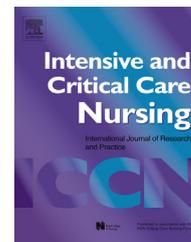




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ORIGINAL ARTICLE

End-of-life care in intensive care unit: Family experiences



Leah C. Kisorio*, Gayle C. Langley¹

Department of Nursing Education, Faculty of Health Sciences, University of the Witwatersrand,
7 York Road, Park Town 2193, Johannesburg, South Africa

Accepted 16 March 2016

KEYWORDS

End-of-life care;
Family experiences;
Intensive care;
Palliative care;
Withdrawal and
withholding of
treatment

Summary

Purpose: To elicit family members' experiences of end-of-life care in adult intensive care units. **Design and methods:** A descriptive, exploratory, qualitative design was utilised. A purposive sampling method was used to select a sample of seventeen family members who had relatives receiving end-of-life care in the intensive care units at three academic affiliated, tertiary/quaternary specialist hospitals in the Johannesburg and Pretoria regions, South Africa. An interview guide was used to facilitate individual, semi-structured interviews with the selected participants. Data collection and analysis took place simultaneously as interviews were transcribed verbatim immediately after the interview. **Tesch's (1990)** steps of analysis were used to establish the major themes that arose from the data. **Lincoln and Guba's (1985)** criteria for ensuring trustworthiness of qualitative research were applied.

Findings: Five major themes emerged: "most of the time we are in darkness", "emotional support", "involvement", "family presence" and "spiritual support".

Conclusion: The findings reflect inadequate care to the families who had dying relatives in the intensive care unit. Negative experiences expressed by the families outweighed their positive experiences, as most families were not happy with the care observed or personally received while their relatives were in the intensive care unit.

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* Corresponding author. Tel.: +27 766 813 094; fax: +27 11 488 4195.

E-mail addresses: ljkisorio@yahoo.co.uk (L.C. Kisorio), Gayle.Langley@wits.ac.za (G.C. Langley).

¹ Tel.: +27 11 488 4270; fax: +27 11 488 4195.

Implications for Clinical Practice

- To enhance family satisfaction with care and maintain regular, honest and direct communication from consistent health care providers.
- Under supervision, families should be allowed to take part in direct patient care if they wish to as this could bring about peace of mind even after death.
- Having a relative present at the end-of-life of a loved one can be distressing, hence there is a need to provide continuous emotional support to the families during the dying process of their relative in the ICU.

Introduction

Despite technological advances, end-of-life care issues occur with greater frequency in the Intensive Care Unit (ICU) (Makino et al., 2014). End-of-life care involves the care and support services that a patient and his/her family receive after the decision has been made to withdraw or withhold treatment(s) (Latour et al., 2009). While foregoing of life-sustaining treatments has become a more common way for ICU patients to die in the past forty years, end-of-life care occur in most ICUs around the world in varying degrees (Sprung et al., 2014).

For example, Datta et al. (2013) indicate that although consideration of end-of-life issues in ICU is relatively new in some countries such as India, western data shows that termination of medical treatment is currently the norm. In one European study, the decision to forgo life-sustaining treatment for patients was made in 40.6% ($n=166/409$) of the cases (Devictor and Latour, 2011) whereas a Brazilian study indicates more frequent withholding/withdrawal of treatment in the paediatric group (33.9%, $n=63/186$) compared to an adult group (24.9%, $n=134/538$) (Piva et al., 2010). Furthermore, withholding (34%, $n=97/283$; 25%, $n=85/347$) or withdrawal (47%, $n=132/283$; 53%, $n=185/347$) of treatment is reported in studies from Australia and Holland respectively (Brieva et al., 2009; Spronk et al., 2009). Another study conducted in seven geographic locations around the world indicates that a decision to withhold treatment occurred in 54.6% ($n=677/1239$) of the patients whereas withdrawal occurred in 45.4% ($n=562/1239$) (Azoulay et al., 2009). With such numbers of ICU patients having treatment withheld or withdrawn, the need for more research in end-of-life care for patients and families is increasingly urgent.

South Africa has a quadruple burden of disease based on its mortality profile and disability-adjusted life-years composition (Econex, 2009). Its actual ICU patient mortality rate is 31.5% (De Beer et al., 2011). The high prevalence of acute and chronic diseases including violent crimes and accidents significantly affects morbidity and mortality (Statistics South Africa, 2013). Because of these factors and the acuity of illness, withholding therapy is a decision required regularly in the ICU especially in state funded practice (Sprung et al., 2014).

Concern for the family members of ICU patients who are at high risk of dying is both a necessity and an integral aspect of providing family-centred care (McAdam et al., 2010). Literature indicates that health care professionals have focused more on patients than on their family members (Yoo et al., 2008). For ICU staff, death is a common

occurrence, but for the families, it is a dramatic experience (Gristina et al., 2011). During the end-of-life process, family members have to face new challenges that may be beyond their ability to adapt to (Yoo et al., 2008).

Fridh et al. (2009) described the experiences of family members during the admission of a loved one to the ICU; the information that their loved one was not expected to survive was a shock as they were not prepared for the fact that their relative was likely to die. In another study, family members expressed high anxiety levels and depression (McAdam et al., 2010). Despite reports that continuous family support and clear communication enhance family members' satisfaction with care (Iglesias et al., 2013; Osborn et al., 2012), inadequate end-of-life care in the ICU still exists due to a lack of communication, inadequate family-centred care as well as lack of emotional and psychological support (Visser et al., 2014).

It is reported that the family and health care professionals may have different views of what is the appropriate level of care at end-of-life (Iglesias et al., 2013). Because of the increased patient severity of illness in South Africa (Kisorio et al., 2009) and the accompanying increased need for end-of-life care in the ICU, there is a need to understand how families make sense of their experiences. This study differs from previous studies in that family experiences were explored prospectively, as such research may help in getting relatives more involved.

Methods

Research design, setting, sampling and sample

A descriptive, exploratory, qualitative design was used to describe the experiences of family members who had a patient receiving end-of-life care in the ICU. The participant representatives were selected from adult ICUs (trauma, cardiothoracic and multidisciplinary (medical and surgical) units) at three academic affiliated, tertiary/quaternary specialist hospitals in the Johannesburg and Pretoria regions of South Africa. The three hospitals serve as referral hospitals for a number of hospitals in their referral chains. Two of these three hospitals are quaternary specialist hospitals that provide super-specialist and limited services such as cardiothoracic surgery, renal and liver transplantations.

Purposive sampling was used to select participants from each of the three hospital ICUs until a point of saturation of themes was reached. In order to participate in this study, each participant met the following criteria: had an adult relative in the ICU with a 'palliative management' or 'not for resuscitation' or 'not for escalation of treatment' order on

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