

APPENDIX B.

LITERATURE REVIEW ON ADVANCE DIRECTIVES

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



LITERATURE REVIEW ON ADVANCE DIRECTIVES

June 2007

Office of the Assistant Secretary for Planning and Evaluation

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ACRONYMS

ACP	advance care planning
AD	advance directive
ADA	Americans with Disabilities Act
AHRQ	Agency for Healthcare Research and Quality
CDSS	Clinical Decision Support System
COPD	chronic obstructive pulmonary disease
CPOE	Computerized Provider Order Entry
CPR	cardiopulmonary resuscitation
DNAR	do not attempt resuscitation
DNR	do not resuscitate
EHR	electronic health record
EMR	electronic medical record
HIT	health information technology
HIV	Human Immunodeficiency Virus
HL7	Health Level Seven
HMO	health maintenance organization
ICU	intensive care unit
NINR	National Institute for Nursing Research
PACS	Picture Archiving Communications Systems
PEG tube	percutaneous endoscopic gastrostomy tube
POLST	Physician's Orders for Life-Sustaining Treatment
PSDA	Patient Self-Determination Act
PVS	permanent vegetative state
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments

I. INTRODUCTION

Advances in medical care and technology have blurred the boundaries between life-and-death and have challenged our expectations about how Americans should experience the end of life.¹ Chronic illnesses, including cancer, organ system failure (primarily heart, lung, liver and kidney failure), dementia, and stroke are now the leading causes of death for Americans and few “die suddenly.” Rather, most will live long, but with increasing disability.^{2,3,4} However, health care, legal and social policy and practice have yet to catch up with this reality. Studies indicate that the end of life is associated with a substantial burden of suffering among dying individuals,^{5,6,7,8} and that negative health and financial consequences extend to family members and society.⁹⁻¹⁴

Most deaths (80%) occur in hospitals or nursing homes, often in the context of aggressive high-technology treatment, even though most people, when asked, would prefer to die at home.^{15,16,17} This transition in the venue of death has been fueled by the development of technology that is capable of sustaining life in very compromised states and, in the view of some, of extending the dying process. For example, just 30 years ago, the development of the percutaneous endoscopic gastrostomy (PEG) tube was a revolutionary advance aimed at establishing long-term enteral feeding in infants. The PEG tube has evolved into a common medical procedure for both children and adults, especially older adults suffering from various forms of dementia,^{18,19} an application quite different from its original intent. This and other interventions delay or slow dying in the United States, although they do not necessarily improve the dying process.

Advance directives (ADs) or advance health care directives were developed to provide a practical process for ensuring patient autonomy at the end of life.^{20,21,22} Ideally, addressing end-of-life issues with the aid of one’s physician will enhance the quality of end-of-life care by helping the patient, family, and provider to converge on a unified plan that gives “voice” to the patient’s preferences for medical care within the spectrum of reasonable clinical options. The decision maker appointed to implement the agreed-upon wishes (and perhaps the preferences themselves) can then be recorded in an AD.²³ The vision of ADs is that patient autonomy can be translated into treatment decisions made by physicians and families on behalf of the incapable patient, which reflect the decisions that the patient would have made for himself or herself.

ADs began as simple requests to avoid medial 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.²⁴ The activities leading up to the completion of an AD -- discussion of clinical circumstances and prognosis, understanding a patient’s goals in this clinical context, and outlining plans for future care to approximate those goals -- constitute the process of advance care planning (ACP), which is central to end-of-life decision making and AD completion. ACP, in its most advanced form, 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.^{25,26} ACP broadens the framework of ADs by emphasizing not only decisions about whether to use a treatment but also by making practical arrangements (e.g., anticipating treatment modalities to have them in place). Additionally, ACP helps to identify what course serves the patient best and then outlines specific steps to make that course more likely. Thus, ADs are not an end in themselves; rather, these documents are most effective when incorporated into a comprehensive ACP process^{27,28} and the patient's goals are incorporated into the care provided by the health care system to the patient.

This report examines the empirical evidence about the degree to which ADs and ACP have met their intended goals. We explore what the medical literature reports concerning the use of ADs and ACP, disparities among groups in their use, and interventions to enhance the use and value of ADs and ACP.

II. TERMINOLOGY

There is some variation in the use of terminology concerning ADs, ACP and end-of-life care, and this variation is at times a source of misunderstanding. Some of these differences relate to words having specialized meanings in the context of end-of-life care as well as due to geographic variation. Each state regulates the use of ADs differently; statutes enacted at the state level often conflict in the definition of terms. Relying largely on the terminology of the Uniform Health-Care Decisions Act (the 1993 federal legislation that encouraged making and enforcement of advance health care directives and provided a means for making health care decisions for those who have failed to do so)²⁹ and the Patient Self-Determination Act (PSDA),³⁰ we will use the following definitions:

- **Advance health care directive or advance directive:** A written instructional 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 AD as including verbal instructions,³¹ we do not include verbal instructions in the definition because this has not been the common use of the term in the medical literature and it is inconsistent with some states' AD laws.
- **Agent:** An individual designated in a legal document know as a power of attorney for health care to make a health care decision for the individual granting the power; also referred to in statute as durable power of attorney for health care, attorney in fact, or health care representative.
- **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.
- **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.
- **Advance care planning:** The process of discussing, determining and/or executing treatment directives and appointing a proxy decision maker.
- **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.
- **Guardian:** A judicially appointed guardian or conservator having authority to make a health care decision for an individual.

Many see the appointment of an agent as more important than creating an instructional health care directive because the latter cannot address all the changing aspects of a health care situation whereas an agent can make decisions based on the latest available information. In addition, the wording of instructional directives is often problematic and it is difficult to address every possible circumstance that could arise in some future medical state. All 50 states and the District of Columbia recognize the appointment of an agent for health care decisions; however, three states do not have laws authorizing instructional health care directives (Massachusetts, Michigan, and New York).³²

ADs are employed to extend patient autonomy into the period in which the patient has lost the ability to make decisions for him or herself. This is important because many of the decisions toward the end of life are value-laden; meaning that they depend on an individual's view of the value of specific health states and how treatments meet their personal goals. ADs are implemented most often toward the end of life when decisions about life-sustaining treatments must be made. Decisions often include which treatments to employ or remove. A special set of terms is often used, which are defined here modified from the Uniform Health-Care Decisions Act,²⁹ the National Hospice and Palliative Care Organization³³ and other sources:

- **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:** 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 is not the same. Competency is a legal status imposed by the court.
- **Cardiopulmonary resuscitation:** A group of treatments used when someone's heart and/or breathing stops. Cardiopulmonary resuscitation (CPR) is used in an attempt to restart the heart and breathing. It usually consists of mouth-to-mouth breathing 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 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 **DNR** (do not resuscitate) order, a **No CPR** order, a **DNAR** (do not attempt resuscitation) order, and an **AND** (allow natural death) order.

- **Intubation:** Refers to "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.³⁴
- **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 requiring most United States hospitals, nursing homes, hospice programs, home health agencies, and health maintenance organizations (HMOs) to provide to adult individuals, at the time of inpatient admission or enrollment, information about their rights under state laws governing ADs, 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 AD; and (4) information on the provider's policies that govern the utilization of these rights. The act prohibits institutions from discriminating against a patient who does not have an AD. The PSDA further requires institutions to document patient information and provide ongoing community education on ADs.
- **Permanent vegetative state:** 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 nontraumatic brain injury, and present for at least one month in degenerative/metabolic disorders or developmental malformations. A permanent vegetative state (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 exceedingly rare).³⁵

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

III. HISTORY OF ADVANCE DIRECTIVES/ ADVANCE CARE PLANNING

End-of-life issues have long been the focus of intense societal debate as providers, medical ethicists, policy makers, legislators, and the public have considered essential questions concerning patient autonomy, quality of life at the end of life, and withdrawal of life-sustaining treatments.¹ 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.²⁰ Traditionally, health care ethics have largely been based on professional authority and beneficence. Physicians made most patient care decisions and focused primarily on cure or comfort. As medical technology advanced (e.g., CPR and 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 ultimately futile life-sustaining treatment through legal measures with the development of the earliest form of AD, the "living will." Living wills were designed to maintain the patient's "voice" in medical decision making and empower individuals to dictate the terms of their own medical care at the end of life.^{22,36-42}

Initially, it was the states, rather than the Federal Government, that moved to give legal support to living wills. In 1976, California passed the Natural Death Act, the first law to give legal force to living wills; soon thereafter states passed legislation authorizing proxy directives. In 1990, Congress enacted the PSDA,³⁰ requiring most health care facilities to ask patients whether they had an AD; 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 AD forms available to patients who did not have one.²¹ The PSDA 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, fostering communication between patients and their physicians, and protecting physicians from litigation in end-of-life decision making.^{20,37,43,44}

Case law has generally upheld patient wishes as the main standard of appropriate care. Interestingly, ground-breaking cases have, for the most part, involved young women. For example, a pivotal case from 1975 involved Karen Ann Quinlan, a 21 year old woman who, after cardiac arrest, was resuscitated but remained in a persistent vegetative state. In 1976, the New Jersey Supreme Court granted her parents the right to withdraw life-support, holding that an individual's constitutional right to privacy outweighed the state's interest in preserving life.³⁹ When the ventilator was removed, Karen Ann Quinlan continued to breathe on her own and, sustained by tube feedings, lived until 1985.²⁰ Ethicists and many in the medical profession interpreted the court's

decision as broad enough to encompass a patient's decision to decline medical treatment under certain circumstances.⁴⁵

A case that further clarified legal authority in end-of-life decision making involved Nancy Cruzan, age 32, who in 1983 was involved in an automobile accident that left her in a persistent vegetative state. Years later, Cruzan's parents concluded that their daughter would never recover and that she would not have wanted to be kept alive in her current state. The hospital refused to discontinue artificial nutrition and hydration without a court order. A trial court issued the order but the Missouri Supreme Court reversed the trial court decision on the basis that Ms. Cruzan's parents were not entitled to terminate her medical treatment in the absence of "clear and convincing evidence" that this choice reflected her wishes. A seven-year court battle reached the Supreme Court,⁴⁶ which ruled that, while Cruzan had the right to refuse tube feedings, the state could demand clear and convincing evidence that this was her expressed desire on the basis that a state may constitutionally set high barriers for decisions to withdraw food and water from incompetent patients when the patients have not spoken clearly themselves.

Today, ACP and ADs, which are recognized in some form throughout the United States, are widely accepted not only as a way to identify preferences for life-sustaining care for use when patients have lost decision making ability but also as a general framework for decision making near the end of life.^{22,47,48,49}

IV. ETHICAL ISSUES IN ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING

Patient autonomy and individual choice are core values in Western bioethics and important components of end-of-life decision making.^{50,51} As such, ensuring the centrality of the patient's and the family's voice in medical decision making and honoring patient preferences for end-of-life care are key goals in patient and family-centered care.^{10,12,13,14,52,53,54} Most ethicists agree that the principle of patient autonomy can be translated into the actions of protecting and promoting patients' ability to make informed decisions resulting, ideally, from capable and uninfluenced deliberation. In this context, medical procedures should be provided to patients only if the procedures are reasonably likely to achieve the patient's goals.⁵⁵ In situations where aggressive therapeutic interventions will not or have ceased to be effective to reach the goals of the patient, care should shift to other interventions including palliative care. These goals should include consideration of the psychosocial and spiritual interests of the patient.⁵³

ADs are a tool to implement patient autonomy -- nearly always toward the end of life -- for patients who have lost the capacity to make decisions for themselves. The AD may derive from the process of ACP in which 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 in their duty to act in the patient's best interest. This interactive process is revisited at critical junctures in the patient's care, when prognosis changes and when desired by patients and proxies. Essential to this process is communication between patient/family and clinician. The content of information, the way in which the information is provided, and continuity are critical to the ACP process. In its optimal form, ACP is a series of interactions in which patients come to expect that they will be fully informed of their clinical status and have direct input into significant decisions, families -- to the extent desired by patients -- are aware of patient decisions and the values on which they are based, and providers become well versed in patients' values and how they connect to treatment preferences and decisions. In this context, providers can analyze clinical circumstances in the context of patients' goals and communicate to patients recommendations about care decisions that patients and families can accept or reject.

An obstacle to decision making toward the end of life arises when families (or rarely patients) desire care of greater aggressiveness than is deemed warranted by providers. This often occurs in the setting of mistrust or disagreement over prognosis. Other times, conflict centers on families desiring life-sustaining treatment in compromised health states (e.g., PVS) for which providers find such treatment to be inappropriate. These situations are most commonly the result of poor early patient-provider communication and ACP.⁵⁶ Rarely, these conflicts are the result of philosophical or religious differences that result in providers implementing what they perceive to be "futile" care. 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 socially-held values on the overall goals of medicine and what is futile care, may hamper ACP.

A number of mechanisms to facilitate ACP have been suggested. These include detailed elicitation of patient preferences for medical treatments under a variety of conditions,⁵⁷ exploration of patient values in construction of approaches to care,⁵⁸ and mechanisms to facilitate discussion and specification of a proxy.⁵⁹ These issues are discussed more fully in Section VI.B. These mechanisms include the following steps, each of which is necessary if an AD is to have an impact on medical care.^{20,21,37,43,47,50,60,61}

- The patient, informed by ACP conversations with one's provider, considers proxy specification and goals of care.
- Optimally, the proxy participates in the ACP conference.
- The AD is completed with proxy specification and a description of goals or desired treatments.
- The AD is *available* to clinicians and proxy.
- The patient's preferences or goals, as reflected in the AD, are accurately interpreted and applied to the clinical situation.
- The proxy and provider *honor* the patient's choices in fashioning and implementing the care plan.

Still, a number of practical limitations to the use of ADs and ACP have been identified,^{31,47,50,55,61} including:

- Patients have difficulty predicting their future treatment preferences.⁴³
- AD documents provide guidance for only a limited set of future medical possibilities.⁶²
- Proxy decision makers may have difficulty converting patients' documented treatment preferences into clinical decisions.^{23,63}
- Preferences for life-sustaining treatment appear to depend on the context in which they are made.⁶⁴
- Some patients have limited desire to exert specific control over end-of-life medical decision making and would prefer instead to leave future specific decisions to their families or physicians.^{37,65}

- Expressed preferences may be subjugated to physician influence concerning the clinical appropriateness of life-sustaining treatment.^{66,67,68}

The ethical framework that underpins ADs and proxy decision making is a hierarchy in which the patient's own choices dominate, and, if these are not known, the proxy's application of the patient's values to reach a decision guides care. This "substituted judgment" is based on knowledge of the patient's goals, on the patient's prior behavior, or on discussions with the patient about preferences. A major goal of ACP is to help proxies understand this. Too commonly, the proxy is unable to render a substituted judgment and must make a best-interest decision on the patient's behalf. Thus, the proxy's primary role is to support patient autonomy by attempting to work with clinicians to have medical care achieve the goals of the patient, if these are possible given the clinical circumstances. Because *expressed preferences* often do not match clinical circumstances, *goals of care* are often more malleable in directing medical care.⁶⁹

Empirical studies suggest that the patient-proxy relationship exists on a contractual to covenantal continuum: disease trajectory, clarity of prognosis, and the clarity and type of patient instructions affect whether proxies are to simply heed patient wishes or need to participate actively in decision making.⁷⁰ Several studies have shown that some patients prefer that proxies make decisions based on what they think is best rather than based on what the patients would have wanted at the end of life.^{37,71}

Using ADs to extend patient autonomy requires that clinicians know when patients lose capacity (or decision making ability) in order to invoke the AD. This skill must be coupled with the realization that capacity may wax and wane and variable levels of capacity may be required for different decisions. In practice, decision making capacity is often assessed informally or inconsistently⁷² and there are many misconceptions about capacity in a clinical context.⁷³ There is little consensus or clinically relevant empirical data about how to assess a person's level of understanding of specific treatment decisions.⁷⁴ Furthermore, there is a need to explore how and in what ways elements of ADs and treatment choices need to be modified to allow greater participation of cognitively impaired patients.

Despite the plethora of practical obstacles, from an ethical perspective, it is imperative that ACP be carried out to the best abilities of providers, patients and families. Without knowledge of the patient's goals to guide care, default medical care often ends up being "everything that can be done" or not as much as might usefully be done, neither of which serves the patient well.

V. METHODS

In preparation for a National Institutes of Health State of the Science Conference on "Improving End of Life Care" in December 2004, RAND conducted a systematic review of the evidence published between 1990 and 2004 regarding the effectiveness of interventions, including ADs and ACP, for improving end-of-life outcomes.⁷⁵ The 2004 review was conducted for the National Institute for Nursing Research (NINR) and the Agency for Healthcare Research and Quality (AHRQ). In this report, we update the systematic review to include the period 2004-2007 and incorporate new topic areas for the period 2000-2007 not included in the original review.

We address the following questions:

- What does the literature say about the utility, feasibility, ethical issues, and success of implementation of ADs and ACP for a diverse array of patient populations and across health care settings?
- What are the salient considerations necessary to more widely apply ADs in vulnerable populations, such as the cognitively or physically disabled, and in determining what will be a wise course for policy development?
- What are the salient legal considerations regarding the wider promotion of ADs/ACP?
- What are the potential methods that can be used to promote and document ADs more widely (including the role of health information technology (HIT) and social marketing)?

RAND searched the traditional health literature databases (e.g., MEDLINE, LOCATORplus, Lexus Nexus, CINAHL, EconLit, PsychInfo, and Wilson Select Plus) for relevant publications. These articles involved human subjects, but did not include individual case reports. To update the original systematic review, we conducted a literature search of articles published in peer-reviewed journals in the United States between 2004 and 2007. We used the literature, search criteria, search terms, protocols, evaluation methods, and materials developed for the original NINR/AHRQ review.

We conducted a separate search of the literature from 2000 to 2007 to identify systematic reviews, randomized or clinical controlled trials, epidemiologic studies, and qualitative studies related to additional topics not addressed in the original review, including legal/policy issues in ADs/ACP; HIT and ADs/ACP; intellectual/physical disabilities and ADs/ACP; and social marketing/public engagement and ADs/ACP.

Our main search strategy, described in detail in Appendix A, included a list of terms intended to identify all research publications, within the time period specified, associated with ADs/ACP and with the following topics:

- Palliative or end-of-life care.
- Global and specific satisfaction with ADs/ACP.
- Measures and measurement.
- Patient, family/caregiver, and health system factors.
- State legislation, policy, or regulations.
- Legal considerations.
- HIT and ADs/ACP.

Additional resources included the Database of Reviews of Effects, the National Consensus Project for Palliative Care, and where specifically relevant, Health Canada. Each systematic review or intervention/observation study was reviewed by at least one project member for relevance and if relevant was summarized and included in this report. The evidence reviewed for this report is organized as follows:

- A. Use of ADs and ACP.
- B. Interventions to increase use of ADs and ACP.
- C. ADs and ACP among disabled persons.
- D. Interventions to improve AD completion and ACP including HIT, social marketing, and legislation/policy.
- E. Outcomes of ADs and ACP.

VI. LITERATURE REVIEW RESULTS

ADs were instituted in response to the perception that care toward the end of life needed to better reflect patient wishes. ACP and ADs were intended to translate the fundamental values of biomedical ethics into bedside care, which was dramatically transformed by the technological breakthroughs of the 1960s through 1980s. The variety of efforts to promote ADs and ACP has been extensively evaluated. Despite two decades of legislation and advocacy, studies show that AD completion rates are low^{20,22,37,38,43,48,76-81} and that these documents often do not drive care.⁸² A variety of interventions have been undertaken, most of which have not been successful in altering care. Certain groups of individuals and venues of care have been particularly resistant to the penetration of ACP and ADs. However, some regional efforts have demonstrated social change, including changes in expectations, and integration of ACP and ADs into care across venues, improving the match of technological care with patient goals. This section summarizes the data concerning AD and ACP use and its effect on care, interventions to increase ACP and AD use, ACP and AD use among disabled persons, and potential mechanisms of improving ACP and AD use.

A. Use of Advance Directives and Advance Care Planning

1. Overview. Despite the institutionalization of ADs in state and federal law and widespread public support for ACP from healthy and ill populations as well as the medical community, the accumulated evidence shows that adoption of ADs is low. Most of the literature suggests that between 18% and 30% of Americans have completed an AD.^{20,22,37,38,43,48,75-81} Acutely ill individuals, a group for which ADs are particularly relevant, complete ADs at rates only slightly higher than the healthy population.^{83,84} At most only one in three chronically ill individuals in the community have completed ADs (e.g., 35% in dialysis patients; 32% in chronic obstructive pulmonary disease (COPD) patients).^{85,86}

Patient factors associated with desire for end-of-life planning information and completion of an AD include older age, greater disease burden, White race; higher socio-economic status; knowledge about ADs 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 physician has an AD.^{75,87} The evidence is mixed regarding the relationship of patient health status and AD completion or end-of-life planning discussion.^{88,89} Care planning differs by clinical environment (e.g., intensive care unit (ICU) versus outpatient settings), medical condition (e.g., cancer versus heart failure) and acuity of illness.^{75,90,91,92}

2. Venue of care. ADs and ACP, by design, should have their greatest impact in the hospital and ICU settings. However, the literature suggests that the effect in high-technology medical settings has been modest. A structured literature review of the use of ADs⁸² found that less than 50% of severely or terminally ill patients had an AD in their

medical record. Additionally, between 65% and 76% of physicians whose patients had an AD were unaware of its existence. Having an instructional health care directive did not increase documentation of preferences in the medical record and ADs often were not considered applicable until the patient was incapacitated or “absolutely, hopelessly ill.” Most providers and families waited until the patient was actively dying before preferences were invoked to direct withholding or withdrawing of life-sustaining treatments. The report also found that proxies often were not present or too overwrought to make decisions and that providers tended to predict patient preferences that reflected under-treatment relative to patient wishes. On the contrary, proxies tended to predict treatment preferences that were *more* aggressive than patients would have wanted. In a separate study that included medical record evaluation after patient death, the authors found that 55% of patients with cancer have ADs but only 14-24% of severely or terminally ill persons without cancer had an AD.⁷⁵

It is in the ICU, where most aggressive care is provided, that ADs and ACP appear to have a particularly weak effect. The majority of deaths in the ICU involve resuscitation or withholding or withdrawing life-sustaining treatment.⁹³ The condition of patients receiving care in the ICU and the complexity of care patterns often makes it difficult to determine patients’ preferences and values. Enthusiasm for technology and cure by patients, families and providers often overshadows consideration of patient’s wishes, quality of life, and assessment of treatment burden versus treatment benefit.⁹⁴

A review by Thelen⁹⁴ found contradictory evidence regarding the impact of proxy knowledge of patient preferences on end-of-life care in the ICU: some studies show that family awareness of patient preferences (written or verbal) influenced decision making^{95,96} while others did not.^{8,97,98,99,100,101} Baggs⁹⁷ systematic review of decision making in the ICU found that decision making often was confused regarding what was appropriate care for dying patients and commonly included inadequate communication. Disagreement between patients, families and caregivers regarding use of life-sustaining treatment was common.

There are approximately 1.6 million residents in the 18,000 nursing homes in the United States.¹⁰² Most long-stay nursing home residents are frail, cognitively and physically impaired elders who have compromised decision making capability.¹⁰³ Approximately 30% of residents die within six months of nursing home admission.¹⁰⁴ Decisions about transferring residents to hospitals for more intensive interventions are common -- more than 25% of nursing home residents are transferred to an acute hospital each year.¹⁰⁵ End-of-life planning for residents often focuses on feeding tubes and antibiotics.^{104,106-113} Although many caregivers believe that palliation is the appropriate goal of care for older nursing home patients with functional and cognitive deficits, terminal care provided to persons residing in a nursing homes is often not so oriented.^{74,114,115}

ADs are completed more often in nursing homes than in other health care venues.^{116,117} 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 PSDA.¹¹⁸ Others found that between 60% and 70% of nursing home residents have some form of AD; however most documents did not contain treatment decisions.^{119,120} Using nursing home assessment data, Suri et al.¹²¹ found that only 11% of residents had ADs and only 17% had a DNR order on admission and only 6% of those without an AD completed a document after admission. Use of ADs varied by the resident's race and cognitive and physical function. Another study found that AD use was greater in urban than rural nursing homes.¹²² AD use has been associated with various nursing home organizational characteristics; nursing homes with more full-time equivalent nursing staff per resident demonstrated greater AD completion rates while for-profit status and higher Medicaid census were associated with lower completion rates.¹²³

Concerning patient factors, Lambert et al.¹²⁴ found that older persons in long-term care tended to base AD decisions on information gathered from personal experiences with death and illness and obtained little information from professionals or the media. Instead, elders relied on spiritual, emotional and social considerations. Rurup et al.¹²⁵ found that differences in religious beliefs and the provider's perspective of the nursing home resident resulted in different attitudes about end-of-life care decisions. White¹²⁶ found that the stress of moving to a nursing home, the health status of the resident, concern for others, age, and residents' understanding of ADs all influenced AD completion on admission to a nursing home. Dobalian¹²⁷ found that the percentage of nursing home residents who had AD care plans varied substantially by residents' age, ethnicity and income. Racial and ethnic minorities were less likely to have advance care plans than Whites; nursing home residents with less daily contact with friends or relatives and lower household income were less likely to have DNR orders or life-sustaining treatment restrictions in place.

Travis et al.¹²⁸ examined patterns of care during the last year of life for a group of nursing home residents and found that while most residents died receiving palliative care, their progression toward a palliative care plan was often slowed by indecision or inaction on the part of key decision makers and sometimes interrupted by aggressive acute care until the last few days of life. Transfer across sites of care is common near the end of life, with approximately 25-30% of Americans cared for in three or more settings (home, hospital, nursing home) in their last months of life.^{129,130,131,132,133} Dying patients, in particular, are at risk for transitions across settings.¹³⁴ One of the goals of ADs is to help clinicians in different care settings provide care that is consistent with the patient's wishes.

3. The role of culture, race, and ethnicity in advance directive use and advance care planning. There has been considerable attention to knowledge and attitudes about and completion of ADs and ACP 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 ACP or complete ADs, but results across studies are mixed. While most studies have found that African-Americans and Hispanics are less likely than Whites to complete ADs and are less likely to specify that life-sustaining treatments be withheld or withdrawn in these documents,^{79,135-141} other research

suggests that African-American and Hispanic adults are just as likely as Whites to have an AD.^{142,143,144}

Morrison and Meier¹⁴⁵ surveyed 700 adults 60 years or older from 34 randomly selected senior centers in New York to determine AD use and willingness to engage in ACP among healthy and ill White, African-American and Hispanic populations. More than 80% of respondents reported being comfortable talking to their physician about ACP and said that they would like to have a conversation about end-of-life care. There were no significant differences in completion rates across the three racial/ethnic groups. Thirty-five percent of participants had completed a health care proxy, comparable to completion rates in White populations found in other studies. However, Hispanic respondents, compared to Whites and African-Americans, were more likely to want their physician or family member to initiate these discussions; were more likely to value collective decision making rather than individual family decision making; and were more likely to worry that they would not be treated “as well” as others or that physicians might prematurely discontinue life-support if they made decisions for less aggressive care. Perkins et al.¹³⁶ interviewed European, African, and Mexican-American community-dwelling adults and found that while all groups agreed with the idea of end-of-life planning, Mexican-Americans and African-Americans were less receptive to the need for an AD. Blackhall et al.,¹⁴⁶ in a study of 800 older White, African-American, Mexican-American, and Korean-American adults found that ethnicity was strongly related to preferences for life-sustaining technology in terminal illness, but the relationship between ethnicity and preferences was complex. Whites were the least likely to want life-support, whereas Mexican-Americans were more likely to want it. Korean-Americans were more positive about the use of life-sustaining treatment than Whites but did not want such technology used personally. African-Americans generally felt it was acceptable to withhold and withdraw life-support, but were the most likely to want to be kept alive on such treatment.

Kwak and Haley¹⁴⁷ reviewed 33 empirical studies investigating racial/ethnic variation in end-of-life decision making and found that non-White groups had less knowledge about ADs and were less likely than Whites to support the use of ADs. There were various reasons for these views: African-Americans were found to more often prefer the use of life-support; Asians and Hispanics were more likely to desire family-centered decision making (rather than an autonomy-based model); and Hispanics were less likely to believe their actions could change the future and were more concerned that life-sustaining treatments would be withdrawn prematurely. Similar results were found in a qualitative study by Shrank et al.¹³⁹ In the nursing home, African-Americans were found to be about one-third as likely to have an AD as Whites, even after controlling for health and other demographic factors.^{148,149}

Limited uptake of ADs in the African-American population has been attributed to distrust of the medical care system and the unfavorable reaction to the concept of ADs. Some researchers argue that cultural differences in AD completion rates are not grounded in racial/ethnic differences, but are based in economics and that failure to execute an AD is based on a differing set of beliefs relative to the dying process.¹⁵⁰

This perspective views race and ethnicity as surrogates for economic and educational differences in access to health care.¹⁵¹ Yet, other research has shown that when socioeconomic factors are taken into consideration, minority groups still tend to express different preferences than Whites for end-of-life care.¹⁴⁶

Differences in minority compared to non-minority views on ADs have been found to include spiritual concerns, cultural concerns, and individualization -- that is, each person should be considered unique, and therefore, the circumstances of their death are unique and their wishes and needs should not be stereotyped based on culture.¹⁵² Johnson et al.¹⁵³ reviewed literature published between 1966 and 2003 to explore spiritual beliefs that may influence the treatment preferences of African-Americans. They found two commonly overlapping themes: the belief that only God has the power to decide life-and-death and a belief in divine intervention or miracles. Consistent with studies noted above, African-Americans were more likely than Whites to favor life-sustaining treatments regardless of illness severity and less likely to complete an AD. Similarly, True et al.¹⁵⁴ examined differences between African-American and White patients with cancer regarding spirituality and found that African-Americans were more likely to report using their spirituality to cope with their cancer as compared to their White counterparts, and patients who reported a belief in divine intervention were less likely to have a living will.

Some research suggests that ADs, as currently constituted, are not compatible with the cultural traditions of some patients.^{43,146} Searight et al.¹³⁸ identified three basic dimensions of end-of-life care that vary culturally: communication of “bad news,” locus of decision making, and attitudes towards ADs and end-of-life care. Some evidence suggests that Hispanic, Asian, Chinese, Pakistani, and Native-American communities prefer to avoid the emotional and physical stress caused by addressing end-of-life issues, and family members actively protect the terminally ill from knowledge of their condition. In terms of decision making, relative to persons of African-American or European descent, Korean and Mexican-Americans appear more likely to consider family members, rather than the patient alone, as holding the decision making power regarding life-support. In Asian cultures, family-based medical decisions are a function of an orientation towards the extended family, rather than the patient’s self-interest.¹⁵⁵ Illness is considered a “family event” rather than an individual occurrence.

An additional factor associated with less AD use among persons in minority groups may include poor communication between White health care providers and racial/ethnic minority patients for whom English is a second language.¹⁵¹ However, there is little evidence of racial/ethnic differences in satisfaction with or expectations about ACP.^{21,75,156}

4. Role of patient/provider communication in advance directive use. Many see ADs as a mechanism to help physicians and patients begin to talk about end-of-life care.^{10,157} However, discussion about ADs requires an emphasis on anticipatory planning and communication research reveals that physicians typically spend little time (less than one minute out of a 20 minute visit) discussing treatment and planning.¹⁵⁸

Although initiation of ACP is viewed as the responsibility of the physician, conveying prognosis and treatment information is widely regarded as a difficult task for health care providers. Breaking bad news is difficult for many physicians.¹⁵⁹

How clinicians talk with patients about end-of-life care does matter. Fried et al.^{160,161} identified three major informational influences on patient decision making concerning treatment preferences: treatment burden, treatment outcome, and the likelihood of the outcome (recognizing that patients' valuations of outcomes may change over time). For some patients, treatment burden would be bearable if the treatment outcome was desirable, but patients were less willing to endure perceived burden for marginal outcomes. Certain outcomes were so unacceptable that they determined preferences regardless of burden. However, some participants' responses revealed that their willingness to tolerate adverse outcomes may increase as their illness progresses. A number of studies have found that older patients are more interested in discussing the outcomes of serious illnesses (specifically how various illness and treatments might affect their valued life activities) than specifying desired medical interventions.¹⁶² These findings suggest that patient-centered approaches to end-of-life planning should incorporate consideration of both treatment burdens and treatment outcomes, including the likelihood of these outcomes.

Barriers to physician-initiated AD discussions and referral to palliative or hospice care include clinicians' reluctance to discuss these matters because they are uncomfortable or lack familiarity with suitable alternatives to aggressive treatment, lack of time for these discussions, belief that patients and families do not want such discussions, association of palliative care or hospice with death, and the belief that ADs and ACP discussions are not needed.^{16,163,164,165,166,167}

Providers receive little formal training in these areas, and conducting ACP discussions is complex.^{168,169} Most health care professionals do not think that their training or clinical experience has prepared them well to help patients and families at the end of life.^{95,167,170,171,172,173} A substantial literature documents serious deficiencies in end-of-life care education during medical school and residency training in the United States^{174,175} and large proportions of medical professionals and nurses report feeling unprepared for end-of-life discussions, such as breaking bad news, addressing patients' emotional concerns, and discussing patients' preferences for life-sustaining treatment.^{170,171,173,176,177,178,179} Several studies examined the competency of medical professionals and residents to conduct end-of-life discussions. Most accepted a professional responsibility to care for dying patients, but the majority felt unprepared to address end-of-life planning, conduct end-of-life discussions, manage their feelings about a patient's death, and help bereaved families.^{171,180,181}

Moreover, as noted above in Section VI.A.3, not all patients want to entertain ACP discussions. Clayton et al.¹⁸² examined the attitudes of terminally ill patients, and their caregivers and providers about how, with whom, and when discussions about prognosis and end-of-life issues should be initiated with dying patients. They found disparate views among respondents about the optimal timing, substance, and context for these

discussions. Patients and families identified five elements as essential for these discussions:

- Feeling comfortable with the health care provider.
- Feeling that the provider showed compassion and respect for the patient.
- Having the provider clarify the degree of detail that patients/caregivers wanted.
- Negotiating who should be present during the discussion.
- Involving their continuity physician in the discussion.

Curtis et al.¹⁸³ asked patients with severe COPD to rate their satisfaction with communication with their physicians and found that patients rated physicians highly at listening and answering questions but reported that most physicians did not address how long the patients had to live, what dying might be like, or patients' spiritual needs.

Patients, families and clinicians may inadvertently collude to avoid mentioning death, dying, or planning for the end of life.^{16,184} As a result, providers frequently misunderstand a patient's end-of-life preferences^{87,94,185} or tend not to follow instructions specified in an AD.¹⁸⁶ Even when AD discussions do take place, studies suggest that clinicians do an inadequate job of communicating with patients and families or providing relevant information in understandable form.¹⁸⁵ For example, Fried et al.¹⁶¹ examined agreement between patients, caregivers, and clinicians regarding prognosis communication and found that in 46% of patient/clinician and 34% of caregiver/clinician pairs, the clinician reported having informed the patient that he or she had a life-threatening condition, whereas the patient or caregiver reported no such discussion. In 23% of patient/clinician and 30% of patient/caregiver pairs, the clinician reported discussing an approximate life expectancy, whereas the patient or caregiver reported no such discussion. Of the patients who reported no life expectancy discussion, 40% reported that they did not want this discussion. In addition, patients and families recall only a fraction of the information physicians transmit, and the evidence suggests that some patients do not desire detailed information.¹⁸⁷⁻¹⁹²

5. Stability of and proxy understanding of patient preferences. In order for ADs to direct medical care according to patients' desires, the preferences contained in these documents must reflect patients' wishes. Because ADs are static documents, the stability of patient preferences concerning end-of-life care is important. Several studies have demonstrated modest stability in preferences over periods of up to two years.^{23,183,193,194} Other studies found that patients' preferences changed enough during the progression of an illness that ongoing discussion and updating of preferences was needed.^{195,196} The manner in which treatment information is presented can influence patient decision making, so discussion factors may affect the stability of preferences.^{197,198,199} Moreover, research suggests that changes in patient preferences

are associated with specific illness events, disease progression, and patient characteristics as well as end-of-life discussions.^{23,43,88,200,201,202}

McParland et al.¹⁹⁵ examined stability of patient preferences over time for nursing home residents and found that preferences regarding CPR and parenteral and enteral nutrition changed over both 12 and 24 month follow-up, but only degree of change in cognitive status proved to be predictive of these changes. Ditto et al.⁶⁴ longitudinally examined stability of patient preferences for life-sustaining treatments in a sample of hospitalized elders and found that treatment preferences showed a significant “hospitalization dip.” Respondents reported less desire to receive life-sustaining treatments at the recovery interview than they did at the annual interview conducted before hospitalization. However, the desire for life-sustaining treatment returned to near pre-hospitalization levels at the annual interview conducted several months after hospitalization. This dip was more pronounced in preferences for CPR and artificial nutrition and hydration than in preferences for less invasive treatments, suggesting that preferences for life-sustaining treatment are dependent on the context in which they are made -- individuals may express different treatment preferences when they are healthy than when they are ill.

The accuracy with which proxy decision makers can predict patient end-of-life treatment preferences has been shown to vary considerably.^{44,63} However, much of this research has used hypothetical scenarios of future health care decision making versus rigorous investigations of actual practice.

Although ADs do not necessarily depend on a proxy’s ability to know patient preferences, part of the goal of ADs and ACP in general is for surrogates to better understand how patient goals and preferences would guide medical decision making toward the end of life. However, observational studies suggest that families rarely reliably 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. Shalowitz et al.²⁰³ reviewed 16 studies examining patient/proxy correspondence in terminally ill patients, hospital outpatients, and community-dwelling chronically ill elders. They found that patient-designated proxies and next-of-kin surrogates correctly predicted patients’ end-of-life treatment preferences in two-thirds of cases (68% accuracy). Proxies were most accurate in predicting preferences in the context of the patient’s current health (versus hypothetical scenarios); predictions were least accurate for patients with dementia or stroke. When proxies erred in predicting patients’ preferences, they tended to provide interventions that the patient did not want,^{204,205,206} although this was not consistent across all studies.²⁰⁷⁻²¹⁴ There was no difference in accuracy in studies comparing patient-designated proxies with legally-assigned proxies. Four studies found that proxies predict patients’ preferences more accurately than do physicians.^{206,207,211,212} Two studies assessed whether discussion of patients’ treatment preferences improved proxy accuracy and found conflicting results.^{63,215}

6. Barriers to advance directive completion. Although older adults and those with serious illnesses seem willing to participate in end-of-life planning,¹⁶⁶ a significant

proportion of patients do not fully understand their options concerning end-of-life care.²¹⁶ Knowledge of ADs alone does not increase their use, and a majority of patients who are aware of ADs do not complete a document.^{43,217} A wide variety of obstacles impede ACP and AD completion,^{85,218} including the following:

- Inadequate knowledge about ADs and how to complete one.
- Perception that ADs are difficult to execute.²¹⁹
- Perception that even if completed, AD statements will not be followed by clinicians.
- Reluctance to broach the issue of “death” and end-of-life planning.
- View that an AD is unnecessary because one’s family or provider will “know” what to do.
- Perception that ADs are important for others, but not for themselves.⁴³

An additional barrier to AD completion appears to be the inflexibility of the documents. While many patients would welcome discussions about end-of-life planning with their clinicians, they would prefer to delegate decision making authority to proxies rather than make rigid decisions now for complex decision making in the future.⁶⁵ Others are willing to state a preference in an AD, but are willing to let a proxy overrule that decision at a future time.⁷⁵

B. Interventions to Increase Advance Directives and Advance Care Planning

Efforts to increase AD completion have primarily been patient and/or provider educational interventions.²⁰ Early consumer education interventions included studies assessing how AD completion was affected by providing written AD materials alone, written AD materials with single educational sessions, or AD materials and/or educational sessions with limited provider guidance or follow-up. Lorenz et al.⁷⁵ conducted a systematic review of the literature (1990-2004) to assess the evidence concerning interventions to improve palliative and end-of-life care, including AD interventions. Simple, single-component consumer education interventions designed to increase knowledge of, or completion of, ADs were mostly unsuccessful, or were only modestly successful. Single-component interventions tended to result in low AD completion rates, especially for interventions without an educational component or for mailed forms alone.^{77,220,221,222,223} Furthermore, few of these educational interventions were shown to decrease the use of life-sustaining treatments. Studies of more structured and/or “facilitated” end-of-life planning interventions with healthy, chronically ill, and seriously ill ambulatory geriatric patients and their caregivers demonstrated more promising, though modest, results.^{75,224} Interventions were more successful when

severely ill patients were targeted and when multi-component, longitudinal approaches were used -- that is, interventions using educational materials combined with repeated treatment preference discussions during clinical encounters over time and with enhanced accessibility of the documentation of patient wishes, when needed. Only multi-faceted interventions (e.g., education in combination with reminders and performance feedback) increased the frequency of physician-initiated AD discussions with patients.²²⁵

Guo and Harstall²²⁶ conducted a systematic review of the literature (1994-2001) on AD consumer education interventions and found similar results: modest increases in completed ADs using simple interventions (e.g., written materials alone, materials with educational videotapes, and physician-initiated discussions) while more comprehensive interventions (e.g., an education session plus telephone reminder or an interactive seminar) yielded higher AD completion rates of 30-40%. A comprehensive and complex education intervention, the *Let Me Decide* program that incorporated a multi-faceted educational approach, increased completion rates by 45%. In this intervention, hospital and nursing home staff and nursing home residents and their families were educated about ADs, and documents were offered in the context of a specific intervention designed to elicit preferences.

Interventions to improve provider communication skills have had mixed results. Some show little effect, while other interventions have increased participants' knowledge, skills, and attitudes related to end-of-life care.²²⁷⁻²³² One study of fellows completing a geriatric medicine rotation focused on end-of-life care found increased physician-reported preparation for care for dying patients.²³³ Song²³⁴ and Walsh et al.²³⁵ reviewed the literature on "breaking bad news" and AD discussion delivery methods with healthy and ill elderly, including the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), and found that end-of-life discussions contributed to increased patient satisfaction with patient/provider communication. They found no evidence of negative psychological adjustment or affective outcomes from these discussions. A controlled trial of preference elicitation and AD completion with patients awaiting cardiac surgery did not find increased anxiety among patients or family members but did find increased congruence between patients and their families concerning preferences.²³⁶

In the nursing home setting, several interventions to improve care at the end of life have used trained facilitators (e.g., non-physicians, nurses, or social workers) and structured AD discussion guides to improve concordance between nursing home resident's stated preferences and the care received. More detailed and meaningful ADs in nursing homes were achieved with more and focused discussion.^{103,109,237,238} In a randomized controlled trial conducted in six nursing homes from 1994-1998, 1,292 residents were evaluated for utilization and satisfaction with health care over 18 months. Forty-nine percent of residents in intervention nursing homes and 78% of families of incompetent residents completed ADs. Satisfaction was not significantly different in intervention and control nursing homes, but intervention nursing homes reported fewer hospitalizations per resident (mean, 0.27 vs. 0.48; $p=0.001$) and less resource use

(average total cost per patient) than control nursing homes. Mortality was similar between intervention and control nursing homes (24% vs. 28%, $p=0.20$).²³⁹

Numerous other models of interventions to increase AD use have been described, including:

- Efforts to increase patient/family/provider shared decision making.¹⁴¹
- Discussion guides for clarifying values.²⁴⁰
- Structured and/or facilitated ACP programs or care coordination models incorporating ACP.^{16,100,166,241,242,243,244}
- Flexible decision making models such as using ADs as a basis for extrapolation and interpretation rather than simplistic application of prior preferences to real-time decisions.^{157,245}
- Open-ended, process-based approaches for reaching agreement for future decisions.²⁴⁶
- ACP materials that utilize open-ended questions and follow-up to elicit a patient's concerns, goals, and values.¹⁶⁷
- AD materials that aim to make completion easy for patients and families working alone.^{32,247}
- Peer mentoring models.⁸⁶
- Comprehensive interventions targeted at community-dwelling elderly.²⁴⁸

An interesting AD intervention tested the use of five educational booklets designed to improve end-of-life knowledge, attitudes, and practices in a multi-ethnic sample of family caregivers of well, homebound, and institutionalized elders.²⁴⁹ At the three-month follow-up, there were small improvements in AD completion rates and significant increases in proportions of caregivers with funeral or burial plans and willingness to consider hospice. Schwartz et al.²²⁴ evaluated the Respecting Choices AD program, in which nurses and social workers facilitated AD discussions with patients and caregivers. They found greater congruence in caregivers' understanding of patients' preferences, less willingness to undergo life-sustaining treatment for a new serious medical problem, but more willingness to receive such treatments for an incurable progressive disease in the intervention groups relative to the control groups. Shorr et al.²²² evaluated whether administrative prompts or mandatory educational interventions increased documentation of physician-initiated end-of-life discussions with seriously ill patients. They found no difference between baseline and three-year follow-up in ACP discussions (35% at baseline and 34% at follow-up) or DNR orders (29% baseline vs. 27% follow-up). Overall, the research indicates that multi-component, longitudinal

educational interventions modestly increase AD completion rate and moderately increase medical record documentation, but more sophisticated techniques are needed to motivate physicians and patients to initiate ACP discussions and to induce patients to complete an AD.⁷⁵

More intensive and community-wide interventions that involve collaborative ACP mechanisms have demonstrated more positive results.^{63,166,242,250,251,252} For example, Hammes and Rooney²⁴² conducted a retrospective study of all adult decedents residing in a defined geographic area who died while under the care of health care organizations participating in a comprehensive, systematic community-wide AD education program (*Respecting Your Choices*). They found that the prevalence of ADs increased from 15% to 85% during the intervention and that the median time between AD documentation and death was 1.2 years. Almost all ADs requested that treatment be forgone as death neared, and treatment followed these instructions in nearly all cases (see also Section VI.D.2.b). A modified version of this model was pilot tested on a small sample of chronically ill adults (congestive heart failure, end-stage renal disease, and preoperative open-heart surgery patients) and their caregivers using quality improvement techniques. The intervention significantly increased congruence in decision making between patients and caregivers for future medical treatment.^{250,251} In addition, the intervention group demonstrated greater satisfaction with the decision making process and less conflict about decisions.

Other palliative care-related interventions incorporating end-of-life planning have shown that home-based ACP for chronically ill patients was able to decrease aggressive treatment and that more patients died at home.^{253,254} For example, Stuart et al.²⁵⁴ implemented the CHOICES ACP and palliative care program and demonstrated that intervention patients had increased hospice length of stay, spent less time in a hospital, and more often died at home. In an implementation of structured models of decision making (e.g., Physician's Orders for Life-Sustaining Treatment (POLST)) designed to travel across treatment settings to ensure continuity of care, orders regarding CPR in nursing homes were universally followed and were honored across settings. Residents with a POLST received more comfort care and were rarely transferred to a hospital for life-sustaining treatments (see also Section VI.D.3.a).^{132,255,256,257}

C. Advance Directives and Advance Care Planning Among Disabled Persons

ACP is founded on the ideals of self-determination, respect for individuals, and attention to compassion and palliation, so one might expect that ADs and ACP would be embraced by the disability rights community. Indeed, the American Association on Intellectual and Developmental Disabilities (formally the American Association on Mental Retardation) in its Position Statement on Caring at the End of Life, lists dignity, autonomy, life, and equality as among its core principles.²⁵⁸ This position statement endorses ACP and use of ADs. However, there has been considerable friction between

the disability community and those advocating for improved end-of-life care and policies.

Disability advocates have tended to feel disenfranchised from development of ACP policy. There is a strong undercurrent of opposition to policies promulgated by end-of-life care advocates.^{66,259} Asch suggests that this conflict arises because the disability community has focused on different sorts of cases than have end-of-life activists and because health care providers and those who champion ACP have different views from disabled individuals concerning how illness and disability affect quality of life.⁶⁶

Disability rights activists have raised concerns that ADs and withdrawal of life-sustaining care, when combined with biased and inaccurate views of patients' quality of life, encourage less aggressive care and withdrawal of life-sustaining treatment, permitting persons with disability to die earlier than warranted.^{258,260,261} Many factors contribute to these concerns, including the history of social and economic persecution of persons with disability,²⁶² lack of attention to improving the conditions or accommodating persons with disabilities so that they can maximize their quality of life^{263,264} and explicit and implicit coercion of disabled individuals.^{263,265} Then there is the paradox that many people in the general population view the situations in which some disabled persons routinely live as states "worse than death" that they would not use life-sustaining treatment to achieve or preserve.²⁶⁶ Some in the disability community view as unacceptable certain diagnoses given to extremely compromised health states (e.g. the persistent vegetative state and the minimally conscious state) and find it unacceptable for clinicians to withhold or withdraw life-sustaining treatment from persons in such states.^{258,267} Others argue that the legal mechanisms of decision making inadequately account for the views of disabled persons.²⁶⁸ The disability community also raises the issue of whether biases concerning quality of life translate into reduced clinician effort to maximize patient's quality of life, which in a self-fulfilling manner yields patients accepting less aggressive care.⁶⁶

There is no uniform definition of disability. According to the Americans with Disabilities Act (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." Major life activities include seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, or working. Examples of disability so defined include individuals with epilepsy, paralysis, Human Immunodeficiency Virus (HIV) infection, substantial hearing or visual impairment, mental retardation, or a specific learning disability.²⁶⁹ Based on this definition, one in every five persons in the United States -- more than 50 million people -- has a disabling condition that interferes with life activities. About 19% of non-institutionalized United States civilians have a disability, and almost half of these people have a severe disability.²⁷⁰

The ADA definition is broad. However, the focus of disability advocacy has been patients with developmental disabilities -- both intellectual and physical -- as well as psychiatric disabilities and acquired disability not due to aging-related illness. Older

patients with chronic disease who have compromised physical and mental function have received less emphasis from the disability community. Thus, concerns about the failings of ACP and ADs among disabled persons have little relevance to treatment of older patients, particularly those with age-related cognitive impairment.

In this section, we summarize the peer-reviewed literature relevant to patients with developmental and early-acquired intellectual, physical, and psychiatric disabilities. Our purpose is to understand:

- The views of disabled patients regarding ACP and ADs.
- The preferences of disabled persons for treatments in current and future adverse health states.
- Disabled persons' use of ACP and ADs.
- The ways in which decisions are made for disabled persons toward the end of life.

As we will discuss below, there is little research about ACP and AD among disabled persons. Where research does exist, it is often restricted to individuals who have *intellectual (usually developmental) disabilities*, individuals with *psychiatric disability*, and those with *physical disability*; studies of this last group often include cognitively impaired persons toward the end of life. We organize our discussion around these groups.

1. Advance care planning and advance directive completion among disabled persons.

a. *Intellectually disabled persons.* Overall, individuals with intellectual disabilities die at an earlier age than their counterparts in the general population. However, many live as long as their peers, and disabled individuals and the general population die of a similar spectrum of causes, namely cardiovascular, respiratory and neoplastic diseases.^{271,272} The need for ADs and ACP among intellectually disabled adults has been recognized for over a decade.²⁷³ However, we found only two empirical studies of ACP or AD use by persons with intellectual disability. In a residential center caring for 850 persons with severe developmental disabilities, two (0.2%) had completed an AD.²⁷⁴ This study did not report whether any ACP discussion had occurred with residents or their families. In a second study, physicians caring for institutionalized intellectually disabled persons in the Netherlands found that among the 67 patients for whom an end-of-life decision was made in 1995, the end-of-life decision was discussed with only two of them.²⁷⁵ This study did not report whether any patient had completed an AD. A review of end-of-life care for people with intellectual disabilities suggested that issues about end-of-life care were raised infrequently and that there were substantial obstacles to integrating discussions about end-of-life care with other services.²⁷⁶

For some intellectually disabled persons, a substituted judgment is impossible because they were never able to form or express preferences. However, for most of these individuals, there is an untapped potential to make end-of-life decisions. A diagnosis of cognitive impairment does not necessarily mean that a person is unable to participate in treatment decisions. A study of 90 adults that included 30 with mild intellectual disabilities and 30 with moderate intellectual disabilities formally evaluated capability to make an informed medical decision.²⁷⁷ Most adults with no or mild disability and almost half of the adults with moderate disability were able to make and justify treatment choices and at least partially understand treatment information. Most adults without intellectual disability, 50% with mild, and 18% with moderate disability were able to partially appreciate relevance of treatment choice to their situation and to weigh treatment risks and benefits. Performance in all groups decreased with increasing complexity of decision making.²⁷⁸ Another small study that focused on older patients with dementia suggests that individuals who had cognitive impairment and were incapable of completing ADs were significantly more likely to opt for life-sustaining interventions.²⁷⁹

b. *Psychiatrically disabled persons.* Whether patients with mental illness have the ability to complete ADs is of concern to patients, families and providers. Measurement tools exist to formally evaluate capacity to complete an AD, although it is not suggested by experts that these tools be used routinely.^{280,281} Several studies of persons with serious mental illness suggest that a substantial number of these individuals are capable of completing ADs.^{282,283,284} One study shows that facilitated discussion increased the ability of persons with psychiatric illness who have borderline capacity to complete an AD.²⁸⁵

We identified three studies of ACP and ADs for medical care in patients with chronic psychiatric disease affecting function. These studies found that such patients are generally predisposed to complete ADs and that many are able to do so. A structured interview study of 142 persons in a community convenience sample who met state criteria for serious and persistent mental illness found that 72% believed a proxy should be designated and 62% were able to choose a proxy to make decisions;²⁸⁶ for 23% of the patients, their proxy would be a health care worker, which would pose difficulty for completing a durable power attorney for health care. Eighteen percent of respondents in this study had selected another person to be their proxy, but it was not reported how many codified this decision in an AD. Twenty-seven percent of persons had existing preferences concerning medical treatment, 5% had discussed these with a physician, and 2% had written them down. Most patients were comfortable with the ACP interview, and interviewers rated nearly all patients as able to understand the topic.²⁸⁶ An evaluation of 18 male veterans on a chronic care psychiatric inpatient unit found that 83% had the capacity to complete an AD (measured by an informal psychiatric assessment); of the 15 patients with capacity, 80% had completed an AD.²⁸⁴ An evaluation of 161 inpatients at a state psychiatric facility found that 44% had full guardians and were ineligible to complete ADs. Of the remaining 90 patients, only 16

(10% of the full population) were deemed sufficiently competent to execute a health care proxy and had done so.²⁸⁷

Analogous to ADs for medical care, ADs for psychiatric care aim to identify preferences concerning psychiatric care and delineate a proxy to make such decisions. There has been more study of these documents than of medical ADs among psychiatric patients, but the evaluations show similar findings: few persons with psychiatric disease have them, but most would like to complete one. A survey study of 1,011 psychiatric outpatients in five United States cities found that more than 13% had completed a psychiatric AD; however, 77% wanted to complete one if given assistance.²⁸³ A study of 303 adults with serious persistent mental illnesses who were receiving community mental health services found that 53% expressed interest in completing a psychiatric AD.²⁸⁸ An intervention study that facilitated completion of psychiatric ADs for 106 community-dwelling mental health center outpatients found that most of the preferences had clinical utility and 46% appointed a surrogate decision maker.²⁸⁹ A randomized clinical trial of 469 patients with severe mental illness found that a semi-structured interview and guided discussion commonly led to completion of a psychiatric AD (61% vs. 3% in the control group).²⁹⁰ Evaluation of the outcome of psychiatric ADs suggests little effect on care received.²⁹¹

c. *Physically disabled persons.* Many studies have described ACP and AD use among patients with a variety of physically disabling conditions. However, all of the studies focused on patients with acquired disabilities, and most had chronic conditions, many toward the end of life. There are important distinctions between those who acquire disability early in life relative to those who acquire disability as a result of the aging process. The studies that address disability acquired late in life are described primarily in other sections of this review. For many areas of physical disabilities, such as hearing and vision impairment, there is recognition of need for attention to ACP and ADs,²⁹² but we could find no data on use of these modalities or preferences for care among these patients.

2. Preferences among persons with disabilities.

a. *Intellectually disabled persons.* We were unable to find any studies of the preferences of individuals with intellectual disabilities regarding their end-of-life care. One study of 60 individuals with severe mental retardation and complex medical problems, age 2-32 years, in a pediatric nursing facility in Massachusetts evaluated an intervention implemented in 1991 to involve *families* in making resuscitation decisions for these individuals. After an institutional policy change whereby all parents and/or guardians were requested to specify formally in writing whether they wished CPR for their children in the event of cardiopulmonary arrest, families were informed of the policy change and provided information about CPR, informed that CPR would be initiated by default in the absence of a DNR order, instructed that they had the right to refuse treatment, including CPR. Additional information on life-sustaining treatment was included as well as the opportunity to discuss the issue with clinicians. No patient was

capable of participating. From a baseline of 18% of patients with DNR orders before the intervention, 43% had DNR orders after the intervention.²⁹³

b. *Psychiatrically disabled persons.* The interview evaluation of 142 persons in a community convenience sample who met state criteria for serious and persistent mental illness also asked about preferences for end-of-life care by presenting two scenarios: (1) if the person had incurable metastatic cancer with pain, would s/he want increased pain medication even if it resulted in confusion or inability to communicate? (2) if the person had total paralysis with irreparable brain damage, would s/he desire continuation of life-sustaining treatment?²⁸⁶ Twenty percent of participants reacted negatively to at least some component of the interview, although none seriously and 4% did not complete it. In response to the first scenario, 66% said they would want a physician to administer as much analgesic as needed even if it meant cognitive suppression. Concerning the second scenario, 28% felt that life-sustaining treatment should be stopped immediately, 43% indicated that it should be stopped within a defined period of time (7-30 days), and 28% felt that it should be continued indefinitely. Many respondents in the latter two categories indicated hope for a miracle.

Analogous to the concern that psychiatrically disabled persons are incapable of completing ADs, there is also concern that patients with mood disorders might make life-sustaining treatment choices that they might not make if unaffected by psychiatric disease. One study of this issue in 43 older patients suffering from major depression interviewed them on admission to a psychiatric inpatient unit and at discharge about their desire for specific medical therapies in their current state of health and in two hypothetical scenarios of medical illness. Twenty-four of the individuals were in remission from depression at the time of discharge. In the majority of patients, remission of depression did not result in an increase in desire for life-sustaining treatment. However, a clinically evident increase in desire for life-sustaining treatment followed treatment of depression in the 26% of subjects who had been initially rated as more severely depressed, more hopeless, and more likely to overestimate the risks and to underestimate the benefits of treatment. The authors concluded that in major depression of mild to moderate severity, a patient's desire to forgo life-sustaining treatment is unlikely to be altered by depression treatment. But severely depressed patients who are hopeless overestimate the risks of treatment, or underestimate the benefits of treatment and should be encouraged to defer specifying preferences concerning life-sustaining treatment until after treatment of their depression.²⁹⁴

c. *Physically disabled persons.* As noted above, a large number of studies have evaluated preferences among persons with physical disabilities, mostly related to late-life acquired disability. Most of these studies characterize the views of persons with progressive chronic diseases most often associated with aging, such as cardiopulmonary disease, HIV, cancer and renal failure. We were unable to find any quantitative evaluation of preferences among patients with developmental physical disabilities or younger patients with disabling conditions. However, two small qualitative studies -- both focused mainly on physician assisted suicide -- evaluated the views of convenience samples of physically disabled individuals about end-of-life care. The first

was an interview evaluation of 45 individuals that found that concern for autonomy and self-determination was a central theme for these individuals.²⁹⁵ The qualitative analysis revealed “many study participants stressed the importance of autonomy in end-of-life decisions, stating that life-and-death decisions should not be in the hands of doctors, family members, HMOs and other bureaucratic bodies. Many shared the experiences of friends and loved ones who they said “suffered needlessly” -- whether disabled or not -- when aggressive treatments for a terminal illness had prolonged pain and suffering.” These participants were also concerned that disabled persons were devalued in society and “there was widespread worry, for example, that doctors, HMOs, and others may hasten death because the lives of people with disabilities are not considered worthy or valuable.” The second study was a qualitative evaluation of the responses of 55 physically disabled individuals to an on-line open-ended question about vulnerability to coercion and ability to make their own decisions.²⁶⁶ There were a variety of views with most respondents believing that they could make voluntary decisions and wanted the uncontested ability to do so. Yet, the potential to be influenced by social pressures came through in many of the responses, for example: “I feel there is potential for the most vulnerable to feel less worthy. This is a function of a society that values beauty and health not wheelchairs and deformities.”

The lack of adequate valuation of disabled persons by health care providers and a major chasm between how clinicians and disabled persons see the world was also a major theme of the findings from a qualitative evaluation of 13 parents of children with mixed developmental disabilities, nine adults with physical disabilities and eight family members.²⁹⁶ This analysis -- which did not consider end-of-life care -- suggested that health care must attempt to understand health perceptions from the vantage of the disabled person including obstacles and goals in order to optimally provide care.

3. End-of-life care for persons with disabilities. This section considers care for patients with intellectual, physical and psychiatric disabilities, but it does not summarize care toward the end of life for patients with conditions typically associated with aging, including dementia.

a. *Intellectually disabled persons.* We were able to identify only two studies that evaluated the care provided to intellectually disabled persons at the end of life. In the above noted residential care facility caring for 850 persons with severe developmental disability, there were 38 deaths during the 2½ year study. For ten of these decedents (26%), an explicit end-of-life decision was made. During that same study period, the institution made 16 end-of-life decisions: 12 were decisions that the resident should not be resuscitated and four were decisions that the resident should continue to receive full medical treatment. In 11 of these cases, the referral for an end-of-life decision was made by the person’s parent or other relative. Among the 12 patients for whom a DNR decision was made, seven died within one week and two more within the year.²⁷⁴ In the survey of physicians in the Netherlands, 89 doctors reported 222 deaths for 1995. An end-of-life decision was made in 97 cases (44%).²⁷⁵

b. *Psychiatrically disabled persons.* A retrospective medical record evaluation of 191 geriatric psychiatric inpatients with major depressive disorder or bipolar disorder found that 48% had orders to forgo resuscitation and 12% wanted CPR only (no ventilation). Patients with suicidal ideation were significantly less likely to choose CPR. Patients with bipolar disorder and patients under age 70 were more likely to choose CPR.²⁹⁷

D. Interventions to Improve Advance Directive Completion/Advance Care Planning: Health Information Technology, Social Marketing, and Legislation/Policy

As noted above, ADs are completed by only a fraction of the adult population; completed ADs may be unavailable when needed clinically; and even when available, ADs may not be followed by providers. Increasing the use and effectiveness of ADs -- both with the public and with providers -- requires widespread behavioral change that motivates both communities to act. In this section, we discuss three different mechanisms of inducing behavioral change. The topics addressed here include the use of HIT to increase the completion of ADs as well as their application in a patient's care, the role of social marketing to increase the perceived importance of and execution of ADs, and the role that legal intervention and policy change may have in improving AD completion implementation.

1. Health information technology. Although health care providers are thought to be the best catalyst to promote the completion of ADs, clinicians do not routinely bring up the discussion during the course of a routine visit or even during an acute event. Even when completed, ADs do not always have the anticipated clinical impact. According to a study conducted by Morrison and colleagues,²⁹⁸ among those who had previously executed ADs, only 26% had their directives recognized when they were hospitalized.

Information technology is widely used in many industries to create efficiencies and produce better quality products. HIT holds promise to improve the quality of care and the efficiency with which it is provided.^{299,300,301,302} HIT could facilitate completion and implementation of ADs. In this section, we briefly define the types of HIT and describe where and how it is currently being used. We then present available evidence on the efficacy of HIT in facilitating ACP and the completion/implementation of ADs.

a. *What is health information technology and how is it used?* HIT has been mostly confined to administrative information technology systems such as billing, scheduling, and inventory management.³⁰³ Clinical HIT is less common. When we think of HIT, we mostly think of the electronic medical record (EMR). EMRs are generally commercially developed (although some notable EMR systems have been developed internally to the organization) and are implemented in a single provider entity (e.g., hospital, physician's office, clinic, etc.). An electronic health record (EHR) incorporates many different types of HIT and characterizes all of a patient's care, not just that from a specific provider.³⁰⁴

Chaudry and colleagues²⁹⁹ recently reviewed the literature evaluating the impact of HIT on quality, efficiency and costs of medical care. Table 1 lists the most commonly cited types of HIT examined in the literature and provides a brief description.

HIT investment in the United States is still relatively low, especially as compared to other countries, particularly Australia, Canada, Germany, Norway and the United Kingdom. The United States invests less than 50¢ per capita on HIT; the investment in these other countries ranges from almost \$5 to about \$192 per capita.³⁰⁹ A 2004 survey of United States provider organizations (both inpatient and ambulatory care) found that approximately 26% of hospitals and 13% of ambulatory providers have installed a basic EMR. Among hospitals, 10% have installed Computerized Provider Order Entry (CPOE) and 28% installed Picture Archiving Communications Systems (PACS). Only about 5% of all hospitals have adopted a more comprehensive system that includes all three components (EMR+CPOE+PACS). HIT adoption is greater among hospitals or provider groups affiliated with an HMO or a preferred provider organization; approximately 38% of HMO-affiliated hospitals adopted a basic EMR as compared to 29% of hospitals without managed care affiliations or investments.³⁰³ These numbers may overstate HIT uptake due to a bias in the survey sampling toward larger hospitals.

Notable HIT users are the Veterans Health Administration, Kaiser Permanente, Regenstrief, Brigham and Women's Hospital, LDS Hospital/Intermountain Health Care, and Partners Health Care.^{299,300,302,308,310,311} In most cases, HIT systems are integrated across ambulatory and inpatient settings. HIT is stimulated by a variety of factors, including governmental initiatives such as the HHS Health Information Technology Initiative.³¹² Although current use of HIT is relatively low, HIT uptake has increased rapidly starting in 2001. It is not clear whether the accelerating trend will continue, but this trend does suggest that many more providers will come on-line with at least some elements of HIT in the coming years.

One of the challenges in developing an EHR is agreeing on and integrating the specific elements of the HIT systems of multiple providers. The ability to share information across providers with a uniform instrument reflecting ADs are two care components important to the appropriate and timely execution of an AD. As described earlier, even when ADs are completed, they are often not available during an acute care situation, where they may be most relevant. In many cases, they do not transfer with the patient or are difficult to find in the medical record. This is certainly true with paper medical records but it is also a concern in the context of HIT. Without standards for system development, information sharing across providers and settings is challenging.

TABLE 1. Types and Definitions of Health Information Technology Systems	
Electronic Health/Medical Record (EHR/EMR)	A secure, real-time, longitudinal record of patient health information generated by one or more encounters in any care delivery setting. ³⁰⁵
Computerized Provider Order Entry (CPOE)	Allows health care providers to electronically order laboratory, pharmacy, and radiology services. ³⁰⁶
Clinical Decision Support System (CDSS)	Either a stand-alone system or integrated with the EHR/EMR and/or CPOE to support clinical diagnosis and treatment planning and to promote use of best practices/clinical guidelines. Such systems might also include reminders or alerts if integrated with the medical record. ³⁰⁷
Electronic Results Reporting	An electronic system for reporting lab values and/or radiology reports (PACS can be included under this heading). This can also be a stand-alone system or integrated with the EHR/EMR. ³⁰⁶
Electronic Prescribing	Involves use of a large electronic database of drug information to support selection and ordering of medications for a patient's condition. This can be considered a type of CPOE. ³⁰⁸

Several standards have been suggested to facilitate integrating HIT across providers and settings. These standards include those created by Health Level Seven (HL7), an American National Standards Institute-accredited standards developing organization. HL7 is relevant to this discussion because its specifications include a messaging standard that can allow for the exchange of key sets of clinical and administrative data. The model standards put forth by HL7 have received support from the industry and user communities and moves the United States closer to establishing nationwide guidelines for EHRs.

b. *Health information technology and health care outcomes.* Hundreds of studies have examined aspects of HIT. We identified a systematic review evaluating 257 studies published between 1995 and 2004 that describes how HIT affects quality of care, efficiency outcomes, and health care costs.²⁹⁹ In addition, a recent study presents data to estimate the potential costs of adoption, safety benefits, and other potential health benefits of widespread HIT adoption.³⁰⁰ We summarize these studies here.

Hillestad and colleagues³⁰⁰ developed a series of simulation models to estimate the potential costs of widespread HIT adoption as well as the potential cost savings assuming that interoperable and integrated EMR systems are widespread. Given this assumption, the study authors found that the cumulative cost for 90% of all hospitals to adopt an EMR system would be \$98 billion, assuming that 20% of hospitals currently have such a system (average yearly costs: \$6.5 billion). The cost for physicians to reach 90% adoption was estimated to be \$17.2 billion, equally split between one-time costs and maintenance costs (average yearly costs: \$1.1 billion). Additionally, at 90% adoption, the potential HIT-related efficiency savings in both the inpatient and outpatient settings could average over \$77 billion per year combined. The largest efficiency savings were estimated to come from reduced hospital lengths of stay, nurse administrative time, drug use in the hospital setting, and drug/radiology use in the outpatient setting.

The systematic review conducted by Chaudry and colleagues²⁹⁹ reports evidence of quality improvement due to increased adherence to guideline-based care, improvements in preventive care, and reductions in complications of inpatient care using computerized surveillance to identify high risk patients and trigger physician alerts. Medication errors were reduced through the introduction of CPOE. Notably absent in this review is any end-of-life application of EHR systems.

c. Health information technology and advance directives/advance care planning. For an AD to be useful in guiding a patient's care, it must be easily accessible to health care providers. As noted above, HIT is capable of improving health care across a number of domains. The most successful interventions were those that involved physician reminders or CDSSs integrated into an EMR. HIT may also help to support the completion of ADs, improve the understanding of patient preferences across multiple providers, and increase the likelihood that they will be available when needed. Still, the evidence to support these benefits of HIT for ADs is very limited. In this section, we describe the existing research and then provide some discussion of what questions remain unanswered.

Two studies were identified that used computer-generated reminders to physicians to encourage them to discuss AD completion with their patients.^{220,313} Dexter and colleagues²²⁰ tested the use of computer-generated reminders to physicians in the outpatient general medicine practice of a teaching hospital. In this study, physicians were randomized to: (1) receive reminders for instruction directives, which allow patients to indicate whether they want or do not want any of eight types of care (e.g., CPR, mechanical ventilation, etc.); (2) receive reminders for proxy directives; (3) receive both reminders; or (4) receive no reminders. Physicians who received a reminder were provided a menu of response options: "discussed today, next visit, not applicable, patient too ill, patient refuses to discuss, I agree with advance directives." An intention-to-treat analysis for 1,009 patients who met study criteria and did not previously complete an AD found that 137 patients reported having a discussion with their provider during the study period. Approximately 24% of patients whose physician received both reminders had a discussion with their physician about ADs as compared to 4% of the patients whose physician received no reminders ($p < 0.001$). This equates to a nearly eight-fold increase in the odds of having an AD discussion. When discussions occurred, physicians initiated conversations about ADs 86% of the time when receiving both types of reminders, 77% of the time when receiving instruction directive reminders only, 43% of the time when receiving proxy directive reminders only, and 38% of the time when no reminders were provided. Approximately 15% of patients whose physician received both reminders completed an AD as compared to 7% (instruction directive reminder only), 3% (proxy directive reminder only), and 4% (no reminder). Overall, 45% of AD discussions were associated with a patient completing an AD.

A study by Pearlman and colleagues³¹³ took place in Veteran's Health Administration outpatient clinics among several provider specialties. The study involved a multi-faceted intervention that included, as one component, an appointment flag to

remind the provider to discuss ACP during that appointment with the patient. The other components of the intervention included a booklet on ADs sent to the patient in advance of the patient's next appointment with their provider, a postcard sent a week prior to their appointment reminding them to review the booklet, and a 30-minute appointment with a social worker immediately before their provider visit to answer questions about the booklet and/or complete the AD. Among the 248 patients enrolled in the study, intervention patients reported more ACP discussions with their providers than did control patients (64% vs. 38%, $p < 0.001$). ACP notes were found in 47% of the intervention patients' charts as compared to 24% of the control group patients' charts ($p < 0.001$). Similarly, living wills were verified in the medical record for 48% of the intervention patients and 23% of the control group patients ($p < 0.001$). In this study, it was not possible to determine how much provider cueing contributed to the success of the intervention. Neither of these studies evaluated clinical outcomes.

In addition to the studies that involve computer-generated reminders to discuss ADs and ACP, one study was identified that examined the role that a computer-based system of reporting ADs played in improving the communication of a procedure-specific DNR order form.³¹⁴ This study, which took place in the ICU of a tertiary care hospital, compared concordance of understanding of patients' DNR status among the attending physician, nurses, and/or residents across three study phases. In the first phase, DNR orders were reported on unstructured physician order sheets; in the second phase, DNR orders were reported on structured, procedure-specific DNR order forms; in the third phase, DNR orders were presented in a computer-based system that generated a DNR communication sheet. A total of 147 patients were enrolled in the study (40 in phase 1, 36 in phase 2, and 71 in phase 3). Concordance between the attending physician and residents averaged across three questionnaire items reflecting components of the DNR order was 44% in phase 1, 70% in phase 2, and 81% in phase 3 ($p < 0.001$). Similarly, concordance between the attending physician and nurses was 40% in phase 1, 58% in phase 2, and 73% in phase 3 ($p < 0.001$). In addition to improved concordance, physicians were better able to detect errors in order entry using the computer-based system and subsequently correct them.

This intervention suggests that computer-based systems can improve the understanding across health care providers about DNR orders, which can increase the likelihood that care will be carried out in concordance with patient wishes and physician orders. However, this study is dependent on a computer-based form; more needs to be done to understand how the specific structure of the form used in this study influenced the study findings.

These studies demonstrate that HIT can increase the incidence of provider-initiated discussions of ADs through computer-generated reminders as well as have an effect on the completion and documentation of ADs in the electronic record. Computer-based systems may also improve cross-provider understanding of patient preferences. Still, there are many unanswered questions about how HIT influences ADs/ACP and where HIT investments should be made to improve ACP. Among the questions that remain unanswered is whether having an EHR/EMR improves accessibility of an AD

(e.g., during an acute episode). AD accessibility is contingent on the type of HIT system developed and how well it is integrated across providers and settings. We also do not know if there is an optimal organization to the EHR/EMR that improves the identification of the directive in the record. It is also unclear whether having an AD in the EMR will influence clinical outcomes differently than current AD use. Finally, we have not identified any literature that addresses patient attitudes about having electronically-stored ADs and whether storage might serve as an impediment to AD completion. The growing number of AD electronic repositories (e.g., Choices Bank) suggests that some individuals are comfortable with having their ADs available in electronic format. However, we do not know if the prospect of having their AD stored electronically would be a barrier for those who have not completed an AD.

2. The role of social marketing in advance directive/advance care planning promotion. There are many ways to effect broad behavioral change. One might envision a continuum of responses to be applied depending on how resistant the target of the behavior change is to that change. These include providing education (for those more likely to behave as desired); changing practices by changing the environment, which includes improving technology; and implementing new laws/policies that induce behavior change (for those most resistant).^{315,316} Many of the interventions to improve AD completion have focused on providing education to patients and/or providers. However, they have had limited effectiveness in part because these types of efforts are difficult to sustain long enough to see permanent behavioral change or because the population to whom they are targeted are particularly resistant to change.^{20,75} As described in the previous section, improvements in technology may increase AD completion and implementation. Legislative and policy efforts (see Section VI.D.3) also can increase AD use and implementation by removing barriers to access and facilitating implementation. Social marketing intervenes at a different level.

a. *What is social marketing?* Social marketing is a less well-studied approach to AD promotion that has been proven successful in achieving widespread behavioral change with respect to other health issues. Social marketing rests somewhere between education and legislative/policy action along the continuum described above. In this section, we define social marketing and its components and present examples of its use to effect behavior change in health care and specifically to promote ADs.

A basic definition of social marketing is: “the planning and implementation of programs designed to bring about social change using concepts from commercial marketing”.³¹⁷ Important to this concept is that social marketing applies these concepts to influence the *voluntary* behavior of target audiences.³¹⁸ Behavior change may involve accepting a new behavior, rejecting a potential behavior, modifying a current behavior, or abandoning an old behavior. Drawing an example from efforts to reduce the incidence of birth defects, several different types of marketing messages might be promoted depending on the type of behavior change desired.³¹⁵ Birth defects or other poor birth outcomes may be the result of poor maternal nutrition, or drinking alcohol or smoking while pregnant. These are examples of behaviors that the mother may currently exhibit, might consider doing, or have never done.

The social marketing message would target a woman depending on her current behavior and encourage a different behavior, if necessary. For example, encouraging women to take a multi-vitamin with the recommended amount of folic acid is an example of a message that attempts to get pregnant women who have not been taking the recommended multi-vitamin to accept a new behavior. Refraining from drinking alcohol among women who currently do not drink (rejecting a potential behavior), drinking at least eight glasses of water a day (modifying a current behavior), and stopping smoking among women who currently smoke (abandoning an old behavior) are additional examples of different messages depending on the behavior change desired.³¹⁵ This example also demonstrates that many different social marketing messages may be introduced to produce behavior change that influences the same outcome (in this case, prevention of birth defects or other poor birth outcomes). Of course, how one develops the message and where it is placed will be dependent on the stated goals of a marketing campaign.

The key elements of any marketing effort are the “4Ps”: product, price, place, and promotion.^{315,317,318,319} To be successful, a marketing campaign must create a “product” or package of benefits that accrue to those who change their behavior. The “price” or costs of behavior change must be minimized. In other words, the target audience must perceive that the benefits of changing the behavior are larger than the associated costs. The exchange of the product for the price must be made available in a “place” that can reach the right target audience. Finally, an effective social marketing campaign “promotes” or creates awareness about the product, its price, and the places in which it can be found.

A successful social marketing campaign recognizes the target audience and tailors the “4Ps” to its characteristics. Target audiences may be diverse and may not respond equally to a single social marketing campaign. 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.^{315,319} Thus, there may be multiple audience segments in the overall target audience for a single behavioral change.

Limited resources may make it impossible to reach all of the target audience. Decisions have to be made about where the biggest “return on investment” might be found among the segments of the target audience. For example, the University of Wisconsin wanted to find ways to reduce or prevent binge drinking among its student population.³¹⁹ Evaluation revealed that about a third of the study population did not currently binge drink; however, for some students, binge drinking started in high school while others started binge drinking as freshman. Based on this knowledge, the social marketing campaign developers segmented the student population into those who may be more likely to behave as desired (e.g., those who did not binge drink in high school and currently were not binge drinking) and those who might be more resistant to change (e.g., those who started binge drinking in high school and continued to do so in college). Those most likely to behave as desired, for whom the intervention aimed at prevention,

might respond to simple educational messages and require little investment to maintain their existing behavior. Those most resistant to change might respond only to a legal intervention. Those who did not binge drink in high school but started to in college were considered the primary target group. These individuals were perceived to be most amenable to change, and the marketing team focused its efforts on designing social marketing efforts that were tailored to this group.

b. *Advance directives and social marketing.* An inherent challenge to social marketing efforts for AD promotion is that some barriers to AD completion and ACP are quite substantial, and current efforts to overcome them (e.g., educational interventions) have not been as effective as would be desired. Particularly when the efforts are targeted to broad target audiences, the marketing campaigns have failed to produce a product where the benefits have outweighed costs for all involved.

Many efforts to promote ADs are broad and do not necessarily attempt to define specific market segments to which messages can be targeted. In some key examples (e.g., Kokua Mau and the La Crosse “Respecting Choices” campaign), the entire community is the target population.^{242,320} In this section, we highlight some of the largest and most well-known programs to influence consumer thinking around ADs/ACP and end-of-life care more generally and discuss their relative merits for effecting behavior change around these issues.

Last Acts was a national communications campaign involving a coalition of over 1,000 national health and consumer groups. The primary goals of the Last Acts campaign 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.³²¹ Task forces were established to develop plans, and communications agencies were hired to manage processes of the task forces and work with the public and policy audiences. Among the successes of the Last Acts campaign was developing the first-ever state-by-state report card that rated each state on eight key indices of the availability and quality of end-of-life care.³²² The campaign also made some important progress in raising professional awareness of end-of-life care issues. Coalition members viewed Last Acts as an important information resource on related issues and benefited from the campaign by feeling part of a larger community and receiving important 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 was perceived to benefit primarily the coalition partners, being somewhat distanced from the public, the primary target audience.³²¹ In addition, there was no specific evaluation of how Last Acts affected AD/ACP behavior. The campaign had been funded by the Robert Wood Johnson Foundation in 1995, but that funding ended in 2005, before the campaign could address these critiques fully.

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 ADs/ACP and end-of-life care more generally. It began with a series of studies to get a better sense of the needs of the community, both patients and providers. This “community profile” characterized, among others, 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.³²³ The project convened a number of task forces comprised of providers and lay community members to determine the types of interventions to be implemented, guided by the community profile. In addition to other data collection efforts by the task forces, the profile enabled a segmented and targeted approach to behavior change around ADs, ACP, and end-of-life care more generally. The effect of this project awaits formal evaluation.

An example of a statewide social marketing campaign to improve end-of-life care is “Kokua Mau” (Hawaiian for “continuous care”).³²⁰ This 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 settings of care, 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. An evaluation published in 2005 (Braun et al. 2005) found that dissemination of campaign efforts stimulated growth of community coalitions to serve different communities and target populations. 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, AD completion rates increased modestly (from 29% to 32%). In addition, hospice admissions increased substantially (by 20% between 1999 and 2001), but the proportion of the population dying in a hospital did not change.

A third social marketing example focused specifically on AD education is the “Respecting Choices” program, which was first implemented community-wide in La Crosse, Wisconsin and has since been implemented in other populations, including the chronically ill community-dwelling elderly.^{242,250,251} Several approaches were taken to effect change that have been integrated as the routine standard of care across the community in La Crosse: training and continuing education for local AD educators; placement of AD educators at all health care organizations; standard policies and practices for documenting, maintaining, and using ADs; and community-wide education through wide dissemination of educational materials. All of the patient education

materials developed for Respecting Choices were developed locally, with input from the target audiences.

An evaluation conducted two years after the implementation of Respecting Choices found that 85% of eligible patients had completed an AD and treatment matched the patients' wishes as stated in the AD for 98% of all deaths.²⁴² A baseline community-wide survey revealed that about 15% of the population had a completed AD prior to the implementation of Respecting Choices. Although the populations are not directly comparable, the findings from the formal evaluation suggest that this program had an important influence on improving AD completion and implementation.

c. *Conceptual framework for approaching behavior change.* As described above, there are several possible approaches to effecting behavior change, including education, social marketing, and legal intervention. These interventions fall along a continuum of behavior change approaches targeting groups from least to most resistant to change. Rothschild³¹⁶ offers a conceptual framework that can serve as a guide for considering the most appropriate approach depending on the following characteristics of the target population: motivation, opportunity, and ability (see Table 2).

Motivation		Yes		No	
Opportunity		Yes	No	Yes	No
Ability	Yes	Prone to Behave <i>Education</i>	Unable to Behave <i>Marketing</i>	Resistant to Behave <i>Law</i>	Resistant to Behave <i>Marketing, Law</i>
	No	Unable to Behave <i>Education, Marketing</i>	Unable to Behave <i>Education, Marketing</i>	Resistant to Behave <i>Education, Marketing, Law</i>	Resistant to Behave <i>Education, Marketing, Law</i>

Based on the principal that we are self-interested beings, individuals will be motivated to change their behavior when they perceive that they will personally benefit from that change. In the context of AD completion, people with serious illness may be more motivated to complete an AD than those who are not. Using marketing principles to appeal to self-interest or to remove barriers might increase motivation to act voluntarily. In this framework, legal intervention would only be appropriate when individuals cannot be motivated to act voluntarily.

A lack of opportunity might occur when an individual is motivated to change behavior but faces environmental barriers to change. Referring back to the binge drinking example provided earlier, students living in small towns might argue that there is nothing else to do but to binge drink on the weekends. In order to reduce binge drinking in this example, university staff might need to create alternative activities that are equally appealing, or more appealing, than binge drinking so that students have the opportunity to avoid the negative behavior. Creating opportunity may not happen simply

by providing education although it can create awareness of existing opportunities; rather, opportunity is created through marketing efforts or legal intervention.

The ability to behave differently is the third element of the conceptual framework. One who has the skills or proficiencies to change may be more likely to change behavior. However, many things might compete with one's ability to behave differently. Again in the context of binge drinking, peer pressure is an example of something that might compete with one's ability to change behavior. Education might be effective in providing the skills to behave differently, but marketing efforts can reinforce education by providing some benefit for changing behavior. Legislative or policy intervention may help someone who does not otherwise have the ability to change to make better choices.

The table presented in this section (Table 2) summarizes the description of this model, offering instruction on what might be the most successful approaches to behavior change depending on the characteristics of the target population. For this conceptual framework to be useful, one must be able to reasonably segment the target population, based on behavioral characteristics and an understanding of the environment in which the population lives.

3. The role of legislation and policy for advance directive/advance care planning use. One mechanism for increasing AD use and ACP is to legislate changes or develop policies to encourage or guide these processes. Several efforts in this regard have been undertaken, most prominently the 1991 PSDA. State legislation has created ADs in every state. In addition, state legislation has aimed at improving portability of ADs, making it easier for emergency personnel to follow ACP decisions and providing mechanisms to make documents available. The scientific literature contains evaluation of many of these legislative and policy interventions.

The first AD legislation was at the state level: in 1976 California passed the Natural Death Act, which gave legal force to living wills. The following year, Arkansas passed legislation authorizing ADs. Fourteen years later, with the recognition that use of ADs and ACP remained uncommon, Congress enacted the PSDA³⁰ requiring all medical facilities receiving Medicare or Medicaid funds to provide written information to all admitted or enrolled patients concerning their rights under state law to refuse or accept treatment and to complete ADs. As described earlier, the PSDA was designed to preserve self-determination in end-of-life care, protect patients from overly aggressive care at the end of life, foster communication between patients and their physicians, and protect physicians from litigation in end-of-life decision making.

Several studies have evaluated the effect of the PSDA on AD use and end-of-life care. The SUPPORT trial instituted its intervention at about the time that the PSDA went into force and thus was able to measure the effect of the PSDA as a natural experiment. Before the PSDA, 21% of patients had an AD, of which 6% were noted in the medical record. After the passage of the PSDA, the proportion of patients in the SUPPORT trial with an AD was no different (24%), but 35% of these were documented

in the medical record ($p < 0.001$). In the post-PSDA period, patients who had an AD, compared to patients without an AD, were only slightly more likely to have medical record documentation of discussions about resuscitation (38% with an AD vs. 33% without an AD) although more patients with ADs reported discussing resuscitation preferences with physicians (43% vs. 30%), DNR orders among those who wanted to forgo resuscitation (58% vs. 54%) or resuscitation attempts at death (9% vs. 17%).³²⁴

A study that evaluated patients just before and after the PSDA implementation showed that ACP increased (61% pre vs. 73% post, $p = 0.01$); however, there was no significant increase in the proportion of patients who had an AD (20% vs. 26%, $p = 0.11$). Implementation of the PSDA was not associated with a significant increase in patients discussing ACP or end-of-life issues with their physicians (14% vs. 17%, $p = 0.25$) or detailed discussions with proxies (34% vs. 33%).³²⁵

A third study used a time series design to evaluate DNR orders among Medicare patients hospitalized with six serious condition in 29 hospitals in Ohio before and after the PSDA. Risk-adjusted rates of early DNR orders increased by 34% between 1991 and 1992 for four of the six conditions and then remained flat or declined slightly between 1992 and 1997. Use of late DNR orders declined by 29-53% for four of the six conditions between 1991 and 1997. Risk-adjusted mortality during the 30 days after a DNR order was written did not change between 1991 and 1997 for five conditions, but increased for stroke patients.³²⁶

A study that compared two academic medical centers on AD completion among electively admitted patients found that providing the AD information by mail before admission was associated with more AD completion.³²⁷ In summarizing the data, one review suggested that the PSDA generally failed to foster a significant increase in AD use or to increase the involvement of clinicians.⁷⁵

However, in the nursing home, the PSDA appeared to induce higher AD completion rates.^{116,117} Oliver et al.³²⁸ conducted a systematic review of end-of-life care in nursing homes and found that after the PSDA the number of nursing home residents with discussions of treatment wishes increased. An evaluation of nursing home residents in 268 facilities in 1990 and 1993 using Minimum Data Set information showed that ADs increased from 7% to 16% ($p < 0.05$) as did DNR orders (32% pre vs. 51% post, $p < 0.05$) and do-not-hospitalize orders (2% vs. 4%, $p < 0.05$).¹²³ Teno and colleagues found that there was considerable variation in the number of DNR and do-not-hospitalize orders by state.³²⁹ A study in eight rural nursing homes found that residents with ADs were more likely to have been admitted to the nursing home after the enactment of the PSDA (25% before vs. 38% after, $p < 0.001$). There was substantial variation among facilities.³³⁰ Bradley and Rizzo³³¹ also found an increase in ADs after the PSDA (from 5% to 35%, $p < 0.01$).

Evaluation of state AD laws performed since the PSDA have demonstrated substantial heterogeneity³³² as well as deficits in these statutes. One evaluation found that state AD laws were too restrictive and suggested relaxing requirements for

witnessing or notarizing ADs completed during a physician visit, permitting oral specification of health care proxies and encouraging discussions.⁴⁹ Another evaluation found that ADs did not empower health care proxies or guide their decision making.³³³ The author suggested specific improvements in ADs:

- State AD laws should permit the creation of immediately effective proxy appointments. The proxies would function as an advisor to and advocate of the patient while the patient retains capacity.
- State AD laws should require health care providers to record the identity of a patient's appointed proxy as early as practicable for a patient suffering from a condition that could lead to death. With patient approval, the provider should invite the proxy to participate in treatment decisions and care planning before the patient loses decision making capacity.
- State law should require health care providers to make available written information and counseling resources to proxies in order to explain the nature and process of health care decision making and the role of proxies.
- State law should define a process of informed consent that emphasizes the physician-proxy discussion process and the opportunity to weigh relevant factors in that process, including determining the wishes and/or best-interests of the patient.
- State AD laws should recognize the authority and discretion of appointed proxies over the authority of ADs.

Regional groups and professional societies^{334,335} have developed policies and states^{336,337} have passed a laws to help determine whether aggressive care toward the end of life is beneficial and should be continued. These methods usually advocate for ACP to guide care but set limits on the goals for which medical intervention may be permitted. To date, these efforts appear to have had little effect on the use of aggressive care.³³⁸

a. *State programs to improve portability of preferences and advance directives.* A significant obstacle to implementing ADs is that they may not move with the patient to across care venues. This is despite the fact that most states have laws permitting out-of-hospital DNR orders (42 as of 1999).³³⁹ For ADs to be effective, clinicians caring for the patient need to be aware of their content. This shortcoming contributes to statewide initiatives that have been undertaken to create mechanisms for ACP to transition with patients as they move within the health care system. The POLST program is a mechanism to elicit preferences for care from patients and then ensure that these wishes are honored wherever the patient receives care. Using a one-page form, the POLST captures patient preferences concerning CPR, transfer, antibiotic use, and tube feeding. Authority to follow the stated preferences is ensured by state law and health

care facilities have incorporated use of the POLST form into standard operating procedure.

A prospective analysis of 180 nursing home patients with a POLST containing a DNR order and a desire for transfer only if comfort measures failed showed that over one year no patient received CPR, ICU care, or ventilator support, and only 2% were hospitalized to extend life. Of the 38 subjects who died during the study year, 63% had an order for narcotics, and only two died in a hospital.¹³² Similarly, among 58 decedents in a Program of All-Inclusive Care for the Elderly in Oregon who had a POLST document, use of CPR, antibiotics, intravenous fluids, and feeding tubes nearly always matched specified preferences.²⁵⁷ A survey of 146 nursing homes in Oregon in 2002 revealed that 71% were using the POLST for at least half of their residents,³⁴⁰ a survey of emergency medical technicians found that most were aware of the form and found it useful.³⁴¹ This mechanism of eliciting preferences and protecting them during care transitions is now used or planned to be used in more than a dozen states.

b. *Programs to improve emergency medical response to patients at the end of life.* Another strategy for matching patient desires and care received just before death is to enable emergency medical services personnel to withhold CPR for out-of-hospital cardiac arrest for patients with a terminal illness who would not have wanted resuscitation. In a natural experiment, 16 of 35 local emergency medical services agencies in Washington volunteered to implement guidelines to withhold CPR if the patient had a terminal condition and if the patient, family, or caregivers indicated, in writing or verbally, that no CPR was desired. Personnel implementing the new guidelines withheld resuscitation in 12% of patients having cardiac arrests, compared with an average of 5% of patients in historical and contemporary control groups. This increase was primarily due to honoring verbal requests.³⁴²

E. Outcomes of Advance Directives and Advance Care Planning

ADs have been promoted as a method of ensuring patient autonomy. How well they serve this function has been investigated extensively, such as comparisons of end-of-life treatment with care requested or refused in an AD; comparisons of desired decision making models with care received; and the relationship of patient preferences and clinical circumstances with resuscitation and life-sustaining care, place of death, degree of aggressive care at the end of life and resource use. Generally, the research suggests that even when ADs are executed, physicians are frequently unaware of them, ADs are not easily available to surrogates when needed, ADs are too general and/or are inapplicable to clinical circumstances, and/or they are invoked late in the dying process or are at times overridden by providers and families.^{43,50,75,93,97,110,220,221,343} Only in the context of a comprehensive community effort do ADs and ACP appear to substantially change care at the end of life.^{242,323} Despite the weakness of ADs as an individual intervention, research points to promising interventions.

Medical care tends to be driven first and foremost by a patient's clinical circumstances. Patient perceived quality of life and the wishes of family affect clinical decisions at the end of life along with preferences expressed in ADs. ADs alone have been shown to be ineffective in reducing unwanted aggressive medical treatments or costs at the end of life.^{43,50,120,329,344,345} A review of interventions to improve end-of-life care concluded that ADs have been construed too narrowly to ensure preference-driven care.⁷⁵

A main concern in the early days of ACP was whether discussions about end-of-life care and ADs would have a negative impact on patients. The evidence suggests that ACP is not distressing to patients and that intensive educational interventions are acceptable to patients, families and physicians (e.g., intensive ethics consults, facilitated family/provider conferences, palliative care consult teams, etc.). Repeated discussions of patient preferences as well as accessible documentation of these preferences are necessary to ensure that care is consistent with the patient's current situation and wishes.^{75,78,93,95,132,166,170,200,225,236,250,251,252,253,254,313,346,347,348,349,350}

Research examining whether AD interventions (e.g., scenario-based ADs, value-based ADs, decision making with and without discussions between patient and surrogate) improved the accuracy of surrogate substituted judgment found that none of the interventions was effective.^{23,63,166,351,352} For example, Hines et al.²⁵² found that conversations between patients and their surrogates were associated with the surrogates believing they had a better understanding of the patient's wishes. However, these conversations were either weakly related or unrelated to a surrogate's actual knowledge of specific patient preferences. Surrogates wanted written and oral instructions more often than patients wanted to provide them and knowing the patient's wish to stop treatment in the present condition was more important to most surrogates than the physician's recommendation to stop treatment. Engelberg et al.³⁵³ found that surrogates displayed greater accuracy in understanding patient preferences if they had had discussions about patient preferences, with family members able to predict patient preferences accurately about half the time. However, other research suggests that even when a patient and the chosen surrogate have conversations about preferences and an AD is completed, the surrogate and the patient do not make similar hypothetical medical choices.^{23,63}

The largest ACP intervention to date, the SUPPORT trial, did not improve communication and prognostication, nor did the intervention facilitate completion of ADs. Patients in the intervention group did not spend fewer days in ICUs, have better concordance between preferences and life-sustaining treatments, or receive resuscitation more appropriately.⁸

Studies of interventions that simply aim for completion of ADs fail to improve patient/provider communication, end-of-life decision making, or the concordance of life-sustaining treatments with patient goals.⁷⁵

Some of the reasons that ADs and related interventions do not change care are described by Hawkins et al.,³⁷ who explored 337 patients' and surrogates' attitudes about using ADs in the context of a two year intervention (the ADVANCE Project: Advance Directives, Values, Assessment and Communication Enhancement Project). The study revealed that patients did not want many to participate in many of the activities that are central to ACP. Few individuals wished to document specific medical treatment preferences and mandate that they be followed. Most desired to express more general preferences, such as values and goals for care in addition to (or instead of) specific treatment preferences. Patients in this study valued cognitive functioning, independence, and dying with dignity, but the priority that each patient assigned to these values varied substantially, suggesting that patients would translate their unique set of personal values and goals into various life-sustaining treatment decisions. In addition, the study showed that patients who documented their preferences in ADs may not have wanted them strictly followed near death; 91% desired that proxies have at least some leeway to override their written directives.

Several more recent studies have suggested links between ADs and clinical processes and outcomes of importance. Kish Wallace et al.³⁵⁴ found that patients with an AD at admission to an ICU more often had DNR orders within the first 72 hours, had shorter ICU stays, and had lower charges than patients without an AD; however having an AD did not appear to affect decisions about using life-supports. Lilly et al.⁹³ found that intensive communication sessions among providers, patients, and families within 72 hours of ICU admission decreased length of stay in the ICU from four days to three days, decreased ICU mortality, and resulted in fewer therapeutic interventions.

a. *Advance care planning interventions in intensive care units.* Post-SUPPORT interventions that incorporate ACP (and to a small degree AD completion) into intensive end-of-life interventions in the ICU, such as prospective ethics consults, intensive communication interventions and counseling sessions, and AD discussions with trained facilitators have demonstrated reductions in ICU and hospital length of stay, reductions in treatment decision conflicts, better alignment of therapeutic interventions with goals, decreased mortality within the ICU, increased access to palliative care, and lower charges.^{93,95,170,173,200,346,347,348,349} These outcomes, which were not consistent across all studies, suggest that patient-provider discussions focusing on acceptable health states, the goals of critical care, and valued life activities more effectively guide end-of-life care than decisions focusing on specific medical interventions.

b. *Advance directives and advance care planning in nursing homes.* There is substantial evidence that ADs affect decision making in nursing homes. AD completion is associated with increases in discussions about end-of-life care and documentation of patient preferences, moderate increases in hospice enrollment, and feeding tube use more consistent with patient goals.^{328,355,356} Three studies evaluated the effect of ACP interventions on nursing home residents' resource utilization. Morrison et al.²³⁸ educated nursing home social workers in ACP and then performed structured interviews with residents to ascertain treatment preferences. Patients in this intervention were less likely to undergo treatments that were discordant with their stated preferences.

Casarett et al.,²³⁷ using a clinical trial design, created a structured interview process to improve hospice enrollment among nursing home patients. Intervention patients had decreased acute care admissions, increased hospice enrollment, and increased family satisfaction, but not decreased resource utilization. Molloy et al.²³⁹ implemented a nurse-led educational program in nursing homes to increase use of ADs that demonstrated a significant reduction in resource use and hospitalizations among intervention nursing homes without a change in patient or family satisfaction.

Happ et al.¹³⁴ conducted a case review of 43 deceased nursing home residents transferred to a hospital. They found that although ADs were part of the nursing home admission process, these discussions focused primarily on CPR preference, and treatment preferences were reviewed only after the crisis of acute illness and hospitalization. AD forms specifying preferences or limitations of life-sustaining treatment contained inconsistent language and vague conditions for implementation. Engel et al.¹⁰⁴ conducted a survey of caregivers to nursing home residents with dementia regarding the caregivers' satisfaction with care. They found that the most significant factor in caregivers' satisfaction was having a longer than 15-minute discussion about ACP with a health care provider at the time a patient was admitted.

c. *Advance directives and site of death.* A key wish toward the end of life that can be included in an AD concerns venue of death. However, the evidence linking patient preferences for place of death and ADs is weak. Gomes and Higginson³⁵⁷ conducted a systematic review of the literature (1972-2004) on the relative influence of different factors on place of death for cancer patients. They found that patients' low functional status, the intensity of patient preferences for home care, living with relatives, and extended family support were significantly associated with home death, with social support the strongest factor. Pekmezaris et al.³⁵⁸ and Degenholtz et al.³⁵⁹ evaluated whether having an AD affected place of death and found that significantly higher proportions of patients dying in nursing homes had living wills and had specified preferences for treatment limitations (e.g., DNR) versus those dying in the hospital. Levy et al.³⁶⁰ examined factors predicting site of death (hospital vs. nursing home) and found that rural, hospital-based, and government-owned nursing homes had the lowest in-hospital death rates. Absence of a DNR order, non-White ethnicity, greater functional independence, and higher cognitive status were associated with in-hospital death.

VII. DISCUSSION AND CONCLUSION

Although ADs can be an important tool 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 toward the end of life, a poor match of aggressive care with prognosis, undue suffering, and wasted resources. The research summarized above shows that most people do not complete an AD and that when they are completed, these documents often do not affect care because they are narrow and legalistic. The focus on preferences concerning life-sustaining treatments commonly proves to be too simplistic and vague instructions (e.g., weigh the burdens and benefits) are difficult to apply, often adding little to the way that family and clinicians would approach decisions. Preferences stated within ADs (or poorly orchestrated ACP) often do not apply to clinical circumstances or can even impede effective decision making (e.g., a statement to “do everything”). In short, ADs and ACP have been ineffective.^{60,361}

Instead of encouraging substantive communication about clinical circumstances and medical possibilities and how the patient’s values would dictate choices given the medical realities, ADs have tended to be considered ends in themselves. But, as numerous studies teach us, there is little connection between the completion of an AD 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 preferred place of death.

Much of the research has focused on whether these documents were completed or documented in the medical record. It is no surprise that these efforts have rarely had an impact on care. More sophisticated approaches such as time limited trials with objective end points do not emerge from “cookie-cutter” documents or simplistic decisions about CPR. In addition, ACP is a process rather than an isolated event or a series of unrelated episodes. Simplistic mechanisms for complex decisions lead to perceptions that clinicians do not follow AD preferences,^{71,186} suggesting that remedies to change clinician behavior are needed, whereas some evidence suggests that it may be the AD instrument and its application that needs improvement.

Some groups of patients are less inclined to complete ADs or engage in ACP. These tend to be individuals who have been disenfranchised or those with less trust in the medical care system. Studies show that for many racial/ethnic groups, autonomy is not always empowering, information about bad news may not be invited, and AD-appointed decision makers may be an unacceptable decision making mechanism.^{138,146,150,155} Not considering the needs of these groups has contributed to development of end-of-life decision making mechanisms that often do not suit the needs of the most vulnerable in American society. Concerning persons with disabilities, the dearth of literature about preferences, decision making mechanisms and capabilities, and end-of-life care hampers the development of appropriate models for decision

making. Not a single study representative of any disabled population was found concerning ACP, ADs or end-of-life care. It is unclear whether the pronouncements of disability rights activists concerning the unacceptability of ACP mechanisms reflect the views of the broader community of persons with disabilities. Yet, it is clear that there is widespread distrust that quality of life judgments of clinicians and others will reflect those of the disabled individuals and that the medical care and social systems will work as hard to maximize patients' quality of life as they will to withhold or withdraw care. Even in the context of these views, qualitative studies show that many disabled individuals desire to invoke autonomous preferences in making end-of-life decisions. This suggests that opening up the discussion about end-of-life care and how decisions should be made in order to create transparent and acceptable methods would improve care for groups now poorly served.

The research summarized above as well as a review of measures demonstrates a lack of well-developed and meaningful metrics of "successful" ACP and patient and family-centered care (e.g., emotional distress, satisfaction with end-of-life communication, appropriate values clarification, etc.).^{362,363,364} Far beyond the mere completion of an AD, the goals of ACP should aim to show that goals of care are 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."^{10,12,13,14,32,52,54}

Interventions that have attempted to take a broader view of ACP have demonstrated some directions for further research. Social marketing models that attempt to change societal expectations for end-of-life care show that improvement is possible. Structured ACP at the community level can induce the expectation that health care providers will elicit and attend to patient preferences in a timely manner.¹⁶⁶ A care transition mechanism that is used widely to protect patients' preferences in a variety of settings can create an expectation at the health care institutional level that these institutions will ensure continuity of preferences and dedicate resources to this process.³⁴⁰

This literature review demonstrates great need for improved end-of-life care and past inadequate attempts to implement improvements, but also indicates directions for renewed interventions. It maps out the need for additional research as well as policy implications. First and foremost, the field needs to understand why ACP works when it does and why it often fails. Second, future research needs to learn from past work demonstrating that end-of-life care is a complex process that defies easy solutions, so that understanding solutions may require parsing out differences by condition, patient characteristics, provider type and venue. Third, models of ACP cannot permit clinicians to abandon their responsibility to render professional judgments based on clinical knowledge and make recommendations that are informed by knowledge of the patient.

Furthermore, efforts to date suggest that ACP holds great promise and future efforts should be based on the most successful models. These should integrate change at the community level with structures and mechanisms at the state level to facilitate decision making and continuity of care. More flexible legal instruments and ACP educational tools will aim the process toward the clinician-patient relationship where it belongs and can best inform care in a clinically relevant way.

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APPENDIX A: LITERATURE SEARCH STRATEGIES

NINR UPDATE SEARCH METHODOLOGY

DATABASE SEARCHED & TIME PERIOD COVERED:

PUBMED -- 2004-2006

OTHER LIMITERS:

English

SEARCH STRATEGY:

death[ti] OR death[mh:noexp] OR "dying loved one" OR "dying patient" OR "dying patients" OR "dying people" OR "dying person" OR "last year of life" OR "end of life" OR "terminal illness" OR "terminal illnesses" OR terminal care OR "death and dying" OR "limited life expectancies" OR "limited life expectancy" OR "limited life span" OR "limited lifespan" OR "limited life spans" OR terminally ill OR critical illness OR frail elderly

AND

delivery of health care OR quality assurance, health care OR "outcome and process assessment (health care)" OR quality of life OR quality indicators OR quality of health care OR patient care management OR continuity of care OR outcome[ti] OR outcomes[ti] OR consumer satisfaction OR patient satisfaction OR personal satisfaction

AND

pain/th OR pain/psychology OR "pain management" OR "pain assessment" OR "relieve suffering" OR "relieve symptoms" OR palliative care[mh] OR pain[ti] OR "pain relief" OR discomfort OR "physical comfort" OR "comfort care" OR "symptom distress" OR "symptom burden" OR "symptom control" OR "symptom intensity" OR "symptom management" OR "symptom relief" OR "pain distress" OR "pain easing" OR "pain free" OR "psychological distress" OR psychology[sh] OR wellbeing OR "well being" OR anxiety OR anxious OR anxiety disorders[mh] OR depression OR depressive disorder[mh] OR depressed OR "attitude to death" OR neoplasms/psychology OR "emotional health" OR spiritual OR emotions OR support[ti] OR supportive OR communication OR relationships OR religion OR religiosity OR "treatment decision" OR decisionmaking OR "decision making"

AND

advance* care plan* OR advance* directive* OR advance care planning[mh] OR
advance directives[mh] OR end of life plan*

NOT

letter³⁶⁵ OR news³⁶⁵ OR editorial³⁶⁵ OR case report*

ETHICS SEARCH METHODOLOGY

DATABASE SEARCHED & TIME PERIOD COVERED:

PUBMED -- 1995-2007

OTHER LIMITERS:

English

SEARCH STRATEGY #1:

Note -- Asterisk indicates term truncation

advance* directive* OR advance care plan* OR advance care planning[mh] OR
advance directives[mh] OR end of life plan

AND

ethics[mh] OR ethic*[tiab]

NOT

letter³⁶⁵ OR news³⁶⁵ OR editorial³⁶⁵

INTELLECTUAL & PHYSICAL DISABILITIES SEARCH METHODOLOGY

DATABASE SEARCHED & TIME PERIOD COVERED:

PUBMED -- 1995-2007

OTHER LIMITERS:

English

SEARCH STRATEGY #1 (Intellectual Disabilities)

advance* care plan* OR advance* directive* OR advance care planning[mh] OR
advance directives[mh] OR end of life plan*

AND

behavior disorders[Multi] OR cognitive disorders OR cognition disorders OR
cognitive disabilit* OR cognitive function* OR developmental disabilities[mh] OR
development* disabilit* OR developmental* disabled OR intellectually disabled OR
intellectual* disabilit* OR mental* disabilit* OR mental disorders OR mental
retardation[mh] OR mental* retard* OR behavio* disabilit* OR behavio* disabled OR
dementia OR autism OR autistic disorder OR asperger* OR asperger syndrome
NOT

letter³⁶⁵ OR news³⁶⁵ OR editorial³⁶⁵

SEARCH STRATEGY #2 (Physical Disabilities)

advance* care plan* OR advance* directive* OR advance care planning[mh] OR
advance directives[mh] OR end of life plan*

AND

physical disabilit* OR physically disabled OR disabled persons[mh] OR hearing
impair* OR hearing disorders[mh] OR deaf* OR speech impair* OR visual* impair*
OR vision disorders[mh] OR eye diseases[mh] OR communication disorders[mh] OR
cerebrovascular accident[mh] OR stroke*[ti]

NOT

letter³⁶⁵ OR news³⁶⁵ OR editorial³⁶⁵

NOT

Results of Search #1

HEALTH INFORMATION TECHNOLOGY SEARCH METHODOLOGY

DATABASE SEARCHED & TIME PERIOD COVERED:

PUBMED -- 1995-2007

OTHER LIMITERS:

English

SEARCH STRATEGY:

Note -- Asterisk indicates term truncation

advance* care plan* OR advance* directive* OR advance care planning[mh] OR
advance directives[mh] OR end of life plan*

AND

medical records[mh] OR medical record*[tiab] OR administrative data OR claims data OR personal health record* OR electronic medical record* OR electronic health record* OR informatics[mh] OR informatic*[tiab] OR computerized health information OR medical records systems, computerized

DATABASE SEARCHED & TIME PERIOD COVERED:

Academic Universe -- Medical News -- 1995-2007

SEARCH STRATEGY:

Note -- Exclamation point indicates term truncation

advance directive! OR advance care plan! OR end of life plan!

AND

medical record! OR health record! OR administrative data OR claims data OR computerized OR informatic!

SOCIAL MARKETING SEARCH METHODOLOGY

DATABASE SEARCHED & TIME PERIOD COVERED:

PUBMED -- 1995-2007

OTHER LIMITERS:

English

SEARCH STRATEGY #1:

Note – Asterisk indicates term truncation

advance* directive* OR advance care plan* OR advance care planning[mh] OR advance directives[mh] OR end of life plan*

AND

social market* OR health promotion

SEARCH STRATEGY #2:

social market*

DATABASE SEARCHED & TIME PERIOD COVERED:

NLM LocatorPlus -- 1995-2007

SEARCH STRATEGY:

"social marketing"

LEGAL/POLICY SEARCH METHODOLOGY

DATABASE SEARCHED & TIME PERIOD COVERED:

PUBMED -- 1995-2007

OTHER LIMITERS:

English

SEARCH STRATEGY #1:

Note -- Asterisk indicates term truncation

advance* directive* OR advance care plan* OR advance care planning[mh] OR
advance directives[mh] OR end of life plan

AND

legal* OR law*[ti] OR legislat* OR court OR courts OR jurisdiction* OR jurisprudence
OR legislation and jurisprudence[sh]

AND

statistics and numerical data OR outcome* OR attitud* OR data

NOT

letter³⁶⁵ OR news³⁶⁵ OR editorial³⁶⁵

SEARCH STRATEGY #2:

PubMed "Related Articles" searches on the following articles:

Sabatino CP. The legal and functional status of the medical proxy: suggestions for
statutory reform. *J Law Med Ethics*. 1999 Spring;27(1):52-68. No abstract available.
PMID: 11657144 - **175**

Sabatino CP. Survey of state EMS-DNR laws and protocols. *J Law Med Ethics*.
1999 Winter;27(4):297-315, 294. PMID: 11067612 - **126**

Sabatino C. Health care power of attorney and combined advance directive
legislation (as of January 1, 1997). *Bioeth Bull*. 1997 Winter-Spring;5(3):14-22. No
abstract available. PMID: 11865905 - **180**

SEARCH STRATEGY #3:

DATABASE SEARCHED & TIME PERIOD COVERED:

Index to Legal Periodicals & Books -- 1995-2007

OTHER LIMITERS:

English

SEARCH STRATEGY:

(kw: advance and kw: directive*) OR (kw: advance and kw: care and kw: plan*) OR
(kw: end and kw: life and kw: plan*)

ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS

Files Available for This Report

Main Report

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>

APPENDIX A. Methods

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt#appendA.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt-A.pdf>

APPENDIX B. Literature Review on Advance Directives

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt-B.pdf>

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

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt-C.pdf>

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

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacp.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt-D.pdf>

APPENDIX E. Commissioned Report: Advance Care Planning and Public Engagement

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/acppe.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt-E.pdf>

APPENDIX F. Roundtable Materials

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt#appendF.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt-F.pdf>

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

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt#appendG.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt-G.pdf>

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

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt#appendH.htm>

PDF: <http://apse.hhs.gov/daltcp/reports/2008/ADCongRpt-H.pdf>