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

Phyllis B. Whitehead, PhD, APRN [a,b,*], Rebecca C. Clark, PhD, RN [a]

[a] Carilion Roanoke Memorial Hospital, Roanoke, VA, USA
[b] Virginia Tech Carilion, School of Medicine, Roanoke, VA, USA

ARTICLE INFO

Article history:
Received 17 March 2015
Revised 14 August 2015
Accepted 14 August 2015
Available online xxxx

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

* Corresponding author at: Carilion Roanoke Memorial Hospital, Palliative Care Service, 1906 Belleview Avenue, Roanoke, VA 24014. Tel.: +1 540 981 8126; fax: +1 540 344 3641.
E-mail address: pbwhitehead@carilionclinic.org (P.B. Whitehead).

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

of patients due to treatments and tests, it was often difficult to schedule interviews. Caregivers were often unavailable during the daytime hours. Staff members were frequently busy providing care on the units. The interviewers were faculty members at a local nursing program and had busy schedules as well. The average length of stay or prognosis of the patients was less than 5 days after study eligibility identification. This short interval coupled with these conflicting schedules created challenges in coordinating interview times.

3.7.2. Interview content

Two master's prepared registered nurses with experience in caring for patients with serious illnesses and formal EOL nursing education interviewed participants. The PI trained the interviewers on how to conduct semi-structured interviews involving sensitive issues such as EOL and how to the use the PADD instrument.

Despite their background and expertise, the interviewers verbalized difficulty in initiating EOL discussions with both patients and caregivers and valued the scripted approach to begin the conversations. Interviewers noted that the patients were open and willing to talk about their preferences once they began the interviews, a finding supported by other studies (Gysels, Evans, & Higginson, 2012; Kumar & Temel, 2013). The interviewers found they often wanted to provide nursing care and/or comfort to the participants. For example, one caregiver participant questioned how she would live without her spouse. The interviewer personally wanted to provide support and counseling for the participant but instead reported the finding to the charge nurse who consulted the unit social worker to support the caregiver.

3.8. Strategies: interview process and patient burden

3.8.1. Scheduling

The PI addressed this challenge by creating a monthly work calendar for the interviewers and coordinating potential meeting dates and times between the nurses, patients and family members after the consent process. She then scheduled the interview dates and times and communicated these to the interviewers. The interviewers were flexible regarding setting up schedules for data collection. It was essential to have at least two interviewers in order to accommodate the varied time commitments for all and the short lengths of stays or prognoses of the patients. The interviewers conducted interviews in the evenings and weekends when there tend to be few hospital-related activities. The interviewers placed a sign on the patient's door indicating that an interview was in progress.

Scripting for introductions to data collection provided a bridge for the interviewers to use in initiating the conversations. The PI worked closely with the interviewers to provide debriefing sessions to discuss their thoughts and feelings regarding the interviews and to reinforce their research roles as data collectors rather than as nurses providing care. The interviewers emphasized the importance and value of including caregivers in the patient interviews, noting that this may provide patients with support and reassurance that their preferences would be heard and honored. Interviewers discussed the importance of developing trust and rapport with patients and families due to the sensitivity of the topic. Furthermore, the interviewers stressed the importance of finding uninterrupted time for these interviews and conversations, but this was a challenge in a busy acute care setting.

3.9. Challenge: questionnaire development

Dr. Ruth Engelberg and associates at the University of Washington developed the PADD tool to study the agreement between patients' preferences during the last week of life and their surrogates' understanding of their preferences. The PADD includes 33 items when completed by patients and 32 items when completed by family members and nurses. Questions represent six domains: symptoms and personal care, preparation for EOL care, moment of death, family and loved ones, treatment preferences, and "whole person" concerns (Engelberg et al., 2005). For patients, each question starts with, "Over the last 7 days of your life, how important will it be to you to….." For family members and nurses each question starts with, "Imagine the last 7 days of (patient's name) life, how important to (patient's name) will it be to…." Examples of the PADD questions include the following: having pain under control, spending time with friends and family, keeping dignity and self-respect, and finding meaning and purpose. Patients are asked the question, "Who would you like to have present at the time of death?" Patients, family members and nurses rate preferences from 0 to 10 with 0 indicating "the least important" up to 10 indicating "the most important." The participants are then asked to rank the five items they imagined as the most important to them during the last 7 days of life (Engelberg, 2006; Engelberg et al., 2005). The PI eliminated a question on assisted suicide, as it is not a legal option in the practicing state.

Since the PADD had not been used in the acute care setting, there were several challenges with the tool. Participants struggled with the wording of many of the questions including the sequencing of the questions that alternated between domains. For example, the question "having control over what is going on around him (the patient)" followed the question regarding "controlling pain". The PADD took approximately 15–20 minutes to complete per interview. Its length and complexity created a "patient burden" in the acute care setting, and interviewers reported patient participants appeared fatigued following the interviews.

Participants noted the rating schema 0-10 had too many options. The responses clustered between 8 and 10. Additionally, participants voiced difficulty with the concept of the "last 7 days of your life." Patients verbalized emotional distress when contemplating what their preferences would be if they only had a week to live.

Participants identified several questions as being confusing or redundant. For example, the question, "have a spiritual service or ceremony" was found to be confusing and interpreted by the patient participant to mean "to have a funeral after death" which was another question later in the questionnaire.

3.10. Strategies: modify the questionnaire

After completion of the study and based upon the findings of the study and the team's experiences with the interview process using the PADD, the research team revised the PADD with the intent to elicit practical dialogues between patients, caregivers and nurses in a busy acute care setting. The team evaluated each question by domain and ease of response by participants with the goal of modifying the instrument for more realistic clinical use.

3.10.1. Rating schema

This pilot revealed limitations with the use of the PADD. Participants rated most of the PADD items very important, i.e. 8–10 indicating that the rating schema of 0-10 was too detailed. To address this finding, the research team modified the instrument rating schema to three choices "very important", "important" or "not important" to promote participant dialogue.

3.10.2. Last 7 days of life

Limiting the timeframe for participants to speculate on what their preferences would be during the "last 7 days of your life" was confusing and emotionally charged for participants. Participants and interviewers expressed discomfort with the words "dying" and "death." Researchers modified the timeframe phrasing and replaced the wording with "serious illness" to minimize nurse and patient hesitancy to converse. The questionnaire was modified for the interviewer to ask participants what their preferences are "right now" in place of if they had seven days to live. By approaching this challenge with other words, nurses can elicit conversations that lead to patients' preferences with less emotional distress for all.

3.10.3. Question sequence

Participants found the original questions groups alternating between domains distracting and confusing. The research team reorganized the questions by domains, starting with symptom management based upon patients' priorities for care. The next step of this work will include studying this revised instrument, Patient Preferences About Serious Illnesses (PASI) with permission of the original PADD creators, in terms of ease of use in eliciting patients' preferences when faced with serious illnesses in both outpatient and acute care settings.

4. Discussions and recommendations

Challenges exist in conducting research to improve EOL dialogues with seriously ill patients(Abba et al., 2013; Au et al., 2012; Caldwell, Arthur, & Demers, 2007; Clayton et al., 2005; Dunn & Litrivis, 2011; Galushko et al., 2012; Morris et al., 2012; Schultz & Bar-Sela, 2013). Recruitment of participants at EOL is difficult as clinicians are hesitant to acknowledge patients' poor prognoses and are uncomfortable with approaching eligible patients as noted by Fischer et al. (2012). 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. EOL investigators should expect participant recruitment challenges and plan for ongoing education and support of referral staff.

It can be a challenge to find convenient, uninterrupted interview times for patients, caregivers and nurses. If EOL research in clinical units is to occur, it is important to allocate resources for flexible staffing for participant referrals and interviews. Other challenges involved interview staff's personal uneasiness of initiating EOL conversations. Researchers should plan regularly scheduled debriefing sessions with interviewers to provide emotional support and encouragement to minimize distress. Additionally, EOL researchers should consider these issues as opportunities to improve EOL education and strengthen communication among HCPs caring for seriously ill patients. Nurses need holistic, practical clinical instruments to facilitate EOL conversations. A scripted approach to introduce EOL research topics can ease clinicians' discomfort while allowing patients the opportunity to have open, honest dialogues with their HCPs.

5. Conclusion

The lessons learned from this study provided valuable insights into the challenges of conducting EOL research with seriously ill patients, caregivers and nurses. The experiences described in this article provide researchers with guidelines for addressing challenges of stakeholder engagement, recruitment and consent of vulnerable patients as well as improvement of the interview process for seriously ill participants. By proactively implementing strategies presented here, researchers can enhance the integration of EOL research into the acute care setting.

References

Abba, K., Byrne, P., Horton, S., & Lloyd-Williams, M. (2013). Interventions to encourage dicsussion of end-of-life preferences between members of the general population and the people closest to them—A systematic literature review. *BMC Palliative Care*, *12*(40), 1–12. , http://dx.doi.org/10.1186/1472-684X-12-40.

Agar, M., Ko, M. N., Sheehan, C., Chapman, M., & Currow, D. C. (2013). Informed consent in palliative care clinical trials: Challenging but possible. *Journal of Palliative Medicine*, *16*(5), 485–490. , http://dx.doi.org/10.1089/jpm.2012.0422.

Au, D. H., Udris, E. M., Engelberg, R. A., Diehr, P. H., Bryson, C. L., Reinke, L. F., & Curtis, J. R. (2012). A randomized trial to improve communication about end-of-life care among patients with COPD. *Chest*, *141*(3), 1–14.

Bullen, T., Maher, K., Rosenberg, J. P., & Smith, B. (2014). Establishing research in a palliative care clinical setting: Perceived barriers and implemented strategies. *Applied Nursing Research*, *27*, 78–83.

Butler, M., Ratner, E., McCreedy, E., Shippee, N., & Kane, R. L. (2014). Decision aids for advance care planning: An overview of the state of the science. *Annals of Internal Medicine*, *161*(6), 408–418.

Caldwell, P. H., Arthur, H. M., & Demers, C. (2007). Preferences of patients with heart failure for prognosis communication. *Canadian Journal of Cardiology*, *23*(10), 791–796.

Clayton, J. M., Butow, P. N., & Tattersall, M. H. N. (2005). When and how to initiate discussion about prognosis and end-of-life issues with terminally ill patients. *Journal of Pain and Symptom Management*, *30*(2), 132–144.

Cox, K., Moghaddam, N., Almack, K., Pollock, K., & Seymour, J. (2011). Is it recorded in the notes? documentation of end-of-life care and preferred place to die discussions in the final weeks of life. *BMC Palliative Care*, *10*(18), 1–9. , http://dx.doi.org/10.1186/1472-684X-10-18.

Downey, L., Au, D. H., Curtis, J. R., & Engelberg, R. A. (2013). Life-sustaining treatment preferences: Matches and mismatches between patients' preferences and clinicians' perceptions. *Journal of Pain and Symptom Management*, *46*(1), 9–19. , http://dx.doi.org/10.1016/j.jpainsymman,2012.07.002.

Dunn, A., & Litrivis, E. (2011). Aligning patient preferences and patient care at the end of life. *Journal of General Internal Medicine*, *26*(7), 681–682.

Engelberg, R. A. (2006). Measuring the quality of dying and death: Methodological considerations and recent findings. *Current Opinion in Critical Care*, *12*, 381–387.

Engelberg, R. A., Patrick, D. L., & Curtis, J. R. (2005). Correspondence between patients' preferences and surrogates' understandings for dying and death. *Journal of Pain and Symptom Management*, *30*(6), 498–509.

Fischer, D. J., Burgener, S. C., Kavanaugh, K., Ryan, C., & Keenan, G. (2012). Conducting research with end-of-life populations: Overcoming recruitment challenges when working clinical agencies. *Applied Nursing Research*, *25*, 258–263 [10.1016].

Galushko, M., Romotzky, V., & Voltz, R. (2012). Challenges in end of life communication. *Current Opinion in Supportive & Palliative Care*, *6*(3), 355–364.

Gysels, M. H., Evans, C., & Higginson, I. J. (2012). Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: A critical interpretive synthesis of the literature. *BMC Medical Research Methodology*, *12*(123) http://www.biomedcentral.com/1471-2288/12/123.

Kumar, P., & Temel, J. S. (2013). End-of-life care discussions in patients with advanced cancer. *Journal of Clinical Oncology*, *31*(27), 3315–3319. , http://dx.doi.org/10.1200/JCO.2013.49.6562.

Morris, D. A., Johnson, K. S., Ammarell, N., Arnold, R. M., Tulsky, J. A., & Steinhauser, K. E. (2012). What is your understanding of your illness? A communication tool to explore patients' perspectives of living with advanced illness. *Journal of General Internal Medicine*, *27*(11), 1460–1466. , http://dx.doi.org/10.1007/s11606-012-2109-2.

Reinke, L. F., Uman, J., Udris, E. M., Moss, B. R., & Au, D. H. (2013). Preferences for death and dying among veterans with chronic obstructive pulmonary disease. *American Journal of Hospice and Palliative Medicine*, *1*(1), http://dx.doi.org/10.1177/1049909112471579.

Schonfeld, T. L., Stevens, E. A., Lampman, M. A., & Lyons, W. L. (2012). Assessing challenges in end-of-life conversations with elderly patients with multiple morbidities. *American Journal of Hospice and Palliative Medicine*, *29*(4), 260–267. , http://dx.doi.org/10.1177/1049909111418778.

Schultz, M., & Bar-Sela, G. (2013). Initiating palliative care conversations: Lessons from Jewish bioethics. *The Journal of Supportive Oncology*, *11*(1), 1–7.

Seaman, J. B. (2013). Improving care at end of life in the ICU: A proposal for early discussion of goals of care. *Journal of Gerontological Nursing*, *39*(8), 52–58.

Slort, W., Schweitzer, B. P. M., Blankenstein, A. H., Abarshi, E. A., Riphagen, I. I., Echteld, M. A., ... Deliens, L. (2011). Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliative Medicine*, *25*(6), 613–629. , http://dx.doi.org/10.1177/0269216310395987.

Teno, J. M., Gozalo, P. L., Bynum, J. P., Leland, N. E., Miller, S. G., Morden, N. E., ... Mor, V. (2013). Change in end-of-life care for medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*, *309*(5), 470–477.

Tuck, K. K., Brod, L., Nutt, J., & Fromme, E. K. (2013). Preferences of patients with Parkinson's disease for communication about advanced care planning. *American Journal of Hospice and Palliative Medicine*, *9*, http://dx.doi.org/10.1177/1049909113504241.

Wiegand, D. L., Norton, S. A., & Baggs, J. G. (2008). Challenges in conducting end-of-life research in critical care. *AACN Advanced Critical Care*, *19*(2), 170–177.

Wohleber, A. M., McKitrick, D. S., & Davis, S. E. (2012). Designing research with hospice and palliative care populations. *American Journal of Hospice and Palliative Medicine*, *29*(5), 335–345. , http://dx.doi.org/10.1177/1049909111427139.

Zaros, M. C., Curtis, J. R., Silveira, M. J., & Elmore, J. G. (2013). Opportunity lost: End-of-life discussions in cancer patients who die in the hospital. *Journal of Hospital Medicine*, *8*(6), 334–340. , http://dx.doi.org/10.1002/jhm.1989.