Research Article

Family Members' Experiences of End-Of-Life Care in a High Care Unit of a Public Hospital

Litana Sibiya, MNur[1]; Isabel Coetzee, PhD[1]; Tanya Heyns, PhD[1]

Citation: Sibiya L, Coetzee I, Heyns T. Family members' end-of-life care experiences in a public hospital's high care unit. *International Journal of Critical Care* 2024;18(2):4-12. doi:10.29173/ijcc85

Academic Editor(s): Ged Williams, RN, Crit. Care Cert., LLM, MHA, FACN, FACHSM, FAAN

Managing Editor: Patricia Zrelak, PhD, RN, NEA-BC, SCRN, CNRN, ASC-BC, CCRN, PHN, FAHA

Published: September 2024

Acknowledgments: Thank you to all the family members and healthcare professionals who participated in this study. Dr. Cheryl Tosh for editing of the manuscript.

[1]Department of Nursing Science, School of Healthcare Sciences, Faculty of Health Sciences, University of Pretoria, South Africa

Corresponding author: Isabel Coetzee at Isabel.coetzee@up.ac.za

ABSTRACT

Introduction: The death of loved ones in hospital settings can be very painful for family members, especially if they are unfamiliar with the hospital environment. End-of-life care to support family members in high-care units is vital for long-term grieving outcomes. Families' experiences regarding end-of-life care are seldom described in South African public hospitals.

Aim: To explore family members' experiences of end-of-life care in a specific high-care unit in a public hospital.

Methods: This was a qualitative descriptive study. We purposively selected family members or significant others of patients managed in the high-care unit, where approximately 70 patients are managed monthly. We scheduled interviews with 10 family members whose loved ones received end-of-life care in the high-care unit, with 8 being interviewed after 2 withdraws. Data were analysed using the collaborative hermeneutic data analysis method.

Results: Six main themes emerged from the data: 1) psychological support, 2) cultural sensitivity, 3) spirituality, 4) coping mechanisms, 5) emotional experiences and 6) psychological healing.

Conclusion: Through the collaborative hermeneutic data analysis approach, healthcare professionals gained a better understanding of the experiences of family members who lost their loved ones in the high-care unit. Healthcare professionals were able to identify strategies to improve the experiences of families who lost loved ones.

Keywords: End-of-life care; family member; high care

INTRODUCTION

Families facing the death of critically ill family members are likely experiencing one of the most painful events of their lives, often reporting feelings of numbness upon first learning that their family member is dying (Hanna et al, 2021). Family members of terminal patients have to cope with impending loss while in the unfamiliar environment of the hospital. They are often overlooked, especially after a sudden decline in their loved one's health. It is essential to provide support to these family members during the

illness as well as after the death of their loved one (O'Sullivan et al, 2021). End-of-life care (EOLC) involves caring for patients and their families from the moment the healthcare team begins to question the purpose of life sustaining treatment and initiates communication to prepare for the patient's death (Anderson et al, 2020). Effective communication with the family is vital for sound end-of-life decision-making (Nickels et al., 2023).–The study's rationale was to understand the experiences of adult family members whose loved ones received end-EOLC in a high care unit (HCU), allowing them to share their experiences during the critical period.

METHODS

Design

This study was qualitative and descriptive, aiming to understand the experiences of family members during EOLC. This approach was appropriate as it allowed for observing, questioning, and listening to obtain rich data. Written permission to conduct the research was obtained from the Research Ethics Committee of the University of Pretoria (see Annexure D). Additionally, ethics approval was granted by the Gauteng National Department of Health through the hospital CEO (see Annexure D).

Study sample

Participants were purposively selected based on their experiences with EOLC and their ability to provide detailed information. The study was conducted in two phases. Phase one involved interviewing eight adult family members of terminally ill patients admitted to the HCU where EOLC was initiated. Data were analyzed during phase two, which included 10 healthcare professionals (HCPs) — three medical doctors, six professional nurses, and one enrolled nurse — all of whom were involved in EOLC in the HCU.

Data collection

In phase one, face-to-face semi-structured interviews were conducted with family members, lasting approximately 45 minutes each. An interview guide was used, with questions focusing on the family members' experiences when EOLC was initiated for their loved ones.

Data analysis

In phase two, the data collected from the interviews were collaboratively analyzed by HCPs using a creative hermeneutic approach (Boomer et al., 2010). This approach emphasizes understanding and interpreting lived experiences. A workshop was conducted with HCPs to analyze the data, during which they gained insights into the family members' experiences and identified strategies to improve EOLC in the HCU (Rawlings, et al, 2010).

RESULTS

Six main themes emerged from the data: 1) psychological support, 2) cultural sensitivity, 3) spirituality, 4) coping mechanisms, 5) emotional experiences, and 6) psychological healing.

Psychological support

The family members indicated that they needed support and that psychological support was important. According to participants:

- *'Help from a counsellor would be of great benefit to us [family members]'.(P6)*
- *'The counsellor also plays a major role in supporting us as family'. (P3)*
- *'Allow at least 2 visitors [family members] so that we can support each other next to his [patient] bed'. (P5)*
- *'All of us [family members] must be there … so that we can support each other'. (P2)*

Patients are often unexpectedly admitted into critical care, leaving family members feeling helpless and vulnerable with little understanding of what is happening and what to expect (Naef et al, 2021). Healthcare professionals could support family members by identifying family needs and having frequent meetings with family members to provide information. Family members of critically ill patients serve as a bridge between HCPs and patients, who are physiologically and psychologically compromised, making family support crucial (Kohi et al, 2016).

The use of proactive support services, such as social workers and meetings with family members, suggests that support should be tailor-made to suit the unique needs of the members involved (Pignatiello et al, 2018). In Saudi Arabia, family members regarded support as crucial to assist them in coping with the shock and stress following the admission of a loved one with a critical illness. Family members need support and reassurance before and after the death of a patient to help with the bereavement process (Morris et al, 2020).

Cultural sensitivity

Family members emphasized the importance of respecting their cultural practices. According to the participants:

- *'Nurses and doctors working in the hospital [HCU] should respect our [family members] cultural practices when we want to "fetch the spirit"'. (P7)*
- *'Consider our culture…that is important to us, when we came to the hospital his body was already takes away, we did not have opportunity to perform our [cultural] ritual'. (P2).*

In providing person-centered EOLC, death and dying to play a central role in all societies and cultures (Krikorian et al., 2020). Critically ill patients and

their families from culturally diverse backgrounds have a right to receive culturally sensitive care. Accordingly, HCPs should have appropriate knowledge, skills, and attributes to respect and effectively respond to the cultural needs of critically ill patients and family members. In African cultures, family members and relatives wish to be close to dying loved ones because the last words of the dying are taken very seriously (Moore et al, 2020). The last words could include a blessing or important last wishes and bequests, particularly as many people do not have formal wills. Cultural competence is learned over time through inner reflection and awareness (Young et al, 2021). HCPs should be aware that many cultures consider discussing impending death to be inappropriate and culturally insensitive (Givler et al, 2022). However, discussing EOLC can have multiple benefits, including giving older people an opportunity to express their preferences or identifying who they would like to be involved in the decision-making process.

Spirituality

Family members indicated that religion and religious practices were important for the spiritual healing of their loved ones. They also stressed the importance of being allowed to perform religious practices. According to participants:

- *'Accommodate us [family members] to practise our religion… Put a rosary around her [patient] neck or her wrist … [or] just come and rub holy oil on our patient'. (P2)*
- *'Prayer helps us [family members] as we lay everything in God's hands, we [family] just prayed without touching anything'. (P3)*

In patient care, spirituality is not a luxury but a necessity for any system that claims to care for patients (Ferrell et al, 2020). Spirituality can be expressed through various religious practices such as rituals and living according to religious values (Paul Victor et al, 2020). Spiritual care is increasingly recognized as a fundamental part of nursing care and meeting the spiritual needs of patients and families can increase satisfaction with care, as well as alleviate 'total pain', which includes the physical, psychological, emotional, and spiritual dimensions (Paul Victor et al, 2020; Cosentino et al, 2020). In Ontario, Canada, Holyoke and Stephenson (2017) found that spiritual care is necessary for the person dying and also for family members and care providers. HCPs should understand the distinctions between faith, religion, and spirituality to understand patients' beliefs and provide spiritual care (Ferrell et al, 2020; Paul Victor et al, 2020). Religious practices such as prayer should be encouraged in the ICU, and opportunities for prayer should be created (Al-Mutair et al., 2013).

Coping strategies

Family members in our study struggled to cope with the realisation that their family members were receiving EOLC, a finding consistent with previous research (Leemann et al, 2020). Family members in our study indicated that their main coping strategies were denial, hope, and acceptance. Some family members denied that their loved ones might die, or hoped that their loved ones would not die. Others accepted that their loved ones would die. According to participants:

- *'I wished they [nurses and doctors] would continue to care for her [patient]…as if maybe she would wake up again'. (P8)*
- *'I hope I would find her opening her eyes today and looking at me'. (P8)*
- *'It was very hard to accept but with your family around you act brave you try to stay strong especially for the people [family] around you'. (P1)*

In intensive care units (ICUs), minor changes in a patient's condition could either boost or diminish the family's hope (Valle et al, 2021). Family members often cling to hope when coping with the impending death of a loved one in ICU. By having hope, family members cope with difficult present circumstances by creating a positive future with uncertain possibilities and hoping for their loved one's survival (Valle et al, 2021; McAlearney et al, 2015). Denial is a defense mechanism that refuses to believe a reality or an unpleasant fact. Family members in our study also experienced denial, which is the first stage of grief and helps people to survive loss (Wang et al, 2021). Acceptance is the fifth stage of grief and means embracing the present, both good and bad, to shape the future (Wang et al, 2021). Acceptance is not necessarily a happy or uplifting stage. It means that people have accepted the grief or loss and have come to understand what it means in their life now. For many people, acceptance is the hardest stage. Some people are never able to accept the loss of their loved ones fully, and grieving people can regenerate their traumatic past and allow themselves to move forward (Wang et al, 2021).

Emotional experiences

In this study, family members reported anxiety and depression as their primary emotional experiences. They described feeling anxious when their loved ones were admitted to the HCU. According to participants:

- *'Anxiety is the worst because you are unsure if you will find your family member in the unit when you arrive'. (P7)*
- *'All the patients are lying flat, motionless, not talking and next to them there is a lot of machines, and some drips they say it's an alarm. …it more of an anxious environment'. (P1)*
- *'I cannot deal with the situation [EOLC] that we are facing...I am so sad….' (P5)*

- *'What is happening [EOLC] with my sister is very traumatic experience…' (P3)*

The ICU is a complex and stressful environment and is associated with significant psychologic morbidity for patients and their families. Many family members experience anxiety, depression, and post-traumatic stress symptoms after their loved one is admitted to the ICU (Beesley et al, 2018; Coombs et al, 2020). Depression is a natural part of grief, when individuals deal with feelings of hopelessness and inadequacy (McAlearney et al, 2015). Family members should thus be treated with dignity and respect to reduce their stress and anxiety (Brown et al, 2018). Family members require information, communication, support, and comfort from HCPs. Family involvement and support can also reduce family members' anxiety (Hetland et al, 2018).

Psychological healing

Family members indicated a need for psychological healing upon hearing the news of their loved one's death. They felt that counselling services could help them cope with their loss. According to participants:

- *'Maybe hold regular meeting with the family where not only medical aspects [EOLC] are dealt with, but other social aspects'. (P8)*
- *'Having a pastor/counsellor will make it easy for us [family members] to accept that death is inevitable'. (P5)*

Grief can manifest emotionally, psychologically, and physically.[28] Bereavement follow-up should be part of any patient plan of care. As family members receive the news of the loved one's death, it is important for HCPs or a dedicated social worker to guide them through the initial loss and help them accept the loss (Norlander, 2014).

Limitations

The study was limited to the experiences of eight family members of patients who received EOLC in the HCU of one provincial hospital in Gauteng. Therefore, the results cannot be generalised.

CONCLUSION

In public hospitals in South Africa, family members of patients receiving EOLC in the HCU have specific support needs. Healthcare professionals should recognize the importance of allowing family members to conduct their cultural and religious practices for their loved ones. Furthermore, family members need emotional, psychological, and spiritual support to cope with their family members' EOLC. Flexible visiting hours and policies should be accommodated once EOLC is initiated.

REFERENCES

Al-Mutair AS, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: A literature review. *Journal of Clinical Nursing.* 2013;22(13-14):1805-1817. https://doi.org/10.1111/jocn.12065.

Anderson RJ, Stone PC, Low JTS, Bloch S. Managing uncertainty and references to time in prognostic conversations with family members at the end of life: A conversation analytic study. *Palliative Medicine*. 2020;34(7):896-905. https://doi.org/10.1177/0269216320910934

Alsharari AF. The needs of family members of patients admitted to the intensive care unit. *Patient Preference amd Adherence.* 2019;13:465-473. https://doi.org/10.2147/ppa.S197769

Beesley SJ, Hopkins RO, Holt-Lunstad J, et al. Acute physiologic stress and subsequent anxiety among family members of ICU patients. Critical Care Medicine. 2018;46(2):229-235. https://doi.org/10.1097/ccm.0000000000002835

Boomer CA, McCormack B. Creating the conditions for growth: a collaborative practice development programme for clinical nurse leaders. Journal of Nursing Management. 2010;18(6):633-644. https://doi.org/10.1111/j.1365-2834.2010.01143.x

Brown SM, Azoulay E, Benoit D, et al. The practice of respect in the ICU. American Journal of Respiratory and Critical Care Medicine. 2018;197(11):1389-1395. https://doi.org/10.1164/rccm.201708-1676CP

Coombs MA, Statton S, Endacott CV, Endacott R. Factors influencing family member perspectives on safety in the intensive care unit: A systematic review. *International Journal for Quality in Health Care.* 2020;32(9):625-638. https://doi.org/10.1093/intqhc/mzaa106

Cosentino C, Harrad RA, Sulla F, et al. Nursing spiritual assessment instruments in adult patients: A narrative literature review. *Acta Biomedica Atenei Parmensis.* 020;91(12-s):e2020015. https://doi.org/10.23750/abm.v91i12-S.10998

Ferrell BR, Handzo G, Picchi T, Puchalski C, Rosa WE. The urgency of spiritual care: COVID-19 and the critical need for whole-person palliation. *Journal of Pain and Symptom Management.* 2020;60(3):e7-e11. https://doi.org/10.1016/j.jpainsymman.2020.06.034

Givler A BH, Maani-Fogelman PA. The importance of cultural competence in pain and palliative care. 2022. In: StatPearls [Internet] [Internet]. Treasure Island (FL): StatPearls Publishing. Available from: https://www.ncbi.nlm.nih.gov/books/NBK493154/

Hanna JR, Rapa E, Dalton LJ, Hughes R, McGlinchey T, Bennett KM, Donnellan WJ, Mason SR, Mayland CR. A qualitative study of bereaved relatives' end of

life experiences during the COVID-19 pandemic. *Palliative Medicine.* 2021;35(5):843-851. doi: 10.1177/02692163211004210

Hetland B, McAndrew N, Perazzo J, Hickman R. A qualitative study of factors that influence active family involvement with patient care in the ICU: Survey of critical care nurses. *Intensive and Critical Care Nursing*. 2018;44:67-75. https://doi.org/10.1016/j.iccn.2017.08.008

Holyoke P, Stephenson B. Organization-level principles and practices to support spiritual care at the end of life: A qualitative study. *BMC Palliative Care.* 2017;16(1):24. https://doi.org/10.1186/s12904-017-0197-9

Kohi TW, Obogo MW, Mselle LT. Perceived needs and level of satisfaction with care by family members of critically ill patients at Muhimbili National hospital intensive care units, Tanzania. *BMC Nursing*. 2016;15(1):18. https://doi.org/10.1186/s12912-016-0139-5

Krikorian A, Maldonado C, Pastrana T. Patient's perspectives on the notion of a good death: A systematic review of the literature. *Journal of Pain and Symptom Management.* 2020;59(1):152-164. https://doi.org/10.1016/j.jpainsymman.2019.07.033

Leemann T, Bergstraesser E, Cignacco E, Zimmermann K. Differing needs of mothers and fathers during their child's end-of-life care: secondary analysis of the "Paediatric end-of-life care needs" (PELICAN) study. *BMC Palliative Care.* 2020;19(1):118. https://doi.org/10.1186/s12904-020-00621-1

McAlearney AS, Hefner JL, Sieck CJ, Huerta TR. The journey through grief: Insights from a qualitative study of electronic health record implementation. *Health Services Research.* 2015;50(2):462-488. https://doi.org/10.1111/1475-6773.12227

Moore KJ, Sampson EL, Kupeli N, Davies N. Supporting families in end-of-life care and bereavement in the COVID-19 era. *International Psychogeriatrics.* 2020;32(10):1245-1248. https://doi.org/10.1017/S1041610220000745

Morris SE, Moment A, Thomas Jd. Caring for bereaved family members during the COVID-19 pandemic: Before and after the death of a patient. *Journal of Pain and Symptom Management.* 2020;60(2):e70-e74. https://doi.org/10.1016/j.jpainsymman.2020.05.002

Naef R, Brysiewicz P, Mc Andrew NS, et al. Intensive care nurse-family engagement from a global perspective: A qualitative multi-site exploration. *Intensive and Critical Care Nursing.* 2021;66:103081. https://doi.org/10.1016/j.iccn.2021.103081

Nickels BM, Tenzek KE, Lattimer TA. This is us: An analysis of mediated family communication at end-of-life. *OMEGA - Journal of Death and Dying*. 2023;87(4):1238-1258. doi: 10.1177/00302228211036307

Norlander L. To comfort always: A nurse's guide to end-of-life care*: Sigma Theta Tau International;* 2014.

O'Sullivan A, Alvariza A, Öhlén J, Larsdotter C. Support received by family members before, at and after an ill person's death. *BMC Palliative Care.* 2021;20(1):92. https://doi.org/10.1186/s12904-021-00800-8

Paul Victor CG, Treschuk JV. Critical literature review on the definition clarity of the concept of faith, religion, and spirituality. *Journal of Holistic Nursing.* 2020;38(1):107-113. https://doi.org/10.1177/0898010119895368

Pignatiello G, Hickman RL, Hetland B. End-of-life decision support in the ICU: Where are we now? *Western Journal of Nursing Research.* 2018;40(1):84-120. https://doi.org/10.1177/0193945916676542

Rawlings D, Yin H, Devery K, Morgan D, Tieman J. End-of-life care in acute hospitals: Practice change reported by health professionals following online education. *Healthcare.* 2020;8(3):254. https://doi.org/10.3390/healthcare8030254

Valle M, Lohne V. The significance of hope as experienced by the next of kin to critically ill patients in the intensive care unit. *Scandinavian Journal of Caring Sciences.* 2021;35(2):521-529. https://doi.org/10.1111/scs.12864

Young JE, Winters J, Jaye C, Egan R. Patients' views on end-of-life practices that hasten death: A qualitative study exploring ethical distinctions. *Annals of Palliative Medicine.* 2021;10(3):3563-3574. https://doi.org/10.21037/apm-20-621

Wang R-R, Wang Y-h. Using the Kübler-Ross Model of grief with post- Beesley SJ, Hopkins RO, Holt-Lunstad J, et al. Acute physiologic stress and subsequent anxiety among family members of ICU patients. *Critical Care Medicine.* 2018;46(2):229-235. https://doi.org/10.1097/ccm.0000000000002835