



Review article

A systematic review of effectiveness of decision aids to assist older patients at the end of life



Magnolia Cardona-Morrell^{a,*}, Gustavo Benfatti-Olivato^b, Jesse Jansen^c, Robin M. Turner^d, Diana Fajardo-Pulido^d, Ken Hillman^{a,e}

^a South Western Sydney Clinical School and Ingham Institute for Applied Medical Research, The University of New South Wales, Sydney, Australia

^b Faculty of Medicine, The University of New South Wales, Australia and Botucatu Medical School, Sao Paulo State University, Botucatu, Brazil

^c Sydney School of Public Health and Centre for Medical Psychology and Evidence-based Decision-making, The University of Sydney, Sydney, Australia

^d School of Public Health and Community Medicine, The University of New South Wales, Australia

^e Intensive Care Unit, Liverpool Hospital, Sydney, Australia

ARTICLE INFO

Article history:

Received 7 June 2016

Received in revised form 18 September 2016

Accepted 8 October 2016

Keywords:

End of life
Decision aid
Decision-making
Support tool
Effectiveness
Systematic review

ABSTRACT

Objective: To describe the range of decision aids (DAs) available to enable informed choice for older patients at the end of life and assess their effectiveness or acceptability.

Methods: Search strategy covered PubMed, Scopus, Ovid MEDLINE, EMBASE, EBM Reviews, CINAHL and PsycInfo between 1995 and 2015. The quality criteria framework endorsed by the International Patient Decision Aids Standards (IPDAS) was used to assess usefulness.

Results: Seventeen DA interventions for patients, their surrogates or health professionals were included. Half the DAs were designed for self-administration and few described use of facilitators for decision-making.

Treatment: options and associated harms and benefits, and patient preferences were most commonly included. Patient values, treatment goals, numeric disease-specific prognostic information and financial implications of decisions were generally not covered. DAs at the end of life are generally acceptable by users, and appear to increase knowledge and reduce decisional conflict but this effectiveness is mainly based on low-level evidence.

Conclusions: Continuing evaluation of DAs in routine practice to support advance care planning is worth exploring further. In particular, this would be useful for conditions such as cancer, or situations such as major surgery where prognostic data is known, or in dementia where concordance on primary goals of care between surrogates and the treating team can be improved.

Practice implications: Given the sensitivities of end-of-life, self-administered DAs are inappropriate in this context and genuine informed decision-making cannot happen while those gaps in the instruments remain.

© 2016 Elsevier Ireland Ltd. All rights reserved.

Contents

1. Introduction	426
2. Methods	426
2.1. Data sources and extraction	426
2.2. Eligibility	426
2.3. Outcomes of interest	427
3. Results	427
3.1. Study characteristics	427

* Corresponding author at: The Simpson Centre for Health Services Research, South Western Sydney Clinical School and Ingham Institute for Applied Medical Research, The University of New South Wales, PO Box 6087 UNSW, Sydney, NSW, 1466, Australia.

E-mail address: m.cardonamorrell@unsw.edu.au (M. Cardona-Morrell).

3.2. Range of decision aid formats available for EOL	427
3.3. How shared decision-making is implemented	428
3.4. Effectiveness or acceptability of the DAs	430
4. Discussion and conclusions	430
4.1. Discussion	430
4.2. Conclusions	433
4.3. Practice implications	433
Funding	433
Authors' contributions	433
Conflict of interest	434
Acknowledgment	434
References	434

1. Introduction

Hospitalised older patients and their surrogate decision-makers (*surrogates*) often face the stressful and precipitous task of making treatment decisions for which they are not prepared [1]. This may lead to healthcare providers making decisions on behalf of patients and presenting them as facts rather than as consultation [2]. A more appropriate approach is shared decision-making, where clinicians enhance the patient's knowledge of their condition and discuss the risks and benefits of the treatment choices through tailored communication and focused consultation on preferences, values and personal circumstances [3].

Decision aids (DAs) are tools designed to support patients' decision making by presenting information about treatment options relevant to patients and their associated results, compared to the existing practice of routine decision processes and/or alternative decision-making interventions. This way they make the decision explicit to patients and/or families [4]. These tools are customised for specific conditions to facilitate diagnostic or treatment decisions [5] by patients themselves or their surrogates. They aim to outline different treatment options including evidence-based information about the probability of their potential benefits and harm as a basis for discussions with patient about their preferences and goals. In end-of-life care these decisions would generally also include family involvement and discussions about the type of support services available and the cost implications [6].

Decision aids are most useful for situations when there is not one clear option and where the treatment or care pathway is highly dependent on individual patient preference, and values [3,4,7]. Decision aids at the end of life (EOL) may be used by both clinicians and patients to make informed management choices in the light of prognostic uncertainty about the time to death.

In this context, hospitalised older patients at the EOL might benefit from such DAs that empower them to make informed choices on care pathways and participate in their advance care planning. An added benefit of using a clinical DA at the EOL may be the opportunity for patients to have individualised models of advance care planning in clinical practice [8] as personalised care pathways are likely to lead to higher satisfaction and less regret. Moreover, DAs may provide evidence-based information on the available options between active interventions or comfort care, their implications and preferred places of death so that the patient can make a decision that is in line with his/her disease-specific prognosis and values [9]. Using DAs, clinicians may engage in decision-making as surrogate themselves⁷ or involve a relative or carer to act in the patient's interest [10,11].

A multitude of DAs exists for screening and disease treatments [12] but, as found in the process of this review, there is a scarcity of comprehensive decision aids for either generic EOL issues or specific EOL management approaches. As old age is associated with repeat visits to hospitals emergency departments, and is a

significant and independent predictor of death [13], our study aimed to identify existing DAs for EOL care in older adults and assess their effectiveness and patient acceptability (hereby referred to as usefulness). For the purpose of this review, *end of life* was defined as any circumstance rather than time period, where the research subject attending a health service (including hospital admission or outpatient) had an advanced chronic illness, or a terminal diagnosis or advanced age or living in residential or supported accommodation and where a decision-making instrument was to be tested on them or their surrogates or healthcare professionals. As the role of carers during medical consultation is known to influence decision-making [14] we also explored family involvement in satisfaction with end-of-life care decision-making.

We aimed to answer the following research questions:

1. What is the range of decision support tools available to enable informed choice at the end of life?
2. How is shared decision-making implemented in practice in this context?
3. What is the effectiveness and/or acceptability of those decision support tools?

2. Methods

2.1. Data sources and extraction

A systematic literature review of seven databases (PubMed, Scopus, Ovid MEDLINE, EMBASE, EBM Reviews, CINAHL and PsycInfo) was conducted between March and May 2015. Two authors (GB and MCM) independently and concurrently conducted online searches, eligibility and quality assessment. We used the quality criteria framework endorsed by the International Patient Decision Aids Standards (IPDAS) to assess the usefulness of the DAs but not all studies had sufficient detail on all of them: (1) systematic development process; (2) providing information about options; (3) presenting probabilities; (4) clarifying and expressing values; (5) using patient stories; (6) guiding or coaching in deliberation and communication; (7) disclosing conflicts of interest; (8) delivering patient decision aids on the internet; (9) balancing the presentation of options; (10) using plain language; (11) basing information on up to date scientific evidence; and (12) establishing effectiveness. For details of study types, intervention types, search strategy and quality assessment tools used refer to Supplement 1.

2.2. Eligibility

Articles and abstracts published between 1995 and 2015. All study types in English language including any modality of DAs for end of life were eligible for inclusion. Participant inclusion criteria were older patients (aged 60 years and above) with advanced or

terminal illness as defined by each article (e.g. stage 4 cancers, advanced dementia) presenting to any health service or their families/caregivers as surrogates in hospital ward, emergency service, private rooms, outpatient clinic, ambulatory or mobile outreach clinics. We chose to focus on older patients as their risk of death from chronic illness is well established, particularly after hospitalisation [13,15] hence the relevance to end-of-life. We excluded case studies due to their inability to demonstrate effectiveness but considered conference abstracts eligible to prevent publication bias as it is known that over a third of these do not result in full publication [16].

2.3. Outcomes of interest

Two main areas were explored based on description in the published manuscripts rather than on review of the actual DAs as they were not generally published:

- Process covered attributes of the DAs (format) decision-making constructs (DAs content) and support for the decision (administration).
- Effectiveness as measured by either of the following:
 - Change in knowledge of condition or prognosis
 - Reduction in decisional conflict
- Concordance between patients and their surrogates
- Acceptability of/satisfaction with the DA, treatment decision or the decision process

3. Results

3.1. Study characteristics

After full text review we analysed 17 articles that met the inclusion criteria as they covered at least one of our research questions (Fig. 1): six RCTs, one quasi-experimental, one prospective, seven before-after and two exclusively qualitative studies. The fourteen studies targeted inpatients, outpatients or nursing home residents, five of them also targeting their surrogates or health professionals, and two targeting exclusively hospital nurses or

surrogates. All studies were conducted in three countries, mainly USA (13) and Canada (3), and one in both Australia and Canada (Table 1).

The bias assessment indicated generally high quality studies, in particular all the RCTs (median quality score = 8 out of 11, with 12/17 studies scoring 8 or above). Target participants were commonly people with advanced cancer (5 studies), multiple chronic conditions in various services (5), or dementia (2).

3.2. Range of decision aid formats available for EOL

All but three of the reviewed decision aids involved EOL participants and three involved surrogates, nurses or elderly people out of hospital; but all aids were about EOL decisions, whether imminent or hypothetical. Decision aid formats (Table 2) varied with the most common component (5 studies) being print version and the least common being the computerised format (2 studies). Often interventions included a combination of print/audio (4), computerised with print/audio or video (2), video and print (2), or video/audio (1).

Nine of the tools used dedicated staff or multidisciplinary teams to administer the tool, conduct interview or run scenario-based for decision-making. The other eight tools were designed for self-administration (Table 2). Details of the formats and ways of administration are available in Supplement 2. Duration of administration ranged from less than 20 min for patients to complete all questions and less than 5 min for the clinician's review [17] to 60–90 min for prognostic scenarios [18] or autobiographic memory interventions [19], and two hours for a self-guided computerised advance care planning aid [20].

Decision aids were mostly related to the particular condition of the patient to whom the decision applied (13 studies). Four cases used hypothetical terminal conditions or scenarios as the only basis for the decision (Table 3). The most common domains incorporated in the reviewed decision aids were treatment options (e.g. life-sustaining therapies, resuscitation vs. vs. comfort care; 13 studies) and weighted or unweighted treatment preferences (e.g. “stop treatment if living with permanent disability or high burden on family”, “definitely don't want that treatment” etc.; 13 studies). One presented scenarios of moderate to severe impairment,

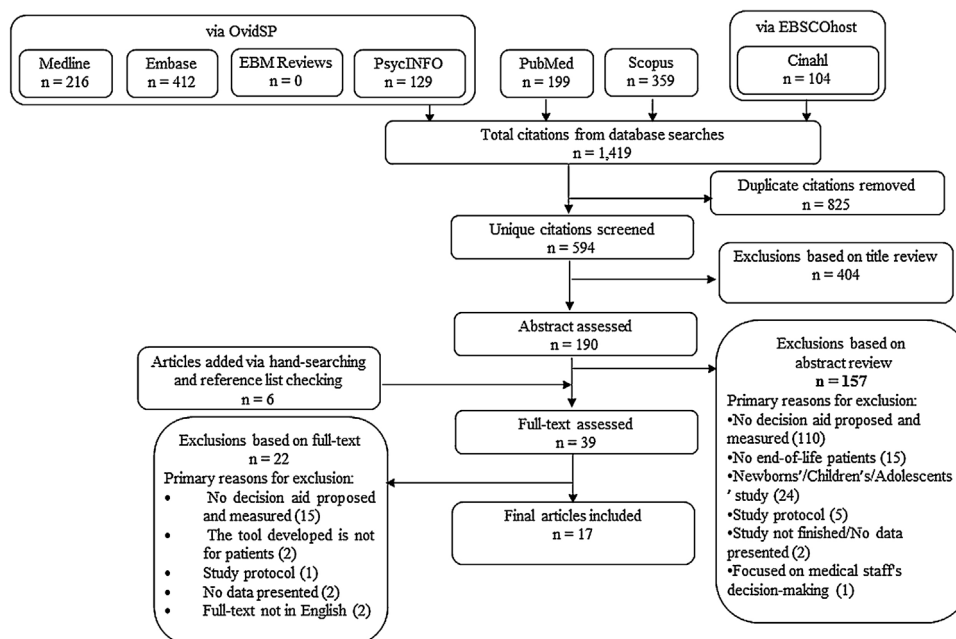


Fig. 1. PRISMA diagram of study screening and selection.

Table 1
Characteristics of studies included in the review by level of evidence (6 RCTs + 11 non-RCTs).

Authors and publication year	Country	Sample size	Study type	Quality score +	Targeted Patients	Targeted Others	Description of Target population
Volandes A. E. et al., 2013 [41]	USA	150	RCT	9 + 3	✓		Patients with advanced cancer.
Hanson L. C. et al., 2011 [29]	USA	256	cRCT	11 + 3	✓	✓	Residents of nursing homes with advanced dementia and feed problems and their surrogates.
Leighl N. B. et al., 2011 [22]	Australia and Canada	207	RCT	10 + 4	✓		Patients with advanced colorectal cancer who were considering chemotherapy.
Matlock D. D. et al. 2014 [25]	USA	51	RCT	8 + 3	✓		Patients recruited from an inpatient palliative care consult service.
Song et al., 2005 [27]	USA	64	RCT	9 + 3	✓	✓	Patients aged 50+ years scheduled for semi-elective cardiothoracic surgery clinic and their surrogate decision-maker
Ditto et al., 2001 [30]	USA	408	RCT	10 + 2	✓	✓	Outpatients aged 65+ years from 6 primary practices affiliated with one health system
Brohard C. L., 2012 [19]	USA	50	Quasi-experimental	8	✓		Older persons with terminal cancer in hospice care
Febretti et al., 2014 [23]	Canada	373	Prospective Qualitative, feasibility with a control	5		✓	Hospital nurses
LaRue M., et al., 2012 [32]	USA	25	B-A	4	✓		Adult inpatients.
Einterz S. F. et al. 2014 [21]	USA	18	B-A	7	✓	✓	Residents of nursing homes over 65 years of age, who had moderate to severe dementia and an English-speaking surrogate decision-maker.
Hollen P.J. et al., 2013 [31]	USA	170	B-A	8	✓	✓	Patients with solid tumours and their supporters and health professionals.
Smith T.J. et al., 2011 [17]	USA	27	B-A	8	✓		Chemotherapy patients with incurable breast, colorectal, lung and prostate cancers.
Hozella J. B. et al., 2011 [50]	USA	20	B-A	4	✓		Patients with stage III–IV Chronic Obstructive Pulmonary Disease (COPD).
Mitchell S. L. et al., 2001 [26]	Canada	15	B-A	8		✓	Substitute decision makers for cognitively impaired inpatients 65 years and older.
Dales R. E. et al., 1999 [28]	Canada	20	B-A	8	✓		Patients from the pulmonary function laboratory, the ambulatory respiratory & from general medicine clinics.
Green M. J. and Levi B. H., 2009 [24]	USA	84	Descriptive Qualitative pilot	8	✓		Adult volunteers from a geriatric and internal medicine outpatient practice and cancer support group, and Patients with cancer recruited from clinics at a medical centre.
Coppola et al., 1999 [18]	USA	50	In-depth interviews	5		✓	Elderly adults in assisted living housing complexes

+ = RCT bonus points RCT = randomized controlled trial cRCT = Cluster RCT B-A = Before-and-after intervention DA = decision aid.

disability or pain with statements such as *no chance of recovery* or *improvement* or *little chance of recovery* or *improvement*. [18] Having at least a slight chance of recovery and the absence of pain prompted people to choose life-sustaining therapies. Another study [21] presented prognosis using photographs of patients with dementia with an explanation of incurability, potential effects and associated these with goals of care such as prolonging life, maintaining function and comfort. Surrogates were then asked to make decision on preferences for 5 treatments: resuscitation, artificial feeding, antibiotics, hospital and hospice. Users of this DA were significantly more satisfied with the symptom control provided.

However, disease-specific quantitative prognostic estimates (e.g. graphic or numeric rates of response to treatment, survival, time without symptoms, treatment toxicity, quality of life, % chance of cure,) were not often used or presented in the decision aid; 2 studies). Generic quantitative estimates of prognosis were presented only in two studies: one showed percentage bar charts on prognosis with and without chemotherapy and risk of severe toxicity. However, the perception of level of information received did not have a significant impact on the treatment decision. [22]

Another decision aid [17] had text and numbers expressing the chances of survival and duration of survival, the chances of cancer shrinkage and the time before recurrence with and without selected treatments. In this case the DA was not used to choose treatment type but to determine the proportion of patients who would opt for full prognostic disclosure after being given graphic representations of treatment options, benefits and side effects. Two other interventions used descriptive prognosis such as depicting the irreversibility of dementia in photos and diagrams [21] or presented scenarios with “a very slight chance of recovery” or “no chance of recovery”. [18] Information on the extent of need for further information on prognosis in qualitative terms was determined if the patient asked: “tell me all, tell me a little, or tell me some”. In other studies [19,23] it appeared that the decisions were only presented as treatment choices without further information about quantitative data on the risks and harms.

3.3. How shared decision-making is implemented

Great variation was observed in the format, decision process and participant support for decision-making. Assessment on level

Table 2

Decision aid format: brief description and mode of administration.

Authors and year	Participants at EOL	Video	Audio	Print format	Computerised	Surrogate involvement*	Multidisciplinary team or dedicated staff required [∞]	Used validated tools or indicators	Brief description
Randomised controlled trials									
Volandes et al., 2013	✓	✓	✓				✓	✓	Video decision support tool + verbal description
Hanson et al., 2011	✓		✓	✓	✓	✓		✓	Self-paced booklet or audio or on computer screen
Leigh et al., 2011	✓		✓	✓				✓	Take-home booklet with audio recording
Matlock et al. 2011	✓	✓		✓			✓	✓	Booklet and DVD
Song et al., 2005				✓		✓	✓	✓	Patient-centered Advance Care Planning interview for cardiac surgery clinic patients
Ditto et al., 2001			✓	✓		✓	✓	✓	Questionnaire with 9 different illness scenarios in primary care practice
Less robust study types									
Eintrez et al 2014	✓	✓		✓		✓	✓	✓	Patient stories, balanced presentation, simple language at an 8th grade level.
Febretti., 2014	✓	✓			✓		✓		Computer screen with case scenarios for nurses
La Rue et al., 2012	✓	✓					✓		Video illustrating treatments for 3 levels of care: (life-prolonging, basic, and comfort oriented).
Brohard et al., 2012	✓			✓			✓		Expert-driven autobiographical memory session to promote advance care directives
Smith et al., 2011	✓			✓			✓	✓	Tables of information with bar graphs
Hozella et al., 2011	✓				✓				Self-guided computerised decision aid
Green & Levi 2009	✓				✓			✓	Interactive computer program
Mitchell et al., 2001	✓		✓	✓		✓		✓	Self-paced audio booklet
Hollen et al., 2013				✓		✓	✓	✓	Theory of decisions and their consequences for newly diagnosed and advanced cancer patients
Coppola et al., 1999	✓			✓			✓	✓	Printed questionnaire with verbal instructions
Dales et al., 1999	✓		✓	✓				✓	Audiocassette and a booklet

* Only for patients with dementia or without decision-making capacity

[∞] Tool administration required the presence of a healthcare provider or team to guide decision-maker (not suitable for self-guided choices)

of difficulty for each decision was covered in only six of the DAs (Supplement 3) [17,19,24–27]. The support instructions or structure of the decision-making process were missing in half the studies (Table 2).

Disease-specific management preferences were generally presented in descriptive terms of the procedure or treatment decisions that lie ahead [27]. Generic expression of preferences used 5-point ranking scales from “very likely to make this decision” or “already made the decision” or “definitely want the treatment” to “very unlikely to make or communicate the decision” and “definitely do not want that treatment” [18]. The more specific descriptors included examples such as hospital transfer [21], invasive mechanical ventilation [28], CPR and artificial nutrition or intravenous hydration. [18,19,21]

The benefits of treatment options were more frequently included (8 studies) in descriptive form including an Expectation of Benefit Index [29] rather than in terms of risk probability, and some were limited to perceived rather than actual benefits [30]. The harms were also incorporated in descriptive form (7 studies)

although many of them did not express the associated probability of harm. In two studies it appeared that the decisions were only presented as treatment choices without further information about risks, harms or values or support for decision-making [19,23].

Only five DAs covered values that might matter to patients at the EOL [21,24,26,30,31]. Many studies did not mention explicit patient values, as recommended in guidelines [11], or did not specify what values were considered [21,31], or mention selected values associated with a particular scenario for surrogates, such as the importance of inability to swallow or eat for each patient [26]. Values statements in one study covered numerical scores for acceptability of various states of dysfunction and their associated quality of life; how highly patients prioritised mental functioning and independence; and whether the symptoms or treatment would be a burden to patients or whether treatment would make the patient a burden to others [24]. While in another, the statement about patient values consisted of a score sheet of pros and cons for self and others [31]; and in another it encouraged participants to produce their own list of activities that brought in well-being and

Table 3
Decision aid content: domains incorporated in the tools reviewed.

Authors and year	Relevant or hypothetical decision	Treatment option(s)	Prognostic information	Values clarification ^Ω	Preferences	Goals of care	Harms	Benefits	Guidance in decision process ^{*§}
RCTs									
Volandes et al., 2013	R	✓			✓				
Hanson et al., 2011	R	✓			✓			✓	
Leighl et al., 2011	R	✓	✓		✓	✓			
Matlock et al., 2011	R				✓				✓
Song et al., 2005	H				✓		✓	✓	✓
Ditto et al., 2001	R & H			✓	✓	✓			✓
Less robust study types									
Eintrez et al 2014	R	✓	✓	✓		✓	✓	✓	
Febretti., 2014	R	✓							
La Rue et al., 2012 ^{Ab}	H	✓			✓				
Brohard et al., 2012	R	✓			✓				✓
Smith et al., 2011	R	✓	✓				✓	✓	✓
Hozella et al., 2011 ^{Ab}	R	✓			✓				✓
Green & Levi 2009	R			✓	✓		✓	✓	✓
Mitchell et al., 2001	R	✓		✓	✓	✓	✓	✓	✓
Hollen et al., 2013	R	✓		✓			✓	✓	
Coppola et al., 1999	H	✓	✓		✓				
Dales et al., 1999	R	✓			✓		✓	✓	

Ab = abstract/no full manuscript R = relevant state of health H = Hypothetical state of health.

^Ω Value clarification statement.

^{*§} Tools given or coaching provided throughout the patient/families deliberation before making the final decision.

where their absence would make life not worth living [30]. Treatment goals defined from the patient were less often mentioned as an integral part of the DAs (3 studies) [21,22,30]. Goals included decisions about prolonging life, maintaining function or promoting comfort as primary goal [21].

3.4. Effectiveness or acceptability of the DAs

The most commonly reported measure of effectiveness of the use of DAs was change in knowledge of prognosis or nature of the illness, either of the patient or SDM (13 studies). With one exception [26], the increases in knowledge about the disease or its prognosis were of small magnitude and only half of them reported significant improvements after exposure to the DA (Table 4). Changes in decisional conflict were also frequently reported (8 studies) but the reduction was only significant in four studies [21,26,27,29]. Only five studies reported decision concordance between paired groups of patients and their surrogates [21,24,27] and after exposure to DAs agreement significantly improved in only three of these (Table 5). Satisfaction or acceptability with the decision process or the decision made was widely reported (11 studies) as high regardless of the type of DA; satisfaction with the decision process was usually higher for intervention groups receiving the DA, but rarely statistically tested for significance (Table 5).

More downstream effectiveness indicators were satisfaction with the decision aid, satisfaction or regret with the treatment decision made, and satisfaction with participation in the process. Instruments used to measure these were Satisfaction with Decision Scale [29], or the Edmonton Symptom Assessment Scale and Palliative Care Outcome Scale [32]. A qualitative study used Multi-Attribute Theory (MAUT) to help translate personal values and

treatment goals into a medical plan of action [24] and another used a 22-item advance care planning survey [19]. Acceptability and satisfaction with amount of information and balance presented was also examined qualitatively in a simplistic way using very brief questionnaires [25,26].

4. Discussion and conclusions

4.1. Discussion

Our review found that there is a relatively limited number of DAs for EOL management but a wide range of formats to be used by patients and or their surrogates, and most of them are to the satisfaction of users. With three exceptions they are multi-format but many of them (11) require additional human or technical resources to be administered, which makes them comforting to patients but less suitable for routine care in busy clinical environments. Frequently the focus of effectiveness studies was on acceptability of the tools and changes in knowledge and decisional conflict. None of the DAs incorporated the direct or indirect financial implications of the choice for the patient or the health system, and this is surprising as many of the studies were undertaken in the US, where costs drive many treatment decisions.

The knowledge of risk level [33] of each options to assist in decision-making was incomplete and generally descriptive. It is acknowledged that cognitive overload to decision-makers is to be avoided [23,25] and it is important to achieve a balance between the presentation of too much information on probabilities harms, and benefits of options [34] and not enough detail, or global choices vs. disease-specific [8]. Many patients would opt for full prognostic disclosure [17] so by omitting disease-specific prognostic information or not addressing the palliative goals of

Table 4

Extent of knowledge, decisional conflict, decision concordance as outcomes of decision aid exposure (14 studies).

Authors and year	Change in Patient/Surrogate Knowledge ^Ω		Change in Decisional Conflict		Decision Concordance	
	Pre	Post	Pre	Post	Pre	Post
Randomised trials						
Volandes et al., 2013 n = 150						
Control	2.1 (1.2)	↑ 2.6 (1.3)				
Intervention	2.0 (1.3)	↑ 3.3 (2.6) ***				
Hanson et al., 2011 n = 256						
Control		15.1		1.97		
Intervention		16.8***		1.65***		
Leighl et al., 2011 n = 207						
Control	21	9.6 ^m		26	24	32%
Intervention	22	11.6***		26	24	35%
Matlock et al., 2011 n = 51						
Control	3.4 (1.5)	3.7 (3.5)	17.5	15.8 ^{NS}		
Intervention	4.3 (1.3)	4.7 (1.3) ^{NS}	11.0	5.0 ^{NS}		
Song et al., 2005 n = 64						
Control	8.38 (1.36)	7.75 (2.14) ^{NS}		2.33	NR	1.38
Intervention	8.87 (1.55)	8.31 (2.15) ^{NS}		2.0*	NR	2.75***
Ditto et al., 2001 ^s n = 408						
Control	NR	4.36 (0.08)			NR	4.32 (0.07)
Intervention	NR	4.61 (0.06)*			NR	4.61 (0.06)*
Less robust studies						
Febretti et al., 2014 n = 373						
Intervention	7.5%	87%***				
Einterz et al., 2014 n = 18						
Surrogates	12.5	14.2***	11%	72%***	50%	↑ 78%***
Hollen et al., 2013 † n = 160						
Patients			NR	25.4		
Surrogates			NR	26.2 ^{NS}		
Smith et al., 2011 ⁿ n = 27	11	17 ^{NS}				
Hozella J. B. et al., 2011 n = 20	NR	62%(±14%)				
Mitchell et al., 2001 n = 15	50.4 (13.5)	84 (13.5)**	2.88	2.29**		
Green & Levi., 2009 n = 84		4.2 ^{NR}				
Dales et al., 1999 n = 20		95% †		90%		65%
% patients who decided MV						

p-values reported as * <0.05, ** <0.01, *** <0.001, NR = not reported, NS = no significant

† Reported an increase post-intervention, † Calculated average MV = mechanical ventilation

^m median knowledge score (rather than mean).^s surrogate results, as patients had high scores at the outset.ⁿ no. patients with correct answers.^Ω Values are mean knowledge scores (SD) unless otherwise indicated.

treatment, the tools have limited utility for relevant patients and surrogates in the decision-making process [22]. Duration of administration of the DA may have precluded this quality time for sufficient information and for dealing with the conflict and anxiety while the health professional is delivering routine care under pressure.

The gap in active healthcare provider support for decision-making by patients has been identified before [8]. There is room for improvement in shared decision-making where choice may not be fully *informed*. A measure of *informed* choice is said to be a combination of domains based on relevant knowledge, consistent with the decision-maker's values [35]. While difficult to measure in routine practice, recognised personal values such as quality EOL, physical functioning, burden on families and attitudes to risk [36] carry weight for patients in the decision-making process but were not generally represented in the decision aid [6]. The most noticeable gaps in areas that matter to patients were symptom burden, disruption to family and patient time, level of family involvement required in alternative care, consideration of the most difficult decision, quality of remaining life, and financial implications of relevant treatment choices. While the impact of knowing patient values on the final choice of treatment is still inconclusive [37], the common method of listing the advantages and disadvantages of a decision is the minimum essential to explore the values that matter to the patient [9,38]. Some studies

recognised that EOL decision-making is not only about increasing knowledge, resolving decisional conflict and expressing a treatment preference. It is also about satisfaction with the decision, not losing hope, measuring effect of the decision on self and others [31] and preventing negative emotional impact of learning the prognostic news, or being prepared to address it when it occurs [17].

Companion/family involvement is only reported in small number of eligible decision aids articles (6 studies, Table 2). As family presence in medical consultations is associated with clinician's enhanced willingness to provide additional biomedical information [39], similar benefits may derive from the inclusion of a companion in the decision at the EOL. Concordance between surrogates and patients choices are important in reliably and effectively reflecting patient's wishes. Clearly the inherent challenges in 3-way communications [39], varying level of participation of companions [14], and the incongruence with surrogate's understanding of patient wishes [30] will need to be addressed.

Given the complexities and sensitivities of EOL decision, it would seem desirable not to offer *do-it-yourself* DAs. Instead, DAs administered with clinicians' input have the benefit of additional resource available to patients for clarifications. This distinction may be important for patients and families who prefer specific information, and for health systems that cannot afford the time.

Table 5

Acceptability of recommended treatment and satisfaction with decision aids under investigation (12 studies).

Authors and year	Sample size	Patient/Surrogate Acceptability of DA or Treatment decision	Patient/Surrogate Satisfaction with decision process
Randomised trials			
Volandes et al., 2013	150		
Control		51%	NR
Intervention		79%***	93%
Hanson et al., 2011	256		
Control		76%	77%
Intervention		89%**	83% ^{NS}
Leighl et al., 2011	207		
Control		71%	63%
Intervention		77% ^{NS}	72% ^{NR}
Matlock et al., 2011	51		
Control		NR	NR
Intervention		59%	88%
Song et al., 2005	64		
Control		NR	NR
Intervention		NR	94%
Less robust studies			
Einterz et al., 2014	18		
Surrogates		83%	89%
Hollen et al., 2013 †	160		
Patients		79.3%	88.2%
Surrogates		79.6%	86.3%
Smith et al., 2011	27		
Control		63%	74%
Hozella J. B. et al., 2011	20		
Control		NR	8.6 ^m
Mitchell et al., 2001	15		
Control		57%	80%
Green & Levi., 2009 (mean score)	84		
Control		↑ 6.5***	8.5
Dales et al., 1999	20		
Control		40%	

Values are proportions satisfied with process unless otherwise indicated.

p-values reported as * <0.05, ** <0.01, *** <0.001, NR = not reported.

† Reported an increase post-intervention, † Calculated average.

^m mean satisfaction score.

However, patient knowledge can be affected by the way in which physicians present risks of harms and extent of benefits, particularly if these are misunderstood or overestimated by the patient [3,34]. For instance, videos on invasive resuscitation efforts tended to bias patient decision towards comfort care [40,41]. And physicians' inclination for withholding or withdrawing treatments are known to be associated with their social values [42]. By implication, it is possible that decisions may be biased towards clinician's preference whether they may believe that limiting intensive management is better than prolonging suffering or whether clinicians opt for pursuing invasive life sustaining therapies [10,43,44]. Contrasting with recent recommendations [45], conflict of interest was not generally acknowledged in our eligible articles.

Changes in treatment preferences as death approaches are not uncommon, both for patients and their SDMs. This is due partly to new knowledge and experience of the burden of treatment cost and symptoms [46]. Use of decision aids, should not be seen as a single episode but their repeat use as disease progresses should be encouraged if feasible in routine practice as an RCT showed the sustainable effect of low regret and high satisfaction with decisions made over time [29]. Opportunities to change the decision as the disease progresses should be available and revisited [47]. Therefore, hypothetical scenarios [18,27,30,32] may not be as helpful or effective as decisions based on scenarios directly relevant to the patient's health state.

The main IPDAS criteria covered by these DAs were presentation of options, engagement of healthcare providers in guidance/coaching, and measured effectiveness. Not all criteria could be assessed from the information published in the manuscripts but the main gaps identified in this review were the lack of integration of patient values in the decision aid, absence of numeric

probabilities, scarcity of values that were important to the patient, and provision of step-by-step resources to support the decision-making process. Patient stories or scenarios were used but in a few cases they were not directly relevant or specific to the patient's condition(s), which is the preferred approach to offer more relevant choices [8].

The direct or indirect financial implications of the choice for the patient or the health system or the effects of decision aids on adherence to the decision over time were not investigated in the studies included. Decision aids should have flexibility to adapt to temporal changes as illness progresses, as care planning is meant to be a dynamic process rather than a single-point decision as changes in treatment preferences as death approaches are not uncommon [8] both for patients and their surrogates. This is both due to new knowledge or experience of the burden of treatment cost and symptoms. This did not transpire from the reviewed studies. Use of DAs should not be seen as a single episode but their repeat use as disease progresses should be encouraged if feasible in routine practice as an RCT showed the sustainable effect of low regret and high satisfaction with decision made over time [29].

The honest and open disclosure of prognostic information to patients at the EOL is an important first step in decision-making at the EOL, emphasising the inherent uncertainty in medicine. Making decision aids an integral part of routine care would ideally incorporate administration of decision aids earlier in the dying process and should as far as possible not require specialised skill except for initial instruction or support if required by the user. Individualised evidence-based prognostic estimates may not be available for all conditions and disease stages to fit a generic DA for EOL. However, more comprehensive and directly applicable instruments covering relevant symptoms or scenarios specific to the patient's condition(s) would be more likely to be useful than

hypothetical scenarios but care must be taken in avoiding cognitive overload for patients or healthcare providers [23,25]. Information is still limited on the effectiveness of DAs beyond satisfaction [8]. Investigating multiple features of the DA beyond numeric efficacy (such as relevance of contents and determinants of choices) would enable translation of research findings to routine practice [48]. Future decision aids for EOL care could cater for various health literacy levels, and need more robust elicitation of values, treatment goals and quantitative estimates of harms, benefits and prognostic information.

Among the strengths of his study is the comprehensive review of over a decade of English medical literature in relevant types of patients nearing the EOL, with a third of studies involving surrogate decision-makers. Only three eligible studies were found in the first decade of our study period, indicating that the development and use of DAs for terminal patients is a relatively new field and our research contributes to fill an identified research gap. A third of the studies were well-conducted RCTs (high-level evidence) but two of them [25,27] had insufficient power to demonstrate effectiveness. In general the quality of studies was high, and the existence of six RCT reassured us of the effectiveness findings. To our knowledge, this summary of domains covered in decision aids and findings on the most effective formats has not been conducted before and can assist healthcare providers and researchers in designing, adapting or improving decision aids for particular patient sub-groups.

This review has some limitations. We recognise that RCT and cohort studies with a control group for effectiveness assessment is ideal, but real-life studies in routine care limit this rigorous process. Our review process was confined to selected indexed databases and excluded the grey literature. Hence there is potential for bias if lack of effectiveness in evaluations was the reason for not getting published. In fact, some DAs are available online but evaluations of their effectiveness –if conducted– have not been published [8]. We decided to be over-inclusive to illustrate the range of tools available and included all study types examining a variety of definitions of effectiveness and only omitting studies that did not assess any of our research questions. Most of the studies (10) in this review were either level III-b evidence interventional studies [49], or qualitative in nature which is expected and affordable in real life settings but deters from the strength of evidence. The sample sizes were generally small, limiting generalisability, and the strength of evidence in more than half of studies is weak. Two publications were conference abstracts [20,32] and insufficient information may have biased the quality assessment in a negative way (both scored 4/11). However, they were included to minimise potential for publication bias [3,16]. Many studies (13/17) were conducted in the US health system where knowledge of prognosis is not the only factor impacting on EOL decisions. The potential influence of differing elements of choice, definitions of ‘care’, alternative care facilities available and substantial out-of-pocket expenses on patient preferences across health systems precluded meta-analyses and limited generalisability to international settings.

4.2. Conclusions

Compared with other ill-health situations, there is a shortage of decision aids for EOL treatment involving initiation or discontinuation. Empowering patients for decision-making should start with giving honest information about individual prognosis as far as possible. Overall the available decision aids seemed to enhance patients or surrogate decision-makers’ knowledge of the care options and reduce decisional conflict. However, more systematic evaluations of effectiveness are needed because the most common components of the reviewed decision aids for EOL care were

treatment options and preferences without concrete or disease-specific prognostic information on the alternatives, harms and benefits.

The reviewed studies presented an incomplete and not too coherent picture of how the decision aid matches expectation by patients or surrogates. The studies mostly fell short of presenting one of the most important pieces of information: quantifiable prognosis about shortened life expectancy and the limitations of medicine to provide good quality survival. This was compounded by poor step-by-step explanations of the DA administration to enable replicability in routine care. Further, the gaps in the patient’s perceived goals of care, personal values and financial implications of their treatment decisions cannot be overlooked. The widespread omission of patient values in the decision-making process suggests that their ascertainment measurement, and reproducibility are problematic and therefore a medicalised approach is often used. This model of care might be appropriate in other healthcare decisions such as screening but is likely to be unsuitable for EOL management. DAs are not useful if the basis for the decision, i.e. prognosis, is withheld or if medical information is disconnected from patient values. Patient autonomy is effectively removed by lack of consultation on the non-clinical aspects that matter to them. A variety of tools are available with medical options and preferences for use in treatment decision-making at the end-of-life. However, significant work is still required in the development of a comprehensive decision aid that includes the patient values and other social implications of those choices to guide consumers in the complex and sensitive treatment choices to be made at the EOL.

4.3. Practice implications

The findings of our review suggest that future decision aids for EOL care need more robust elicitation of values, treatment goals, quantitative estimates of harms, benefits and prognostic information to be considered holistic and useful for improved decision making. Yet, current low-level evidence suggests that DAs at the end of life are generally acceptable by users, and appear to increase knowledge and reduce decisional conflict, so their refinement and use in routine practice to better document advance care planning is worth exploring further. In particular, this would be useful for conditions such as cancer, or situations such as major surgery where prognostic data is known, or in dementia where concordance on primary goals of care between surrogate and the treating team can be improved. The role of health professional in step-by-step guidance and support through the decision-making process is important. Self-administered DAs are inappropriate in this context given the sensitivities of end-of-life, and genuinely informed decision-making cannot happen while those gaps in the instruments remain.

Funding

This review was funded by a grant from the National Health and Medical Research Council of Australia (grant # 1054146). The funding body had no role in the design or conduct of the research, interpretation of findings, preparation of the manuscript, choice of journal or the decision to publish.

Authors’ contributions

MCM conceived the research question, designed the study, conducted parallel article search and eligibility/bias assessment, led data interpretation, and wrote the first draft, subsequent revisions and final version of the manuscript incorporating co-authors’ comments. GBO concurrently conducted literature search

and independently performed eligibility/bias assessment and contributed tables for the manuscript production. RMT, JJ and KH contributed refinements to the concept and substantial input into the interpretation of findings, manuscript contents and direction. DFP contributed to the analytic search for effectiveness, interpretation of quantitative analysis and table design. All authors contributed input into the draft versions of the manuscript and approved the final version.

Conflict of interest

None to declare

Acknowledgment

We thank the university librarian Anthony Natoli for his valuable assistance with training and support of research assistants on systematic literature searches.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.pec.2016.10.007>.

References

- [1] M.K. Song, F.C. Lin, C.A. Gilet, R.M. Arnold, J.C. Bridgman, S.E. Ward, Patient perspectives on informed decision-making surrounding dialysis initiation, *Nephrol. Dial. Transplant.* 28 (2013) 2815–2823.
- [2] E.H. Ofstad, J.C. Frich, E. Schei, R.M. Frankel, P. Gulbrandsen, Temporal characteristics of decisions in hospital encounters: a threshold for shared decision making? A qualitative study, *Patient Educ. Couns.* 97 (2014) 216–222.
- [3] T.C. Hoffmann, C. Del Mar, Patients' expectations of the benefits and harms of treatments, screening, and tests: a systematic review, *JAMA Intern. Med.* 175 (2015) 274–286.
- [4] D. Stacey, F. Legare, N.F. Col, C.L. Bennett, M.J. Barry, K.B. Eden, et al., Decision aids for people facing health treatment or screening decisions, *Cochrane Database Syst. Rev.* 1 (2014).
- [5] K. McCaffery, L. Irwig, P. Bossuyt, Patient decision aids to support clinical decision making: evaluating the decision or the outcomes of the decision, *Med. Decis. Mak.* 27 (2007) 619–625.
- [6] The Choice in End of Life Care Programme Board, What's important to me, A Review of Choice in End of Life, National Health Service, UK, 2015.
- [7] A.M. Stiggelbout, T. Van der Weijden, M.P. De Wit, D. Frosch, F. Legare, V.M. Montori, et al., Shared decision making: really putting patients at the centre of healthcare, *BMJ* 344 (2012) e256.
- [8] M. Butler, E. Ratner, E. McCreedy, N. Shippee, R.L. Kane, Decision aids for advance care planning: an overview of the state of the ScienceDecision aids for advance care planning, *Ann. Intern. Med.* 161 (2014) 408–418.
- [9] C. Corke, Personal values profiling and advance care planning, *BMJ Support. Palliat. Care* 3 (2013) 226.
- [10] L. Willmott, B. White, M.K. Smith, D.J. Wilkinson, Withholding and withdrawing life-sustaining treatment in a patient's best interests: Australian judicial deliberations, *Med. J. Aust.* 201 (2014) 545–547.
- [11] D. Stacey, C.L. Bennett, M.J. Barry, N.F. Col, K.B. Eden, M. Holmes-Rovner, et al., Decision aids for people facing health treatment or screening decisions, *Cochrane Database Syst. Rev.* (2011) CD001431.
- [12] K.R. Sepucha, C.M. Borkhoff, J. Lally, C.A. Levin, D.D. Matlock, C.J. Ng, et al., Establishing the effectiveness of patient decision aids: key constructs and measurement instruments, *BMC Med. Inform. Decis. Mak.* 13 (Suppl. 2) (2013) S12.
- [13] J. Kellett, S. Rasool, B. McLoughlin, Prediction of mortality 1 year after hospital admission, *QJM* 105 (2012) 847–853.
- [14] M. Andrades, S. Kausar, A. Ambreen, Role and influence of the patient's companion in family medicine consultations: the patient's perspective, *J. Fam. Med. Prim. Care* 2 (2013) 283–287.
- [15] C. van Walraven, F.A. McAlister, J.A. Bakal, S. Hawken, J. Donze, External validation of the Hospital-patient One-year Mortality Risk (HOMR) model for predicting death within 1 year after hospital admission, *CMAJ* 187 (2015) 725–733.
- [16] R.W. Scherer, P. Langenberg, E. von Elm, Full publication of results initially presented in abstracts, *Cochrane Database Syst. Rev.* R0 (2007) (MR0000005).
- [17] T.J. Smith, L.A. Dow, E.A. Virago, J. Khatcheressian, R. Matsuyama, L.J. Lyckholm, A pilot trial of decision aids to give truthful prognostic and treatment information to chemotherapy patients with advanced cancer, *J. Support. Oncol.* 9 (2011) 79–86.
- [18] K.M. Coppola, J. Bookwala, P.H. Ditto, L.K. Lockhart, J.H. Danks, W.D. Smucker, Elderly adults' preferences for life-sustaining treatments: the role of impairment, prognosis, and pain, *Death Stud.* 23 (1999) 617–634.
- [19] C.L. Brohard, The Feasibility and Efficacy of an Autobiographical Memory Intervention on Advance Care Planning with People with Terminal Cancer [Thesis], University of Utah, 2012.
- [20] J.B. Hozella, R. Bascom, M.J. Green, B.H. Levi, Using An Interactive Computer Program To Create An Advanced Directive In Patients With Stage III-IV Chronic Obstructive Pulmonary Disease: A Feasibility Study [conference Abstract #17316], American Thoracic Society, 2011.
- [21] S.F. Einterz, R. Gilliam, F.C. Lin, J.M. McBride, L.C. Hanson, Development and testing of a decision aid on goals of care for advanced dementia, *J. Am. Med. Dir. Assoc.* 15 (2014) 251–255.
- [22] N.B. Leighl, H.L. Shepherd, P.N. Butow, S.J. Clarke, M. McJannett, P.J. Beale, et al., Supporting treatment decision making in advanced cancer: a randomized trial of a decision aid for patients with advanced colorectal cancer considering chemotherapy, *J. Clin. Oncol.* 29 (2011) 2077–2084.
- [23] A. Febretti, K.D. Lopez, J. Stifter, A. Johnson, G.M. Keenan, D.J. Wilkie, Evaluating a Clinical Decision Support Interface for End-of-Life Nurse Care [Poster] Extended Abstracts on Human Factors in Computing Systems, 14, CHI, Toronto, Canada, 2014, pp. 1633–1638.
- [24] M.J. Green, B.H. Levi, Development of an interactive computer program for advance care planning, *Health Expect.* 12 (2009) 60–69.
- [25] D.D. Matlock, T.A. Keech, M.B. McKenzie, M.R. Bronsert, C.T. Nowels, J.S. Kutner, Feasibility and acceptability of a decision aid designed for people facing advanced or terminal illness: a pilot randomized trial, *Health Expect.* 17 (2014) 49–59.
- [26] S.L. Mitchell, J. Tetroe, A.M. O'Connor, A decision aid for long-term tube feeding in cognitively impaired older persons, *J. Am. Geriatr. Soc.* 49 (2001) 313–316.
- [27] M.K. Song, K.T. Kirchoff, J. Douglas, S. Ward, B. Hammes, A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery, *Med. Care* 43 (2005) 1049–1053.
- [28] R.E. Dales, A. O'Connor, P. Hebert, K. Sullivan, D. McKim, H. Llewellyn-Thomas, Intubation and mechanical ventilation for COPD: development of an instrument to elicit patient preferences, *Chest* 116 (1999) 792–800.
- [29] L.C. Hanson, T.S. Carey, A.J. Caprio, T.J. Lee, M. Ersek, J. Garrett, et al., Improving decision-making for feeding options in advanced dementia: a randomized, controlled trial, *J. Am. Geriatr. Soc.* 59 (2011) 2009–2016.
- [30] P.H. Ditto, J.H. Danks, W.D. Smucker, J. Bookwala, K.M. Coppola, R. Dresser, et al., Advance directives as acts of communication: a randomized controlled trial, *Arch. Intern. Med.* 161 (2001) 421–430.
- [31] P.J. Hollen, R.J. Gralla, R.A. Jones, C.Y. Thomas, D.R. Brenin, G.R. Weiss, et al., A theory-based decision aid for patients with cancer: results of feasibility and acceptability testing of DecisionKEYS for cancer, *Support. Care Cancer* 21 (2013) 889–899.
- [32] N.M. LaRue, M.K. Paasche-Orlow, A.E. Volandes, Video decision support tool to supplement goals-of-care discussions with hospitalized patients with advanced illness: preliminary findings [abstract #1334457], *J. Gen. Intern. Med.* (2012) S350.
- [33] L.J. Trevena, B.J. Zikmund-Fisher, A. Edwards, W. Gaissmaier, M. Galesic, P.K. Han, et al., Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers, *BMC Med. Inform. Decis. Mak.* 13 (Suppl. 2) (2013) S7.
- [34] G. Elwyn, A. O'Connor, D. Stacey, R. Volk, A. Edwards, A. Coulter, et al., Developing a quality criteria framework for patient decision aids: online international Delphi consensus process, *BMJ: Br. Med. J.* 333 (2006) 417–419.
- [35] T.M. Marteau, E. Dormandy, S. Michie, A measure of informed choice, *Health Expect.* 4 (2001) 99–108.
- [36] Drug and Therapeutics Bulletin, An introduction to patient decision aids, *BMJ* 347 (2013) f4147.
- [37] A. Fagerlin, M. Pignone, P. Abhyankar, N. Col, D. Feldman-Stewart, T. Gavaruzzi, et al., Clarifying values: an updated review, *BMC Med. Inform. Decis. Mak.* 13 (Suppl. 2) (2013) S8.
- [38] A.E. Turnbull, J.R. Krall, A.P. Ruhl, J.R. Curtis, S.D. Halpern, B.M. Lau, et al., A scenario-based, randomized trial of patient values and functional prognosis on intensivist intent to discuss withdrawing life support, *Crit. Care Med.* 42 (2014) 1455–1462.
- [39] R.C. Laidsaar-Powell, P.N. Butow, S. Bu, C. Charles, A. Gafni, W.W. Lam, et al., Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations, *Patient Educ. Couns.* 91 (2013) 3–13.
- [40] A. El-Jawahri, L.M. Podgurski, A.F. Eichler, S.R. Plotkin, J.S. Temel, S.L. Mitchell, et al., Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial, *J. Clin. Oncol.* 28 (2010) 305–310.
- [41] A.E. Volandes, M.K. Paasche-Orlow, S.L. Mitchell, A. El-Jawahri, A.D. Davis, M.J. Barry, et al., Randomized controlled trial of a video decision support tool for cardiopulmonary resuscitation decision making in advanced cancer, *J. Clin. Oncol.* 31 (2013) 380–386.
- [42] C.J. Cohen, Y. Chen, H. Orbach, Y. Freier-Dror, G. Auslander, G.S. Breuer, Social values as an independent factor affecting end of life medical decision making, *Med. Health Care Philos.* 18 (2015) 71–80.
- [43] J.L. Hart, M.O. Harhay, N.B. Gabler, S.J. Ratcliffe, C.M. Quill, S.D. Halpern, Variability among US intensive care units in managing the care of patients admitted with preexisting limits on life-sustaining therapies, *JAMA Intern. Med.* 175 (2015) 1019–1026.

- [44] E. Somogyi-Zalud, Z. Zhong, M.B. Hamel, J. Lynn, The use of life-sustaining treatments in hospitalized persons aged 80 and older, *J. Am. Geriatr. Soc.* 50 (2002) 930–934.
- [45] M.J. Barry, E. Chan, B. Moulton, S. Sah, M.B. Simmons, C. Braddock, Disclosing conflicts of interest in patient decision aids, *BMC Med. Inform. Decis. Mak.* 13 (Suppl. 2) (2013) S3.
- [46] C.L. Auriemma, C.A. Nguyen, R. Bronheim, S. Kent, S. Nadiger, D. Pardo, et al., Stability of end-of-life preferences: a systematic review of the evidence, *JAMA Intern. Med.* 174 (2014) 1085–1092.
- [47] R.D. Froman, S.V. Owen, Randomized study of stability and change in patients' advance directives, *Res. Nurs. Health* 28 (2005) 398–407.
- [48] R.E. Glasgow, H.G. McKay, J.D. Piette, K.D. Reynolds, The RE-AIM framework for evaluating interventions: what can it tell us about approaches to chronic illness management, *Patient Educ. Couns.* 44 (2001) 119–127.
- [49] National Health and Medical Research Council. NHMRC levels of evidence and grades for recommendations for developers of guidelines. In: NHMRC, editor. 2009.
- [50] J.B. Hozella, R. Bascom, M.J. Green, B.H. Levi, Using An Interactive Computer Program To Create An Advanced Directive In Patients With Stage III-IV Chronic Obstructive Pulmonary Disease: A Feasibility Study [conference Abstract #17316], 183, American Thoracic Society, 2011.