Decision Aids for Advance Care Planning: An Overview of the State of the Science

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Advance care planning honors patients' goals and preferences for future care by creating a plan for when illness or injury impedes the ability to think or communicate about health decisions. Fewer than 50% of severely or terminally ill patients have an advance directive in their medical record, and physicians are accurate only about 65% of the time when predicting patient preferences for intensive care. Decision aids can support the advance care planning process by providing a structured approach to informing patients about care options and prompting them to document and communicate their preferences.

This review, commissioned as a technical brief by the Agency for Healthcare Research and Quality Effective Health Care Program, provides a broad overview of current use of and research related to decision aids for adult advance care planning. Using interviews of key informants and a search of the gray and published literature from January 1990 to May 2014, the authors found that many decision aids are widely available but are not assessed in the empirical literature. The 16 published studies testing decision aids as interventions for adult advance care planning found that most are proprietary or not publicly available. Some are constructed for the general population, whereas others address disease-specific conditions that have more predictable end-of-life scenarios and, therefore, more discrete choices. New decision aids should be designed that are responsive to diverse philosophical perspectives and flexible enough to change as patients gain experience with their personal illness courses. Future efforts should include further research, training of advance care planning facilitators, dissemination and access, and tapping potential opportunities in social media or other technologies.

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Advance care planning is a way to inform care choices for a patient who cannot express a preference and a planning tool that helps patients begin to prioritize their treatment goals. The preferences of seriously ill patients for life-sustaining interventions depend on their care goals. Some prioritize living longer to achieve life goals, whereas others may not wish to be kept alive when meaningful recovery or a particular quality of life is no longer possible (1–3). Religious and spiritual values and beliefs also affect goals of care (4, 5). Advance care planning helps to honor patient preferences and goals if incapacitating illness or injury prevents adequate communication (6).

Decision aids help patients consider health care options. Such aids for advance care planning support the 3 key components of the process: learning about anticipated conditions and options for care; considering these options; and communicating preferences for future care, either orally or in writing. The most important information a decision aid can provide to a decision maker depends on the patient's current health status and the predictability of illness trajectories (**Figure**). A healthy person may benefit most from general decision aids focused on choice of health care proxies and goals of care for hypothetical catastrophic situations, such as after loss of function or cognition or terminal illness. For patients with a life-threatening illness, appropriate aids focus on decisions to accept, withhold, or terminate specific treatments. Advance care planning with decision aids takes place in various settings; it is often done outside clinical settings, particularly among healthy older adults. Nonclinical partners in shared decision making may include family members, caregivers, or attorneys or other professionals.

Opportunity exists for expansion and improvement of advance care planning. A 2003 Agency for Healthcare Research and Quality (AHRQ) literature summary (7) found that fewer than 50% of the severely or terminally ill patients who were studied had an advance directive (a common outcome of the advance care planning process) in their medical records (8–11). Furthermore, only 12% of patients with an advance directive had received input from their physician in its development (9), and physicians were accurate only about 65% of the time when predicting patient preferences; they tended to assume that patients would want less life-prolonging treatment than they actually desired, even after reviewing the patient's advance directive (12). Decision aids may improve participation in advance care planning and the effectiveness of communication by facilitating clear documentation across platforms and providers and by offering insights into why patients make the decisions they do.

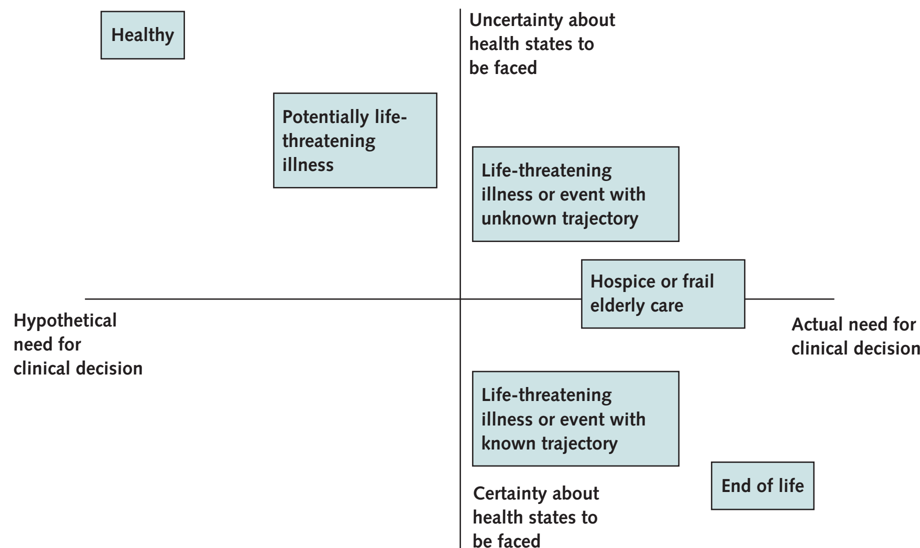
This review, commissioned as a technical brief by the AHRQ Effective Health Care Program, provides an overview of advance care planning decision aids for adults. It describes available tools, identifies a framework for future research, and summarizes published studies that used a decision aid as an intervention.

Methods

Key Informants

In November 2013, we conducted semistructured telephone interviews (**Appendix Table 1**, available at www.annals.org) with 7 key informants, including practicing clinicians and attorneys involved in advance care planning, experts in medical law and medical ethics, consumer advo-

Figure. **Continuum of health states during which advance care planning may be considered.**



cates, and decision aid researchers and developers. We identified these informants via frequently listed and cited authors of relevant literature, Internet searches for persons with potentially relevant viewpoints, and nominations by other key informants. They contributed information about decision aids, the context in which they are used, and important issues to consider.

Literature Search

We searched MEDLINE (via Ovid), the Cochrane Library, PsycINFO, and CINAHL from January 1990 to May 2014 using a search strategy based on relevant Medical Subject Headings terms and text words (**Appendix Table 2**, available at www.annals.org). We also conducted a gray literature search of federal and state government Web sites, the Ottawa Hospital Research Institute's Decision Aid Library Inventory, Web sites of professional organizations, and leads from key informants for decision aids available to the public and in use.

We screened abstracts and full-text articles to identify English-language studies of any sample size and design that assessed the effect of a decision aid on outcomes relevant to advance care planning. We excluded studies that involved children or advance planning for psychiatric care. We also excluded studies of decision aids for current (not future or hypothetical) end-of-life decisions; studies of forms for completing advance directives, living wills, or provider orders for life-sustaining treatment that did not include an educational component, help clarify values, or prompt action; and studies that focused on implementation science questions. The reviewers read the full text of selected articles and used a standardized data extraction form to collect reported information about study populations, decision aids, and outcomes. One reviewer abstracted data by using standardized abstraction tables, and a second reviewer provided a quality check.

We used the criteria developed by the International Patient Decision Aids Standards (IPDAS) Collaboration to provide a structure for describing and comparing decision aids. These criteria have been used formally to judge quality and effectiveness in existing systematic literature reviews (13, 14). Because we followed technical brief methods, we did not synthesize outcomes, rate risk of bias, or grade the strength of evidence of the literature.

Role of the Funding Source

The Minnesota Evidence-based Practice Center (EPC) prepared this technical brief with funding from AHRQ. The EPC collaborated with AHRQ to develop the research protocol. Staff at AHRQ helped formulate questions and reviewed the draft report but were not involved in the study selection, data extraction, or drafting of the manuscript for publication. The full report is available at www.effectivehealthcare.ahrq.gov.

RESULTS

Existing Advance Care Planning Decision Aids and Context for Use

In shared clinical decision making, patients and clinicians use evidence-based knowledge, weigh options against treatment goals, and consensually arrive at a clinically prudent decision concordant with patient preferences (15, 16). Although advance care planning lies within the bounds of clinical decision making, it differs from many well-studied decision processes for medical procedures (such as surgical

Table 1. **Examples of General Advance Care Planning Decision Aids Publicly Available on the Internet**

Decision Aid (Developer)	Topics Addressed							
	Living Will or Other Advance Directive	Health Care Proxy	Life-Sustaining Treatment	States Worse Than Death	Organ and Tissue Donation	Conversation Prompts	Treatment Location	Comfort Care Preferences
MyDirectives (ADVault)	√	√	√		√	√	√	√
Five Wishes (Aging with Dignity)	√	√	√					√
Consumer's Toolkit for Health Care Advance Planning (American Bar Association)		√	√	√	√	√		√
End-of-Life Decisions (Caring Connections, National Hospice and Palliative Care Organization)	√	√	√					
Caring Conversations (Center for Practical Bioethics)	√	√	√					√
Advance Care Planning Conversation Guide (Coalition for Compassionate Care of California)						√		
Conversation Starter Kit and How to Talk to Your Doctor (The Conversation Project, Institute for Healthcare Improvement)						√		√
The One Slide Project (Engage with Grace)						√		
CRITICAL Conditions Planning Guide (Georgia Health Decisions)	√	√			√			√
Preferred Priorities of Care (Lancashire and South Cumbria Cancer Services Network)		√					√	√
PREPARE (The Regents of the University of California)	√	√				√		√

HHS = U.S. Department of Health and Human Services.
* Ratings refer to the amount of information or effort the decision aid incorporated.

or nonsurgical options for cancer) because patients can make decisions with no health care provider involvement by using readily available, do-it-yourself decision aids. These aids tend to target persons with only general risks for life-threatening conditions, for whom advance care planning may involve considering a wide range of possible future scenarios, eliciting preferred goals of care, or choosing a health care proxy.

Although not exhaustive, **Table 1** summarizes advance care planning decision aids that target a general, predominantly healthy, older adult audience. These aids, identified through the gray literature search and by key informants, are relatively easy to find online by using common search engines. The most popular issues they address include designation of a health care proxy, clarification of values and desire for comfort care at the end of life, information on living wills or other advance directives, conversation prompts for talking to loved ones or physicians about wishes, and general preferences for various life-sustaining treatments. These aids vary in the degree to which they

Table 1—**Continued**

Developer's Description	Decision Aid Components*			Web Site
	Provides Education	Structured Approach	Decision Communication	
"MyDirectives is the first completely online advance directive that is secure, legal, easy to understand, and free. MyDirectives is also the first advance care platform to receive 'meaningful use' certification from HHS so that hospitals may be eligible for incentive payments from Medicare and Medicaid under the American Recovery and Reinvestment Act when using this technology."	Medium	Medium	High	www.mydirectives.com/?MyD
"The *Five Wishes* document helps individuals express care options and preferences. The advance directive meets the legal requirements in most states and is available in 20 languages for a nominal fee."	Low	Low	Medium	www.agingwithdignity.org/five-wishes.php
"The tool kit does not create a formal advance directive for you. Instead, it helps you do the much harder job of discovering, clarifying, and communicating what is important to you in the face of serious illness."	Low	Medium	Medium	www.americanbar.org/groups/law_aging/resources/consumer_s_toolkit_for_health_care_advance_planning.html
"This booklet addresses issues that matter to us all, because we will all face the end of life. Advance directives ... are valuable tools to help us communicate our wishes about our future medical care."	Medium	Low	Low	www.caringinfo.org/files/public/brochures/End-of-Life_Decisions.pdf
"Caring Conversations equips you with the tools you will need to communicate your wishes when you can no longer speak for yourself and advocate on your own behalf. The workbook includes a Durable Power of Attorney for Healthcare Decisions form and a Healthcare Treatment Directive form."	Low	Medium	Medium	www.cpbmembers.org/documents/Caring-Conversations.pdf
"The conversation guide provides suggestions on how to raise the issue, responses to concerns your loved one might express, and questions to ask."	Low	Low	Low	http://coalitionccc.org/wp-content/uploads/2014/01/Advance-Care-Planning-Conversation-Guide1.pdf
"The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care with family members and physicians."	Medium	Medium	Medium	http://theconversationproject.org/wp-content/uploads/2013/01/TCP-StarterKit.pdf
"The One Slide Project was designed with one simple goal: to help get the conversation about end of life experience started. The idea is simple: Create a tool to help get people talking. One Slide, with just five questions on it. Five questions designed to help get us talking with each other, with our loved ones, about our preferences."	Low	Low	Low	www.engagewithgrace.org
"The CRITICAL Conditions Planning Guide walks you through advance care planning, beginning with meaningful conversations among your family members and resulting in the legal documentation of your preferences."	Low	Medium	Medium	www.critical-conditions.org/preview.html
"The ... document is recommended to help identify patient preferences for end-of-life care and prevent unwanted hospital admissions at the end of life."	Low	Low	Medium	www.dyingmatters.org/sites/default/files/user/images/PPC%20final%20document.pdf
"PREPARE is an interactive website serving as a resource for families navigating medical decision making. PREPARE is a program that can help you: make medical decisions for yourself and others, talk with your doctors, get the medical care that is right for you."	Medium	High	High	www.prepareforyourcare.org

include the 3 components of our working definition of advance care planning decision aids, which is based on the IPDAS criteria (13, 14): an education component, a structured approach to thinking about the choices a patient faces, and a way for those choices to be communicated.

General decision aids for advance care planning are often used in conjunction with tools to document the decisions. Health care preferences can be documented in an advance directive and stored at a Web site, such as MyDirectives (www.MyDirectives.com). One or more proxies and their powers can be documented in a durable power of attorney for health care or as part of a more comprehensive advance directive. Health care providers can record advance care planning results (from oral discussions or an advance directive) in health care records; a specific order (such as a do-not-resuscitate order); or a template most commonly called a Physician Orders for Life-Sustaining Treatment form (found at www.polst.org), which has the advantage of serving as standing orders.

Most patients gain clarity about what information can best support specific advance care planning treatment decisions as they move from hypothetical to actual clinical

Table 2. **Examples of Advance Care Planning Decision Aids Publicly Available on the Internet for Persons With Serious or Advanced Illness**

Decision Aid (Developer)	Topics Addressed									
	Living Will or Other Advance Directive	Health Care Proxy	Life-Sustaining Treatment	Life Support and CPR	Kidney Dialysis	Pain	Artificial Nutrition and Hydration	Conversation Prompts	Treatment Location	Comfort Care Preferences
PEACE Series (American College of Physicians)		√				√		√		√
Should I Have Artificial Hydration and Nutrition? (Healthwise)							√			√
Questions to Ask Your Doctor About Advanced Cancer (National Cancer Institute)								√		
Should I Stop Kidney Dialysis? (Healthwise)					√					√
Should I Receive CPR and Life Support? (Healthwise)				√						√
Should I Stop Treatment That Prolongs My Life? (Healthwise)			√							√
Looking Ahead: Choices for Medical Care When You're Seriously Ill (Informed Medical Decisions Foundation)†	√	√	√							√
When You Need Extra Care, Should You Receive It at Home or in a Facility? (Ottawa Patient Decision Aid Research Group)									√	

CPR = cardiopulmonary resuscitation; PEACE = Patient Education and Caring: End-of-Life.
* Ratings refer to the amount of information or effort the decision aid incorporated.
† Became proprietary under a different organization during the preparation of this article.

decisions and their familiarity with health states increases or when the health state for which a decision is needed becomes more certain. For patients with predictable progressive disease (such as amyotrophic lateral sclerosis), chronic critical illness, or frailty, a structured approach to decisions in advance care planning often requires information on prognosis. **Table 2**, which is not exhaustive, summarizes decision aids for advance care planning that target patients with a life-limiting illness, for which the decision trajectory is often more clearly defined. These tools are distinct from the general population tools in **Table 1** because they are more likely to focus on a single advance care planning topic. They also are more likely to be designed by decision-making organizations (such as the Informed Medical Decisions Foundation or Healthwise) and to be reviewed by the Ottawa Hospital Research Institute, but they do not appear in the published, peer-reviewed literature. A disconnect exists between the gray literature and the empirical literature.

Current Evidence

As noted, the tools and decision aids found through the Internet search and consultation with key informants were not uncovered in the published literature search. Of the 363 citations screened, 16 studies, including 1 identified in the gray literature search (17–32), met the inclusion criteria and are summarized in **Table 3** and **Appendix Table 3** (available at www.annals.org).

Of these 16 studies, 9 were randomized, controlled trials (RCTs) (17, 19, 21, 26, 27, 29–32) and 7 were case series (18, 20, 22–25, 28). Two RCTs used a multiple-treatment design (17, 19). We could not determine whether information on harms was systematically collected in many studies. Three studies included patient levels of

Table 2—Continued

Developer's Description	Decision Aid Components*			Web Site
	Provides Education	Structured Approach	Decision Communication	
"The Consensus Panel project convened a second group of experts to develop patient education materials and Web content on end-of-life care for patients with serious or advanced illness.... PEACE Series patient education brochures are available in print or to view online."	Medium	Low	Low	www.acponline.org/patients_families/end_of_life_issues/peace
"This decision aid is for patients considering artificial hydration and nutrition if or when they are no longer able to take food or fluids by mouth."	High	High	Medium	https://print.healthwise.net/kaiser/kpisg/Print/PrintTableOfContents.aspx?token=kpisg&localization=en-us&version=&docid=tu4431
"If you learn that you have advanced cancer, you may have choices to make about care and next steps. When you meet with your doctor, consider asking some of the following questions."	Low	Low	Low	www.cancer.gov/cancertopics/cancerlibrary/questions/advanced-cancer
"This decision aid helps patients with kidney failure who have been undergoing dialysis, and for whom kidney transplantation is not possible, decide whether to continue kidney dialysis, which will allow you to live longer, or stop kidney dialysis, which will allow death to occur naturally."	High	High	Medium	https://print.healthwise.net/kaiser/kpisg/Print/PrintTableOfContents.aspx?token=kpisg&localization=en-us&version=&docid=tu6095
"This decision aid helps patients with serious or advanced illness decide whether or not to receive CPR and be put on a ventilator if heart or breathing stops."	High	High	Medium	https://print.healthwise.net/kaiser/kpisg/Print/PrintTableOfContents.aspx?token=kpisg&localization=en-us&version=&docid=tu2951
"This decision aid helps patients with serious or advanced illness decide whether to stop treatment that prolongs life and instead receive only hospice care, or to continue treatment that prolongs life."	High	High	Medium	https://print.healthwise.net/kaiser/kpisg/Print/PrintTableOfContents.aspx?token=kpisg&localization=en-us&version=&docid=tu1430
"This program is for people with a serious illness that is or may become life threatening. This program is also for family members and caregivers. The program describes different types of medical care, such as palliative care and hospice care, and reviews various types of advance directives."	Medium	Low	Medium	www.healthdialog.com/Utility/News/PressRelease/14-01-17/Health_Dialog_and_the_Informed_Medical_Decisions_Foundation_Restructure_Longstanding_Relationship.aspx#
"This decision aid helps patients with serious or advanced illness decide whether they would like to receive care at home or in a facility."	High	High	High	http://decisionaid.ohri.ca/docs/das/Place_of_Care.pdf

stress and anxiety or hope to assess whether increased distress was an adverse effect of using the tool (20, 25, 26). The 7 case series had no comparison group by design. Participants in the comparison groups in the RCTs received usual care (32), received usual care in the same format as the intervention group (31), did not complete an advance directive (19), were given advance directive forms without education or with written educational materials (21, 26), or received verbal and vignette descriptions of conditions without video enhancement (17, 27, 29, 30).

Patient Populations

The patient populations included both patients with serious or advanced illness and community-dwelling older adults or older adults without serious or advanced illness. This distinction is important because the valuation of health states changes with increasing age and experience of illness (33). Of the 16 included studies, 9 evaluated decision aids in community-dwelling or general older adult populations (17–19, 21, 23, 24, 27, 29, 30), 6 evaluated decision aids in patients with serious or advanced illness (22, 25, 26, 28, 31, 32), and 1 evaluated a decision aid in both general and disease-specific populations (20). The populations studied included patients with advanced cancer (20, 25, 28, 31), those having cardiac surgery (26), those with amyotrophic lateral sclerosis (22), and those receiving inpatient palliative care (32). Many studies had additional inclusion criteria for age (17–19, 26, 27, 29, 30), language comprehension (17, 21, 24, 27, 30), level of cognitive functioning (17–19, 22, 27–30), availability of a health care proxy (19, 26, 29), and presence of a target condition (22, 25, 26, 28). One study required participants to have access to a computer (31).

Decision Aid Methods

Decision aids took various forms, including a self-directed computer program or Web page (20–23, 31), enhanced information (17), a scenario-based or value-based

Table 3. **Outcomes Assessed in Studies of Advance Care Planning Decision Aids**

Study, Year (Reference)	Population	Decision Aid	Format
Volandes et al, 2012 (28)	Patients with advanced cancer	ACP Decisions advanced cancer goals of care video	Video
Deep et al, 2010 (18)	Community-dwelling older adults	ACP Decisions advanced dementia video	Video
Volandes et al, 2009 (29)	Community-dwelling older adults	ACP Decisions advanced dementia video	Video
Volandes et al, 2009 (30)	Community-dwelling older adults	ACP Decisions advanced dementia video	Video
Volandes et al, 2011 (27)	Community-dwelling older adults	ACP Decisions advanced dementia video	Video
Smith et al, 2011 (25)	Patients with advanced cancer	Adjuvant!	Disease prognosis and probability statistics
Allen et al, 2008 (17)	Community-dwelling older adults	Enhanced information on life-sustaining treatment risks, benefits, and alternatives	–
Ditto et al, 2001 (19)	Community-dwelling older adults	HCD and VLA directive	Scenario-based and value-based advance directives
Matlock et al, 2014 (32)	Inpatient palliative care patients	Looking Ahead: Choices for Medical Care When You're Seriously Ill	Booklet and DVD
Murphy et al, 2000 (24)	Community-dwelling older adults	Making Decisions About Health Care	Interactive CD-ROM
Green and Levi, 2009 (20)	Community-dwelling older adults and patients with cancer	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program
Green and Levi, 2011 (21)	Community-dwelling older adults and medical students	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program
Hossler et al, 2011 (22)	Patients with ALS	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program
Levi et al, 2011 (23)	Community-dwelling older adults	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program
Song et al, 2005 (26)	Patients having cardiac surgery	PC-ACP	Structured interview
Vogel et al, 2013 (31)	Patients with advanced ovarian cancer	Self-directed computer program	–

ACP = advance care planning; ALS = amyotrophic lateral sclerosis; HCD = health care directive; NE = no effect found; PC-ACP = patient-centered advance care planning; VLA = valued life activities.
* Check mark indicates that study reported positive findings for outcome. Blank cell indicates that outcome was not evaluated.
† African Americans differed from white persons in preferences for receiving comfort care vs. life-sustaining care.

advance directive (19), a video depiction of patients with advanced disease (18, 27, 28, 30), disease prognosis statistics (25), a structured interview (26), an interactive CD-ROM (24), and a DVD with an accompanying booklet (32). Eleven unique decision aids were studied. One of these, the self-directed computer program titled "Making Your Wishes Known," is directed at individuals rather than organizations and is publicly available at www.makingyourwishesknown.com/default.aspx. However, the video-based aids produced by the nonprofit foundation Advance Care Planning (ACP) Decisions (www.acpdecisions.org/videos) and the structured patient-centered advance care planning interview are marketed to specific health systems' beneficiaries and are not for general public use. The former comprises commercial products that were primarily designed for health care organizations, and the latter was created by such an organization. The cancer prognosis statistics decision aid is available in the appendix of the original article (25), and similar tools are available to physicians on the Adjuvant! Web site (www.adjuvantonline.com/index.jsp). Five tools were described in the original articles but are not easily found in the public domain: the interactive CD-ROM (24), the enhanced information aid (17), a Web site intervention in pilot stage (31), and the scenario-based and value-based advance directives (19).

Decision Aid Outcomes

Table 3 summarizes the outcomes assessed in the 16 studies we reviewed. Primary outcomes included patient satisfaction with or perceived helpfulness of the decision aid (13 studies), clarity of patient preferences for comfort care (7 studies), patient knowledge of advance directives or disease processes (11 studies), decisional conflict or confidence in decision (5 studies), effect of the decision aid on patient stress (3 studies), patient–proxy decision concordance (2 studies), effect of the decision aid on patient hope (2 studies), patient–physician decision concordance (1 study), preference stability over time (1 study), and advance directive documentation and scheduled palliative care consultation (1 study). Most of the studies examined outcomes that could be assessed contemporaneously with the intervention. Only 3 evaluated the ability of the decision aid to improve surrogate decision making or to increase the likelihood of a patient's wishes being honored at the end of life (19, 23, 26). Outcomes were not standardized across studies.

Table 3—**Continued**

Outcomes Assessed*									
Satisfaction With or Perceived Helpfulness of Decision Aid	Clarity of Patient Preferences for Comfort Care	Knowledge of Advance Directives or Disease Processes	Preference Stability Over Time	Reduction of Decisional Conflict	Patient–Proxy Concordance	Patient–Physician Concordance	Patient Hope	Patient Stress or Anxiety	Advance Directive Documentation/ Palliative Care Consultation
√	NE	√							
√	√	√							
√	√	√							
√	√	√	√						
√	√								
√		√					NE	NE	
	√†			√					
√	NE				NE				
√		NE		NE					
√		√							
√		√					NE	NE	
√		√							
√		√							
				√		√			
		NE		√	√			NE	
NE				NE					NE

Describing Advance Care Planning Decision Aids by Using the IPDAS Criteria

According to the IPDAS criteria, an important component for the evaluation of a decision aid is an index decision. When evaluating advance care planning decision aids, we excluded tools for which the primary goal was to prompt discussion of individual values for end-of-life care with loved ones and physicians because these issues, although important, do not easily equate to index decisions. Twelve tools from the gray literature and the 3 publicly available tools from the published literature (**Table 4**) were evaluated by using the IPDAS criteria. The ACP Decisions videos depicted a woman with advanced Alzheimer disease but did not focus on a decision. A few of the decision aids were not publicly available (17, 23, 34). The Respecting Choices patient-centered advance care planning interview is proprietary and is only used by patients completing proprietary training modules.

General decision aids provided less information on the index decisions than condition-specific aids. For the most part, these tools were less likely to help patients deliberate on their decision. One notable exception is PREPARE, an interactive online resource that helps patients deliberate and communicate their decisions while providing considerable information and video examples for each decision.

Decision-specific aids are more likely to provide high levels of information and help with the decision. Five of the decision-specific tools have been reviewed by the Ottawa Patient Decision Aid Research Group using the IPDAS criteria. Although the content criteria can be evaluated by a person viewing the tool, the development criteria are less apparent on most of the organizations' Web sites. The 5 tools reviewed by the Ottawa Patient Decision Aid Research Group had this information available in their decision aid summaries.

DISCUSSION

The disconnect between the widely available decision aids and the empirical literature highlights the general lack of effectiveness information. An effective decision aid leads to informed decisions consistent with the patient's values. Few tools could be described by all of the IPDAS criteria. Evaluated decision aids typically used some form of satisfaction measure rather than IPDAS effectiveness measures.

Decision aids for advance care planning can promote a staged approach with goals and outcomes that vary according to the patient's circumstances. Only those with advanced illness or at high risk for catastrophic health events would be advised to seek specific information on their condition and options for life-sustaining treatments and then be encouraged to name a health care proxy and ensure that person is aware of care preferences. Those with less certain future health needs would simply be encouraged to choose

Table 4. **Advance Care Planning Decision Aids Described by Using the IPDAS Criteria**

Decision Aid	Index Decision				Content	
	Selection of Health Care Proxy	Preference for Multiple Advance Care Planning Decisions	Preference for Specific Life-Prolonging Treatment	Preference for Site of Care	Amount of Information Provided	Presents Probabilities
Five Wishes	√	√			Low	
Consumer's Toolkit for Health Care Advance Planning	√	√			Medium	
End-of-Life Decisions	√	√			Medium	
Caring Conversations	√	√			Medium	
CRITICAL Conditions Planning Guide	√	√			Medium	
"Thinking Ahead"—GSF Advance Care Planning Discussion	√	√		√	Not evaluated	
PREPARE	√	√			High	
Should I Have Artificial Hydration and Nutrition?			√		High	
Should I Stop Kidney Dialysis?			√		High	√
Should I Receive CPR and Life Support?			√		High	√
Should I Stop Treatment That Prolongs My Life?			√		Medium	
Looking Ahead: Choices for Medical Care When You're Seriously Ill	√	√			Medium	
When You Need Extra Care, Should You Receive It at Home or in a Facility?			√		Medium	
Adjuvant!			√		High	√
Making Your Wishes Known: Planning Your Medical Future	√	√			Medium	

CPR = cardiopulmonary resuscitation; GSF = Gold Standards Framework; IPDAS = International Patient Decision Aids Standards.

and document a decision maker. The information that best serves the needs of patients depends on a clearly defined target audience, which is often easiest to accomplish for disease-specific tools.

Patients with established conditions need to consider knowledge of their prognosis in advance care planning decisions. High-quality decision aids could inform patients about their prognosis and allow them to consider potential implications of health care decisions. Ideally, patients would be given information on the expected natural history of their condition, the efficacy of various life-sustaining interventions to change the course or experience of illness, and potential harms. Better interactive or patient-specific tools are needed to help patients and clinicians estimate probabilities of intervention benefits in various circumstances near the end of life.

Prognosis and planning are even more difficult for diseases with less certain trajectories (for example, heart disease or dementia vs. metastatic cancer). Without concrete information, clinicians struggle to know what to talk about and when, and designers of decision support materials do not know what information to include. Patients with an uncertain disease trajectory base their decisions on hypothetical understanding. Advance care planning ideally would be an ongoing process rather than a one-time decision and would be revised as the patient's familiarity with the health condition increases.

The IPDAS criteria reflect the importance of balanced presentations and neutral agendas. Decision aids need to recognize diverse philosophical perspectives, be sensitive to cultural and spiritual traditions, and support nuanced decisions. Decision aids that facilitate choices for comfort care and life-sustaining treatments are effective if the resulting choices are consistent with the informed consumer's values and wishes.

Several future research efforts could help improve advance care planning decision aids. The effectiveness of widely used aids should be formally evaluated. In addition, more well-designed, validated tools that are easily accessible, readable, understandable, and appropriate for patients working with various facilitators across various settings are needed. A broad array of tools may be needed for use by various professionals, in different settings, and at various stages of the map shown in the **Figure**. In particular, further work on helping patients choose an appropriate proxy is needed. Criteria for assessing decision aids should include patient and provider satisfaction, effect on stated preferences, and efficiency of the advance care planning process. The IPDAS criteria may provide a structure for judging quality and effectiveness of decision aids (35, 36). Serious consideration should also be given to what harms should be consistently assessed in research on advance care planning decision aids. Comparative studies might include attention to who facilitates decisions and how. Educational components of advance care planning decision aids would be improved with more effectiveness studies of various end-of-life interventions in different clinical populations and ways to design aids that enable patients to work backward from their preferred site of care to then decide which therapies they might accept in that setting (because location of care is sometimes a dominant preference in advance care planning).

Table 4—**Continued**

Content			Development					Effectiveness (Decisions Are Informed and Value-Based)
Clarifies Patient Values	Guides Decision Deliberation	Guides Decision Communication	Presents Balanced Information	Systematic Development	Cites Scientific Evidence	Discloses Conflicts of Interest	Uses Plain Language	
√		√					√	Not evaluated
√		√						Not evaluated
√								Not evaluated
√	√	√					√	Not evaluated
√		√					√	Not evaluated
√		√					√	Not evaluated
√	√	√	√	√				Not evaluated
√	√	√	√	√	√	√	√	Medium
√	√	√	√	√	√	√	√	Medium
√	√	√	√	√	√	√	√	Medium
√	√	√	√	√		√	√	Medium
√								Not evaluated
√	√	√	√			√	√	Not evaluated
	√		√	√		√	√	Medium
√		√	√	√		√		Medium

Advance care planning decision aids often lack systems to encourage routine reconsideration of preferences. When a person moves from hypothetical to actual experience with a health state, advance planning becomes an ongoing process rather than a one-time decision to be documented. However, having patients complete at least 1 care plan takes precedence over creating decision aids to support dynamic plans. Computer-based decision aids and documentation that relies heavily on Web-based tools may be unavailable to vulnerable populations.

Ultimately, decision aids can help patients to thoughtfully consider and document their preferences and assess important relationships. A well-considered and well-communicated preference helps physicians feel comfortable about the ethics of providing or withholding treatments that affect survival. Effective decision aids help provide closure to family and loved ones who will live with the consequences.

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Appendix Table 1. **Interview Probes for Key Informants**

Questions for experts/researchers/provider organizations/practicing clinicians
- What decision aids do you use in advance care planning?
- What specific advance care planning tools and aids characterize your program? (May we see them?)
- What do you see as the strengths and weaknesses of the decision aids you have used? The barriers and facilitators of using the decision aids?
- Gray literature: Which professional organizations are important to consult regarding:
  - Tools
  - Preliminary study findings
- Review/comment on definitions of advance care planning and decision aid models.
- What types of research are needed most? What outcomes? What designs? When should outcomes be measured (length of follow-up)?
- What format works best in your experience?
- Which health care directive form do you prefer?

Questions for patient advocates/families/caregivers
- What information do patients need to know when planning advance care?
- Does that information change based on your level of health?
- What do you view as the advantages/disadvantages of advance planning?
- How did the decision aid help with the planning process?

Questions for ethicists/clergy/law
- What do you consider important ethical considerations that need to be addressed with regard to advance care planning and decision aids?
- How do decision aids help or change the dynamics of the advance care planning process itself and, if conducted as a dialogue, discussions among patients, family members, and providers?
- What information do you believe is most needed by people considering advance care planning?
- What kinds of research would be most useful? What outcomes?
- To what extent should the health care professional facilitating the conversation give advice (person as decision aid)?

Appendix Table 2. **MEDLINE Search Strategy***

1. exp Advance Care Planning/
2. exp Advance Directives/
3. "advanced care plan*".ti.
4. "advance* care plan*".m_titl.
5. (advance* adj2 directive*).ti.
6. "living will*".m_titl.
7. "end of life".mp.
8. exp Decision Support Techniques/
9. exp Decision Support Systems, Clinical/
10. decision aid*.mp.
11. decision tool*.mp.
12. decision support.mp.
13. instrument*.ti,ab.
14. intervention*.ti,ab.
15. program*.ti,ab.
16. exp *Decision Making/
17. 13 or 14 or 15
18. 15 and 16
19. 8 or 9 or 10 or 11 or 12 or 18
20. 1 or 2 or 3 or 4 or 5 or 6 or 7
21. 19 and 20

* Modified for other databases.

Appendix Table 3. **Studies of Advance Care Planning Decision Aids**

Study, Year (Reference)	Design	Population	Decision Aid	Format	Comparator
Volandes et al, 2012 (28)	Case series	80 patients with advanced cancer	ACP Decisions advanced cancer goals of care video	Video	Patients served as own control before and after viewing video (all patients received verbal description of care choices)
Deep et al, 2010 (18)	Case series	120 community-dwelling older adults	ACP Decisions advanced dementia video	Video	Patients served as own control before and after viewing video (all patients received verbal description of care choices)
Volandes et al, 2009 (29)	RCT	14 community-dwelling older adults and their surrogates	ACP Decisions advanced dementia video	Video	Patients randomly assigned to verbal description with or without video decision aid
Volandes et al, 2009 (30)	RCT	200 community-dwelling older adults	ACP Decisions advanced dementia video	Video	Patients randomly assigned to verbal description with or without video decision aid
Volandes et al, 2011 (27)	RCT	76 community-dwelling older adults	ACP Decisions advanced dementia video	Video	Patients randomly assigned to verbal description with or without video decision aid
Smith et al, 2011 (25)	Case series	27 patients with advanced cancer	Adjuvant!	Disease prognosis and probability statistics	Patients served as own control before and after using decision aid
Allen et al, 2008 (17)	RCT	78 community-dwelling older adults	Enhanced information on life-sustaining treatment risks, benefits, and alternatives	–	Patients randomly assigned to LSPQ vignettes with or without enhanced information and medical information stimuli
Ditto et al, 2001 (19)	RCT	401 community-dwelling older adults	HCD and VLA directive	Scenario-based and value-based advance directives	Patients randomly assigned to HCD with no discussion, HCD with discussion, VLA directive with no discussion, VLA directive with discussion, or no advance directive
Matlock et al, 2014 (32)	RCT	51 inpatient palliative care patients or their decision makers	Looking Ahead: Choices for Medical Care When You're Seriously Ill	Booklet and DVD	Patients randomly assigned to usual palliative care consultation services or usual care and the decision aid
Murphy et al, 2000 (24)	Case series	31 community-dwelling older adults	Making Decisions About Health Care	Interactive CD-ROM	Patients served as own control before and after using decision aid
Green and Levi, 2009 (20)	Case series	50 community-dwelling older adults and 34 patients with cancer	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program	Patients reported satisfaction and enhanced knowledge with use of aid
Green and Levi, 2011 (21)	RCT	121 community-dwelling older adults and 121 medical students	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program	Medical student–patient dyads were randomly assigned to usual care or decision aid group
Hossler et al, 2011 (22)	Case series	17 patients with ALS	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program	Patients served as own control before and after using decision aid
Levi et al, 2011 (23)	Case series	19 community-dwelling older adults	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program	Evaluation of aid's ability to appropriately guide decision making
Song et al, 2005 (26)	RCT	32 cardiac surgery patients and their surrogates	PC-ACP	Structured interview	Patients randomly assigned to usual care (advance directive information packet and access to pastoral care facilitator) or decision aid
Vogel et al, 2013 (31)	RCT	53 women with ovarian cancer*	Self-directed computer program	–	Patients randomly assigned to a control Web site with usual care information or the decision aid

ACP = advance care planning; ALS = amyotrophic lateral sclerosis; HCD = health care directive; LSPQ = life support preferences questionnaire; PC-ACP = patient-centered advance care planning; RCT = randomized, controlled trial; VLA = valued life activities.
* 35 completed the study.

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