International Journal of Nursing Studies 66 (2017) 47–59

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

Review

Preconditions for successful advance care planning in nursing homes: A systematic review

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ARTICLE INFO

Article history:
Received 1 August 2016
Received in revised form 6 December 2016
Accepted 6 December 2016

Keywords:
Advance care planning
Elderly care
Long-Term care
Nursing home
Systematic review
Theory of change

ABSTRACT

Objectives: There is growing evidence of the potential effectiveness of advance care planning. Yet important knowledge gaps remain regarding the preconditions for successful implementation of advance care planning in the nursing home setting. We aim to identify the preconditions related to successful advance care planning in the nursing home setting. By specifying those, we would be able to make well-founded choices for the future design and planning of advance care planning intervention programs.
Design: A systematic review.
Data sources: PubMed, PsycINFO, EMBASE and CINAHL.
Review methods: Two authors independently screened publications. One author assessed methodological quality and extracted textual data, which was double-checked for a random sample. We extracted textual data and used thematic synthesis to identify "preconditions", defined as requirements, conditions and elements necessary to achieve the desired outcome of advance care planning, i.e. attaining concordance between residents' preferences and actual care or treatment received at the end of life.
Main findings: Based on 38 publications, we identified 17 preconditions at five different levels: resident, family, health-care professional, facility and community. Most preconditions were situated on multiple levels but the majority addressed professionals and the nursing home itself. We summarized preconditions in five domains: to have sufficient knowledge and skills, to be willing and able to participate in advance care planning, to have good relationships, to have an administrative system in place, and contextual factors supporting advance care planning within the nursing home.
Conclusion: There are multiple preconditions related to successfully implementing advance care planning in the complex nursing home setting that operate at micro, meso and macro level. Future interventions need to address these multiple domains and levels in a whole-system approach in order to be better implementable and more sustainable, while simultaneously target the important role of the health-care professional and the facility itself.

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What is already known

- Advance care planning has the potential to positively influence patient and family outcomes in nursing homes (e.g. improved compliance between wishes and care received, better quality of end-of-life care and more family satisfaction with care).
- Only a minority of nursing home residents actively engage in advance care planning, suggesting its implementation in nursing homes is less than optimal.
- Until now research has paid little attention to identifying the various preconditions for successful implementation of advance care planning interventions in nursing homes.

What this paper adds

- Health-care professionals and nursing home structures play an important role in successful implementation of advance care planning.

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http://dx.doi.org/10.1016/j.ijnurstu.2016.12.003
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- Crucial elements of change such as willingness of staff, a good administrative and monitoring system to evaluate practice, a supportive culture and an open attitude in the whole facility, have not been taken into account by existing advance care planning programs.
- This systematic review supports the claim that advance care planning should entail a whole-systems approach; requiring the development of new structures, care delivery processes, attitudes, roles and skills.

1. Background

Advance care planning (ACP) is a continual, dynamic process of reflection and dialogue between patients, family and care providers concerning preferences and values for future treatment and care including end-of-life care, and is aimed at enhancing the concordance between preferences and actual care or treatments received (Teno, 2003; Gillick, 2004a; Singer et al., 1998; Kolarik et al., 2002; Sudore and Fried, 2010; Ahluwalia and Gordon, 2012). If a patient wishes, the contents of such conversations can be recorded in the form of a positive or negative advance directive, and may include the appointment of a proxy decision-maker or lasting power of attorney in anticipation of future deterioration (Seymour and Horne, 2016; Royal College of Physicians of London, 2009). The process of advance care planning has been identified as particularly relevant for nursing home residents as they are a group with a high prevalence of frailty and multimorbidity and they often develop cognitive problems and become unable to take decisions about their end-of-life care (Givens et al., 2009; Boockvar and Meier, 2006). However, research shows that only a minority of older people actively engage in advance care planning, and that there is still a low prevalence of advance care planning in nursing homes (Musa et al., 2015; Vandervoort et al., 2014a; De Gendt et al., 2010; Meeussen et al., 2011). Nonetheless, a majority of this growing population would appreciate an opportunity for such a discussion (Sharp et al., 2013).

Advance care planning is a complex intervention (Boockvar and Meier, 2006). It consists of multiple interacting components such as training professionals in their conversation skills, the actual discussions about end-of-life care and the documentation of wishes. All of these can operate at different levels in the nursing home (the level of the resident and family, the care providers, the care facility itself, or even the community), resulting in a variety of possible outcomes (De Gendt et al., 2010; Meeussen et al., 2011).

Despite growing evidence from randomized controlled trials regarding the efficacy of advance care planning interventions on patient and family outcomes (Houben et al., 2014a; Brinkman-Stoppelenburg, 2014; Detering et al., 2010; Morrison et al., 2005; Vandervoort et al., 2014b; Martin et al., 2016) (e.g. improved compliance between wishes and care received (Detering et al., 2010; Morrison et al., 2005; Kirchhoff et al., 2012), higher quality of end-of-life care (Bischoff et al., 2013) and greater family satisfaction with care (Detering et al., 2010)), important knowledge gaps remain. Most importantly, we do not have a clear overview of all the important elements that contribute to optimally implementing and organizing advance care planning in the complex nursing home context (Houben et al., 2014a; Gillick, 2004b). More specifically, it is unclear to care providers and policymakers what is needed to effectively carry out advance care planning in the nursing home setting so that its ultimate goals are attained. Understanding and mapping the most important elements is a prerequisite for an effective advance care planning intervention that is likely to be implementable in practice and sustainable in the long run (De Silva et al., 2014). It is highly important knowledge given the time and human and financial resources that facilities invest when implementing advance care planning (Klingler and Marckmann, 2015).

The aim of this study is to identify – through a systematic literature review – the preconditions for implementing and organizing advance care planning in the nursing home setting to ultimately achieve the desired outcome i.e. concordance between residents' preferences and the actual care or treatments they receive at the end of life. This work is a first crucial step in a larger project that aims to develop and evaluate an advance care planning intervention program for nursing homes.

2. Methods

We conducted a systematic review of published literature.

2.1. Search strategy

Two systematic searches were conducted in four electronic databases: PubMed, PsycINFO, EMBASE and CINAHL. Articles were retrieved on May 7th, 2015. JG created a search string for PubMed and, with support from a university medical library advisor and Wolters Kluwer, translated it for use in other databases. In the first search, we extracted empirical articles on advance care planning specifically in nursing homes, published between 2004 and 2015. A second search identified reviews and meta-analyses concerning advance care planning in general with reference to the specific setting, published between 2004 and 2015. The electronic search strategy is provided as Supplementary file 1.

2.2. Screening and study selection

Titles and abstracts were screened independently and in duplicate by two reviewers (JG and one other author, TS/LP/LVdB/CG or LD) for potential eligibility against inclusion and exclusion criteria (see Supplementary file 2). In case of disagreement, consensus was reached through discussion with a third researcher. The articles selected for full text evaluation were acquired, if not electronically available, from the first author through e-mail, ResearchGate or inter-library lending, and were stored in a Zotero database. One reviewer (JG) assessed the full texts against the inclusion and exclusion criteria. In case of doubt, a second reviewer (LP) independently assessed the article. Disagreements were resolved by discussion and a third reviewer was available for arbitration (LVdB) (Kirchhoff et al., 2012). A flow diagram of the review process can be found in Fig. 1.

2.3. Theory of change as theoretical framework

To identify the important preconditions for advance care planning from the reviewed literature, we used the Theory of Change framework as described by the Aspen Institute (Anderson, 2016, 2004). A Theory of Change is 'a theory of how and why an initiative works which can be empirically tested by measuring indicators for every expected step on the hypothesized causal pathway to the desired outcome'(Anderson, 2016). A first and crucial step in building a Theory of Change is to identify all intermediate outcomes or "preconditions" that must be fulfilled in order for this long-term outcome to be achieved. Such preconditions are defined as all necessary requirements, conditions, elements or milestones that need to be in place for the long-term outcome to be achieved, including possible facilitators or barriers to be overcome. In a later phase of the project, these preconditions will be mapped chronologically in a causal pathway or Theory of Change map to be used in the development and evaluation of an advance care planning intervention program for nursing homes.

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