Patient Education and Counseling xxx (2016) xxx–xxx

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Review article

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

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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.

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http://dx.doi.org/10.1016/j.pec.2016.10.007
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Please cite this article in press as: M. Cardona-Morrell, et al., A systematic review of effectiveness of decision aids to assist older patients at the end of life, Patient Educ Couns (2016), http://dx.doi.org/10.1016/j.pec.2016.10.007

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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 themselves [7] 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

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