



Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial



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ABSTRACT

Background: Although evidence increasingly demonstrates the effects of advance care planning, the relevant studies are of questionable quality, and lack consensus regarding when and with whom to initiate the conversation.

Objective: To examine the effects of a structured, nurse-led post-discharge advance care planning programme on congruence between the end-of-life care preferences of the patient and family members, decisional conflicts and the documentation of care preferences.

Design: A two-arm parallel-group randomised controlled trial.

Participants: A total of 230 dyads comprising community-dwelling patients screened by the Gold Standards Framework Prognostic Indicator Guidance and their designated family members.

Methods: Patients in the experimental group participated in a structured advance care planning programme administered by a trained nurse during three weekly home visits following hospital discharge. In contrast, the post-discharge home visits provided to the control group focused on self-care management as attention control. The study outcomes were the dyadic congruence regarding end-of-life care preferences, the patients' level of decisional conflict regarding end-of-life decision-making and the documentation of these preferences at baseline and 1 and 6 months after enrolment. Generalised estimating equation models were used to compare changes in the outcomes between the groups across time.

Results: At baseline, few participants had ever heard of advance directives (12/460, 2.6%) and few patients had ever discussed end-of-life issues with family members (34/230, 14.8%). After six months, the experimental group exhibited a greater increase in dyadic congruence regarding various end-of-life care preferences than the control group ($P_s < 0.04$). The experimental group also exhibited a greater improvement in decisional conflict at 6 months relative to the control group ($P = 0.003$). However, the groups did not differ significantly in terms of changes in any outcomes after one month. The experimental group had significantly higher rates of completion of advance directives and electronic medical record documentation of do-not-attempt cardiopulmonary resuscitation orders than the control group.

Conclusions: This study showed that a nurse-led structured advance care planning programme could effectively improve dyadic congruence regarding end-of-life care preferences, reduce patients' decisional conflict and increase the documentation of care preferences. The findings underscored the importance of supporting nurses to introduce advance care planning at an earlier time that enable patients with sufficient time to contemplate end-of-life issues, empower patients to deliberate their choices and engage patients and their family members in open discussion.

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What is already known about the topic?

- Patients nearing the end of life were poorly prepared to make informed end-of-life care decisions.
- Discrepancies between patients' and family members' views in end-of-life care are evident.
- Previously published findings regarding the effects of advance care planning on eliciting end-of-life care preferences and reducing decisional conflicts are inconsistent.

What this paper adds

- This study demonstrates that the designation of a trained nurse as an advance care planning facilitator effectively improved dyadic congruence and reduced the patient's decisional conflict regarding end-of-life decision-making.
- The findings suggest that providing written information about end-of-life care and regular assessments of preferences may encourage patients to contemplate these issues.
- Furthermore, the findings underscore the importance of allowing time for nurses to conduct advance care planning.

1. Introduction

1.1. Background

Advance care planning is defined as the process through which individuals are encouraged to clarify their personal values regarding future medical care, discuss their preferred care goals and preferences regarding end-of-life scenarios with their family members and health care team and document these preferences before they lose decisional capacity (Rietjens et al., 2017; Sudore et al., 2017). Primarily, advance care planning aims to improve concordance between an individual's end-of-life care preferences and the actual care received (Houben et al., 2014; McMahan et al., 2013). Existing recommendations widely advocate the integration of advance care planning into the care provided to all people with chronic progressive diseases (i.e., not limited to patients with cancer diagnoses) (The National Council for Palliative Care, 2008).

1.2. Quality of evidence

Advance care planning is a complex intervention that encompasses various interacting components and dimensions and may be influenced by the attitudes and behaviours of those delivering or receiving the intervention (Gilissen et al., 2017; Medical Research Council, 2008). This complexity has led to increasing interest in the active ingredients and mechanisms associated with advance care planning with the intent to enhance the effectiveness and sustainability of this process (Medical Research Council, 2008). However, several systematic reviews have noted the low level of quality of many relevant studies (Brinkman-Stoppenberg et al., 2014; Houben et al., 2014; Oczkowski et al., 2016; Ng et al., 2016; Robinson et al., 2011), particularly regarding major limitations such as a lack of random allocation or blinding among assessors, small sample size, failure to describe the strategies implemented to ensure implementation fidelity and the use of inappropriate methods for data analysis. These limitations have raised concerns that compromised internal validity might have led to an overestimation of clinical efficacy.

Apart from these methodological issues, most studies were disease-specific and conducted in institutionalised settings such as hospitals and nursing homes (Brinkman-Stoppenberg et al., 2014; Newbould et al., 2012). Moreover, the outcomes of these studies mainly involved the completion of advance directives (Brinkman-Stoppenberg et al., 2014; Houben et al., 2014), and the reported effects of advance care planning on eliciting end-of-life care preferences and reducing

decisional conflicts were inconsistent (Houben et al., 2014).

1.3. Dyadic congruence in end-of-life care preferences

The evidence consistently demonstrates fair to poor agreement between patients and family members regarding end-of-life care preferences (Liu et al., 2017; Malhotra et al., 2015; Schmid et al., 2009). Family members tend to be more optimistic or aggressive in terms of treatment decisions or to make decisions for patients based on their own values (Kwok et al., 2006; Liu et al., 2017; Tang et al., 2005). These discrepancies between patients and family members' views suggest that advance care planning should not simply aim to prepare patients to make difficult decisions. The provision of support to patients to inform their families about their care preferences and to family members to make substituted decision-making are also critical steps in advance care planning (Izumi, 2017; McMahan et al., 2013). Gilissen et al. (2017) maintained that the participation of both individuals and family members is one of the preconditions for successful advance care planning. Hence, it is highly important to include both patients and family in the advance care planning so as to improve their congruence in end-of-life care preferences and thus optimizing the quality of care at the end of life.

1.4. Advance care planning facilitators

Previous reports have consistently noted that advance care planning should be conducted by health care professionals with necessary skills and knowledge. However, these studies have not reached consensus regarding the party responsible for conducting advance care planning (Gilissen et al., 2017), nor have they clarified the responsibilities of generalists and specialists in the initiation of advance care planning, which have hindered the process (Izumi, 2017; Ke et al., 2015). Recent studies found that both patients and health care professionals perceived that non-physicians broached end-of-life care issues more tactfully (Arnett et al., 2017; Clark et al., 2015; Scott et al., 2016). Similarly, a Delphi consensus process involving an international expert panel yielded a high level of agreement with the initiation of advance care planning by a non-physician (Rietjens et al., 2017). Izumi (2017) argued that nurses are well positioned to initiate advance care planning because they experience more frequent and regular contact with patients and family members and often act as the hub in a multidisciplinary team. Ke et al. (2015) also identified that the various roles held by nurses, which include educator, assessor, communicator, advocator and case manager, facilitate advance care planning.

This study aimed to examine the effects of a nurse-led, structured advance care planning programme on end-of-life care decision making for patients nearing the end of life. We hypothesised that compared with the control group, the experimental group would exhibit significantly higher levels of dyadic congruence regarding end-of-life care preferences, significantly lower levels of decisional conflict among patients and higher rates of documentation of the care preferences in medical records.

1.5. Conceptual framework of the nurse-led advance care planning programme

The advance care planning programme applied in this study was modified from the Let Me Talk programme developed for nursing home residents, which uses a narrative approach (Chan and Pang, 2010). The programme was modified to be more succinct while addressing three aspects: My Stories, My Views and My Wishes (Fig. 1). It was expected to provide an avenue by which individuals could identify values stemming from past experiences. McMahan et al. (2013) also noted in a qualitative study of the sharing of patients and surrogates who involved in end-of-life decision making that advance care planning should not only be focused on specific treatment. The nurse was provided with the

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