Applied Nursing Research 30 (2016) 12–15

Contents lists available at ScienceDirect

Applied Nursing Research

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

Clinical Methods

Addressing the challenges of conducting research with end-of-life populations in the acute care setting

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ARTICLE INFO

Article history:
Received 17 March 2015
Revised 14 August 2015
Accepted 14 August 2015

Keywords:
Palliative care
Research strategies
End of life
Patient preferences

ABSTRACT

End-of-life (EOL) conversations are difficult for patients, families, and nurses. The purpose of this article is to describe the challenges encountered and strategies implemented during a research study designed to elicit information about the congruence among patients' stated preferences at EOL with perceptions of their caregivers and nurses using the Preferences About Dying and Death (PADD) instrument in an acute care setting. With the proper study inclusion criteria, education and support from more confident, experienced colleagues, nurses can be coached to identify appropriate participants for EOL research. Researchers should plan regularly scheduled debriefing sessions with interviewers to provide emotional support and encouragement to minimize distress. A scripted approach to introduce EOL research topics can ease clinicians' discomfort while allowing patients the opportunity to have open, honest dialogues about their care preferences. By proactively implementing strategies, researchers can enhance the integration of EOL research into the acute care setting.

1. Introduction

End-of-life (EOL) conversations are difficult for patients, families, and healthcare providers (HCPs) (Au et al., 2012; Clayton, Butow, & Tattersall, 2005; Galushko, Romotzky, & Voltz, 2012; Kumar & Temel, 2013; Morris et al., 2012; Schultz & Bar-Sela, 2013; Seaman, 2013; Slort et al., 2011; Teno et al., 2013; Tuck, Brod, Nutt, & Fromme, 2013; Zaros, Curtis, Silveira, & Elmore, 2013). Although these dialogues may be emotionally charged, they are critical to ensure that patients receive care they really desire. Interventions directed at improving communication about EOL care can enhance patient outcomes (Butler, Ratner, McCreedy, Shippee, & Kane, 2014; Dunn & Litrivis, 2011; Galushko et al., 2012). Nurses are in a unique position to assist patients and families with these discussions.

Clinicians and patients face significant barriers with EOL discussions in the clinical setting, and new approaches and tools are needed to facilitate this process (Abba, Byrne, Horton, & Lloyd-Williams, 2013; Au et al., 2012; Cox, Moghaddam, Almack, Pollock, & Seymour, 2011; Downey, Au, Curtis, & Engelberg, 2013; Galushko et al., 2012; Kumar & Temel, 2013; Morris et al., 2012; Reinke, Uman, Udris, Moss, & Au, 2013; Schonfeld, Stevens, Lampman, & Lyons, 2012; Seaman, 2013; Zaros et al., 2013). However, it has been difficult to develop valid, reliable tools to use in these situations due to the multiple challenges in conducting research in the clinical setting. Some of these challenges include engaging stakeholders; recruiting and obtaining consent of vulnerable patients; managing the interview impact upon participants; and negotiating professional and organizational concerns (Agar, Ko, Sheehan, Chapman, & Currow, 2013; Bullen, Maher, Rosenberg, & Smith, 2014; Fischer, Burgener, Kavanaugh, Ryan, & Keenan, 2012; Fischer et al., 2012; Fischer et al., 2012; Wohleber, McKitrick, & Davis, 2012; Wohleber et al., 2012). The purpose of this article is to describe the challenges encountered and strategies implemented during a research study designed to elicit information about the congruence among patients' stated preferences at EOL with perceptions of their caregivers and nurses.

2. Background: study purpose and design

The purpose of this clinical study was to compare patients' stated preferences for EOL care with family members' perceptions and registered nurses' perceptions of the patients' preferences. Participants included 1.) seriously ill, adult patients with a prognosis of 3 months or less to live who had been admitted to the inpatient oncology unit for acute care issues (e.g. chemotherapy and/or symptom management) or to the inpatient palliative care unit for symptom management; 2.) caregivers of the patients; and 3.) registered nurses who provided inpatient care for participant patients for at least one shift. The institutional review board (IRB) of the participating medical center approved the study. All participants signed an informed consent.

The Preferences About Dying and Death (PADD) tool was used to elicit patient preferences at EOL (Engelberg, 2006; Engelberg, Patrick, & Curtis, 2005). The PADD had been used to assess agreement between patients' and surrogates' understanding of patients' preferences, but it had not been used in an acute care setting to directly elicit patients' preferences. However, this tool provided a comprehensive framework for

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http://dx.doi.org/10.1016/j.apnr.2015.08.006
0897-1897/

interviewing patients, caregivers and nurses, thus the PI selected it for use in this study. The PADD does not have a section that discusses prognosis nor does it have a limitation on what one's prognosis should be in order to speculate on what one's preferences would be if one "only had 7 days to live". Research associates interviewed participants (patient, caregiver and nurse) to determine their responses to the PADD.

Structure of the interviews: The interviewers conducted face-to-face interviews with ten patients on the oncology and palliative care units; eight caregivers; and ten nurses between August 2011 and April 2012, using the PADD. Each interview lasted 15–20 minutes and took place in a private setting between the participants and the interviewer to ensure confidentiality.

3. Key challenges and strategies

3.1. Challenges to engage stakeholders

The study was conducted on two inpatient units in a large acute care hospital and many stakeholders were involved in the execution of this project. The literature suggests that it is important to establish a trusting relationship between the researchers and the stakeholders to ensure successful implementation (Bullen et al., 2014; Fischer et al., 2012). Stakeholders included nursing and medical directors, admitting physicians and nursing staffs. One of the oncologists was concerned that the oncology nurses might inadvertently divulge the 3 months or less prognosis inclusion criterion to patients during the screening process. The palliative medicine physicians did not mention that this was an issue. The nurse directors and unit nurses expressed concerns about how staff would find the time to conduct the research in view of busy patient care responsibilities.

3.2. Strategies to engage stakeholders

The principal investigator (PI) was a clinical nurse specialist, a clinician and researcher who was well known to physicians and nurses. She had worked with the staff of these units for over 12 years. During the study design phase and prior to initiating the study, the PI met with the nursing unit directors and the medical directors of both units to secure their trust and support.

The PI reviewed the screening and informed consent procedures with key oncologist stakeholders. The informed consent process included the following statements: "You are being asked to take part in a research study because you are a patient with a life-limiting illness that could benefit from symptom management. The purpose of this research is to learn about preferences regarding dying and death." She assured the physicians that the context of the screening inclusion criterion of 3 months or less prognosis was not discussed with potential patient participants. The oncology and palliative care nurses provided potential patient participants the IRB approved flyer and read it verbatim to the patients. The recruitment flyer included the purpose of the study as follows "The purpose of the research is to learn about preferences regarding life limiting illnesses. The researchers will interview people about what their concerns may be during their treatment." If patients had questions about their prognoses, the researchers would notify the oncologists so they could answer their patients' questions. The PI worked with the nurse directors to minimize the time commitments by creating quick study talking points for the nurses and by meeting daily with the unit nurse leaders to elicit potential participants that minimized interruptions in nurses' routines. Additionally, the study was funded by an internal research grant that allowed the PI to hire individuals to conduct the interviews to alleviate nursing concerns about time restrictions.

3.3. Challenge of participant recruitment

The IRB of our organization requires that someone other than the PI identify and approach potential subjects about their interest in participating in a research study. To meet this requirement, the unit nurses had to identify potential participants with a 3-month prognosis or less and provide these patients with a flyer that contained information about the study. Then the nurses were to ask the patients if they were interested in talking with the PI about the study.

Participant recruitment was initially a challenge as unit nurses had difficulty identifying patients with a 3 month or less prognosis. The PI used role-playing strategies to instruct unit nurses how to recruit potential participants and provided them with a flyer and script to use when informing patients about the study. However, as the study progressed, the PI found that nurses were reluctant to state that the patient had a life-limiting prognosis despite being educated and given explicit inclusion criteria based upon national standards. Even after identification of appropriate patients for inclusion in the study, nurses expressed reluctance about approaching patients and caregivers. This situation is consistent with findings by Fischer et al. (2012) where they noted that physician residents and fellows were hesitant to identify persons with severe heart failure who were approaching EOL.

3.4. Strategies to enhance recruitment

The PI met with nursing leaders from both units to discuss the recruitment challenges. Based upon these conversations, the PI worked with the charge nurses to identify potentially eligible patient participants using the inclusion criteria. Once the charge nurses were comfortable identifying appropriate participants using the inclusion criteria, then they reinforced the inclusion criteria with their staffs. The PI redistributed the study flyer and script and personally worked with the nurses on when and how to approach patients and caregivers. Staff nurses were not required to state anything about patient prognosis or the details of the study. Following direct discussion with individual nurses by the PI, coupled with support from an experienced charge nurses, staff nurses were able to identify and approach patients who met the inclusion criteria, confirming findings by Fischer et al. (2012) and other palliative care researchers (Bullen et al., 2014; Fischer et al., 2012; Wiegand, Norton, & Baggs, 2008; Wohleber et al., 2012).

3.5. Challenge of informed consent

Participation in this study required informed consent, necessitating that patients be able to understand and give consent. This is essential to the protection of human subjects, but it can be difficult to obtain informed consent from terminally ill patients, as they are more likely to have higher rates of impaired cognitive capacity due to disease progression and/or pharmacological management of their symptoms (Agar et al., 2013; Bullen et al., 2014).

3.6. Strategies of informed consent

To insure capacity to participate in the study, the PI conducted the Short Portable Mental Status Questionnaire (SPMSQ) with each potential patient participant. If the results indicated the patients were confused or impaired, they were excluded from the study. One participant was excluded from the study based upon the SPMSQ. Capacity screening, consenting and interviews were scheduled around patients care to minimize interruptions in patient care and minimize the potential for patient fatigue. The PI then obtained written consent from each patient to participate in the study.

3.7. Challenge: interview process and patient burden

3.7.1. Scheduling

Scheduling the participant interviews was a challenge. As the intent of the study was to interview patients, caregivers and the nursing staff who provided patient care, the logistics of obtaining the data were difficult. Due to variability in patient conditions (rapid deterioration and fluctuations in symptoms and psychological distress) and availability