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Tools to promote shared decision making in serious illness: A systematic review

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IMPORTANCE  Serious illness impairs function and threatens survival. Patients facing serious illness value shared decision making, yet few decision aids address the needs of this population.

OBJECTIVE  To perform a systematic review of evidence about decision aids and other exportable tools that promote shared decision making in serious illness, thereby (1) identifying tools relevant to the treatment decisions of seriously ill patients and their caregivers, (2) evaluating the quality of evidence for these tools, and (3) summarizing their effect on outcomes and accessibility for clinicians.

EVIDENCE REVIEW  We searched PubMed, CINAHL, and PsychInfo from January 1, 1995, through October 31, 2014, and identified additional studies from reference lists and other systematic reviews. Clinical trials with random or nonrandom controls were included if they tested print, video, or web-based tools for advance care planning (ACP) or decision aids for serious illness. We extracted data on the study population, design, results, and risk for bias using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) criteria. Each tool was evaluated for its effect on patient outcomes and accessibility.

FINDINGS  Seventeen randomized clinical trials tested decision tools in serious illness. Nearly all the trials were of moderate or high quality and showed that decision tools improve patient knowledge and awareness of treatment choices. The available tools address ACP, palliative care and goals of care communication, feeding options in dementia, lung transplant in cystic fibrosis, and truth telling in terminal cancer. Five randomized clinical trials provided further evidence that decision tools improve ACP documentation, clinical decisions, and treatment received.

CONCLUSIONS AND RELEVANCE  Clinicians can access and use evidence-based tools to engage seriously ill patients in shared decision making. This field of research is in an early stage; future research is needed to develop novel decision aids for other serious diagnoses and key decisions. Health care delivery organizations should prioritize the use of currently available tools that are evidence based and effective.
 Serious illness raises the stakes for engaging patients and families in health care decisions. Patients with serious illness include those with critical life-threatening illness, advanced stages of major chronic diseases, or multimorbidity and frailty. They confront debilitating symptoms and impending threats to function, decisional capacity, and survival. Patients, caregivers, and health care practitioners identify communication and shared decision making as essential components of good care in serious illness. However, poor quality of communication between patients and practitioners limits the patients’ knowledge of prognosis and treatment options, management of symptoms, and use of treatments consistent with their preferences.

Structured tools are a novel method to improve knowledge transfer and promote patient engagement in health care choices. Tools that use print, video, or web-based media are designed to share information about an illness and promote informed decisions about treatment. These tools are not a substitute for clinical communication, but are intended to prepare and empower patients and their families for shared decision making with clinicians. Some tools are designed to improve the patients’ knowledge about clinical issues. Other tools are formal decision aids, which are more highly structured to address the risks and benefits of and alternatives to treatment and are designed to prepare patients for their role in key decisions. Randomized clinical trials (RCTs) have shown that decision aids improve the quality and efficiency of decision making, increase comprehension and decisional participation, and decrease decisional conflict. Despite the importance of shared decision making in serious illness, most formal decision aids have addressed the needs of healthier outpatients, and a recent Cochrane review excluded advance care planning (ACP) tools.

No systematic review, to our knowledge, has synthesized the evidence for communication tools and decision aids in serious illness. We therefore sought to assess the quality and accessibility of decision aids and tools for ACP designed to empower and improve the care of patients with serious illness. To meet this objective, we conducted a systematic review of published clinical trials of decision aids and ACP tools to promote shared decision making in serious illness. The goals of this study are to (1) identify tools relevant to the needs of treatment decision making by seriously ill patients and their caregivers, (2) evaluate the quality of evidence for these tools, and (3) summarize their effect on patient-centered outcomes and accessibility of tools for clinicians.

Methods

Data Sources and Searches
We searched PubMed, CINAHL, and PsychInfo from January 1, 1995, through October 31, 2014, and identified additional studies from reference lists and relevant systematic reviews. Our electronic search strategy included the following terms using text word (tw) or MeSH field tags: (brochure*tw OR pamphlet*tw OR booklet*tw OR communication tool*tw OR DVD*tw OR multi-media*tw OR Multimedia*tw OR Decision Aid*tw OR Internet[MeSH] OR website*tw OR web site*tw OR videotape recording[MeSH] OR videodisc recording[MeSH] OR video-audio media[publication type]) AND (terminal*tw OR chronic*tw OR advanced*tw OR severe*tw OR failure*tw OR end stage*tw OR end stage*tw OR dying*tw OR Intensive Care Units[MeSH] OR intensive care*tw OR ICU*tw OR hospice*tw) AND (Patient[MeSH] OR Patient*tw OR patients*tw OR family[MeSH] OR family*tw OR families OR son*tw OR sons*tw OR daughter*tw OR parent*tw OR parents*tw OR spouse*tw OR spouses*tw OR husband*tw OR wife*tw OR wives*tw OR caregiver*tw).

Study Selection
This systematic review includes published nonrandomized clinical trials and RCTs that test decision tools intended for use by patients and their caregivers. Studies were included if they tested tools to improve treatment decision making for patients living with serious illness. Decision tools were included whether or not they met the International Patient Decision Aid Standards Collaboration definition for decision aids, that is, tools that present treatment options in a balanced and evidence-based manner. Tools were included if they were structured for use by the patient or family caregiver without immediate clinician support. For instance, we excluded interventions that required communication training for clinicians or extensive patient coaching. Formats included print, video, or web-based decision tools. Content had to be relevant for communication about major treatment decisions in serious illness. Included studies could be from any health care setting or country if they were written in English and amenable to quality analysis. Given the early stage of this field of research, we accepted randomized or nonrandomized controls and diverse outcomes and lengths of follow-up.

We defined an eligible patient population as adults living with advanced-stage or potentially life-limiting diseases, including critical illness, metastatic cancer, advanced stages of renal or liver disease, chronic obstructive pulmonary disease, cystic fibrosis, systolic congestive heart failure, human immunodeficiency virus infection and/or AIDS, or advanced neurodegenerative diseases, such as Parkinson disease, amyotrophic lateral sclerosis, or dementia. Studies were excluded if they addressed prevention or stable chronic disease at an early stage. Because communication and decision making differ greatly for children, we included only interventions for patients 18 years or older.

Two of us (D.M. and L.C.H.) reviewed all titles and abstracts and excluded abstracts that did not address patients with serious illness. Two of us (C.A.A. and L.C.H.) independently reviewed all the remaining abstracts and excluded observational studies, studies of patients with insufficient illness severity, or studies of nonexportable interventions. At least 2 of us then examined each full article of the remaining published studies to determine final inclusion and exclusion. Any disagreements were resolved by consensus discussion. Additional studies were accepted after hand searching reference lists of the included studies and asking content experts for additional suggestions.

Data Extraction and Quality Assessment
We created a standardized data extraction instrument to prepare evidence tables. This instrument followed the CONSORT criteria and the Transparent Reporting of Evaluations With Nonrandomized Designs (TREND) criteria. Data extraction included study design and the type of control or comparison group; target population and severity of illness; primary and secondary outcome measures; reported results; and intervention type categorized as ACP for a future decision or support for a current clinical decision.
Data Synthesis and Analysis

Two of us (C.A.A. and L.C.H.) analyzed the studies’ risk for bias based on the presence or absence of the following 8 elements: randomization with or without allocation concealed, binding of outcome assessment, binding of participants, specification of outcomes, specification of inclusion criteria, greater than 75% completion of outcome data, adjustment for confounding, and intention-to-treat analysis. Analysis followed the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) criteria used in Cochrane systematic reviews.12,33 Studies meeting 5 or more of these criteria were assessed as high quality (GRADE A) with a low risk for bias; those meeting 3 to 4 criteria, as intermediate quality (GRADE B) with a medium risk for bias; and those meeting 0 to 2 criteria, as lower quality (GRADE C) with a high risk for bias. To reduce bias in reporting, one of us (C.A.A.) led the review of studies authored by investigators conducting this systematic review. We used the PRISMA checklist to design and report the study.34

To summarize the potential clinical impact of each decision tool, we developed categories to describe the degree of change in patient-centered outcomes. Interventions that lead to improvement in patient outcomes of symptom distress, satisfaction, or quality of life or changes in treatment experiences were termed high impact. Tools with evidence of patient or caregiver behavioral changes or actual treatment choices were termed moderate impact. Tools with no effect on outcomes or those addressing intermediate outcomes, such as change in knowledge or attitudes, were termed lesser impact. To describe the accessibility of each tool, we searched the published studies and the Internet for information on how to view and use the tool and whether it was free or had to be purchased.

Results

Of the initial 9995 titles identified by the search strategy, 389 met our criteria for full abstract review, and 110 met our criteria for full text review. Seventy-five studies were excluded, and 3 additional titles were included from hand searching reference lists. In total, 38 articles met all inclusion criteria (Figure).

Seventeen of the included studies were RCTs, and the remaining 21 studies were trials with a small pilot or preintervention-postintervention study design. Six of the RCTs tested tools for ACP for future decisions, and 11 tested tools to support immediate treatment choices.

Small Pilot and Preintervention-Postintervention Studies

The 21 pilot studies75-34 were designed to examine feasibility and to provide preliminary evidence for newly developed decision tools (Table 1). Seven pilot trials tested ACP tools for future decisions,15,23-27,34 and 14 tested tools to support patient engagement in current decisions.76-22,28,33 Seven of the pilot trials15,19,21,22 have been followed by published RCTs,35-42 and a search of trial registries revealed that 2 additional studies7,25 are being tested in clinical trials.

RCTs of Decision Tools for ACP

Six RCTs35-37,43-45 tested 4 different ACP tools, including a short video, a low-health-literacy print tool, a workbook, and a website. Within this group, nearly all studies were of high quality and targeted out-patient populations (Table 2). All but 1 tool improved patient knowledge,35-37,43,44 and 2 tools had an effect on clinical decisions.43,44

Three high-quality (GRADE A) clinical trials tested a 2-minute video developed by Volandes et al35-37 on features of advanced dementia to inform ACP discussions, should individuals develop this health condition. Each study tested the video in different outpatient populations. The largest of these 3 trials35 enrolled 200 outpatients 65 years and older and found that viewing the video resulted in a significant increase in patients reporting that they would choose comfort as their primary goal for a future health state of advanced dementia (86% vs 64%; P = .003). Another study37 examined 76 rural outpatients and demonstrated an increased choice of comfort as their primary goal for advanced dementia (91% vs 72%; P < .001). A third study of 14 outpatients older than 65 years36 demonstrated increased concordance between patients and their surrogates after viewing the video (100% vs 33%; P = .02). These trials examined immediate preference change, but they did not examine outcomes such as documentation of preferences or discussion of preferences with health care practitioners.

The remaining 3 ACP studies43-45 tested the effect of 3 different tools on the expression and documentation of treatment preferences. One high-quality (GRADE A) RCT by Sudore et al15 examined an advance directive that was modified for patients with lower health literacy and found it improved ease of use when compared with a standard advance directive document (69.1% vs 48.7%; P < .001). Six months later, those patients who used the literacy-adjusted advance directive were more likely to have completed a written directive (18.5% vs 77%; P = .03). The RCT by Pearlman et al44 was of intermediate quality (GRADE B). The authors examined an ACP workbook and found a significant increase in the discussion of ACP with health care practitioners (64% vs 28%; P < .001) and in documentation of living wills (48% vs 23%; P < .001). Finally, a
poor-quality small RCT45 tested a website to promote ACP and palliative care consultation for women with ovarian cancer. This small study found no effect of the website tool on advance directive evaluation by a palliative care team.

RCTs of Decision Tools for Current Treatment

Eleven RCTs38-42,46-51 tested decision tools to support current treatment choices in serious illness. All but 1 study49 improved knowledge (Table 3). Three tools40,46,47 also provided evidence of improved clinical communication or choice of options.

Seven of these studies38,39,41,46-48,51 involved populations with advanced cancer. One high-quality (GRADE A) study of outpatients with advanced cancer by Clayton et al46 found that a booklet prompting communication about prognosis and palliative care led to significantly more patient questions asked during an initial palliative care visit (2.31 times more questions; P < .001). Another large high-quality (GRADE A) study by Leight et al48 examined the impact of a 15-minute online module intended to help patients with metastatic cancer prepare for an initial oncology visit. Although no change in decisional conflict or choice of palliative chemotherapy was observed, the authors noted an increase in satisfaction with P = .03 and ease of decision making (P < .01).

In a large high-quality (GRADE A) study by Yun et al49 a booklet assisting family members with the decision about disclosure of

Table 1. Small Pilot and Preintervention-Postintervention Studies

<table>
<thead>
<tr>
<th>Source</th>
<th>Intervention and Study Population Description</th>
<th>Follow-up RCT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision Making Tools for ACP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Braun et al,23 2006</td>
<td>Booklets on 5 end-of-life topics to be targeted to the elderly</td>
<td>NA</td>
</tr>
<tr>
<td>Hickman et al,24 2014</td>
<td>Video and web-based interactive education regarding completion of advance directive</td>
<td>NA</td>
</tr>
<tr>
<td>Hossler et al,46 2010</td>
<td>Interactive, computer- based tool on ACP for patients with ALS</td>
<td>NA</td>
</tr>
<tr>
<td>Enguidanos et al,25 2011</td>
<td>Brochure on African Americans and hospice care for outpatients with chronic illnesses</td>
<td>NA</td>
</tr>
<tr>
<td>Schiff et al,26 2009</td>
<td>Booklet on ACP for elderly hospitalized patients</td>
<td>NA</td>
</tr>
<tr>
<td>Schubart et al,7 2012</td>
<td>Computer-based tool about ACP for elderly outpatients</td>
<td>NA</td>
</tr>
</tbody>
</table>

Decision Making Tools to Support Current Choices

<table>
<thead>
<tr>
<th>Source</th>
<th>Intervention and Study Population Description</th>
<th>Follow-up RCT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brundage et al,28 2000</td>
<td>Booklet with descriptions of treatment options for advanced NSCLC and adverse effects</td>
<td>NA</td>
</tr>
<tr>
<td>Cox et al,7 2012</td>
<td>Ten-page booklet describing chronic critical illness to aid families of patients in the ICU</td>
<td>Study in progress and recruiting, <a href="https://clinicaltrials.gov">https://clinicaltrials.gov</a></td>
</tr>
<tr>
<td>Dales et al,29 1999</td>
<td>Booklet with accompanying audio portion about MV in severe COPD</td>
<td>NA</td>
</tr>
<tr>
<td>Deep et al,36 2010</td>
<td>Two-minute video showing features of advanced dementia and goals of care for families of patients with advanced dementia Volandes et al,35 2009; Volandes et al,36 2009; and Volandes et al,37 2011</td>
<td></td>
</tr>
<tr>
<td>Leight et al,17 2008</td>
<td>Twenty-five-page booklet on lung cancer treatment and outcomes for patients with advanced NSCLC</td>
<td>Leight et al,36 2011</td>
</tr>
<tr>
<td>Matlock et al,30 2014</td>
<td>Booklet on palliative care, including importance of ACP and clarifying goals and wishes for inpatients undergoing evaluation by a palliative care team</td>
<td>NA</td>
</tr>
<tr>
<td>McCannon et al,25 2012</td>
<td>Three-minute video on CPR and mechanical ventilation for families of critically ill patients</td>
<td>Epstein et al,39 2013</td>
</tr>
<tr>
<td>Mitchell et al,19 2001</td>
<td>Audiobooklet addressing feeding options for families of patients with advanced dementia</td>
<td>Hanson et al,40 2011</td>
</tr>
<tr>
<td>Sepucha et al,31 2009</td>
<td>Thirty-minute video with booklet that addresses living with metastatic breast cancer</td>
<td>NA</td>
</tr>
<tr>
<td>Smith et al,32 2011</td>
<td>Printed booklet with review of diagnoses, prognosis, treatment options, and adverse effects for advanced malignant disease</td>
<td>NA</td>
</tr>
<tr>
<td>Sudore et al,26 2014</td>
<td>Easy-to-read, culturally appropriate, interactive, website that includes a 5-step ACP process and the use of how-to videos that model ACP behavior. The program is focused on teaching elderly patients how to identify what is most important in life, how to communicate that with others, and how make informed medical decisions.</td>
<td>Study in progress and recruiting, <a href="https://clinicaltrials.gov">https://clinicaltrials.gov</a></td>
</tr>
<tr>
<td>Snyder et al,42 2013</td>
<td>Printed booklet written at sixth-grade level on advanced dementia and feeding options for families of these patients</td>
<td>Hanson et al,40 2011</td>
</tr>
<tr>
<td>Volandes et al,22 2012</td>
<td>Six-minute video depicting the following 3 possible levels of care: full, limited, or comfort focus for patients with advanced cancer El-Jawahri et al,41 2010; Volandes et al,42 2012</td>
<td></td>
</tr>
<tr>
<td>Wilson et al,33 2005</td>
<td>Booklet with audio portion describing COPD and MV for Canadian outpatients with severe COPD</td>
<td>NA</td>
</tr>
</tbody>
</table>

Abbreviations: ACP, advance care planning; ALS, amyotrophic lateral sclerosis; COPD, chronic obstructive pulmonary disease; CPR, cardiopulmonary resuscitation; ICU, intensive care unit; MV, manual ventilation; NA, not applicable; NSCLC, non-small cell lung cancer; RCT, randomized clinical trial.
Table 2. RCTs of Decision Tools for ACP

<table>
<thead>
<tr>
<th>Source</th>
<th>Study Population</th>
<th>Intervention and Control</th>
<th>Evidence of Effect on Patient-Centered Outcomes</th>
<th>Rating and Accessibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearlman et al,44 2005</td>
<td>280 Outpatients aged ≥55 y with chronic illness Severity of illness: moderate</td>
<td>Intervention: 52-page workbook Your Life, Your Choices on ACP and 30-min visit with social worker Control: packet of advance directive forms</td>
<td>Moderate impact Increased patient report of ACP discussions after index visit (64% vs 28%; P &lt; .001); increased ACP-related notes written by the clinicians (48% vs 23% of the medical records, respectively; P = .001)</td>
<td>GRADE B Free online (<a href="http://www.rhlp.org">http://www.rhlp.org</a>)</td>
</tr>
<tr>
<td>Sudore et al,45 2007</td>
<td>205 Outpatients aged ≥50 y in an urban medical clinic Severity of illness: moderate</td>
<td>Intervention: 12-page advance directive document modified for low health literacy, available in English or Spanish Control: Standard California advance directive</td>
<td>Moderate impact Improved ease of use and understanding (69.1% vs 48.7%; P &lt; .001) Increased completion of advance directives in 6 mo (18.5% vs 7.7%; P = .03)</td>
<td>GRADE A Free online (<a href="http://www.iahealth.org/wp-content/uploads/2014/03/CAHCD_English_no_Script_3.14.13.pdf">http://www.iahealth.org/wp-content/uploads/2014/03/CAHCD_English_no_Script_3.14.13.pdf</a>)</td>
</tr>
<tr>
<td>Vogel et al,46 2013</td>
<td>35 Outpatients with stages III and IV ovarian cancer Severity of illness: moderate to severe</td>
<td>Intervention: website information on ovarian cancer, shared decision making, advance directive completion, and palliative care consultation Control: usual care, clinical documents available on a website</td>
<td>Lesser impact No effect on completion of advance directives (P = .220) No effect on palliative care consultation (P = .440)</td>
<td>GRADE C Not accessible</td>
</tr>
<tr>
<td>Volandes et al,47 2009</td>
<td>200 Outpatients aged ≥65 y Severity of illness: moderate</td>
<td>Intervention: verbal description followed by a 2-min video showing features of advanced dementia Control: verbal description of advanced dementia</td>
<td>Lesser impact Increased choice of comfort care as primary goal (86% vs 64%; P = .003)</td>
<td>GRADE A Clinicians may purchase online (<a href="http://www.acpdecisions.org/">http://www.acpdecisions.org/</a>)</td>
</tr>
<tr>
<td>Volandes et al,48 2009</td>
<td>14 Outpatients aged ≥65 y Severity of illness: moderate</td>
<td>Intervention: verbal description followed by a 2-min video showing features of advanced dementia Control: verbal description of advanced dementia</td>
<td>Lesser impact Increased concordance between patients and surrogates (100% vs 33%; P = .015)</td>
<td>GRADE A Clinicians may purchase online (<a href="http://www.acpdecisions.org/">http://www.acpdecisions.org/</a>)</td>
</tr>
<tr>
<td>Volandes et al,49 2011</td>
<td>76 Rural outpatients aged ≥65 y Severity of illness: moderate</td>
<td>Intervention: verbal description followed by a 2-min video showing features of advanced dementia Control: verbal description of advanced dementia</td>
<td>Lesser impact Increased choice of comfort care as primary goal (91% vs 72%; P &lt; .001) Decreased choice of life-prolonging care as primary goal (0 vs 16%; P = .047)</td>
<td>GRADE A Clinicians may purchase online (<a href="http://www.acpdecisions.org/">http://www.acpdecisions.org/</a>)</td>
</tr>
</tbody>
</table>

Abbreviations: ACP, advance care planning; GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized clinical trial.

* GRADE ratings are explained in the Data Synthesis and Analysis subsection of the Methods section.

terminal status to Korean patients with cancer offered no change in the decision to discuss a terminal prognosis, but a significant decrease in decisional conflict (P = .008) and caregiver depression (P = .007) occurred. Further, both benefits were sustained at 6 months (P = .03 and P = .008, respectively).51

An intermediate-quality (GRADE B) study by Peele et al47 showed that an online decision tool decreased the choice for adjuvant chemotherapy with limited medical benefits in patients with breast cancer (P < .05). In a large study of intermediate quality (GRADE B), Meropol et al48 tested an online training module to prepare patients with advanced cancer for their first oncology visit. This intervention improved patients’ satisfaction with and ease in decision making.

Two studies49,50 examined 2 different video decision making tools for cancer patients. One intermediate-quality (GRADE B) study50 of a 3-minute video on cardiopulmonary resuscitation and mechanical ventilation assessed subsequent decisions by inpatients with late-stage gastrointestinal tract cancer, and they found no change in cardiopulmonary resuscitation or ventilation preferences. However, a high-quality (GRADE A) study51 testing a similar 6-minute video on the goals of care resulted in a large increase of choice of comfort measures (91% vs 22%; P < .001) in a population with malignant glioma. This 6-minute video was also shown to individuals who were newly admitted to nursing homes in another high-quality RCT.42 and more patients in the intervention group preferred comfort-oriented care (80% vs 57%; P = .02).

Two of the remaining studies40-49 addressed patients with advanced dementia. A high-quality (GRADE A) study by Hansson et al40 found that a decision making tool on feeding options in patients with advanced dementia in nursing homes led to significant decreases in decisional conflict (Decisional Conflict Scale score, 1.65 vs 1.97; P < .001) and increased the use of a dysphagia diet (89% vs 76%; P = .04). An intermediate-quality (GRADE B) Australian study by Stirling et al40 of a decision tool on supportive resources for dementia care did not find any change in decisional conflict or treatment preferences.

Finally, Vandemheen et al50 led a high-quality (GRADE A) study of a decision tool for patients with cystic fibrosis who were considering lung transplant and found that the tool increased knowledge and realistic expectations while decreasing decisional conflict (P < .001). However, the tool did not change the choice to undergo transplant at 12 months.50

Discussion

Key Findings

This study is, to our knowledge, the first systematic review of clinical tools to improve communication and decision making for patients facing serious illness. Seventeen RCTs, nearly all of moderate or high quality, form the primary body of evidence for these tools. Study results show that decision tools clearly improve patient
<table>
<thead>
<tr>
<th>Source</th>
<th>Study Population</th>
<th>Intervention and Control</th>
<th>Evidence of Effect on Patient-Centered Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clayton et al, 2002</td>
<td>774 Australian outpatients with malignant glioma</td>
<td>Severe of illness: moderate</td>
<td>No change in anxiety or information need at 3 wk</td>
</tr>
<tr>
<td>Epstein et al, 2005</td>
<td>112 Australian outpatients with advanced dementia</td>
<td>Moderate impact</td>
<td>No change in decisional conflict, knowledge, or treatment preferences</td>
</tr>
<tr>
<td>Hanson et al, 2006</td>
<td>256 Patients in new admissions to skilled nursing facilities in Boston area</td>
<td>Severe</td>
<td>Decrease in decisional conflict initially (P = .007) and at 6 mo (P = .031)</td>
</tr>
<tr>
<td>Lesser et al, 2007</td>
<td>56 Ambulatory outpatients with progressive parkinson's disease or cognitive impairment</td>
<td>Lesser impact</td>
<td>Decreased decisional conflict initially (P = .008) and at 12 mo (P = .01)</td>
</tr>
<tr>
<td>Levin et al, 2008</td>
<td>406 Patients with breast cancer and eligible for adjuvant therapy</td>
<td>Severe</td>
<td>No change in decisional conflict, knowledge, or treatment preferences</td>
</tr>
<tr>
<td>Meropol et al, 2009</td>
<td>432 Outpatients with breast cancer</td>
<td>Severe</td>
<td>No change in transplant choice at 12 mo</td>
</tr>
<tr>
<td>Stirling et al, 2009</td>
<td>151 Outpatients with advanced cancer in Canada and Australia</td>
<td>Severe</td>
<td>Decrease in overall satisfaction with communication at 3 mo</td>
</tr>
<tr>
<td>Vandemheen et al, 2010</td>
<td>101 Patients aged ≥65 years with advanced cancer in Korea</td>
<td>Severe</td>
<td>Decreased caregiver depression initially (P = .007) and at 6 mo (P = .008)</td>
</tr>
<tr>
<td>Yun et al, 2011</td>
<td>944 Participants in Korea</td>
<td>Severe</td>
<td>Decreased caregiver depression initially (P = .007) and at 6 mo (P = .008)</td>
</tr>
<tr>
<td>Abbreviations: ACP, advance care planning; CF, cystic fibrosis; CPR, cardiopulmonary resuscitation; DCS, Decisional Conflict Scale; FEV, forced expiratory volume in the first second of expiration; GRADE, Grades of Recommendation, Assessment, Development, and Evaluation; MV, manual ventilation; RCT, randomized clinical trial; s/p, status post.</td>
<td></td>
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<tr>
<td>Table 3. RCTs of Decision Tools for Current Treatment</td>
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</table>
knowledge and preparation for treatment choices, including ACP, palliative care and goals of care communication, feeding options in dementia, lung transplant in cystic fibrosis, and truth telling in terminal cancer.

**Methodological Considerations**

Although many trials do not measure outcomes beyond knowledge, 5 published decision tools provide evidence of an effect on clinical outcomes, changes in advance directive documentation, clinical decision making, and treatments received. Three of these tools have been tested in a high-quality RCT, including a tool to promote ACP for persons with low literacy, a booklet to prepare patients with advanced cancer to talk with a palliative care team, and a decision aid for feeding options in dementia. All 3 tools are currently available for free on the Internet.

The strongest evidence to promote ACP and to prepare patients for future choices supports 2 tools. The first tool is a video ACP tool available to clinicians from the developer that can discuss decisions in treatment preferences for the future health state of patients with advanced dementia. The second tool is an advance directive documentation guide available for free on the Internet that is designed for patients with low health literacy.

Several tools to support immediate clinical choices are available and evidence based. Most of these tools improve knowledge, and some are proven to change actual treatment decisions. Only 2 tools are standardized decision aids—one addressing feeding options in dementia care and one addressing advanced treatment choices in cystic fibrosis. Decision aids differ in important ways from other decision tools and meet formal standards for framing the presentation of medical information to patients in line with principles of shared decision making.

This study makes a novel contribution to the existing literature by systematically reviewing exportable decision tools designed to empower patients and caregivers in decision making. However, these data have important limitations. Many study populations were small, leaving studies inadequately powered for meaningful results. Study populations all have serious illness, but diagnoses are heterogeneous and limit conclusions about application to specific diseases. More than half of the identified studies used convenience samples and followed a pre-intervention-postintervention study design. The nature of interventions designed to improve these outcomes often results in a nonblinded study design. We only searched for articles published since 1995, so we might have missed earlier articles. However, our review did not reveal any articles before 1998; therefore, this possibility seems less likely. Finally, this review is limited to published research. The analysis might have had a publication bias toward positive studies that could skew our review. However, some of the studies reviewed reported negative findings, so this possibility seems less likely.

**Implications**

Given the clear need to improve shared decision making in serious illness, improving this body of evidence should be a research priority. Research is needed to test decision aids for major serious illnesses, such as advanced heart failure or end-stage renal disease. Because the effect on knowledge is well established, future research needs to focus on outcomes measuring the effect of the change in knowledge on treatment decisions, receipt of care consistent with preferences, and satisfaction with care. Furthermore, decision aids for the seriously ill could reduce health care intensity and costs by decreasing unwanted major high-cost interventions or hospitalizations; these outcomes have not been studied.

Tools to promote patient engagement in treatment decisions are a policy priority in the United States since the passage of the Affordable Care Act. Therefore, investigators with proven tools may consider the importance of implementation research and effective dissemination strategies to ensure that clinicians and patients can truly benefit. Making proven decision tools available online or embedding them in electronic health record systems would be appropriate first steps. However, meaningful adoption of this novel practice may require peer leadership, incentives, new time and space in clinical settings, training, and feedback.

This body of evidence is promising, yet it lags far behind the rapid dissemination of tools—primarily for ACP—that are developed outside a clinical research framework. A recent review by the Agency for Healthcare Research and Quality combined scientific and gray literature sources to describe a multitude of published ACP tools that are diverse in quality and rarely supported by evidence of effectiveness or patient benefit. Unlike our study, that review excluded decision aids for current health care choices, which may be most relevant once serious illness develops. Healthcare organizations may be more successful at improving shared decision making if they demand decision tools with evidence of effectiveness. This phenomenon suggests a significant opportunity for collaboration in implementation, blending the best of decision science with the broad public reach of innovations in web-based technology.

**Conclusions**

A small but promising body of research demonstrates the clinical potential to improve patient engagement with tools to enhance decision making in serious illness. A small number of these tools are supported by evidence of their impact and are available for clinical practice. Future research should expand the work to new decisions in serious illness and emphasize outcomes beyond knowledge, such as care consistent with preferences and satisfaction with care.
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REFERENCES

Tools to Promote Shared Decision Making in Serious Illness

Shared decision making is often challenging and never entirely rational. Even seemingly simple decisions, such as taking antibiotics for an upper respiratory tract infection or repairing a fractured bone, may encompass trade-offs, are influenced by cognitive biases, and can be clouded by emotion. Serious illness amplifies these biases and their effects. Decision making is even more complicated in the setting of advance care planning, when patients are trying to decide for their future selves rather than their current selves.

When seriously ill patients make decisions that are uninformed, not reflective of deeply held values, or clouded by unaddressed emotional considerations, profound negative consequences may follow. In some cases, patients may receive treatments and outcomes inconsistent with their goals. In others, decisional conflict can lead to a patient’s emotional distress or, for caregivers, traumatic bereavement. In situations where patients, families, and physicians default to undesired and aggressive nonbeneficial care, not only are patients harmed but resources are wasted. In response to these known risks, a robust literature, echoed in the recent Institute of Medicine publication Dying in America, emphasizes the need to enhance advance care planning and improve decision making for patients with serious illness. However, understanding complicated medical information, confronting the emotions presented by considering death and other poor outcomes, and needing to manage uncertainty challenge patients’ and physicians’ abilities to achieve true shared decision making in the setting of serious illness.

Decision aids have been developed to help patients navigate a wide range of diagnostic and treatment choices. By giving patients information in plain language that they can readily understand and by making clear the trade-offs that they face, decision aids aim to ease the choices that patients make and increase the likelihood that these choices reflect their preferences most accurately. Decision aids promote shared decision making, creating informed patients who can ensure that their values, needs, and wishes are taken into account. The review by Austin et al seeks to identify decision aids that have been tried in a population of seriously ill patients and to systematically evaluate their success.

This exhaustive and rigorous study characterizes all the work in this area and, despite limitations of the data, identifies consistent findings and a clear story. Even though advance care planning is widely recommended and countless patients may receive treatments and outcomes inconsistent with their goals. In others, decisional conflict can lead to a patient’s emotional distress or, for caregivers, traumatic bereavement. In situations where patients, families, and physicians default to undesired and aggressive nonbeneficial care, not only are patients harmed but resources are wasted. In response to these known risks, a robust literature, echoed in the recent Institute of Medicine publication Dying in America, emphasizes the need to enhance advance care planning and improve decision making for patients with serious illness. However, understanding complicated medical information, confronting the emotions presented by considering death and other poor outcomes, and needing to manage uncertainty challenge patients’ and physicians’ abilities to achieve true shared decision making in the setting of serious illness.

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This exhaustive and rigorous study characterizes all the work in this area and, despite limitations of the data, identifies consistent findings and a clear story. Even though advance care planning is widely recommended and countless patients with serious illness face major treatment decisions every day, few rigorously designed studies have attempted to introduce decision aids into this setting. The authors uncovered 17 randomized clinical trials: 6 for advance care planning and 11 for current treatment decisions. These trials have found that decision aids in this population are acceptable and feasible and can modify patients’ expressed preferences. In advance care planning, they can increase the number of discussions with physicians and the number of advance directive documents completed by patients. When used to assist with a current treatment decision, they may increase ease of decision making, reduce decisional conflict, and modify the decisions made. One