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Position statement

A national Position Statement on adult end-of-life care in critical care

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ABSTRACT

Patient death in critical care is not uncommon. Rather, the provision of end-of-life care is a core feature of critical care nursing, yet not all nurses feel adequately prepared for their role in the provision of end-of-life care. For this reason, the Australian College of Critical Care Nurses (ACCCN) supported the development of a Position Statement to provide nurses with clear practice recommendations to guide the provision of end-of-life care, which reflect the most relevant evidence and information associated with end-of-life care for adult patients in Australian critical care settings. A systematic literature search was conducted between June and July, 2020 in CINAHL Complete, Medline, and EMBASE databases to locate research evidence related to key elements of end-of-life care in critical care. Preference was given to the most recent Australian or Australasian research evidence, where available. Once the practice recommendations were drafted in accordance with the research evidence, a clinical expert review panel was established. The panel comprised clinically active ACCCN members with at least 12 months of clinical experience. The clinical expert review panel participated in an eDelphi process to provide face validity for practice recommendations and a subsequent online meeting to suggest additional refinements and ensure the final practice recommendations were meaningful and practical for critical care nursing practice in Australia. ACCCN Board members also provided independent review of the Position Statement. This Position Statement is intended to provide practical guidance to critical care nurses in the provision of adult end-of-life care in Australian critical care settings.

1. Introduction

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 critical care nurses with specific practice recommendations to support the facilitation of high-quality end-of-life care.

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, which relate 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,

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limb exercises, and pharmacological management; [2] organ donation criteria and processes and supports for donor families;[9] culturally sensitive communication and care;[4,5,10] the nature and scope of bereavement support measures for family;[11–13] nurse self-care;[14,15] and 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.

2. Aim

The aim of this discussion article was to develop a Position Statement that reflected the most relevant evidence and information related to end-of-life care for adult patients in Australian critical care practice settings.

2.1. 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 specialty 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 before 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".[3] 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.

3. Development steps

The Australian College of Critical Care Nurses (ACCCN) is a not-for-profit membership–based organisation representing critical care nurses across Australia.[22] The aims of the ACCCN include the provision of leadership, representation, development, and support for critical care nurses.[22] In-principle support was provided by the ACCCN National Board for the development of this Position Statement, with a request to involve ACCCN members with clinical currency as 'experts', as a way of ensuring the resultant Position Statement would be meaningful to practising critical care nurses and also to provide a professional development opportunity for interested critical care nurses. The Position Statement was developed using a five-step process.

3.1. Creation of an academic expert team

To ensure the Position Statement was informed by research evidence and was also clinically relevant and meaningful, a staged process was used to guide its development. As a first step, ACCCN members with demonstrated expertise in end-of-life care research were invited to participate in the first stage of the Position Statement development. Four academics committed to undertaking a comprehensive review of the literature to guide the development of the Position Statement and practice recommendations.

3.2. Literature review

A literature search was conducted between June and July, 2020 in CINAHL Complete, Medline, and EMBASE to locate research evidence related to multiple key elements of end-of-life care in critical care. Medical Subject Headings (MeSH) or equivalent terms/phrases according to each database (e.g. CINAHL Subject Headings) for each element and/or keywords were combined with 'critical care', 'intensive care', 'ICU', 'end-of-life care', 'palliative care', 'death', and 'dying' (Table 1). In addition to the articles retrieved in the original searches, a process of forward and backward chaining was undertaken to locate additional research evidence either cited by or citing articles retrieved in the original search and those citing articles retrieved in the original search.

In developing this Position Statement, preference was given to Australian or Australasian research evidence from the last 10 y; however, older research publications were used where newer research evidence was not available or the newer evidence was insufficient on its own to inform practice recommendations. Similarly, international research publications were included where Australian or Australasian research evidence was sparse. Only research publications pertaining to adult populations and published in English in peer-reviewed journals were included and used to guide drafting of the practice recommendations. Publications were not assessed for quality; rather articles utilising any methodology and/or sample size were included, so long as the findings were considered to contribute to the development of practice recommendations. An *a priori* decision was made to not include other position statements and/or practice recommendations as in some cases, these are based wholly or in part on expert opinion or consensus, rather than on research evidence.

3.3. Establishment of a clinical expert review panel

An opportunity for critical care nurses to participate was advertised in the ACCCN newsletter, via an Expression of Interest process. To be eligible to participate, critical care nurses had to hold current financial membership of the ACCCN, be working primarily in a clinical capacity (at least 0.5FTE), have a minimum of 12 months critical care experience, and have experience with and interest in providing end-of-life care. For the purposes of this process, given that any nurse working in critical care may be required to care for a dying patient, irrespective of role, seniority, or qualification, these nurses were considered expert. A total of 11

Table 1
Search strategy.

bereav*		CCU
child*		Critical Care
comfort		Death
communicat*		Dying
cultur*		End-of-Life
"decision making"		End-of-Life Care
educat*		ICU
family		Intensive Care
family-cent*red	AND	Palliative Care
grief		
keepsake		
memento		
"memory making"		
palliat*		
"place of death"		
presen*		
visit*		

Quotation marks were used to ensure phrases are searched for in the exact order as written. The asterisk was used as a truncation wildcard to find all words with the same root term.

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applications were received, with 10 applicants meeting the eligibility criteria. Participants had a mean of 9 y (range 3–15 y) of experience in critical care, with eight of the 10 participants reporting a postgraduate critical care qualification (Table 2).

The 10 clinical experts were asked to commit to a two-stage process involving a modified eDelphi survey and online meeting. A copy of the draft Position Statement was sent via email, along with a link to a modified eDelphi survey, housed on the Qualtrics platform.[23] The purpose of the survey was to measure the relevance of each practice recommendation. A four-point scale was used, where *1 = not relevant*, *2 = somewhat relevant*, *3 = quite relevant*, and *4 = highly relevant*.[24–27] Using the relevance ratings provided, the item-level content validity (I-CVI) of each practice recommendation was calculated by dividing the number of experts that rated the items as 3 or 4, by 10, the number of clinical experts. An I-CVI score at or above 0.80 was considered satisfactory for I-CVI.[26,27] I-CVI ratings for the draft practice recommendations ranged from 0.70 to 1.00, with only two items scoring below 0.80.[25–27] Overall content validity (S-CVI) was also determined by calculating the sum of I-CVI scores for all practice recommendations and then dividing by the total number of recommendations. The S-CVI for the practice recommendations was 0.94, with an S-CVI equal to or greater than 0.90 considered satisfactory.[25–27]

In both the eDelphi survey and online meeting, the clinical experts were asked to provide face validity, with suggested additions, deletions, or modifications to the practice recommendations. Results of the eDelphi survey were presented for discussion during the online meeting. The two practice recommendations that initially received an I-CVI score of 0.70 were discussed and modified by consensus to achieve group agreement. This process ensured the final practice recommendations are meaningful and practical for critical care nursing practice in Australia.

3.4. Review by ACCCN board members

To ensure the Position Statement aligned with ACCCN objectives to provide practical and relevant guidance for critical care nurses, two members of the ACCCN National Board undertook an independent review of the Position Statement and provided recommendations for all sections of the Position Statement excluding the practice recommendations.

3.5. Approval by the ACCCN National Board

Feedback from the clinical expert review panel and ACCCN board members was used to guide revision and refinement of the Position Statement, which was subsequently submitted to and approved by the ACCCN National Board in February, 2021.

Table 2
Demographics – linical xpert eview anel (N = 10).

Variable	Mean (range)
Years in critical care	9 (3–15)
Highest qualification	**n (%)**
Master	4 (40)
Graduate diploma	2 (20)
Graduate certificate	4 (40)
Completed postgraduate critical care training	
Yes	8 (80)
No	2 (20)
State	
Victoria	4 (40)
New South Wales	3 (30)
Queensland	2 (20)
Australian Capital Territory	1 (10)

4. Review of the literature

Critical care admissions account for 1.4% (or 161,000) of Australian hospital admissions every year,[28] and as many as 15% of these patients will die in critical care settings.[29] Patient death is most often the result of consensus regarding treatment futility,[30] followed by a planned and deliberate withdrawal of life-sustaining treatment.[31] Whilst a tension can exist between the provision of life-sustaining treatment in an environment with high mortality rates,[32] nurses are key to the provision of high-quality end-of-life care.[8]

4.1. 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.[6,33] Family-centred care is demonstrated by timely, open, and sensitive communication initially directed towards identified primary family spokespersons,[5] open flexible visiting hours, specific consideration of family needs including facilities within or near the intensive care unit (ICU), and the provision of bereavement supports.[7]

A patient- and family-centred approach to end-of-life care ensures that 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.[10,34] To ensure accurate communication, this includes use of professional interpreters where language barriers exist.[10] Given that culture and attitudes towards death and dying may differ between the critical care nurse, patient, and family,[10,35] critical care nurses need specific knowledge and skills that include highly developed intercultural communication skills.[10,36] Respect for diverse customs, values, and beliefs[36] is required 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.[35] Developing a relationship with and caring for a dying patient's family is as important as caring for the patient.[37–41] Sharing information about the patient's unique characteristics and personality as a way of emphasising personhood,[42] the use of touch or physical presence, and alignment between verbal and nonverbal communication are key features of the nurse–patient and nurse–family relationship.[38,41,43,44] Ensuring family members are able to spend time at the bedside[45] and hold vigil[37] is important and not only contributes to family satisfaction[46] 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.[37] These actions contribute to family perceptions of a 'good death'[41] and satisfaction with care.[46]

The practice of collecting and creating mementos throughout a patient's stay in critical care and after death[47–49] aids family grieving, with one study suggesting that mementos are provided for up to 75% of all deceased patients in critical care settings.[48] Most mementos are provided to families by nursing staff after the patient has died[48] and can include patient photos, word clouds, electrocardiogram rhythm strips, patient diaries, handprints, locks of hair, and patient name bands.[7,8,11,44,48–50] Mementos are thought to improve family understanding, create positive memories, and aid family coping.[11,47–51] 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.[47,50,51] The use of mementos should be considered on an individual basis,

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with consideration of family dynamics and culture as well as the timing of when mementos are offered.[50,51]

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 owing to concerns over their young age, potential infection control issues, and fears over the emotional and psychological impacts on the child's wellbeing.[52–56] Being able to see their unwell family member, however, may help to allay a child's imagined fears or anxieties, reduce any misconceptions about what is occurring,[56,57] confirm their family member is safe,[55] provide an opportunity to talk to or touch their loved one,[56,57] and decrease the child's feelings of helplessness and guilt.[54,57] Where a child's visit to the ICU can be facilitated, 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.[54,58] Nurses can work with adult family members to support the visit and minimise distress.[54]

For critical care nurses, the therapeutic relationship with family members of a dying patient can be a positive and rewarding aspect of end-of-life care.[40,44] It can also be a significant source of stress and emotional distress.[37,38,40,41,59–61] For some nurses, managing family distress and grief and their own emotions[37,40] and disengaging from the relationship after the patient has died can be difficult.[38] Many critical care nurses feel unprepared for this,[16] citing both a lack of guidelines and education to underpin the scope of the boundaries of their relationship with families.[16,37,38,59] It is important that critical care nurses have access to opportunities for debriefing and counselling, where desired.[7]

4.2. Communication and decision-making

Effective communication and the provision of information are identified as critically important to end-of-life care in critical care.[5,45,62] Whilst talking with the patient should continue even when sedated or nearing death, nurses also communicate caring through the use of touch.[63] Key for families is the desire to be informed of what is going on and what to expect[45] 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.[64] Bedside communication with family provides time for them to ask questions, seek clarification, and understand what is going on and what to expect.[45] In this way, communication may focus not only on explaining physiological changes in the patient but also on addressing family's information needs, demonstrating support for families.[65]

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.[66] Even when the news is bad, families can experience a sense of relief from receiving information that is sensitively delivered.[45]

In addition to bedside communication, formal family meetings are also key to informing families about the patient's condition, prognosis,[67] and goals of care.[4,64] Most family meetings focus on the withdrawal or withholding of life-sustaining treatments.[45,67,68] 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.[45] The timing of family meetings, the difficult nature of the conversations, and lack of consensus regarding treatment all pose challenges.[69] Given critical care nurses establish a rapport with families,[67] their inclusion in family meetings is central to supporting families.[45,70]

More than 80% of deaths in ICUs are the result of a decision to withdraw or withhold life-sustaining treatment.[71] 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.[72] However, consultation with the patient and family may include consideration of transfer to a ward, hospice, or home,[73,74] and/or exploring opportunities and feasibility for facilitating dying on country for Aboriginal and Torres Strait Islanders.[75]

4.3. Patient comfort and family support

Promoting patient comfort is central to the nurse's role in the provision end-of-life care,[76,77] and includes the management of pain, anxiety, dyspnoea, restlessness, and psychological distress[76] through both pharmacological and nonpharmacological strategies.[18] Pharmacological strategies may include administration of antimuscarinics, analgesia, and sedation[18,41,77] and/or use of oxygen.[41] Nonpharmacological strategies include removing unnecessary monitoring and equipment, repositioning, hygiene, and psychosocial support.[18,41] These are all considered essential aspects of providing a good death.[41]

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. This will help to ensure a shared understanding of the plan of care[8] and 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,[78] the provision, or at least perception of privacy for the family and encouraging family to personalise the space.[41] It is also most important family members are prepared for what they may see or hear as the patient approaches death, such as changes in their breathing pattern or sounds, changes in the level of consciousness, movement, temperature, and colour.[17,79]

4.4. Organ donation

In addition to caring for the dying patient and supporting their family, nurses have an essential role in supporting organ donation processes[80,81] whilst remaining impartial in relation to the donation decision.[82] Nurses may be involved in early assessment of patients for potential organ donation and liaison with organ donation teams.[80] However, given the potential for family distress associated with organ donation conversations,[80] specifically trained organ donation coordinators 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.[82]

4.5. Care after death

After death, nursing care for the family continues.[12,37] Nurses facilitate time for families to be with the deceased[12,37] and perform or observe cultural and religious rituals before and after death.[10,34,36] 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.[37] One significant challenge in the provision of bereavement support is that clinicians may not feel adequately prepared to address the needs of bereaved families[37] 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

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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.[51] For those initiatives that involve making contact with bereaved family after death, the person who makes contact should be someone experienced with bereavement support.[51]

4.6. Nurse self-care

Whilst providing quality end-of-life care can be uniquely satisfying for nurses,[70] 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.[14,70] 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.[70] Seeking support from colleagues, reflecting, and participating in debriefing activities are recommended.[14,70] Almost 90% of critical care nurses in Australia and New Zealand have access to formal debriefing opportunities after a death;[83] 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.[70]

5. Practice recommendations

The ACCCN endorse the following 28 end-of-life care practice recommendations aimed at ensuring optimal end-of-life care in critical care and 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[10,34]
   - The need for social work or other support services to address additional family needs including those that may extend beyond the critical care unit, for example, family accommodation
   - Location of death e.g. remain in unit, transfer to hospice, ward, home,[73] or on country[75]
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[36]
4. Seek family interest in the collection and provision of mementos throughout the critical care admission and after death[11,47,48]
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[69]
6. Support and facilitate the visit of children by working with parents to
   - Prepare children for what they might see, hear, feel, and smell[54,58]
   - Encourage and support children to ask questions, with information given in a sensitive and age-appropriate way[54,58]

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 nonverbal cues[5]
   - Preferences for communication including provision of written material in addition to verbal information[5,45]
   - 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[45]
   - Support family member's contribution to decision-making in accordance with the patient's prior expressed goals of care[64] and family preferences[45,84]
   - Provide immediate support for family, during and after family meetings[67]
   - Comprehensively document family involvement, family perspectives, and key outcomes of the family meeting[68,85]
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,[78] and oxygen therapy[41]
    - Use of sedation, analgesics, anticonvulsant, and/or antimuscarinic drugs[18,41,77]
11. Remove any unnecessary equipment and monitoring from the patient bedside, rationalising lines and equipment attached to the patient[18,41]
12. Seek a review of the patient's medication regimen, with a priority on pharmacological strategies that assist relief of symptoms and distress, such as the use of analgesia and sedation[18,41,77]
13. Monitor and assess the patient for signs of discomfort, including but not limited to pain, anxiety, dyspnoea, restlessness, and psychological distress[76]
14. Continue regular repositioning and hygiene[18,41]
15. Ascertain family preferences for the timing of withdrawal of treatment and communicate this to the treating team[78]
16. Determine whether family would like to be present for withdrawal of treatment and before and after death[78]
17. Prepare and guide family for what they will see, hear, and experience as death approaches[17,79]

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[80]
19. Continue to provide high-quality patient care to maintain vital organs, prevent haemodynamic deterioration,[86] 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[12,37]

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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 postdeath procedures, for example, 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[14,70]
28. Notify the nurse-in-charge in circumstances where they feel they are unable to care for a dying patient.

6. Discussion

In the development of this Position Statement, it was evident that several key areas that might be considered core to research and end-of-life care practice recommendations were absent or underrepresented in the evidence. Whilst advance care planning is promoted,[3] some studies have reported on their prevalence in critical care settings,[87,88] but the relevance and meaningfulness of advance care planning in guiding end-of-life care decision-making in critical care is not widely reported or understood. Similarly, whilst nurse coping self-care and wellbeing after patient death is acknowledged as important across practice settings,[89] evidence specifically pertaining to Australasian nurses in critical care nurses practice settings is sparse.

7. Conclusion

The purpose of this Position Statement was to provide specific evidence-based practice recommendations for critical care nurses to support the facilitation of high-quality end-of-life care. The review of the literature, used to inform this Position Statement, coupled with the contribution of clinical experts and ACCCN board members, has resulted in 28 practice recommendations that are evidence-based and also feasible and meaningful for critical care clinicians across Australia.

CRediT authorship contribution statement

Melissa Bloomer: Conceptualisation, Methodology, Writing – Original Draft, Review and Editing, Supervision, Project Administration; **Kristen Ranse:** Conceptualisation, Methodology, Formal Analysis, Writing – Original Draft, Review and Editing; **Ashleigh Butler:** Conceptualisation, Methodology, Writing – Original Draft, Review and Editing; **Laura Brooks:** Conceptualisation, Methodology, Writing – Original Draft, Review and Editing

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