



Perceptions of dying well and distressing death by acute care nurses



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ABSTRACT

Aim: This study aims to identify perceptions of nurses practicing in four adult inpatient units regarding their actions to provide quality end of life care for dying patients, their definitions of dying well, and their symptoms of distress and actions they took for relief.

Background: Nurses caring for patients who are dying want them to have the best death possible; however, many nurses are not prepared for every death which may occur.

Methods: Qualitative questionnaire data were collected from 49 nurses on four adult inpatient nursing units to analyze nurse perceptions of distressing death and dying well.

Results: Three main concepts emerged describing the nurses' definition of dying well: emotional and spiritual support for the patient and family, patient and family control, and promotion of a peaceful environment. Eight categories of nursing actions to promote dying well were identified, which include communication with disciplinary team/nursing staff, provision of optimal physical care, demonstration of caring and compassion, supporting dignity in death for patient/family, education of patient/family to support dying well, emotional support for patient/family, advocacy for dying well, and fostering a peaceful environment. Symptoms of distress among nurses, and actions for relief were also indicated by participants.

Conclusion: Future research is indicated to expand the sample to more hospitals and more disciplines. Administrators need to enhance their policies such as event debriefing or shifting workloads to support nurses caring for dying patients. They also need to offer nurses education in providing end of life care and how to become more resilient in the face of trauma. Nurses need to be aware of their symptoms and practices to relieve their stress such as crisis debriefing. They also need to seek education on how to educate patients and families about the process of dying and the value of comfort care.

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1. Introduction

This study asked nurses working on medical, surgical, oncology (Med/Surg/Onc), intensive care and progressive care (ICU/PCU) units in an acute care hospital to describe their experiences in caring for dying patients including their actions, personal definition of dying well and any distressing symptoms they had and actions for stress relief. Suggestions were also solicited for ways the hospital could support nurses more fully.

The research questions were:

1. How do acute care nurses act to promote dying well among their patients?
2. What suggestions do acute care nurses make for actions to promote a good death?
3. How do acute care nurses define dying well?

4. What symptoms have acute care nurses experienced after distressing deaths?
5. What actions have acute care nurses taken to relieve symptoms after a distressing death?
6. What suggestions do acute care nurses have for the hospital to respond to the unit crisis of a distressing death?

1.1. Background and literature review

Although death is not usually considered a likely outcome in acute care hospitals, the majority of end of life care in America is provided in the hospital setting (National Institute on Aging, 2012). Overall, the population is aging and experiencing more multiple chronic diseases where death is inevitable. Whether sudden or expected, death places an emotional strain on nurses (Boyd, Merkh, Rutledge, & Randall, 2011; Efstathiou & Walker, 2014; Espinosa, Young, Symes, Haile, & Walsh, 2010; Festic, Wilson, Gajic, Divertie, & Rabatin, 2012; Gerritsen et al., 2013; King & Thomas, 2013).

Nurses have been found to express difficulty talking to patients about death and dying, even when a patient appears to be dying

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(Gerow et al., 2010; Udo, Danielson, & Melin-Johansson, 2013). Chronic and progressive diseases that lead to multiple hospital admissions sometimes make it difficult for caregivers to determine when to shift from curative care to discussions of comfort focused care (O'Connor, Harris, & Lee, 2011). In 1998, the Institute of Medicine (IOM) defined a good death as “one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients and families wishes; and reasonably consistent with clinical, cultural, and ethical standards” (Forero et al., 2012, p. 2). This description of a good death is supported by 12 principles that were defined by the *Debate of the Age, Health and Care Study Group* (1999) and adopted by the IOM as fundamental guidelines (Needham, 2012). Acute care often results in some obstacles that prevent all 12 principles to be followed. Examples related to the unstable patient status result in obstacles such as knowing when death is expected or choice and control over where death occurs or access to hospice care. This is in conflict with the statement by the National Consensus Project for Quality Palliative Care (NCPQPC) that palliative care should be given concurrently with disease-modifying care from the moment of diagnosis of a serious illness to the end stages (NCPQPC, 2009). Palliative care programs are growing within hospitals, but access is still highly variable across the United States (Meier, 2011).

Death may be sudden and unexpected for the patient and family and, in some cases, for the nurses and other staff. The trajectories of approaching death include unexpected death such as pre-hospital resuscitation with subsequent death or a patient is alive and interactive on arrival and then has an arrest. The issue of resuscitation is often fraught with uncertainty among the team as to continuing or ending and accepting death. Death may be impending upon arrival such as when a terminally ill or very frail or severely injured person comes to the ED and is admitted to the medical unit. A third type of trajectory is death due to preventable error of omission or commission (Chan, 2011).

Another factor which may make coping with death difficult is the nature of nursing work. Nurses are expected to be empathetic, skilled, knowledgeable, and culturally competent when communicating and caring for patients and families. Despite agreement that family members will be offered presence during invasive procedures and resuscitation, this often does not occur due to lack of family members being present or lack of staff to provide explanation and comfort during the procedures or hospital policies that do not support this practice. Patients may remain for some time on an acute care unit or be admitted multiple times leading to bonding with the nursing staff. This continuity of care promotes cultural competence in meeting patient's needs, but may also lead to cumulative grief as patients die over time (Stayt, 2009).

Providing care for a dying patient and their family often leaves the nurse feeling emotionally strained, stressed, and conflicted (Efstathiou & Walker, 2014; Espinosa et al., 2010). Nurses need to be alert for active dying and negotiating with the physician to change the path of care from cure to comfort. This is especially difficult when the family and patient have not been included in planning and are not prepared for the person to be dying (Espinosa et al., 2010; Festic et al., 2012; Gerritsen et al., 2013; King & Thomas, 2013; Pattison, Dolan, Carr, & Turnock, 2013). Communication can be challenging for nursing staff. One multi-hospital study reported only 24.4% of patients having a loved one present at death because of the uncertainty of the time of death and communication issues with loved ones (Ferrand et al., 2008). This was a factor which decreased nurse perception of the quality of death.

Symptom control may be difficult with chronic illnesses; issues of respiratory care, pain management, nausea, constipation, diarrhea, and pressure sores are common complications that can make a death appear more traumatic than need be (Festic et al., 2012). Acute care nurses describe their goal with dying patients as “a haven for safe passage” (Granda-Cameron & Houldin, 2012, p. 635). Strategies include facilitating and maintaining a change to comfort care, advocating for patients to get what is needed, spending time being there with a patient and family, being honest but not forcing acceptance, and manipulating

the care environment to provide privacy, quiet and support (Granda-Cameron & Houldin, 2012; Pavlish & Ceronsky, 2009).

Units where the culture is to continue with the work at hand, rather than to acknowledge the distress of nurses after a patient dies, are a barrier to good end of life care. Nurses on these units are more likely to act to protect themselves by not communicating with the patient about impending death (Casey et al., 2011). All of these factors have resulted in awareness of the goal of acute care nurses should be for a “good enough death” in light of the trajectories, obstacles and supports available at the time of a patient's death (Molan, 2012).

2. Research methods

2.1. Design, study setting, and sample

This study received human subject approval from the Institutional Review Board of the hospital under study. The research design selected for this study was a descriptive study with no intervention, with questions reflecting the literature review about situations where nurses felt distressed when patients died. Data for this study were obtained through qualitative written narratives, using an anonymous semi-structured questionnaire. Demographic information and a checklist of distressing symptoms and stress relief actions were culled from the literature for collection.

The setting for the study was a 128-bed urban community hospital in the southeastern region of the United States. The target population was registered nurses employed on the medical-oncology, surgical, progressive, and intensive care nursing units. All registered nurses on the target units who had worked in an acute care environment for at least 12 months were asked to participate. A convenience sample of nurses on the units was obtained. Investigators collected questionnaires until over 10 were received for the first analysis round. After the analysis, the next batch was taken for analysis and collection suspended until analysis. Saturation was achieved after the second round. No more participants were recruited.

2.2. Procedures/measures

Recruitment was a two-step process. It began in October 2013 and ended in February 2014. First, the nurse managers of the target units sent out an email informing staff nurses of the study and that they would be asked to participate. After the email was distributed, a member of the research team visited units during shift change huddles or staff meetings. During the visit, the research team member explained the study, answered any questions, and requested the participation of staff nurses, no incentives were offered. Questionnaires were distributed to the nursing staff during the meetings with explanation that completion of the questionnaire implied their consent to participate and to not put their names or other identifiers on the questionnaire. Staff nurses were also informed how to confidentially return the questionnaire in the sealed envelope provided to a confidential research box and who to contact with any additional questions.

The data collection was standardized through use of an anonymous semi-structured questionnaire to be completed and returned by medical-oncology, surgical, progressive, and ICU registered nurses. Demographics were also collected to describe the sample. The questionnaires were anonymous, but were tracked per nursing unit. Questionnaires administered to nursing staff asked to describe their actions to support dying well for patients experiencing expected, unexpected, and preventable deaths. A question regarding their actions with families experiencing conflict in accepting the death was also included. Nurses were asked for their definition of dying well and for what symptoms of personal distress they experienced after distressing deaths and actions taken for relief. Suggestions for increasing actions to promote a good death and increasing support for nurses after a distressing death were solicited.

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