POSITION STATEMENT

ACCCN POSITION STATEMENT ON ADULT END-OF-LIFE CARE IN CRITICAL CARE

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FOREWORD

Death in critical care is not uncommon.[1] The provision of end-of-life care is a core feature of critical care nursing.[2] The purpose of this Position Statement is to provide specific practice recommendations for critical care nurses to support the facilitation of high-quality end-of-life care.

INTRODUCTION

Having an educated and skilled nursing workforce is essential to providing high-quality end-of-life care.[3] Given not all nurses are adequately prepared for their role in providing end-of-life care,[4, 5] clear practice recommendations are essential to guiding care. However, recommendations for practice must also be supported by ongoing targeted education programs for nurses, related to end-of-life care of the patient and the family.[6] Education priorities include processes for withdrawing life-sustaining treatments,[7, 8] the use of supplemental oxygen, hydration and nutrition support, limb exercises and pharmacological management at end of life,[2] organ donation criteria, processes and supports for donor families,[9] culturally-sensitive end-of-life communication and care,[4, 5, 10] the nature and scope of bereavement support measures for family,[11-13] and mechanisms to support nurse self-care[14, 15] including debriefing.[7] In addition to theoretical education, opportunities for clinical support at the bedside and for nurses to learn through mentoring, formal and informal role modelling[6, 16, 17] and supported clinical exposure to end-of-life care situations at a pace commensurate with the nurse's individual readiness[18] are essential.

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DEFINITIONS AND TERMINOLOGY

For the purposes of this Position Statement, the term **critical care** will be used to refer to critical care and intensive care, a speciality and an area specifically staffed and equipped for the continuous care of critically ill patients.[19] **End-of-life care** *"includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals…includes support of families and carers, and care of the patient's body after their death"*[20] and typically refers to the last 12 months prior to death.[21] The term **family** is used to refer to *"those who are closest to the patient in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice".*[22] For this Position Statement, the term **nurse** is used to refer to all registered nurses working in critical care settings, including those with or without specialist critical care postgraduate education.

BACKGROUND

Critical care admissions account for 1.4% (or 161,000) of Australian hospital admissions every year,[23] and as many as 15% of these patients will die in critical care settings.[24] Patient death is most often the result of consensus regarding treatment futility,[25] followed by a planned and deliberate withdrawal of life-sustaining treatment.[26] Whilst a tension can exist between the provision of life-sustaining treatment in an environment with high mortality rates,[27] nurses are key to the provision of high-quality end-of-life care.[8]

FAMILY-CENTRED CARE

Family-centred care is widely accepted as an important component of patient care in critical care, and is of particular importance at the end of life.[6, 28] Family-centred care is demonstrated by timely, open and sensitive communication directed first to identified primary family spokespersons,[5] open or flexible visiting hours and specific consideration of family needs including facilities within or near the ICU, and the provision of bereavement supports.[7]

A patient and family-centred approach to end-of-life care ensures care is individualised to respect the wishes of the patient and family, and is sensitive and adaptive to their cultural and religious customs, values and beliefs.[10, 29] This includes use of professional interpreters where language barriers exist, to ensure accurate communication.[10] Given that culture and attitudes toward death and dying may differ between the critical care nurse, patient and family,[10, 30] critical care nurses need specific knowledge and skills including highly-developed intercultural communication skills.[10, 31] This includes respect for diverse customs, values and beliefs[31] in order to provide culturally-sensitive care at the end of life. Cultural diversity, as it may pertain to clinicians as well as the patient and family, must also be considered during end-of-life care planning, decision making and physical care.[30] Developing a relationship with, and caring for a dying patient's family is as important as caring for the patient.[32-36] Sharing information about the patient's unique characteristics and personality as a way of emphasising personhood,[37] the use of touch or physical presence, and alignment between verbal and non-verbal communication are key features of the nurse-patient and nurse-family relationship.[33, 36, 38, 39] Ensuring family members are able to spend time at the bedside[40] and hold vigil[32] is important to families and not only contributes to family satisfaction[41] but also provides an opportunity for nurses to support and prepare family members for what may occur in the lead up to and after death.[32] These actions contribute to family perceptions of a 'good death'[36] and satisfaction with care.[41]

The practice of collecting and creating mementos throughout a patient's stay in critical care, and after death[42-44] aids family grieving, with one study suggesting that mementos are provided for up to 75% of all deceased patients in critical care settings.[43] Most mementos are provided to families by nursing staff after the patient has died[43] and can include patient photos, word clouds, ECG rhythm strips, patient diaries, handprints, locks of hair, and patient name

bands.[7, 8, 11, 39, 43-45] Mementos are thought to improve family understanding, create positive memories and aid family coping.[11, 42-46] Yet not all families want or appreciate receiving mementos, as they may represent a negative memory or do not compare to other possessions of the deceased person.[42, 45, 46] Hence, the use of mementos should be considered on an individual basis, with consideration of family dynamics and culture as well as the timing of when mementos are offered.[45, 46]

Consideration must also be given to the needs of child relatives of patients dying in critical care. Historically, child visitors in critical care units were discouraged due to concerns over their young age, infection control issues, and fears over the emotional and psychological impacts on the child's wellbeing.[47-51] However being able to see their unwell family member may help to allay a child's imagined fears or anxieties, reduce any misconceptions about what is occurring,[51, 52] confirm their family member is safe,[50] provide an opportunity to talk to or touch their loved one,[51, 52] and decrease the child's feelings of helplessness and guilt.[49, 52] Where a child's visit to the ICU can be facilitated, and is supported by the critical care team, family and policy, appropriately preparing the child for what they might see and hear, and ensuring an opportunity for the child to ask questions and receive age-appropriate responses is key.[49, 53] Nurses can work with adult family members to support the visit and minimise distress.[49]

For critical care nurses, the therapeutic relationship developed with family members of a dying patient can be a positive and rewarding aspect of end-of-life care[35, 39] but also a significant source of stress and emotional distress.[32, 33, 35, 36, 54-56] For some nurses, managing family distress and grief and their own emotions[32, 35] and disengaging from the relationship after the patient has died, can be difficult.[33] Many critical care nurses feeling unprepared for this,[16] citing both a lack of guidelines and education to underpin the scope of the boundaries of their relationship with families.[16, 32, 33, 54] Hence it is important that critical care nurses have

access to opportunities for debriefing and counselling, where desired.[7]

COMMUNICATION AND DECISION-MAKING

Effective communication and providing information are key components identified as critically important to the provision of end-of-life care in critical care.[5, 40, 57] Whilst talking with the patient should continue even when sedated or nearing death, nurses also communicate caring through the use of touch.[58] For families, the desire to be informed of what is going on and what to expect[40] and to have the opportunity to support the patient's previously expressed goals of care, even if not formally documented as part of an advance health directive,[59] is key. Bedside communication with family provides time for family to ask questions, seek clarification and understand what is going on and what to expect.[40] In this way, communication may not only focus on physiological changes in the patient but also on addressing family's information needs, emphasising support and caring.[60]

With recognition that there is an 'art' to effective communication at the end of life, navigating family communication is a complex and multifaceted nursing activity.[5] Verbal and nonverbal cues provide an indication of family readiness for information.[5] Word choice and pace of communication should also be tailored to individual family member's needs and preferences,[5] accompanied by emotional support.[61] Even when the news was bad, families can experience a sense of relief from receiving information that is sensitively delivered.[40]

In addition to bedside communication, formal family meetings are key to informing families about the patient's condition, prognosis[62] and goals of care.[4, 59] Most family meetings focus on the withdrawal or withholding of life-sustaining treatments.[40, 62, 63] For family members who may feel they know most about the patient's preferences, the opportunity to act as patient advocate in the discussions and decision-making process is important.[40] The timing of family meetings, the difficult nature of the conversations and

lack of consensus regarding treatment all pose challenges.[64] Given critical care nurses have typically established rapport with families[62] their inclusion in family meetings is key to supporting families.[40, 65]

More than 80% of deaths in ICUs are the result of a decision to withdraw or withhold life-sustaining treatment.[66] Where family meetings include a decision to withdraw or withhold life-sustaining treatment, consideration for place of death is important. A single room in the critical care unit is preferred for family involvement and privacy.[67] However, consultation with the patient and family may include consideration of transfer to a ward, hospice or home[68, 69] and/or exploring opportunities and feasibility for facilitating dying on country for Aboriginal and Torres Strait Islanders.[70]

PATIENT COMFORT AND FAMILY SUPPORT

Promoting patient comfort is central to the nurse's role in the provision end-of-life care,[71, 72] and includes the management of pain, anxiety, dyspnoea, restlessness and psychological distress[71] through pharmacological and non-pharmacological strategies.[18] Pharmacological strategies may include administration of antimuscarinics, analgesia and sedation[18, 36, 72] and/or use of oxygen.[36] Non-pharmacological strategies include removing unnecessary monitoring and equipment, repositioning, hygiene and psychosocial support,[18, 36] considered essential aspects of providing a good death.[36]

In addition, nurses are able to act as a liaison between members of the interprofessional clinical team, the patient (where possible) and the patient's family to ensure a shared understanding of the plan of care[8], ascertain preferences for the timing of withdrawal of life-sustaining treatment, whether family would like to be present in the lead up to patient death,[73] the provision, or at least perception of privacy for the family and encouraging family to personalise the space.[36] It is also most important family members are prepared for what they may see or hear as the patient approaches death, such as changes to their breathing

pattern or sounds, changes to level of consciousness, movement, temperature and colour.[17, 74]

ORGAN DONATION

In addition to caring for the dying patient and supporting their family, nurses have an essential role in supporting organ donation processes[75, 76] whilst remaining impartial in relation to the donation decision.[77] Nurses may be involved in early assessment of patients for potential organ donation and liaison with organ donation teams.[75] However given the potential for family distress associated with organ donation conversations,[75] organ donation coordinators, who are specifically trained for the role, will lead communication with family members. Nursing care for the potential organ donor continues, including ensuring adequate oxygenation and care for the person's organs, whilst also continuing to provide simple and clear information, that is communicated with sensitivity at all times.[77]

CARE AFTER DEATH

After death, nursing care for the family continues.[12, 32] Nurses facilitate time for families to be with the deceased[12, 32] and perform or observe cultural and religious rituals (before and) after death.[10, 29, 31] Given that the psychological impact of death on family members is well recognised,[12] supporting families in their immediate grief and bereavement is an essential component of care after death.[32] One significant challenge in the provision of bereavement support is that clinicians may not feel adequately prepared to address the needs of bereaved families[32] or be aware of the range of actions and services that can contribute to supporting family bereavement. Aside from brochures about external bereavement support services available to families after a death,[12] bereavement support activities can also include a follow-up phone call to family members, a sympathy card sent on behalf of the critical care team, and memorial services run by the health service/hospital.[46] For those initiatives that involve making contact with bereaved family after death, the person who makes

contact should be someone experienced with bereavement support.[46]

NURSE SELF-CARE

Whilst providing quality end-of-life care can be uniquely satisfying for nurses,[65] this care does include a component of emotional work.[13] The significance of death, and establishing and maintaining interpersonal relationships with family may be sources of emotional stress for the nurse.[13] For this reason, self-care is essential for nurses to remain efficient and successful in their work.[14, 65] This includes processing their own feelings about providing end-of-life care, taking time to disconnect from the workplace grief and prioritising self-care activities such as exercise and journaling.[65] Seeking support from colleagues, reflecting, and participating in debriefing activities are recommended.[14, 65] Almost 90% of critical care nurses in Australia and New Zealand have access to formal debriefing opportunities after a death,[78] however this should be in addition to nurse leaders providing immediate support, responding to concerns for nurses, and ensuring that the time-intensive nature of providing end-of-life care is considered in unit workload allocation.[65]

RECOMMENDED PRACTICE

The ACCCN endorse the following 28 end-of-life care practice recommendations aimed at ensuring optimal end-of-life care in critical care, in accordance with local unit practice and resources, staffing and patient profiles.

To ensure **family-centred care** at the end of life, the nurse should:-

1. Undertake and document an assessment of patient and/or family needs and preferences including:-
   - Ensuring key members of the patient's family, their relationship to the patient and contact details are documented[5]
   - Cultural preferences including cultural and religious beliefs and customs[10, 29]

   - The need for social work or other support services to address additional family needs including those that may extend beyond the critical care unit e.g. family accommodation
   - Location of death e.g. remain in unit, transfer to hospice, ward, home[68] or on country[70]
2. Orientate family to the critical care unit environment, available facilities and contact information[7]
3. Seek family interest in and permission to involve religious/spiritual/cultural leaders for ongoing family support[31]
4. Seek family interest in the collection and provision of mementos throughout the critical care admission and after death[11, 42, 43]
5. Facilitate privacy and space for the patient and/or family by offering to relocate the dying patient to a single room or larger bed space, where available[64]
6. Support and facilitate the visit of children by working with parents to:-
   - Prepare children for what they might see, hear, feel, and smell[49, 53]
   - Encourage and support children to ask questions, with information given in a sensitive and age appropriate way[49, 53]

To ensure optimal **communication and decision-making**, the nurse should:-

7. Undertake and document an assessment of patient and family needs and preferences including:-
   - Readiness for information through verbal and non-verbal cues[5]
   - Preferences for communication including provision of written material in addition to verbal information[5, 40]
   - The need for professional interpreters[10]

8. Participate and contribute to family meetings for their allocated patient to:-
   - Advocate for the needs of the dying patient and family[40]
   - Support family member's contribution to decision-making in accordance with patient's prior expressed goals of care[59] and family preferences[40, 79]
   - Provide immediate support for family, during and after family meetings[62]
   - Comprehensively document family involvement, family perspectives and key outcomes of the family meeting[63, 80]

9. Acknowledge, communicate and document family concerns. This may include lack of concordance between family members and/or the treating teams and religious/cultural differences[10]

To ensure **patient comfort and family support**, the nurse should:-

10. Seek clear instruction to guide the process for withdrawal and withholding of life-sustaining treatment including:-
    - Reducing and/or ceasing life-sustaining drugs and treatment modalities (e.g. continuous renal replacement therapy)
    - Weaning ventilation, extubation[73] and oxygen therapy[36]
    - Use of sedation, analgesics, anticonvulsant and/or antimuscarinic drugs[18, 36, 72]

11. Remove any unnecessary equipment and monitoring from the patient bedside, rationalising lines and equipment attached to the patient[18, 36]

12. Seek a review of the patient's medication regimen, with a priority on pharmacological strategies that assist with relief of symptoms and distress, such as the use of analgesia and sedation[18, 36, 72]

13. Monitor and assess the patient for signs of discomfort, including but not limited to pain, anxiety, dyspnoea, restlessness and psychological distress[71]

14. Continue regular repositioning and hygiene[18, 36]

15. Ascertain family preferences for the timing of withdrawal of treatment and communicate this to the treating team[73]

16. Determine whether family would like to be present for withdrawal of treatment, and before and after death[73]

17. Prepare and guide family for what they will see, hear and experience as death approaches[17, 74]

In considering possible **organ donation**, the nurse should:-

18. Work collaboratively with organ donation coordinators and the treating team to ensure consistent communication with the family relating to potential organ donation[75]

19. Continue to provide high-quality patient care to maintain vital organs, prevent haemodynamic deterioration[81] and demonstrate ongoing respect for the patient.

To ensure optimal **care after death**, the nurse should:-

20. Facilitate continued privacy, time and space for family to spend time with the deceased patient[12, 32]

21. With the consent of family members, source and arrange for hospital pastoral care personnel or cultural or religious officials/representatives from the community to enter the critical care unit to provide additional support[10]

22. With the consent of family members, refer to social work or other bereavement support service for ongoing support[11, 12]

23. Provide additional written materials about post-death procedures e.g. viewing the body, and community-based grief and bereavement support for families to read at a later time

To ensure **optimal self-care,** nurses should:-

24. Participate in formal structured in-unit debriefing, where available, after caring for a dying patient and their family[14, 15]

25. Seek and participate in informal debriefing and support with colleagues including the nurse-in-charge[14, 15]

26. Make use of hospital-supported services such as the Employee Assistance Program for ongoing support for emotions related to patient death

27. Engage in self-care practices, such as taking time to disconnect from the workplace grief, exercise, journaling, and debriefing with colleagues[14, 65]

28. Notify the nurse-in-charge in circumstances where they feel they are unable to care for a dying patient

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