Encouraging early discussion of life expectancy and end-of-life care: A randomised controlled trial of a nurse-led communication support program for patients and caregivers

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ABSTRACT

Background: Patients are often not given the information needed to understand their prognosis and make informed treatment choices, with many consequently experiencing less than optimal care and quality-of-life at end-of-life.
Objectives: To evaluate the efficacy of a nurse-facilitated communication support program for patients with advanced, incurable cancer to assist them in discussing prognosis and end-of-life care.
Design: A parallel-group randomised controlled trial design was used.
Settings: This trial was conducted at six cancer treatment centres affiliated with major hospitals in Sydney, Australia.
Participants: 110 patients with advanced, incurable cancer participated.
Methods: The communication support program included guided exploration of a question prompt list, communication challenges, patient values and concerns and the value of discussing end-of-life care early, with oncologists cued to endorse question-asking and question prompt list use. Patients were randomised after baseline measure completion, a regular oncology consultation was audio-recorded and a follow-up questionnaire was completed one month later. Communication, health-related quality-of-life and satisfaction measures and a manualised consultation-coding scheme were used. Descriptive, Mixed Modelling and Generalised Linear Mixed Modelling analyses were conducted using SPSS version 22.
Results: Communication support program recipients gave significantly more cues for discussion of prognosis, end-of-life care, future care options and general issues not targeted by the intervention during recorded consultations, but did not ask more questions about these issues or overall. Oncologists' question prompt list and question asking endorsement was inconsistent. Communication support program recipients' self-efficacy in knowing what questions to ask their doctor significantly improved at follow-up while control arm patients' self-efficacy declined. The communication support program did not impact patients' health-related quality-of-life or the likelihood that their health information or shared decision-making preferences would be met. Satisfaction with the communication support program was high.
Conclusions: Given the importance of clarifying prognostic expectations and end-of-life care wishes in the advanced cancer context, the communication support program appears to be an effective and well-received solution to encourage early information seeking related to these issues though, its long-term impact remains unclear. The manualised nature of the intervention, designed with existing clinical staff in mind, may make it suited for implementation in a clinical setting, though additional work is needed to identify why question asking was unaffected and establish its impact later in the illness trajectory.

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What is already known?

- Clarifying prognostic expectations and end-of-life care wishes in the advanced cancer context is an important aspect of quality end-of-life care.
- Patients are often not given the information needed to understand their prognosis and make informed treatment choices
- Many consequently experiencing less than optimal care and quality-of-life at end-of-life

What this paper adds

- This randomised controlled trial of a nurse-facilitated communication support program for patients with advanced, incurable cancer to assist them in discussing prognosis and end-of-life care demonstrated an impact on patient cues for discussion but not direct questions related to these issues
- The communication support program was a well-received solution to encourage early information seeking related to these issues and could feasibly be delivered by existing nursing staff
- Additional work is needed to identify why question asking was unaffected and establish the impact of the intervention later in the illness trajectory

1. Introduction

Despite treatment advances, cancer remains an often-lethal disease. Timely communication about prognosis and care preferences may afford patients and families opportunities to prepare for the end-of-life (EOL) and ensure care is consistent with their values. Such discussions may reduce aggressive EOL medical care and associated costs (Zhang et al., 2009), increase early palliative care or hospice referral (Wright et al., 2008), increase satisfaction with care and improve quality-of-life and survival (Detering et al., 2010; Heyland et al., 2009).

Communication regarding prognosis and EOL care can be challenging for clinicians and patients. Clinicians' avoidance of life expectancy discussions is common (Lamont and Christakis, 2001), often for fear of destroying hope or the therapeutic relationship (Buiting et al., 2011). Patients' readiness to discuss such issues is variable; depending on factors including exposure and adjustment to disease, coping style and spirituality (Walczak et al., 2013a). Consequently, clinicians and patients may "collude" to avoid these discussions (The et al., 2000). EOL care conversations often first occur near death during acute hospital admissions (Mack et al., 2012), when critical chemotherapy and aggressive life support decisions may already have been made. Such communication can be poor-quality with as few as 14% of doctors knowing patients' pain management or place of death preferences (DesHarnais et al., 2007) and many palliative chemotherapy recipients misunderstand its non-curative intent (Weeks et al., 2012).

Interventions to improve patient and caregiver communication have included Question Prompt Lists (QPLs) (Bruera et al., 2003; Clayton et al., 2003, 2007; Dimoska et al., 2008) and nurse-led communication support (Alfred et al., 1995). QPLs are thematically grouped, evidence-based lists of suggested questions patients and caregivers can ask healthcare providers, often valued for showing the range of topics to discuss, assisting with question formulation and highlighting clinicians' willingness to discuss all topics. Previous QPL studies have demonstrated substantial improvements in patient question asking (Clayton et al., 2007), recall and anxiety (Bruera et al., 2003). Communication support has included utilising nurses as communication brokers to assist patients, families and clinicians in EOL discussions (Alfred et al., 1995). Outcomes of such studies have been modest to null, however they appear to be feasible and of some value to patients and caregivers

(Walczak et al., 2016). Given such interventions have focussed only on facilitating discussion, have inadequately targeted patient and caregiver activation and did not provide much-needed concrete communication tools, a communication support intervention may be enhanced by pairing it with a QPL.

This paper reports the results of a parallel group randomised controlled trial of a nurse-led Communication Support Program (CSP) for oncology patients with a prognosis < 1-year. The CSP paired education and communication support with a QPL highlighting EOL-relevant issues. Its primary goal was to assist patients and caregivers in seeking information regarding prognosis, EOL and future care and promote discussion of advance care planning (ACP). We hypothesised that when compared to controls, participants receiving the CSP would:

Primary Outcome:

- Ask more questions and express more cues for discussion in total and regarding issues specifically targeted by the intervention during a follow-up oncology consultation.

Secondary Outcomes:

- Report increased self-efficacy in communicating with their oncologist.
- Be more likely to meet their preferences for information receipt and involvement in decision-making.
- Report improved health-related quality-of-life.

We also aimed to examine participant satisfaction with all aspects of the intervention.

2. Methods

2.1. Participants and procedure

Participants were English-speaking, adult, medical oncology patients with various advanced, incurable cancer diagnoses and an oncologist-assessed 2–12 month life expectancy. Informal adult caregivers optionally participated if nominated by the patient. Oncologists at six cancer treatment centres affiliated with hospitals in Sydney, Australia identified consecutive patients meeting selection criteria at follow-up consultations and obtained consent for researcher contact. Oncologists were instructed to refer patients where they would not be surprised if they died within the next 12 months, but they thought there was a good chance they would live at least another 2 months. Research assistants obtained informed consent.

All consented participants completed demographic and baseline questionnaires and were randomised to receive the CSP or standard care, stratified by referring oncologist. A computer generated random number table was used to generate blocks of 1:1 balanced randomisation codes for each referring oncologist. These were individually concealed in sequentially numbered opaque envelopes. A research manager, blinded to participant identity, opened the next envelope in sequence for the referring oncologist to determine randomisation. Participants and oncologists could not be blinded. Participants' oncology consultation following CSP-completion or assignment to the control group was audio-recorded. A follow-up questionnaire containing the same measures completed at baseline plus an intervention satisfaction measure was completed 1 month later. All measures were validated except purpose-designed demographic and satisfaction questionnaires. Measures relevant to current analyses included the Perceived Efficacy in Physician/Patient Interactions Scale (PEPPI) (Maly et al., 1998), the FACT-G health-related quality-of-life measure (Webster et al., 2003), the Cassileth Information Styles