

THE EXPERIENCES OF CRITICAL CARE NURSES WITH REGARD TO END-OF-LIFE ISSUES IN THE INTENSIVE CARE UNIT

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ABSTRACT

Nurses in the intensive care unit may be faced with emotional conflict, stress and anxiety when dealing with end-of-life issues and thus need to be supported. In understanding the experiences of nurses, enhanced support can be given in order to assist nurses to deal better with end-of-life issues in the intensive care unit. The purpose of the study was to explore and describe the experiences of nurses with regard to end-of-life issues in the intensive care unit. A qualitative, explorative, descriptive and contextual research design using a semi-structured interview approach was used. The target population for the study comprised 20 registered nurses in the intensive care unit. Of the 20, only 9 were willing to participate in the study. A purposive sampling method was used to interview nine nurses in a private intensive care unit. Data collected were thematically analysed, using Tesch's method. Four major themes were identified, namely: (1) conflicting emotions, (2) family relations, (3) multidisciplinary team relations, and (4) supportive strategies when dealing with end-of-life issues. The study concluded that nurses experienced different emotions, conflict and stress when dealing with end-of-life issues in the intensive care unit. A need for supportive relations with family members, the multidisciplinary team and support from management were reported. Immediate debriefing, enhancing communication amongst multidisciplinary team members, having a permanent counsellor or pastoral counselling, an ethics committee and training programmes in place to address end-of-life issues are a few of the support strategies that can assist critical care nurses in dealing with end-of-life issues in the intensive care unit.

Keywords: critical care nurses, end-of-life issues, intensive care unit, withdrawal of treatment

INTRODUCTION

End-of-life issues involve decisions related to the dying process or death of a patient. Palliative care measures, decisions on withdrawing treatment, medical interventions, end-of-life decision-making and dealing with the families of patients in the end stages of life are some of the end-of-life issues that health-care professionals might have to face (Morton & Fontaine, 2013:65; Thelen, 2005:28, Langley & Schmollgruber, 2006:60).

The demands of the intensive care unit, conflicting prescriptions, ethical conundrums and end-of-life decision-making can lead to emotional stress, anxiety and inner conflict amongst nurses that care for these patients (Fumis & Deheinzelin, 2010: R235). Critical care nurses might experience different emotions, feelings and thoughts as they are faced with end-of-life issues in the intensive care unit. It is thus important to explore the experiences of critical care nurses in order to understand and support them when dealing with end-of-life issues.

BACKGROUND

Despite the advancing technology and specialised workforce, many patients die in intensive care units and end-of-life care is common practice. According to estimates, approximately 20 percent of deaths in the United States occur in intensive care units and the majority of deaths occur after the withdrawal of life-sustaining treatment. As advocates of patients and key members of the health-care team, critical care nurses are uniquely positioned to assist patients and their families with facing end-of-life concerns and issues (McGowan, 2011:65; Hampson & Emaneul, 2005:973; Langley & Schmollgruber, 2006:60).

To care for patients who are approaching death or who require palliative care in intensive care units requires a physical, moral and psychological intensity surpassing most other clinical procedures. The physical, psychosocial and spiritual needs of patients and their family members need to be addressed and this requires extraordinary expertise in communication and providing information, comfort, care and pharmacological management. Critical care nurses are the front-line caregivers and spend the most time at the bedside of critically ill patients and those who are faced with end-of-life issues. In delivering end-of-life care, nurses are exposed to emotional stress and physical burnout (Langley & Schmollgruber, 2006:63). Although attempts have been made to raise awareness and improve end-of-life care by developing consensus statements, the extent of end-of-life issues in nursing practice is unclear (Carlet et al, 2003:771). Despite past experience, physicians and nurses still feel unprepared to facilitate end-of-life issues.

Nurses are part of a multidisciplinary team, where ambiguity regarding role clarification, the need for continuous dialogue, disagreement as result of different views amongst

team members, avoidance of family or giving false hope can cause inner conflict, stress and anxiety amongst nurses caring for patients in critical care units (Hansen, Goodell, DeHaven & Smith, 2009:264; Kuschner et al, 2009:28).

End-of-life issues involve the family and the critical care nurse as part of the multidisciplinary team. Critical care nurses often assist the family to accept the end-of-life decision and help them to redirect their hope from cure to a comfortable death (Thelen, 2005:29). Family members often experience high levels of stress because of the severity of their loved ones' illness and the uncertainty associated with the outcome. The intensive care environment, medical technology and the lack of understanding about disease and medical treatment often lead to increased anxiety and stress experienced by nurses, patients and their family members. Critical care nurses therefore need to establish trusting relationships, maintain open communication and serve as the patients' advocate when dealing with end-of-life issues (Scherer et al, 2006:31).

STATEMENT OF RESEARCH PROBLEM

The intensive care unit is a dynamic environment wherein nurses deal with a variety of patient situations, including withdrawal of treatment and death. Nurses caring for patients in a critical condition and their families are frequently faced with end-of-life issues, which can be stressful. Implementing care for these patients might cause moral distress for nurses, particularly when disagreements amongst health-care professionals and inner conflict arise. End-of-life care is further compounded by a lack of effective communication amongst members of the health-care team and the family of the patient (Kuschner et al, 2009:27).

Langley et al (2013:10) state that traditionally, critical care nurses lack knowledge and skills related to end-of-life issues and receive minimal training in dealing with dying patients and their families. Very few intensive care units have systems in place to guide and support nurses who are involved in end-of-life care. Education, work environment, communication, palliative care services and support for health-care practitioners, patients and their families have been identified as important in dealing efficiently with end-of-life issues. However, in order to develop these support structures, it is essential to explore the experiences of critical care nurses with regard to end-of-life issues in an intensive care unit.

PURPOSE OF STUDY

The purpose of the study was to explore and describe critical care nurses' experiences with regard to end-of-life issues in an intensive care unit.

DEFINITION OF CONCEPTS

A critical care nurse refers to a professional nurse who is practising in an intensive care unit. It is a person who is qualified and competent to practice comprehensive nursing independently in the manner and to the level prescribed and who is capable of assuming responsibility and accountability for such practice (Nursing Act no 33 of 2005).

End-of life issues refer to any issue surrounding the dying process or death of a patient. These may include palliative care measures, decisions on withdrawal treatment, medical interventions, mechanically supporting and prolonging the dying process (Morton & Fontaine, 2013:65).

An intensive care unit is a hospital ward where patients with life-threatening illness or injury are treated and require intense monitoring and individualised care (Urden, Stacy & Lough, 2014:9).

Withdrawal of treatment refers to actions taken at the end stages of life when it is clear that current or additional treatment will no longer be of benefit to the patient, but will prolong suffering (Morton & Fontaine, 2013:77).

RESEARCH METHODOLOGY

The section discusses the research design and method as applied in the study.

Research design

A qualitative, explorative, descriptive and contextual research paradigm was used to collect data from critical care nurses to gain a deeper understanding of their experiences with regard to end-of-life issues in the intensive care unit.

Research site

The research study was undertaken in the intensive care unit of a private health-care institution in the Eastern Cape, South Africa. The intensive care unit was a multidisciplinary 16-bed unit, comprising surgical, trauma and medical patients. Approximately 500 patients were admitted annually, with the majority of patients who underwent surgery being mechanically ventilated. The death rate in the intensive care unit ranged from 80–90 patients per year, of which the causes of death were not all known.

Study population

The study population comprised 20 registered nurses who were permanently employed in the private intensive care unit.

Sampling method

Purposive sampling was used to collect data from the participants. Of the 20 permanent registered nurses working in the private intensive care unit, only 10 indicated that they had previously experienced dealing with end-of life issues. The remainder of the staff were either not willing to partake in the study or had not yet experienced working with a patient from whom treatment was being withdrawn. Of the ten nurses who responded initially, one withdrew from the study due to personal reasons. The sample size thus consisted of nine critical care nurses who had experienced end-of-life issues in caring for patients in the intensive care unit, and were willing to participate in the study.

INSTRUMENT

An interview guide was developed for the study; see table 1. The expertise of three researchers (one primary investigator and two research supervisors), which included intensive care and research experience, assisted in the development of the interview questions. The suitability of the interview guide was established by means of a pilot study, which proved that the questions were comprehensive and elicited the response required from the participants.

Table 1: Interview questions

1. How long have you been working in the ICU?
2. In caring for the patients in the ICU, were you ever involve in end-of life issues?
3. Tell me about your experiences related to end-of life issues in the ICU.
4. Tell me about the support you received during your experiences with end-of life issues in the ICU.
5. What recommendations would you suggest to assist registered nurses to deal with end-of life issues more effectively?

ETHICAL CONSIDERATIONS

Ethical approval to conduct the research study was granted by the Nelson Mandela Metropolitan University Research Ethics Committee; reference number H11-HEA-NUR-006. Furthermore, ethical approval was granted by the research ethics committee, as well as hospital and unit managers of the health-care institution where the study was conducted. Each participant who was willing to participate in the study had to complete an informed consent form granting voluntary participation to the study. Ethical principles of confidentiality, privacy and anonymity were maintained throughout the study.

DATA COLLECTION METHOD

Critical care nurses who were willing to participate in the study were invited to attend a session. The purpose of the research, data collection method and ethical principles were discussed. After written informed consent was obtained from the participants, a semi-structured interview with each of the participants was undertaken by one of the researchers (the primary investigator). A convenient time and place for the interviews were established with each participant. Data was collected (from July to September 2013) until data saturation occurred. Data saturation occurred when sufficient data was collected and no new themes emerged from the research interviews. Interview data were subsequently transcribed verbatim after which the interviews were checked for accuracy by the three researchers involved in the study. Field notes were made during each interview and were captured by the primary investigator (IC) to document the various responses from the participants. The researcher recorded certain facial expressions, emotions and non-verbal cues in order to supplement and add a deeper understanding to the participants' responses.

DATA ANALYSIS

Data were analysed according to Tesch's method (Creswell, 2013). Once all the interviews were transcribed, the transcriptions were read and short notes were made. Each document was read in order to make meaning of its content and all the identified topics or units of meaning were then listed. Similar topics were then clustered together and formed into columns that were arranged as major and unique topics. The topics were abbreviated as codes, which were written next to the appropriate sections of the text. The most descriptive wording for the topics was identified and the topics were formulated into categories. The data belonging to each category were gathered and a preliminary analysis was performed. Thematic analysis was conducted once the process had been completed with all the transcribed interviews. An independent coder assisted with reaching consensus on the thematic analysis of data. A literature control was conducted to validate the identified themes.

RIGOUR

Data integrity and trustworthiness was ensured through the interviewer keeping an audit trail, member checking, reviewing transcribed data for accuracy and using an independent coder. Transferability was ensured by giving a dense description of the participants, the research methodology, data collection and data analysis process. Furthermore, transcriptions of the one-on-one interview were provided. Excerpts, in the form of participant quotes were also included in the results section of the reported data. Credibility of the data was ensured by including copies of the transcribed interviews in the research report.

RESULTS

Interviews were conducted with nine registered nurses in an intensive care unit. Data were saturated after the nine semi-structured interviews were conducted and therefore no additional interviews were conducted. All the participants were female, four of which held additional qualifications in critical care nursing and five had experience in critical care nursing. All the participants were permanently employed in the intensive care unit. On average the participants had 12 years of practice in an intensive care unit. The findings were presented in four major themes, namely: (1) conflicting emotions in the caring for patients with end-of-life issues, (2) family relations, (3) multidisciplinary team collaborative relations, and (4) supportive strategies (table 2).

Table 2: Main themes derived from the data analysis

Theme	Description
Conflicting emotions in the caring for patients	Nurses experience conflicting emotions and inability to function as a patient advocate when faced with withdrawal of life-sustaining treatment.
Family relations	A supportive relationship with family members was formed when caring for end-of-life patients and the need for support and family involvement was evident.
Multidisciplinary team collaborative relations	A need for more effective team collaboration was expressed.
Supportive strategies	Supportive strategies, for instance debriefing, use of a counsellor, education, were recognised.

Conflicting emotions in the caring for patients with end-of-life issues

All nine registered nurses were involved in caring for critically ill patients who presented with end-of-life issues. Three of the participants, who had been involved in withdrawal of life-sustaining treatment, stated that they felt as though they were killing the patient by performing the instructions given by the doctors to withdraw treatment. One participant described this experience as follows:

I just personally feel that it should not really be my job to turn the ventilator down. Um, I really, I'll be honest I don't like doing it. I avoid it at all costs, whether it's my patient or not. I kind of get somebody else to do it, because I have done it once and I just felt like I killed the patient, type of thing.

Five of the participants reported that being involved in withdrawal of life-sustaining treatment, as part of the end-of-life issues, caused conflicting emotions. One participant

verbalised the following: ‘And it was so difficult for me to enforce what had been prescribed; that it just went against all, every grain in me ... it was just against everything I stand for. I mean we say first do no harm’.

Participants expressed feelings of helplessness when unable to do more for their patients. Futile or unnecessary care was also reported by the participants as having an influence on the helplessness experienced when dealing with end-of-life issues. The following quote illustrates these feelings:

I think the one is this futile at times, this ... I won't say (angry) ... I would say, why are we doing all this ... I don't know, helplessness maybe is the one, is a feeling, because you know you really, you look at some of the patients, especially with multiple organ failure, I mean, you do, even this patient we had the other day with the ECMO [Extra-corporeal membrane oxygenation], you know in your heart this is futile, um, and you look at it and you think you know we have to go on for medical reasons.

The majority of the participants expressed mixed emotions of sadness, grief and anger when caring for patients who presented with end-of-life issues. One participant explained it as follows: ‘Guilt, anger... helplessness, because... you want to fix it, but you can't. That's kind of sadness obviously...extreme sadness... (participant is silent for a while)’.

Furthermore, contributing to the conflicting emotions, participants in the study expressed feelings of frustration at not being able to effectively advocate on behalf of their patients. Participants related that being the patient's advocate was an important aspect of end-of-life issues. However, advocacy was affected by the conflict experienced by the nurses with regard to their role as an individual practitioner versus their position in a hierarchical system: ‘We are not there to even be the advocate of our patient anymore. We are there to follow doctors' orders. In some instances we can't even use our own initiative.’

The need for patient advocacy was expressed by another participant as follows:

And also I always think what if this patient was awake and knowing that he's suffering like this, what would he have said to us. Would he have said carry on and let me suffer? So I always think maybe the patient doesn't want to suffer anymore. It's the way that the patient should go ... We don't have a say in the management of the patient. I wish we could have a say ... to say to the doctors, doctor please don't do anything in this case.

Family relations

The participants highlighted the importance of developing good relationships with the family of the patient. Experiences of grief appeared more profound in situations when the nurse had developed a close relationship with the patient and the family. Some nurses reported that it was difficult for them not to develop a relationship with the patient or the family, as this was simply part of being human. One participant highlighted the importance of family relations as follows:

Because I feel family support in ICU is sometimes much more important than the patient support. The patient we can support mechanically and give them all the drugs, but we cannot heal the family. The patient we can let go in peace and we can let him meet his maker or whatever his belief is, but the family is the one that got to be able to cope. So I'm more for loving and hugging the family and make sure they are okay and comfy.

Participants stated that the family of the patient should be more involved in the care decisions for that patient. Involving the family in care decisions was found to be of value because this gave the family a better understanding of why treatment was withdrawn. The need for family involvement was described by one participant as follows:

Um, so, but I really think one should have ... sit down with the family and um, doctors and nurses, and explain to them, you know this is what's going on ... we just going to or we can't do anything further.

Multidisciplinary team collaborative relations

The research findings indicated that the participants experienced the need for multidisciplinary team collaborative relationships, for doctors to be more approachable regarding end-of-life issues, for hospital management to be more supportive and for support from other nursing colleagues. Five of the participants expressed that they did not feel part of the team in caring for these patients.

I feel comfortable discussing this with family, yes, but honestly, no, I don't feel comfortable discussing this with the doctors.... I find that your feelings ... or you are not really kind of taken into consideration as the nurse, you know.

Participants related the need for hospital management to be more supportive towards them when caring for patients with end-of-life issues. The lack of support is highlighted by the following quote: 'I feel the need that maybe management should be supportive also.... So really from my side it is enough, but for a junior person I think they need more support'.

Despite the lack of support from management, registered nurses found that they supported each other, which aided in their coping. They expressed that these support systems in the intensive care unit were very beneficial and helped them as illustrated by the following quote:

So it's nice in this ICU, because we support each other a lot. If you've got a problem you never sit alone with a dying patient. There will be times that someone will pat your shoulder, ask how you are, or ask if they can bring you a cup of coffee or do something for you.

Supportive strategies

The research findings indicated that nurses experienced the need for supportive strategies within the intensive care unit in order to assist them in dealing with end-of-life issues. Immediate debriefing was identified by the participants as an important support strategy that might assist nurses in dealing with end-of-life issues in the intensive care unit: 'I think debriefing does help, but it needs to be done in a certain time frame, or else it's kind of pointless'.

Participants generally agreed that having a permanent counsellor available to the staff would assist the nurses in dealing with end-of-life issues. Some participants felt that a counsellor would be of benefit to the patient and the family as well, assisting them to come to terms with the impending death of the patient. Some participants reported that having a pastoral counsellor would be beneficial as indicated by the following quote:

Get a clinical psychologist or a minister or somebody to help us with how to get our people through things like ... and help each other... Not all the time ... be there so we can go and talk or we can even get him to talk to the family ... that is prepared to work with staff and with family, sort of on a ... he must be permanently available, even if it's one or two days a week.

Participants acknowledged the importance of education and accompaniment for staff during the orientation period upon starting nursing in the intensive care unit. Some participants verbalised that they had received minimal education in dealing with the end-of-life issues and/or death of a patient. One participant stated that she would have liked to be taught skills in how to deal with the patient and the family during this difficult time.

But I think they should teach nurses and people who come into ICU, when they do those orientations, they should go on a course of how ... to handle death and dying. Sit down and talk to these people and teach them the skills, because you need skills ... to handle it ... you really, really do.

DISCUSSION OF RESEARCH RESULTS

The findings of this qualitative study based on the experiences of nine registered nurses in the intensive care unit in a private health-care institution provided insight into the experiences related to end-of-life issues. The participants experienced conflicting emotions in caring for patients who presented with end-of-life issues. These emotions varied from helplessness, inner conflict, and feelings of guilt, sadness and anger. The results of this study are supported by Calvin, Lindy & Clingon (2009:216) who state that grief is often experienced by nurses when patients suffer or die and when the grief is suppressed, it can lead to stress and anxiety. Espinosa et al (2010:275) concur in stating that nurses experience mixed emotions and inner conflict when they participate in end-of-life decisions and care of patients. Nurses in this study felt that they were ineffective at being patient advocates and communicating the needs of patients when needed most. Enactment of the advocacy role may take the form of speaking to the family or the medical team on behalf of the patient (Adams, Bailey, Anderson, & Docherty, 2011:4; Hebert, Moore & Rooney, 2011:326). Nurses also experienced moral distress when they felt that they could not advocate effectively for their patients. Therefore, nurses need to recognise their responsibility to serve as patient advocates (Calvin et al, 2009:218).

Participants in this study viewed the family as an important component in the rendering of care to patients who present with end-of-life issues. They felt that developing meaningful, supportive relationships with the family would assist in dealing with the end-of-life experience. Furthermore, it was highlighted by the participants that communication between the family and health-care providers was essential and should be encouraged. Adams et al, (2011:13) indicate that nurses play an important role as information givers and facilitate communication between family members, the patient and the medical team. Festic et al (2010:151) support this, stating that time at the patient's bedside and regular communication with family members facilitates family-patient and team relations and should be supported and encouraged in order to optimise the end-of-life experience. Uncertainty and ambiguity surrounding the prognosis of the patients and decisions regarding end-of-life issues may result in distress and anxiety, not only for the patient's family, but also for the health-care professionals. Communication or the lack thereof between team members and family members can be the largest cause of internal conflict for nurses (Ranse, Yates & Coyer, 2010:4; Festic et al, 2010:155). Therefore, it is essential that good communication be maintained between members of the team, family and patient.

In this study the participants experienced the need for doctors to be approachable regarding end-of-life issues. The majority of the participants felt that they were not part of a team working towards a common goal, which caused anxiety and influenced the care rendered to the patients. In other studies (Calvin et al, 2009; Festic et al, 2010) it was identified that differing opinions amongst the multidisciplinary team could be an

obstacle to optimal end-of-life care. Conflicting information can be transferred to the family of the dying patient, which might add to the stress experienced by the nurse, who is the primary caregiver. Palliative care teams (interdisciplinary teams devoted to supporting patients and their families through life-threatening illnesses or injuries) is one strategy to improve the collaboration and coordination of end-of-life issues and care to be rendered (Campbell & Guzman,2003:267).

Participants in this study viewed the hospital management as being unsupportive towards them and unapproachable with regard to end-of-life issues. The lack of support made them feel unable to cope with the end-of-life issues and rendering patient care. The study findings were supported by Ranse et al (2010:11) where the participants in their study felt that organisational support, in the form of guidance and encouragement, was needed in dealing with end-of-life issues. Hospital management need to be aware of the stress and anxiety that nurses face when dealing with end-of-life issues and put the necessary action plans in place to support nurses.

Participants in this study expressed a need for support strategies in order to assist them with dealing with end-of-life issues. These support strategies included debriefing, the presence of a counsellor or pastoral counselling and education to be rendered to nurses. Debriefing assists nurses to acknowledge their thoughts and feelings in order to deal with the emotions experienced when dealing with end-of-life issues. Debriefing allows nurses to gain knowledge from other nurses' experiences and expertise in order to help them cope with end-of-life issues (Ranse et al (2010:9).The participants' need for pastoral care was strengthened by Coffey, Everett, Miller & Brown (2011:130) who state that pastoral care is important in allowing patients, families and nurses to communicate their thoughts and needs while experiencing end-of-life issues. Pastoral care can aid in alleviating feelings of being overwhelmed, stress or anxiety when nurses are faced with end-of-life issues. Furthermore, the need for a formal senior nurse support structure should be put into place to assist nurses, especially junior nurses, to cope with end-of-life issues.

RECOMMENDATIONS

Recommendations for nursing education would be to include end-of-life issues in the curriculum content, short learning programmes and in-service educations programmes. Recommendations for nursing practice are: debriefing sessions for nurses after caring for patients with end-of-life issues, multidisciplinary team discussions and care meetings, reflection and debriefing sessions with the management team and other team members who are involved in the caring of these patients, family discussion meetings, and the effective use of ethics committees that can assist with end-of-life issues in the health-care institutions. Regarding future research, it is recommended that the study be duplicated in other private and public intensive care units in order to compare findings; to extend

the study to other members of the multidisciplinary team members, for instance the physicians; and to do an intervention study after implementing support strategies to assist registered nurses with end-of-life issues.

LIMITATIONS OF STUDY

The study was conducted in one intensive care unit of a private health-care institution. The inclusion of another intensive care unit in the public sector would have enriched the data. The participants were all female, and the inclusion of males might have elicited different responses.

CONCLUSION

End-of-life care is a significant component of nursing in the intensive care unit and impacts the registered nurses in various ways. This study highlighted the experiences of end-of-life issues in the intensive care unit as perceived by the nurses employed in an intensive care unit. The need for support from the multidisciplinary team and management and the need to build relations with the family members were highlighted as important factors for optimal end-of-life care.

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