



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING:

REPORT TO CONGRESS

August 2008

Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared under contract #HHS-100-03-0023 between HHS's ASPE/DALTCP and the RAND Corporation. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the ASPE Project Officers, Susan Polniaszek and Judith Peres, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Their e-mail addresses are: Susan.Polniaszek@hhs.gov and Judith.Peres@hhs.gov.

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This report was prepared through a contract with RAND Health (Neil S. Wenger, M.D., M.P.H., Lisa R. Shugarman, Ph.D., with Anne Wilkinson, Ph.D.) and staff from the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (including Judith Peres, L.C.S.W.-C.). In addition, specific commissioned papers by Myra Christopher, John Carney, M.Ed., Charles Sabatino, J.D., and Gary Stein, J.D., M.S.W. are reflected in this work.

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PREFACE

In 2006, Congress requested that the Department of Health and Human Services (HHS) conduct a study on how best to promote advance directives. This HHS report is a product of research by RAND Health, commissioned papers, “Roundtable Discussions” with experts and the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE).

Included in the 2006 appropriation bill for the Departments of Labor, Health and Human Services, and Education was language that directed the Secretary of HHS to consider how best to promote advance directives:

Senate Report 109-103 -- Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriation Bill, 2006

“Advance Directives -- The Committee believes that through the execution of advance directives, including living wills and durable powers of attorney for health care according to the laws of the State in which they reside, individuals can better protect their right to express their wishes about end-of-life care and have those wishes respected. The Committee directs the Secretary to conduct a study to determine the best way to promote the use of advance directives among competent adults as a means of specifying their wishes about end of life care, and provide recommendations to Congress on changes to Federal law needed to ensure appropriate use of advance directives. As part of that study, the Department shall consider that decisions relating to advance directives are often made without adequate information about what it is like to live with a significant disability. The Committee intends that the study directly involve persons with disabilities, family members, disability experts and organizations in assessing this reality and identifying what information and support is necessary. This study should also review options related to those individuals whose significant cognitive disabilities limit or prohibit them from making decisions about directing their care and treatment.”

As a result of this provision in the Bill, HHS conducted this study to: (1) determine the best way to promote the use of advance directives and advance care planning among competent adults as a way to specify their wishes about end-of-life care; and (2) address the needs of persons with disabilities with respect to advance directives. The study addressed five questions:

1. What does the literature say about the utility, feasibility, ethical issues, and success of implementing advance directives and/or advance care planning for a diverse array of patient populations and across health care settings?
2. What factors must be considered in promoting wider use of advance directives in vulnerable populations, such as the cognitively or physically disabled, and in guiding policy development regarding advance directives?

3. What are the key ethical issues regarding advance directives/advance care planning?
4. What are the key legal issues regarding wider promotion of advance directives/advance care planning?
5. How can advance directives be promoted more widely while still achieving more flexibility in practice?

LIST OF ACRONYMS

AAIDD	American Association on Intellectual and Developmental Disabilities
ADA	Americans with Disabilities Act
AND	allow natural death
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
CPR	cardiopulmonary resuscitation
DNR	do not resuscitate
DNAR	do not attempt resuscitation
DPAHC	durable power of attorney for health care
DPOA	durable power of attorney
EHR	electronic health record
G-tube	gastrostomy tube
HHS	U.S. Department of Health and Human Services
HIT	health information technology
ICU	intensive care unit
PCP	primary care physician
POLST	Physician Order for Life-Sustaining Treatment
PQRI	Physician Quality Reporting Initiative
PVS	persistent vegetative state

EXECUTIVE SUMMARY

Introduction

Advances in medical care and technology during the latter half of the 20th century have prolonged life expectancy in the United States. However, these same advances have blurred the boundary between life and death, challenging our expectations about how Americans could experience the end of life. Many individuals survive illnesses or traumatic injuries that would once have been fatal. For others, medical technology only serves to prolong survival in an unacceptable quality of life. Decisions concerning life and death issues affect a large and increasing number of individuals in the United States. In 2005, approximately 2.45 million Americans died.

There is substantial evidence that the treatment people would choose at the end of life commonly is different from the treatment they receive. Too often individuals receive more aggressive care than they desire. However, some individuals, particularly those with disabilities, find that the health care system and sometimes their families undervalue their quality of life, and as a result, withhold life-prolonging treatments that these patients want.

Individuals' preferences for where they wish to spend the end of their lives are also often not met. Most deaths occur in hospitals or nursing homes, but many people, when asked, say they would prefer to die at home. Thus, there is an apparent need to improve end-of-life care in the United States.

Advance care planning and the use of advance directives provide mechanisms for ensuring individual autonomy at the end of life. In 1991, Congress enacted the Patient Self-Determination Act to encourage competent adults to complete advance directives. Advance directives are legal tools that people can use to state their treatment preferences and to name a proxy decision maker (also known as the durable power of attorney for health care agent) in case they lose their capacity to make health care choices. In general, this Act did not reduce unwanted aggressive treatment at the end of life (or its associated costs), perhaps because advance directives are underused.

Congress requested that HHS conduct a study on the best way to promote the use of advance directives among adults as a means of specifying their wishes about end-of-life care. In addition, the report specifically looks at the needs of persons with disabilities with regard to advance care planning.

To address these issues a synthesis of the literature on end-of-life care, specifically focusing on advance directives and advance care planning was conducted. In addition, experts were invited to prepare three commissioned background papers addressing the specific topics of interest pertaining to advance directives and legal/ethical issues, people with disabilities and public engagement/social marketing efforts. Finally, HHS convened a two-day Roundtable discussion that included experts

in end-of-life care, advance directives and advance care planning, individuals with disabilities and other stakeholders nationwide to discuss the contents of the reports and to share their perspectives. This report summarizes the findings from these efforts.

This report, relying largely on the terminology of the Uniform Health Care Decisions Act and the Patient Self-Determination Act, defines an advance directive as a written health care directive and/or appointment of an agent, or a written refusal to appoint an agent or execute a directive. Advance care planning is defined as the process of discussing values and goals of care, determining and/or executing treatment directives and appointing a proxy decision maker. An agent is an individual designated in an advance directive while a proxy is a more general term indicating any designated substitute decision maker, including a guardian or conservator. A surrogate is a proxy by default; that is a person who, by default, becomes the decision maker for an individual who has no appointed proxy.

The report presents findings around five key areas: (1) Historical Perspectives on Advance Directives and Advance Care Planning; (2) Structure and Use of Advance Directives and Advance Care Planning; (3) Advance Directives and Advance Care Planning Among Persons with Disabilities; (4) Barriers to Advance Care Planning and Advance Directive Completion; (5) Interventions to promote Advance Care Planning and Advance Directive Completion.

(1) Historical Perspectives on Advance Directives and Advance Care Planning

Issues regarding end-of-life treatment decisions have long been the focus of debate among providers, policy makers and the public. Traditionally, decision making concerning end-of-life care was based on professional authority under the assumption that physicians acted in the patient's best interest. As life-saving medical technology advanced, individuals and families, in the context of the consumer rights movement, sought to reduce the use of life-sustaining treatments under certain circumstances. Beginning with the California Natural Death Act of 1976, the first attempts to refocus end-of-life care was with the living will. Both state and federal courts, as well as Congress, helped to lay the foundation for current approaches to end-of-life care decision making.

Well-publicized legal cases in the 1970s and 1980s focused the public's attention on withdrawing life-sustaining treatments from individuals who had lost decision making capacity. Two cases involving young women (Karen Ann Quinlan and Nancy Cruzan) challenged the laws regarding end-of-life decisions. These and other cases, as well as legislation at the state level, gave rise to a legal model of advance care planning that focused on legal or procedural protections of vulnerable individuals.

Despite the increase in states with laws governing living wills in the 1980s, recognition grew that these laws were not improving the application or restriction of life-sustaining medical care toward the end of life.

Considerable effort has been made to unify the various state laws governing advance directives and to promulgate the use of advance directives. The Patient Self-Determination Act was enacted by Congress in 1990 to encourage competent adults to complete advance directives. The Act required all health care facilities receiving Medicare or Medicaid reimbursement to ask patients whether they have advance directives, to provide information about advance directives, and to incorporate advance directives into the medical record. The Uniform Health Care Decisions Act of 1993 was promoted as a national model. In the late 1990s, state legislation focused on the issue of unwanted resuscitation of terminally ill patients at home or in hospice settings with development of explicit do not resuscitate (DNR) instructions for use outside the hospital. These concerns focused attention on advance directive portability and resulted in the creation of out-of-hospital DNR protocols in most states. Despite the development of tools to improve patient-centered decision making and care, methods of matching aggressiveness of care with prognosis and preferences toward the end of life and societal awareness of the need to participate in shared decision making concerning implementation of medical technology have not kept pace with the questions posed by currently available medical care.

(2) Structure and Use of Advance Directives and Advance Care Planning

Ideally advance directives are the product of advance care planning, an interactive process between the person/family and clinicians that helps to determine the course of a person's care and appoints a proxy to make decisions in the event of loss of capacity. A number of approaches have been suggested to facilitate advance care planning. They include detailed elicitation of a person's preferences for treatment under a variety of conditions, exploration of values, and assistance in identifying a proxy.

Historically, only 18-36 percent of the adult population has completed advance directives. Individuals with serious medical conditions, a group for whom advance directives are particularly relevant, have completed advance directives at only a slightly higher rate. In spite of widespread efforts to promote advance care planning and advance directives, most end-of-life decisions emerge from the interactions of individuals, family members, and doctors, without formal advance care planning processes or advance directive documents. Physicians are often unaware that their patients have completed an advance directive.

A number of factors are associated with greater desire for participation in advance care planning and advance directive completion. Older age, greater disease burden, certain conditions, white race, higher socioeconomic status, knowledge about advance directives or end-of-life treatment options, a positive attitude toward end-of-life

discussions, a long-standing relationship with a primary care physician (PCP), and whether a person's PCP has an advance directive are all related to greater likelihood of advance directive completion. For many individuals, such as those losing decision making capacity and for whom life-sustaining decisions will be needed, advance care planning and advance directive completion is particularly important. However, advance care planning and advance directive completion is uncommon even for persons with dementia, for whom incapacity develops most often while receiving medical care.

Advance directive use is higher in some care settings than in others. Hospitals, especially intensive care units (ICUs), would seem to be the most likely environment for advance directives to be applied. However, evidence suggests that is not the case, and that much care provided to patients in ICUs does not conform to their advance directives. Residents of nursing homes are most likely to have completed advance directives. Even when an advance directive exists, the frequent transfer of patients between care settings near the end of life makes portability a concern.

Advance directive completion rates also differ by race and ethnicity. Factors such as access to care and trust in clinicians and the healthcare system contribute to a willingness to engage in advance care planning and complete advance directives. Furthermore, currently structured advance directives are incompatible with some cultural beliefs and traditions. A more practical impediment for members of some cultural minorities is the language barrier between patients and their physicians.

Another major barrier to advance directive completion appears to be the reluctance of many physicians to discuss advance care planning with their patients. Reasons physicians cite include lack of time, lack of formal training in and knowledge of palliative care measures, belief that patients and families do not want to engage in such discussions, association of palliative care with death, and lack of belief that such discussions are needed.

For advance directives to be effective, they must reflect patient preferences. However, patient preferences may change considerably over the course of illness, suggesting that ongoing discussion is needed. Advance directives should be reviewed and modified to reflect the evolution of patient preferences. Proxies also may not understand or agree with patients' wishes. It is unclear whether increased communication between individuals and their proxies improves proxy understanding.

(3) Advance Directives and Advance Care Planning Among Persons with Disabilities

Contrary to what one would expect, considerable friction has developed between advocates for improved end-of-life care and the disability rights community. Disability advocates feel that they have been excluded from development of advance care planning policy.

This rift is related to two main factors: (1) difference in the kinds of cases focused on by promoters of advance care planning compared with the cases focused on by the disability community; and (2) divergence of views between people with disabilities and those who promote advance care planning about how illness and disability affect quality of life. While the underpinnings of advance care planning are accepted by all, some disability advocates fear that the able-bodied community undervalues the quality of life of many individuals with disability. This concern, coupled with the history of discrimination against people with disabilities, leads the disability community to feel disenfranchised in decisions and legislation concerning advance care planning and advance directives.

Some 20 percent of the United States population has a disability that interferes with daily life.

PHYSICAL DISABILITY

Although many studies have examined advance care planning and advance directive use among persons with a variety of physically disabling conditions, these studies have focused primarily on people with acquired disabilities, most due to chronic conditions, many acquired late in life. A number of organizations representing the interests of persons with physical disabilities have issued statements explicitly supporting the use of advance directives by individuals with disabilities. However, there is concern that some clinicians (and infrequently, some family members) of physically disabled individuals undervalue the quality of life of these individuals, and therefore will make decisions concerning life-sustaining care that contrast with what these individuals would want.

INTELLECTUAL DISABILITIES

Although the need for advance care planning and advance directives among intellectually disabled persons long has been recognized, little research has been conducted in this area. Legally, all individuals are presumed to have the capacity to make their own health care decisions unless declared incompetent. Nevertheless, adults with intellectual disabilities have traditionally been excluded from such decisions. Several organizations representing persons with intellectual disabilities have issued policy statements endorsing the rights of these individuals to participate in end-of-life decisions to the extent of their capacity. Recently, materials and resources have been developed to promote advance care planning among those with intellectual disabilities, including materials for consumers, providers, and policy makers. For those with limited or no capacity to participate in their own end-of-life decisions who do not have a specified proxy, a standard of “best respect” has been proposed, in which those most familiar with a patient’s life and values are convened in order to maximize the extent to which a substituted judgment can be brought to bear in making decisions for the individual. If decisions based on the person’s values are infeasible, this process brings together the views of these interested individuals in making a best interest decision.

(4) Barriers to Advance Care Planning and Advance Directive Completion

The low rate of engagement in advance care planning and completion of advance directives suggests that a significant proportion of patients do not fully understand their options concerning end-of-life care, or face other strong barriers to advance care planning. Knowledge of advance directives alone does not increase their use; a majority of patients who are aware of advance directives do not complete them. Numerous obstacles impede advance care planning and advance directive completion. Some have already been mentioned, including those related to patients and their families and the experience and training of health care providers regarding end-of-life decision making and care. Other barriers include the utility of advance directives, deficiencies intrinsic to the advance directive document, and the organization of the United States health care system. Furthermore, the discomfort of Americans with death and the marginalized place in society of dying creates obstacles to raising the topic of dying within families and in the clinical setting.

THE UTILITY OF ADVANCE DIRECTIVES

Many people think that advance directives are difficult to execute or feel they do not know enough to complete one. Another common perception is that even if completed, advance directives will not be followed by clinicians. Still others believe that formal advance directives are unnecessary because a close family member or care provider will know the person's wishes and ensure that they are carried out. Some individuals perceive that advance directives are important for others, but not for themselves. Some people have concerns about the flexibility and availability of advance directives; for example, as discussed earlier, an advance directive in a patient's hospital chart may not be accessible to care providers at the nursing home to which the patient is discharged. Others may fear that an advance directive completed in one state will not be respected in another state.

THE ADVANCE DIRECTIVE DOCUMENT

Another barrier to the completion of advance directives is that they provide guidance for only a limited and over-simplified set of hypothetical future medical circumstances. A related issue is that these hypothetical scenarios require a medical understanding well above that of the average person. Moreover, individuals are often less interested in specific treatment deliberations and more interested in the goals of care and maintaining the integrity of their personal values. Additionally, most advance directives emphasize the appointment of a specific agent; yet, some individuals have no one that they feel comfortable designating as their agent.

HEALTH CARE ORGANIZATION

An entire set of barriers to advance care planning and advance directive completion stems from a lack of accountability: no specific part of the traditional health care system is responsible for initiating the discussions needed for advance care planning. An added complication has been fractured continuity across the system and the lack of advance directive portability. Legislative efforts have been focused, largely ineffectively, on this problem, which might in the future be alleviated by universal adoption of health information technology (HIT). Finally, the design of the current Medicare hospice benefit limits availability of the full range of interventions needed or desired by many persons at the end of life.

(5) Interventions to Promote Advance Care Planning and Advance Directive Completion

A variety of interventions have been tested to promote engagement in advance care planning and completion of advance directives. Such interventions usually aim to change a particular aspect of an individual's health behavior or a physician's practice pattern. These interventions tend to be based on a model that envisions that behavior change is a process that depends on motivation, opportunity and ability to change.

The majority of interventions have been educational in nature and focused on patients and providers. A more broadly targeted form of education is social marketing, which focuses on particular populations. Recently, multi-component interventions have demonstrated promise.

EDUCATIONAL INTERVENTIONS

Two systematic reviews concluded that simple, single-component consumer education interventions designed to increase knowledge about advance directives were largely unsuccessful or only slightly successful in increasing advance directive completion or reducing the use of life-sustaining treatment. Studies of more-structured or facilitated advance care planning interventions with healthy, chronically ill, and seriously ill ambulatory geriatric patients and their caregivers demonstrated more promising, but still modest, results. Interventions aimed at improving physician communication skills have had mixed results. The limited effectiveness of educational efforts in improving use of advance directives may be hampered because these types of efforts are difficult to sustain and the populations on which they focus may be particularly resistant to change.

SOCIAL MARKETING INTERVENTIONS

Social marketing, the planning and implementation of programs designed to bring about social change using concepts from commercial marketing, has proven successful in achieving widespread behavioral change with respect to other health issues.

However, its application to promotion of advance directives is relatively new. While increased awareness has been demonstrated in some campaigns, efforts to date have not demonstrated changes in care or utilization.

MULTI-COMPONENT INTERVENTIONS

Interventions that used multi-component, longitudinal approaches have tended to be more successful. More intensive and community wide-interventions that involve collaborative advance care planning mechanisms have demonstrated more positive effects. An example is the Respecting Choices intervention that aimed at improving advance care planning and advance directive completion in the community of La Crosse, Wisconsin. The intervention, which included patient and provider education, and changes in documentation policies and practices in order to alter community expectations and provider standards of care, demonstrated a nearly six-fold increase in advance directive completion and a match between treatments received and dying patients' wishes.

OTHER INTERVENTIONS

Another approach to promoting advance directive completion is the development of advance directive/living will registries, both public and proprietary. Little is known about the effectiveness of these repositories. A related effort is that of placing a notice of an advance directive on driver's licenses. As of 2007, six states provided for driver's license notice of advance directives. The effect of this effort is yet to be evaluated.

LEGAL AND POLICY APPROACHES

The 1991 Patient Self-Determination Act was found not to increase the overall proportion of patients with an advance directive but increased the proportion of advance directives documented in patient medical records as well as the proportion of patients who reported having discussed advance care planning with their physicians. Subsequent to this Act there was a large increase in advance directive completion among nursing home residents. However, legislation, in general, has not been seen as a major influence in improving care toward the end of life. Legal and policy approaches appear to be undergoing a paradigm shift from focusing on the static act of advance directive completion to a process that involves ongoing communication, which emphasizes an iterative process over time to discern an individual's priorities, values, and care goals and to engage a proxy and others who will knowledgeably participate in the health care decision making.

The Physician Order for Life-Sustaining Treatment (POLST) program, begun in Oregon, is a mechanism to elicit patients' care preferences, translate them into a set of medical orders addressing several high probability interventions relevant to the patient's current condition, document them on a highly visible form, and ensure their portability across care settings. Studies demonstrate the effectiveness of this program in translating preferences into care across selected settings.

APPROACHES THAT USE HEALTH INFORMATION TECHNOLOGY

The increasing adoption of HIT in the form of the electronic health record (EHR) provides a mechanism to encourage advance care planning and advance directive completion and use. EHRs can automatically remind physicians to initiate advance care planning or advance directive completion, and also make it possible to share medical record documentation about preferences and proxies among providers within a system.

Thus far, only a few studies have assessed the capability of HIT to influence advance care planning and the use of advance directives. Two studies of electronic reminders found that physicians who received the reminders were more likely to initiate advance care planning discussions with patients, and the patients were more likely to complete an advance directive. Another study found that computerized forms improved understanding of inpatient resuscitation decisions. However, many unanswered questions remain regarding the capability of HIT to improve advance care planning.

Summary

Although advance directives and advance care planning can be important tools to assist those facing the end of life, the evidence suggests that end-of-life decision making in the United States is often poorly implemented.

- Patients often receive care that is inconsistent with their preferences.
- Care that is inconsistent with a patient's prognosis or preferences causes undue suffering and wastes resources.
- Most people do not complete an advance directive; when they do, the documents often do not affect care because they are limited in applicability and legalistic or simply physically inaccessible.
- The focus on preferences concerning life-sustaining treatments commonly proves to be too simplistic, and vague instructions are difficult to apply, often adding little to the way that proxies and clinicians approach care decisions.
- Preferences stated within advance directives (or poorly orchestrated advance care planning) are often at odds with clinical circumstances or can even impede effective decision making.

The research, with a few exceptions, demonstrates not only a lack of abundant evidence for the effect of interventions aimed at increasing advance care planning and advance directive completion but also a paucity of well-developed and meaningful measures of "successful" advance care planning and patient and family-centered care

(e.g., reduced emotional distress, satisfaction with end-of-life communication, clarification of values).

The failure of advance care planning and advance directive use and the very limited success of advance care planning/advance directive interventions suggests several important factors to be considered for improving end-of-life care. First, recognition is increasing that effective advance care planning and discernment of end-of-life care preferences is an ongoing process best accomplished through continuing communication among individuals, clinicians, and family members. Advance directives have been considered ends in themselves instead of encouraging substantive communication about clinical circumstances and medical possibilities and facilitating communication about how the individual's values would dictate choices, based on medical realities.

Second, some groups of people are even less likely than others to engage in advance care planning or to complete advance directives. These groups include: individuals who have been disenfranchised by or simply have less trust in the medical care system; some racial/ethnic groups whose cultural norms do not value autonomy, advance directive-appointed agents (proxies); and the most vulnerable (i.e., those with physical and intellectual disabilities).

Third, while formal legal remedies and simple educational interventions have been largely unsuccessful, newer multi-component interventions show that advance care planning and advance directives can be carried out successfully, at least in defined populations. Replication and extension from such interventions and implementation via HIT hold promise for improving care toward the end of life.

Promoting Advance Care Planning and Advance directive Completion: Opportunities for Improvement

The literature review, the commissioned papers and the Roundtable discussions point to several opportunities to enhance the effectiveness of advance care planning and advance directives. The foundation of these suggestions is the recognition of the importance of being inclusive of all persons' views and the essential goal of creating a community and professional expectation that end-of-life care without advance care planning (except in the case of sudden death) is unacceptable. The four broad areas are listed below.

ADVANCE CARE PLANNING MODELS

The focus of advance care planning must shift from a focus on formal written advance directive forms to a developmental discussion process. Support a variety of models that recognize advance care planning as fundamentally a process rather than a product. Specific attention could be given to models that translate into immediate

medical orders to guide specific treatment decisions such as the POLST program paradigm.^{43,216,246-247}

SOCIAL MARKETING/PUBLIC EDUCATION

Use social marketing and public education opportunities to affirm that any authentic expression of a person's wishes with respect to health care should be honored. Coordinated efforts involving relevant federal, state and local agencies could be used for: providing information in understanding the stages and impact of advance chronic disease and raising awareness of the importance of planning for care near the end of life. Aim advance care planning messages at the different developmental stages in a person's life. Provide the public options for means of carrying information on their person (such as a check-off box on driver's licenses). Consider developing a national information clearinghouse where consumers could receive state-specific information and consumer-friendly documents and publications.^{140,178,208,222}

HEALTH SYSTEM ISSUES

Use existing mechanisms to ensure that individual preferences are translated into care decisions and that these decisions are transmitted across care settings. Existing efforts might include: ensuring that EHR development include components for advance care planning;²⁵²⁻²⁵³ highlighting Medicare provisions in the Physician Quality Report Initiative (Measure #47 Advance Care Plan) and the initial preventive physical exam for Medicare (\$1861(ww) provides for "end-of-life planning"); promote individual preferences be translated into care decisions and transmitted across care settings through vehicles like the POLST program.^{43,216,246-247}

CONTINUING RESEARCH

Research continues to shed light on improving end-of-life and palliative care, and advance care planning for all people. Research on evaluating the process of goal elicitation, proxy designation and creative models implementing advance care planning could be encouraged. Continuing research on approaches and tools for assessing the parameters of decisional capacity among people with intellectual disabilities is especially important. Inclusion of persons with disabilities is an important component for any research protocol.

I. INTRODUCTION

Advances in medical care and technology during the latter half of the 20th century have prolonged life expectancy in the United States. However, these same advances have blurred the boundary between life and death, challenging our expectations about how Americans could experience the end of life. Chronic illnesses, including cancer, organ system failure (primarily heart, lung, liver and kidney failure), dementia, and stroke are the leading causes of death for Americans with less than 6 percent of deaths occurring in a truly sudden manner. Rather, most will live long, but with increasing disability.¹⁻³ However, many aspects of health care, and legal and social policy have yet to catch up with the reality of advanced medical technology. Studies indicate that for many dying persons, the end of life is associated with a substantial burden of suffering,⁴⁻⁷ and that negative health and financial consequences extend to family members and society.⁸⁻¹³

Decisions concerning life and death issues affect a large and increasing number of individuals in the United States. In 2005, approximately 2.45 million Americans died. This reflects an absolute increase in the number of deaths, although the age-adjusted mortality rate is decreasing.¹⁴ Over 80 percent of decedents in the United States are Medicare beneficiaries. About 5 percent of Medicare beneficiaries die each year and over one quarter of Medicare expenditures are for care in the final year of life.¹⁵ With the aging and growth of the United States population, the number of Medicare beneficiaries more than doubled between 1966 and 2004, and is projected to double in size again by 2030 to 78 million.¹⁶

There is evidence that the treatment people would want to receive if faced with the end of life is often different from the treatment actually received. In most cases, individuals receive more aggressive care than desired, prolonging life and sometimes suffering.⁴⁻⁶ However, persons whose quality of life is undervalued by family members or health care providers may not receive all the care they desire. Individuals in this latter category include those with physical or mental disabilities and others with special needs. Preferences for where individuals wish to spend the end of their lives also are often not met. Although most deaths occur in hospitals or nursing homes, many people, when asked, express the wish to die at home.¹⁷⁻¹⁸ Thus, there is a clear need in the United States to improve consideration of a person's preferences for end-of-life care.

In 1990, Congress enacted the Patient Self-Determination Act to encourage competent adults to complete advance directives. Advance directives provide a standardized process for ensuring an individual's autonomy at the end of life¹⁹⁻²¹ and are important legal tools that individuals can use to state their treatment preferences and to name a proxy decision maker. The vision of advance directives is that care for patients who cannot decide will be guided by treatment decisions made by physicians and families reflecting the decisions that the patient would have made for himself or herself. However, advance directives have not been widely used and they may not

reduce unwanted aggressive treatments or unnecessary burdens or costs at the end of life.

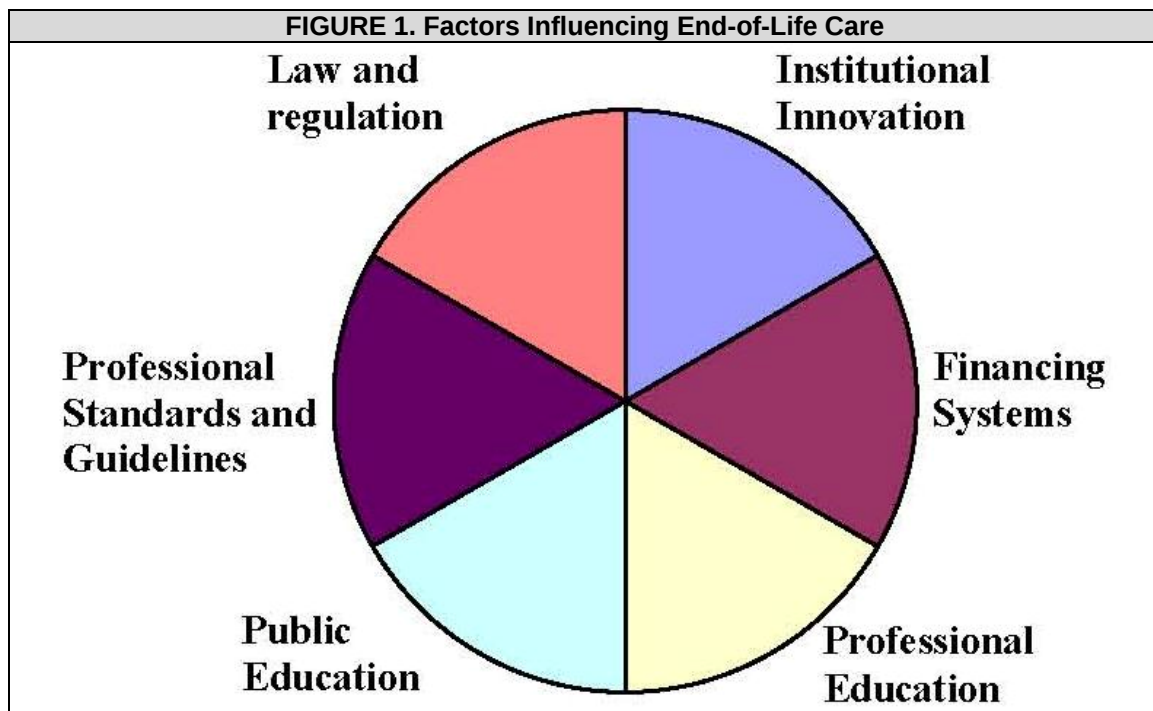
Advance Directives in the Context of Advance Care Planning and Other Factors that Influence End-of-Life Care

Since the mid-1970s, advance directives have become the central legal tool to formally communicate one's health care wishes. Advance directives began as simple requests to avoid medical treatment that would prolong life in undesirable conditions. However, they have evolved, becoming increasingly detailed and specific, often containing patient preferences for a variety of medical treatments in hypothetical medical scenarios.²²

The activities that should lead up to completion of an advance directive -- discussion of clinical circumstances and prognosis, understanding a person's goals in this clinical context, and outlining plans for future care to approximate those goals -- constitute the process of advance care planning, which is central to end-of-life decision making and advance directive completion. All too often, these discussions do not take place. In its most advanced form, advance care planning is a comprehensive, ongoing, and holistic communication pattern between a physician and his or her patient (or the patient's designated proxy) about values, treatment preferences, and goals of care.²³⁻²⁴ In this process, patients (and their families) receive information about a patient's clinical condition and consider the patient's values and goals in order to guide clinicians' choices. Essential to advance care planning is placing the patient's goals in the context of available treatment options. The interactive advance care planning process is revisited at critical junctures in the patient's care, when prognosis changes, or when patients and/or their proxies wish to do so.

The advance directive crystallizes many of the conclusions from the advance care planning process, including who will speak for the patient and how that individual will make the patient's values take form in clinical decisions. Thus, the advance directive might be seen as an integral piece of the larger process of advance care planning. This report adopts the view that advance directives must be considered within the broader context of advance care planning in evaluating the importance of advance directives for end-of-life care.

In addition to the laws and regulations surrounding advance directives, a constellation of factors influence the experience of dying in the United States. Other key variables include institutional innovation, the role of financing systems, professional and public education, and professional standards and guidelines (see Figure 1). All these operate in a larger framework that is defined by family, workplace, community life, and spirituality. Thus the effect of advance directives and advance care planning must be considered within the context of the many strong forces influencing end-of-life care [Figure from Sabatino, see Appendix C for details].



Advance Care Planning Models, the Disability Community, and Other Under-Represented Groups

The concerns, perspectives, and values of people with disabilities have been largely overlooked in the research, programs, and policies regarding advance directives, advance care planning and end-of-life care more generally. Other groups for which attention to devising practical advance care planning models has been inadequate include minority populations, individuals for whom English is not their primary language, and those with different cultural backgrounds. Advance care planning mechanisms dedicated to the needs of individuals within these groups are needed to facilitate access to necessary care and to ensure that preferences for care are recognized and honored.

This Report

Included in the 2006 appropriation Bill for the Departments of Labor, Health and Human Services, and Education was language that directed the Secretary of the U.S. Department of Health and Human Services (HHS) to consider how best to promote advance directives:

“The Committee believes that through the execution of advance directives, including living wills and durable powers of attorney for health care according to the laws of the State in which they reside, individuals can better protect their right to express their wishes about end-of-life care and have those wishes respected. The Committee directs the Secretary to conduct a study to determine the best

way to promote the use of advance directives among competent adults as a means of specifying their wishes about end of life care, and provide recommendations to Congress on changes to Federal law needed to ensure appropriate use of advance directives. As part of that study, the Department shall consider that decisions relating to advance directives are often made without adequate information about what it is like to live with a significant disability. The Committee intends that the study directly involve persons with disabilities, family members, disability experts and organizations in assessing this reality and identifying what information and support is necessary. This study should also review options related to those individuals whose significant cognitive disabilities limit or prohibit them from making decisions about directing their care and treatment."

As a result of this provision in the Bill, HHS was asked to conduct a study to: (1) determine the best way to promote the use of advance directives and advance care planning among competent adults as a way to specify their wishes about end-of-life care; and (2) address the needs of persons with disabilities with respect to advance directives. The study addressed five questions:

1. What does the literature say about the utility, feasibility, ethical issues, and success of implementing advance directives and/or advance care planning for a diverse array of patient populations and across health care settings?
2. What factors must be considered in promoting wider use of advance directives in vulnerable populations, such as the cognitively or physically disabled, and in guiding policy development regarding advance directives?
3. What are the key ethical issues regarding advance directives/advance care planning?
4. What are the key legal issues regarding wider promotion of advance directives/advance care planning?
5. How can advance directives be promoted more widely while still achieving more flexibility in practice?

To address the first question, a synthesis of the literature on end-of-life care, specifically focusing on advance directives and advance care planning was conducted. Three background papers to address questions 2, 4 and 5 were commissioned with national experts. When the papers were completed, HHS convened a Roundtable discussion that included experts in end-of-life care and advance care planning, persons with disabilities and other national stakeholders to discuss the contents of the reports and to share their perspectives. Details of the methods used are contained in Appendix A. This Report to Congress summarizes the study findings.

This report comprises eight chapters. Chapter II discusses the terminology used in the field and in the remainder of the report. Chapter III provides a historical perspective

and discusses ethical issues in advance care planning. Chapter IV discusses the structure and use of advance directives. Chapter V takes up the issue of advance care planning among persons with disabilities. Chapter VI discusses barriers to the completion of advance directives and to advance care planning. Chapter VII reviews interventions that have been implemented to promote advance care planning and advance directive use. Finally, Chapter VIII summarizes the state of the field and suggests future considerations for improving the use of advance care planning and advance directives. Details of the report's content can be found in the full literature review and commissioned papers, which are contained in Appendices B-E. Where appropriate, the reader is directed to Appendix papers for a more complete discussion of the topic.

II. TERMINOLOGY

Variations in the terminology used to discuss advance directives, advance care planning, and end-of-life care can lead to misunderstandings. Some variation stems from the assignment of special meanings to common terms used in the context of end-of-life care, and some variation is geographic. Each state regulates use of advance directives differently; statutes enacted at the state level often conflict in the definition of terms. In our discussion, we will use the following definitions, relying largely on the terminology of the Uniform Health Care Decisions Act²⁵ and the Patient Self-Determination Act.²⁶

Advance care planning: The process of discussing, determining and/or executing treatment directives, appointing a proxy decision maker, and periodically reviewing those plans.

Advance health care directive or advance directive: A written health care directive and/or appointment of an agent, or a written refusal to appoint an agent or execute a directive. Although the President's Council on Bioethics defines an advance directive as including verbal instructions,²⁷ we do not include verbal instructions in the definition because this usage of the term has not been the common one in the medical literature, and it is inconsistent with advance directive laws in some states.

Agent: An individual designated in a legal document known as a *power of attorney for health care* to make a health care decision for the individual granting the power; also referred to in some statutes as *durable power of attorney for health care* (DPAHC), attorney in fact, proxy, or health care representative.

Artificial nutrition and hydration: Artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving nutrients and fluids through a tube placed directly into the stomach (gastrostomy tube or G-tube), the upper intestine, or a vein.

Capacity to make a health care decision: An individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision. The term is frequently used interchangeably with competency but it is not the same. Competency is often distinguished as a legal status imposed by the court, although most states have dropped the term in favor of "legal incapacity."

Cardiopulmonary resuscitation (CPR): A group of treatments used when a person's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It usually consists of mouth-to-mouth breathing or other method of ventilation and pressing on the chest to cause blood to circulate. Electric shock and drugs also are used to restart or control the rhythm of the heart.

Do not resuscitate (DNR) order: A physician's order written in a patient's medical record indicating that health care providers should not attempt CPR in the event of cardiac or respiratory arrest. In some regions, this order may be transferable between medical venues. Also called a **No CPR** order, **DNAR** (do not attempt resuscitation) order, and an **AND** (allow natural death) order.

Guardian: A judicially appointed guardian or conservator having authority to make a health care decision for an individual.

Instructional health care directive (also referred to as a *living will*): A written directive describing preferences or goals for health care, or treatment preferences or willingness to tolerate health states, aimed at guiding future health care. In many states, the statutory directive is operative only when the individual lacks capacity and is diagnosed with a terminal condition, permanent unconsciousness, or other end-stage condition.

Individual instruction: An individual's direction concerning a health care decision. This may be written or verbal describing goals for health care, treatment preferences, or willingness to tolerate future health states.

Intubation: A shortened form of the term, "endotracheal intubation," the insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing.

Life-sustaining treatment: Medical procedures that replace or support an essential bodily function. Life-sustaining treatments include CPR, mechanical ventilation, artificial nutrition and hydration, dialysis, and certain other treatments.

Mechanical ventilation: Treatment in which a mechanical ventilator supports or replaces the function of the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). Mechanical ventilation often is used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists due to injuries to the upper spinal cord or a progressive neurological disease.

Minimally conscious state: A neurological state characterized by inconsistent but clearly discernible behavioral evidence of consciousness and distinguishable from coma and a vegetative state by documenting the presence of specific behavioral features not found in either of these conditions. Patients may evolve to the minimally conscious state from coma or a vegetative state after acute brain injury, or it may result from degenerative or congenital nervous system disorders. This condition is often transient but may exist as a permanent outcome.²⁸

Palliative care: Also called "comfort care," a comprehensive approach to treating serious illness that focuses on the physical, psychological, and spiritual needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving

suffering, controlling pain and symptoms, and enabling the patient to achieve maximum functional capacity. Respect for the patient's culture, beliefs, and values is an essential component.

Patient Self-Determination Act: An amendment to the Omnibus Budget Reconciliation Act of 1990, the law became effective December 1991 and requires most United States hospitals, nursing homes, hospice programs, home health agencies, and health maintenance organizations to give adult individuals, at the time of inpatient admission or enrollment, information about their rights under state laws governing advance directives, including: (1) the right to participate in and direct their own health care decisions; (2) the right to accept or refuse medical or surgical treatment; (3) the right to prepare an advance directive; and (4) information on the provider's policies governing use of these rights. The act prohibits institutions from discriminating against a patient who does not have an advance directive. The Patient Self-Determination Act further requires institutions to document patient information and provide ongoing community education on advance directives.

Persistent vegetative state (PVS): A vegetative state is a clinical condition of complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brainstem autonomic functions. The persistent vegetative state is a vegetative state present at one month after acute traumatic or non-traumatic brain injury, and present for at least one month in degenerative/metabolic disorders or developmental malformations. PVS can be diagnosed on clinical grounds with a high degree of medical certainty in most adult and pediatric patients after careful, repeated neurologic examinations by a physician competent in neurologic function assessment and diagnosis. A PVS patient becomes permanently vegetative when the diagnosis of irreversibility can be established with a high degree of clinical certainty (i.e., when the chance of regaining consciousness is considered exceedingly rare).²⁹

Proxy: Substitute decision maker.

Surrogate: Proxy by default; a person who, by default, becomes the proxy decision maker for an individual who has no appointed agent.

Withholding or withdrawing treatment: Forgoing or discontinuing life-sustaining measures.

III. HISTORICAL PERSPECTIVE AND ETHICAL ISSUES IN ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING

Before considering how advance care planning is conducted and advance directives are created and used, it is important to understand the history of advance care planning and advance directives in the United States and the ethical issues involved in decision making at the end of life.

The History of Advance Care Planning and Advance Directives in the United States

Issues regarding end-of-life treatment decisions have long been the focus of intense societal debate, as providers, medical ethicists, policy makers, legislators, and the public have considered essential questions concerning individual autonomy, quality of life, and withdrawal of life-sustaining treatments.³⁰ As far back as 1914, case law established the requirement to obtain a patient's consent for invasive medical procedures, based on the right of self-determination.¹⁹ Traditionally, health care ethics had largely been based on professional authority and beneficence: the assumption that physicians act in the patient's best interest. Thus, physicians made most patient care decisions and focused primarily on cure or comfort. However, as life-saving medical technology advanced (e.g., mechanical ventilators), the focus of care shifted to the more technically feasible pursuit of sustaining life.

By the 1960s, patient and consumer rights movements, as well as hospice care advocates, sought to free terminally ill patients from aggressive and often ineffective life-sustaining treatment through legal measures, with the development of the earliest form of advance directive, the "living will." Living wills were designed to maintain an individual's "voice" in medical decision making and empower individuals to dictate the terms of their own medical care at the end of life.^{21,31-37}

Both state and federal actions helped to lay the foundation for current approaches to end-of-life decision making, although the initial efforts to enact legislation in support of living wills were led by the states.

State Efforts

Beginning the first wave of state legislation was the 1976 passage of the Natural Death Act in California, the first law to give legal force to living wills; soon thereafter, a number of states passed legislation authorizing instructional health care directives or "living wills."

At about the same time, several legal cases played a pivotal role in publicizing end-of-life issues and advancing the need for better advance care planning.³⁸ The first was the case of Karen Ann Quinlan, who in 1975 at the age of 21 was left in a PVS after a cardiac arrest. In 1976, the New Jersey Supreme Court granted her parents the right to withdraw the mechanical ventilator, maintaining that a person's constitutional right to privacy outweighed the state's interest in preserving life.³⁴ Medical ethicists interpreted the court's decision as also encompassing a patient's decision to decline medical treatment under particular circumstances.³⁹

Between 1975 and the 1990's, about 90 reported trial and appellate cases, mostly in state court, addressed the so-called "right to die." Most affirmed the right of a competent person to refuse life-sustaining treatment with very few exceptions, most notably where the welfare of a child dependant of the patient was at stake. Where the patient lacked decisional capacity, most decisions also affirmed that the right was exercisable by an appropriate proxy under some variation of standards described as "substituted judgment" and "best interest."

The case of Nancy Cruzan further challenged the laws regarding end-of-life decision making when a person's wishes were uncertain. In 1983, at the age of 32, Ms. Cruzan was involved in an auto accident that left her in a PVS. Years later, her parents concluded that their daughter would not want to be kept alive in her current state, but the Missouri hospital caring for her refused to comply with their wishes. Local courts mandated that the hospital withdraw life-sustaining treatment, but the state supreme court reversed the decision on the grounds that Ms. Cruzan's parents lacked the right to terminate her life in the absence of "clear and convincing evidence" that this choice reflected her wishes. Although the United States Supreme Court affirmed her right to refuse life-sustaining treatment, they held that the state had the right to impose what it referred to as a "procedural safeguard" in the form of a requirement of clear and convincing evidence that this was her expressed wish.

The Quinlan and Cruzan cases gave rise to a legal model of advance care planning that emphasized the extension of autonomous wishes to guide decisions when individuals could not speak for themselves, and also instituted legal or procedural protections for vulnerable individuals and populations from decisions that might not be made in their best interest [see Appendix C].

As the number of state living will laws increased throughout the early 1980s, their shortcomings became apparent: there was no power of enforcement if the maker lost the capacity to speak for him or herself, and these documents covered only a small number of decisions relating to life support, often not addressing the myriad issues that arose in the care of persons toward the end of life. This recognition led to efforts to apply the concept of the durable power of attorney (DPOA) to health care, resulting in a wave of durable power legislation from the mid-1980s to early 1990s. These laws reflected an attempted balancing between private, flexible decision making and possible abuses of the power.

Additional state legislation arose from a growing awareness that decisions about aggressiveness of care needed to transition among the many settings visited by patients toward the end of life. Nearly one-third of Americans receive care in three or more settings (home, hospital, nursing home) in their last months of life.⁴⁰⁻⁴⁴ The proportion of Americans with chronic illness dying in the hospital has declined from 64 percent in 1989 to 49 percent in 2001⁴⁵ while the proportion of people who died at home and in nursing homes increased. Decisions about resuscitation and other treatments needed to transition with patients. The resulting legislation allowed for the use of out-of-hospital DNR orders [see Appendix C].

Another thread of state legislation, which really began in the 1960s and continues today, involves decision making in the absence of advance directives. Such efforts were stimulated by the awareness that few people had advance directives in place and the fact that state law frequently failed to identify who was authorized to make decisions for patients in the event of decisional incapacity. As a result of these efforts, 40 states now have default surrogate/family consent laws.⁴⁶

A final wave of state effort involved the merging and clarification of the separate state health care decision laws governing living wills and advance directives and the appointment of proxies, driven in part by the population's confusion surrounding advance directives and their lack of use. New Jersey enacted the first combined statute in 1991, merging the living will (called an "instruction directive") and the DPAHC (called "a proxy directive") into a single "advance directive for health care."⁴⁷ By the beginning of 2000, 16 states had comprehensive or combined advance directive statutes that, at a minimum, combined living wills and proxies in the same law.⁴⁸ By 2008, the number had increased to 26. The primary model is the Uniform Health Care Decisions Act, promoted as a national model in 1993.⁴⁹ The Act establishes very simple rules for recognizing almost any kind of written or oral statement as an advance directive. Even unwitnessed, signed documents are valid under the Uniform Act. However, states that have adopted the Uniform Act have almost always added more procedural formalities to the Act's baseline requirements.⁵⁰

Federal Efforts

Health care decision making has traditionally been considered a province of state law, not federal. Federal law generally defers to state law in this area, including the selection and authority of chosen and default surrogates. Yet the Federal Government weighed in as the issues took form in the 1980s with the convening of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Among other issues, the Commission addressed the difficult topics of defining death, patients with permanent loss of consciousness, the withholding and withdrawing of life-sustaining treatment, and the importance of advance directives.³⁹

In 1991, Congress enacted the Patient Self-Determination Act,²⁶ requiring health care facilities receiving Medicare and Medicaid funds to ask patients whether they had

an advance directive; to provide written information on rights to make treatment decisions to adult patients on admission or enrollment to a health care facility; and to make information about advance directive forms available to patients who did not have one. The Patient Self-Determination Act was designed to acknowledge a patient's right to either refuse or accept medical treatment, empowering patients by safeguarding their autonomy and preserving self-determination, protecting patients against maltreatment, and fostering communication between patients and their physicians.^{19,32,51-52} Also included in the Patient Self-Determination Act was a mandate directing HHS to conduct a public awareness campaign about advance directives. Finally, the military advance directive provision enacted in 1996 states that advance directives executed by members of the armed forces are "exempt from any requirement of form, substance, formality, or recording that is provided for advance medical directives under the laws of a state."⁵³

Ethical Issues

Self-determination of the individual is a core value in Western bioethics and provides the ethical framework supporting advance directives and medical decision making by proxies. Advance directives are a tool to implement self-determination and autonomy when people have lost the capacity to voice their preferences. Ideally advance directives are the product of advance care planning, the interactive process between an individual/family and clinicians that helps to determine the course of care for the individual. This process can lead to the documentation of preferences in the form of an advance directive and may also result in establishing a proxy for future decision making.

Problems that arise in end-of-life decision making almost always result from a breakdown in communication between the individual or family and clinicians or mistrust or disagreement between family members and clinical staff regarding the patient's prognosis. Tension arises when the clinician's beneficent responsibility to the patient and professional responsibility to strive for the goals of Medicine conflicts with families' (or rarely patients') desire for care that is more aggressive than what providers think is warranted. This friction most often occurs in the setting of poor communication. However, it may also be precipitated if families desire life-sustaining treatment for family members in compromised health states (e.g., PVS) when providers find the treatment inappropriate. These conflicts may also be the result of philosophical or religious differences.

Providers may respond to this situation by attempting to reduce the influence of patient/family preferences on care decisions. Under these circumstances, the lack of social consensus about the goals of medicine and the definition of futile care may hamper advance care planning.

IV. STRUCTURE AND USE OF ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING

Ideally, the advance care planning process results in creation of an advance directive. However, only a minority of the adult population has completed an advance directive. Instead most end-of-life decisions emerge from informal interactions of patients, families and doctors, without completion of formal advance directive documents. Because decisions are often made late, the bulk of end-of-life decisions are made without direction from the patient.

Only a Small Percentage of Adults Complete Advance Care Planning and Advance Directives

In spite of widespread efforts to promote advance care planning and the use of advance directives (see Chapter VII), studies find that only 18-36 percent of Americans have completed an advance directive.^{19,21,32-33,45,51,54-61} Individuals with serious medical conditions, a group for whom advance directives are particularly relevant, have completed advance directives at only a slightly higher rate than the general population.⁶²⁻⁶³ Fewer than half of severely or terminally ill patients had an advance directive in their medical record, and among individuals with chronic illnesses, only one in three completed an advance directive.⁶⁴⁻⁶⁶ In addition, studies suggest that two-thirds of physicians whose patients had advance directives were unaware of the existence of those documents.⁶⁴

Factors associated with participation in advance care planning and advance directive completion include older age, greater disease burden, type and acuity of condition, White race, higher socioeconomic status, knowledge about advance directives or end-of-life treatment options, a positive attitude toward end-of-life discussions, a long-standing relationship with a primary care physician, and whether the patient's primary care physician has an advance directive.^{15,55,67-69} Patients with cancer were far more likely to complete advance directives than severely ill patients with some other condition.⁵⁵

Advance directives are not always effective in directing care. Having an advance directive that includes preferences does not necessarily translate into documentation of preferences in the medical record, and advance directives often are not considered applicable until the patient is incapacitated or "absolutely, hopelessly ill." Most providers and families wait until the patient is dying before preferences are translated into care plans, which means that palliative approaches often are initiated too late. Proxies are often absent or too overwrought to make decisions. In their absence, providers' predictions of individual's care preferences may not reflect the treatments that these individuals prefer. Furthermore, proxies often predict *more* aggressive treatment preferences than patients would want.⁵⁵

Advance Directive Use Differs by Care Setting

Advance care planning prevalence varies according to the clinical environment. Because of the high concentration of acutely and chronically ill individuals in hospitals, one might expect advance directive completion to be highest in that setting and especially in intensive care settings. However, use of advance directives in such medical settings appears to be modest. Advance care planning and advance directives seem to have their weakest effects in ICUs, where the most aggressive care is provided, and where the majority of deaths will involve resuscitation or withholding or withdrawing life-sustaining treatment.⁷⁰ In addition to patient selection, reasons for this include difficulty in determining patients' preferences and values due to the patients' conditions and complexity of care; enthusiasm for technology and the overriding cultural belief that cure is possible (instead of pressure to balance the burdens and benefits of treatments); confusion regarding appropriate care for dying patients; poor communication; influence of family wishes on patient wishes; and disagreement among family members regarding use of life-sustaining treatment.⁷¹

Advance care planning and advance directive use would also be expected to be high in nursing homes, which house some 1.6 million residents nationwide.⁷² Long-stay nursing home residents are often frail and cognitively and physically impaired, and many die within six months of admission.⁷³⁻⁷⁴ Decisions about re-hospitalization for more intensive treatment and use of feeding tubes tend to overshadow consideration of palliative measures.⁷⁵⁻⁸⁵

Nevertheless, advance directives are completed in nursing homes more often than in other care settings.⁸⁶⁻⁸⁷ A systematic review of end-of-life care in nursing homes (1995-2002) found that the number of nursing home residents with discussions of treatment wishes increased after the Patient Self-Determination Act.⁸⁸ While studies conflict regarding the actual proportion of nursing home residents with some form of advance directive and the proportion of advance directives that include information on treatment preferences,⁸⁸⁻⁹¹ it appears that over one-third of nursing home residents have an advance directive.⁴⁵ A higher rate of advance directive completion in nursing homes is associated with urban location, higher staff/resident ratio, not-for-profit status, and fewer Medicaid patients.⁹²⁻⁹³

Adherence to individuals' advance directives at the end of life appears to be complicated by frequent transfer across care sites: 25-30 percent of dying patients are cared for in three or more settings (home, hospital, nursing home) in the last months of life.⁴⁰⁻⁴⁴ Dying patients, in particular, are at risk for transitions across settings.⁹⁴ Advance directives completed in one care setting may not be transferred to a new setting with the patient. As a result, palliative care may be interrupted by fits of aggressive care that is counter to a person's wishes.⁹⁵

Knowledge and Use of Advance Directives Vary by Race, Ethnicity and Culture

There has been considerable attention to knowledge and attitudes about and completion of advance directives and advance care planning among racial or ethnic minority groups in the United States. Studies tend to find that some race/ethnicity groups, such as African Americans, are less likely to engage in advance care planning or complete advance directives, but results across studies are mixed. A systematic review of studies of end-of-life decision making found that non-White groups had less knowledge about advance directives and were less likely than Whites to support the use of advance directives.⁹⁶ Limited uptake of advance directives in the African American community has been attributed to a number of factors, including distrust of the health care system and unfavorable reactions to the concept of advance directives based on spiritual concerns.⁹⁷

Some studies suggest that advance directives are incompatible with the beliefs and traditions of Hispanic, Asian, and Native American cultures, which hold that the stress of addressing end-of-life issues should be avoided and that it is the responsibility of families to protect affected individuals from such knowledge and the attendant decisions.^{51,97-99} A practical factor limiting the engagement of some minority groups with the advance directive process is a language barrier between patients and physicians.

Use of Advance Directives among Individuals with Cognitive Impairment (including Dementia)

People with dementia would appear to be a group for who advance care planning and advance directives would be particularly useful. Dementia is due to a prevalent group of conditions often diagnosed before patients have fully lost decision making ability. These patients will lose capacity to make subsequent decisions concerning life-sustaining interventions that will be needed over the course of their illness. About 5 percent of those age 71-79 have evidence of dementia; the figure rises to 37 percent of those 90 years and older.¹⁰⁰ In long-term care facilities, the prevalence of dementia among residents approaches 50 percent.¹⁰¹

An interview study of cognitively normal men and women age 65 years and older revealed that most would not want CPR, mechanical ventilation or artificial nutrition or hydration if they developed milder forms of dementia and 95 percent or more said that they would not want these treatments in the setting of severe dementia.¹⁰² Alzheimer's Association guidelines urge clinicians to elicit preferences from persons with cognitive impairment and their families and to carry out advance care planning, including completion of an advance directive with consideration of the use of artificial feeding, mechanical ventilators, CPR and other invasive treatments.¹⁰³⁻¹⁰⁴ There is empirical evidence from physician surveys that clinicians may choose different life-sustaining treatments for demented patients than patients and families may desire¹⁰⁵ and that

physicians might be unwilling to follow some preferences in withholding and withdrawing life-sustaining treatment from persons with dementia.¹⁰⁶

Data from the 1990s estimated that only about 15 percent of patients with dementia had some kind of advance directive.^{93,107} More recent data suggest an advance directive prevalence of 36-60 percent^{45,89,108} among nursing home residents -- most of whom are cognitively impaired; nursing home residents with dementia are more likely to have advance directives than nursing home patients without dementia.⁸⁹⁻⁹⁰ Yet, many persons with dementia are too cognitively impaired at the time of nursing home admission to complete an advance directive. Questions about whether persons with dementia are capable to complete advance directives may hinder the advance care planning process, as do concerns about frightening persons with dementia, many of whom have tendencies toward paranoia.¹⁰⁹

A small study of older persons with dementia found that those who were incapable of completing an advance directive were more likely than others to choose life-sustaining interventions, suggesting that those with cognitive impairments are more likely to express wishes to engage in treatment interventions that persons without cognitive impairment would avoid.¹¹⁰ While the preferences expressed in the prior study were likely obtained from individuals incapable of guiding care, many patients with early and moderate dementia can participate in advance care planning and do complete advance directives.¹¹¹ Such patients can be identified¹¹² but the process requires special expertise.

Even in nursing facilities, residents with advanced dementia often receive aggressive care. A study of institutionalized older persons with advanced dementia in New York in the mid-1990s using the Minimum Data Set showed that only 1 percent were designated as having a life expectancy of less than six months, although 71 percent died within that period. Before death, only 55 percent of demented residents had a DNR order, 1 percent had a do-not-hospitalize order, and non-palliative interventions were common.¹¹³ A nationwide analysis of severely cognitively impaired nursing home residents found that more than one-third had feeding tubes, and that nursing homes' fiscal and organizational features were related to having a feeding tube.¹¹⁴

An ethnographic study of care provided to residents in nursing facilities with dementia suggested that physicians' decisions about life-sustaining treatments were influenced more by the clinical course of the illness and presumed quality of life than by advance care planning.¹¹⁵ This is particularly important for persons with dementia with respect to artificial nutrition and hydration: at the end stage of dementia, many people become unable to eat. However, providing nutrition through tubes or parenteral means seldom improves nutritional status, prevents aspiration pneumonia, minimizes suffering, or improves functional status.¹¹⁶ Interventions in the hospital have reduced placement of tubes to feed people with advanced dementia.¹¹⁷

Although the need for persons with dementia to engage in advance care planning and complete an advance directive is clear, there are theoretical concerns about applying advance care planning completed when an individual had decision making ability to that person when he/she has severe dementia. It has been argued that the person who made the decisions is *different* from the individual whom those decisions affect and that these decisions (as opposed to choices applied to a permanently comatose individual) might harm the incompetent patient.¹¹⁸ This line of reasoning suggests that instead of pre-specified preferences, a best interest standard should be applied in such cases.¹¹⁹ However, there is agreement among experts and guidelines that a person's autonomy should carry forward to guide medical decisions made in the future and that such decisions reflect a better method of making decisions than a generic standard.^{104,120-121} A study of proxy decision making using hypothetical scenarios showed that predictions were particularly inaccurate for scenarios in which patients had dementia, suggesting the need for discussions while individuals retain decision making capacity.¹²²

Preferences May Change

For advance directives to be effective, they must reflect what a person would want done for them in the future. However, preferences may change over the course of an illness. Thus, preferences need to be revisited, and advance directives should be updated to reflect changes.¹²³⁻¹²⁴ Changes in preferences can be associated with how information is presented,¹²⁵⁻¹²⁷ specific illness events, disease progression, demographic and clinical characteristics, and end-of-life discussions.^{51,78,123,128-132}

Although advance directives do not necessarily depend on a proxy's ability to know an individual's preferences, one of the general objectives of advance directives and advance care planning is to help surrogates better understand how a person's goals and preferences would guide medical decision making toward the end of life. However, observational studies suggest that families rarely know enough about illnesses and treatments to make "informed decisions," and find it hard to "imagine ahead" to anticipate how patient preferences might change over time.

The accuracy of proxy decision makers in predicting a person's care preferences varies considerably.^{52,78} A systematic review of studies examining the correspondence between patient and proxy decisions for terminally ill patients, hospital outpatients, and non-institutionalized, chronically ill elders showed that proxies correctly predicted end-of-life treatment preferences with 68 percent accuracy.¹²² Whether discussion about care preferences improves proxy accuracy is controversial. Concerns about stability of preferences have pushed advance care planning toward a focus on goals of care, but this requires skilled clinicians who can dedicate the necessary time.

Patient-Provider Communication Affects Use of Advance Care Planning and Advance Directives

Although advance directives can be a mechanism to stimulate patient-provider discussion of end-of-life care, broaching the topic of advance care planning and discussing surrogate decision makers requires spending time on anticipatory planning. However, research reveals that physicians typically spend less than 5 percent of a visit discussing treatment and planning.¹³³

Treatment preferences are influenced by three types of knowledge: treatment burden, treatment outcome, and the likelihood of the outcome,¹³⁴⁻¹³⁵ although the relative importance of each of these factors may vary with an individual's characteristics.¹³⁶ These findings suggest that patient-centered approaches to advance care planning should incorporate consideration of both potential treatment outcomes and associated burdens. However, many physicians are reluctant to initiate advance care planning discussions. Reasons include lack of time, lack of formal training in and knowledge of palliative care approaches, belief that patients and families do not want to engage in such discussions, association of palliative care with death, and believing that such discussions are not needed.¹³⁷⁻¹⁴¹

Not all people are willing to engage in advance care planning, and they and their families express varying views on the optimal timing, content, and context for such discussions. For many individuals, contemplation and discussion of death is difficult, and this is an impediment to advance care planning and medical decisions.¹⁴² Discussion is facilitated by: (1) comfort with the health care provider; (2) feeling that the provider shows compassion and respect; (3) having the provider clarify how much detail patients and families want; (4) negotiating who should participate in such discussions; and (5) involvement of the primary care provider.¹⁴³

In practice, patients, families and clinicians often inadvertently collude to avoid mentioning death, dying, or planning for the end of life.¹⁴⁴⁻¹⁴⁵ As a result, providers frequently misunderstand a patient's end-of-life preferences^{67,71,146} and at times do not to follow instructions specified in an advance directive.¹⁴⁷ Even when advance directive discussions take place, studies suggest that clinicians do an inadequate job of communicating with patients and families or providing relevant information in understandable form.¹⁴⁸ In addition, patients and families recall only a fraction of the information physicians transmit, and the evidence suggests that some patients do not want detailed information.¹⁴⁸⁻¹⁵³

V. ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING AMONG PERSONS WITH DISABILITIES

The concerns, perspectives, and values of people with disabilities have often been overlooked in the research, programs, and policies regarding advance directives, advance care planning, and end-of-life care more generally. However, people with disabilities need to plan for times of serious illness. Advance care planning is necessary to ensure that people with disabilities have access to necessary care, services and supports, and are included in the societal dialogue about care near the end of life.

The position statement of the American Association on Intellectual and Developmental Disabilities (AAIDD) on *Caring at the End of Life* lists among its core principles those underlying advance care planning. However, considerable friction has developed between advocates for improved end-of-life care and the disability rights community, and disability advocates feel that they have been excluded from development of advance care planning policy.

There are two major sources of conflict between these communities: (1) difference in the kinds of cases focused on by promoters of advance care planning compared with the cases focused on by the disability community; and (2) the divergence of views between disabled individuals and those who promote advance care planning about how illness and disability affect quality of life.⁸¹

Disability rights activists have raised concerns that advance directives and withdrawal of life-sustaining care, when combined with “biased and inaccurate views of many disabled patients’ quality of life held by the non-disabled,” encourage less aggressive care and withdrawal of life-sustaining treatment, permitting persons with disability to die earlier than warranted.¹⁵⁴⁻¹⁵⁶ Many factors contribute to these concerns, including the history of social and economic persecution of persons with disability,¹⁵⁷ lack of attention to improving the conditions for or accommodating persons with disabilities so that they can maximize their quality of life,¹⁵⁸⁻¹⁵⁹ and explicit and implicit coercion of disabled individuals.^{158,160}

Perhaps the strongest concern is that many in the general population view the routine quality of life of some disabled persons as less preferable than death or at least not worth using life-sustaining treatment to achieve or preserve.¹⁶¹ Some in the disability community view certain diagnoses given to extremely compromised health states (e.g., PVS and the minimally conscious state) as untenable because they do not believe them to be clinically accurate, and find it unacceptable for clinicians to withhold or withdraw life-sustaining treatment from persons in such states.^{154,162} Others argue that the legal mechanisms of decision making inadequately account for the views of disabled persons by creating decision making mechanisms that inadequately protect autonomy and that are ill-suited to the perspectives of many persons with disabilities.¹⁶³ The disability community also raises concerns that biases about quality of life translate

into reduced clinician efforts to maximize patients' quality of life, which in a self-fulfilling manner causes patients to accept less aggressive care.⁸¹

Who are Persons with Disabilities?

Disability has no uniform definition. According to the Americans with Disabilities Act of 1990 (ADA), a person with a disability "has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment."¹⁶⁴⁻¹⁶⁵ Major life activities include seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, or working. Examples of disability so defined include a seizure disorder, paralysis, HIV infection, substantial hearing or visual impairment, cognitive developmental disability, or a specific learning disability.¹⁶⁵ Based on this definition, 20 percent of the United States population -- more than 50 million people -- has a disabling condition that interferes with life activities. About 19 percent of the non-institutionalized population in the United States have a disability, and almost half of these people have a severe disability.¹⁶⁶

Although a variety of definitions of disability are used, this section focuses on the non-elderly disabled (Cognitive disability acquired due to aging-related illness is addressed in Chapter IV.) using the following definitions:

- "Intellectual disability" refers to people with cognitive limitations, primarily resulting from mental retardation, at varying degrees of severity (commonly diagnosed through IQ measures as mild, moderate, severe, or profound), with the onset at birth or early in life.
- "Physical disability" refers to individuals with irreversible, serious orthopedic and mobility impairments, such as spinal cord injury, paralysis, cerebral palsy, multiple sclerosis, muscular dystrophy, and congenital conditions.

How Would Advance Care Planning be Different if the Disabled Community were Engaged from the Start?

The framework for advance care planning applies equally to all. All individuals have legal rights and personal interests in preparing advance directives and engaging in planning conversations with family members, significant others, and health care professionals. Although these rights may be constrained by diminished decision making capacity, even those with limited capacity should be encouraged to participate in advance care planning to the extent their abilities allow. However, many in the disability community feel that their advance care planning needs and preferences are not addressed in the general discussion and interventions undertaken in the United States to enhance care toward the end of life.

In fact, there is a wealth of understanding that could be imparted by people with disabilities about quality of life issues. People with disabilities offer a unique perspective in refuting overly pessimistic perceptions of quality of life, and misconceptions about life satisfaction. The tools that people with disabilities use to lead their lives (ventilators, feeding tubes, wheel chairs, etc.) are simply methods of accomplishing the tasks that let people continue to do the things they want. If the “voice” of the disability community was stronger in the initial development of advance directives, the focus would not be about treatments and modalities and treatment choices, but about what do people want in their lives as they are dying. What are their values and goals? What capacities do they want to maintain? Disability advocates believe they can help inform discussions about what makes a life meaningful and what assistance is available to sustain activities that matter to the individual. [For more detail see the remarks of Adrienne Asch, Ph.D., in Appendix G.]

Advance Directives and Advance Care Planning for People with Physical Disabilities

Although many studies have examined advance care planning and advance directive use among people with a variety of physically disabling conditions, these studies have focused primarily on people with acquired disabilities, and most had chronic conditions, many acquired near the end of life. Those who acquire disability prior to age 65 differ in important ways from those who acquire disability as a result of the aging process.

Although the literature on advance care planning for people with physical disabilities is limited, disability theorists, advocates, and organizations have addressed the issue of autonomy in end-of-life decision making, mainly in the context of assisted suicide and surrogate decision making. Two small qualitative studies suggest that individuals with physical disabilities are particularly concerned about retaining self-determination.¹⁶⁷⁻¹⁶⁸ Some research suggests that physician attitudes regarding disability may predict whether or not life-sustaining care is provided. For example, a study of ventilator use for people with severe neuromuscular disease, such as Duchenne’s muscular dystrophy and amyotrophic lateral sclerosis, found that the likelihood of receiving mechanical ventilation and similar therapeutic interventions depended on clinic directors’ estimation of their patients’ life satisfaction rather than on informed decisions made by the patients.¹⁶⁹ However, the complexity of such decisions is emphasized by a survey of people with physical disabilities that found wide variation in their views toward withholding life-sustaining treatment and the kind of life that is worth living.¹⁷⁰

A number of organizations representing the interests of people with physical disabilities have issued statements explicitly supporting the use of advance directives by people with disabilities. Other disability organizations have taken a more direct approach in support of advance care planning. For example, the Multiple Sclerosis Association of America published a detailed article for consumers explaining the

importance of advance directives as part of life planning, with instructions and resources for their completion.¹⁷¹

Despite the keen level of concern about respectful care among people with physical disabilities, little is known about preferences for end-of-life care among those with physical disabilities acquired during the developmental or working years. In two small surveys, concern for autonomy and self-determination in end-of-life decisions were voiced frequently as were concerns about prolonged suffering and premature termination of lives thought to be of lesser quality [see Appendix D for more detail].^{161,167}

Advance Care Planning for People with Intellectual Disabilities

Although the need for advance care planning and advance directives among intellectually disabled persons has been recognized for over a decade,¹⁷² little empirical research has been conducted in this area. Two small studies, one in the United States and one in the Netherlands, found that only a tiny fraction of intellectually disabled persons had completed advance directives, end-of-life care issues are seldom raised, and substantial barriers exist to integrating such discussions with other services.¹⁷³⁻¹⁷⁴

Legally, all individuals are presumed to have the capacity to make their own health care decisions unless declared incompetent. Nevertheless, adults with intellectual disabilities have traditionally been excluded from such decisions.¹⁷² Recent trends in life expectancy and in views of autonomy and medical decision making among those with intellectual disabilities are challenging this exclusion. However, advance care planning among people with intellectual disabilities is complicated by the wide range of cognitive limitations and needs for assistance. The overarching goal is to balance protection from harm with a person's right to self-determination. Most individuals with mild or moderate cognitive impairment are able to understand and participate in decision making regarding their treatment, although performance decreased with increasing complexity of decision making.¹⁷⁵⁻¹⁷⁶ In addition, the capacity needed to name a trusted person as health care proxy may be significantly less than that needed to direct treatment decisions or preferences.

Several organizations representing persons with intellectual disabilities have issued policy statements endorsing the rights of these individuals to participate in end-of-life decisions to the extent of their capacity and defining appropriate end-of-life care options and conditions for treatment withdrawal. These organizations include AAIDD in its *Position Statement on Caring at the End of Life*¹⁵⁴ and the ARC of the United States (formerly Association for Retarded Citizens).¹⁷⁷

Materials and resources have also been developed to promote advance care planning among those with intellectual disabilities. The resources include online and printed materials for consumers, providers, and policy makers.¹⁷⁸⁻¹⁷⁹ Advocates have promoted various ways to help identify and document preferences for end-of-life care, including "person-centered planning,"¹⁸⁰ "assisted capacity,"¹⁷² and the methods used

by Project BRIDGE.¹⁸¹ Person-centered planning can help people identify their wishes, such as who they would like to have present, how they would like to be made comfortable, what kinds of treatment they wish to have or not have, and what religious or spiritual support they want. For those with limited or no capacity to participate in their own end-of-life decisions and no proxy decision maker, a standard of “best respect” has been proposed, which involves convening those most familiar with a patient’s life and values to elicit input into treatment decisions.¹⁸² However a number challenges remain. For example, parents and guardians of persons with intellectual disabilities who have sought to complete advance directives on their behalf found these had no legal standing.

As with persons with physical disability, little is known about the end-of-life care preferences of persons whose intellectual disability was acquired early in life [see Appendix D for more detail].

Advance Care Planning for People with Psychiatric Disability

Whether persons with mental illness have the capacity to engage in advance care planning and complete an advance directive is controversial. Several studies of persons with serious mental illness found that a substantial number of such individuals are capable of completing advance directives,¹⁸³⁻¹⁸⁶ and that facilitated discussion can enhance the capacity to do so.¹⁸⁷ However, one study found that only 10 percent of inpatients at a state mental health facility were fully capable of completing an advance directive.¹⁸⁸

There is particular concern that those with mood disorders might express preferences about life-sustaining treatments that they would not express if unaffected by the disorder. A study assessing persons undergoing inpatient treatment for major depression concluded that decisions to forgo life-sustaining treatment among persons with severe depression were likely to change with treatment and improvement in the depression.¹⁸⁹

The advance directive for psychiatric care is another way to extend autonomous wishes into future periods of incapacity. These written documents are intended to help individuals with psychiatric disability to identify preferences concerning psychiatric care at a future time when they are unable to make decisions for themselves. These documents also permit specification of a proxy to make such decisions. Although few individuals have completed psychiatric advance directives, surveys show that many persons with serious mental illness would like to complete one.^{184,190} Limited evaluation of the outcome of psychiatric advance directives suggests only a minor effect on care received.¹⁹¹ The National Resource Center on Psychiatric Advance Directives reports that 25 states currently have psychiatric advance directive laws.¹⁹²

VI. BARRIERS TO ADVANCE CARE PLANNING AND ADVANCE DIRECTIVE COMPLETION

Although evidence suggests that people with serious illness are willing to participate in advance care planning,¹⁴⁰ the low rate of engagement in advance care planning and completion of advance directives suggests that people do not fully understand their opportunities to influence end-of-life care,¹⁹³ or the existence of barriers to advance care planning. Knowledge of advance directives alone does not increase their use.^{51,194} In fact, numerous obstacles impede advance care planning and advance directive completion. Barriers include those intrinsic to the advance directive document and its regulation, those related to patients and their families, ineffective application of advance directives, the experience and training of health care providers regarding end-of-life decision making and care, and the organization of the U.S. health care system. Some of these barriers might be minimized or eliminated by legal, social, or clinical interventions (see Chapter VII and Chapter VIII), but others may be more intractable. Below we describe some of these barriers.

Barriers Related to the Design and Purpose of Advance Directives

Advance directives are legally-constructed, static documents containing a variety of limitations that constrain their effectiveness [see Appendix C]. Most states have non-mandatory statutory forms that provide guidance for only a limited set of future medical possibilities, rather than the full spectrum of eventualities.⁷⁷ Furthermore, preferences for life-sustaining treatment appear to depend largely on the context in which they are made.⁷⁹ Advance directives are designed to elicit specific care preferences in response to specific clinical scenarios, but patients might more easily describe values and goals for care.³² Finally, a few states require use of specific forms or adherence to rules concerning language (for example, the terms used to describe various types of health impairment) and detailed witnessing requirements; these requirements may act as impediments to the completion of advance directives.

Barriers Related to Patients and Their Families

Perhaps one of the greatest obstacles to widespread engagement in advance care planning is reluctance to broach the issue of “death” and end-of-life planning. Some people have limited desire to exert specific control over end-of-life medical decision making, preferring instead to leave specific decisions about future care to their families or physicians.^{32,80,143} People with serious illness may have difficulty predicting their future treatment preferences.⁵¹ As discussed in Chapter IV, preferences are often unstable, changing with time, aging, and changes in health status.^{51,128-132} In addition, many people think that advance directives are difficult to execute or feel they do not know enough about advance directives to complete one.^{193,195-196}

When an individual does not appoint a proxy, decision making may default to a surrogate (such as the closest kin), who may not be knowledgeable about the person's preferences and goals for care. Even when a discussion occurs, those speaking for the person without capacity may have difficulty translating the discussed preferences into clinical decisions.^{78,128} For some people, the capacity to participate meaningfully in advance care planning and advance directive completion may be lost before discussion is ever initiated.¹⁹⁷ Alternatively, as discussed in Chapter V, some individuals may never have had the capacity to participate in advance care planning, and current laws impede decision making by interested family and others. Additional impediments include views that formal advance directives are unnecessary because a close family member or care provider will know the person's wishes and see that they are carried out. Some individuals perceive that advance directives are important for others, but not for themselves.⁵¹ Finally, inadequate provisions exist to guide decision making for individuals who do not have capacity or interested others to help make decisions.

Barriers Related to Ineffective Application of Advance Directives

Even if completed, advance directives may not affect end-of-life care as expected. Specified preferences may be overruled by physicians' opinions concerning the clinical appropriateness of life-sustaining treatment⁸¹⁻⁸³ or the advance directive may not be specific enough to guide care decisions concerning aggressive medical treatment. For these reasons, experts suggest that advance directives and advance care planning focus on goals for care,⁸⁴ but these discussions are complex. Several studies have shown that some people prefer proxies to make decisions based on what they think is best rather than on what the patients would have wanted at the end of life.^{32,198}

Some barriers to completion of advance directives involve concerns about their utility and flexibility. For example, as discussed earlier, an advance directive in a patient's hospital chart may not be accessible to providers at the nursing home to which the patient is discharged.

Barriers Related to Clinical Experience and Training

Clinicians contribute to the reluctance or failure of many of their patients to engage in advance care planning or to complete an advance directive. Limited prognostic capability makes it difficult to pinpoint when to initiate end-of-life care conversations and complicates the content of these discussions. Similarly, clinicians cannot predict when patients are approaching loss of decision making capability and are not good at judging capacity.¹⁹⁹

As discussed in Chapter IV, many physicians lack (or believe they lack) sufficient formal training and experience in communicating with their patients about end-of-life issues.^{123-127,193-199} In addition, communication, particularly about illness and death, is

steeped in culture, and clinicians are not always aware of or sensitive to the different communication preferences of patients from different racial/ethnic/cultural backgrounds. For example, in some Hispanic and Asian cultures, family members actively protect the terminally ill from knowledge of their condition; in some Asian cultures, family members, rather than the patient, may be responsible for end-of-life care decisions.^{97,99} Communication problems may be exacerbated between health care providers and patients who do not share a common language.

Barriers Related to Organization of the Health Care System

An entire set of barriers to advance care planning arises from the fact that responsibility for initiating the discussions needed for advance care planning does not fall to any specific part of the traditional health care system. Thus, no single entity is held accountable for preparation for or the care of people at the end of life. The substantial time commitment required for advance care planning is not an expectation of any particular venue of care and no mechanism exists to compensate clinicians to carry out the task. Only for patients cared for in hospice is planning ahead and palliation a clear expectation -- and by then advance care planning is largely complete.

The fragmentation of the health care system is another barrier to optimal end-of-life care. Patients often change venue of care toward the end of life, causing discontinuity among providers. Even in the context of the Medicare hospice benefit, which aims to provide holistic palliative care toward the end of life, limits on the availability of the full range of interventions needed or desired by many persons at the end of life contribute to late enrollment or less than optimal care [see Appendix E].

VII. INTERVENTIONS TO PROMOTE ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING

A number of approaches have been suggested to facilitate advance care planning. They include detailed elicitation of individuals' preferences for treatment under a variety of conditions, exploration of people's values, and dialog to help people identify proxies. Ideally, an effective advance care planning process follows the following steps:

- The individual, informed by advance care planning conversations with his/her provider, considers specifying a proxy and defining the goals of care.
- Optimally, the proxy participates in the advance care planning process.
- The advance directive is completed specifying a proxy and describing the proxy's authority and scope of discretion, the goals for treatment, and any other factors important to the individual.
- The advance directive is *available* to clinicians and the proxy.
- The person's preferences or goals, as reflected in the advance directive, are accurately interpreted and applied to the clinical situation.
- The proxy and provider *honor* the person's choices in fashioning and implementing the care plan.
- Advance care planning is reassessed periodically.

A variety of interventions, generally aimed at the processes enumerated above, have been tested to promote engagement in advance care planning and completion of advance directives. Most of the interventions have been educational in nature, targeted to patients and providers.¹⁹ Other efforts have involved social marketing and public engagement strategies, legal or policy interventions, and interventions utilizing the capabilities of health information technology to change provider behavior.

In this chapter, a conceptual framework for analyzing the elements of health behavior change and targeting individuals at various stages of willingness and ability to change is briefly described. Interventions aimed at each stage of this model are then reviewed.

Models of Behavior Change

All interventions designed to promote advance care planning and the use of advance directives aim to change a particular aspect of a person's health behavior

and/or a physician's practice pattern. The interventions tend to be based on a model of behavioral change as a process that depends on motivation, opportunity and ability, and fashions interventions to target those stages. A conceptual framework has been developed that places educational, legal, and social marketing approaches along a continuum that targets groups from the least to the most resistant to change.²⁰⁰

The first element of the framework is **motivation to change behavior**. Individuals will be motivated to change when they believe they will benefit personally from the change. Thus, a person with serious illness might be more motivated to change than a healthy person and might be open to less-coercive interventions such as education or a social marketing campaign. In this framework, a legal or policy intervention would be appropriate only when individuals cannot be motivated to act voluntarily.

The second element of the framework is **opportunity to change**. A lack of opportunity might occur when an individual is motivated to change behavior but faces environmental barriers to change. For example, a provider may want to spend time with patients to engage in advance care planning but cannot be reimbursed for a complete, perhaps multi-session, discussion. Change at the organization level would be needed to compensate a provider. Educational efforts alone would be insufficient to stimulate change, but marketing efforts or legal/policy interventions might be successful.

The third element of the conceptual framework is the **ability to behave differently**. Many things might compete with one's ability to change behavior. Education might be effective in providing the skills to behave differently, but social marketing efforts can reinforce education by highlighting the benefit for changing behavior. Legislative or policy intervention may help someone who lacks motivation and particularly those without ability or opportunity.

Educational Efforts and Single Modality Interventions to Promote Advance Care Planning and Advance Directive Completion

Efforts to promote advance care planning and the use of advance directives through education have been the subject of two systematic reviews.^{55,201} Both reviews concluded that simple, single-component consumer education interventions designed to increase knowledge were largely unsuccessful or only slightly successful in increasing completion of advance directives or reducing the use of life-sustaining treatments. Studies of more-structured or facilitated advance care planning interventions with healthy, chronically ill, and seriously ill ambulatory geriatric patients and their caregivers demonstrated more promising, but still modest, results.^{55,202} The limited effectiveness of educational efforts alone in improving the use of advance directives may be attributed to at least two factors. One is that these types of efforts are difficult to sustain long enough to see permanent behavioral change. Another factor is that the population to whom they are targeted may be particularly resistant to change.^{19,55}

More successful were interventions that targeted seriously ill patients and/or that used multi-component, longitudinal approaches -- that is, interventions that combined educational materials with repeated treatment preference discussions during clinical encounters and that increased the likelihood that documentation of patient wishes would be available when needed. For example, a comprehensive, multi-faceted education intervention, the *Let Me Decide* program, increased advance directive completion rates by 45 percent.²⁰¹ Numerous other intervention models have also been described.^{113,130-143,203-207}

Interventions designed to improve physician communication skills have had mixed results. Two reviews of the literature on “breaking bad news” and methods for conducting advance directive discussions with healthy and ill elderly found that end-of-life discussions contributed to increased patient satisfaction with patient/provider communication without evidence of negative psychological effects.²⁰³⁻²⁰⁴ However, these interventions induced no changes in clinical care.

In the nursing home setting, several interventions to improve decision making and care at the end of life have used trained facilitators (e.g., nurses or social workers) and structured advance directive discussion guides to improve concordance between nursing home residents’ stated preferences and the care received. More-detailed and meaningful advance directives in nursing homes were achieved with more focused discussion.^{73,205-207}

Intensive Multi-Component Interventions to Promote Advance Care Planning and Advance Directive Completion

More intensive, multi-component community wide-interventions that involve collaborative advance care planning mechanisms have demonstrated more positive results.^{78,140,208-211} As noted by Dr. Joan Teno, an expert in end-of-life care, “In principle, increasing the use of advance directives is important. However, they are not sufficient....Improving the quality of end-of-life care requires moving from a focus on single interventions, such as the living will, to a focus on public policies that use multi-faceted interventions...”⁹⁰ Several interventions have demonstrated that multi-faceted interventions that include policy perspectives change clinician and community behavior:

- **Respecting Choices.** First implemented community wide in La Crosse, Wisconsin, it has since been implemented in other populations, including non-institutionalized, chronically ill elderly.²⁰⁸⁻²¹⁰ Several interventions were incorporated into the routine standard of care across the La Crosse community: training and continuing education for local advance directive educators; placement of advance directive educators at all health care organizations; standard policies and practices for documenting, maintaining, and using advance directives; and community wide education through wide dissemination of educational materials. All of the program’s patient education materials were developed locally with input from the target audiences.

An evaluation conducted two years after the implementation of the Respecting Choices program found that 85 percent of eligible patients had completed an advance directive, and treatment matched patients' wishes as stated in the advance directive for 98 percent of all deaths.²⁰⁸ A baseline community wide survey had revealed that about 15 percent of the population had completed an advance directive before the program was implemented. Pilot testing of a modified version of the program on a sample of adults with chronic illness showed increased congruence in decision making between patients and caregivers for future medical treatment.²⁰⁹⁻²¹⁰

- **CHOICES.** Home-based advance care planning for chronically ill patients also decreases aggressive treatment and allows more patients to die at home.²¹²⁻²¹³ One example is CHOICES,²¹³ a program designed to bridge the gap between home health and hospice for Medicare managed care enrollees in Northern California. The intervention included both physician and patient/family education components and demonstrated that intervention patients had increased hospice length of stay, spent less time in a hospital, and more often died at home.
- **POLST.** Numerous studies have assessed Physician's Orders for Life-Sustaining Treatment (POLST), a structured model of decision making designed to promote care planning and portability across treatment settings and to ensure continuity of care. The POLST intervention (which in some venues includes regulatory or legislative changes, see below) resulted in orders regarding CPR being universally followed in nursing homes and honored across settings. Residents with a POLST received more comfort care and were rarely transferred to a hospital for unwanted life-sustaining treatments.^{43,214-216} POLST is not a strategy for replacing advance directives, but rather to translate a patient's wishes into actionable, highly visible medical orders relevant to the patient's current condition.

The Role of Social Marketing and Public Engagement Strategies

Social marketing is "the planning and implementation of programs designed to bring about social change using concepts from commercial marketing."²¹⁷ It is less well studied as an approach to advance directive promotion than some of the others described here, but it has proved successful in achieving widespread behavioral change with respect to other health issues. On the continuum of behavioral change described earlier, social marketing rests somewhere between education and legislative/policy action. Social marketing applies concepts from commercial marketing to influence the *voluntary* behavior of target audiences. A successful social marketing campaign recognizes the target audience and tailors the key elements of product, price, place, and promotion to audience characteristics.

Behavior change may involve accepting a new behavior, rejecting a potential behavior, modifying a current behavior, or abandoning an old behavior. The social marketing message would target a person's current behavior and encourage a different behavior, if necessary. Many different social marketing messages may be introduced to produce behavior change that influences the same outcome. Of course, how one develops the message and where it is placed will be dependent on the stated goals of a marketing campaign.

Target audiences may be diverse and may not respond equally to a single campaign. Thus, social marketing campaigns may segment populations by population characteristics (e.g., age, gender, race, physical condition), geographic region, and behavioral characteristics (such as readiness for change).²¹⁸⁻²¹⁹ The overall target audience for a single behavioral change may comprise multiple audience segments. Limited resources may make it impossible to reach all of the target audience. Therefore, decisions must be made about where the biggest "return on investment" might be found among the various segments of the target audience and the effort focused on those targets.

Social Marketing and Advance Directives

Some of the largest and most prominent social marketing efforts to promote advance directive completion were programs for which entire communities were the target population.

Last Acts was a Robert Wood Johnson-funded national communications campaign begun in 1995 that involved a coalition of over 1,000 national health and consumer groups. The campaign's primary goals were: (1) to improve communication and decision making for consumers; (2) to change the culture in health care institutions; and (3) to change American culture and attitudes around death and dying.²²⁰ Task forces were established to develop plans, and communications agencies were hired to manage the task forces' efforts and work with the public and policy audiences. Among the successes of the Last Acts campaign was developing the first report card to rate each state on eight key indices of the availability and quality of end-of-life care.²²¹

The campaign also made progress in raising professional awareness of end-of-life care issues. Coalition members viewed Last Acts as an important information resource and benefited from the campaign by feeling part of a larger community and receiving support to do their work on the local level.

Nevertheless, Last Acts faced several challenges. An evaluation found that the campaign did not have a visible public presence and thus was perceived to benefit primarily the coalition partners, rather than its primary audience, the public.²²⁰ In addition, how the intervention affected advance care planning/advance directive behavior was never specifically evaluated. Funding ended in 2005, before the campaign could fully address these shortcomings.

The Missoula Demonstration Project was established in 1996 as an effort to better understand the experience of dying and to demonstrate the value of a community-based approach to medical and psychosocial support to improve the quality of life for dying patients. This project took a social marketing perspective in planning and pursuing community change with respect to advance care planning/advance directive and end-of-life care more generally.

The project began with a series of studies to assess the needs of the community, both patients and providers. This *community profile* characterized how people die in Missoula, how they view death and dying, how people experience medical and social care at the end of life, and how people in Missoula care for and support one another during dying and grief.²²² The project convened a number of task forces comprising providers and lay community members to determine the types of interventions to be implemented, guided by the community profile. The profile enabled a segmented and targeted approach to behavior change around advance directives, advance care planning, and end-of-life care. The effect of this project awaits formal evaluation.

“Kokua Mau” (Hawaiian for “continuous care”) is an example of a statewide social marketing campaign to improve end-of-life care.²²³ It was a community-state partnership funded by the Robert Wood Johnson Foundation, other foundations, the state of Hawaii, health care provider organizations, and insurance companies. The behavior change approach of Kokua Mau involved numerous tactics targeted to different populations: health care providers, faith communities, policy makers, and the general public. Included in these efforts were policy analysis and communication of policy recommendations to key policy makers, developing new courses for health care professionals and providing training in various care settings, offering training in faith communities and supporting churches to expand outreach programs, maintaining a speakers’ bureau, and producing informational materials to be disseminated widely across the state.

A 2005 evaluation found that campaign efforts stimulated growth of community coalitions to serve various communities and target populations.²²³ The campaign reached over 17,000 people through direct education efforts and almost 850,000 through print, radio, television, and electronic public service announcements and stories. Between 1998 and 2000, advance directive completion rates increased modestly (from 29 percent to 32 percent), and hospice admissions increased substantially (by 20 percent between 1999 and 2001), but the proportion of the population dying in a hospital did not change.

Advance Directive/Living Will Registries are public or proprietary databases that electronically store advance directives and make them available to patients and providers when they are needed. Data on the number of persons who register are unavailable or unreported by the host sites; thus few attempts have been made to test their effectiveness. A partial list of sites is provided in Table 1.

TABLE 1. Advance Directive/Living Will Directories		
Title	Site	Description
U.S. Living Will Registry (USLWR)	http://uslivingwillregistry.com	A commercial advance directive online registry offered for a one-time fee if registration is done directly with USLWR or free through member health care providers.
LifeLedger	http://www.elderissues.com/index.cfm	A private company based in Florida, created by a care management organization, offering subscription online storage of personal medical information and advance directives.
Parting Wishes	http://www.partingwishes.com	A privately held company in Ontario, Canada, providing a subscription online service for document creation, storage, and retrieval of advance directives, funeral plans, and other legal documents.
My Health Directive	http://myhealthdirective.com/index.jsp	A privately owned company (Healthcare Directive Partners LLC), affiliated with the Five Wishes advance directive and offering storage and retrieval services on a subscription basis.
DocuBank	http://www.docubank.com/advance_choice/advance_choice.asp	A service of Advance Choice, Inc., providing electronic document storage and emergency access to health care documents on a subscription basis.
America Living Will Registry	http://www.alwr.com	A privately held company based in Florida that provides electronic document storage and access for an initial fee and annual service fee.
FullCircle Registry	http://fullcicleregistry.com	A privately held company based in Kentucky that provides electronic document storage and access, as well as maintenance of personal medical information, for an annual fee.
GIFTS Advance Directive Registry	http://www.giftsdirectives.com/Articles_pps/Giftsbooklet.pdf	An information management service for health care facilities providing electronic storage and retrieval of advance directives and other medical information.
MedicAlert Foundation	http://www.medicalert.com/Main/AdvanceDirectives.aspx	A not-for-profit, membership organization founded in 1956, providing a repository of health information accessible to patients and providers and known for its "Medic Alert" products.
Microsoft Healthvault	https://health.live.com/results.aspx?q+Advance%20Directives	Microsoft, a large for-profit publicly-traded company, has created a method of storing one's medical information including an advance directive.

A related effort is placing a notice of an advance directive on driver's licenses, just as drivers can indicate their intent to be an organ donor. As of 2007, at least six states provide for driver's license notice of advance directives.²²⁴⁻²²⁹ These efforts have not yet been evaluated.

Legal and Policy Interventions to Promote Advance Directive Completion and Advance Care Planning

In Chapter III, we described the evolution and implications of state and federal laws aimed at encouraging individuals to complete advance directives. Advance directive legislation is undergoing a paradigm shift, evolving from a legal transactional approach to a communications approach [see Appendix C].

The Transactional Approach

The traditional transactional approach focused on formally creating and implementing legal tools to direct or delegate health care decisions in advance of incapacity. In this way, advance directives are similar to other legal conveyances of interest in property or contracts. Because these transactions often are executed without the advice of legal counsel, detailed standardized formalities are relied on to ensure that they are executed properly, voluntarily, and in an informed manner (similar to giving informed consent). However, the very nature of deciding how one wants to be treated in some future hypothetical situation is far more subjective than making a contemporaneous choice and providing informed consent to treatment for a condition about which one has been fully informed.²³⁰⁻²³¹

States have devised a number of legal formalities (including standardized forms, required disclosures, prescribed language for authorizing particular wishes, requirements regarding witnesses, and limitations on who may serve as an agent/proxy) to enhance the recognition of and compliance with advance directives. However, abundant evidence suggests that the legal approach to advance care planning may impede rather than promote effective advance care planning.²³² Furthermore, the transactional approach raises what should be unnecessary concerns about the portability of advance directives across state lines.²³³ Although 42 states expressly recognized the validity of out-of-state advance directives in 2007, states may not interpret an advance directive exactly according to the laws of the state where it was executed.

The Communications Approach

In response to the shortcomings of the transactional approach, a paradigm is emerging: a communications approach, derived from the concept of advance care planning. As described above, advance care planning is broader and less legally focused than advance directive completion; it is intended to elucidate a care plan based on a person's preferences and beliefs. Advance care planning emphasizes an iterative

process that, over time, will identify an individual's priorities, values, and care goals. Advance care planning also aims to engage a proxy and others who will knowledgeably participate in the health care decision making process when the individual loses capacity. The growing prominence of this approach is reflected in the incremental steps toward simplification of state law, particularly with respect to language. The 1993 Uniform Health Care Decisions Act is a model for such simplification [see Appendix C].

Simplification of the Advance Directive Process

That simplification is occurring is evidenced by three measures. One measure of simplification is the number of states that have merged all or some of their multiple laws dealing with health care decision making into single comprehensive statutes. For example, until 2000, West Virginia had four separate laws dealing with substitute decision making -- a Living Will Act, a Medical Power of Attorney Act, a Health Care Surrogate Act (for decision making when there is no agent or living will), and a Do-Not-Resuscitate Act. In 2000, it merged and simplified its disparate existing laws into a comprehensive Health Care Decisions Act. At the beginning of 1998, some 13 states had combined advance directive statutes, that at a minimum, addressed living wills and proxies in a single law.²³⁴ By the beginning of 2008, that number had doubled to 26 states.²³³ Second, when *Five Wishes*, the only model advance directive form marketed nationally, was first released in 1978, it met the statutory requirements in only 33 states and the District of Columbia. By 2007, this number had increased to 40, enabled by the trend toward simplification of state law.²³⁵⁻²³⁶ Third, although no state recognized oral individual instructions prior to 1993, there is a trend toward increasing statutory recognition of oral individual instructions that are documented in medical records. Fourteen states now recognize them, most following the Uniform Health Care Decisions Act approach.^{50,237}

Evaluations of Legal Interventions to Promote Advance Directive Completion

A number of studies have attempted to assess the effects of legislation, both state and federal, designed to promote advance directive completion.

The Federal Patient Self-Determination Act of 1991 has been evaluated in several studies with respect to its effect on advance directive use and end-of-life care. The SUPPORT trial, which serendipitously instituted its intervention contemporaneously with the Patient Self-Determination Act, found that the number of patients with an advance directive did not increase after passage of the Act. However, the proportion of those advance directives documented in patient medical records increased significantly, and the percent of patients who reported having had advance care planning discussions with physicians also increased.²³⁸ Another study confirmed the increase in advance care planning after Patient Self-Determination Act implementation.²³⁹ Although advance directive completion did not increase at two academic medical centers,^{55,240} the Patient Self-Determination Act appears to have increased advance directive completion in nursing homes.^{86-87,93,241-242}

Evaluation of state advance directive laws performed since the implementation of Patient Self-Determination Act shows considerable differences as well as deficits in these laws. One evaluation found that state advance directive laws were too restrictive and suggested relaxing requirements for witnessing or notarizing advance directives completed during a physician visit, permitting oral specification of health care proxies, and encouraging discussions.²⁴³ Another evaluation found that advance directives did not empower health care proxies or guide their decision making.²⁴⁴

Legislation has also targeted the disconnect between advance directives and the medical orders that result (or do not result) from them. This issue was first addressed in connection with preferences not to be resuscitated of terminally ill patients living in the community. Out-of-hospital DNR orders translated such preferences into doctor's orders recognizable by emergency medical services personnel and other health care providers. Most states now have laws permitting out-of-hospital DNR orders (47 as of 2007).²⁴⁵ The POLST protocol builds on this model by addressing a larger range of decisions than just those about resuscitation. The protocol requires eliciting patient preferences about high-probability medical interventions for seriously chronically ill patients. The medical interventions addressed may include resuscitation, hospitalization, artificial nutrition and hydration, ventilation, and antibiotics. Patients, proxies or advance directives may serve as the source of direction. Patient wishes are then translated into physician's orders on a highly visible, standard form that travels with the patient across care settings and are reviewed as the patient's condition changes. Authority to follow the stated preferences is ensured by state law or other regulation. More than a dozen states, several after statewide legislation, use or plan to begin using this mechanism of eliciting preferences and protecting them during care transitions. Studies have found the form to be effective in promoting compliance with patient care preferences,^{43,216,246} and a survey of emergency medical technicians found that most were aware of the form and found it useful.²⁴⁷

Health Information Technology Interventions to Increase Advance Directive Completion and Advance Care Planning

Although health care providers have a central role in promoting advance directive completion and advance care planning, clinicians do not typically discuss advance care planning during routine visits or even during acute health crises. Over the past two decades, the practice of placing reminders in patient charts to prompt health care providers to perform particular procedures has demonstrated success in improving performance of a number of underperformed care processes. Recent efforts to increase the efficiency of health care by incorporating information include the computerization of medical records. Electronic Health Records (EHRs) incorporate many features, including documentation of all of a patient's care, regardless of the provider.²⁴⁸ EHRs enable physician reminders to be added automatically to charts, as appropriate, and also enable a patient's medical chart to be shared among all providers with access to the system. Thus, health information technology (HIT) has the potential both to

stimulate advance care planning and advance directive completion and to increase the accessibility of a patient's advance directive across care sites.

Promoting the use of HIT is a major health initiative of DHHS. The implementation of interoperable HIT is a national priority as well.

The Use of HIT to Promote Advance Care Planning, Advance Directive Completion, and Advance Directive Accessibility

Thus far, only a small number of studies have assessed the capability of HIT and EHR systems to influence advance care planning and the use of advance directives: two studies used computer-generated reminders to prompt physicians to discuss advance directive completion with patients, and one examined how the EHR affected common understanding of life-sustaining treatment orders.

Computer-generated physician reminders were tested in the outpatient general medicine practice of a teaching hospital.²⁵⁰ Physicians were randomized to receive reminders to elicit care preferences from patients, reminders to elicit proxy directives, both reminders, or none. Among patients with no previous advance directive, physicians who received both reminders were significantly more likely than physicians receiving one or zero reminders to initiate discussions of advance directives and their patients were significantly more likely to complete an advance directive.

Physician reminders were also one component of a multi-faceted intervention to promote advance care planning discussion at a group of Veterans' Health Administration outpatient clinics.²⁵¹ The intervention, which included chart reminder flags, a booklet sent to intervention patients in advance of their appointment, a postcard reminder to review the booklet, and a meeting with a social worker to answer questions or complete an advance directive, resulted in a nearly two-fold increase in advance care planning discussions (64 percent vs. 38 percent), advance care planning chart notes (47 percent vs. 24 percent) and living wills (48 percent vs. 23 percent), compared with a control group of patients; however it was not possible to assess the relative role of provider reminders in the intervention's success.

The role of HIT in improving understanding of the contents of a procedure-specific DNR order form was assessed in a hospital ICU.²⁵² The study compared concordance of understanding patients' DNR status among physicians, nurses, and medical residents, using three methods of charting, in sequential phases: unstructured sheets of the type clinicians use to record their notes and orders, structured procedure-specific DNR order forms, and DNR order forms presented in a computer-based record system. Concordance as well as error-detection improved significantly when the computer-generated forms were used.

These early studies suggest that EHRs may improve advance care planning, advance directive completion, and the documentation of DNR orders. However, unanswered questions remain regarding the capability of HIT to improve advance care planning, including whether it will improve the accessibility of advance directives and the clinical impact of these interventions. It also remains to be confirmed whether clinician reminders alone increase the frequency of physician-initiated advance directive discussions with patients or whether multi-component interventions (such as those that combine reminders with patient education) are needed.²⁵³

VIII. FUTURE CONSIDERATIONS FOR IMPROVING ADVANCE CARE PLANNING AND ADVANCE DIRECTIVE COMPLETION

Summary

This HHS study provides a comprehensive understanding of the current use of advance directives and reviews the most successful approaches to promoting advance directives/advance care planning as a means of specifying individual wishes about end of life care.

Although advance directives and advance care planning can be important tools to assist those facing the end of life, the accumulated evidence suggests that end-of-life decision making in the United States is often poorly implemented, with patients receiving care inconsistent with preferences. Aggressive care that is inconsistent with a patient's prognosis or preferences results in undue suffering and wasted resources. Research shows that most people do not complete an advance directive and that when they are completed, the documents often do not affect care because they are narrow and legalistic or simply physically inaccessible. The focus on preferences concerning life-sustaining treatments commonly proves to be too simplistic, and vague instructions are difficult to apply, often adding little to the way that families (or other proxies) and clinicians approach care decisions. Preferences stated within advance directives (or poorly orchestrated advance care planning) are often at odds with clinical circumstances or can even impede effective decision making. In short, advance care planning and advance directives have been ineffective.^{75,254} Several dimensions of this problem are particularly salient.

First is the recognition that difficulties with care at the end of life represent not a single issue, but a variety of different concerns. What began as a focus on developing ways to avoid care that prolonged the dying process and did not meet a person's goals now includes concerns that individuals may not have access to or be offered all the care they desire, that proxies may not act in patients' best interest or make the decisions that these individuals would want, that decisions for people without decision making ability or proxies will be driven by influences other than what would be best for them, and that individuals or proxies or providers will promulgate treatments that do not fit within the goals of medicine.

Advance care planning and advance directives have been promoted as the solution for end-of-life care not meeting the needs of dying individuals. However, they address only some of the sources of difficulty; other sorts of solutions may be needed. To the degree that advance care planning and advance directive completion promote integration of a person's values and goals in guiding care toward the end of life, these processes should be valuable tools in improving end-of-life care if fully implemented. Multi-component interventions such as *Respecting Choices* show that this can be the

case. Thus, finding ways to implement advance care planning in an effective and broadly applicable fashion is an important initial component.

Second, recognition is increasing that effective advance care planning and discernment of end-of-life care preferences are an on-going process. This ongoing process is best accomplished through continuing communication among individuals, clinicians, and family members. Instead of encouraging substantive, ongoing communication about clinical circumstances, medical possibilities and how the patient's values would dictate choices based on medical realities, current advance directives have been considered ends in themselves. The evidence suggests little connection between completion of an advance directive and subsequent appropriate outcomes of care such as improved communication between patient and provider or caregiver, greater concordance between patient preferences and proxy reports of patient preferences, reductions in aggressive care, appropriate palliation, or dying in the preferred place. Clinicians often feel poorly prepared to initiate or engage in the ongoing dialog needed to capture patients' end-of-life care preferences, particularly when patients' racial, ethnic or cultural identity and/or their native language differ from the physician. Much of the research assessing the effectiveness of advance care planning and whether physicians tend to follow advance directive preferences has focused solely on the existence of an advance directive in a patient's medical record, without regard to whether the advance directive provides guidance that can direct relevant care reflecting patient's preferences.^{66,198}

Third, some groups of patients are even less likely than others to engage in advance care planning or to complete advance directives. These groups include individuals who have been disenfranchised by or simply have less trust in the medical care system; racial/ethnic groups whose cultural norms may not value autonomy; advance directive-appointed decision makers (proxies); and the most vulnerable, including those with physical, intellectual, or psychiatric disabilities.^{97-99,255-256}

Advance care planning for disabled individuals involves a unique set of challenges. Yet, there has been little rigorous study of advance directives among individuals with disabilities. It is unclear whether the positions of disability rights advocates concerning the unacceptability of advance directives and mechanisms to elicit and employ them reflect the views of the broader community of persons with disabilities. However, it is encouraging that a number of organizations representing the interests of persons with disabilities have issued policy statements supporting the use of advance directives.²⁵⁶ In addition, it is critical to engage and learn from persons with disabilities about advance care planning. People with disabilities offer a unique perspective in refuting overly pessimistic perceptions of quality of life, and misconceptions about life satisfaction.

Fourth, the concept of decision making capacity has been given inadequate consideration in development of models of advance care planning and interventions to improve treatment decisions and end-of-life care. Decision making and identification of treatment goals require evaluating a person's capacity to make decisions of differing complexity. The capacity to understand and make a decision about a highly

complicated medical intervention is higher than the capacity needed to provide more general instructions about one's goals of care. The capacity needed to understand and make a decision about who will act as one's proxy is arguably even less. While the law recognizes the task-specific nature of capacity, it provides little guidance on navigating the nuances of capacity assessment for these kinds of decisions.

For incapable people, decision making should incorporate information from existing advance directives and communication with proxy decision makers. Person and family-centered planning regarding life-sustaining treatment should be carried out in a culturally appropriate fashion. Early advance care planning is ideal because a person's capacity to make decisions may diminish over time and he/she may suddenly lose the ability to participate. The most successful interventions have created an environment in which advance care planning is "routine" community and clinical practice.

Beyond the mere completion of an advance directive, the aim of advance care planning is to ensure that goals of care were informed by a patient's present condition; that decisions were prospectively mapped out so that comfort and resource use could be maximized and anxiety minimized; that access to pain and symptom management was ensured; that patients and families were prepared for what to expect; that emotional, spiritual and practical support were available; and that the goal of care was a sense of completion in life and relationship resolution, treating the patient as a "whole person."^{9,11-13,260-262}

Opportunities for Promoting Advance Care Planning and Advance Directive Use to Improve Care

The following opportunities are drawn from the literature review, the commissioned papers and the Roundtable discussion to offer suggestions for promoting advance care planning and advance directive use [for additional detail see Appendix H]. The foundation of these suggestions is recognition of the importance of being inclusive of all persons' views and the essential goal of creating a community and professional expectation that end-of-life care without advance care planning (except in the case of sudden death) is unacceptable.

Advance Care Planning Models

The focus of advance care planning should shift from a focus on formal written advance directive forms to a developmental discussion process. Support a variety of models that recognize advance care planning as fundamentally a process rather than a product. Specific attention could be given to models that translate into immediate medical orders to guide specific treatment decisions such as the POLST program paradigm.

The advance care planning process can be promulgated at the individual patient-provider level and also can be incorporated into broad, community wide interventions.

Structured advance care planning at the community level (e.g., the *Respecting Choices* program) can induce the expectation that health care providers will elicit and attend to patient preferences in a timely manner, and that these preferences will affect the process and outcomes of care. Community-based, clinically-oriented projects that incorporate advance care planning into routine and specialized care, and that evaluate the effects of these efforts are now underway. Models that remove advance care planning from the medical setting may engage additional individuals in locations such as workplaces, schools and libraries.

Advance care planning can be advanced by creating improved tools to facilitate this task. People who have capacity need help understanding proxy decision making so that they can choose the most appropriate person to make health care decisions for them. Proxies need training to understand their role in decision making, to prompt discussions with patients while they can communicate, and to participate fully as advocates for patients facing the end of life. For patients without full capacity, models using aids to facilitate the elicitation of goals or preferences, such as from the *Let Me Decide* and *Peace* interventions are important to consider.

Broad application of advance care planning in communities should reduce the number of individuals for whom goals of care have not been entertained. However, for individuals with limited or no decision making capacity whose wishes are not known, better mechanisms for approaching decision making are needed. For patients without appointed or identified surrogates, but for whom interested individuals familiar with the person's behaviors and values are available, the process of "best respect" should be employed in which health care decisions are made by individuals most familiar with the patient's life. For "unbefriended" individuals without capacity, approaches are needed to facilitate decision making and evaluations could ensure that care at the end of life attempts to approximate what would be best for the person without a voice.

One of the major themes of this report is that traditional advance directives present problems because they do not translate into immediate medical orders to guide specific treatment decisions. The POLST program paradigm is designed to improve end-of-life care by converting patients' treatment preferences in to medical orders that are transferable throughout the health care system. The POLST program, originally developed in Oregon, has now spread beyond Oregon. Approximately 20 states are in the process of exploring implementation. Encouraging additional POLST efforts that translate chronic care patient's care goals into easily identifiable, portable, and reviewable medical orders that follow the patient across settings would go a long way toward enhancing advance care planning in this country.

Social Marketing/Public Education

Making use social marketing and public education opportunities to affirm that any authentic expression of a person's wishes with respect to health care should be honored. Coordinated efforts involving relevant federal, state and local agencies could be used for: providing information in understanding the stages and impact of advance chronic disease and raising awareness of the importance of planning for care near the end of life. Aim advance care

planning messages at the different developmental stages in a person's life. Provide the public options for means of carrying information on their person (such as a check-off box on driver's licenses). Consider developing a national information clearinghouse where consumers could receive state-specific information and consumer-friendly documents and publications.

Social marketing is a less well-studied approach to advance directive promotion that has been proven successful in achieving widespread behavioral change with respect to other health issues. In social marketing campaigns, target populations may be segmented by population characteristics (e.g., age, gender, race, physical condition), geographic region, and behavioral characteristics such as readiness for change.

Advance care planning messages could be developed to the different developmental stages in a person's life. A "case" for advance care planning could be made in order to induce broad societal behavior change through implementation of a campaign that communicates the health and social benefits of advance care planning. Advance care planning messages might aim at the different developmental stages in a person's life: first as a likely proxy and later as a person for whom a proxy may speak. The messages could be carefully structured to avoid over-emphasizing documents over communication.

A variety of social marketing/public education efforts could be explored including a coordinated effort involving all relevant agencies to provide uniform information on advance care planning to individuals. Public forums and town hall meetings could be held, and the information could include assistance to patients and families in understanding the stages and impact of advance chronic disease, multiple diagnoses and comorbidities.

In addition, encouraging coordinated state and private efforts to provide the public with a means of carrying information on their person to alert physicians or facilities that they have an advance directive. Initiatives such as a check-off box on driver's licenses for individuals with advance directives; or using wallet/pocket cards such as the AHA's "Put it in Writing" campaign. Wallet cards or ID bracelets can provide quick reference for clinicians about advance directive content and instructions with regard how to access the important information, including if it is in an electronic registry.

Health System Issues

Consider using existing mechanisms to ensure that individual preferences are translated into care decisions and that these decisions are transmitted across care settings. Existing efforts might include: ensuring that EHR development include components for advance care planning; highlighting Medicare provisions in the PQRI (Measure #47: Advance Care Plan) and the initial preventive physical exam for Medicare (§1861(ww) provides for "end-of-life planning"); promoting individual preferences be translated into care decisions and transmitted across care settings through vehicles like the POLST program.

Use existing mechanisms to ensure that individual preferences are translated into care decisions and that these are transmitted across care settings. Protocols such as POLST that follow the individual across care venues could be promoted (see discussion under “Models”). Pointing out programmatic elements in Medicare, such as *Measure #47: Advance Care Plan* in the PQRI, could be useful to both the beneficiary and provider as a means of encouraging the advance care planning process. The best advance care planning models has physicians and patients thinking about options beforehand, making decisions jointly and reviewing those decisions whenever circumstances change.

In addition, Section 101 of the Medicare Improvements for Patients and Providers Act (HR 6331) provides for “end-of-life planning” in the “Welcome to Medicare” visit (§1861(ww) Initial Preventive Physical Examination) this is an opportunity for the Medicare beneficiaries to understand the need for and express their preferences for selecting a proxy health care decision maker.

Early studies suggest that EHRs may improve advance care planning, advance directive completion, and the documentation of DNR orders. EHR development will be enhanced by including these components as they move forward.

Maximizing understanding of issues for persons with disabilities could be enhanced through developing a disability curriculum to teach health care and social service professionals and trainees to provide person-centered care that maximizes capabilities. It takes into account the experiences of many who, due to personal characteristics, have received inadequate or inappropriate care. In addition, medical and other relevant professional schools could hire persons with disabilities and persons with varied cultural backgrounds to teach trainees and to serve as advisors and role models.

Continuing Research

Research continues to shed light on improving end-of-life and palliative care, and advance care planning for all people. Research on evaluating the process of goal elicitation, proxy designation and creative models implementing advance care planning could be encouraged. Continuing research on approaches and tools for assessing the parameters of decisional capacity among people with intellectual disabilities is especially important. Inclusion of persons with disabilities is an important component for any research protocol.

Research is needed to evaluate the process of goal elicitation, surrogate designation and implementation of advance care planning. Application of measurement of advance care planning processes is particularly important for care provided to persons with disabilities. Innovative research design is needed to inform new service initiatives to improve end-of-life and palliative care, and advance care planning for all people. Specific topics for research, guided by this study include:

- attitudes, concerns, and values about end-of-life care;
- experiences regarding and strategies for advance care planning;
- the quality of end-of-life care for diverse disability populations; and
- the impact of health care professional and public attitudes.

In addition, research is needed on approaches and tools for assessing the parameters of decisional capacity among people with intellectual disability, especially regarding the range of complex choices near the end of life. Prior research using vignettes of low-risk health-related treatments may provide a model. In addition, studies should examine the effectiveness of strategies and tools for advance care planning among those with limited capacity, such as shared decision making and assisted capacity. More information is needed on which strategies support decision making abilities, and whether these approaches unintentionally influence decisions that are made.

For patients without full capacity, aids should be developed to facilitate the elicitation of goals or preferences, such as from the *Let Me Decide* and *Peace* interventions, and further work should be done to describe strategies of assisted capacity to maximize the participation of persons with impaired capabilities. Better tools are also needed to facilitate culturally relevant advance care planning, including materials that are linguistically sensitive to the needs of culturally diverse communities.

How we die says a lot about a society. This report points the way for how all parts of our society must grapple with improving planning for the care of people nearing the end of their lives.

TABLE 2. Roundtable Discussion Summaries*

The Roundtable discussions held in October 2007 convened many of the nation's experts on important issues related to advance directives and advance care planning: legal and policy issues, issues related to those with intellectual and physical disabilities, and the public's engagement on these issues. The synthesis of the meeting's proceedings presented here identifies a number of opportunities to improve and promote advance care planning and advance directive completion:

Advance Care Planning Models

- Change the focus of advance care planning from formal written forms to a developmental discussion process.
- Build on demonstration projects testing promising advance care planning methods, such as *Respecting Choices*.
- Develop alternatives to the default decision making model.
- Develop tools to facilitate choice of best proxy and to prepare proxies for decision making.
- Develop tools to facilitate decisions from persons without full capacity.
- Develop tools to facilitate culturally relevant advance care planning and create a better array of advance directives.
- Develop and test health care decision making mechanisms for "unbefriended" individuals without capacity.

Education

- Educate social workers, case managers, lawyers, guardians, and care providers about advance care planning, advance directives and the person-centered approach to care.
- Develop a disability curriculum to teach health care and social service professionals and trainees to provide person-centered care that maximizes capabilities and takes into account the experiences of many who, due to personal characteristics, have received inadequate or inappropriate care.
- Medical and other relevant professional schools should hire persons with disabilities and persons with varied cultural backgrounds to teach trainees and to serve as advisors and role models.

Health System Issues

- Create and promote mechanisms to ensure that an individual's preferences are translated into care decisions and are transmitted across care settings, such as the POLST protocol.
- Ensure that health care benefits cover evidence-based treatments proven to achieve clinically important outcomes so that advance care planning can realistically anticipate the availability of care to attain desired goals.
- Link funding to facilitation of advance care planning and outcomes.
- Encourage proxy designation from all persons enrolling in Medicare/Medicaid programs and advise them about the availability of advance directives.
- Hospitals collect and maintain advance directives for their patient population.
- Inclusion of persons with disabilities and from marginalized communities on ethics committees.
- Incorporate advance care planning discussions into "Welcome to Medicare" consultations.

Measurement

- Grade hospitals on advance care planning processes and outcomes.
- Recognize poor advance care planning as a medical error.
- Evaluate advance care planning in diverse populations and investigate outcomes.
- Measure processes and outcomes of care for persons with disabilities.

TABLE 2 (continued)
<u>Legislation</u> • Federal legislation to ensure portability of advance directives across states. • Federal legislation to ensure that, in the absence of a statutory advance directive, any authentic expression of an individual's wishes is respected. • Federal legislation concerning default surrogate identification for states without such laws. • Develop an advance care planning information clearinghouse. • Modify Patient Self-Determination Act language to require health care facilities to describe their mechanisms to: (1) elicit patients' goals for care; (2) honor patients' wishes; and (3) facilitate continuity and periodic reassessment.
<u>Public Engagement</u> • Create a social marketing "case" for advance care planning. • Create advance care planning messages appropriate to the different developmental stages in a person's life. • Target the role of the health care proxy in marketing and education.
* See Appendix H for a full summary of Roundtable discussions.

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APPENDIX A. Methods

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APPENDIX B. Literature Review on Advance Directives

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APPENDIX C. Advance Directives and Advance Care Planning: Legal and Policy Issues

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APPENDIX D. Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities

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APPENDIX G. Adrienne Asch's Comments at the October 2007 ASPE Roundtable

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APPENDIX H. Summary of the Roundtable Discussions on Advance Directives and Advance Care Planning

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