

Overcoming barriers in hospice and palliative care research is a multifaceted challenge for researchers conducting intervention studies. The complexity and variations of these barriers are abundant and serious in nature and can threaten the success of intervention research for the hospice and palliative care patient population. This article explores how challenges and barriers to intervention research can be mitigated by nurses caring for patients in hospice and palliative care settings.

#### AT A GLANCE

- Terminally ill patients participate in intervention research studies for highly personal and altruistic reasons.
- Bedside nurses play a key role in recruiting patients for hospice and palliative care research.
- Nurse practitioners can collaborate with researchers to establish effective strategies for conducting intervention research on hospice and palliative care.

#### KEYWORDS

nursing interventions; research; hospice; palliative care; barriers

#### DIGITAL OBJECT IDENTIFIER

10.1188/20.CJON.227-230

# Barriers to Hospice and Palliative Care Research

## A patient-centered approach to intervention studies

Cheryl Brohard, PhD, RN, CNS-ONC, AOCN®, CHPCA®

Patients with cancer at the end of life can have altruistic goals, such as having a life that mattered, being part of a larger existential self, feeling free to express themselves, using unrestrained and honest talk, giving back to society, and reconciling and integrating themselves into complete human beings who are engaged in the world (Bloomer et al., 2018). A systematic review by Alexander et al. (2018) reported that patients at the end of life viewed participating in research studies as worthwhile, with the positive benefits outweighing any negative risks, such as an increase in symptoms. According to Wohleber et al. (2012), denying this vulnerable population the right to participate in intervention research studies would also deny their autonomy and show a lack of respect for their humanity.

### Patient-Related Barriers and Comorbidities

Cancer progression, preexisting conditions, and end-of-life symptoms are some factors that can prevent seriously ill patients from enrolling in intervention studies. Depending on the patient's cancer stage and comorbidities, common physical symptoms at the end of life include pain, dyspnea, congestion, edema, ascites, and nausea and vomiting (Stark et al., 2012). Possible psychological symptoms at the end of life can include anxiety, depression,

confusion, diminished responsiveness, hallucinations, and delirium (Stark et al., 2012). On average, older adult patients with cancer have at least five comorbid conditions (Hamaker et al., 2018). Comorbid conditions can negatively influence patients' physical and psychological well-being at the end of life. Although the deterioration of a patient's physical and mental faculties is inevitable, the timing of this decline is unpredictable. The intensity of the patient's deteriorating condition and the level of caregiver strain and burden on family members have been cited as primary reasons for patients deciding not to participate in research studies (Kaasa et al., 2018).

### Gatekeeper Perspective

Access to patients may be limited by family members or caregivers, who can also be known as gatekeepers (Walter & Read, 2011). The patient's gatekeeper may be his or her family member or a member of the palliative care team, hospice ethics committee, or the interprofessional healthcare team. Research involving patients at the end of life was thought to be damaging, insensitive, and intrusive, and these ethical concerns have been evaluated to determine whether such clinical research exploits an already vulnerable patient population (Walter & Read, 2011). In a systematic review of 30 studies on gatekeeping in palliative care research, Kars et al. (2016) found that the fear of burdening patients is the most commonly reported