

Respecting Choices[®]

**Advance Care
Planning Facilitator
Course**

Chapter 1



Chapter 1 Contents:

The Respecting Choices Approach to Advance Care Planning and Advance Directives	3
Part I. Introduction to Respecting Choices: Overview and Background.....	3
Why Planning for Decisions at the End Of Life is Important	5
What Do Adults Fear? What Are They Willing To Do?	5
Improving End-Of-Life Care	6
A Short History of Advance Directives	7
Overview of Law and Ethics Related to Advance Care Planning.....	8
Advance Care Planning and the Law.....	8
The Ethics of Advance Care Planning.....	10
The La Crosse Experience	11
Part II. Advance Care Planning and Advance Directives: Understanding the Language and Concepts.....	13
Advance Care Planning: The Process.....	13
Advance Care Planning in Clinical Practice.....	17
Advance Directives: The Plan.....	19
Informal Directives Are Also Acceptable	20
Keeping the Advance Care Planning/Advance Directive Language Straight.....	21
Exercises	22
Appendix	23
Advance Care Planning and the Law: Common Misunderstandings.....	23
Further Reading	25



Chapter 1

The Respecting Choices Approach to Advance Care Planning and Advance Directives

Part 1. Introduction to Respecting Choices: Overview and Background

Advance care planning (ACP) is heralded as a critical component in promoting respect for self-determination and in improving end-of-life* care. However, there are multiple barriers to designing an effective ACP approach that produces successful outcomes. To promote ACP, many programs have focused their attention on a narrow set of outcomes, such as the completion of advance directive documents, the design of a user-friendly document, the education of consumers on the terminology and rationale for completing written documents, or the development of an improved storage and retrieval system. To be successful, ACP must be viewed as a comprehensive system that defines clear expectations, develops strategies to address multiple outcomes, and requires monitoring for ongoing improvement.

Respecting Choices is a comprehensive ACP program that advocates four key elements: training of health professionals and others to skillfully facilitate ACP discussions, developing community and organizational systems and practices to incorporate ACP into the routine of care, designing effective patient and community ACP engagement materials, and monitoring outcomes with continuous quality improvement methods. A description of the importance of each of these elements in achieving successful and sustainable ACP outcomes follows.

- 1. ACP facilitation skills development.** Effective ACP involves much more than assisting an individual in completing an advance directive document. It is a staged, ongoing process of assisting individuals in understanding their medical condition and potential future complications; understanding the options for future medical care as it relates to

* The phrase “end-of-life” in this program is used in a broad context. It is meant to include all decision making in the last days, months, or even years of an individual’s life.

their medical condition; discussing choices with family, loved ones, and providers; and reflecting upon these choices in light of personal goals, values, and beliefs, to include religious and cultural perspectives. Effective ACP emphasizes the personal relationships embedded in making difficult choices for future medical care. Embracing this definition of ACP acknowledges that it is an ongoing process that requires the commitment of multiple professionals who develop skills in uncovering the patient's perspective and facilitating shared decision making among patient, family, provider, and other loved ones.

Having discussions about future healthcare decisions, including end-of-life care, can be uncomfortable for health professionals and individuals for many reasons:

- a. Asking someone to talk about core values and beliefs is very personal.
- b. Discussions can produce strong emotional responses, touching on deep feelings and fears we may want to avoid.
- c. We may be unsure how to start or finish such a conversation and do not want to appear lacking in appropriate skills.
- d. The conversation is complex and time-consuming, without a clear endpoint.

With education and a willingness to gain knowledge and skills, expertise in initiating discussions about future healthcare decisions and assisting in the development of individualized advance care plans can be attained.

- 2. Consumer/patient engagement.** Community and patient engagement involves developing a plan to expose individuals to consistent, reliable, and repetitive messages about the importance of the process of ACP for all adults. Ideally, exposure occurs through normal daily interactions with religious organizations, ethnic and cultural communities, advocacy groups, and organizations that provide healthcare services.
- 3. Systems to Honor Choices.** Respecting Choices advocates system-wide changes throughout the community and related healthcare organizations. In order for an individual's preferences to be honored at the end of life, systems must be built that ensure the storage and retrieval of plans, the transfer of plans throughout the healthcare continuum, the availability of skilled facilitators working in concert with other health professionals, the transfer of preferences into medical orders, and the education of all staff about basic ACP concepts.

- 4. Continuous Quality Improvement.** Effective systems need ongoing monitoring and revision. The Respecting Choices approach defines quality ACP outcomes, offers data collection suggestions, and explains how to use data to create momentum for change.

As a participant in this program, you will learn about each of these important elements and we invite you to personally engage in the meaning of this work. Critical to your success as an ACP facilitator is your ability to work through your personal goals, values, and beliefs. To effectively help others, you must become knowledgeable about the range of healthcare choices, including end-of-life decisions, and be at peace with these issues in your own life.

Why Planning for Decisions at the End Of Life is Important

The facts about how we die are clear (Field & Cassel, 1997):

2. Most of us will die after experiencing a chronic, progressive, and ultimately fatal illness
3. Approximately 80% of deaths will occur under the care of health professionals in some type of health organization.
4. When the time comes to make important end-of-life decisions, approximately 50% of people are incapable of participating in those decisions.
5. When health professionals are uncertain about what decisions to make, the default is to treat.
6. If health professionals or loved ones have not spoken with a patient about end-of-life issues, they cannot reliably predict what the patient would have chosen and they find the decision making responsibility burdensome and stressful.

These facts highlight the importance of taking the initiative to discuss and plan for future treatment choices. The past decade has seen some critical, although not always successful, strategies to provide opportunities for advance care planning.

What Do Adults Fear? What Are They Willing To Do?

The prevalence of completing advance directives in the general population remains at 25% to 30%, but adults continue to be concerned about future healthcare decisions for a variety of reasons. Many fear that technology will keep them alive in a state they would not find acceptable, or that their families might get embroiled in a difficult prolonged battle with each other or with health professionals over medical decisions. Adults fear that their written plans will not be honored or are unsure who to contact for assistance. Despite these fears and the low incidence of completion of documents, there is a growing interest for individuals to participate in advance care planning and protect their loved ones from the burden of decision making.

Evidence suggests that many adults have not taken the time to complete a written advance directive although a majority have had some discussions with persons close to them about situations in which they would or would not want medical treatment. It is this great inclination to talk about our fears regarding end-of-life issues that we need tap into. We need to help adults move from a simple comment like “Don’t keep me alive like that young woman” to a more complete and helpful planning process. The focus needs to be more on the conversation about future medical care rather than the right to complete a legal document. The focus of community and patient engagement needs to be on how to have discussions with those close to you. How do you start the conversation? What do you talk about? When have you completed the conversation? Most individuals think that their health professional should be the one to begin the conversation. Most desire help in having these conversations with their families or other loved ones.

Improving End-Of-Life Care

A disconcerting body of evidence on the experience of dying patients and their families continues to emerge. As life expectancy increases, so has the pain and suffering associated with the dying process. Many people have unwanted physical symptoms related to either the underlying medical condition or treatment consequences. Many will suffer pain, nausea, constipation, breathlessness, loss of function, and loss of independence. Psychologically, many will be anxious, depressed, afraid, sad, and alone. Additionally, many are cared for by professionals who lack the knowledge to optimally treat symptoms of the dying, the time to assess needs, and the communication skills or confidence to address innermost fears. Initiatives to change this reality and systematically address all aspects of end-of-life care are evolving. Healthcare leaders and scholars are challenging private, professional, and political organizations to develop creative strategies to improve care of the dying. In summary, recommendations include the following:

- 1.** Improving end-of-life care must be a national priority.
- 2.** End-of-life outcomes must be developed and studied in order for continued improvement to be measured.
- 3.** The process of advance care planning should begin well before a healthcare crisis.

One of the central themes of these recommendations is the need to shift the focus of attention from the completion of the advance directive document to the process of advance care planning. With improvements in the approach, skills, and systems related to end-of-life discussions with patients and their families, the quality and effectiveness of the advance directive as a tool for communication will improve. These changes will ideally result in the overall intended outcome of improving the experience of dying patients and their families.

A Short History of Advance Directives

The advance directive document, as a tool for communicating preferences for future healthcare decision making, has been advocated for more than three decades to provide individuals a mechanism with which their choices can be respected should they become unable to make their own decisions. Currently, all 50 states have statutory documents and other countries have advocated or regulated the right of all adults to record their healthcare preferences in writing. The U.S. federal government passed the Patient Self-Determination Act (PSDA) in 1991, requiring all health institutions to inquire upon admission whether a patient has an advance directive. The PSDA also requires health institutions to provide information about a patient's right to have an advance directive and to educate and inform staff and patients about advance directives. There was hope that these simple requirements would increase the prevalence of advance directives and reduce the conflict over end-of-life decision making. Unfortunately, neither the PSDA nor the use of the statutory advance directive as a communication tool has produced the intended results. Research has demonstrated the following (Miles, 1996; Teno, 1997; Meisel, 2000; Convinsky, 2000; Lynn, 2000; Fagerlin, 2004):

1. The prevalence of written advance directives, while improving especially among certain populations such as patients with cancer and AIDS, remains low. Patients and families remain confused over terminology, documents, and processes of advance care planning.
2. Clinicians remain uncomfortable talking to patients about these issues, thus creating inadequate processes for patients and families to learn about end-of-life options.
3. Advance directives often disappear, are unknown to physicians, cannot be produced by patients or healthcare facilities, and are not available during transfer of the patients. Organizational structures and processes are major determinants of these inadequacies.
4. Statutory advance directives are often too vague or poorly understood. There is little evidence the information in these advance directives affects treatment decisions.
5. If a healthcare agent is chosen, often this person has not had meaningful conversations with the patient and does not know what the patient would have wanted.
6. Information regarding advance directives is often provided only during the stressful times of admission to a hospital or a long-term care facility.
7. Socioeconomic and cultural differences pose barriers to completion and use of advance directives. Those most likely to have an advance directive are white, elderly, educated, and tend to plan for the future.

Ironically, not only has the advance directive as a mechanism for improving end-of-life care failed, dying patients and their families have revealed continued dissatisfaction with the experience of dying. Given these disappointing results regarding the effectiveness of advance directives, it is not surprising that there is skepticism on their continued usefulness. However, evidence exists that when health professionals establish a comprehensive system of advance care planning, effective outcomes can be achieved. Attention has turned toward the creation and testing of improved systems of advance care planning.

Overview of Law and Ethics Related to Advance Care Planning

Advance care planning has strong ethical and legal roots that are often poorly understood or misinterpreted. As a facilitator of this process, you may need to clarify terms and misunderstandings, provide information on your state or local requirements, and validate that decisions made can be supported by legal and ethical principles.

Advance Care Planning and the Law

The rights of a competent adult to refuse medical care are well established in common law, state statutes, federal regulations and standards, and court decisions. A brief review is provided:

1. The Karen Quinlan Case in 1976 captured the attention of the public and raised awareness of the right to privacy and the appointment of surrogates as end-of-life decision makers. The court also introduced the concept of an ethics committee to review such cases and assist with determination of prognosis.
2. California was the first state to proactively pass a law, the Natural Death Act of 1976, establishing the rights of patients and their surrogates to forgo life-sustaining treatments through the development of a written directive. While there were many restrictions and limitations to the execution of such a document, it paved the way for future advances and improvements.
3. In the Saikewicz case of 1977, a Massachusetts court extended the rights of self-determination to those individuals who were never decisional, basing surrogate decision making on the best interests of the patient.
4. In 1983, The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published a document entitled "Deciding to Forgo Life-Sustaining Treatment" that summarized the emerging consensus in the United States on these issues. It not only emphasized the obligation to respect the rights of individuals who have expressed wishes for end-of-life care, but also offered the notion of a durable power of attorney as a substitute decision maker, should an individual become incapable.

5. Legal rulings in the 1980s applied the right to forgo treatment to more routine treatments such as cardiopulmonary resuscitation (CPR), medications, and artificial nutrition and hydration, basing these decisions on the analysis of benefits and burdens to the individual.
6. Continuing to support an individual's right to refuse treatment even if incapacitated, the 1990 United States Supreme Court Cruzan decision held that the most a state can require is clear and convincing evidence that a patient would not want medical care. Individual states may use a less restrictive standard. It does not require that this evidence be based on written documents, and this ruling pertains to adults who had decision-making capacity at one time.
7. An outcome of the Cruzan case was the Patient Self-Determination Act (PSDA) of 1991. This federal statute and regulation requires all health institutions (hospitals, long-term care facilities, hospices, and home health agencies) to
 - a. ask adults at admission if they have a written advance directive and document their responses.
 - b. provide written information to adults about their right to refuse medical and surgical treatment under the statutes of the state and the policies and standards of that institution.
 - c. inform adult patients of their right to file a complaint concerning a provider's noncompliance with advance directive requirements. Patients must be given a telephone number where their complaints may be filed with the state.
 - d. maintain policies about patients' rights to refuse treatments and to have advance directives.
 - e. provide education about advance directives to their staff and community.
 - f. inform patients about changes in state laws concerning advance directives within 90 days of the law going into effect.
8. Currently, all 50 states have statutory documents (e.g., the living will and/or the Power of Attorney for Healthcare) that are recognized as legal tools for documenting patients' preferences.
9. In 2005 the Terri Schiavo case came to national attention and to final resolution. This case involved a young woman who had suffered a significant brain injury following a cardiac arrest. Ms Schiavo's husband, after 5 years of seeking all forms of medical care and rehabilitation, came to realize and accept that his wife was in a persistent vegetative

state (PVS) and would not recover. As his wife's legal guardian he requested that her feeding tube be withheld, as he believed that there was clear evidence that this is what Ms. Shiavo would want. Ms. Shiavo's parents challenged the medical findings, the integrity of the husband/legal guardian, and the fact that their daughter would want the feeding tube withheld. After years of court hearings on all these matters, the courts upheld the findings that Terri Shiavo was in PVS, that her husband was acting in her interest, and that there was evidence that she would not want a feeding tube used to sustain her life in her existing condition. This ruling, objectionable to some religious groups and to Ms. Shiavo's parents, continued the 30 years of precedent of the US courts to allow medical treatment to be forgone when there was adequate evidence that the patient would not want that treatment in the existing medical condition.

In addition to these legal underpinnings, several professional organizations (e.g., the American Medical Association [AMA] and the American Nurses Association [ANA] have established advance care planning as an integral component of standard professional practice. Regulatory agencies such as the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) have mandated standards on protecting patients' rights to make their own decisions.

Health professionals may have legal misunderstandings and myths and may, therefore, need assistance clarifying the law as well as the related ethical principles. Common legal misunderstandings are summarized in the appendix at the end of this chapter.

The Ethics of Advance Care Planning

There are many ways to explain the ethical roots of advance care planning. One of the most important foundations is the doctrine of informed consent. Adult patients with decision-making capacity have a right to consent to or to refuse medical and surgical treatment recommended to them by a physician. The values underlying informed consent include promoting people's well-being and respecting their right to self-determination.

In promoting well-being, more is being cared for than a biological organism. Medical and nursing care must take into account the goals, values, and beliefs of the individual who is ill. These variables can alter judgment about whether a treatment is of benefit to a patient, and since a health professional's duty is to do what is good for the individual, knowing the patient's goals, values, and beliefs is an essential part of good care.

In respecting individuals' rights to self-determination, more is involved than simply understanding goals, values, and beliefs. These goals, values, and beliefs need to be translated into individualized and informed decisions. The elements of informed consent include understanding the interventions, their risks, benefits, and goals; understanding the alternatives, their risks, benefits, and goals; and understanding the right to refuse. In order for

patients to participate in this understanding, they must have decision-making capacity. If these types of discussions occur late in a patient's illness trajectory, their chances of participative decision making decreases.

In the spirit of true informed consent, advance care planning discussions can create an environment of shared decision making between the patient, family, and health professional. If initiated early, while patients are capable, these conversations can provide needed information, as well as the time and resources to assist patients in understanding and interpreting information in the context of their goals, values, and beliefs. In this way, respect for individual well-being and the right to self-determination can be ensured.

While a patient's right to refuse treatment and the right to make informed decisions clearly provide justification for advance care planning, there are additional ethical roots. From an experiential perspective, advance care planning is consistent with an ethic of care and of caring relationships. Making decisions for loved ones who are too ill to speak for themselves and unlikely to recover may include the difficult decision of forgoing life-sustaining treatment. Rather than relying on rights to self-determination and refusal of care, a well-prepared healthcare agent can be guided in this decision-making process by previous discussions and by the caring relationship that exists between loved ones.

The La Crosse Experience

The La Crosse Respecting Choices program presents a variety of strategies to address the multiple components of an effective advance care planning system. We have designed training materials and courses to develop skills in the process of advance care planning and not solely on the completion of a document. These skills include initiating discussions and helping individuals identify their goals, values, and beliefs regarding their healthcare. Respecting Choices also had developed approaches to designing organizational systems that are effective in implementing an individual's plan of care. We have learned how to design and implement effective patient and community engagement strategies. Finally, we have developed methods and tools for monitoring this system to determine whether important outcomes are being achieved and how to make improvements when they are not.

This program has demonstrated success. Initiated in 1991, the major provider organizations in La Crosse, Wisconsin, (now Franciscan Skemp Healthcare and Gundersen Lutheran Health System) cooperated in a joint effort to improve advance care planning. The results of this effort were studied during an 11-month period in 1995 and 1996 and include the following:

1. Among the 540 decedents eligible for the study, more than eight of 10 had written advance directives found in the medical record.

2. In 98% of the cases, patient written preferences were consistent with the decisions made at the end of life.
3. Of those who had written advance directives, 77% completed a power of attorney for healthcare. Of these documents, 83% contained written preferences for or against specific medical treatments.
4. More than half (271 of 459) of all written documents contained a specific request not to attempt CPR at some point. In 90% of these instructions, there was a request to never attempt CPR.
5. Those who had written advance directives were significantly less likely to die in a hospital and more likely to be admitted to hospice care than those who did not have an advance directive.

The strategies implemented and lessons learned from this endeavor will be shared throughout this program in order to stimulate discussion and elicit thought-provoking questions.

Part II. Advance Care Planning and Advance Directives: Understanding the Language and Concepts

Advance Care Planning: The Process

Advance care planning is an organized process of communication to help an individual understand, reflect upon, and discuss goals, values, and beliefs for future healthcare decisions. When this process is done well, it has the power to produce a written plan (i.e., advance directive) that accurately represents individuals' preferences and thoroughly prepares others to make healthcare decisions consistent with these preferences. When this process is not done well, it produces written plans that are ambiguous and loved ones who are unprepared to make substituted decisions. It is the goal of this facilitator manual to describe the skills and strategies in facilitating quality advance care planning discussions. We begin by providing a general overview of the three components of an effective and rewarding advance care planning process.

1. Understanding

What do people need to understand in order to participate in the planning process? First, they need to understand why advance care planning is important for any adult, the components of the planning process, the benefits of planning, and the consequences of not planning. Practices that focus solely on informing people that they have a legal right to plan, without engaging them in the benefits of planning and addressing their fears or misunderstandings about such planning, are often ineffective. Second, they need to understand what they are planning *for*. This step involves individualizing the discussion to the individual's state of health. A healthy adult, for example, does not need to plan for the same decisions as a patient with end-stage heart failure. This will require people to understand their health condition and identify if there is a need for more information. Third, they need to understand the range of choices for future decisions based on their health condition and to receive information on the benefits and burdens of these choices. Fourth, they need to understand the dynamic nature of advance care planning, that health status and personal goals and values may change over time, and that preferences frequently need to be revisited. Last, they must be helped to appreciate that advance care planning is an opportunity to learn how to communicate with loved ones and healthcare providers.

2. Reflection

The next component of the advance care planning process involves the opportunity to *reflect* upon personal goals, values, and beliefs. As you will learn later in this manual, effective techniques to assist people in identifying goals, values, and beliefs include encouraging them to tell their story, exploring experiences with loved ones who have been seriously ill and

what was learned through these experiences, expressing fears and concerns, and describing what *living well* means. Allowing people to reflect upon such important questions and to verbalize goals, values, and beliefs provides them with a framework for weighing the benefits and burdens of future healthcare decisions. It also helps their loved ones to become more informed and provides guidance for making substituted decisions in the future if needed.

3. Discussion

Discussion encourages people to communicate with their chosen healthcare agent(s), other loved ones, healthcare providers, and religious or spiritual advisors, among others. An effective advance care planning process identifies communication channels that need to be opened and offers suggestions for how to initiate discussion with others. Patients may need assistance formulating questions for their physician regarding a health condition, or treatment decision, such as CPR. Individuals also may need referral to a palliative care specialist regarding pain and symptom management, or to a religious advisor regarding the teachings of their tradition.

Ideally, this advance care planning process leads to the development of a written plan, an *advance directive*, that accurately represents the goals, values, beliefs and preferences uncovered through the advance care planning discussions.

In summary, advance care planning is done well when

1. an individual is motivated to learn more and actively participate in planning.
2. future options are understood.
3. options are considered in light of the persons' goals, values, and beliefs.
4. choices are discussed.
5. a plan is formulated and supported.
6. healthcare agents and loved ones accept that following the plan is a loving act.
7. a healthcare agent is selected and the agent's authority to make decisions is clarified.
8. guidelines are provided on when medical treatment should be continued or forgone.
9. guidelines are provided on what it would mean to live well when the time for living may be short.

Conceptual Framework: Underpinnings of the Respecting Choices Advance Care Planning Process

The three components (understanding, reflection, and discussion) of the advance care planning process and the ACP facilitation skills have evolved from a clear conceptual framework. This framework was woven from a set of four interrelated, theoretical underpinnings:

1. The Doctrine of Informed Consent

Planning (and decision making more generally) can be effective only when barriers to understanding, discussion, and reflection are first identified and addressed. Considering advance care planning as a type of informed consent for medical care (Litz, 1988), it follows that removing barriers that interfere with good decisions is an essential first step (Cassell, 1978). For example, if a person were in severe pain, a health professional would want to relieve the pain (i.e., remove the barrier) before asking the patient to make important healthcare decisions. Similarly, beliefs, emotions, gaps in knowledge, and prior experiences may impair one's ability to effectively participate in advance care planning. Unless these gaps in knowledge, fears, or misunderstandings are identified and addressed, individuals are unable to make truly informed healthcare decisions. In this respect, advance care planning is not simply a matter of giving a person what they need to know (transfer of information from an expert to another person) but a process of exploration that can be achieved only by listening to the individual's unique set of beliefs and circumstances (Delbanco, 1992). If this exploration is not done, individuals in the process may not fully understand (Cassell, 1985, Engelhart, 1986), and gaps in knowledge, fears, misunderstandings, or other barriers may not be identified and addressed (Quill, 1989, Lazare, 1987). Failure to do this exploratory work will result in uninformed planning and misunderstanding.

2. The Adult Learning Principle of Engagement

Planning can be effective only if it actively engages a person in the planning process. Engagement is one of the foundational principles of adult learning (Redman, 1992). The Respecting Choices advance care planning approach attempts to engage individuals in several ways: identifying what information a person needs to know; determining what is already known; affirming what is known or learned; and explaining what's in it for the person (e.g., what are the consequences of planning or not planning). The intended outcomes of these engagement activities go well beyond the straightforward act of providing information. Effective, personal engagement results in motivating individuals to take action (e.g., to talk to their loved ones; to understand their health condition; to reflect on goals, values and beliefs, and to make specific decisions). These engagement activities will ultimately result in changing a person's willingness to participate in advance care planning

and in creating a more effective written plan. This theoretical underpinning has strong connections to the more modern concepts of motivational interviewing and transtheoretical change (Miller & Rollnick, 2002).

3. The Narrative Approach

Planning begins by listening and exploring the individual's story. The narrative approach is well supported in the literature as a valuable strategy to gain insight into one's own worldview (Dunne, 1965, 1967, 1973). Respecting Choices advocates the use of narrative to gain insight into individuals' goals, values, and beliefs. These insights can have a powerful, positive impact on the understanding needed to make future health decisions and on the motivation to plan. Narratives are also more useful to help individual's to gain new insights by hearing and exploring not only their own stories, but also by exploring archetypical and cultural stories.

This theoretical underpinning of Respecting Choices holds that the use of narrative to improve understanding, reflection, and discussion is crucial because it can help integrate learning, motivation, and action. The use of narrative is a driving force in the process that connects the theoretical ideas described in items 1 and 2 above.

4. An Ethic of Caring Relationships

Planning is more accurately supported by an ethic of *care* (Gilligan, 1982) rather than an ethic of *rights*. While advance directives have most often been seen as a way for individuals to exercise the right of self-determination and the right to refuse medical care, the Respecting Choices approach postulates that in daily human experience most people are primarily concerned about the ethical boundaries of their relationships and roles (Taylor, 1985, Pellegrino, 1988). For a daughter of a seriously ill mother, the primary question is not "What are my mother's rights?" but, rather, "What does a good daughter do to care for her mother at this moment?" or "How do I love my mother now?"

This final theoretical underpinning of Respecting Choices holds that if the ethics of caring relationships can be explored and addressed in the planning process, it will be critical to the process of understanding, reflection, and discussion and will, in turn, be extremely useful to loved ones when healthcare decisions need to be made at some future point. This theory has specific meaning and connection when identifying the approach to advance care planning for diverse populations. It complements the use of narrative as described above, as stories are commonly about dilemmas in how we care or fail to care for those closest to us.

The interaction among these four theoretical underpinnings forms the conceptual framework upon which Respecting Choices has developed the components of the advance care planning

process and the related facilitation skills. This work gains increased credibility and utility as it is continually tested in clinical practice.

Advance Care Planning in Clinical Practice

In contrast to the consequences of completing a typical advance directive document without discussion, the process of advance care planning has positive effects. These types of discussions have demonstrated the following patient outcomes (Steinhauser, 2001, 2002; Tierney, 2001; Tilden, 2004):

1. improvement in physical symptoms of depression.
2. increase in patients' beliefs that physicians understand their preferences.
3. increase in patients' beliefs that physicians care more.
4. better preparation for death.
5. lessening of the burden on loved ones (i.e., decrease in family stress associated with the decision to withdraw treatment).

Inherent in achieving these positive outcomes from advance care planning is the quality and commitment to the conversation and to a system of using and honoring the plans that they create. There are several reasons to actively initiate and engage in this dynamic process:

1. Professionals have an ethical and legal responsibility to honor a people's decisions even if they become unable to speak for themselves.
2. Individuals have an opportunity to better understand their overall healthcare status and, armed with helpful information, are better prepared to begin to make those difficult end-of-life decisions.
3. The focus can be shifted from a medical crisis in which short-term goals for each potential medical condition are decided, to a more holistic approach of anticipating prognosis considering all of a patient's multiple problems and what long-term goals the patient has envisioned—or needs to begin to imagine. An emerging objective of advance care planning, therefore, is to not only guide decision making for life-sustaining treatment if a person becomes incapable, but to anticipate potential complications and discuss related goals and preferences.
4. A unique opportunity is opened for health professionals, individuals, and their families to establish common communication pathways that will assist in the identification of

individual goals and values for quality of life, decrease anxiety and fear, and build trust and a sense of true partnership.

While the legal or regulatory support for creating written advance directives is often considered important, these documents, when created without good advance care planning, most often fail. Seeking healthcare for a loved one who has become ill or injured is most often considered an act of love. In contrast, when a family member is asked in a hopeless situation if treatment should be stopped, it is often emotionally and morally difficult to make decisions. To the family member, treatment may represent or symbolize an act of caring, and for some people the value of the symbolism alone is sufficient justification to continue treatment, even if the treatment has no benefit or may even cause harm.

When families discuss their goals, values, and beliefs in advance, it is possible to change attitudes toward medical treatments that only prolong a hopeless situation. The focus of a helpful advance care planning discussion is not on patients' rights, but on how they would define *good care* if they were so ill they would not recover. When individuals have told a family member when treatment should be stopped, the family finds both emotional comfort and moral direction in what is always a difficult decision.

With good advance care planning, forgoing treatment can become an act of caring. Conversely, when people have communicated their desire to continue treatment under specified situations, perhaps based on religious or cultural beliefs, families can support these decisions with full knowledge it is consistent with what their loved one has expressed.

Many adults claim that close family members know what they want, even though they have never discussed future healthcare decisions with them. This claim may seem plausible—or it may be a way of avoiding a difficult subject. Whatever the reason, the claim is not accurate. Neither loved ones nor health professionals are able to accurately predict what another person would choose for medical treatments. Unless people talk explicitly about these issues, they do not adequately understand how to choose for others.

While the potential outcomes of a successful advance care planning program are laudable, a variety of significant barriers may interfere with implementation:

1. avoidance of the subject by health professionals, possibly due to a belief that the person is not sick enough, may become upset, is incapable of understanding, or may be robbed of hope.
2. professionals feeling uncomfortable or lacking confidence in their skills related to delivering bad news, counseling on end-of-life issues, dealing with loss and grief, and developing practical written advance directives.

3. perceived (or real) lack of time.
4. lack of reimbursement for advance care planning as a legitimate healthcare intervention.
5. the belief that there are simply too many contingencies for individuals to consider regarding their future medical conditions.
6. a sense that ACP discussions make no difference because there is no way to share or convey discussions and plans with other health professionals at some future time.

Advance care planning facilitators need to assess and understand the unique barriers to effective planning within their organization. Throughout this program, a variety of strategies will be offered to address these barriers.

Advance Directives: The Plan

The ideal outcome of advance care planning for many individuals is the creation of an advance directive that acknowledges the specific healthcare decisions that have been discussed and understood by all participants involved in the process. The term *advance directive* is commonly used by health professionals, although its meaning is not universally understood. For those who undertake advance care planning facilitation, it is important to have a clear understanding of this concept, of the ways others use it, and of related concepts such as *living will* and *Power of Attorney for Healthcare*.

This program uses the terms *Power of Attorney for Healthcare* and *healthcare agent* generically. Power of Attorney for Healthcare will refer to a written advance directive in which one person appoints another person(s) to make health decisions should the person making the appointment become incapacitated. Other terms used for the Power of Attorney for Healthcare document include *durable power of attorney for healthcare*, *medical power of attorney*, *advance directive for healthcare*, *special power of attorney*, *terminal care document*, and *advance healthcare directive*. The term used in this program for the designated person to make healthcare decisions is *healthcare agent*. Terms used elsewhere include *agent*, *healthcare proxy*, *representative*, *surrogate* and *attorney in fact*. Additionally, the substance of the Power of Attorney for Healthcare document and the authority given to the healthcare agent vary by state statute. Some states have combined the living will with the option to designate a healthcare agent into one document. It is important to become familiar with the terminology and content of your local or regional laws related to advance directives.

Many sources speak of advance directives as only written documents; we use a broader definition. Throughout *Respecting Choices*, the phrase *advance directives* will be understood to be plans made by adults about how they want their healthcare decisions made if they should become unable to make decisions for themselves. Advance directives in this

definition can be made either verbally or in writing. Adults, for example, may provide clear instructions for their families about when not to continue life-sustaining treatment. Instructions of this nature may be clear and understood by family, but never put in writing. Such verbal communication is considered an advance directive as it represents evidence of a person's goals, values, and beliefs, and can be helpful in any decision-making situation.

Many persons choose to put some or all of their instructions in writing, and Respecting Choices encourages adults to do this in the final stages of the process. This can take several forms. Documents can instruct family, friends, and physicians on when to continue or stop medical treatment. Such a document is typically called a *living will*. Another type of document identifies and authorizes another person to make medical and health decisions, should the person become incapable. Such a document is called a *Power of Attorney for Healthcare*. Other documents now combine the type of instructions given in a living will with the possibility of appointing a person called a *healthcare proxy, agent, or representative*. Terminology varies widely in different geographic areas. It is important for you to understand the advance directive terminology in your community.

Informal Directives Are Also Acceptable

Written advance directives may be executed under the rules and definitions of legal or regulatory guidelines, or they might be written more informally like a letter or physician's narrative. While there are advantages and disadvantages to using forms that comply with legal or regulatory guidelines, any written document should strive to clearly and specifically communicate the goals, values, and beliefs of the person making it. It should also be written so health professionals who might need to refer to it will understand it and know when and how to act on it.

Confusion can exist with many of the terms used in discussing advance directives. The phrase *advance directive* is not widely known to the general public. In asking someone if they have an advance directive, additional explanation and questions are important. The phrase *living will* is widely recognized, but not always understood correctly. Many people believe that it is a will for financial matters made while one is living. Confusion can also exist with the phrase *Power of Attorney for Healthcare*. Many people have heard of, and in fact have, a power of attorney for financial matters. They often assume that the one for healthcare is the same. In educating people about written advance directives, it is important to first assess their level of understanding of these terms. People sometimes say that they have a living will or a Power of Attorney for Healthcare when they, in fact, have a written document that deals exclusively with financial matters. When possible, it is best to actually review advance directive documents that people say they have created.

Keeping the Advance Care Planning/Advance Directive Language Straight

<i>Will</i>	A legal document created by a competent adult to specify how to divide assets and property after death
<i>Living Will</i>	Written instructions that tell physicians and family members what life-sustaining treatment one does or does not want at some future time if a person becomes unable to make decisions. This document may go by many different names in different jurisdictions.
<i>Power of Attorney</i>	A legal document in which one person gives another the authority to make specified financial decisions or to assume certain financial responsibilities. If this authority extends after the time that the person who made the appointment is competent, it is called a durable power of attorney.
<i>Power of Attorney for Healthcare</i>	In this legal document a person (a principal) appoints someone else (e.g., an agent) to make healthcare decisions in the event that the person becomes incapable of doing so. Such documents often allow the person creating the document to also provide instructions for the person they appoint.
<i>Legal Guardian</i>	This is a person appointed by a judge to make another's (the ward's) personal decisions, including consenting to or refusing medical treatment. In order to appoint a legal guardian, the judge first would have to determine the person in question to be legally incompetent. The legal guardian's authority could be limited to only financial decisions, to only personal decisions, or to both.

Chapter 1:
Exercises

1. List three reasons why planning for decisions at the end of life is important.

2. The results of studies on the effectiveness of advance directives have yielded what kind of negative outcomes?

3. Name three important distinctions between advance care planning and advance directives.

4. Define the following:
 - Living Will

 - Durable Power of Attorney for Healthcare

 - Legal Guardian

Appendix

Advance Care Planning and the Law: Common Misunderstandings

Misunderstandings of what the law does and does not say regarding advance care planning and end-of-life treatment decisions can cause unnecessary concern and frustration. These misunderstandings exist for both individuals as well as health professionals. Advance care planning facilitators may often need to clarify and explain how many of the legal issues have been resolved. Review the following examples of common misunderstandings. How would you respond?

Misunderstandings from the Patient's Perspective:

1. An attorney is needed to complete an advance directive.
2. Completing an advance directive and naming a proxy means that I give up control over what happens to me.
3. Completing an advance directive means that I have a terminal illness.
4. An advance directive means I will no longer receive treatment.
5. If I change my mind from what is in my advance directive, no one will listen to me.
6. I must use my state's advance directive form in order for my wishes to be followed.
7. No matter what I say in my advance directive, the doctors can do what they want.
8. I don't need an advance directive because my family can make my decisions for me.
9. If I complete an advance directive in my state, it will not be legally valid if I travel to another state.
10. The best way to let my family know my choices is by signing a document.

Misunderstandings from the Health Professional's Perspective:

1. Advance directives are useless because they are not specific enough to be used for decision making when needed.
2. Advance directives must comply with statutory forms, do not transfer to other states, and must be in writing to be enforced.

3. Forgoing life-sustaining interventions for patients who lack capacity requires evidence of the patient's wishes.
4. Withholding or withdrawing artificial fluids and nutrition from terminally ill or permanently unconscious patients is illegal.
5. When a terminally ill person has uncontrollable suffering, there are no legal options to ease this suffering.
6. A relative is always the best proxy.
7. Stopping life-sustaining treatment is the same as suicide or murder.
8. Providing comfort/care measures, such as pain medication that may hasten the patient's death, is murder.
9. Patients do not have the ability to really understand all of the treatment decisions they are asked to make.
10. In completing an advance directive, it is better if no specific instructions are given in order to avoid confusion in interpreting what is meant.
11. In the absence of an advance directive, the next of kin is the best substitute decision maker.
12. When patients are admitted to the hospital, it is not appropriate to talk about any issues related to end-of-life treatment decisions.
13. It is legal to withdraw such "extraordinary" treatments such as a ventilator, but not "ordinary" treatments such as intravenous fluids.
14. When conflicts arise over end-of-life treatment decisions, it is always best to let the courts decide.

Chapter 1: **Further Reading**

- Allen, R., & Ventura, N. (2005). Advance directives use in acute care hospitals. *JONA's Healthcare Law, Ethics, & Regulation*, 7(3), 86-91.
- Back, A. L., Arnold, R. M., & Quill, T. E. (2003). Hope for the best, and prepare for the worst. *Annals of Internal Medicine*, 138(5), 439-443.
- Baker, R., Wu, A. W., Teno, J. M., Kreling, B., Damiano, A. M., Rubin, H. R., et al. (2000). Family satisfaction with end-of-life care in seriously ill hospitalized adults. *Journal of the American Geriatrics Society*, 48(5 Suppl), S61-S69.
- Berns, R., & Colvin, E. R. (1998). The final story: Events at the bedside of dying patients as told by survivors. *ANNA Journal / American Nephrology Nurses' Association*, 25(6), 583-587.
- Bookwala, J., Coppola, K. M., Fagerlin, A., Ditto, P. H., Danks, J. H., & Smucker, W. D. (2001). Gender differences in older adults' preferences for life-sustaining medical treatments and end-of-life values. *Death Studies*, 25(2), 127-149.
- Callahan, D. (2003). Too much of a good thing: How splendid technologies can go wrong. *Hastings Center Report*, 33(2), 19-22.
- Callahan, D. (2005). Death: "The distinguished thing." *Hastings Center Report*, (Spec No), S5-S8.
- Calvin, A. O., & Eriksen, L. R. (2006). Assessing advance care planning readiness in individuals with kidney failure. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*, 33(2), 165-170.
- Cassell, E. J. (1985). *Talking with patients*. Cambridge, MA: MIT Press.
- Cassell, E. J. (1978). Informed consent in the therapeutic relationship: Clinical aspects. In W. T. Reich (Ed.), *Encyclopedia of Bioethics* (pp. 767-769). New York: Simon & Schuster Macmillan.
- Collins, S. E. (1999). Rethinking the Patient Self Determination Act: Implementation without effectiveness. *Journal of Nursing Law*, 6(3), 29-46.
- A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). The SUPPORT principal investigators. (1995). *JAMA: The Journal of the American Medical Association*, 274(20), 1591-1598.
- Covinsky, K. E., Fuller, J. D., Yaffe, K., Johnston, C. B., Hamel, M. B., Lynn, J., et al. (2000). Communication and decision-making in seriously ill patients: Findings of the SUPPORT project. The Study to Understand Prognoses and Preferences for

- Outcomes and Risks of Treatments. *Journal of the American Geriatrics Society*, 48(5 Suppl), S187-S193.
- Crane, M. K., Wittink, M., & Doukas, D. J. (2005). Respecting end-of-life treatment preferences. *American Family Physician*, 72(7), 1263-1268.
- Crawley, L., & Kagawa-Singer, M. (2007). *Racial, cultural and ethnic factors affecting the quality of end-of-life care in California*. Retrieved March 2007
<http://www.chcf.org/topics/chronicdisease/index.cfm?itemID=131674>.
- Curtis, J. R. (2000). Communicating with patients and their families about advance care planning and end-of-life care. *Respiratory care*, 45(11), 1385-1394.
- Delbanco, T. L. (1992). Enriching the doctor-patient relationship by inviting the patient's perspective. *Annals of Internal Medicine*, 116(5), 414-418.
- Della Santina, C., & Bernstein, R. H. (2004). Whole-patient assessment, goal planning, and inflection points: Their role in achieving quality end-of-life care. *Clinics in Geriatric Medicine*, 20(4), 595-620.
- Derse, A. R. (2005). Limitation of treatment at the end-of-life: Withholding and withdrawal. *Clinics in Geriatric Medicine*, 21(1), 223-238.
- Ditto, P. H., & Hawkins, N. A. (2005). Advance directives and cancer decision making near the end of life. *Health Psychology*, 24(4 Suppl), S63-S70.
- Ditto, P. H., Jacobson, J. A., Smucker, W. D., Danks, J. H., & Fagerlin, A. (2006). Context changes choices: A prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Medical Decision Making*, 26(4), 313-322.
- Ditto, P. H., Smucker, W. D., Danks, J. H., Jacobson, J. A., Houts, R. M., Fagerlin, A., et al. (2003). Stability of older adults' preferences for life-sustaining medical treatment. *Health Psychology*, 22(6), 605-615.
- Dresser, R. (2005). Schiavo's legacy: The need for an objective standard. *Hastings Center Report*, 35(3), 20-22.
- Dunne, J. S. (1965). *The city of Gods: A study in myth and mortality*. New York: Collier-MacMillan Publishers.
- Dunne, J. S. (1967). *A search for God in time and memory*. New York: Collier-MacMillan, Ltd.
- Dunne, J. S. (1973). *Time and myth: A meditation on storytelling as an exploration of life and death*. Garden City, NY: Doubleday and Company, Inc.
- Engelhardt, H. T. (1986). The social meanings of illness. *Second Opinion*, 1, 27-39.

- Fagerlin, A., & Schneider, C. E. (2004). Enough. The failure of the living will. *Hastings Center Report*, 34(2), 30-42.
- Farber, N. J., Simpson, P., Salam, T., Collier, V. U., Weiner, J., & Boyer, E. G. (2006). Physicians' decisions to withhold and withdraw life-sustaining treatment. *Archives of Internal Medicine*, 166(5), 560-564.
- Feeg, V. D., & Elebiary, H. (2005). Exploratory study on end-of-life issues: Barriers to palliative care and advance directives. *American Journal of Hospice & Palliative Care*, 22(2), 119-124.
- Field, M., & Cassel, C. (Eds.). (1997). *Approaching death: Improving care at the end of life*. Washington, DC: National Academy Press.
- Fins, J. J., Maltby, B. S., Friedmann, E., Greene, M. G., Norris, K., Adelman, R., et al. (2005). Contracts, covenants and advance care planning: An empirical study of the moral obligations of patient and proxy. *Journal of Pain & Symptom Management*, 29(1), 55-68.
- Fried, T. R., Bradley, E. H., O'Leary, J. R., & Byers, A. L. (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. *Journal of the American Geriatrics Society*, 53(1), 59-65.
- Fried, T. R., Bradley, E. H., Towle, V. R., & Allore, H. (2002). Understanding the treatment preferences of seriously ill patients. *New England Journal of Medicine*, 346(14), 1061-1066.
- Gilligan, C. (1982). *In a different voice*. Cambridge, MA: Harvard University Press.
- Hammes, B.J. (1978). The views of scientific change and their evaluation: an epistemological approach. Unpublished doctoral dissertation, University of Notre Dame, South Bend, Indiana
- Hammes, B. J. (2001). What does it take to help adults successfully plan for future medical decisions? *Journal of Palliative Medicine*, 4(4), 453-456.
- Hammes, B. J., & Rooney, B. L. (1998). Death and end-of-life planning in one Midwestern community. *Archives of Internal Medicine*, 158(4), 383-390.
- Hawkins, N. A., Ditto, P. H., Danks, J. H., & Smucker, W. D. (2005). Micromanaging death: Process preferences, values, and goals in end-of-life medical decision making. *Gerontologist*, 45(1), 107-117.
- Heyland DK, Dodek P, Rucker G, Groll D, Gafni A, Pichora D, Shortt S, Tranmer J, Lazar N, Kutsogiannis J, Lam M. Canadian Researchers End-of-Life Network (CARENET). (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *CMAJ Canadian Medical Association Journal*, 174(5), 627-633.

- Hickey, D. P., Shriner, C. J., & Perry, S. E. (2005). Patients' initiation of advance care planning discussions with their family physician. *Family Medicine*, 37(8), 536.
- Hickman, S. E., Hammes, B. J., Moss, A. H., & Tolle, S. W. (2005). Hope for the future: Achieving the original intent of advance directives. *Hastings Center Report*, (Spec No), S26-S30.
- Hines, S. C., Glover, J. J., Babrow, A. S., Holley, J. L., Badzek, L. A., & Moss, A. H. (2001). Improving advance care planning by accommodating family preferences. *Journal of Palliative Medicine*, 4(4), 481-489.
- Jennings, B. (2005). Preface: Improving end of life care: Why has it been so difficult? *Hastings Center Report*, (Spec No), S2-S4.
- Jordens, C., Little, M., Kerridge, I., & McPhee, J. (2005). From advance directives to advance care planning: Current legal status, ethical rationales and a new research agenda. *Internal Medicine Journal*, 35(9), 563-566.
- Kass-Bartelmes, B. L., & Hughes, R. (2004). Advance care planning: Preferences for care at the end of life. *Journal of Pain & Palliative Care Pharmacotherapy*, 18(1), 87-109.
- Kirschner, K. L. (2005). When written advance directives are not enough. *Clinics in Geriatric Medicine*, 21(1), 193-209.
- Kolarik, R. C., Arnold, R. M., Fischer, G. S., & Tulsky, J. A. (2002). Objectives for advance care planning. *Journal of Palliative Medicine*, 5(5), 697-704.
- Lambert, H. C., McColl, M. A., Gilbert, J., Wong, J., Murray, G., & Shortt, S. E. (2005). Factors affecting long-term-care residents' decision-making processes as they formulate advance directives. *Gerontologist*, 45(5), 626-633.
- Larson, D. G., & Tobin, D. R. (2000). End-of-life conversations: Evolving practice and theory. *JAMA: The Journal of the American Medical Association*, 284(12), 1573-1578.
- Lazare, A. (1987). Shame and humiliation in the medical encounter. *Archives of Internal Medicine*, 147(9), 1653-1658.
- Leahman, D. (2004). Why the Patient Self-Determination Act has failed. *North Carolina Medical Journal*, 65(4), 249-251.
- Levine, C. (2006). The President's Council on Autonomy: Never mind! *Hastings Center Report*, 36(3), 46-47.
- Lidz, C. W., Appelbaum, P. S., & Meisel, A. (1988). Two models of implementing informed consent. *Archives of Internal Medicine*, 148(6), 1385-1389.
- Lo, B., & Steinbrook, R. (2004). Resuscitating advance directives. *Archives of Internal Medicine*, 164(14), 1501-1506.

- Loewy, E. H. (1998). Ethical considerations in executing and implementing advance directives. *Archives of Internal Medicine*, 158(4), 321-324.
- Lorenz, K. A., Shugarman, L. R., & Lynn, J. (2006). Health care policy issues in end-of-life care. *Journal of Palliative Medicine*, 9(3), 731-748.
- Lowder, J. L., Buzney, S. J., French, C. M., & Loue, S. (2004). The importance of planning for the future. *Care Management Journals*, 5(4), 235-244.
- Lynn, J., Schuster, J. L., & Kabcenell, A. (2000). *Improving care for the end of life: A sourcebook for health care managers and clinicians*. New York: Oxford University Press.
- Lynn, J. (2005). End-of-life options. *Health affairs*, 24(5), 1377-1378.
- Lynn, J., Arkes, H. R., Stevens, M., Cohn, F., Koenig, B., Fox, E., et al. (2000). Rethinking fundamental assumptions: SUPPORT's implications for future reform. Study to Understand Prognoses and Preferences and Risks of Treatment. *Journal of the American Geriatrics Society*, 48(5 Suppl), S214-S221.
- Maltby, B. S., & Fins, J. J. (2004). Informing the patient-proxy covenant: An educational approach for advance care planning. *Journal of Palliative Medicine*, 7(2), 351-355.
- Meier, D. E. (2004). Variability in end of life care. *British Medical Journal*, 328(7449), E296-7.
- Meier, D. E., & Morrison, R. S. (2002). Autonomy reconsidered. *New England Journal of Medicine*, 346(14), 1087-1089.
- Meisel, A. (2003). Quality of life and end-of-life decisionmaking. *Quality of Life Research*, 12(Suppl 1), 91-94.
- Meisel, A., Snyder, L., Quill, T., & American College of Physicians—American Society of Internal Medicine End-of-Life Care Consensus Panel. (2000). Seven legal barriers to end-of-life care: Myths, realities, and grains of truth. *JAMA: The Journal of the American Medical Association*, 284(19), 2495-2501.
- Miles, S. H., Koeppe, R., & Weber, E. P. (1996). Advance end-of-life treatment planning. A research review. *Archives of Internal Medicine*, 156(10), 1062-1068.
- Miller, W. R., & Rollnick, S. (2002). *Motivational interviewing: Preparing people for change* (2nd ed.). New York: The Guilford Press.
- Molloy, D. W., Guyatt, G. H., Russo, R., Goeree, R., O'Brien, B. J., Bedard, M., et al. (2000). Systematic implementation of an advance directive program in nursing homes: A randomized controlled trial. *JAMA: The Journal of the American Medical Association*, 283(11), 1437-1444.

- Moore, C. D. (2005). Communication issues and advance care planning. *Seminars in Oncology Nursing*, 21(1), 11-19.
- Morrison, R. S., Chichin, E., Carter, J., Burack, O., Lantz, M., & Meier, D. E. (2005). The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *Journal of the American Geriatrics Society*, 53(2), 290-294.
- Morrison, R. S., Siu, A. L., Leipzig, R. M., Cassel, C. K., & Meier, D. E. (2000). The hard task of improving the quality of care at the end of life. *Archives of Internal Medicine*, 160(6), 743-747.
- Morrison, W. (2006). Thoughts on advance directives. *Journal of Palliative Medicine*, 9(2), 483-484.
- Moseley, R., Dobalian, A., & Hatch, R. (2005). The problem with advance directives: Maybe it is the medium, not the message. *Archives of Gerontology & Geriatrics*, 41(2), 211-219.
- Moskop, J. C. (2004). Improving care at the end of life: How advance care planning can help. *Palliative & Supportive Care*, 2(2), 191-197.
- Murray, T. H., & Jennings, B. (2005). The quest to reform end of life care: Rethinking assumptions and setting new directions. *Hastings Center Report*, (Spec No), S52-S57.
- National Institutes of Health State-of-the-Science Conference Statement. Improving End-Of-Life Care. December 6-8, 2004.(2005). *Journal of Pain & Palliative Care Pharmacotherapy*, 19(3), 75-83.
- Nelson, L. J. (2003). The Wendland case: On families and fantasies. *Medical Ethics*, 10(2), 8.
- Patel, R. V., Sinuff, T., & Cook, D. J. (2004). Influencing advance directive completion rates in non-terminally ill patients: A systematic review. *Journal of Critical Care*, 19(1), 1-9.
- Patrick, D. L., Curtis, J. R., Engelberg, R. A., Nielsen, E., & McCown, E. (2003). Measuring and improving the quality of dying and death. *Annals of Internal Medicine*, 139(5 Pt 2), 410-415.
- Pearlman, R. A., Starks, H., Cain, K. C., & Cole, W. G. (2005). Improvements in advance care planning in the Veterans Affairs system: Results of a multifaceted intervention. *Archives of Internal Medicine*, 165(6), 667-674.
- Pellegrino, E., & Thomasma, D. C. (1988). *For the patient's good: The restoration of beneficence in health care*. New York: Oxford University Press.
- Porter, T., Johnson, P., & Warren, N. A. (2005). Bioethical issues concerning death: Death, dying, and end-of-life rights. *Critical Care Nursing Quarterly*, 28(1), 85-92.

- Prendergast, T. J. (2000). Handling conflict in end-of-life care. *JAMA: The Journal of the American Medical Association*, 283(24), 3200.
- Prendergast, T. J. (2001). Advance care planning: Pitfalls, progress, promise. *Critical Care Medicine*, 29(2 Suppl), N34-N39.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research* (1983). Washington, DC: U.S. Government Printing Office.
- Quill, T. E. (1989). Recognizing and adjusting to barriers in doctor-patient communication. *Annals of Internal Medicine*, 111(1), 51-57.
- Redman, B. K. (1992). *The process of patient education* (7th ed.). St. Louis, MO: C.V. Mosby.
- Romer, A. L., & Hammes, B. J. (2004). Communication, trust, and making choices: Advance care planning four years on. *Journal of Palliative Medicine*, 7(2), 335-340.
- Sass, H. M. (2005). Narrative approaches in patient information and communication. *Formosan Journal of Medical Humanities*, 6(1-2), 15-29.
- Schwartz, C. (2005). Decision making at the end of life: Shifting sands. *Journal of the Royal Society of Medicine*, 98(7), 297-298.
- Schwartz, C. E., Merriman, M. P., Reed, G. W., & 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(2), 233-245.
- Schwartz, C. E., Wheeler, H. B., Hammes, B., Basque, N., Edmunds, J., Reed, G., et al. (2002). Early intervention in planning end-of-life care with ambulatory geriatric patients: Results of a pilot trial. *Archives of Internal Medicine*, 162(14), 1611-1618.
- Schwartz, J., & Estrin, J. (2005). Many seeking one final say on end of life. *New York Times*, A1.
- Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S. H., & Clark, D. (2004). Planning for the end of life: The views of older people about advance care statements. *Social Science & Medicine*, 59(1), 57-68.
- Shugarman, L. R., Lorenz, K., & Lynn, J. (2005). End-of-life care: An agenda for policy improvement. *Clinics in Geriatric Medicine*, 21(1), 255-272.
- Singer, P. A., & Bowman, K. W. (2002). Quality care at the end of life. *British Medical Journal*, 324(7349), 1291-1292.
- Skene, L. (2005). The Schiavo and Korp cases: Conceptualising end-of-life decision-making. *Journal of Law & Medicine*, 13(2), 223-229.

- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., Grambow, S., Parker, J., et al. (2001). Preparing for the end of life: Preferences of patients, families, physicians, and other care providers. *Journal of Pain & Symptom Management*, 22(3), 727-737.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA: The Journal of the American Medical Association*, 284(19), 2476-2482.
- Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132(10), 825-832.
- Taylor, S. G. (1985). Rights and responsibilities: Nurse-patient relationships. *Image - the Journal of Nursing Scholarship*, 17(1), 9-13.
- Teno, J. M. (2004). Advance directives: Time to move on. *Annals of Internal Medicine*, 141(2), 159-160.
- Teno, J. M. (2005). Measuring end-of-life care outcomes retrospectively. *Journal of Palliative Medicine*, 8(Suppl 1), S42-S49.
- Teno, J. M., Casey, V. A., Welch, L. C., & Edgman-Levitan, S. (2001). Patient-focused, family-centered end-of-life medical care: Views of the guidelines and bereaved family members. *Journal of Pain & Symptom Management*, 22(3), 738-751.
- Teno, J. M., Fisher, E. S., Hamel, M. B., Coppola, K., & Dawson, N. V. (2002). Medical care inconsistent with patients' treatment goals: Association with 1-year Medicare resource use and survival. *Journal of the American Geriatrics Society*, 50(3), 496-500.
- Teno, J. M., Licks, S., Lynn, J., Wenger, N., Connors, A. F., Jr, Phillips, R. S., et al. (1997). Do advance directives provide instructions that direct care? SUPPORT investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Journal of the American Geriatrics Society*, 45(4), 508-512.
- Tierney, W. M., Dexter, P. R., Gramelspacher, G. P., Perkins, A. J., Zhou, X. H., & Wolinsky, F. D. (2001). The effect of discussions about advance directives on patients' satisfaction with primary care. *Journal of General Internal Medicine*, 16(1), 32-40.
- Tilden, V. P., Tolle, S., Drach, L., & Hickman, S. (2002). Measurement of quality of care and quality of life at the end of life. *Gerontologist*, 42(Spec 3), 71-80.
- Tilden, V. P., Tolle, S. W., Drach, L. L., & Perrin, N. A. (2004). Out-of-hospital death: Advance care planning, decedent symptoms, and caregiver burden. *Journal of the American Geriatrics Society*, 52(4), 532-539.

- Tilden, V.P., Tolle, S.W., Nelson, C. A., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatments for hospitalized patients. *Nurs Res*, 50(2), 105-115
- Torke, A. M., Garas, N. S., Sexson, W., & Branch, W. T. (2005). Medical care at the end of life: Views of African American patients in an urban hospital. *Journal of Palliative Medicine*, 8(3), 593-602.
- Tulsky, J. A. (2005). Beyond advance directives: Importance of communication skills at the end of life. *JAMA*, 294(3), 359-365.
- van Delden, J. J. (2004). The unfeasibility of requests for euthanasia in advance directives. *Journal of Medical Ethics*, 30(5), 447-451.
- Virmani, J., Schneiderman, L. J., & Kaplan, R. M. (1994). Relationship of advance directives to physician-patient communication. *Archives of Internal Medicine*, 154(8), 909-913.
- Weiner, J. S., & Cole, S. A. (2004). ACare: A communication training program for shared decision making along a life-limiting illness. *Palliative & Supportive Care*, 2(3), 231-241.
- Weiner, J. S., & Cole, S. A. (2004). Three principles to improve clinician communication for advance care planning: Overcoming emotional, cognitive, and skill barriers. *Journal of Palliative Medicine*, 7(6), 817-829.
- Weiner, J. S., & Efferen, L. S. (2005). Recognition and communication: Essential elements to improving end-of-life care. *Chest*, 127(6), 1886-1888.
- Weitzen, S., Teno, J. M., Fennell, M., & Mor, V. (2003). Factors associated with site of death: A national study of where people die. *Medical Care*, 41(2), 323-335.
- Westley, C., & Briggs, L. A. (2004). Using the stages of change model to improve communication about advance care planning. *Nursing Forum*, 39(3), 5-12.
- White, Y., & Fitzpatrick, G. (2006). Dialysis: Prolonging life or prolonging dying? Ethical, legal and professional considerations for end of life decision making. *Edna-Erca Journal*, 32(2), 99-103.
- Winzelberg, G. S., Hanson, L. C., & Tulsky, J. A. (2005). Beyond autonomy: Diversifying end-of-life decision-making approaches to serve patients and families. *Journal of the American Geriatrics Society*, 53(6), 1046-1050.
- Wreen, M. J. (2004). Hypothetical autonomy and actual autonomy: Some problem cases involving advance directives. *Journal of Clinical Ethics*, 15(4), 319-333.
- Yarborough, M. (2005). Deciding for others at the end of life: Storytelling and moral agency. *Journal of Clinical Ethics*, 16(2), 127-143.