

TITLE: NURSES' PERCEPTIONS OF CARING FOR DYING PATIENTS IN AN OPEN
CRITICAL CARE UNIT: A DESCRIPTIVE EXPLORATORY STUDY

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Abstract

Background: Nurses in critical care areas play a vital role in providing end-of-life care and recognise that an ideal death should be peaceful, dignified and comfortable. However, environmental restrictions in critical care units can make a peaceful death unachievable and can have a profoundly negative impact on end-of-life care.

Purpose: The purpose of this study is to describe the provision of end-of-life care in an open high dependency unit.

Method: A descriptive exploratory approach was used involving semi structured interviews with a purposive sample of 5 registered nurses working in the high dependency area at a major teaching hospital. The interviews were audio taped and transcribed. Thematic analysis was used to code the data and identify themes.

Results: Three themes emerged from the data. The core theme was *Nurse as Protector*. Two other themes were *Conflict of Care* and *Peace and Quiet*. Within these themes characteristics of an ideal death were identified and barriers to providing an ideal death were acknowledged.

Conclusion: This study illustrates nurses' perceptions of caring for dying patients in an open critical care unit. This environment influences the development of the nursing role as protector. Barriers to achieving an ideal death are also identified.

Key Words:

Critical Care

End-of-life

Barriers

Nursing roles

Introduction

Most individuals express a wish to die in peaceful and familiar surroundings, although recent evidence suggests that in the western world a majority of patients die within the hospital setting (Tan et al. 2006; Costello 2006; Porock, Pollock & Jurgens 2009). Despite medical technological advancements death remains certain for some critically ill patients (Bloomer et al. 2010). The sole purpose of critical care medicine is to save lives, however, when treatment can no longer sustain life appropriate and timely end-of-life care is required (Fridh, Forsberg & Bergbom 2007a). The role of the critical care nurse must then change from acute care to end-of-life care (Faber-Langendoen & Lanken 2000).

Providing end-of-life care is a fundamental aspect of nursing. Nurses recognise that an ideal death should be peaceful, comfortable and dignified (Hopkinson, Hallett & Luker 2003). When death occurs unexpectedly creating an appropriate environment for the patient and their family is not always achievable (Fridh, Forsberg & Bergbom 2007b). An inappropriate environment, compounded by the lack of resources, greatly affects the nurse's ability to provide good end-of-life care for the dying patient and their family (Costello 2006).

In critical care death can occur unexpectedly and creating an appropriate environment for the patient and their family is not always achievable (Fridh, Forsberg & Bergbom 2007b). Fridh, Forsberge and Bergbom (2007a) suggest that over 45% of patient deaths in the intensive care unit (ICU) take place in shared rooms with other patients present, because of a lack of available single rooms. In this environment dying patients and their families have no privacy, which is not compatible with good end-of-life care (Fridh, Forsberg & Bergbom 2007b).

Open critical care units, set up as 'Nightingale wards', are common in Australian health care facilities and a significant number of patients die in a critical care area of this type. Environmental constraints such as lack of space and privacy have a significant impact

on the delivery of end-of-life care (Costello 2006; Fridh, Forsberg & Bergbom 2007b; Porock, Pollock & Jurgens 2009). To date, limited studies have explored how nurses deliver a dignified end-of-life experience in this environment. The aim of this study is to describe and explore these experiences to gain more information about the nurses' experiences.

Methods

A qualitative, descriptive exploratory design was used for this study which encouraged the critical care nurses to describe how they have delivered care to dying patients in an open unit. The research design enabled detailed insight into influences that impact on the delivery of end of life care (Sim & Wright 2000). The high dependency unit (HDU) at a major metropolitan tertiary hospital in Perth, Western Australia, is an open eight bedded unit that cares for surgical and medical patients who are critically ill and require close haemodynamic monitoring. The HDU employs 31 Registered Nurses.

Approximately 75% of patients admitted to the HDU are booked admissions following a surgical procedure. The other 25% comprise of patients being transferred from the Emergency Department (ED), another ward within the hospital following a Medical Emergency Team (MET) call or patients admitted to HDU from another hospital. Patients admitted to the HDU are critically ill and require extensive monitoring but are not mechanically ventilated and in most cases are conscious throughout their stay in the unit. The HDU is part of the critical care division and patients are cared for by the Intensive Care Specialists. The nurse to patient ratio is one nurse to every two patients. Approximately 1,100 patients are admitted to the HDU every year and in 2011 the medical and nursing staff provided end-of-life care for 12 patients.

The inclusion criteria for the sample were: Registered Nurses working in HDU for more than 12 months who had cared for a dying patient in HDU. Twenty five Registered Nurses met the inclusion criteria. Nurses were excluded if they were holding a graduate or

rotational position. The research project was conducted as part of a Masters Degree, due to time constraints a purposive sample of five Registered Nurses were recruited. This allowed the investigators to select participants who will openly share information and provide the most detailed data (Kumar 2005). Participants were chosen for their varied length and breadth of nursing experience. Potential participants were approached by the investigator, given an information sheet and were required to sign a declaration of informed consent.

Semi structured, one to one interviews were used to obtain data as it allows for unanticipated responses thereby enhancing the richness of the data (Ryan, Coughlan & Cronin 2009; Speziale & Carpenter 2003). An interview guide of seven open ended questions was developed to ensure key issues were identified. The questions were provided to the participants prior to the interview so they had time to process and prepare their responses.

Interviews were held at a time and place suggested by each participant and lasted between 21 and 54 minutes. Interviews were recorded and transcribed verbatim. All identifying information was removed from the transcripts.

Ethical Considerations

Ethical approval was obtained from the Curtin University Human Research Ethics Committee (SON&M 5-2011) and from the participating hospital ethics committee (EC 2011/042). Protection of the participant's anonymity and confidentiality was upheld during the research process (Polgar & Thomas 2008). This was a low risk study, with confidentiality being the main issue because of the small sample size. Due to the small sample size and limited setting demographic data has been reported as group data, for example median age and length of time spent as a nurse in HDU, to reduce the risk of incidental identification occurring. Study documents and data were stored in a password protected electronic data base. Audio-recordings of the interview were destroyed at the conclusion of analysis.

Data Analysis

Thematic analysis was used to elicit themes that reflect a detailed account of the participant's firsthand experience in caring for dying patients in an open critical care environment (Braun & Clarke 2006). NVivo 9 was used to manage data (QRS International 2010). Initial lists of ideas were documented while reading the transcripts. Then lists were organised into codes. Codes were then collated and collapsed to form categories. Themes were identified from the categories.

Rigour

To address credibility the participants were invited to verify the final themes and comment on the findings. Consistency in the interview process was maintained by the same interviewer conducting all interviews and participants were asked the same questions, which helps establish similarity of the data (McClement & Degner 1995). Credibility was achieved by two researchers carrying out independent coding of the data. Confirmability was addressed by having two investigators independently analyse the data and verify themes and an 'audit trail' of decisions was kept. A range of participants with varying nursing background and experience aided in ensuring in the transferability of the findings.

Results

Five participants were interviewed for this study, all of whom were female registered nurses. The median age of participants was 36 years. The median number of years of work experience was 10 years and the median number of years of work experience in the HDU was 8.5 years. There is a 20 year age range between the youngest and eldest participant.

The core theme that emerged from the study was *The Nurse as Protector*. Two other themes, *Conflict of Care* and *Peace and Quiet* were related to this theme.

Nurse as Protector

Participants reported their nursing role was to provide comfort and care, and to nurture and protect patients and their families as well as work colleagues in the HDU. They

felt very strongly that it was their duty to protect the patients from unnecessary suffering. Adequate pain relief and symptom management was seen as essential. One participant described symptom management as beneficial for both the patient and the family:

Recognising that your patient is dying and taking steps to make it a comfortable end. If you take off the CPAP and if they need a milligram of morphine. That is not going to kill them but it might make it easier for the family to listen to their work of breathing. [P5]

Protecting the patient's dignity by making sure they are well cared for was considered imperative. The participants viewed physical care as an important aspect in maintaining dignity and a reassurance that the patient was comfortable and well cared for. This included basic nursing duties such as pressure care, eye care and mouth care. A participant described this:

We still have to provide care...wash the patient regularly, you know make them warm and make the family feel that they are comfortable and they are looked after. [P3]

The practice of a patient not dying alone was considered to be central to delivering a dignified death. If family were not present the participants felt it was their responsibility to sit with a dying patient and offer emotional comfort. Not allowing a patient to die alone was a way of protecting the patient from feeling scared, frightened or alone. One participant expressed her feelings about this:

I personally feel uncomfortable that there is no one sitting with that person.....and I think it is a terrible way to die, by yourself with no one with you. [P2]

Protecting dignity after the patient had died was considered as important as when they were alive. The participants saw caring for the dead body as an important nursing duty and by demonstrating respect for the dead patient the participants felt they were protecting the patient's dignity. A participant commented on care of the deceased:

I think it's a privilege to be able to look after a dead body.
To do it properly. It's part of being a good nurse, that end
bit...And if you have the idea that you do it with as much
respect for the person that you would give them when they
were alive. And you will do it well and that's what they
deserve. [P5]

Providing care for the family was an important part of caring for a dying patient. The participants ensured that the families were comfortable, well supported did not feel alone. A participant commented on family care:

I think just basically just being there for the family as well.
Making sure that they are okay even if they say you know
they are fine just keep checking to make sure if they want
anything. I think even just a cup of tea can go a long way
with any family. [P4]

The participants all mentioned the importance of patients dying with dignity, and protecting the patient's privacy was one way to maintain dignity. This was usually achieved by closing the curtains between beds to provide some privacy. However, the attempt to protect the dying patient's privacy led to other patients in the HDU becoming aware of the impending death. The participants expressed a desire to protect the other patients from facing their own mortality. This was described by one participant:

This poor lady she was just groaning and groaning and

curtains aren't going to shield that. And you've got another patient across from them who is really sick and they're just thinking "is that going to be me, is that?" Because they know what is going on...And so I just think, it's not pleasant at all. [P4]

The camaraderie between the staff and a team focused work environment created a feeling of safety and security that buffered the distress related to caring for a dying patient. The participants felt supported by their colleagues and they identified and sympathised with them when a patient died. The staff protected each other by looking out for their well-being. This helped the participants cope with the situation, as described by a participant:

It makes it easier, the close team of nurses to debrief. You know that you can chat to someone about it and they understand. [P1]

Conflict of Care

Conflict of care was a great source of frustration for the participants. They experienced moral and ethical dilemmas associated with aggressive medical management, particularly when they knew it would not change the patient's outcome. The participants struggled with medical decisions that appeared to exacerbate the patient's suffering and experienced distress if they felt patients were exposed to unnecessary suffering. Participants saw it as their duty to relieve suffering. One participant described this:

HDU is no place for anybody to die. The nurses know that the people are dying, why do the doctors persist in it? I mean we've advocated for things to be switched off and CPAP to be removed and monitors to be switched off and the doctors are like let's just...watch it happen, let's see if

we can prolong it another two hours or whatever. Let's keep that mask slapped on their face. [P5]

Participants viewed the role of patient advocate as an integral part of their nursing role. When the role of patient advocate was not fulfilled participants felt powerless to influence decisions regarding patient care. The participants felt they were not accorded professional respect when attempting to fulfill the patient advocate role. One participant explained:

I think sometimes as well the doctors keep pushing they are trying to be god and they push just another day, another day of aggressive management. And you can see that it's not going to happen but obviously as nurses they don't listen to us. Even though you are the patient advocate they just keep trying and trying and you can see the patient is struggling. [P1]

Conflict between medical staff and the nurses was described by all participants. Often the two groups did not agree on treatment options, creating conflict. The participants struggled with this because morally they did not agree with the treatment they were being asked to deliver. One participant described her experience:

We don't want them to suffer anymore and it's happened a few times. The doctor called us "the angel of death"...that was so insulting because we're trying to make this guy just die in a peaceful way with his family around him, instead of pumping him full of medications [P4]

The lack of recognition of when current treatment options are no longer enhancing life and a palliative approach is needed to replace it was of great concern for the participants.

Participants were conflicted when providing curative care to one patient and end-of-life care to another because it required them to deliver two different kinds of care with different outcomes. Participants felt uneasy as they felt that the palliative care was neglected because the focus of the HDU was to save lives. A participant explained:

Yeah and then you kind are of torn, it's like - do I make jokes? Do I carry on with my normal caring with the other patients? Or do I try to keep it down to have that respect? It's just really hard...sometimes it's hard because we have to divide between other patients...we have to save other patients and treat them [P3]

Peace and Quiet

All five participants had similar perceptions of delivering quality end-of-life care for patients and the families. The delivery of care encompassed providing emotional and physical peace. Emotional peace was achieved by meeting the end-of-life wishes and spiritual needs of the patient and their family. Spiritual care involved the patient's spirituality, their religious and personal beliefs and cultural needs. Participants believed that respecting patients' spiritual wishes was part of preserving dignity. One participant discussed spiritual care:

She had long term cancer and we couldn't do anything and she died. The family really wanted us, as she was an Aboriginal patient, to leave everything in and provide them with the time for her spirit to leave her body...we tried as much as we could to just kind of provide the peacefulness and for the family to stay. [P3]

The participants acknowledged that end-of-life wishes are greatly influenced by the patient's beliefs and personal ideals. They felt that by facilitating the patient's end-of-life wishes they were delivering excellent end-of-life care and sense of achievement if wishes were met. A participant discussed meeting her patient's end-of-life wishes:

He wanted a beer so I just went down to the local bottle shop and got him a couple of Crownies and dipped mouth swabs into him. And the family was so grateful for that and he was sitting there sucking on the mouth swabs with the beer dipped in it. And the joy it...was like a joy for him. [P1]

Physical peace referred to the ward environment and organisational barriers that impacted on providing the physical peace. The HDU environment was identified as a significant barrier to achieving a peaceful, quiet death. The small size of the unit and lack of space directly impacted on the ability to provide privacy. The inability to provide privacy was not conducive to delivering a dignified death. This was recognised by one participant:

There is no space between the beds and there is no privacy for grief...it's just the whole environment here is so bad because of all the equipment and everybody's monitors and pumps beeping at you. I don't think it's possible to give anybody a dignified death. [P5]

The participants acknowledged that the unit was not designed for the dying. Single rooms were seen as the ideal environment for a dying patient because they provided space, privacy and quiet, all of which were considered essential elements for a dignified death. A Participant stated:

If you could identify who is going to be palliated and move them to the ward to a single room where it's quiet, it's peaceful, it's private so the family can come and go as they please. [P4]

Demands on beds, staff work load, staff shortages and hospital policy and procedures significantly impacted on the quality of end-of-life care. Participants felt a sense of urgency to move the body to the morgue, thereby rushing the final stages of end-of-life care. One Participant explained how these work demands directly impacted on patient and family care:

I had no time to talk to them, to explain what's happening and why it is happening...I felt awful and they were crying and I couldn't even support them or explain anything...I had no time to give them any support [P3]

Discussion

The three themes that emerged from this study reflected the nurses' perceptions of caring for dying patients in an open critical care unit. Within these themes characteristics of what the nurses considered an ideal death should be have been identified, including to relieve unnecessary suffering, not letting a patient die alone, awareness of end-of-life and spiritual wishes, maintaining dignity and providing peace and quiet. These characteristics are well documented in current literature (Hopkinson, Hallett & Luker 2003; Porock, Pollock & Jurgens 2009; Bratcher 2010).

Protection of patient privacy is central in maintaining patient dignity but can be challenging in an open critical care environment (Espinosa, Young & Walsh 2008). The participants in this study took the only practical measure available to protect the privacy of the dying patient and their family: closing the curtains. Authors suggest that attempting to hide death with the use of curtains reflects discomfort about the event (Costello 2006; Fridh,

Forsberg & Bergbom 2007a). However, in this study the participants did not appear to experience discomfort about death, rather the use of curtains was a means of protecting the privacy of the dying patient and their grieving family well as protecting other patients from experiencing distress as they are confronted by their own mortality.

A team focused work environment and the strong sense of camaraderie between the nurses helped nurses to cope and to maintain emotional stability while caring for a dying patient in the HDU. Participants felt they could protect each other from emotional stress and could rely on each other for support and debriefing. While formal support opportunities such as counselling are considered desirable the participants preferred to seek informal support, such as debriefing with each other (Aranda & O'Connor 1999). Informal debriefing with colleagues has been reported as an effective coping strategy amongst nurses. In an informal setting nurses share their grief and find the supportive relationship with other nurses strengthens camaraderie (Hopkinson, Hallett & Luker 2003; Shorter & Stayt 2009). Offering educational programs on strategies to improve and deliver effective support to work colleagues and family would increase nurses' confidence in offering the support. Time allocated to debriefing may also be helpful when a death has occurred.

The theme *Conflict of Care* exposed the strain between the nurses and medical staff. The participants struggled with the moral and ethical issues of providing aggressive medical interventions to prolong life when it appeared futile. Treatment options that prolong death have been reported to cause great distress to the nurses and have created tension between professional groups (Oberle & Hughes 2001; Nordgren & Olsson 2004; Beckstrand, Callister & Kirchhoff 2006). A clear understanding of patient prognosis and what life saving measures entail help the patient and family members make an informed decision on treatment options, including end-of-life care (Beckstrand & Kirchhoff 2005; Bratcher 2010). Open channels of communication between the professional groups will improve patient care with team

members working towards the achieving the same goals. For improved communication to occur a change in critical care culture must be attained. The realization that curative care and end-of-life care can co-exist in the critical care environment will lead to the improved communication between all professional groups. More inclusion of palliative care teams in HDU settings should also be encouraged as a way of both promoting communication about end-of-life issues and to support HDU staff in the provision of care.

Peace and quiet was seen as the ideal environment for dying patients. The participants acknowledged that the HDU was not an ideal environment for dying patients and their families because it was considered noisy, with limited space and little privacy. These environmental factors have been reported as challenges for critical care nurses to overcome so a dignified death can be realised. The critical care environment is notorious for limited space, lack of privacy and large amounts of noise produced by the highly technical equipment (Nordgren & Olsson 2004; Espinosa, Young & Walsh 2008; McKeown et al. 2010). These factors impact on the ability to provide a quiet and peaceful environment.

Conflict between the professional groups, environment and organisational constraints were all identified as barriers that affected the nurses' ability to provide an ideal death. This study highlights nurse's perception of an ideal death. Further research is needed to identify what families' consider essential for an ideal death and barriers that may prevent this from occurring. The family's perceptions may differ greatly from the nurse's and an understanding of the family's perceptions can only enhance end-of-life care.

Most end-of-life studies in the critical care environment are conducted in intensive care setting. This study highlight the uniqueness of small open critical care units such as HDUs and how the environmental barriers impact on how the nurses' deliver end-of-life care. This study was conducted in a single care setting with a small sample size. While the findings are relevant to this HDU they cannot be generalised to other critical care settings. A larger

study with a multi centred approach would be useful to determine if these issues are common to other critical care areas.

Conclusion

Nurses are the largest group of healthcare providers, which places them in a unique position to encourage and deliver quality end-of-life care. This study illustrates nurses' perceptions of caring for dying patients in an open critical care unit. The unique environment of the HDU has influenced the development of the nursing role as protector to ensure a good death can be achieved. Providing a peaceful, quiet and private environment is pivotal in maintaining the dignity of a dying patient and for an ideal death to be realised. Nurses in HDU strive to provide excellent end-of-life care despite professional, organisational and environmental barriers. For nurses to maintain quality care improved communication between professional groups, support and education on end-of-life care needs to be delivered.

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