP Study (Surrogate
Version)**

1) Age (please check one):

- 21-29
- 30-39
- 40-49
- 50-54
- 55-59
- 60-64
- 65-69
- 70-74
- 75-79
- 80 & up

2) Gender (please check one):

- Male
- Female

3) Marital Status (please check one):

- Single
- Married
- Separated
- Divorced
- Widowed
- Domestic Partnership

4) Religious Affiliation that you were raised in (please check one):

- Christian
- Catholic
- Jewish
- Muslim
- Hindu
- Other

5) Religious affiliation that you currently practice (please check one):

- Christian
- Catholic
- Jewish
- Muslim
- Hindu
- Other

6) How often do you attend religious services (please check one):

- Once a week or more
- About once a month
- Holy Days and special occasions only
- Never
- Other (please specify):

7) Education Level (please check one):

- Less than High School
- High School Diploma/GED
- Some College
- Associates Degree
- Bachelors Degree
- Masters Degree
- Doctorate

8) Occupation (please check one):

- Administrative Support
- Arts/Design/Entertainment
- Business
- Computer Technology
- Construction
- Education
- Engineers/Architects
- Forestry - Agriculture
- Food Service
- Graphic Design
- Healthcare
- Homemaker or Parenting
- Legal

- Maintenance
- Management
- Military
- Services
- Repair/Installation
- Sales
- Science
- Social Service
- Transportation
- other

9) Income Level (please check one):

- \$0-\$9,999
- \$10,000-\$19,999
- \$20,000-\$34,999
- \$35,000-\$44,999
- \$45,000-\$54,999
- \$55,000-\$64,999
- \$65,000-\$74,999
- \$75,000-\$99,999
- \$100,000 & up

10) Relationship to Patient (please check one):

- Spouse
- Child
- Parent
- Sibling
- Other Relative
- Friend
- Other (please specify): _____

11) Where and how did you learn about this study?

12) What is your understanding of your loved ones cancer diagnosis?

APPENDIX G: DECISIONAL CONFLICT SCALE

Traditional Decisional Conflict Scale (DCS) – Statement Format: 16 item 5 response categories

This is our most tested version. Many people like the personal response format. However, it is more difficult to respond to than questions in those with limited reading and response skills. Note: We always precede the DCS with an option preference question, which is not included in scoring. [See item ‘A’ below].

My difficulty in making this choice

A. Which [insert treatment/screening] option do you prefer? Please check one.

- [Option 1]
- [Option 2]
- [Option 3]
- Unsure

B. Considering the option you prefer, please answer the following questions:

| | Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |
|---|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| | [0] | [1] | [2] | [3] | [4] |
| 1. I know which options are available to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I know the benefits of each option. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I know the risks and side effects of each option. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I am clear about which benefits matter most to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I am clear about which risks and side effects matter most to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I am clear about which is more important to me (the benefits or the risks and side effects). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I have enough support from others to make a choice. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I am choosing without pressure from others. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I have enough advice to make a choice. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. I am clear about the best choice for me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. I feel sure about what to choose. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. This decision is easy for me to make. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. I feel I have made an informed choice. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. My decision shows what is important to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. I expect to stick with my decision. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. I am satisfied with my decision. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

APPENDIX H: SPIELBERGER STATE ANXIETY SCALES

SELF-EVALUATION QUESTIONNAIRE STAI Form Y-1

Please provide the following information:

Name _____ Date _____ S _____

Age _____ Gender (Circle) **M** **F** T _____

DIRECTIONS:

A number of statements which people have used to describe themselves are given below. Read each statement and then blacken the appropriate circle to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

VERY MUCH SO
MODERATELY SO
SOMEWHAT
NOT AT ALL

- | | | | | |
|---|---|---|---|---|
| 1. I feel calm..... | 1 | 2 | 3 | 4 |
| 2. I feel secure..... | 1 | 2 | 3 | 4 |
| 3. I am tense..... | 1 | 2 | 3 | 4 |
| 4. I feel strained..... | 1 | 2 | 3 | 4 |
| 5. I feel at ease..... | 1 | 2 | 3 | 4 |
| 6. I feel upset..... | 1 | 2 | 3 | 4 |
| 7. I am presently worrying over possible misfortunes..... | 1 | 2 | 3 | 4 |
| 8. I feel satisfied..... | 1 | 2 | 3 | 4 |
| 9. I feel frightened..... | 1 | 2 | 3 | 4 |
| 10. I feel comfortable..... | 1 | 2 | 3 | 4 |
| 11. I feel self-confident..... | 1 | 2 | 3 | 4 |
| 12. I feel nervous..... | 1 | 2 | 3 | 4 |
| 13. I am jittery..... | 1 | 2 | 3 | 4 |
| 14. I feel indecisive..... | 1 | 2 | 3 | 4 |
| 15. I am relaxed..... | 1 | 2 | 3 | 4 |
| 16. I feel content..... | 1 | 2 | 3 | 4 |
| 17. I am worried..... | 1 | 2 | 3 | 4 |
| 18. I feel confused..... | 1 | 2 | 3 | 4 |
| 19. I feel steady..... | 1 | 2 | 3 | 4 |
| 20. I feel pleasant..... | 1 | 2 | 3 | 4 |

sample

State-Trait Anxiety Inventory for Adults Scoring Key (Form Y-1, Y-2)

Developed by Charles D. Spielberger in collaboration with R.L. Gorsuch, R. Lushene, P.R. Vagg, and G.A. Jacobs

To use this stencil, fold this sheet in half and line up with the appropriate test side, either Form Y-1 or Form Y-2. Simply total the scoring **weights** shown on the stencil for each response category. For example, for question # 1, if the respondent marked 3, then the **weight** would be **2**. Refer to the manual for appropriate normative data.

| Form Y-1 | NOT AT ALL | SOMEWHAT | MODERATELY SO | VERY MUCH SO | Form Y-2 | ALMOST NEVER | SOMETIMES | OFTEN | ALMOST ALWAYS |
|----------|------------|----------|---------------|--------------|----------|--------------|-----------|-------|---------------|
| 1. | 4 | 3 | 2 | 1 | 21. | 4 | 3 | 2 | 1 |
| 2. | 4 | 3 | 2 | 1 | 22. | 1 | 2 | 3 | 4 |
| 3. | 1 | 2 | 3 | 4 | 23. | 4 | 3 | 2 | 1 |
| 4. | 1 | 2 | 3 | 4 | 24. | 1 | 2 | 3 | 4 |
| 5. | 4 | 3 | 2 | 1 | 25. | 1 | 2 | 3 | 4 |
| 6. | 1 | 2 | 3 | 4 | 26. | 4 | 3 | 2 | 1 |
| 7. | 1 | 2 | 3 | 4 | 27. | 4 | 3 | 2 | 1 |
| 8. | 4 | 3 | 2 | 1 | 28. | 1 | 2 | 3 | 4 |
| 9. | 1 | 2 | 3 | 4 | 29. | 1 | 2 | 3 | 4 |
| 10. | 4 | 3 | 2 | 1 | 30. | 4 | 3 | 2 | 1 |
| 11. | 4 | 3 | 2 | 1 | 31. | 1 | 2 | 3 | 4 |
| 12. | 1 | 2 | 3 | 4 | 32. | 1 | 2 | 3 | 4 |
| 13. | 1 | 2 | 3 | 4 | 33. | 4 | 3 | 2 | 1 |
| 14. | 1 | 2 | 3 | 4 | 34. | 4 | 3 | 2 | 1 |
| 15. | 4 | 3 | 2 | 1 | 35. | 1 | 2 | 3 | 4 |
| 16. | 4 | 3 | 2 | 1 | 36. | 4 | 3 | 2 | 1 |
| 17. | 1 | 2 | 3 | 4 | 37. | 1 | 2 | 3 | 4 |
| 18. | 1 | 2 | 3 | 4 | 38. | 1 | 2 | 3 | 4 |
| 19. | 4 | 3 | 2 | 1 | 39. | 4 | 3 | 2 | 1 |
| 20. | 4 | 3 | 2 | 1 | 40. | 1 | 2 | 3 | 4 |

Sample

APPENDIX I: QUALITY OF COMMUNICATION ABOUT END-OF-LIFE CARE

The quality of patient-interviewer communication about end-of-life care
(Completed by Patients)

ID# : _____

The following questions are to evaluate the discussion that you just had. Please show how you think about the communication with these comments by circling the number from 1 (no) to 3 (definitely yes). The last question is to rate overall quality of the discussion you had. Your answers are confidential.

| | No | Probably yes | Definitely yes | | |
|---|------|-----------------|----------------------|-----------|---|
| Regarding the kinds of treatment you would want if you got too sick to speak for yourself: | | | | | |
| 1. Do you think that your treatment preferences are known? | 1 | 2 | 3 | | |
| When you talked about the kinds of treatment: | | | | | |
| 2. Did you feel that the interviewer cared about you as a person? | 1 | 2 | 3 | | |
| 3. Did you feel that the interviewer listened to what you said? | 1 | 2 | 3 | | |
| 4. Did you feel that the interviewer gave you enough of her attention? | 1 | 2 | 3 | | |
| Ratings: | Poor | Fair | Good Very good | Excellent | |
| How would you rate the overall quality of the discussions you just had with the interviewer about the kinds of treatment you would want if you got too sick to speak for your self? | 1 | 2 | 3 | 4 | 5 |

Adapted from Schwartz, C. E., Merriman, M., Reed, G., & Hammes, B. J. (2004). Measuring patient treatment preferences in end-of-life care research: Applications for advance care planning interventions and response shift research. *Journal of Palliative Medicine*, 7, 233-245

The quality of patient-interviewer communication about end-of-life care
(Completed by Surrogates)

ID# : _____

The following questions are to evaluate the discussion that you just had. Please show how you think about the communication with these comments by circling the number from 1 (no) to 3 (definitely yes). The last question is to rate overall quality of the discussion you just had. Your answers are confidential.

| | No | Probably yes | Definitely yes | | |
|---|------|-----------------|----------------|--------------|-----------|
| Regarding the kinds of treatment your loved one would want if he/she got too sick to speak for him/herself: | | | | | |
| 1. Do you think that your loved one's treatment preferences are known? | 1 | 2 | 3 | | |
| When you talked about your loved one's kinds of treatment: | | | | | |
| 2. Did you feel that the interviewer cared about your loved one as a person? | 1 | 2 | 3 | | |
| 3. Did you feel that the interviewer listened to what you and your loved said? | 1 | 2 | 3 | | |
| 4. Did you feel that the interviewer gave enough of attention? | 1 | 2 | 3 | | |
| Ratings: | Poor | Fair | Good | Very good | Excellent |
| How would you rate the overall quality of the discussions you just had with the interviewer about the kinds of treatment your loved one would want if he/she got too sick to speak for him/herself? | 1 | 2 | 3 | 4 | 5 |

Adapted from Schwartz, C. E., Merriman, M., Reed, G., & Hammes, B. J. (2004). Measuring patient treatment preferences in end-of-life care research: Applications for advance care planning interventions and response shift research. *Journal of Palliative Medicine*, 7, 233-245.

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