MEMORY MAKING IN END-OF-LIFE CARE IN THE ADULT INTENSIVE CARE

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Statement of originality

This is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Melissa Riegel

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The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

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Supervisor Confirmation

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Supervisor name: Associate Professor Thomas Buckley

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Dedication

To my mom for finally getting a passport and driving me to get this done a year sooner than I might have otherwise.

Abstract

Background

Family members of patients who die in the intensive care setting are reported to be at increased risk of prolonged psychological stress during bereavement. One potential intervention to assist the family is memory making: an activity that provides a tangible object(s) such as handprint, lock of hair, or teddy bear, which can help a bereaved individual create a connection with and provide meaningful memories about a deceased person.

Methods

This thesis utilised a two-study arm design that adopted a pragmatist epistemology. The first study was a survey administered to healthcare professionals at a 17-bed tertiary referral intensive care in Sydney from June-August 2017. The survey explored factors influencing provisions of end-of-life care and experiences with memory making.

The second study was a descriptive qualitative study from a purposeful, convenience sample of relatives who received memory making at a tertiary referral intensive care in Sydney from May 2019-December 2020. Interviews were conducted using a semi-structured format.

Results

Data from ninety-six valid surveys from healthcare professionals (75% response rate: 75 registered nurses, 19 medical practitioners, and 2 social workers) were analysed. Participants reported memory making to include creating tangible objects and nontangible activities. Participants highest overall opinions included believing families value memory making and the offer being beneficial. Enablers to offering included organisational supports, personal qualities, good interpersonal relationships. Barriers included workloads, inexperience, and being afraid. Participants with experience offering memory making reported higher level of confidence and comfort offering memory making, ability to spend time supporting the family, and were less likely to be limited by family's behaviours or be time limited to offer memory making.

Qualitative data was collected from 18 semi-structured interviews of 21 family participants. Data analysis generated three themes: guidance during end-of-life by healthcare professionals that recognises the autonomy of the family; object used as a trigger to access memories; and storage and preservation of the object as an indication of its sentimental value and use in early bereavement.

Conclusion

Healthcare professionals offering and relatives receiving memory making appear to be associated with overall positive experiences, where a high proportion of healthcare participants offered memory making as part of their clinical practice. Further, family participants welcomed the offer of making memory objects during end-of-life care in the adult intensive care, and commonly described the objects to embody their deceased loved one, which maintained bonds to and memories of them during early bereavement.

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Keywords

Adult

Bereavement

Critical care

Death

Diary

Electrocardiogram

End of life

Family

Grief

Hair

Intensive care units

Keepsake

Memory

Memory making

Needs assessment

Nurses

Palliative care

Photography

Physicians

Terminal care

Transitional object

Word cloud

List of Abbreviations

DPM: Dual Process Model of Coping with Bereavement

ECG: electrocardiogram

EOLC: end-of-life care

HCP: healthcare professionals

ICU: intensive care unit

LOSS: Loved One Support Service

MP: medical practitioner

RN: registered nurse

SW: social worker

Chapter 1: Introduction

This chapter begins in section 1.1 with a historical background on the use of memorial objects obtained from the deceased. It then presents the framework for this thesis by including the background to the practise of memory making in the adult intensive care in section 1.2, and the aim of this thesis in section 1.3. Section 1.4 describes the significance and scope of this research and provides definitions of terms used. Finally, section 1.5 includes an outline of the remaining chapters of the thesis.

1.1 HISTORICAL BACKGROUND TO THE PRACTICE OF MEMORY MAKING

The practice of memory making and mementos in the hospital setting has its beginnings in the neonatal population as noted by its prominence in perinatal bereavement literature (Butler et al., 2019; Carlson, 2012). The phrase "memory making" in this population is predominately used to describe parents' time spent with their stillborn child, which includes holding, washing, and dressing the deceased baby. These acts have been suggested to assist the parents with solidifying their personal identity of being a mother or father and creating the time-limited memories with their stillborn (Brierley-Jones et al., 2014; Butler et al., 2015; Crawley et al., 2013; Hennegan et al., 2015; Tan et al., 2012). However, the use of memory making is less reported in adults, perhaps because it is assumed time would have been afforded throughout the deceased adult's life to obtain mementos. For the adult population, the act of memory making in end-of-life/bereavement care is defined as an activity that provides a tangible object, such as a handprint, footprint, lock of hair, or teddy bear, that intends to help a bereaved person create a continued connection with and provide meaningful memories of a deceased person for use during bereavement (Miller et al., 2014).

After a death, the notion of family members keeping mementos and other inheritances of the deceased is not new. Keepsakes and mementos may be used as transitional objects in the grief process where the objects become a symbol of the relationship and person lost. These objects can act as a physical substitution and reminder of the deceased through tactile stimulation such as touching, holding or stroking the objects (Finch & Mason, 2000; Gibson, 2004; Richardson, 2014; Sas & Coman, 2016). Mementos such as clothing, photographs, locks of hair, jewellery, and other personal objects act as reminders and connections to those deceased and are frequently discussed by disciplines such as in design and material culture, sociology, anthropology, and psychiatry (Ash, 1996; Bennett & Bennett, 2000; Finch & Mason, 2000; Gibson, 2004, 2010; Hallam & Hockey, 2001; Richardson, 2014; Sas & Coman, 2016; Volkan, 1972).

Memorial objects have historically been used after adult deaths as far back as the sixteenth century with the use of the deceased's hair to create jewellery posthumously (Hallam & Hockey, 2001; Pointon, 1999). After a person's death, the body decays, but the hair survives allowing it to serve as a physical connection and substitute for the deceased's body. The use of hair as a jewellery item allows a physical, touchable, and wearable remembrance of the body of the person deceased. Though the use of hair jewellery is not reported in more recent times, the keeping of locks of hair is a continued practice in neonatal, paediatric, and adult populations (Butler et al., 2015; Gibson, 2010; Reeve et al., 2021; Widger & Caroline, 2008). According to Gibson (2010), the use of a lock of hair as a memorial object is often classified as a sacred object, kept in an intimate space such as a bedroom within multiple storages, such as a box within a drawer. The lock of hair is reported to help to create a connection to the whole body of the deceased to assist in remembrance. Worn clothing is also used as a memento of the deceased (Ash, 1996; Brierley-Jones et al., 2014; Davies, 2005; Gibson, 2004; Richardson, 2014) and can also be classified as sacred, where it may be treasured and kept in an intimate space, or profane, where they are ordinary and without special meaning (Gibson, 2010). Clothing can potentially be used as a memory object due to its ability to retain the smell and body shape of its previous owner, as well as evoke memories of how and where it was worn (Ash, 1996). In the neonatal and paediatric environment, clothing could be what the parents decided to dress their child in (Brierley-Jones et al., 2014), but in relation to adults, clothing more often appears to refer to the left behind personal possessions that the owner decided on and purchased for themselves (Ash, 1996; Gibson, 2010). Richardson (2014) reports that objects such as clothing can be transformed from an object into a symbol of the deceased, where touching the object has similar properties to touching the person. It is also reported that the power of touch can elicit greater, and sometimes overwhelming emotions that are not evoked from looking at an object such as a photograph (Richardson, 2014).

The use of photography in creating memories after death has origins in the nineteenth century where its scarcity and expense led to its use predominately after death to capture the image of the deceased ‘sleeping’ during the funeral wake, as well as allow the deceased to be included in family group photos during the wake (Hilliker, 2006; Linkman, 2011). In contrast to today, photography’s high accessibility through devices such as mobile phone, its ease of use, and its low cost allows the photographs to be predominately used before death to remind the bereaved of the deceased as they were in the living form (Hallam & Hockey, 2001). Additionally, the increased prominence of social media and sharing photographs has also allowed for more public displays of mourning rituals where at times the funeral event and family photographs are widely shared over the social media platforms (Gibbs et al., 2014).

1.2 BACKGROUND TO THE THESIS

The mortality rate for adult intensive care units (ICU) in Australia is around 7.7%, so providing end-of-life care is routine intensive care management (Australian and New Zealand Intensive Care Society, 2018). Experiences in bereavement and adjusting to a life without a loved one will be unique in each circumstance. When experiencing a death of someone close and faced with the reality of the person’s permanent absence, it can be difficult to prepare for and anticipate the effects it might have on those newly bereaved. Others have reported that deaths occurring in the adult ICU have strong impacts on loved ones, and end-of-life care should prioritise the family’s needs (Bloomer et al., 2022; Buckley et al., 2015). Providing support before, during, and after the death are desired and appreciated by many families and can assist in adjusting to the loss and potentially help limit the physical and emotional strain after the death (Efstathiou et al., 2019; Fauri et al., 2000; van der Klink et al., 2010).

This body of work with memory making originated as a result of developing an end-of-life and family bereavement program, referred to at the adult ICU of the Prince of Wales Hospital, Sydney as the Loved One Support Service (LOSS). The LOSS program included interventions that were primarily extracted from perinatal and paediatrics literature and from clinician suggestions based on their past clinical experiences, which included memory making. The act of memory making in end-of-life care is predominately described in the perinatal literature to assist parents in identifying as a mother or father, but in other populations is considered an activity that provides a tangible object to help maintain a continued connection with and provide meaningful memories of a deceased person (Brierley-Jones et al., 2014; Butler et al., 2019; Crawley et al., 2013; Hennegan et al., 2015; Miller et al., 2014; Tan et al., 2012).

LOSS was officially launched in November 2015 as a local quality improvement initiative to complement existing social work and pastoral care referrals, and program interventions included relocating the patient to a private bedspace; encouraging the family to personalise the bedspace with pictures or music; open visitation; increased communication among healthcare professionals to alert them of a grieving family; softening the environment with electric candles and scent diffusers; teddy (huggy) bears given to children; handprints, footprints, or locks of hair offered as memory making objects; ensuring bereavement books were distributed; condolence cards mailed one to two weeks after death; and follow-up phone calls to the next of kin to answer lingering questions around weeks three to five. Implementation of a structured, standardised program, championed by senior ICU nurses helped solidify consistent patient and family care expectations and directed healthcare professional's learnings for patient and family end-of-life care delivery.

A significant practice change was the introduction of memory making items offered to all families as a component of the LOSS program. If desired by the family, the creation of the objects occurred at the bedside and was performed by the offeror with varying levels of family assistance in the creation. Memory making has been described as being valued by family in the perinatal bereavement literature (Brierley-Jones et al., 2014; Butler et al., 2015), and bereaved family in the adult population have also been reported to have positive reactions regarding the objects (Beiermann et al., 2017; Neville et al., 2020). However, less is known about the use of memory making in the adult intensive care environment from both the perspective of healthcare professionals who offer memory making opportunities as part of end-of-life/bereavement care and family members who are recipients of memory making objects. Additionally, it was unknown if the intervention of memory making would be acceptable and appropriate to families as a bereavement intervention.

1.3 AIMS

This thesis aims to *explore the experience of memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU) from the* *healthcare professionals offering and the family receiving the intervention*. To do this, two research questions were utilised:

1) What is the experience of healthcare professionals offering memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?
2) What is the experience of relatives receiving memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?

To explore the experience of healthcare professionals offering memory making opportunities to family members in an adult ICU, one study of this research thesis included a survey of intensive care healthcare professionals. To explore the experience of family members receiving memory making, a second study of this research thesis used semi-structured interviews of family members who receive memory making during end-of-life/bereavement care. Both studies will help inform of the experiences of the providers and receivers of the memory making intervention during end-of-life/bereavement care in the adult ICU.

1.4 SIGNIFICANCE, SCOPE AND DEFINITIONS

The research presented in this thesis was conducted to determine if the memory making intervention was valued and used in bereavement by families or if alternative family support interventions would be better use of the healthcare professional’s time and resources.

For the purpose of this study:

- Bereavement is the period after the death of a significant other (Buckley et al., 2015).
- End-of-life care is the care provided after a decision is made to cease life-sustaining medical treatment with death as the expected outcome (Ranse et al., 2015).
- Grief is a complex emotion occurring from various emotional responses as a result of a loss (Jakoby, 2012).
- Family are individuals who have a significant relationship to a person where they may or may not be related to that person (Davidson et al., 2017). This phrase is used rather than 'next of kin' to encompass a larger range of individuals who have formed these meaningful relationships.
- Memory making is as an activity that provides a tangible object, such as a handprint, footprint, lock of hair, or teddy bear, that intends to help a bereaved person create a continued connection with and provide meaningful memories of a deceased person for use during bereavement (Miller et al., 2014).

Frequently, the severity of a person's critical illness in ICU creates a shortened time between withdrawal of medical treatment where end-of-life care is provided and the death where family bereavement care begins. Due to this shortened time, care provided is commonly overlapped with end-of-life and bereavement care and commonly includes care of the family in both aspects. In this study, memory making was reported to be offered before death as part of end-of-life care as well as after death during bereavement care.

1.5 THESIS OUTLINE

Chapter 1 has provided the background regarding the catalyst that ignited this thesis and research topic.

Chapter 2 will provide a review of the literature, including a peer-reviewed manuscript (Riegel et al., 2019) and an updated literature review since the manuscript's publication. It then includes the summary of the research literature regarding memory making and its implications with regard to this thesis' research question and aim.

Chapter 3 will present the methodology used in this thesis, including the paradigm, research design, and theoretical perspectives utilised.

Chapter 4 will outline the methods used to answer the research question. First the methods used to explore the healthcare professionals experience will be presented and includes participants, instrument used, the procedure and timelines, data analysis, and ethical considerations. Then, the methods used to explore the family members who are bereaved will be presented and includes participants, data collection, data analysis, rigour, and ethical considerations.

Chapter 5 will provide the results of the research findings, including three peer-reviewed international nursing journal manuscripts regarding the healthcare professionals’ survey exploring factors that influence their provision of end-of-life care (Riegel et al., 2021), their knowledge, skills and roles in memory making (Riegel et al., 2022b), and factors associated with the decision to offer memory making (Riegel et al., 2022a). Finally, results from the family members who are bereaved is provided in the fifth manuscript that has been submitted for consideration to a peer-reviewed international nursing journal.

Chapter 6 discusses the interpretation of the results from Chapter 5 related to the thesis aim.

Chapter 7 includes the conclusions, strengths and limitations of the thesis, and recommendations for future research.

Chapter 2: Literature Review

This chapter begins in section 2.1 with a peer-reviewed manuscript performing a scoping review of the research literature (Riegel et al., 2019). An updated scoping review of the literature is next presented in section 2.2. Section 2.3 provides the implications from the literature and develops the conceptual framework for this study.

2.1 SCOPING REVIEW OF THE RESEARCH LITERATURE

This manuscript reports the practices of memory making during end-of-life care within adult intensive care settings from a scoping review the of literature. Results identified four memory making activities including a computer-generated word cloud image, copies of electrocardiograms, patient diaries, and photography. This manuscript concluded limited evidence is available within the adult ICU environment, but studies did report family mostly valuing memory making when offered (Riegel et al., 2019).

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Review Paper

Memory making in end-of-life care in the adult intensive care unit: A scoping review of the research literature

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ABSTRACT

Objective: The objective of this review is to describe the practice of memory making as part of end-of-life care within an adult intensive care setting and determine reported outcomes.

Methods: A scoping review of the literature was performed. Data were collected from sources such as ProQuest, CINAHL, Medline, Embase, PsycINFO, and PubMed using combinations of the keywords: including adult, critical care, intensive care, ICU, death, dying, grief, bereavement, end?of?life, memento*, memor*, keepsak*, and transitional object. Peer-reviewed studies reporting on the use of memory making within an adult intensive care setting and its outcomes for family members were included.

Results: Four activities facilitating memory making as part of end-of-life care for adults are reported in the literature, all in the intensive care setting. Use of a computer-generated word cloud image received by families in the intensive care was reported as a meaningful keepsake and sometimes displayed in places such as the patient's funeral memorial. Offering a printed copy of the patient's electrocardiogram as a memento was considered by some to be extremely or very helpful during their bereavement experience and was reported by nursing staff to be well received by family members. The use of patient diaries during bereavement has been reported with the potential to promote better understanding of the events leading to the death, and photography was also included in some patient diaries as a visual memento.

Conclusion: Although limited evidence is available concerning memory making in the adult intensive care environment, from studies to date, surviving family members of deceased patients in the intensive care unit mostly report valuing memory-making opportunities when offered. However, further research is required to evaluate both healthcare staff's competence and confidence in offering memory making and determine if such offerings promote the family's adjustment to the loss of their loved one after a death in the intensive care area.

1. Introduction

Studies have reported significant, and sometimes prolonged, psychological stress in relatives of patients who die.[1,2] The prevalence of complicated grief is reported to be about 6.7% in the general population after a major bereavement,[3] but the prevalence is reported at much higher levels when the death of a loved one occurs in the intensive care setting.[1,2] For example, in one study of family members who experienced a death in an intensive care unit (ICU), 46% reported grief levels meeting criteria for complicated or intense and persistent grief at 6 months after the death.[1] Similarly, another study of patients' families in a medical ICU reported that 34% experienced major depression, anxiety, panic disorder, or complicated grief between 3 and 12 months (average of 8 months) after the death of their loved one.[2] Psychological morbidity appears more prevalent in surviving spouses although siblings and children of deceased also reported experiencing significant levels of psychological stress after the death of a family member.[2]

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Psychological stress after the death of a loved one can contribute to the surviving family members neglecting their self-care, including changes in eating habits, increased alcohol use and cigarette smoking,[4] and decreased physical activity, as well as failure to adhere to personal medical treatment.[5] In addition, the early period of bereavement is associated with increased cardiovascular morbidity and mortality risk, secondary to the complex interaction between psychological, behavioural, and physiological responses.[6–8]

Providing bereavement support before, during, and after the death of a loved one can assist surviving family members adjust to their loss and help limit physical and emotional strain after the death.[9,10] Some examples of bereavement support discussed in the acute care setting include compassionate communication, a quiet room outside of the patient's area, religious support, flexible visiting hours, providing comfort and dignity for the patient, private viewing of the deceased, counselling, community service resource information, and follow-up correspondence.[9,11–14]

The role of the nurse in end-of-life care has also been considered to be important in creating positive memories for families, such as making the patient appear comfortable and minimising visibly invasive technology.[14] The concept of creating memories is also highlighted by the reported use of memory boxes in bereavement care practices in an Australian and New Zealand survey of ICUs, although it was not reported if this practice was performed in neonate, paediatric, or adult ICUs; exactly what was included in the memory box; or how they were used in end-of-life/bereavement care practices.[15]

After an adult death in any setting, the concept of surviving family members keeping memory boxes, mementos, or other inheritances of the deceased is frequently reported.[16–25] Memorial objects have historically been used after adult deaths as far back as the sixteenth century with the use of the deceased's hair to create jewellery posthumously.[16,17] These objects can act as a physical substitution and reminder of the deceased through tactile stimulation such as touching, holding, or stroking the objects.[18–21] Mementos such as clothing, photographs, locks of hair, jewellery, and other personal objects act as reminders and connections to those deceased and are frequently discussed in other disciplines such as anthropology, design and material culture, psychiatry, and sociology.[16,18–25]

The practice of memory making and mementos in the hospital setting has its beginnings in the neonatal population.[26,27] The phrase "memory making" is predominately used to describe parents' time spent with their stillborn child, which includes holding, washing, and dressing the deceased baby. These acts have been suggested to assist the parents with solidifying their personal identity of being a mother or father and creating the time-limited memories with their stillborn,[26,28–31] although a Cochrane review in 2008 concluded that the true benefits were unclear.[32] These mementos, e.g., photos, hand/footprints, and clothing, may be displayed in the home and actively shared with family and friends, assisting the family in remembering the entire completed family unit and their experience with their baby.[29]

In the paediatric context, memory making may not always be offered because some health professionals may believe that the family have already obtained tangible mementos of the child throughout his or her life and therefore do not need to create the mementos at the time of death.[33] Despite this belief, parents of children or adolescents report the desire for memory-making opportunities at the time of death.[26] Memory-making objects reported in the paediatric population include locks of hair, hand/footprints, memory books/boxes, photos, and the hospital ID band.[26] The act of offering parents the opportunity to make mementos of their child has been reported by family members as one of the most helpful, caring gestures hospital staff can do for the family.[34]

Despite reports of the utility of memory-making objects for surviving family members during end-of-life/bereavement care in the perinatal and paediatric settings, little is known about the use of memory making in the adult intensive care environment. The aim of this scoping review is to describe the practice of memory making as part of end-of-life care within an adult intensive care setting and determine reported outcomes from studies to date.

2. Methods

The methodology of Peters et al.[35] was followed for this scoping review to answer the question "What is known in the research literature about memory making in the adult intensive care unit?" A systematic search of the following databases was conducted to source original research publications reporting on memory making in the adult intensive care setting: ProQuest, Cummulative Index of Nursing and Allied Health Literature (CINAHL), Medline, Excerpta Medica dataBASE (Embase), PsycINFO, and PubMed. Boolean operators were used with a combination of following keywords: adult, critical care, ICU, intensive care, death, dying, grief, bereavement, end?of?life, memento*, memor*, keepsak*, and transitional object. Owing to the limited number of articles found, it was not necessary to apply further limits. Removal of the search terms 'critical care', 'intensive care', or 'ICU' did not reveal any additional studies in the adult population. Reference lists of retrieved articles were manually searched for potentially relevant articles, and Scopus was used to retrieve shared reference lists of relevant articles and books. Peer-reviewed studies were included if they reported on memory-making activities initiated as part of end-of-life care in the adult hospital setting. Studies were excluded if the memento discussed was not created or obtained during ICU end-of-life care (e.g., objects from home). No date limits were applied to the search because of the limited number of search results. A summary of the search is presented in Fig. 1.

3. Results

Seven publications related to the practice of offering four types of memory-making objects in the adult ICU including word cloud images, electrocardiogram (ECG) mementos, patient diaries, and photographs were retrieved.

3.1. Word cloud images

The use of a computer-generated word cloud image, offered as part of an ICU end-of-life care program the "3 Wishes Project", aimed to facilitate a narrative medicine approach to ICU care.[36,37] In this study conducted in Canada, 50 family members of 40 patients were offered at least three wishes granted either before or after the death. The wishes were chosen from five categories: humanising the environment; personal tributes (such as the word cloud keepsake); family reconnections; rituals and observances; and paying it forward (such as organ donation or charity donation). For the word cloud intervention, project team members derived words and phrases from family members' stories about the patient's life. Those words were then entered into an image generator to create a printable image using the words and phrases.[36,37]

It was reported that the word cloud intervention was received by 42 family members, 22 (52%) before death and 20 family members requested the memento after death. It is also reported that the word cloud intervention was usually initiated as a wish by the clinical team for the family, and at times, the family received the word cloud as a surprise gift.[37] If the unsolicited surprise gift was

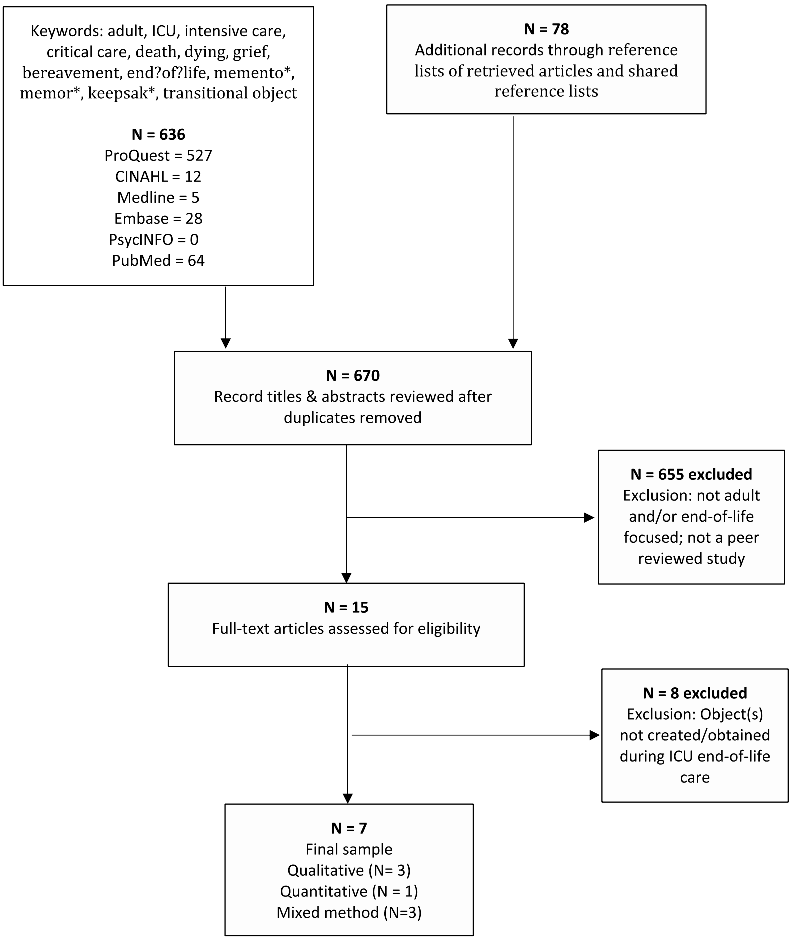

Fig. 1. Summary of literature search and selection.

always welcomed by the family, the subsequent level of family involvement in the words used to create the image, or how those family members used it during bereavement was not reported. It is reported that the placing of words in the collage was performed through the family's engagement and prioritisation of the words, which allowed for a focus on the whole person rather than a beginning, middle, or end to the person's life story.[37] For the family members who received the word cloud memento after death, it is uncertain if the word cloud was offered to them before death or after the death.

It is reported that the creation of the word cloud encourages a remembrance and sharing of the patient's life stories between his/her family, and it assists with creating close connections between the patient, family, and healthcare staff. Some families displayed the memento in places such as the patient's funeral memorial.[37] It is also reported that bedside clinicians perceived that the word cloud assisted with changing the focus of family conversations towards reminiscing about the patient's life story, helped calm the family, and contributed towards acceptance of end of life.[36,37]

Patients who received a word cloud image spent an average of 9 days (interquartile range, 4–24) in the ICU before death,[37] compared to 5.5 days (interquartile range, 3.5–13) in the ICU for the overall 3 Wishes Project participants.[36] It is not reported if the longer time spent by the patient in the ICU and the increased time to facilitate the narrative are required for an effective word cloud creation. Outcomes are not reported for patients or families who spent a short time in the ICU or if their response to the intervention varied from those who spent increased time in the ICU. It is also not reported if the most useful portion of this bereavement intervention is the physical memento of the word cloud or the increased time spent on family–staff interpersonal relationships through their narrative approach to care.

3.2. *ECG memento*

A study from the United States evaluated the impact of a printed copy of the patient's ECG within a card signed by nursing staff as a family memento received during end-of-life care.[38] To evaluate the memento, the researchers used the Satisfaction with Bereavement

Experience Questionnaire[39] and included two additional quantitative questions, which sought to determine how helpful the memento was and how often recipients found comfort in the ECG memento within the card. Fifty family members (46% spouse, 46% children, and 89% female) were enrolled in the study and received the questionnaire 5–6 weeks after the death of their family member in the ICU, of whom 56% ($n = 28$) responded. Time spent by the patient in the ICU until death was 9.5 days, and 61% ($n = 17$) of respondents considered the ECG keepsake extremely or very helpful during their bereavement. The memento was considered somewhat or slightly helpful by 25% ($n = 7$) of respondents, and 14% ($n = 4$) never looked at the memento or found it helpful during their bereavement.[38] In addition, it is unclear if the ECG would have had the same impact if it was not accompanied by the signed card from the nursing staff or if there were differences between spouses and adult children recipients. Nurses reported that the memento was very well received by family members, although the questionnaire response rate was only 38%. Despite the small sample size and only two nonvalidated questions used to evaluate the ECG memento, the findings suggest that families may be receptive to the ECG as a memento.[38]

3.3. Patient diaries

The third type of memory-making object reported in the adult ICU is the use of diaries, which may be given to family members after a patient death.[40–43] Patient diaries in the ICU are typically initiated by healthcare staff during periods of critical illness and are written in regularly by the staff and family relatives to communicate and document the events of the day. After ICU discharge, diaries are usually provided to the patient with the aim to assist them in understanding the daily events during their ICU admission and filling in memory gaps.[42] The use of patient diaries by bereaved family members has been described in a few studies, although only one[40] focused solely on the family's experiences with diaries in the context of bereavement. In this Swedish study, the average length of ICU stay was 38 days (range 6–95 days),[40] which is a significantly longer period than that in other memento studies.[37,38] This qualitative study interviewed individuals 3–11 months after ICU death and included six adult children and three spouses, of which 55% were male. Four out of the nine family members interviewed reported reading the diary after the death of their family member, although it is unclear how long after the death they read the diary. Similar to the word cloud study,[37] participants reported that during the time in the ICU, the diary enhanced their feelings of togetherness and engagement among themselves, as well as with the nursing staff, and assisted with communication.[40] After the death, some family members reported that the diary acted as a bereavement support tool and contributed to their understanding of the ICU events and eventual death. The use of photography in the diaries to compliment the written entries was positively reported by some family members as it helped them solidify their presence at the bedside and document the person's final positive moments and memories. However, for other family members, the diary symbolised death, and they had no intention of reading the diary, indicating that this type of memory making may not be acceptable for everyone.[40]

Three other studies reported the use of patient diaries in bereavement, although their use during bereavement was not the primary focus of these studies.[41–43] A pilot study in Sweden by Bergbom et al.[43] explored patients' and relatives' opinions on ICU patient diaries from the initiation of 18 patient diaries, where eight of those patients subsequently died in the ICU. After the ICU death, the diaries were given immediately to the families,[43] which is earlier after the death than reported in other diary studies.[41,42] Four of the eight families opted to participate in the study, and three of these four respondents believed that the diary memento helped them return to everyday life, whereas the one respondent stated it had not. Family members described that reading the diary helped them to understand, reconcile, and accept the events that occurred in the ICU. Limitations of this study include a small sample size and not knowing if the other four family members who did not participate in the study used the diary at all during bereavement.[43]

Bäckman and Walther[42] explored the use of patient diaries in an ICU in Sweden, which included photos as a debriefing tool for patients after their ICU admission. In this observational study of 51 patients, 10 patients did not survive the ICU admission and an additional four died within the first 6 months after ICU discharge. Patients (mean age, 58 years; range, 2–87 years) who died in the ICU spent an average of 18.7 days in the ICU (range, 4–39 days).[42] Patients and families received the diary during the follow-up visit 2–4 weeks after discharge from the ICU, and questionnaires were sent after 6 months. The response rate to the questionnaire was reported as 100% for the bereaved relatives ($n = 10$). The authors reported that all surviving relatives read the diary, that it helped them cope with their loss, and that the use of photography was “supported” in the diaries, although “supported” is not defined in the manuscript.[42] Questionnaire respondents' demographics were not provided in this study, so it is uncertain how these responses were compared to other participants. In addition, the study reported that four individuals were lost to complete follow-up due to death before the questionnaire was sent, but it is uncertain if these bereaved families were then given the opportunity to respond to the questionnaire.[42]

A pilot study conducted in the United Kingdom by Combe[41] also reported family members' use of patient diaries after ICU death. In this study, the diary, which included photographs, was used as a debriefing tool in ICU follow-up clinics to assist former patients' memory of their time in the ICU. The diary was offered to the bereaved family by letter, and four of the five bereaved families opted to receive the diary after the ICU. The author reports that families were thankful for the diary that helped solidify their memory of the ICU and the events leading to death. However, it was also reported that “some” relatives were upset at viewing photographs used in the diary, although it is not reported why they were upset or how many reported this.[41] The author did not report how these data were collected or the methodological framework applied, so it is difficult to compare these results to other diary studies. In addition, no demographics were reported for the bereaved families, so their age or their relationship to the deceased was unclear. The time taken by the families to opt to receive the diary after receiving the letter was not reported.[41]

3.4. Photographs

The use of photography was described in some studies reporting the use of ICU patient diaries. Photographs in patient diaries are usually reported to be taken to provide a visual image of the written diary entries and are aimed to assist a patient surviving ICU to see what they looked like during their illness.[41,42] One study reported positive experiences with the photographs where the families could reflect on their last memories of their loved one,[40] whereas another reported some relatives being upset at viewing the pictures.[41] It was not reported in the studies if photos were taken with invasive lines hidden from view, if the patient was posed to look sleeping or peaceful, or if anything in particular with the photographs contributed to the positive or negative reactions from families.

4. Discussion

The major findings in this review are that in the limited evidence available, memory-making activities do appear to occur in adult end-of-life care, although the activities of memory making differ from those reported in the neonatal and paediatric literature. We discovered four types of memory-making objects used in adult ICU including word clouds, patient ECGs, diaries, and the use of photographs within patient diaries. In addition, when offered in end-of-life care in the adult ICU, memory making is mostly well received by family members, and the mementos appear to be used in bereavement by many family members after the death of their loved one. These results further suggest that despite families having been afforded time throughout the deceased adult's life for memory-making opportunities, there are objects that can be provided in the adult ICU that families may value during their bereavement. This is consistent with findings from a literature review of parents of deceased children and adolescents who appear to welcome memory-making opportunities at the time of death, despite having had opportunities for memory making throughout their child's life before hospitalisation.[26]

The objects reported in the adult ICU literature mostly differ from those reported in the neonatal and paediatric literature. It is unknown if any one object has greater acceptability, utility, or comfort as an end-of-life and bereavement support strategy after adult ICU death or if the utility of the object varies with the recipient's age or relationship to the deceased. In addition, some studies reported that families spent over a week in the ICU before death and that they developed good interpersonal relationships with the healthcare staff through the memory-making interventions.[37,38] It is unknown if the most useful portion of these end-of-life interventions are the physical mementos or if it is the staff's caring and compassionate gesture and interpersonal interaction in offering a memory-making opportunity, as it has been suggested in the paediatric context.[34] It is also unknown if the goal of creating an object assists the healthcare staff to develop these interpersonal relationships or vice versa. Future research is needed to explore these areas of practice further.

In the studies reviewed, healthcare staff generally described positive experiences with offering memory-making opportunities to families during end-of-life care and reported it being well received by family members from their perspective.[36,38] Although there is limited evidence to fully understand healthcare staff's knowledge, beliefs, and experiences with memory making in the context of end-of-life care, Beiermann et al.[38] did report the importance of educating nursing staff to successfully implement the intervention, including when to approach the families, how to identify the family's acceptance of withdrawal of treatment to discuss the topic, and what to say when offering the memento.[38] Future research is needed to identify enablers and barriers to offering memory making to families and determine the optimal time to engage families in considering such activities, especially for patients and families who might spend a short time in the ICU before death.

Bereavement support is intended to assist families adjust to the loss and help limit the emotional and physical stresses that occur after a death of a loved one,[9,10] which can be particularly important after an ICU death because of their increased risk of developing complicated grief.[1,2] No such evidence exists to date in the adult ICU context. Nurses who provide memory-making opportunities have been described by parents as providing care and attention above and beyond standard clinical duties,[44] which can help to provide a positive reflection of the family's hospital experience.

It has been reported in the neonatal literature that mothers who are able to share the memories they created with their stillborn child with others report fewer symptoms of posttraumatic stress.[30] However, no research was found in the adult population regarding the effect of memory making on the survivor's psychological stress during bereavement. Similar to reports in the neonate population, evidence to date suggests that the adult population may be receptive to memory-making opportunities,[36–38,40–43] although the optimal time to approach relatives is unclear, as well as who is more likely to value such offerings.[37] For example, Beiermann et al.[38] reported that some participants never looked at or did not find the ECG memento helpful during bereavement. Receiving a patient diary after the death was not always well received or wanted by survivors and could possibly be an additional stressor for some individuals by viewing confronting pictures within the diaries.[41] In addition, some individuals interpreted the diary as a symbol of death[40] or found it unhelpful,[43] so sensitivity to the family's wishes to receive the memory-making object should be considered before the object is provided. This variation in response to mementos is also reflected in the neonatal literature, where although offering memory making is a common practice, sensitivity of staff to the receptiveness of parents is encouraged.[32] Future research is needed to explore the effects of memory making on psychological stress as well as whom to approach and the optimal time to approach with the intervention.

We did not find evidence of use of other forms of bereavement mementos and transitional objects, such as locks of hair or clothing, in the adult ICU population. Although photographs were reported as part of patient diaries, we did not find evidence of their use as stand-alone mementos. The use of photography in creating memories after death has origins in the nineteenth century. Its scarcity and expense led to its use predominately after death to capture the image of the deceased ‘sleeping’ during the funeral wake and allow the deceased to be included in family group photos during the wake.[45] In contrast, photography today is highly accessible and frequently used through devices such as mobile phones. Its ease of use and low cost allow the photographs to remind the bereaved of the deceased as they were in the living form, rather than in the nineteenth century's postmortem state.[16] Perhaps relatives do take photographs themselves without being prompted by nursing staff, and this activity is not captured in the studies. Findings from this review indicate that further research is needed to explore the use of photography in adult ICU memory making and determine its potential use in helping surviving family members adjust during bereavement.

Worn clothing is also used as a memento of the deceased[18,19,24] and can also be classified as sacred, where it may be treasured and kept in an intimate space, or profane, where it is ordinary and without special meaning.[22] Clothing can potentially be used as a memory object because of its ability to retain the smell and body shape of its previous owner and evoke memories of how and where it was worn.[24] In the neonatal and paediatric environment, clothing is sometimes what the parents decided to dress their child in,[29] but in relation to adults, clothing more often appears to refer to the left-behind personal possessions that the owner decided on and purchased for themselves.[22,24] Although not described in the literature, personal clothing could be used as a memento in the adult ICU as the last object worn during end-of-life care, and the family could receive their loved one's last worn clothing as an object of memory making.

The use of hair as a memento allows a physical, touchable, and wearable remembrance of the body of the person deceased. Although the use of hair jewellery is not reported in more recent times, the keeping of locks of hair is a continued practice in neonatal, paediatric, and adult populations,[22,26,33] with hair classified as a sacred object by its recipient[22] and therefore could be considered as a memento during end-of-life care in the adult ICU.

The evidence to date regarding memory making in the adult ICU is mostly from studies with small sample sizes, and there appears an absence of randomised control trials or studies with comparison groups. Although evidence to date suggests that family members are mostly receptive to memory-making offerings, owing to the limited number of adult studies discovered in our search, further research is warranted to determine which memory-making objects should/could be offered in the adult ICU population, the acceptance and utility of the objects, and who is most likely to benefit and explore when and how often to approach the family about this intervention. In addition, future research is required to determine healthcare staff's perspectives and beliefs regarding offering memory making, as well as potential facilitators and barriers to offering such opportunities in the adult ICU.

5. Conclusion

From the evidence to date, offering opportunities for memory making at or around the time of death in the adult ICU appears to be generally accepted and valued by surviving family members. However, further research is required on the acceptability and utility of memory making in the ICU environment from both a survivors' and healthcare staffs' perspective as well as to determine whether such practice has benefits in family members' adjustment to the loss of their loved one.

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2.2 UPDATE TO SCOPING REVIEW (APRIL 2018 - AUGUST 2022)

The original scoping review of the literature reported four types of memory making objects from seven research studies performed in the adult ICU including word cloud images, electrocardiogram mementos, patient diaries, and photographs (Riegel et al., 2019). To update the published scoping review describing the practice of memory making as part of end-of-life care within an adult ICU, a systematic search for original research publications between April 2018-August 2022 was conducted. The search used the same criteria as the original scoping review in 2019 (Riegel et al., 2019) using Boolean operators with a combination of keywords: adult, critical care, ICU, intensive care, death, dying, grief, bereavement, end of life, memento*, memor*, keepsak*, and transitional object. The search was performed in the databases: ProQuest, CINAHL, Medline, Embase, PsychINFO, and PubMed, and reference lists of relevant research articles were also reviewed. See Figure 2.1. Since 2018, additionally reported memory making objects include handprints (Harris et al., 2021), locks of hair (Harris et al., 2021; Reeve et al., 2021), hand moulds, fingerprint keychains, and paired crochet hearts (Reeve et al., 2021).

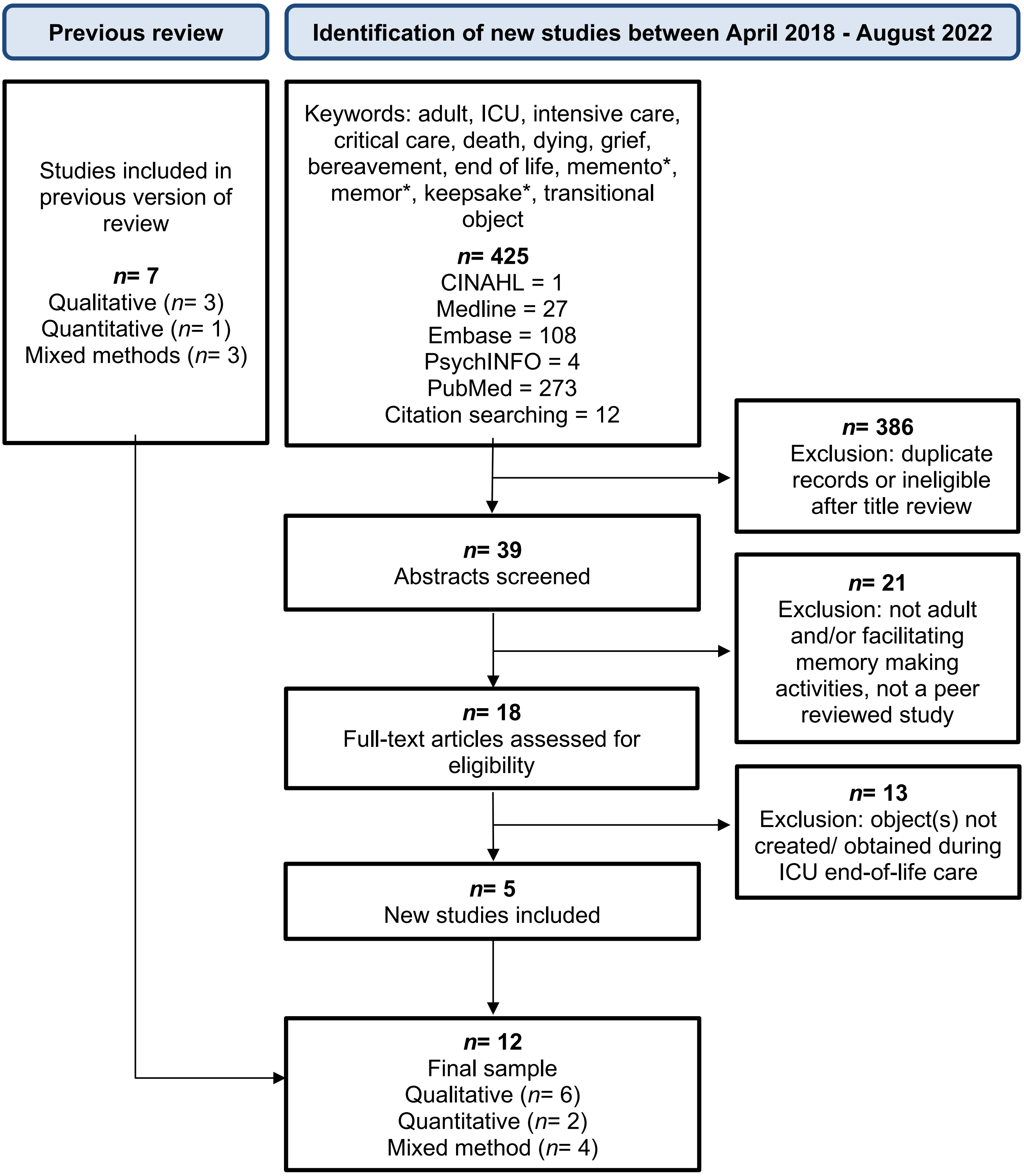

Figure 2.1: Summary of updated literature search and selection between April 2018-August 2022.

As reported in the original scoping review in this thesis (Riegel et al., 2019), a word clouds image was a component of a reported ICU end-of-life/ palliative care program in the “3 Wishes Project” (Cook et al., 2015). This program has since reported medical practitioners, social workers, spiritual care clinicians, and nurses to have lead expansion of this program into other adult ICUs, including community hospitals (Neville et al., 2020; Reeve et al., 2021; Vanstone et al., 2020). One study regarding the 3 Wishes Project reported a secondary analysis of data obtained from 36 semi-structured interviews from bereaved participants experiences with an end-of-life/ palliative care program, reporting that the object(s) received through the adult ICU program were highly valued by participants. It was also reported that the gesture of offering was equally as valuable as the memory making object received (Neville et al., 2020). This secondary analysis reports from a large sample size of participants mentioning the objects as part of their experience, although the authors acknowledge study limitation to include the interviews not having been structured to explore the memory making objects in detail (Neville et al., 2020).

In addition to the previously reported word clouds, one observational, descriptive study from the Three Wishes Project reported memory making objects to also include paired crochet hearts, locks of hair, fingerprint keychains, photographs, and hand moulds (Reeve et al., 2021). Though this study reported an expansion on the types of memory making objects, the study’s aim was to report the adaptability and implementation strategies for the Three Wishes program within a community hospital and had limited reports of experiences with the memory making objects. However, it did report that nurses had championed the overall bereavement intervention at the study site (Reeve et al., 2021).

A questionnaire study of healthcare professional in a general ICU reported objects such as handprints and locks of hair being offered to family by some participants as part of their bereavement care delivered (Harris et al., 2021). The study reported bereavement care to be nursing led, which was similarly reported by Reeve et al. (2021). Detailed into when, who, and how the objects were provided was not reported (Harris et al., 2021). Study data was reported to be collected using a questionnaire instrument that was untested prior to its use, and the response rate was 18.4% and predominately nurses. Information from this study was acknowledged to be limited due to low response rate and an imbalance of responses from the eligible sample of healthcare professional (Harris et al., 2021).

A qualitative, exploratory study of bereaved participants following a cardiac ICU death reported mixed feelings concerning participant’s desire to have received a memory box containing objects such as locks of hair or fingerprints, if offered (Erikson et al., 2019). The opinions of the study’s 12 participants was reported to be divided (Erikson et al., 2019), but it was not reported if particular item(s) would have been more acceptable than others within the box. Additionally, participants were 13-15 months after the death event, which might have affected their opinions about potential bereavement interventions.

A phenomenology study reporting the experiences of participants receiving post-mortem ICU patient diaries and photos reported participants felt the diaries provided comfort and support (Melby et al., 2020). The diary entries were primarily composed by the ICU nursing staff, which was reported to be preferred by the participants rather than them composing the diary entries. Additionally, it was reported that reading the nurses' entries reinforced the acts of caring the nurses performed and were meaningful for the participants. The photography included in the diaries was reported to be highly cherished because participants commonly did not take their own pictures while in ICU (Melby et al., 2020). All diary recipients in this recent study were reported to have read the diary, unlike the previously reported study by Johansson et al. (2018) of post-mortem patient diaries. The reasons for the mixed participants' reaction to the patient diaries is uncertain but could be attributed to the writing style or content of the diary entries. In the earlier Johansson et al. (2018) study, it was reported that the family had read and written in the diary while in ICU, whereas in the more recent Melby et al. (2020) study, nurses were reported as the primary patient diary authors.

2.3 SUMMARY AND IMPLICATIONS

The scoping review of the research literature revealed a significant increase in research over the last four years reporting memory making as an end-of-life care and bereavement intervention in the adult ICU. From the peer-reviewed research studies identified where memory making was offered in the adult ICU, the types of objects included word cloud images, electrocardiogram mementos, patient diaries, photographs, and has now expanded to include crochet hearts, locks of hair, fingerprint keychains, and hand moulds. Despite the increase in identified research studies, there remains uncertainty in memory making as an end-of-life care and bereavement intervention in the adult ICU due to limited empirical evidence for the utility of memory making from bereaved loved ones and its use during their bereavement. Additionally, there is little evidence related to healthcare professionals' experience with providing memory making opportunities to family during end-of-life/bereavement care and what factors are required to integrate this intervention into their standard patient and family care provided.

The aim of this thesis is to *explore the experience of memory making interventions during end-of-life/bereavement care in the adult intensive care unit from the healthcare professionals offering and the family receiving the intervention*. To do this, a two-study arm design was utilised to address the questions:

1) What is the experience of healthcare professionals offering memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?

2) What is the experience of relatives receiving memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?

Chapter 3: Methodology

This chapter describes the methodology used for data collection and analysis of the two studies to address the thesis aims and the objectives of the two research questions. This chapter begins in section 3.1 by stating the use of the philosophy of pragmatism as the paradigm for this study. Then section 3.2 provides the research design for this thesis. An overview of the theoretical perspectives utilised is next presented in section 3.3.

3.1 PARADIGM

This thesis is situated within a pragmatic paradigm. The philosophy of pragmatism was first introduced around 1870, and the classic pragmatists most influential in this philosophy were Charles Peirce, William James, and John Dewey (Hookway, 2013). The philosophy of pragmatism theorises knowledge claims are fallible and revisable; they are the results of one's actions, situations and consequences in life, not the metaphysical discussion about the nature of truth (Creswell, 2003; Morgan, 2014). It emphasises the importance of the problem and is not limited to a single method to understand the problem (Creswell, 2003; McCready, 2010). Due to the extensive work in the philosophy of pragmatism by Dewey, including his descriptions of scientific inquiry and its relations to human actions and experience, and Peirce's work in sign, object, and interpretant, their theories will be the primary focus in this exploration of the experience of memory making (Biesta &

Burbules, 2003; Cashell, 2007; Dewey, 2003; Hookway, 2000; Morgan, 2014; Peirce, 1994).

According to Dewey, organisms (i.e., people) continually interact and adapt to their environment to maintain balance, which is referred to as transactional approach, or transactional realism. Through this approach, reality can be revealed as a result of the person's activities and experiences with the environment (Biesta & Burbules, 2003). The experience is based on a continual and interconnected cycle: what are the sources of our beliefs, and what are the meanings of our actions? (Morgan, 2014). Because the person continually seeks to maintain a balance between themselves and the environment, there is a continual change in both the environment and the actions of the person in response to the environment. Uncertainty always exists though, and previous actions could be fallible and probabilistic for future problems. The philosophy of pragmatism argues that knowledge and action are inseparable and are continually feeding back into one another (Biesta & Burbules, 2003; Younas, 2020).

According to Peirce, a triadic relationship exists where 1) a sign functions as a signifier for something, 2) the object is what is signified by the sign, and 3) the interpretant (a person) applies meaning and understanding between the sign and the object (Peirce, 1994). Peoples' memories serve as a source of knowledge about the deceased, and their creation requires the person to actively construct within their mind the ideal presence of the person that is no longer present. This new ideal presence exists only as a mental image for the bereaved survivor (Dewey, 2003). Applying Peirce's theory of signs, a keepsake object or a memento (the sign) may serve as an instrument of memories, thoughts, and knowledge for the bereaved family, as the deceased (the object) are represented to the bereaved family (the interpretant) through the keepsakes (Cashell, 2007; Hookway, 2000; Peirce, 1994). Keepsakes are classified as thus when a survivor applies meaning to the object that then they link back through their memories of the deceased when they want to remember them (Cashell, 2007; Jensen, 1991; Peirce, 1994). Memory created through keepsakes are specific to each person, as survivors have the ability to weave together mixtures of real and imagined memories through varying contexts, feelings, and experiences triggered by the object (West, 2013).

3.2 RESEARCH DESIGN

In the philosophy of pragmatism, the process of research is not limited by a set of techniques or instruments, but allows for multiple tools of inquiry to gain different perspectives to address the research question (Biesta & Burbules, 2003). To explore the experience of memory making interventions during end-of-life/bereavement care in the adult ICU from the healthcare professionals offering and the family receiving the intervention, two studies were conducted to explore this topic. See Figure 3.2 for the thesis research design.

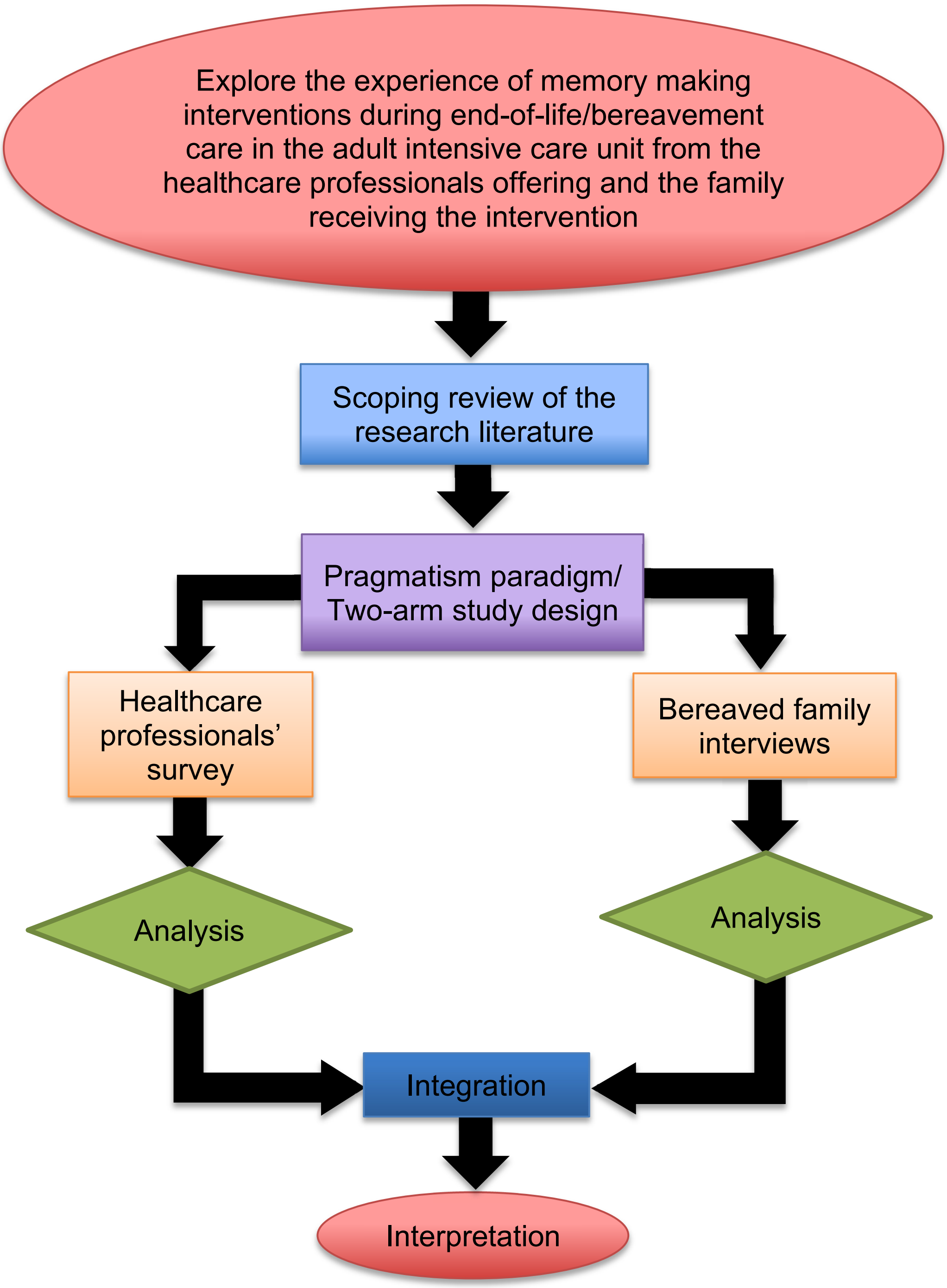

Figure 3.2: Thesis research design

The decision was made to conduct this study as two-study arms rather than mixed methods because mixed methods is defined as the utilisation of qualitative and quantitative data in one study that is to be integrated (Andrew & Halcomb, 2009). Since this current study required two unrelated sets of participants to address the thesis aim, it was concluded that two-study arms with a subsequent integration during this thesis discussion was a more appropriate approach.

The first study was a survey design that was administered to adult intensive care healthcare professionals to answer the question “What is the experience of healthcare professionals offering memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?”

The second study was conducted as a descriptive qualitative study using semi-structured family interviews to answer the question “What is the experience of relatives receiving memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?”

After data was analysed from both studies, data was integrated and interpreted in the discussion of this thesis to explore the experience of memory making during end-of-life/bereavement care in the adult ICU. The location of this study was chosen because it routinely offers memory making to family members who are bereaved.

3.3 THEORETICAL PERSPECTIVE

3.3.1 Behaviour theory

The Theoretical Domains Framework (TDF) was utilised as the framework to guide the design of the survey instrument to evaluate the healthcare professionals’ experience offering memory making in the first study of this thesis. The TDF was chosen because it is a synthesis of several behaviour and behaviour change theories that highlights cognitive, affective, social and environmental behavioural influences on healthcare practice implementation (Atkins et al., 2017; Michie et al., 2005). Additionally, the TDF has been reported as a valid and reliable framework for questionnaire development and can be utilised with existing interventions to facilitate understanding of the clinicians' behaviours that drives their practice (Huijg et al., 2014; Michie et al., 2021).

For this thesis, the original 12-domain TDF was utilised due to its continued applicability for determining behaviour influences (Atkins et al., 2017; Huijg et al., 2014; Michie et al., 2005). The domains, or categorisations of related theoretical constructs, explored were 1) knowledge, 2) skills, 3) social/professional role and identity, 4) beliefs about capabilities, 5) beliefs about consequences, 6) motivation and goals, 7) memory, attention and decision processes, 8) environmental context and resources, 9) social influences, 10) emotion, 11) behavioural regulation, 12) nature of the behaviours (Michie et al., 2005).

3.3.2 Dual Process Model of Coping with Bereavement

The Dual Process Model of Coping with Bereavement (DPM) was utilised to explore and provide contextual understanding to the bereavement experience of family study participants in the second study of this thesis. The DPM was chosen because of its reported ability to accurately represent experiences during bereavement, and its ability to account for differences in grieving during bereavement, including gender differences and social and cultural differences (Fiore, 2021; Stroebe & Schut, 1999). According to the DPM, individuals adjust to bereavement by oscillating between confronting and avoiding stressors within loss-orientation and restoration- orientation (Stroebe & Schut, 2010). Loss- orientation refers to concentrating on, processing the experience, and possibly ‘searching’ for the deceased. Restoration- orientation refers to restoring and reorienting oneself in a world without the deceased. The DPM theorises that individuals who are able to perform the effective coping processes and oscillate between loss- orientation and restoration- orientation should experience a reduction in mental and physical complications from the bereavement (Stroebe & Schut, 2010).

Chapter 4: Methods

This chapter discusses the methods used for each study arm where section 4.1 presents the survey of intensive care healthcare professionals and section 4.2 the bereaved family interviews. A summary of this chapter is then presented in section 4.3.

4.1 SURVEY OF INTENSIVE CARE HEALTHCARE PROFESSIONALS

The author of this thesis was a healthcare professional in the adult ICU where this study was performed. Due to professional relationships with potential participants, qualitative methods to explore the healthcare professionals' experience with memory making might have led to questions about trustworthiness of findings from the study participants since they might not have felt free to speak openly about their experience to their co-worker/ the author of this thesis (Conneeley, 2002). To overcome potential bias in data collection of the ICU healthcare professionals, an anonymous survey designed with Likert scales and open-ended questions was created and administered.

4.1.1 Instrument

The survey instrument consisted of three sections. The first section of the survey gathered participant demographic information. The second section was adapted from a previous national survey that explored factors influencing the provision of end-of-life care in registered nurses in critical care settings (Ranse et al., 2015). Adaptations included omitting the phrase "nurse" or replacing it with an inclusive term such as "healthcare staff" to be applicable to non-nurse participants. This survey section measured provisions of end-of-life care across eight concepts, which were organised by the Promoting Action on Research Implementation in Health Services (PARiHS) framework: knowledge, preparedness, patient and family preferences, organisational culture, resources, palliative values, emotional support, and care planning (Ranse et al., 2015).

The third section of the survey related specifically to the participants' experiences in facilitating memory making activities as part of end-of-life/bereavement care in the adult ICU. Questions were developed using the original Theoretical Domains Framework (TDF) as a guide for factors that influenced the individual's behaviours with regards to memory making. The domains explored were 1) knowledge, 2) skills, 3) social/professional role and identity, 4) beliefs about capabilities, 5) beliefs about consequences, 6) motivation and goals, 7) memory, attention and decision processes, 8) environmental context and resources, 9) social influences, 10) emotion, 11) behavioural regulation, 12) nature of the behaviours (Michie et al., 2005).

Survey questions consisted of 6-point Likert scales, where: 1= completely disagree; 2= mostly disagree; 3= slightly disagree; 4= slightly agree; 5= mostly agree; 6= completely agree. For questions where experience in memory making was believed to be necessary to answer the question, the option of 'not applicable' was available to participants. Open-ended questions were also included in the third section exploring memory making to allow participants the ability to further elaborate on topics, which provided a richer understanding of their experience beyond the Likert scalable answers. An expert panel consisting of two intensive care registered nurses and one intensive care medical specialist reviewed the survey instrument for face validity prior to use. See Appendix A-B for the survey instrument.

4.1.2 Participants

The survey was administered to 128 eligible healthcare professionals where they self-determined participation eligibility based on provided criteria. Inclusion criteria for the survey included all medical practitioners (MP), registered nurses (RN), and social workers (SW) employed full time, part time, or casual pool at the Prince of Wales Hospital adult ICU who have had experience in implementing end-of-life/bereavement care. Exclusion criteria included medical practitioners, registered nurses, and social workers working as agency staff or having worked less than three months in the study site. Healthcare professionals without experience in end-of-life/bereavement care were excluded from this study. These healthcare professional groups were most commonly involved in routine end-of-life/bereavement care at the study site, so these groups were eligible for participation to gain a greater understanding of the practice of memory making. Complimentary and advanced practitioners such as nurse practitioners or dedicated ICU chaplains are not employed in this ICU, so these professions were not eligible for study inclusion.

The survey data was collected anonymously, so investigators did not know who had or had not completed the survey.

4.1.3 Procedure and timeline

The survey was administered in both a paper version as well as the online platform REDCap electronic data capture tools hosted at the University of Sydney institution (Harris et al., 2019). The paper version was available in the ICU staff tea (break) room to allow for anonymity and communal access to the survey during work hours, and the link to the online survey was distributed through the healthcare professionals' work email account and the ICU's private social media page. To promote and maximise survey participation, encouragement to participate in the survey on email and social medial was completed as an initial invitation, then a follow-up reminder to prior to study closure. Healthcare professionals were also directly notified of the survey in person by the author of this thesis, the ICU nursing educators, and/or a medical staff specialist. The survey was administered between June - August 2017.

Data from the paper surveys were transcribed into an electronic version using the REDCap interface by the author of this thesis. Transcription verification was performed by the author of this thesis following data entry for all transcriptions.

4.1.4 Analysis

Statistical analysis was conducted using IBM SPSS, version 24 (IBM Corp, 2016). Survey section two containing the Ranse provisions of end-of-life care questionnaire with the adaption of the term “healthcare staff” consisted of 42 questions from eight provisions of end-of-life care factors. The original Ranse factors were utilised because this study’s respondents compared to the number of variables would have limited reliability of exploratory factor analysis results (Mundfrom et al., 2005; Yong & Pearce, 2013). Internal reliability for the Ranse’s original provisions of end-of-life care study scale has been previously reported with Cronbach’s alphas ranging from 0.69-0.85 (Ranse et al., 2015). Cronbach’s alpha for the adapted scales were calculated as: knowledge (0.79), preparedness (0.67), patient and family preferences (0.73), organisational culture (0.53), resources (0.78), palliative values (0.69), emotional support (0.82), and care planning (0.78). According to the original Ranse factors, organisational culture is described as the perception of a nurse-led practice during end-of-life care. The Cronbach’s alpha in this study could be low due to having only three questions within this factor (Tavakol & Dennick, 2011).

Analyses were performed for each item of the survey as well as the eight provisions of end-of-life care. There has been no adjustment for multiple testing as such corrections can be overly conservative and fail to reveal potentially relevant findings in a novel and under researched area of practice (Perneger, 1998). Normality of the descriptive data was assessed by calculating the Fisher skewness coefficient, Kolmogorov-Smirnov statistic, and inspecting the shape of the distribution of the histograms. Descriptive statistics were reported as mean (M) (standard deviation [SD]) as appropriate. Comparisons and post hoc analysis between the responses of RNs' and medical practitioners' as well as those with self-reported experience offering memory making were reported using Mann-Whitney U, Spearman Rank Order, and Chi-squared (X^2) tests as appropriate. Alpha level was set to 0.05. Substitution of the missing data was not performed as the missing data (0.5%) was considered random (Altman & Bland, 2007).

To add value and insight for knowledge creation beyond pattern reporting (Thorne, 2020), open-ended question data from the third section regarding memory making were analysed through the six-phase process of inductive reflexive thematic analysis (Braun & Clarke, 2006, 2020). The six-phase process performed by this thesis author included data immersion and familiarisation, systematic data coding, initial theme generating, reviewing of the themes, further refining of the themes, and report writing (Braun & Clarke, 2020). This was performed for each individual question to provide as detailed and accurate a reflection of the data as possible (Braun & Clarke, 2006). All study investigators reviewed and agreed on the extracted themes, as the use of reflexive thematic analysis recognises the researcher's subjectivity, contextual, and situational knowledge as a resource for knowledge creation (Braun & Clarke, 2020).

4.1.5 Ethical considerations

Ethics and site approval were obtained from the South Eastern Sydney Local Health District Human Research Ethics Committee (HREC Ref 17/152). See Appendix C for copy of site approval.

The main ethical considerations involved participant consent, privacy and confidentiality. Support was enlisted from relevant members of the healthcare team at the hospital where the study was conducted. Information about the survey was supplied on a participant information sheet to all potential participants prior to start of the survey. Healthcare professionals were reminded of the Employee Assistance Program in the event they experience distress from any questions in the survey. Consent was implied for all returned surveys. A secure box to collect the paper surveys was in a staff communal area to allow for anonymous return of the paper surveys. Online submissions were anonymous. Although participants were free to omit parts of the survey if desired, some participants might be able to be identified based on their response in the demographic section requesting the country of their primary professional health education/training or if their provided profession did not have a significant number of survey responses.

Permission to use the previously published survey related to provisions of end-of-life care was sought and granted from the original Australian author for use in this study (See Appendix D).

Electronic files were stored on a hard drive that is password protected. Surveys received through the online platform REDCap are only accessible to the author of this thesis through password protection and have been removed after completion of the survey. Storage of paper surveys are located in a double-clocked cabinet. Data will be stored for a minimum of 5 years after project completion as required according to the Research Code of Conduct 2019 (The University of Sydney, 2019). The findings of this study have been disseminated to the critical care profession through a conference presentation and publications in peer-reviewed nursing and critical care journals. See section 5.1 for results of the survey.

4.2 BEREAVED FAMILY INTERVIEWS

Qualitative description was chosen for the second study for its ability to provide rich descriptions of a lesser-known experience and describe the phenomenon from the perspectives of the study participants (Bradshaw et al., 2017; Hammarberg et al., 2016). Bereaved family interviews were conducted using an interview guide informed by a review of the literature to assist with discussion points during the semi-structured interviews:

1. Tell me about your loved one.
2. How did you find the ICU staff/environment during this time?
3. What made you decide to receive a memory making object?
4. What did you initially think about the object/staff when you were approached about it?
5. When were you approached about the object?

6. How did they approach you?
7. Tell me about the object.
8. What makes that object special?
9. How did you treat/react to the object in the first few weeks?
10. How do you treat/react to the object now?
11. Where is the object kept?
12. What do you think you'll do with the object in a year/2/5 years from now?
13. Is there anything else you'd like to add that I haven't already asked you about?

4.2.1 Participants

A purposeful, convenience sample of consenting surviving spouse/ partner/ children/ parents whose loved one died while in a single centre adult ICU and who did participate in memory making activities during their family members stay in ICU were invited to participate. Such activities included handprints, footprints, locks of hair, or teddy bears.

After family members freely decided and received a memory making object(s) as part of standard ICU end-of-life/bereavement care, the ICU healthcare professional provided them with an initial information sheet to briefly inform them of this study. The author of this thesis provided multiple education sessions and information to the ICU healthcare professionals concerning this planned study and the timing of when to distribute the initial information sheet to the family to ensure they were free to consider participation in a memory making activities before being notified of this study. As part of standard bereavement care in the study ICU, all ICU bereaved family members received follow-up phone calls around week five post ICU discharge by the author of this thesis as part of her ICU clinical nurse specialists' role. The follow-up calls were primarily placed to the designated family member according to their hospital discharge records. If the call was unanswered or if requested by the family, other family members also received follow-up phone calls as part of standard bereavement care. If family members reported significant bereavement experience during the phone call such as nightmares, they were not approached for participation at the discretion of the author of this thesis. At the conclusion of the phone call, appropriate family members that met initial evaluation of study inclusion criteria were reminded about the initial information sheet obtained in ICU, and their interest in study participation discussed. For participants who agreed, a future time and location for a meeting was arranged based on the potential participants' preferences. At the arranged meeting, potential participants were provided the full participant information sheet, given time to read and ask questions, then decided if they wished to continue with the interview during that meeting.

Exclusion criteria included survivors who are 17 years of age or younger and/or did not receive a memory making object during end-of-life care while at the single centre adult ICU were excluded from this interview. Family members were also excluded if the death event was more than six months prior to an arranged interview time. Individuals who did not speak English were not included in the study, due to their inability to give informed consent or conduct the study interview without a translator. Family members were not utilised for translation due to possible inaccuracies in translation (Flores et al., 2012).

Initially, family members who lived more than two hours driving time of the study site were excluded from this study to allow for the interviews to occur face-to-face. This initial decision was made to allow for a more intimate interaction with the interviewer to provide a more humanistic opportunity to discuss these sensitive topics and for the interviewer to console the interviewee or direct them towards further assistance if necessary. As a result of public health measures related to the COVID-19 global pandemic, interviews from March 2020 were conducted over online video conference to limit health risk to the participant and interviewer. For these interviews, participant information sheet, consent form, and demographics information were supplied to the participant over the online platform REDcap through a website URL and demographic data collected through REDcap. Paper copies were also mailed by the postal service to consenting participant after the online video interview.

For the qualitative family interviews, it was planned that a sample of approximately 20 participants would be recruited or until the data provided adequate complexities and richness to generate meaningful knowledge to answering the research question (Braun & Clarke, 2019).

4.2.2 Data collection

The author of this thesis conducted all interviews at the participant's location of choice. An interview guide informed by a review of the literature was utilised to assist with discussion points during the semi-structured interviews. Throughout the interview, the author of this thesis followed the participant's lead on topics and utilised these as a bridge between topic areas as appropriate.

Between May 2019-December 2020, 18 semi-structured interviews were conducted with 21 individuals. Sixteen interviews were conducted face to face at the participant's location of choice, which was predominately at their home (*n*=12, 67%), four at other locations such as their place of employment (22%), and two over videoconferencing (11%). In three interviews, other family members also consented to study participation. In nine interviews, there was also the presence of non-participants, which were other family members who were present to support the interviewee or who lived in the home. Three eligible participants were invited to participate but declined. One declined after being informed about the study at the end of the follow-up phone call for reasons including not desiring to talk about it, and two individuals declined participation after reading the full participant information sheet with no reasons stated. No participants chose to withdraw from the study after participation.

After participant’s consent, audio recordings of the interviews conducted both in person and using videoconferencing were recorded using recording devices and stored on a password protected computer. Transcriptions of the audio recordings were completed by the author of this thesis and were checked back against the original audio recordings for accuracy by the author of this thesis and Investigator S.R. Transcripts and the participant’s demographic information were stored on a password protected computer. The interviews occurred on average 55 days after the death (range 38 to 81 days). The average interview was conducted over 81 minutes, with the shortest interview conducted over 12 minutes and the longest at 246 minutes.

4.2.3 Data analysis

To add value and insight for knowledge creation beyond pattern reporting (Thorne, 2020), interview data were analysed through inductive reflexive thematic analysis (Braun & Clarke, 2006, 2020) focusing on the participant’s experience of receiving memory making interventions. Since this is an under researched area, the entire data set was analysed together without attempting to fit the data into pre-existing codes or the researcher’s presumptions (Braun & Clarke, 2006). To perform a trustworthy account of the participant’s experience, the 6-phase process for reflexive thematic analysis was followed, including data immersion and familiarisation through listening to audio recordings, transcribing the data and re-reading transcripts; systematic data coding through reading transcripts line-by-line; initial theme generation by looking for larger patterns amongst the codes; review of the themes by all investigators in relation to the study aim and objective; further refining of the themes, and report writing (Braun & Clarke, 2020; Connelly, 2016).

4.2.4 Rigour

Following data interpretation using reflexive thematic analysis, the investigators' subjectivity is a source to assist in knowledge production within this study (Braun & Clarke, 2020). The author of this thesis is a senior registered nurse in the ICU where the research was conducted and is experienced in supporting family members during end-of-life care and into the initial time of bereavement. While the author of this thesis did not provide direct patient care during the hospital admission to any of the patients or family members interviewed, she was recognised during the interview by one family member as having been in-charge of the intensive care unit during one nursing shift of their loved one's admission. The author of this thesis did maintain a personal diary to document reflections of all interviews immediately afterwards, which assisted in self-reflections concerning the author of this thesis' role in the research process, and maintained an audit trail in electronic format (Greene, 2014; Lincoln & Guba, 1985).

4.2.5 Ethical considerations

Ethics and site approval, as well as amendments in response to COVID-19 public health restrictions, was sought and obtained from the South Eastern Sydney Local Health District Human Research Ethics Committee to conduct the study

(HREC Ref 17/325). See Appendix E for copy of approval. It has been reported that individuals do appreciate participating in research following death of their loved one to share their experiences and can provide informed consent (Whitfield et al., 2015). Consequently, the predominate ethical consideration involved the interviews having the potential to cause participants to experience some degree of heightened emotions. The author of this thesis conducting the interviews was sensitive to participants' needs during the interview and planned to stop the interview should the participant express a wish to do so, or if the participant showed signs of distress beyond normal grief reactions. At all times, the investigator monitored for any risks for the well-being and health of the participants during the performing of the study assessments, and suggestions for visiting their general practitioner for referrals or to a community bereavement service were made as required. Participants were also given the option to receive information about community bereavement counselling services through a copy of the study site's social work department's standard bereavement booklet if they had not already received a copy as part of routine ICU end-of-life care.

Interview location was chosen by the participants, including their home (*n*= 12), or a location such as their place of employment (*n*= 4). To ensure investigator safety, the local health district procedure *WHS – Working Off Site Risk Management Procedure* (SESLHDPR/230) was followed for visiting participant's when not at the study site. Interviews conducted using videoconferencing (*n*= 2) were only audio recorded using the same devices had the interview been conducted in person. At the start of the videoconference, the participant consent form and demographic information sheet were distributed and returned using REDCap electronic database capture tools (Harris et al., 2019) hosted at the University of Sydney institution. Participants were advised that they may withdraw their consent at any time during the study and were given or mailed a paper copy of a withdraw request.

The family interviews were recorded on secure audiotape devices and were then transcribed by the author of this thesis. The demographic data and audio recordings were allocated study specific codes, only handled by study specific investigators. Electronic files are stored on a hard drive that is password protected. Participant information received through the online platform REDCap were only accessible to the author of this thesis through password protection and have been removed after completion of the analysis. Storage of paper copies of the demographic information and consent forms are located in a double-clocked cabinet. Data will be stored for a minimum of five years after project completion as required according to the Research Code of Conduct 2019 (The University of Sydney, 2019). The findings of this study have and will be disseminated to the profession through conference presentations and publication in peer-reviewed nursing and critical care journals.

4.3 CHAPTER SUMMARY

This chapter has discussed the methods used for the two studies to explore the experience of memory making interventions from the healthcare professionals offering and the family receiving. The survey instrument in the first study of this thesis will be utilised to obtain data answer the question “What is the experience of healthcare professionals offering memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?" For the second study of this thesis, family interviews will be utilised to gather data to answer the question "What is the experience of relatives receiving memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?"

Chapter 5: Results

Results from the two studies are presented in this chapter to explore the experience of memory making interventions during end-of-life/bereavement care in the adult ICU from the healthcare professionals offering and the family receiving the intervention.

Section 5.1 reports results of the first study with ICU healthcare professionals' survey, including participant demographic information. This section begins in 5.1.1 by presenting a peer-reviewed manuscript reporting the end-of-life care values and experiences for the healthcare professionals (Riegel et al., 2021). Section 5.1.2 provides results concerning the knowledge, skills and roles for offering memory making (Riegel et al., 2022b). Section 5.1.3 provides the factors associated with the healthcare professional's decision to offer memory making (Riegel et al., 2022a).

Finally, the second study of the bereaved family interviews is presented in section 5.2, including demographic information and results provided in section 5.2.1 in a draft manuscript format that has been submitted for peer review for publication. Section 5.3 provides a chapter summary.

5.1 SURVEY OF INTENSIVE CARE HEALTHCARE PROFESSIONALS

The survey instrument obtained data to answer the question “What is the experience of healthcare professionals offering memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?”

There were 128 eligible healthcare professionals working within the ICU study setting. From this population, a sample of 97 participants was required to achieve a confidence level of 95% and margin of error of 5% (CheckMarket, 2020). In this study, 100 participants responded (78% response rate); four respondents were then excluded from final analysis due to survey incompleteness of 75% or more. Valid survey participants included: 75 registered nurses (75% response rate), 19 medical practitioners (76% response rate), and 2 social workers (66.7% response rate). The mean age of participants was 38.1 years and was similar among professional groups. Just over half reported completing their professional education in Australia, and length of experience as a registered health professional ranged 1.5 to 40 years, with length of experience in ICU ranging from 3 months to 37 years (Riegel et al., 2022b).

5.1.1 Healthcare professionals end-of-life care values and experiences

Healthcare professional participants’ values and experiences with facilitating end-of-life care is presented in the following peer-reviewed publication.

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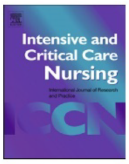

Research Article

Healthcare professionals' values about and experience with facilitating end-of-life care in the adult intensive care unit

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ABSTRACT

Objectives: To evaluate values and experience with facilitating end-of-life care among intensive care professionals (registered nurses, medical practitioners and social workers) to determine perceived education and support needs.
Research design: Using a cross-sectional study design, 96 professionals completed a survey on knowledge, preparedness, patient and family preferences, organisational culture, resources, palliative values, emotional support, and care planning in providing end-of-life care.
Setting: General adult intensive care unit at a tertiary referral hospital.
Results: Compared to registered nurses, medical practitioners reported lower emotional and instrumental support after a death, including colleagues asking if OK ($p = 0.02$), lower availability of counselling services ($p = 0.01$), perceived insufficient time to spend with families ($p = 0.01$), less in-service education for end-of-life topics ($p = 0.002$) and symptom management ($p = 0.02$). Registered nurses reported lower scores related to knowing what to say to the family in end-of-life care scenarios ($p = 0.01$).
Conclusion: Findings inform strategies for practice development to prepare and support healthcare professionals to provide end-of-life care in the intensive care setting. Professionals reporting similar palliative care values and inclusion of patient and family preferences in care planning is an important foundation for planning interprofessional education and support with opportunities for professionals to share experiences and strengths.

Implications for clinical practice

- Decisions regarding end-of-life care in the intensive care can be complex and challenging for healthcare professionals involved.
- Support strategies are needed to support healthcare professionals providing end-of-life care. Such strategies may include greater peer-to-peer emotional support, in-service education in topics such as communication techniques, and changes in workloads to allow professionals enough time to spend with the family.
- Interprofessional approach to ongoing supports and education may be beneficial so healthcare professionals can learn from each other's strengths and experiences and may also help promote a supportive climate among intensive care professionals when delivering end-of-life care.

Introduction

Intensive care is predominately used for people with a reversible critical illness where the treatment goal is to return them to their acceptable level of quality of life (Australian and New Zealand Intensive Care Society, 2014). In situations where this goal

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is unable to be met, life-sustaining treatment is ceased, and the focus of care is changed to providing dignity, comfort and limiting distress during the dying process (Australian and New Zealand Intensive Care Society, 2014).

Providing end-of-life care is routine intensive care management with mortality rates for adult intensive care units reported around 5.6–19.1% (Australian and New Zealand Intensive Care Society, 2018; Capuzzo et al., 2014; Lilly et al., 2017). Despite end-of-life care being common management, the decision to change the primary focus of care for the intensive care unit (ICU) patient from delivering lifesaving treatment to promoting dignity and comfort during the dying process can be complex and contain some levels of uncertainty for ICU health professionals with prior research reporting potential personal feelings of distress delivering the care, struggles with prognostication, conflicts between family or interprofessional teams, role dissatisfaction, and being emotionally burdened with providing the care (Donnelly and Psirides, 2015; Pattison et al., 2020; Taylor et al., 2020). Healthcare professionals' experience with providing end-of-life care is a dynamic process that is influenced by their learned behaviour in approaching and implementing end-of-life care, the emotions associated with the behaviour, and deliberations required to make choices in times of conflict between behaviour and emotion (Farjoun et al., 2015). This triad may be influenced by an individuals' values and the workplace organisational culture (Farjoun et al., 2015).

Healthcare professionals who have received education on end-of-life care topics are reportedly better able to cope with a patient's death and are consequently reported to be able to provide higher quality end-of-life care (Zheng et al., 2018), but healthcare professionals commonly report gaps in their knowledge, skills, and the supports received to implement this type of ICU care (Brooks et al., 2017; Carvajal et al., 2019; Ganz, 2019; Ranse et al., 2020).

Despite evidence that providing end-of-life care can take a toll on bedside professionals, limited empirical evidence is available on healthcare professionals' values and experiences with end-of-life care (EOLC) (Efstathiou et al., 2019), and the majority of available evidence is based on qualitative studies (Pattison and Campbell, 2016). Having a greater understanding of the healthcare professionals' values and experiences with end-of-life care using a quantitative approach will inform future multidisciplinary emotional and instrumental support strategies, including targeted education programs to facilitate best practices in end-of-life scenarios.

The aim of this study was to evaluate values about and experiences with facilitating end-of-life care among nursing, medical, and social work professionals to determine the perceived supports and educational needs of healthcare professionals in providing EOLC. Specifically, this study evaluates health professionals: knowledge, preparedness, patient and family preferences, organisational culture, resources, palliative values, emotional support, and care planning. This study is the first of our knowledge to explore, through survey, provisions of end-of-life care for ICU healthcare professionals.

Materials and methods

Study design

A survey was administered both by paper and online using REDCap electronic data capture tools hosted at the University of Sydney (Harris et al., 2019) to achieve the objectives of the study.

Study site

This study was conducted at a combined 13-bed general adult ICU, 4-bed high dependency unit at a tertiary referral centre in Sydney, Australia. This hospital does not have a separate palliative care ward, so end-of-life care during a person's terminal phase of life is conducted within the ICU, or at times, a patient may be transferred to an appropriate ward for more long-term nursing care. Ethics and site approval were obtained from the South Eastern Sydney Local Health District Human Research Ethics Committee (HREC Ref 17/152).

Sampling and recruitment

All registered nurses (RNs), medical practitioners, and social workers (SWs) employed full time, part time, or regular casual staff who had worked more than three months in this ICU and had experience in implementing end-of-life and bereavement care were invited by the researchers through flyers placed in staff common areas, employee email, and the unit's private social media page to participate between June and August 2017. Staff self-determined participation eligibility prior to participation, and consent was implied for all returned anonymous surveys.

Physicians Assistants, Nurse Practitioners, Respiratory Therapists, and dedicated ICU Chaplains are not employed in this ICU.

Instrument

The survey was adapted from a previous national cross-sectional survey developed by Ranse et al. (2015) that explored factors influencing the provision of end-of-life care in registered nurses in critical care settings (Ranse et al., 2015). Adaptations included omitting the phrase "nurse" or replacing it with an inclusive term such as "healthcare staff" so as to be applicable to non-nurse participants. Unlike prior surveys on the quality of the dying process (Levy et al., 2005) or professionals' experience providing end-of-life care (Boissier et al., 2020), the survey by Ranse et al. (2015) was designed to assist with strategies for practice development to prepare and support RNs with EOLC in the intensive care setting. The survey consists of 38 items measured across eight concepts related to provisions of end-of-life care: knowledge (four items), preparedness (three items), patient and family preferences (six items), organisational culture (three items), resources (five items), palliative values (five items), emotional support (six items), and care planning (six items) (Ranse et al., 2015). These concepts are organised based on the Promoting Action on Research Implementation in Health Services (PARiHS) framework's elements of *evidence*, *context*, and *facilitation* (Ranse et al., 2015). *Evidence* relates to all forms of credible knowledge from a range of sources informing clinical practice. *Context* pertains to the environment where the health practice occurs. *Facilitation* is the process of help and support needed to make things easier for others; see Table 1 (Ranse et al., 2015; Rycroft-Malone, 2004).

Levels of agreement for individual items were measured on a 6-point Likert scale where: 1 = completely disagree; 2 = mostly disagree; 3 = slightly disagree; 4 = slightly agree; 5 = mostly agree; 6 = completely agree with potential ranges for knowledge (4–24), preparedness (3–18), patient and family preferences (6–36), organisational culture (3–18), resources (5–30), palliative values (5–30), emotional support (6–36), and care planning (6–36). In the intensive care setting where death can occur shortly after withdrawal of life-sustaining treatment during a person's terminal phase of life, locally, the term 'palliative' is commonly used interchangeably with end-of-life care. For this survey, the palliative values section encompassed end-of-life care concepts.

Internal reliability for the original Ranse et al. (2015) scale has been previously reported with Cronbach's alphas ranging from 0.69 to 0.85 (Ranse et al., 2015). In the study reported here, Cronbach's alpha for the adapted scales were calculated as: knowledge (0.79), preparedness (0.67), patient and family preferences (0.73),

Table 1
Description of concepts measured related to provisions of end-of-life care adapted from Ranse et al. (2015).

Promoting Action on Research Implementation in Health Services (PARiHS) element	Survey concept	Description
Evidence	Knowledge	Availability of learning opportunities in continuing professional education
	Preparedness	Perception of one's ability to care for patient and family during end-of-life care
	Patient and family preferences	Inclusion of patient and family preference during end-of-life decision making
Context	Organisational culture	Perception of a nurse-led practice during end-of-life care
	Resources	Availability of environmental space, equipment, and staffing to provide end-of-life care
Facilitation	Palliative values	Expressed values of a palliative approach to care
	Emotional support	Staff's perception of support and assistance received from colleagues and managers while providing end-of-life care
	Care planning	Healthcare team's support for and agreement on a plan for end-of-life care

organisational culture (0.53), resources (0.78), palliative values (0.69), emotional support (0.82), and care planning (0.78).

Statistical analysis was conducted using SPSS version 24 (IBM Corp, Released 2016) and descriptive statistics reported as mean (standard deviation [SD]). There were 128 eligible healthcare professionals working within the ICU study setting. From this population, a sample of 97 participants was required to achieve a confidence level of 95% and margin of error of 5% (CheckMarket, 2020). Since this is the first known instance of this survey being adopted and administered to ICU medical practitioners and social workers in addition to registered nurses, analyses were performed for each item of the survey as well as the eight concepts in order to identify specific areas requiring additional support. A comparison between the responses of RNs' and medical practitioners' survey responses was conducted. The small sample size of social worker participants did not allow for valid statistical comparison with either RNs or medical practitioners, but descriptive findings are reported in this manuscript for transparency of those surveyed. Parametric and non-parametric tests (independent samples t-test or Mann-Whitney U Test, respectively) were conducted for comparison between RNs and medical practitioners. Alpha has been set to 0.05. There has been no adjustment for multiple testing as such corrections can be overly conservative and fail to reveal potentially relevant findings. Substitution of missing data was not performed as any missing data (0.5% of all questions) was considered random (Little's Missing Completely at Random [MCAR] test $p = 0.09$).

Results

Subjects' characteristics

One hundred healthcare professionals responded. Four respondents were excluded from final analysis due to survey incompleteness of 75% or more. Valid survey participants included: 75 RNs (75% response rate), 19 medical practitioners (76% response rate), and 2 social workers (SW) (66.7% response rate). See Table 2.

The mean age of the subjects was 38.1 years and was similar among professional groups (Table 2). Just over half reported completing their professional education in Australia, and length of experience as a registered health professional ranged 1.5–40 years with length of experience in ICU ranging from 3 months to 37 years (Table 2).

Evidence for practice

RNs and medical practitioners reported similar scores for knowledge, preparedness, and patient and family preferences, although some differing responses to individual questions within the scales were observed (Table 3). Compared to medical practitioners, RNs reported higher scores related to receiving in-service education to assist with supporting and communicating with families of dying patients, receiving education in the care and management of patient symptoms, and higher scores for the question "I don't know what to say to the family of a patient at the end-of-life" (Table 3).

Context of practice delivery

RNs scored significantly higher than medical practitioners on the overall organisational culture scale (Table 4), specifically scoring higher related to the perception that EOLC becomes a nurse-led practice once the decision to withdraw care has been made (Table 4). In addition, RNs reported higher scores to the question: "When a patient dies in ICU, healthcare staff have sufficient time to spend with the family" (Table 4).

Facilitation of end-of-life care

Registered nurses and medical practitioners reported similar scores on palliative values, availability of emotional support, and patient care planning (Table 5). However, RNs report higher scores than medical practitioners in response to the question "After caring for a patient at the end-of-life, my colleagues will ask me if I am OK" and lower scores for the question "The medical staff support end-of-life care for dying patients in ICU" (Table 5).

Discussion

This study is the first of our knowledge to explore, through survey, provisions of end-of-life care for ICU healthcare professionals as well as compare responses among RNs and medical practitioners. The main findings of this study are that overall, RNs and medical practitioners reported similar values concerning EOLC and patient and family preferences. However, differences were observed between professionals, specifically in relation to organisational culture and aspects of emotional support, education, and time availability.

Participants' responses do suggest shared values among health professionals in relation to similar decision making, implementation, and end-of-life care. Participants mostly agreed that end-of-life care is as important as curative care, which is in contrast to what is sometimes termed a 'denial of death' approach to ICU medical treatment (Nelson, 2006) and has been previously proposed to occur in larger hospitals (Long et al., 2019). The similar values observed among the RNs and medical practitioners may contribute

Table 2
Sociodemographic characteristics of study participants.

	All staff n = 96	Registered Nurses, n = 75	Medical Practitioners, n = 19	Social Workers, n = 2
Age in years mean (SD)	38.1 (10.7)	38.7 (10.6)	35.4 (10.7)	42 (11.3)
Male	25 (26%)	14 (19%)	11 (57.9%)	0
Female	70 (73%)	60 (80%)	8 (42.1%)	2 (100%)
Did not state gender	1 (1%)	1 (1%)	0	0
Country of professional education				
Australia	52 (54.2%)	39 (52%)	11 (57.9%)	2 (100%)
United Kingdom of Great Britain and Northern Ireland and Ireland	31 (32.2%)	25 (33.3%)	6 (31.6%)	0
India	3 (3.1%)	2 (2.7%)	1 (5.3%)	0
Philippines	4 (4.2%)	4 (5.3%)	0	0
Other	6 (6.3%)	5 (6.7%)	1 (5.3%)	0
Highest level of education completed				
Hospital Certificate	4 (4.2%)	3 (4%)	1 (5.3%)	0
Bachelor's Degree	38 (39.6%)	27 (36%)	9 (47.4%)	2 (100%)
Post Graduate Certificate or Graduate Diploma	38 (39.6%)	36 (48%)	2 (10.5%)	0
Master's Degree	14 (14.6%)	9 (12%)	5 (26.3%)	0
PhD/Professional Doctoral	2 (2.1%)	0	2 (10.5%)	0
Mean length of experience in years as a registered health professional (SD)	14.8 (10.8)	15.4 (10.7)	10.9 (11)	14 (8.5)
Mean length of experience in years in ICU (SD)	10.2 (9.5)	11.1 (9.4)	7.1 (9.6)	4.5 (4.9)

Table 3
Evidence for practice: knowledge, preparedness, and patient and family preferences in end-of-life care results.

Summary of concept score results Survey question	All staff, n = 96 M (SD)	Registered Nurses, n = 75 M (SD)	Medical Practitioners, n = 19 M (SD)	Social Workers, n = 2 M (SD)	Mann-Whitney *U* test of RNs and Medical Practitioners *p* value
Knowledge concept total scores	**15.6 (5)**	**16.1 (4.7)**	**13.8 (5.7)**	**15 (7.1)**	**0.13**
I have received in-service education that assists me to support and communicate with families of dying patients	3.9 (1.7)	4.2 (1.5)	2.8 (1.9)	3.0 (2.8)	0.002
I have received in-service education that assists me to provide care and manage patient symptoms at the end-of-life	3.8 (1.7)	4.0 (1.6)	3.0 (1.8)	3.0 (2.8)	0.02
I draw on evidence from the literature to provide end-of-life care to patients and their families	4.3 (1.3)	4.2 (1.3)	4.4 (1.3)	5.5 (0.7)	0.65
My postgraduate education included end-of-life care content relevant to the critical care context	3.5 (1.7)	3.5 (1.6)	3.7 (1.8)	3.5 (2.1)	0.59
Preparedness concept total scores	**14.3 (2.8)**	**13.9 (2.7)**	**15.3 (2.8)**	**16 (2.8)**	**0.06**
I feel adequately prepared to care for patients at the end-of-life	5.0 (1.0)	5.0 (1.0)	5.1 (0.9)	6.0 (0.0)	0.90
I don't know what to say to the family of a patient at the end-of-life[a]	2.7 (1.5)	2.9 (1.5)	2.1 (1.3)	1.0 (0.0)	0.01
I have limited knowledge of symptom management for patients at the end-of-life[a]	2.1 (1.1)	2.1 (1.1)	1.7 (0.9)	3.0 (2.8)	0.09
Patient and Family Preferences concept total scores	**30.9 (3.3)**	**30.9 (3.4)**	**30.7 (2.9)**	**32 (2.8)**	**0.54**
In ICU, families are given adequate time to consider decisions to withhold/withdraw treatment for the patient	5.2 (0.8)	5.3 (0.8)	4.9 (1.0)	5.0 (0.0)	0.09
In ICU, family meetings with the healthcare team are held to resolve differing views about a patient's treatment	5.1 (0.9)	5.1 (0.9)	4.9 (1.0)	5.5 (0.7)	0.50
In ICU, the patient's preferences (or their likely preference according to family) for end-of-life care are considered	5.1 (0.9)	5.0 (1.0)	5.4 (0.5)	5.5 (0.7)	0.09
In ICU, families are involved in decisions about the dying patient	5.1 (0.7)	5.1 (0.8)	5.3 (0.6)	5.5 (0.7)	0.24
In ICU, withdrawal of treatment is delayed whilst waiting for relatives of the patient to arrive	5.1 (0.7)	5.2 (0.7)	4.8 (0.8)	5.0 (0.0)	0.12
When a patient dies in ICU, families have sufficient time to spend with the patient	5.3 (0.9)	5.3 (0.9)	5.3 (0.8)	5.5 (0.7)	0.90

n = number of survey responses; M = mean; SD = standard deviation.

[a] Question reversed to calculate factor's summary scores.

towards interprofessional cohesiveness and has been associated with greater job satisfaction and intent to stay (Gates and Mark, 2012). The prevalence of similar values likely also assists with emotional support since healthcare professionals commonly rely on each other as a coping strategy for dealing with a patient's death (Ffrench-O'Carroll et al., 2019; Vanderspank-Wright et al., 2018).

Despite similar fundamental end-of-life care values among participants, organisational culture was the only overall survey concept significantly different between the RNs and medical practitioners. In our survey, the organisational culture concept describes the perception of a nurse-led practice during EOLC (Ranse et al., 2015), and RNs in our survey reported higher perceptions of being left to manage the care of the patient after withdrawal of treatment. However, it is uncertain if the term "left" was perceived by survey participants as a negative or positive situation, and its relation to the level of perceived supports to enable delivery of end-of-life care.

Differences between RNs' and medical practitioners' responses could be attributed to silos of continuing education between the professions rather than an interprofessional approach since organ-

Table 4
Context of practice delivery: organisational culture and resources results.

Summary of concept score results Survey question	All staff, *n* = 96 M (SD)	Registered Nurses, *n* = 75 M (SD)	Medical Practitioners, *n* = 19 M (SD)	Social Workers, *n* = 2 M (SD)	Mann-Whitney *U* test of RNs and Medical Practitioners *p value*
Organisational Culture concept total scores	**11.5 (2.7)**	**11.9 (2.5)**	**9.9 (2.9)**	**9.5 (4.9)**	**0.01**
After a decision is made to withdraw treatment, less time is spent with the patient by the critical care medical team	4.6 (1.2)	4.7 (1.2)	4.1 (1.3)	3.5 (2.1)	0.06
After a decision is made to withdraw treatment, nurses are left to manage the care of the patient	4.2 (1.3)	4.5 (1.2)	3.2 (1.3)	4.5 (2.1)	<0.001
In ICU, end-of-life care is mostly allocated to junior healthcare staff	2.7 (1.2)	2.7 (1.2)	2.6 (1.4)	1.5 (0.7)	0.56
Resources concept total scores	**21.6 (4.2)**	**21.9 (4)**	**20.9 (5)**	**18.5 (3.5)**	**0.69**
The physical environment of ICU is ideal for providing end-of-life care	3.5 (1.3)	3.5 (1.4)	3.5 (1.3)	3.0 (1.4)	0.98
ICU is adequately equipped to support the comfort needs of the family during end-of-life care	4.0 (1.2)	4.0 (1.2)	4.1 (1.4)	4.0 (1.4)	0.83
Private rooms are available to care for the patient at the end-of-life	4.4 (1.1)	4.4 (1.1)	4.4 (1.2)	4.0 (0.0)	0.91
ICU is adequately staffed for providing the needs of dying patients and their families	5.0 (0.9)	5.1 (0.8)	4.8 (1.3)	4.5 (0.7)	0.49
When a patient dies in ICU, healthcare staff have sufficient time to spend with the family	4.6 (1.1)	4.8 (1.0)	4.1 (1.1)	3.0 (2.8)	0.01

n = number of survey responses; M = mean; SD = standard deviation.

Table 5
Facilitation of end-of-life care: palliative values, emotional support, and care planning results.

Summary of concept score results Survey question	All staff, *n* = 96 M (SD)	Registered Nurses, *n* = 75 M (SD)	Medical Practitioners, *n* = 19 M (SD)	Social Workers, *n* = 2 M (SD)	**Mann-Whitney *U* test of RNs and Medical Practitioners** *p value*
Palliative Values concept total scores	**28.5 (2)**	**28.4 (2)**	**28.8 (1.8)**	**29.5 (0.7)**	**0.53**
End-of-life care is as important as curative care in the critical care environment	5.7 (0.7)	5.7 (0.6)	5.7 (0.8)	6.0 (0.0)	0.89
I can influence the patient and family's experience of end-of-life care	5.6 (0.7)	5.6 (0.7)	5.6 (0.6)	6.0 (0.0)	0.73
End-of-life care should include care of the patient's family	5.8 (0.4)	5.8 (0.4)	5.8 (0.4)	6.0 (0.0)	0.71
It is a privilege to care for a patient at the end-of-life and their family	5.7 (0.6)	5.6 (0.7)	5.8 (0.4)	6.0 (0.0)	0.44
Analgesia should be titrated to keep the patient comfortable even if this hastens death	5.7 (0.6)	5.7 (0.6)	5.9 (0.3)	5.5 (0.7)	0.13
Emotional Support concept total scores	**27.9 (4.6)**	**27.9 (4.7)**	**27.5 (4.1)**	**32.5 (0.7)**	**0.48**
My supervisors/managers ensure staff caring for patients at the end-of-life are supported	4.9 (1.0)	4.8 (1.1)	5.2 (0.8)	5.5 (0.7)	0.08
My supervisors/managers provide guidance that assists me to provide end-of-life care	4.9 (0.9)	4.8 (0.9)	5.2 (0.7)	5.0 (1.4)	0.10
After caring for a patient at the end-of-life, my colleagues will ask me if I am OK	4.2 (1.3)	4.3 (1.2)	3.6 (1.4)	5.0 (0.0)	0.02
I feel supported when caring for a patient at the end-of-life	4.7 (1.0)	4.6 (1.0)	5.0 (0.8)	5.5 (0.7)	0.14
My colleagues appreciate the stressors associated with caring for patients at the end-of-life	4.8 (1.0)	4.8 (0.9)	4.6 (1.1)	5.5 (0.7)	0.80
When a patient dies in ICU, counselling is available if I need it	4.5 (1.2)	4.7 (1.2)	3.8 (1.0)	6.0 (0.0)	0.01
Care Planning concept total scores	**27.8 (4.6)**	**27.3 (4.8)**	**29.2 (3.5)**	**30 (1.4)**	**0.22**
The medical staff support end-of-life care for dying patients in ICU	4.8 (1.0)	4.6 (1.0)	5.2 (0.9)	6.0 (0.0)	0.02
In ICU, when a diagnosis with a likely poor outcome is made, families are informed of end-of-life care options	4.7 (1.0)	4.7 (1.1)	4.9 (0.8)	5.0 (0.0)	0.55
In ICU, the team expresses its opinions, values and beliefs about providing care to dying patients	4.3 (1.2)	4.2 (1.2)	4.6 (0.8)	3.0 (2.8)	0.27
All members of the healthcare team in ICU agree with and support end-of-life care when it is implemented	4.9 (1.0)	4.9 (1.0)	4.5 (1.0)	5.5 (0.7)	0.10
In ICU, a plan of care for the patient is clearly documented by the medical team	4.4 (1.3)	4.3 (1.3)	4.8 (1.0)	5.5 (0.7)	0.14
In ICU, the critical care team and the patient's primary medical or surgical team agree on a plan of care	4.7 (1.0)	4.6 (1.1)	5.0 (0.7)	5.0 (0.0)	0.20

n = number of survey responses; M = mean; SD = standard deviation.

isational culture is the shared basic assumptions, values, and beliefs that characterise an environment and are taught formally and informally to new employees as the proper way to think and feel (Schneider et al., 2013). Though not entirely supported by these survey results, others have reported that the ICU medical consultants being a significant influence in the shaping of the unit's EOLC culture due to their decision-making role in the use of ICU technology and resources (Baggs et al., 2007), and the tradition of an intensivist-led model of ICU care. This model of care can support feelings of ICU medical practitioners' 'ownership' for the patient's decision making and is likely engrained into the experience and expectations of the ICU medical practitioners (Conn et al., 2016), regardless of other factors that might favour EOLC being nurse-led such as the amount of time spent with the patient or the level of ICU specific care required. Other research has reported the role of the RN to be more dominant in end-of-life care and to include helping families understand treatment options based on the patient's actual or presumed wishes, managing patient's comfort, providing emotional support, facilitating cultural or religious practices, and creating positive memories for the families (Anderson et al., 2019; Raymond et al., 2017; Riegel et al., 2019).

Registered nurses and medical practitioners reported differing perceptions of receiving support when delivering EOLC. Supports can be received as either emotional support (sympathy and encouragement) or instrumental support (tangible aspects such as information or feedback), and the type of supports received varies in importance depending on the situation (Pohl and Galletta, 2017). In our survey, it is uncertain which type of supports played a larger role or how the supports affected the staff's perception of who leads EOLC.

Registered nurses reported lower levels of agreement than medical practitioners in relation to the question concerning medical staff supporting end-of-life care for dying patients, and medical practitioners reported receiving lower levels of emotional support in areas of peer-to-peer support and knowledge of counselling services. The process of changing a patient's plan of care from treatment to comfort relies on the deliberation between emotions and their learning (Farjoun et al., 2015). Decisions to change a patient's focus of care from curative to end-of-life can be a significant burden, and at times a distressing experience for the care providers (Childers and Arnold, 2019; Holms et al., 2014; Konstantara et al., 2016). Alternatively, providing medical treatment that healthcare professionals perceive to be too aggressive when they believe a patient is nearing their end-of-life has been reported to also cause intense moral distress for ICU healthcare professionals (Epstein et al., 2019; Whitehead et al., 2015). High levels of emotional support are required for healthcare professionals to be able to determine and deliver EOLC. Without this type of support, there is increased risk of experiencing emotional exhaustion and possible workplace burnout (Rotenstein et al., 2018), which will further limit their ability to provide emotional support to co-workers, patients, and families.

Our findings suggest a need for more instrumental support with in-service education for aspects of end-of-life care including communication and symptom management, particularly for medical practitioners, which is consistent with prior studies (Brooks et al., 2017; Ffrench-O'Carroll et al., 2019; Ho et al., 2016; Mohamed et al., 2016; Ozga et al., 2020; Ranse et al., 2020; Visser et al., 2014). It is uncertain if the limited in-service educational opportunities are due to unavailability or a disinterest in attending sessions since ICU healthcare professionals have been previously reported to be less receptive to updating their knowledge and skills in EOLC, despite being committed to attending ongoing education in other skills such as ventilator management or cardiac perfusion (Levy, 2001). Overconfidence in abilities, rather than actual skills, has also been suggested to potentially contribute to resistance to attend ongoing training in end-of-life topics when they are available (Billings et al., 2010).

The survey responses do suggest, though, that learning end-of-life topics is facilitated through managers' or supervisors' guidance when providing end-of-life care for both RNs and medical practitioners. While informal learning opportunities should be included, others have suggested that formal in-service education is also required because it cannot be assumed that skills in providing EOLC will be gained with experience over time (Vanderspank-Wright et al., 2018), and managers' or supervisors' guidance at the bedside could be of better assistance as follow-up reinforcement training (Bonvicini et al., 2009).

In our study, RNs reporting greater access to ongoing education about end-of-life care might provide them with increased skills and confidence to act as leaders for this aspect of patient care compared to the medical practitioners. The differences in received education and training to provide EOLC and manage patient symptoms may contribute to the RNs reporting being left to manage the patient's care as they might consider themselves as experts and are comfortable delivering and communicating about the care (Peden-McAlpine et al., 2015; Vanderspank-Wright et al., 2018). Equally, a deficiency in in-service education and training in EOLC topics might influence the medical practitioner's comfort level of being near death, especially if they view the death as a treatment failure and are uncertain how to deliberate between appropriate treatment options and possible emotional strain (Ho et al., 2016; Levy, 2001; Visser et al., 2014).

Compared to RNs, medical practitioners reported lower levels of agreement that healthcare professionals have enough time to spend with the family to provide for patient's and family's needs, and RNs also reported a lower level of agreement that medical staff support end-of-life care for dying patients in the ICU. Once causes of illness are determined to be irreversible and a shift in care is made from curative to end-of-life, it is likely that the medical practitioners prioritise and reallocate their time to focus on other critically ill patients requiring their medical expertise. Alternatively, nurses report their physical presence and providing comfort as being a professional obligation in EOLC (Vanderspank-Wright et al., 2018). Nurses being physically closer to the patient and family for typically longer periods of time places them in a greater position to facilitate and interpret verbal and nonverbal forms of communication, manage patient symptoms, and assist with rituals and comforts for the patient and family (Bloomer et al., 2017; Hamric and Blackhall, 2007; Vanderspank-Wright et al., 2018).

While the small sample size of social worker participants did not allow for comparisons with either RNs or medical practitioners, social worker participants reported drawing their knowledge for end-of-life care predominately from literature evidence, reported high levels of agreement to feeling prepared for EOLC, and were confident in speaking to families. They also reported high levels of agreement in the *facilitation* of end-of-life care, including palliative values, availability of emotional supports, and patient care planning. While unable to be broadly inferred due to low participant numbers, these responses are reflective of the social workers' unique and valuable role in ICU, which includes providing patient and family psychosocial assessments, counselling and support, facilitating communication, supporting health care professionals, and assisting in EOLC, including practical concerns such as funerals (Hartman-Shea et al., 2011; Rose and Shelton, 2006).

Optimal delivery of end-of-life care requires a collaborative team approach by healthcare professionals to allow for their overlapping expertise and unique contributions to be combined to assist with decision making and working towards a common goal (Brooks et al., 2017; Carvajal et al., 2019; Donovan et al., 2018; Ely et al., 2019). Providing interprofessional EOLC education is one intervention that has been reported to provide knowledge about the entirety of the patient's care outside of one's scope of practice, assist with communication between ICU disciplines, and promote teamwork (Graham et al., 2018). When a team of healthcare professionals contribute to end-of-life decision making, rather than a subset group, all professions will be able to work to their full scope of practice (Ely et al., 2019).

This study highlights that potential opportunities for improvement exists, including emotional support, education, and time availability for healthcare professionals to provide high quality end-of-life care. Specifically, utilising an interprofessional approach to ongoing supports and education may facilitate opportunities to discover each profession's strengths and challenges, and foster better collaboration and peer emotional support when delivering end-of-life care. Additionally, such an approach to unit-based education and support may foster an organisational culture that encourages teamwork and shared decision-making during end-of-life care delivery.

Limitations

A limitation to this study is that values, culture, and supports provided to assist with EOLC will vary with each ICU and may not be representative of other ICUs. This study represents a self-selected sample of healthcare professionals and provides a snapshot of participant's perceptions at one point in time. As such, results are only relevant to the healthcare professionals who participated and may not represent perspectives of those who did not participate, although some findings are consistent with prior studies and extend these findings. Statistical analysis in our study was also limited due to the sample size of medical practitioners and social workers. However, responses from each professional group were representative of the proportion of healthcare professionals within the study ICU.

Conclusion

Overall, healthcare professionals reported similar palliative values and inclusion of patient and family preferences, an important foundation for interprofessional cohesiveness where end-of-life care can be provided and expanded upon. The differences observed between registered nurses and medical practitioners would suggest that an interprofessional approach to ongoing supports and education may be beneficial as each profession brings unique values, perceptions, skills, and experiences to end-of-life care in the intensive care.

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Ethical statement

Ethics and site approval was obtained from the South Eastern Sydney Local Health District Human Research Ethics Committee (HREC Ref 17/152).

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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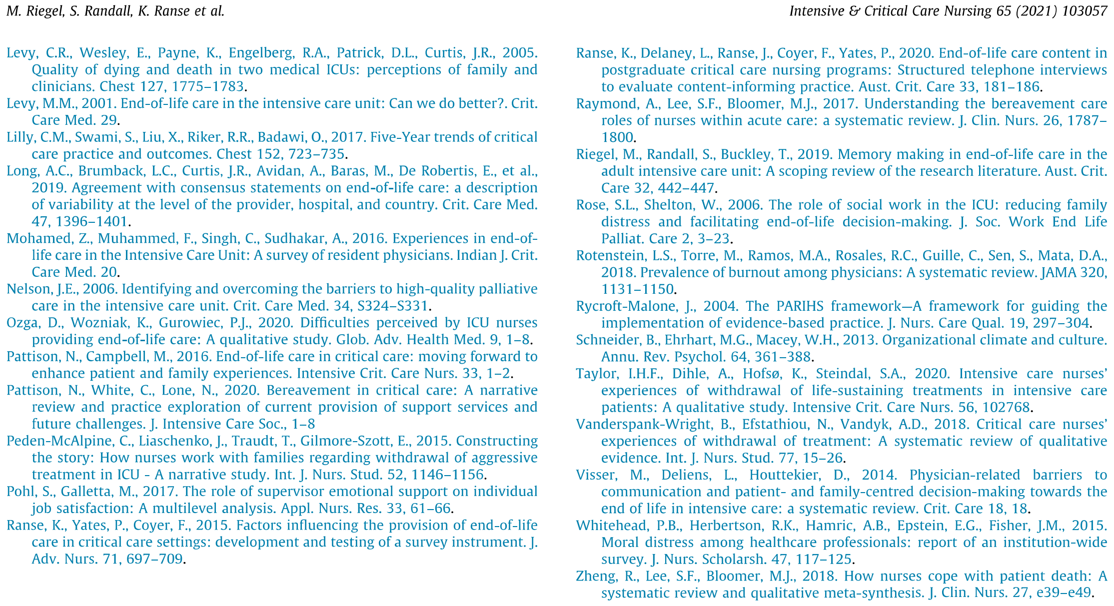

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Key findings from the above peer-reviewed publication are registered nurses and medical practitioners reported similar values concerning end-of-life care and patient and family preferences. Differences were observed between professionals, particularly regarding organisational culture and aspects of emotional support, education, and time availability (Riegel et al., 2021).

5.1.2 Knowledge, skills, and role in offering and facilitating memory making

Healthcare professional participants' perception of what memory making is, their facilitation of it within their practice, who's role it is, and if they perceive to have the necessary skills to accomplish it is presented in the following peer-reviewed publication.

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Research paper

Healthcare professionals' knowledge, skills, and role in offering and facilitating memory making during end-of-life care in the adult intensive care unit

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ABSTRACT

Background: An activity to provide a tangible keepsake following the death of a loved one is termed 'memory making'. However, limited evidence is available related to professionals' education and support to provide memory making opportunities in the adult intensive care unit (ICU). Having a greater understanding of healthcare professionals' experiences can inform future patient/family care and support for professionals in end-of-life care.

Objective: The objective of this study was to describe what participants perceive memory making to be, if they have facilitated memory making activities as part of their practice, if they perceive it as part of their role, and if they have the necessary skills to do so.

Methods: Seventy-five registered nurses (75% response rate), 19 medical doctors (76% response rate), and two social workers (66.7% response rate) completed a survey at a single tertiary referral centre in an adult ICU.

Results: Participants reported memory making to include the creation of tangible keepsakes as well as nontangible activities. Overall, participants reported high agreement scores that the responsibility for initiating memory making predominately belonged to the nurse. Participants reported skills most needed involved the ability to interact with the family, being open to the concept, and integrating memory making into their standard of care. Having developed a rapport with families was considered an enabler, whereas lack of knowledge and clinical workload were reported as inhibitors to offering memory making.

Conclusions: Overall, participants in this study reported positive experiences with offering memory making to families during end-of-life care in the adult ICU. Nurses are more likely to perceive professional responsibility for offering memory making, likely due to their increased time at the bedside and higher prominence and leadership in other end-of-life practices. To support professionals, education should include conceptual knowledge, procedural knowledge of keepsake creations, communication techniques using reflective practices, and organisational support to facilitate time requirements.

1. Introduction

Families who experience the death of a loved one in the intensive care unit (ICU) are reported to retain significant details of the event over a year later,[1] suggesting that memories obtained during ICU are significant and lasting. The salient memories of the 'little touches' of ICU care delivered to the families are reported to be predominate memories for bereaved family members compared with other details of the hospitalisation.[2] These memories of the 'little touches' are reported to demonstrate compassionate and humanistic care in the ICU that families carry into their bereavement experience.[2]

Family members whose loved ones become acutely unwell and require intensive care level of support are reported to experience heightened psychological stresses, including anxiety, depression,

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and anger that can last beyond the hospitalisation period and place them at a greater risk of developing posttraumatic stress disorder.[3] In death, the experience is not isolated to the individual who died, but rather it affects the survivors within the deceased's social realm and culture.[4] After a death, survivors must learn to adapt to the new absence and the changes in their social structure while oscillating through loss- and restoration-oriented coping for their adjustment to the death experience.[5,6] While restoration-orientation includes distractions and time off from grieving, the loss-orientation phase involves the survivor's active concentration and processing of the experience, reflections and yearning for the deceased, and breaking bonds to the deceased.[5,6]

Our memories serve as a source of knowledge about the deceased, and their creation requires the person to actively construct within their mind the ideal presence of the person who is no longer present. This new ideal presence exists only as a mental image for the bereaved survivor.[7] Signs, objects, or keepsakes may serve as instruments of memories, thoughts, and knowledge for the survivors as the dead are represented to the survivors through the keepsakes.[8–10] Keepsakes are classified as an object a survivor applies meaning to, that they then link back through their memories of the deceased when they want to remember them.[9–11] Memories created through keepsakes are specific to each person, as survivors have the ability to weave together mixtures of real and imagined memories through varying contexts, feelings, and experiences triggered by the object.[12] Keepsakes such as pictures, hand photos/prints, clothing, jewellery, blankets, and furniture[13–17] have been described by survivors during the loss-orientation phase of their learning to adapt to the death of their loved one.

Within the hospital setting, assisting with the creation of keepsakes to serve as an instrument for memories has been mostly reported in the neonatal population,[18] with less evidence from the adult ICU context.[18,19] For the purpose of this study, creation of mementos in end-of-life care is termed memory making, an activity that provides an object or keepsake that can help a bereaved individual create a connection with and provide meaningful memories about a deceased person.[20] In other disciplines, the memento objects can be referred to as linking, transitional, or melancholy objects.[13,21] Providing families the opportunity for memory making has the ability to be considered a ‘little touch’ during end-of-life care that families might value receiving for use in their bereavement, but limited evidence is available related to healthcare professionals' (HCPs’) experiences with offering memory making in the adult ICU and the education and support needed to provide this option to grieving families.

The aim of this manuscript was to report healthcare professionals’ knowledge and perceived skills in offering and facilitating memory making in an adult ICU. Specifically, the aim of this study was to describe what participants perceive memory making to be, if they have facilitated memory making activities as part of their practice, whether they perceive memory making as part of their professional role, and if they have the necessary skills to do so. Having a greater understanding of HCPs’ experiences with memory making in the adult ICU has the potential to inform future patient and family care and support, as well as inform education and support of HCPs in providing end-of-life care.

1.1. *Study design*

The descriptive analysis results are reported as part of a survey designed using Likert and open-ended questions and administered both by paper and online using REDCap electronic data capture tools hosted at the University of Sydney[22] to achieve the objectives of the study.

1.2. *Study site*

This study was conducted at a single tertiary referral centre in Sydney, Australia, in a general adult ICU. Ethics and site approval was obtained from the South Eastern Sydney Local Health District Human Research Ethics Committee (HREC Ref 17/152).

To support the family surrounding the death of a loved one, a patient and family end-of-life/bereavement program, called the Loved One Support Service (LOSS), was implemented in November 2015 in a 17-bed combined ICU/high-dependency unit (HDU) at this study site. This program encourages open visitation; allows for personalisation and humanising the environment with pictures, music, aroma diffusers, and electric candles; distributes bereavement booklets; sends sympathy cards to the next of kin around week 1 after ICU death; and provides follow-up phone calls around week 5 to assist with lingering questions and direct the next of kin to resources if needed. One component of this program includes supporting facilitation of memory making around the time of death by providing the loved ones options of obtaining keepsakes/mementos, including handprints or footprints, locks of hair, and teddy bears for children. This hospital does not have a separate palliative care ward, so end-of-life care in the terminal phase of life is predominantly conducted within the ICU, although at times, a patient may be transferred to an appropriate ward for longer term end-of-life nursing care.

1.3. *Sampling and recruitment*

Eligible registered nurses (RNs), medical doctors (MDs), and social workers (SWs) employed full-time, part-time, or casual who had experience with implementing end-of-life/bereavement care and had worked more than 3 months within this study site were invited to participate through flyers in staff common areas, email, and the unit's closed social media page between June and August 2017. There were 128 eligible HCPs working within this ICU study setting. Staff self-determined participation eligibility prior to participation, and consent was implied for all returned anonymous surveys.

1.4. *Instrument*

The survey included individual questions related to memory making activities as part of end-of-life care in the ICU assessed on a 6-point Likert scale where 1 = completely disagree; 2 = mostly disagree; 3 = slightly disagree; 4 = slightly agree; 5 = mostly agree; and 6 = completely agree in addition to participant demographic information. For questions where experience in memory making was believed by the researchers to be necessary to answer the question, the option of ‘not applicable’ was available to participants. Open-ended questions were also included to explore several topic areas in more detail. The questions reported in this study were developed by the researchers for descriptive analysis based on the behaviour domains of knowledge, skills, and social/professional role and identity from the Theoretical Domains Framework,[23] and an expert panel consisting of ICU RNs and medical specialists reviewed the survey instrument for face validity prior to use. See supplementary material for the survey instrument.

1.4.1. *Data analysis*

Statistical analysis was conducted using IBM SPSS, version 24,[24] and descriptive statistics was reported as mean (M) (standard deviation [SD]). A comparison of RN and MD participants’ means scores of agreements related to responsibility for initiating memory making was conducted using the Mann–Whitney U test. The small sample size of SW participants did not allow for valid statistical comparison with either RNs or MDs. Chi-squared test (χ^2) was used for post hoc analysis of the proportion of RN participants to MD participants who indicated they had prior experience of offering memory making. An inductive thematic analysis was undertaken from each open-ended question from the survey data to provide as accurate a reflection of the data as possible.[25] All study investigators (MR, SR, and TB) reviewed and agreed on the extracted themes.

2. Results

2.1. Participants' characteristics

One hundred participants responded (78% response rate); four respondents were then excluded from final analysis owing to survey incompleteness of 75% or more. Valid survey participants included 75 RNs (75% response rate), 19 MDs (76% response rate), and two SWs (66.7% response rate) (See Table 1).

The mean age of the participants was similar among professional groups (Table 1). Most participants reported their highest education level as either bachelor's degree or postgraduate certificate/graduate diploma, and their length of experience in the ICU ranged from 3 months to 37 years. Most participants (93%) reported more than 6 months of experience in adult ICUs, including medical, surgical, or cardiothoracic surgery, 5.2% reported experience in paediatric intensive care, and no participants reported prior experience in the neonatal intensive care (See Table 1).

2.2. Knowledge

The survey questions related to *knowledge* explored the constructs of knowledge about the phenomenon/scientific rationale and procedural knowledge of memory making.[23] Prior to being given the definition of memory making, survey participants reported what they considered to be acts of memory making. Participants reported that for them, the act of memory making included the creation of hand or footprints and keeping locks of hair and also could involve other nontangible objects such as preparing the body for family viewing (see Table 2). Additionally, participants were asked to report other activities or items they considered acts of memory making during end-of-life care, where themes included memory integration through the staff promoting the reminiscence about the person with the loved ones (see Table 3).

Following the participants' responses to these questions regarding their perception of what constitutes memory making, the following definition was provided for reference for the reminder of the questions: "*Memory making is an activity that provides a tangible object(s) that can help a bereaved individual create a connection with and provide meaningful memories about a deceased person. For this survey, tangible objects include handprints, footprints, and/or locks of hair*".[20]

2.3. Skills

The survey questions on *skills* included the constructs of competence, ability, practice, and skills development.[23] Almost 70% of participants reported that they had experience offering memory making opportunities to families (Table 2). Of the respondents, 80% ($n = 60$) of RNs versus 26.3% ($n = 5$) of MDs (χ^2 $p < 0.001$) and both SW respondents reported experience offering memory making. Participants who had not offered memory making to families reported that it was predominately due to not having had opportunity to do so, a perceived knowledge deficit regarding memory making, or the inability due to perceived workloads (Table 3).

Participants reported that the skills and personal attributes required to offer memory making included the ability to interact with the family, to be open to the concept of creating memories, and to integrate memory making as a standard of care in their own practice through focussing on person-centred care and prioritising time for offering (Table 3). Participants also reported that the skills they believe they needed to improve on included improvements in self-maturity, skills to care of the person and family, and communication skills.

2.4. Social/professional role and identity

The survey questions related to *social/professional role and identity* included the constructs of professional identity and role and group norm.[23] Overall, participants reported high agreement scores that the responsibility for initiating memory making predominately belonged to the nurse ($M = 4.6$, $SD = 1.3$), followed by SWs ($M = 3.8$, $SD = 1.3$) and then MDs ($M = 3.1$, $SD = 1.3$). Further analysis revealed that nurse participants reported statistically significant higher rates of agreement that initiating memory

Table 1
Sociodemographic characteristics of study participants.

Characteristic	All participants, n = 96	Registered nurses, n = 75	Medical doctors, n = 19	Social workers, n = 2
Age in years mean (SD)	38.1 (10.7)	38.7 (10.6)	35.4 (10.7)	42 (11.3)
Male	25 (26%)	14 (19%)	11 (57.9%)	0
Female	70 (73%)	60 (80%)	8 (42.1%)	2 (100%)
Did not state gender	1 (1%)	1 (1%)	0	0
Country of professional education				
Australia	52 (54.2%)	39 (52%)	11 (57.9%)	2 (100%)
United Kingdom of Great Britain and Northern Ireland and Ireland	31 (32.2%)	25 (33.3%)	6 (31.6%)	0
India	3 (3.1%)	2 (2.7%)	1 (5.3%)	0
Philippines	4 (4.2%)	4 (5.3%)	0	0
Other	6 (6.3%)	5 (6.7%)	1 (5.3%)	0
Highest level of education completed				
Hospital certificate	4 (4.2%)	3 (4%)	1 (5.3%)	0
Bachelor's degree	38 (39.6%)	27 (36%)	9 (47.4%)	2 (100%)
Postgraduate certificate or graduate diploma	38 (39.6%)	36 (48%)	2 (10.5%)	0
Master's degree	14 (14.6%)	9 (12%)	5 (26.3%)	0
PhD/professional doctoral	2 (2.1%)	0	2 (10.5%)	0
Mean length of experience in years as a registered health professional (SD)	14.8 (10.8)	15.4 (10.7)	10.9 (11)	14 (8.5)
Mean length of experience in years in the ICU (SD)	10.2 (9.5)	11.1 (9.4)	7.1 (9.6)	4.5 (4.9)

ICU, intensive care unit; SD, standard deviation.

Table 2
Questions related to domains of knowledge, skills, and social/professional role and identity.

Survey question	All participants, n = 96 Yes *n*, %
The act of memory making involves the following:	
Allowing the family to spend time with the person after death.	95 (99%)
Allowing the family to create hand or footprints of the person.	91 (94.8%)
Allowing the family to keep a lock of hair of the person.	89 (92.7%)
Preparing the body for the family's viewing.	86 (89.6%)
Asking the family questions about the person (patient) to learn more about them.	83 (86.5%)
Being present at the time of death.	78 (83%)
Giving the family written information about bereavement care.	77 (81.1%)
Talking to the family or patient about his or her prognosis.	69 (71.9%)
I have received education related to memory making for families.	63 (65.6%)
I have read literature/published information about memory making.	23 (24.2%)
If so, where did you read about it?	
Medical/nursing journal.	11 (11.5%)
Website.	8 (8.3%)
Social media.	4 (4.2%)
Medical/nursing textbook.	3 (3.1%)
Blog.	1 (1%)
Other.	5 (5.2%)
Participants reporting in-service lectures in ICU or colleagues.	4 (4.2%)
I have offered memory making to families in intensive care.	67 (69.8%)
	M (SD)
I know the benefits of memory making for the family.[a]	4.9 (1.0)
I have the necessary skills to offer families the opportunity to create memories after a death.[a]	4.6 (1.2)
I find it difficult to offer families the opportunity to create memories after a death.[b]	2.9 (1.4)

ICU, intensive care unit; M, mean; SD, standard deviation.

[a] Question utilised a 6-point Likert scale.

[b] Question utilised a 6-point Likert scale and included the option of 'not applicable to me'.

making was their responsibility compared with MDs or SWs ($p < 0.001$) (See Fig. 1).

3. Discussion

The aim of this study was to report HCPs' knowledge and skills in facilitating memory making in the adult ICU. The key findings include the following: (i) participants perceived memory making to include the creation of tangible keepsakes as well as nontangible activities; (ii) almost 70% of participants reported experience in offering memory making to families; (iii) nurse participants reported higher rates of agreement that initiating memory making is the responsibility of the nurse; (iv) participants reported not offering memory making owing to lack of procedural knowledge, despite a high level of agreement for knowing the benefits of memory making; (v) participants had high levels of agreement to having the necessary skills to offer families memory making opportunities, but educational opportunities exist in areas of communication and how to integrate memory making into one's standard of care, and support is needed to allow for the time required to complete the family's requests; (vi) meeting families for a short period of time did not prevent the offering of memory making, but having a rapport with the family did assist.

Survey participants reported to perceived memory making to include the creation of tangible keepsakes as well as nontangible activities such as allowing the family to spend time with the person after death. The phrase 'memory making' was also viewed by participants to encompass other activities that may create 'positive memories' for the surviving loved ones, which is consistent with prior literature, where making the dying person look as 'normal' as possible and modifying the environment are considered important end-of-life care activities.[26,27] These nontangible activities reported by participants suggest a more holistic view of end-of-life care where the offering of memory making is not separated from other acts of patient care during end of life. Participants might be reporting the nontangible activities as memory making owing to previously learned professional responsibilities in end-of-life care, including nurses applying models of care, such as Orem's Self-Care Deficit Model of Nursing when a person is limited or incapable of providing effective self-care,[28] SWs' focus of reducing family stress through individual and family therapy and advocacy,[29,30] and possibly demonstrates reported MDs' shift to a more conversational framework that supports emotionally therapeutic encounters, as has been reported by others.[28,31]

In this study, almost 70% of participants reported experience in offering memory making to families, with the highest proportion of experience being reported by RNs. It is uncertain if this rate of experience is unique to this study site or is representative of other sites as there are no known comparable prior studies in the adult ICU. Additionally, participants reported higher levels of agreement that the responsibility for initiating memory making predominately falls to the nurse, particularly from nurse participants. Nurses might feel an increased professional ownership and obligation in offering memory making owing to having a greater presence at the bedside for longer periods of time than other HCPs and therefore being in a greater position to facilitate communication and assist with end-of-life care rituals and comforts for the patient and family.[28,32–34] Results in this study are consistent with others reporting nurses in acute and critical care settings having more of a leadership role in end-of-life care and feeling a professional duty to be at the bedside to support the patient and family.[18,34–38]

Perceived high workloads and feelings of memory making being unnecessary were reported by some participants as barriers to offering, and the ability to prioritise/allow time to offer and provide memory making is a reported required skill. Prior research has reported that RNs are more likely to report having time available to spend with the family after a patient dies than medical professionals,[34] which might contribute to nurse participants' reporting greater professional responsibility for offering memory making.

Table 3
Open-ended questions for the domains of knowledge and skills.

Survey question	Theme	Subtheme	Example quotes (participant number)
Other acts of memory making:	Palpable	Practical arrangements	*“Discussing with family regarding the process beyond death as to pt [patient] body, movement and logistics of funeral, cremations, arrangements”* (6-MD)
		Tangibles	*“Diaries, photos”* (37-RN)
	Memory integration	ICU memory	*“Surrounding the room with photos/memorabilia/music”* (61-RN)
		Reminiscence	*“Talking to the family, asking questions only to help them think about the patient's life, good moments, valuable times, to help them communicate with the patient and each other about the patient's life and loved* (sic) *for each other”* (60-RN)
What has prevented you from offering memory making to families in intensive care?	No opportunity	Other staff completed	*“Already done by nursing staff prior to my input”* (6-MD)
		No exposure to the patient population	*“Never chance to care of dying for a while”* (78-RN)
		Family absent	*“Family not ready for death then not present once they've come to that acceptance”* (48-RN)
	Knowledge deficit	Unfamiliarity of offerings	*“Not familiar with all aspects of memory making or how it is delivered locally”* (20-MD)
		Felt unnecessary to offer	*“Older patient/death expected and was seen as the only way forward. Older people and family have a lot of ‘memories’ around them”* (30-RN)
	Workload	Time poor	*“Busy schedule* (*only had one opportunity this was an organ donation so I was busy doing tasks for this*)*”* (86-RN)
The skills most needed to offer families the opportunity to create memories after a death are:	Staff's interactions with family	Communication	*“Speak to them, explain what's involved and if they like to do it. Communication skills”* (76-RN)
		Empathy	*“Empathy/compassion. Ability to communicate and initiate the discussion.”* (50-RN)
		Listening	*“Listening and asking the family what they want. I cannot assume I know what they want but need to ask.”* (43-RN)
		Rapport	*“Need to have built rapport with the specific family beforehand”* (91-RN)
		Approachability	*“Being open/approachable/sensitive, instilling confidence”* (27-RN)
		Situational awareness	*“Knowing/judging families' reaction to accept end of life”* (34-RN)
	Staff's openness	Willingness	*“Willingness to do so, getting hand on, it's just another aspect of pt [patient] care”* (69-RN)
	Standards of care	Person-centred care	*“Giving families the ability to decide if they want to participate”* (39-RN)
		Allowing time/prioritizing	*“Making time to involve the family members”* (41-RN)
		Protocol knowledge	*“How and when to take a hand print”* (65-RN)
The skill(s) I think I need to improvement on to provide memory making is(are):	Self-maturity	Grief support	*“Embracing the family in time of grief and meet their needs, perhaps being more on board with the process”* (31-RN)
		Experience	*“As a JMO [junior medical officer] I am usually involved in the administrative aspects of end-of-life care (i.e., paperwork!) and it is normally the consultant/fellow who deal directly with the family”* (91-MD) *“Having some exposure. My only opportunity was declined by family”* (55-RN)
		Own comfort with death	*“Controlling my emotions — sometimes I take a step back when I gets too much for me. I feel a nurse's responsibility is to remain at pts [patients'] and families' bedside”* (70-RN)
	Care of the person and family	Practical arrangements	*“Practical tips, best paints to use”* (15-SW)
		Education	*“Awareness and knowledge of memory making activities and how to facilitate them”* (20-MD)
		Time management	*“Time management in allowing enough time for memory making”* (58-RN)
	Communication	How to have difficult conversations	*“Therapeutic communication — this is just too subjective at times and you can never really know whether you're lacking or being too much in this aspect”* (7-RN) *“approaching those families who are angry about the death”* (33-RN)
		Approaching families	*“Determining the appropriate time to discuss it”* (99-RN)

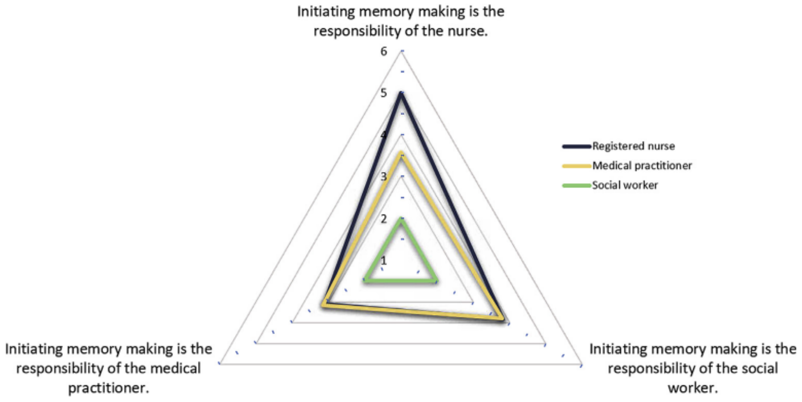
ICU, intensive care unit; MD, medical doctor; RN, registered nurse; SW, social worker.

Many participants reported not offering memory making owing to their lack of knowledge, despite a high level of agreement for knowing the benefits of memory making. These responses suggest that conceptual knowledge about the potential benefits of memory making is insufficient to ensuring its offering. Inadequate procedural knowledge about keepsake creation and unfamiliarity with local processes was reported by participants as aspects preventing the offering. The need for practical tips was reported by participants as skills requiring improvement. Other literature has reported that both conceptual and procedural knowledge is necessary to develop procedural fluency in order to solve a variety of problems efficiently and with flexibly.[39,40] Educational opportunities that address a variety of potential patient and family end-of-life care situations should be provided, with increased focus on procedural knowledge for memory making offerings and facilitating the keepsake creations, as well as conceptual didactic education. Providing both procedural and conceptual knowledge can help professionals gain procedural fluency in memory making. Lack of education has also been reported in other studies as a barrier to implementing bereavement services[37,38] where regular reexposure is needed for optimal retention.[41]

HCPs had high levels of agreement in having the necessary skills to offer families memory making and levels of disagreement when asked if they find it difficult to offer the opportunity. Participants reported the required skills most needed to offer memory making involved the ability to interact with the family, being open to the memory making concept, and integrating memory making into the HCPs' standard of care. The process of memory making does require several steps for the HCP to complete, including determining the timing of when to offer, effective communication skills to convey the opportunity to the appropriate person(s), and the actual act of creating the keepsake(s) if desired. For this study, participants did not indicate that having met families for a short period of time prevented them from offering memory making opportunities, but having skills to develop a rapport with the family did assist. This could be because HCPs in this study ICU are accustomed to meeting new families and patients regularly, often caring for new patients most shifts, medical teams change and rotate weekly, and there is typically one main SW assigned to the ICU at any time who is consulted by nursing and medical staff as required. Future research is needed to determine if frequent changes in healthcare staffing influences family members' decision to create memory making items when offered.

Determining when to approach grieving families in the ICU, how to approach them, the skills for participating in difficult or uncomfortable conversations, and time management was reported by participants as skills perceived needing improvement. The family's reaction to the impending or eventual death, whether ranging from peacefulness and acceptance to shocked and intense emotions, is reported by participants to affect their timing of when, how, or even if they decide or have the opportunity to offer memory making. Memory making in this setting is encouraged to be offered to all families and is not obtained unless desired by the family; therefore, HCPs require a degree of comfort communicating about this topic in order for the family to have the opportunity to receive these time-limited keepsakes. The process of allowing loved ones to decide what they choose to obtain, keep, and use during bereavement is also consistent with other research reporting that families consider bereavement to be an individual experience and unique in each situation, making it challenging to predetermine what families require without involving them in the decision-making process.[1,42,43] Other literature has reported that HCPs appreciate having the opportunity to connect to patients and families and have used memory making items as starting points for conversations to assist in providing these meaningful connections.[36,44,45]

Based on the participants' responses in this study, increased education sessions could be beneficial, including incorporating simulations on communication techniques encompassing problem-solving strategies using reflective practices to help increase exposure and knowledge opportunities for different end-of-life scenarios.[46,47] Additionally, supporting HCPs' participation in regular observations of more experienced professionals conducting family meetings and discussions could help provide knowledge opportunities,[46,47] especially for HCPs who reported in this study to not have opportunities to offer memory making owing to limited exposure to patients receiving end-of-life care. When encountering an end-of-life situation, HCPs must reflect on their possible actions of when, how, and who to approach about memory making and the likely outcomes of each potential action before deciding on the most suitable one to take.[48] Because each end-of-life situation is unique, the professionals' knowledge and experience will not always be adequate for future family encounters. Exposure to different experiences, both theoretical and clinical, could develop new knowledge for the professionals' use in future encounters.[1,48] Communication skill deficits for difficult conversations and end-



of-life scenarios, as well as barriers of time availability to have the conversations, has been reported in prior studies,[38,46,49,50] and this study extends these findings. Future research is also needed to explore the family's preferences and experience in offering memory making to inform best practice.

4. Limitations

This study represents a self-selected sample at a single-centre and provides a snapshot of participant's perceptions at one point in time. As such, results are only relevant to the participants who participated and may not represent perspectives of those who did not participate. Some of the responses provided by participants under the skills category represent personal attributes rather than skills that can be obtained. For transparency, results are reported as the participants have provided them.

5. Conclusion

Overall, participants appear to have positive experiences with offering memory making in the adult ICU, with a high proportion of participants reporting offering keepsakes and reporting it to be integrated into their standard practice. Memory making can be perceived to include multiple aspects of the end-of-life care provided, in addition to offering the tangible keepsakes. The ICU nursing profession is most likely to perceive professional responsibility for initiating and facilitating memory making, which is supported through their increased time at the bedside and higher prominence and leadership in other end-of-life care practices. To support HCPs gaining procedural fluency in offering and providing memory making, education should include providing not just conceptual knowledge of potential benefits to family members but also procedural knowledge of keepsake creation and communication techniques using reflective practices. Support should also be provided to allow for the additional time and workload assistances required to help complete the family's requests.

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Conflict of Interest

T Buckley is an Editor for Australian Critical Care. In keeping with currently policy, this submission was handled by members of the Editorial Committee and Buckley did not have access to the submission, other than that provided to authors.

CRediT authorship contribution statement

Melissa Riegel: Conceptualisation, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing, Funding acquisition. **Sue Randall**: Conceptualisation, Methodology, Formal analysis, Writing – review & editing, Supervision. **Thomas Buckley**: Conceptualisation, Methodology, Formal analysis, Writing – review & editing, Supervision.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.aucc.2021.08.003.

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Key findings from the above peer-reviewed publication include participants reporting overall positive experiences with offering memory making to families. Registered nurses are more likely to perceive professional responsibility for offering memory making (see Figure 1 in the above manuscript or Figure A.3 in this thesis). Education to support professionals offering memory making should include conceptual knowledge, procedural knowledge of keepsake creations, and communication techniques. Organisational supports are also required to facilitate the time requirements for offering and providing memory making.

5.1.3 Factors associated with the decision to offer memory making

The next peer-reviewed publication reports the healthcare professionals' experiences and behaviour influences associated with offering memory making. Results include enablers and barriers to offering memory making and compares responses from participants with self-reported experience offering memory making to those with no experience.

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ORIGINAL ARTICLE

Factors associated with the decision to offer memory making in end-of-life: A survey of healthcare professionals in adult intensive care

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Abstract

Aim: Report experiences and behaviour influences with healthcare professionals' decision to and experiences of offering memory making during end-of-life care in the adult acute population.

Background: Little is known about healthcare professionals' experiences offering memory making during adult acute end-of-life care.

Design: Survey.

Methods: Registered nurses, medical practitioners and social workers employed at a single tertiary referral adult intensive care, where memory making had been implemented nearly two years prior were invited to participate between June and August 2017. Reporting adheres to the STROBE checklist.

Results: Ninety-six valid surveys (75% response rate: 75 registered nurses, 19 medical practitioners, and 2 social workers) were analysed with 67 participants reporting experience offering memory making. Highest overall agreement scores included believing families value memory making and the offer of memory making being beneficial. Enablers were described as organisational supports, personal qualities and good interpersonal relationships. Barriers identified included the intensive care environment, workload, inexperience offering/facilitating memory making, being afraid to offer, lack of resources and legality concerns. Compared with non-experienced participants, experienced participants reported higher level of confidence and comfort offering memory making, pride in their ability, ability to spend time supporting families and had observed colleagues offering memory making. Experienced participants were less likely to be afraid to offer, be limited by the family's behaviours, report lack of resources or be time limited to offer memory making.

Conclusion: Findings identify elements needed for the development and support for offering memory making to assist bereaved families in adult acute care including role modelling, support to reduce negative emotions, workload assistance and leadership/organisational support.

Relevance to clinical practice: Discoveries have important implications in addressing evidence gaps regarding behaviour influences linked to the decision to offer memory making. Findings inform development and sustainability to integrate memory making as routine end-of-life care intervention in adult acute care.

KEYWORDS
bereavement, critical care, end of life, grief, keepsake, memory, memory making, nurses, terminal care, transitional object

1 | BACKGROUND

Memory making is defined as an activity that provides an object, keepsake or memento that can help a bereaved individual create a connection with and provide meaningful memories about a deceased person (Miller et al., 2014), as the dead are represented to their bereaved loved ones through the memento objects (Cashell, 2007; Hookway, 2000; Peirce, 1994). Sometimes referred to in other disciplines as linking, transitional or melancholy objects (Gibson, 2004; Sas & Coman, 2016), memory making opportunities seem well received by families, although are more commonly reported in the neonatal bereavement literature (Butler et al., 2015). In the adult acute population, memory making opportunities appear rarely offered by healthcare professionals. Despite the rarity of memory making opportunities offered in adult acute care, mementos are reportedly utilised by survivors during bereavement (Riegel et al., 2019).

Limited evidence is available concerning healthcare professionals' decision to offer memory making in the adult acute population during end-of-life care. Nearly two years prior to the study reported in this manuscript, an end-of-life and bereavement care programme was commenced and referred to locally as the Loved One Support Service (LOSS). One key component of the LOSS programme includes assisting with memory making by providing families the option of creating remembrance objects, such as handprints or footprints, locks of hair, and, if applicable, provides teddy bears to children. Other components of the LOSS programme include unrestricted visiting hours; encourages visually softening and personalising the patient's bed space with electric candles, photographs, scent diffusers and music; provides bereavement information booklets; mails condolence cards the first week after ICU; and telephones the next of kin around week five for follow-up and to clarify any questions and/or direct them to further support resources if needed.

We have previously reported memory making interventions to be predominately considered a nursing responsibility (Riegel, Randall, & Buckley, 2021), which is consistent with nurses' roles in end-of-life care to facilitate a dignified death (Puente-Fernandez et al., 2020). We have also reported important skills that enable the offer of memory making to include the healthcare professional's ability to connect and interact with the next of kin, being open to the potential of memory making as an intervention, and incorporating it as a standard end-of-life care practice they provide (Riegel, Randall, & Buckley, 2021). However, limited empirical data are available regarding memory making for the adult acute population and the supports required to facilitate memory making becoming an established and sustained end-of-life care intervention.

What does this paper contribute to the wider global clinical community?

- Behaviour influences that support the offering of memory making to bereaved families include organisational supports and resources, the ability to develop interpersonal connections, time to spend with the family, confidence, comfort, pride, role modelling and having resources available.
- Recommendations for future practice to assist healthcare professionals offer memory making as an end-of-life care intervention includes use of simulation and practice, promotion of problem-solving strategies, addressing paternalism, role modelling opportunities, support to reduce negative emotions including stress management strategies, workload assistance and leadership support of memory making.

Investigating the experiences and behaviour influences from the perspective of healthcare professionals with and without experience offering memory making in a setting where it is already an established practice will help to determine the behaviour influences that guides their decision to offer this time-sensitive intervention to families.

2 | AIM

The aim of this study is to report the experiences and behaviour influences associated with healthcare professionals' decision to and experiences of offering memory making as part of end-of-life care in the adult acute population.

This information can be used to inform the development and sustainability of memory making as a routine practice to support bereaved families, including what influences and inhibits the offering of memory making, and the supports required to offer memory making. Having a greater understanding of the experiences offering memory making from healthcare professionals in an environment where memory making had been introduced nearly two years prior to this study has the potential to help inform the sustainability of this practice. These findings can also help to inform other areas of healthcare internationally that wish to support families through the offer of memory making.

3 | METHODS

3.1 | Design

Survey designed using Likert scale and open-ended responses was administered through both a hard paper copy and an electronic version using REDCap electronic data capture tools hosted at the University of Sydney (Harris et al., 2019). This exploratory study was reported based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for cross-sectional study (Vandenbroucke et al., 2007). See Supporting Information S1 for the survey instrument and Supporting Information S2 for the STROBE checklist.

3.2 | Setting

The study site was a 17- bed tertiary referral, adult intensive care unit (ICU)/high-dependency unit located in Sydney, Australia between June and August 2017.

A designated palliative care floor/ward is not available at this hospital, so care provided during this stage of life is managed within the intensive care unit. If the patient requires long-term nursing care, they may be transferred to a suitable hospital floor/ward.

3.3 | Participants

A convenience sample was used to invite full time, part time and regular casual registered nurses (RNs), medical practitioners (MPs) and social workers (SWs) employed at the study site to participate in this study. The invitations were distributed through the ICU's private social media page, communal areas such as break/tea rooms and through the organisation's email. Participant eligibility included having worked longer than three months in the ICU; therefore, the eligible sample size was determined to be 128 participants. Eligibility for participation also included experience implementing end-of-life care but was self-determined by the healthcare professional.

This ICU does not employee other advanced and complimentary practitioners such as Nurse Practitioners.

3.4 | Variables

In the survey, participants were provided the definition of memory making to be 'an activity that provides a tangible object(s) that can help a bereaved individual create a connection with and provide meaningful memories about a deceased person'. Participants were categorised as having had 'experience' or 'no experience' based on their response to the survey question 'I have offered memory making to families in intensive care'.

3.5 | Data source

Data were collected using an anonymous survey. Eligibility for participation was self-determined by the healthcare professionals, and consent was implied from participants who returned the survey. Survey questions were created using the original Theoretical Domains Framework (TDF) due to its continued applicability for determining behaviour influences in implementing evidence-based practice (Atkins et al., 2017; Michie et al., 2005). Questions were designed to explore the participants' experiences in facilitating memory making activities as part of end-of-life care on a 6-point Likert scale where: 1 = completely disagree; 2 = mostly disagree; 3 = slightly disagree; 4 = slightly agree; 5 = mostly agree; 6 = completely agree. To explore topics in more detail and to provide a richer understanding of experiences beyond Likert scalable answers, open-ended questions to allow for participant elaboration was also included. See Table 1 for a description of the constructs explored within the domains of this study and Supporting Information S1 for the survey instrument.

3.6 | Ethical considerations

The South Eastern Sydney Local Health District Human Research Ethics Committee granted the ethics and site approval for this study (HREC Ref 17/152). Main ethical considerations involved participant consent, privacy and confidentiality. Data were gathered using a survey format to allow for an anonymous choice in participant's participation and responses. A secure box to collect the paper surveys was located in a staff communal area to allow for anonymous returns.

3.7 | Data analysis

Descriptive statistics are reported as mean (M) (standard deviation [SD]), and IBM SPSS, version 24 was used to conduct this analysis (IBM Corp, Released 2016). Comparisons between participants with and

TABLE 1 Constructs explored from the Theoretical Domains Framework (Michie et al., 2005)

Theoretical domain	Explored the constructs of
Knowledge	Knowledge about the phenomenon/scientific rationale and procedural knowledge of memory making
Skills	Competence, ability, practice, and skills development
Beliefs about capabilities	Self-efficacy, self and professional confidence, empowerment, self-esteem, and optimism/pessimism
Beliefs about consequences	Outcome expectancies, evaluation/review, attitudes, consequences, incentives/rewards, and beliefs
Motivation and goals	Intention, goals (controlled, target/setting, priority), intrinsic motivation, and commitment
Memory, attention, and decision processes	Memory, attention, attention control, and decision making
Environmental context and resources	Resources/material resources (availability and management), environmental stressors, and person and environment interaction
Social influences	Social support, social pressure, social/group norms, team working, and organisational culture
Emotion	Affect, stress, anticipated regret, and fear, cognitive overload/tiredness
Behavioural regulation	Action planning, barriers, and facilitators
Nature of the behaviours	Routine/automatic/habit, and direct experience/past behaviour

without self-reported experience with offering memory making was performed using Mann–Whitney U and Spearman Rank Order tests. Alpha of .05 was utilised. No adjustments were performed for multiple testing as corrections can risk being exaggeratedly conservative and unsuccessful in revealing significant findings for novel and under researched areas of practice (Perneger, 1998). Missing data were determined to be random, so no substitutions for missing data was made (Little's Missing Completely at Random [MCAR] test $p = .53$).

Open-ended questions elicited a high volume of responses. These were analysed using thematic analysis (Braun & Clarke, 2006), and the adoption of a pragmatist epistemology. Each individual question was analysed to allow for a more detailed and truthful representation of the data. Responses to the open-ended questions were analysed as a full sample.

3.8 | Validity, reliability, and rigor

The survey instrument was assessed for face validity by an expert panel of critical care registered nurses and medical professionals prior to use; however, it was not assessed for reliability. Within thematic analysis, knowledge is considered contextual, and the researcher's subjectivity is considered a resource for knowledge production (Braun & Clarke, 2020). The lead author is a senior Registered Nurse who practices in the ICU and is highly experienced in the provision of memory making in end-of-life care. Rigor was ensured through the criteria of dependability, credibility, transferability and confirmability (Lincoln & Guba, 1985; Nowell et al., 2017) by looking for similarities among all participants' responses, all study investigators (MR, SR, TB) reviewing and agreeing on extracted themes, providing participants' words and how data were reduced for analysis, and including descriptions of the sample participants and the study setting.

4 | RESULTS

4.1 | Participants' characteristics

One hundred participants responded from 128 eligible participants (78% response rate). Four respondents had survey incompleteness of 75% or more, so were excluded from the final analysis. Valid participants included as follows: 75 registered nurses (75% response rate), 19 medical practitioners (76% response rate) and 2 social workers (66.7% response rate). See Table 2.

4.2 | Overall participants' responses

Most study participants reported receiving memory making education (n = 63, 65.6%). Participants reported the highest agreement scores for survey questions related to believing families value memory making after a death and believing the offer of memory making is beneficial for families. Participants reported the lowest agreement scores in relation to being afraid to offer memory making and the ICU environment being a barrier to offering. See Figure 1 for Likert scale responses in descending order of scores of agreements for all study participant responses.

The open-ended survey questions explored topics within the domains of: beliefs about consequences; motivation and goals; memory,

TABLE 2 Sociodemographic characteristics of participants

Characteristic	All participants n = 96	Experience n = 67	No experience n = 29	*p* value
Age in years mean (SD)	38.1 (10.7)	38.7 (10.2)	36.7 (11.7)	.34
Gender				
Male	25 (26%)	13 (52%)	12 (48%)	
Female	70 (73%)	54 (77.1%)	16 (22.9%)	
Did not state gender	1 (1%)	0	1 (100%)	.04
Profession				
Registered Nurses	75 (78%)	60 (80%)	15 (20%)	
Medical Practitioners	19 (20%)	5 (26.3%)	14 (73.7%)	
Social Workers	2 (2%)	2 (100%)	0	<.001
Country of professional education:				
Australia	52 (54.2%)	35 (67.3%)	17 (32.7%)	
United Kingdom and Ireland	31 (32.2%)	24 (77.4%)	7 (22.6%)	
India	3 (3.1%)	2 (66.7%)	1 (33.3%)	
Philippines	4 (4.2%)	1 (25%)	3 (75%)	
Other	6 (6.3%)	5 (83.3%)	1 (16.7%)	.26
Highest level of education completed				
Hospital Certificate	4 (4.2%)	3 (75%)	1 (25%)	
Bachelor's Degree	38 (39.6%)	22 (57.9%)	16 (42.1%)	
Post Graduate Certificate or Graduate Diploma	38 (39.6%)	31 (81.6%)	7 (18.4%)	
Master's Degree	14 (14.6%)	9 (64.3%)	5 (35.7%)	
PhD/Professional Doctoral	2 (2.1%)	2 (100%)	0	.28
Mean length of experience in years as a registered health professional (SD)	14.8 (10.8)	15 (10.2)	14.3 (12.2)	.40
Mean length of experience in years in ICU (SD)	10.2 (9.5)	10.4 (8.8)	9.6 (11)	.20
Mean length of experience in years in current ICU department (SD)	7.5 (7.7)	8.0 (7.44)	6.4 (8.3)	.03

Abbreviations: *N*, number of survey responses; *p* value, Mann U or X^2 between experience and no experience participants.

attention, and decision processes; social influences; emotion; and behavioural regulation. In relation to outcomes from offering memory making, themes included to facilitate grieving, allow for family involvement, and for memory making to be used as a recollection of the ICU time. Themes extracted in relation to participants' motivation for offering memory making included positive anticipation of the family's response, providing a reciprocation of care expectations, grief assistance and workplace care delivery expectations. See Table 3 for example quotes.

Participants described a range of situations where they believed it was not appropriate to offer memory making to families, including alternative patient care priorities, assuming the family will not want or need it, religion, culture, confidence approaching and the family's behaviour. They also described it as not being appropriate to approach families if it was previously offered and refused, legality concerns (such as a coroner's case or police involvement), and no immediate relatives available (Table 3).

Participants described examples of memory making observed to include tangible mementos, environmental modifications, emotional support and providing practical information. Some participants expressed being afraid to offer memory making due to family reactions, their reduced confidence, communication deficiencies, and if they were uncomfortable with the concept. Enablers for offering memory making were described to include organisational supports and resources, personal attributes and having interpersonal relationships between the healthcare professional and the family. Alternatively, barriers reported included workloads, inexperience in offering and facilitating memory making, lack of resources and legal concerns (Table 3).

4.3 | Factors associated with the decision to offer memory making in clinical practice

A higher proportion of participants with experience offering memory making reported they had received education, had read about it and perceived having the necessary skills to provide the offer. Experienced participants also reported significantly higher scores

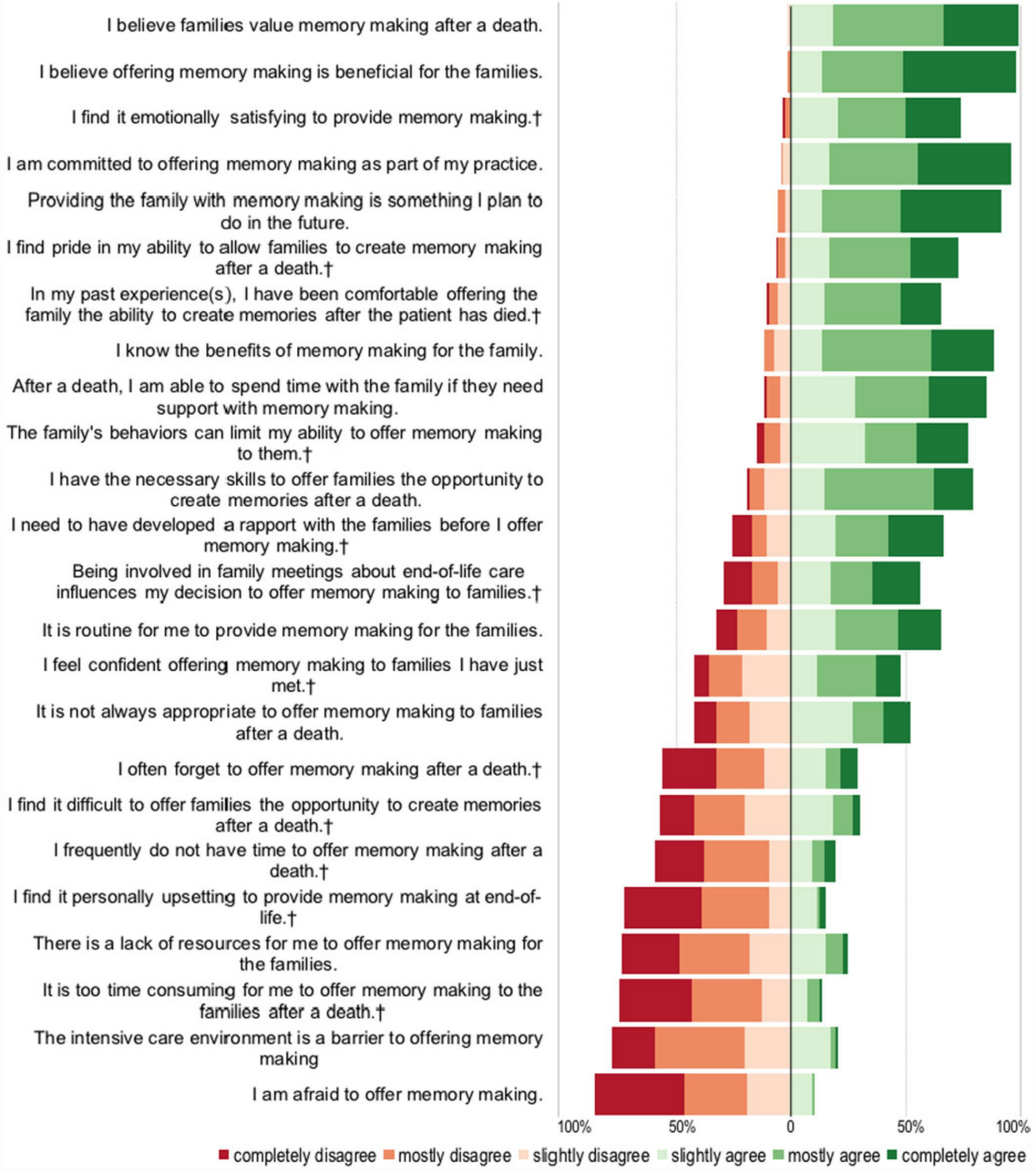

FIGURE 1 Likert scale responses for overall participants in descending order of scores of agreements as represented in percentages. †Question utilized the option of 7 = not applicable to me

of agreements concerning their confidence and being comfortable offering memory making. Participants with no experience offering memory making reported significantly lower agreement scores to knowing the benefits of memory making. However, both participant groups had similar scores of agreement concerning rapport with the families being required in order to offer memory making (Table 4).

Participants with experience offering memory making reported statistically higher scores of agreement that offering memory making is beneficial to families, were committed to having it as part of

TABLE 3 Themes, subthemes and example quotes from open-ended survey questions for the domains: beliefs about consequences; motivation and goals; memory, attention, and decision processes; social influences; emotion; and behavioral regulation

Survey question (*Theoretical Domain*)	Theme	Subtheme	Example quotes (participant number)
The outcomes(s) I anticipate from families being offered and/or doing memory making include: (*Beliefs about consequences*)	Facilitate grieving	Remembrance	*“…Remembering loved one without technology attached to them. Able to have something with them always.”* (8-RN)
		Object to interact with	*“Tangible item to look at and touch when pt* [patient] *passes”* (39-RN)
		Better path to grieve	*“Better coping with grief, memory making as a part of grieving process”* (19-MP)
		Finality	*“…‘some’ element of closure +* [plus]*/or acceptance to what is happening with loved one &* [and] *create a ‘good’ death +* [plus]*/or positive outcome”* (51-RN)
	Family involvement	Distraction for the family	*“Doing something productive- end of life is a lot of sitting & standing around…”* (70-RN)
		Family as the carers	*“…It is also a practical exercise that potentially allows the family to feel involved in the end-of-life process”* (66-RN)
		Family centered	*“…I hope they remember it as a time that their family member were well cared for and the family was respected & listened to”* (83-RN)
	Recollection of ICU time	Positive memories	*“I believe it's a lovely gesture. Encouraging a positive rapport with families, creating good memories at a difficult time. I believe families will reflect and only truly appreciate memory making when away from the ICU environment.”* (14-RN)
		Thoughtfulness	*“All the families I have asked, have declined but appreciate being asked”* (56-RN)
		Care of the person	*“Greater satisfaction with management of their loved one's end of life care”* (20-MP)
I offer memory making to families because: (*Motivation and goals*)	Positive anticipation of family's response	Positive family reactions	*“… have seen it done prior and seen families to cherish it. Thus indicating to me as a positive process of acceptance of the death and connection with the deceased.”* (6-MP)
		Extending kindness	*“It is a nice gesture”* (40-RN)
	Reciprocation of care expectations		*“I would like the same done for myself & family.”* (47-RN)
	Grief assistance	Facilitate bereavement	*“It is a simple and effective activity that may help families through the bereavement process.”* (20-MP)
		Remembrance token	*“It helps give the family something to remember the patient by.”* (46-RN)
		Death acceptance	*“it is valued by patients families in my experience.”* (94-MP)
		Unknown to families what they can do	*“…during such a time people need guidance about what to do.”* (3-SW)
		Time-sensitive options	*“…It might be their only chance, once their relative is gone & buried that option is forever gone.* (77-RN)
	Workplace care delivery expectations	Unit standards of practice	*“Since LOSS* [Loved One Support Service] *program started in AICU* [adult intensive care unit] *I have followed guidelines & offered memory making.* (74-RN)
		Care partnership	*“It is the families choice to have memory making or not. I offer a choice I do not make the decision for them.”* (43-RN)
		Professional role	*“It is good practice. It is the right thing to do even in death a nurse is an advocate to the patient.”* (70-RN)

TABLE 3 (Continued)

Survey question (*Theoretical Domain*)	Theme	Subtheme	Example quotes (participant number)
I feel it is NOT appropriate to offer memory making to families if: (*Memory, attention, and decision processes*)	Alternative patient care priorities		*"When desired activities will be an infection risk or will unreasonably delay care to other patients in the department/needing to come to the department."* (2-MP)
	Assume the family won't want or need it		*"The patient is older & death is anticipated. These N.O.K.* [next of kin] *have a house-full of memories to go through. If there is a strong support network about the family – they will often be discussing the patient. They don't need random nurses intervene"* (30-RN). *"It does not appear that this is something families would appreciate & value"* (58-RN)
	Religion		*"… cultural/religious/etc background is against it"* (4-RN)
	Culture		*"If there are cultural observations that would deem memory making inappropriate??"* (66-RN) *"culturally inappropriate"* (91-MP)
	Confidence approaching	Situational discomfort	*"Blame the loss of their loved one on the healthcare team. …"* (42-RN) *"Severe trauma with disfigurement. Medical negligence led to death"* (96-MP)
		Timing of offering	*"Perhaps the death was sudden, unexpected or the family is unconsolable* [sic]. *…"* (34-RN)
		Lack of rapport	*"…Some families very private & difficult to establish a rapport with them which makes it difficult to broach the subject."* (74-RN)
	Family behavior	Communication breakdown	*"hostile towards staff, not appropriate timing"* (51-RN)
		Meaningless gesture	*"Some people might think it's a small (concession) to receive when someone dies who they loved."* (77-RN)
		Disenfranchised grief	*"suicide"* (86-RN)
	Previously offered and refused		*"The family has expressed that they wouldn't want memory making"* (56-RN)
	Legality		*"There is a coroners case or a social/police involvement that is stopping us."* (81-RN)
	No reason not to offer		*"I can't think of a situation where it isn't appropriate to make the offer – it doesn't have to be accepted!!"* (50-RN)
	No immediate relatives		*"… if the pt* [patient] *has no family & a 'friend' is the only contact.* (47-RN)
Examples **I** observed of colleagues offering/ facilitating memory making to families (*Social influences*)	Tangibles		*"offering locks of hair, hand print, passing around card to sign"* (74-RN). *"Nurses offering family locks of hair, or children being given toys"* (53-RN) *"Handprints & locks of hair"* (91-MP)
	Environmental modification		*"… liaised with nursing staff about wishes of the family, e.g. dressing patient in favourite t-shirt, having music playing etc."* (3-SW) *"… NOK [next of kin] time to be with the patient with privacy; ensuring the patient is decent for viewing"* (7-RN)
	Emotional support		*"kindness & listening & reacting to families wants & needs"* (31-RN)
	Practical information		*"Within our unit I have observed-… bereavement information packs."* (14-RN)

TABLE 3 (Continued)

Survey question (*Theoretical Domain*)	Theme	Subtheme	Example quotes (participant number)
I am afraid to offer memory making when/ because: (*Emotion*)	Family reactions	Aggressive	*"patient's family very aggressive"* (68-RN)
		Heightened emotions	*"When family is actively/visibly distressed. May wait for them to settle first."* (76-RN)
	Reduced confidence	Inexperience	*"At this stage that I don't know much of memory making I'm quite afraid to initiate but definitely I will open the topic to them but will ask my senior colleagues to help me."* (28-RN)
		Staff fear of mistake	*"I have found the act of doing hand prints a little difficult to achieve in some cases and a messy thing. (i.e.- had an elderly pt* [patient] *with very knarly, arthritic hands and was very difficult to get a good quality print) (with family assisting)"* (67-RN)
		Cultural and social institutional uncertainty	*"overly emotional families, disjointed families, different culture/background/religion"* (86-RN)
		Rejection	*"Last family I discussed this with gave me a strange look- let subject go/they were not the sort to get excited about hand prints"* (30-RN)
	Communication deficiencies	No rapport	*"As a JMO* [junior medical officer] *I don't normally have the time to get to know a family & build rapport before end-of-life care, also I am less involved in the decision making."* (91-MP)
		Lost for words	*"I don't know what to say"* (52-RN)
	Uncomfortable with the concept		*"I find the concept personally confronting and I don't think I would want it personally"* (56-RN)
What enables you to provide memory making for families? (*Behavioral regulation*)	Organizational supports and resources	Time	*"Having time is essential"* (39-RN) *"approaching family, offer memory making, involve family, not be pressured by in charge to get pt* [patient] *moved onto morgue for new admission"* (55-RN)
		Supportive co-workers	*"cooperation, support from my team"* (86-RN) *"Connection with family and patient during their care. The nursing support of my providing this."* (6-MP)
		Supplies accessibility	*"Availability of memory making box as this can be required in a short space of time and if we had to go searching for it this service would probably not be offered."* (33-RN)
		Guidelines	*"Development of department guidelines for memory making so that it can become established practice"* (20-MP) *"Kit, instructions/guidelines time support from team"* (66-RN)
		Education	*"loss* [Loved One Support Service] *program techniques"* (37-RN)
	Personal attributes	Experience	*"My experiences with death in the ICU have helped me grow in my abilities to care for families of dying patients"* (29-RN)
		Adopted responsibility	*"my duty"* (31-RN)
		Empathy	*"Time. Compassion"* (36-RN)
	Interpersonal relationship of healthcare professional - family	Rapport	*"I find it easier when I have made a connection with the family and/or pt* [patient] *during their admission"* (44-RN)
		Believe family appreciate	*"knowing that family members would find the idea appealing/appropriate – establishing rapport"* (27-RN)
		Family's reactions	*"Often it's positively received an this makes offering it easier"* (12-RN)

(Continues)

TABLE 3 (Continued)

Survey question (*Theoretical Domain*)	Theme	Subtheme	Example quotes (participant number)
What barriers prevent you from offering memory making to families? (*Behavioral regulation*)	Workload	Time	*"Possible other work and time constraints."* (6-MP) *"once someone has died, I am expected to prepare the body, etc & clear the bed space for the next pt [patient]. Not much time to stay with family."* (61-RN)
		Unsupportive co-workers	*"Lack of time, if unsupported by colleagues"* (52-RN)
		Patient priorities	*"Pressure of new patients waiting for admission & insufficient help to move things along/prepare without appearing to rush to grieving family"* (50-RN) *"If it's a really busy shift and I need to help others cope with their serious sick patient"* (57-RN)
	Inexperience offering and facilitating	Knowledge deficit	*"Knowledge of memory making and how to facilitate it"* (20-MP)
		Skills deficit	*"Sometimes hard to do hand prints – puts you off offering it. Messy/poor prints. Bit embarrassing"* (77-RN)
		Limited exposure	*"lack of experience/practice of doing so"* (48-RN)
		Communication deficit	*"intimidated by a grieving family"* (56-RN)
	Lack of resources	Location of	*"Unable to locate appropriate tools"* (9-RN)
		Environment	*"If the unit is busy/noisy/chaotic. Much easier in private room"* (12-RN)
	Legality concerns		*"? If pt [patient] is for coroners (unsure if you can take hair, paint hands etc)"* (34-RN)

their practice, and were able to spend time with the family after a death. In addition, experienced participants had lower agreement scores of forgetting to offer memory making, for not having time to offer memory making, and considering it to be too time consuming to offer (Table 4).

Participants with experience offering memory making reported higher instances of observing colleagues offering/facilitating memory making (Table 4). Most participants (76%, *n*=73) reported they had observed colleagues offering/facilitating memory making to families.

Participants with experience offering memory making reported higher scores of agreement related to pride in their ability to offer memory making, it being something they plan to provide in the future, and considered it to be routine in their practice. They also had lower agreement scores in relation to being afraid to offer memory making and that the family's behaviours limited their ability to offer (Table 4).

5 | DISCUSSION

The aim of this study is to report the experiences and behaviour influences associated with healthcare professionals' decision to and experiences of offering memory making as part of end-of-life care in the adult acute population. Determining behaviour influences associated with the healthcare professional's decision to offer memory making can be used to inform the development of more effective interventions to support memory making becoming a routine and sustainable end-of-life care practice (Michie et al., 2005, 2021). By reporting healthcare professional's behaviour influences, these study results have the potential to be transferrable to other acute care settings and international environments, regardless of the models of end-of-life care used.

Healthcare professionals are less likely to offer memory making without having received prior education, despite similar levels of agreement between all participants of whether they find it difficult to offer. Additionally, participants without experience offering memory making still had levels of agreement to knowing the benefits of offering, but were less likely to think offering memory making is beneficial for families compared with experienced participants. These responses suggest that education is an important factor in relation to healthcare professionals offering memory making. The need for continued end-of-life care education has been frequently highlighted in the literature as areas of opportunity for professional growth and improvement for end-of-life care delivery (Ganz, 2019; Ranse et al., 2020; Riegel, Randall, Ranse, et al., 2021), and this study extends those findings by reporting behaviours associated with offering memory making as part of the healthcare professionals' end-of-life care interventions.

Participants with experience offering memory making had higher perceived confidence, were more comfortable offering and had greater pride in their ability to offer. Those without experience

TABLE 4 Comparison of participants' responses based on self-reported experience offering memory making to families

Theoretical Domain	Survey question	Experience $n = 67$	No experience $n = 29$	p value
Knowledge		**Yes *n*, %**	**Yes *n*, %**	
	I have received education related to memory making for families	56 (83.6%)	7 (24.1%)	<.01
	I have read literature/published information about memory making	20 (29.9%)	3 (10.3%)	.04
	If so, where did you read about it?			
	Medical/nursing textbook	1 (1.5%)	2 (6.9%)	.2
	Medical/nursing journal	9 (13.4%)	2 (6.9%)	.4
	Website	6 (9.0%)	2 (6.9%)	.7
	Social media	2 (3.0%)	2 (6.9%)	.4
	Blog	1 (1.5%)	0	.5
	Other	5 (7.5%)	0	.1
	Participants reporting in-service lectures in ICU or colleagues	4	0	
		M (SD)	**M (SD)**	
	I know the benefits of memory making for the family	5.1 (0.9)	4.3 (1.2)	.002
Skills	I have the necessary skills to offer families the opportunity to create memories after a death	4.9 (0.9)	3.7 (1.3)	<.001
	I find it difficult to offer families the opportunity to create memories after a death[a]	2.8 (1.4)	3.4 (1.3)	.06
Beliefs about capabilities	I need to have developed a rapport with the families before I offer memory making[a]	4.1 (1.6)	4.6 (1.5)	.11
	I feel confident offering memory making to families I have just met[a]	4.0 (1.5)	3.2 (1.3)	.02
	In my past experience(s), I have been comfortable offering the family the ability to create memories after the patient has died[a]	4.8 (1.1)	4.0 (1.3)	.047
Beliefs about consequences	I believe families value memory making after a death	5.2 (0.7)	5.0 (0.8)	.26
	I believe offering memory making is beneficial for the families	5.5 (0.7)	5.0 (0.9)	.01
Motivation and goals	I am committed to offering memory making as part of my practice	5.4 (0.7)	4.5 (0.9)	<.001
Memory, attention and decision processes	It is not always appropriate to offer memory making to families after a death	3.6 (1.6)	3.6 (1.2)	.975
	I often forget to offer memory making after a death[a]	2.5 (1.5)	3.9 (1.6)	.001
Environmental context and resources	The intensive care environment is a barrier to offering memory making	2.4 (1.1)	2.8 (1.1)	.08
	After a death, I am able to spend time with the family if they need support with memory making	4.9 (1.1)	4.0 (1.1)	<.001
	There is a lack of resources for me to offer memory making for the families	2.3 (1.4)	3.1 (1.1)	.004
	I frequently do not have time to offer memory making after a death[a]	2.3 (1.3)	3.5 (1.7)	.01
	It is too time consuming for me to offer memory making to the families after a death[a]	2.0 (1.1)	2.8 (1.5)	.02
Social influences		**Yes *n*, %**	**Yes *n*, %**	
	I have observed my colleagues offering/facilitating memory making to families	60 (89.6%)	13 (44.8%)	<.001
		M (SD)	**M (SD)**	
	Being involved in family meetings about end-of-life care influences my decision to offer memory making to families[a]	3.8 (1.8)	4.4 (1.7)	.27

(Continues)

TABLE 4 (Continued)

Theoretical Domain	Survey question	Experience *n* = 67	No experience *n* = 29	*p* value
Emotion regulation	I am afraid to offer memory making	1.9 (1.0)	2.4 (1.0)	.02
	I find it emotionally satisfying to provide memory making[a]	5.0 (1.0)	4.5 (1.2)	.08
	I find pride in my ability to allow families to create memory making after a death.[a]	5.0 (0.9)	4.1 (1.4)	.01
	I find it personally upsetting to provide memory making at end-of-life[a]	2.1 (1.2)	2.3 (1.5)	.83
Behavioural regulation	The family's behaviours can limit my ability to offer memory making to them[a]	4.2 (1.4)	4.9 (0.9)	.04
Nature of the behaviour	It is routine for me to provide memory making for the families	4.7 (1.2)	2.6 (1.5)	<.001
	Providing the family with memory making is something I plan to do in the future	5.4 (0.8)	4.7 (1.2)	.003

Abbreviations: M, mean; *p* value, Spearman Rank Order or Mann U between experience and no experience participants; SD, standard deviation.

[a] Question utilized 7-point Likert scale with the option of 7 = not applicable to me.

were more likely to be afraid to offer memory making. Healthcare professionals' emotional responses for offering memory making such as pride or being afraid, as well as beliefs about their capabilities, will be subjected to situational background variables and previous experiences, events, and conversations for everyone involved (Lazarus, 2006). In the adult population, an unplanned ICU admission is reported to cause family members to experience heightened emotional vulnerability and psychological responses including anxiety, depression and anger symptoms (Ruckholdt et al., 2021; Wong et al., 2019). Additionally, as the patient's condition evolves, previous personal experiences will affect how individuals interact during the continuous actions and reactions between all healthcare professionals and the patient and family members (Lazarus, 2006).

When healthcare professionals manage these potentially heightened emotional responses caused by the anticipated patient death, their actions taken will, morally, be the ones determined to provide the best result with the least amount of discontent (Talisse et al., 2008). The effort by healthcare professionals to choose their actions that will best improve the circumstance could be considered a form of meliorism—the belief that humans can aid in the betterment of the world (McCready, 2010; Talisse et al., 2008). After the chosen action is enacted and the circumstance concluded, the healthcare professional, ideally, reflects on the outcomes of the actions they have taken and will then use this experience as a source of knowledge for future situations (Younas, 2020). Having positive experiences with the family's response to offering memory making has been described to enable the motivation for future offerings by healthcare professionals.

At times, the decision to offer memory making was also influenced by participants' resource management and care priorities. To assist the healthcare professional providing end-of-life and bereavement care to the patient and family, rather than divert their care delivery to other patients, assistance with workloads, including time and support from co-workers, and environmental and supply resources is necessary. The healthcare professional's time required to provide bereavement interventions has been reported to be a worthwhile investment by some organizations (Vanstone et al., 2020). Despite this, patient privacy, time availability, and high workloads are commonly reported as influencing the end-of-life care able to be provided (Karbasi et al., 2018; Riegel, Randall, Ranse, et al., 2021; Ruiz-Fernandez et al., 2021). This study extends those findings to include factors affecting the offering of memory making.

Paternalistic beliefs also influenced some participants' decision to offer memory making, including believing the family already having enough mementos/keepsakes at home or believing the patient's friends would not be interested. In general, each individual will have varying predispositions in their beliefs about the death experience, and these beliefs may guide their behaviours in how they approach end-of-life situations (Hobbs, 2011). The paternalistic view of knowing what the family best needs during bereavement and the decision to not offer memory making to particular families can reflect what healthcare professionals believe to be true concerning death and bereavement, rather than considering or exploring the family's individualistic values (Azoulay et al., 2014). Healthcare professionals are reportedly prone to emotional decisions-making and paternalism during instances of heightened emotional situations, including if they believe the conversation might cause distress (Bowers & Redsell, 2017; Murgic et al., 2015).

Providing opportunities for participating and conducting difficult conversations might be useful to limit instances of paternalism by enhancing personal capabilities to offer memory making during instances of heightened emotional situations. Educational opportunities using active learning strategies such as simulations with end-of-life scenarios is reported to help increase the healthcare professional's competence, confidence, and self-efficacy. It is also reported to provide potential benefit for all levels of professional experience (Edwards et al., 2020; Karbasi et al., 2018). Interventions to support healthcare professionals offer memory making should include active learning strategies of simulation training in offering memory making, practicing the skills of creating objects, and the promotion of problem-solving strategies to support healthcare professionals overcome barriers to offering memory making (Centre for Behaviour Change, 2021). In instances of limited resources, these supports should be first targeted for nursing professionals since it is reported that nurses play a dominant role in communicating with the families throughout the ICU admission (Wong et al., 2019) and perceive a professional responsibility for offering memory making to families (Riegel, Randall, & Buckley, 2021).

Participants with experience offering memory making were more likely to have observed colleagues offering/facilitating memory making compared with those without experience, suggesting that seeing memory making being offered is an important enabler (Gross, 2009). It is likely that witnessing the family's responses and receptiveness to memory making influences their personal beliefs about memory making and increases motivation to integrate it into their end-of-life care practice. Others have also reported healthcare professionals experiencing positive family responses from memory making interventions (Beiermann et al., 2017), and the positive responses contribute to an increased engagement in bereavement interventions (Vanstone et al., 2020). Healthcare professionals witnessing the offer of memory making could also provide opportunities to observe potential problem-solving strategies that the healthcare professional can later reflect on for developing new knowledge to utilise in future situations (Younas, 2020).

Participants without experience offering memory making were more likely to believe that the family's behaviours limited their ability to offer. Additionally, healthcare professionals can feel afraid to offer memory making due to the family's reactions during end-of-life care, or if they perceive communication deficiencies when interacting with the family. Others have also reported healthcare professionals can feel ill-prepared to manage the emotional reactions during end-of-life care (Puente-Fernandez et al., 2020), and inadequate knowledge and skills for managing heightened emotional responses can be an obstacle to providing end-of-life care (Karbasi et al., 2018; Riegel, Randall, Ranse, et al., 2021). Those without prior education or experience providing end-of-life care are reported to frequently cope with an impending death through actively avoiding and escaping the care that the dying patient might need, running away from family issues, and/or employing emotional disconnection (Puente-Fernandez et al., 2020; Ruiz-Fernandez et al., 2021).

As participants without experience offering memory making are less likely to have received education related to memory making, their lack of education may contribute to their emotional response of being afraid related to the family's behaviours. Additionally, others have reported that healthcare professionals' emotions can influence their clinical decisions (Kozlowski et al., 2017). Supports should be provided to reduce potential negative emotions associated with offering memory making, including stress management strategies, and continuing education incorporating problem-solving strategies. This can support the healthcare professional overcome barriers and increase enablers for managing challenging situations that may occur during end-of-life care and memory making opportunities (Centre for Behaviour Change, 2021).

6 | STRENGTHS AND LIMITATIONS

This study explores an under researched area of adult acute end-of-life care practice and addresses the evidence gaps regarding the healthcare professional's decision to offer memory making. The study took place in an environment where memory making had been integrated into routine practice for nearly two years, and care provided during this stage of life is commonly managed within the intensive care unit. Using this single study site with a high survey response rate (78%) allowed for the study's results to be reflective of memory making being used in clinical practice at the study site.

However, the findings of this self-reported survey provide insights from a self-selected sample of participants at one point in time and are only applicable to those who partook in this single-centre study. Results may not represent the perspectives of non-participants. The comparison of participants with experience versus no experience is based on their response to a single, subjective question. Although memory making was clearly defined in the survey for participants to reflect on. While findings are novel and informative, they may not represent healthcare professionals' experiences in other environments.

7 | CONCLUSIONS

The presented new empirical evidence suggests elements needed for the development and support for offering memory making as a routine practice to assist bereaved families in the adult acute care environment. Behaviour influences that support the offering of memory making to families include organisational supports and resources, the ability to develop interpersonal connections, time to spend with the family, confidence, comfort, pride, role modelling and having resources available. Barriers to offering included workloads, inexperience offering and facilitating, lack of resources, and legality concerns. These findings are reflective of healthcare professionals' perspectives, but future research is needed to explore the family's experiences, preferences and the utility of memory making to fully inform best practices for end-of-life and bereavement care.

8 | RELEVANCE TO CLINICAL PRACTICE

In our study, we reported the experiences and behaviour influences associated with offering memory making from healthcare professionals with experience working in an environment where memory making had been integrated into routine end-of-life and bereavement care for nearly two years. Our findings have important implications in addressing evidence gaps regarding experiences and behaviour influences linked to the decision to offer memory making in the adult acute population and explores links between behaviour change techniques and their mechanisms of action (Michie et al., 2005, 2021).

To enable the development and sustainability of integrating memory making as routine end-of-life care practice in adult acute care, recommendations for future practice should include the use of active learning strategies with simulation, opportunities to practice creating the objects, continuing education targeting nursing professionals to participate in and conduct difficult conversations, and the promotion of problem-solving strategies. Support to reduce negative emotions including stress management strategies should also be offered. Providing role modelling opportunities and addressing paternalism may also help to influence the routine offering of memory making. Leadership support such as workload assistance to allow the time required to communicate with and support families with the memory making intervention is also necessary for practice sustainability.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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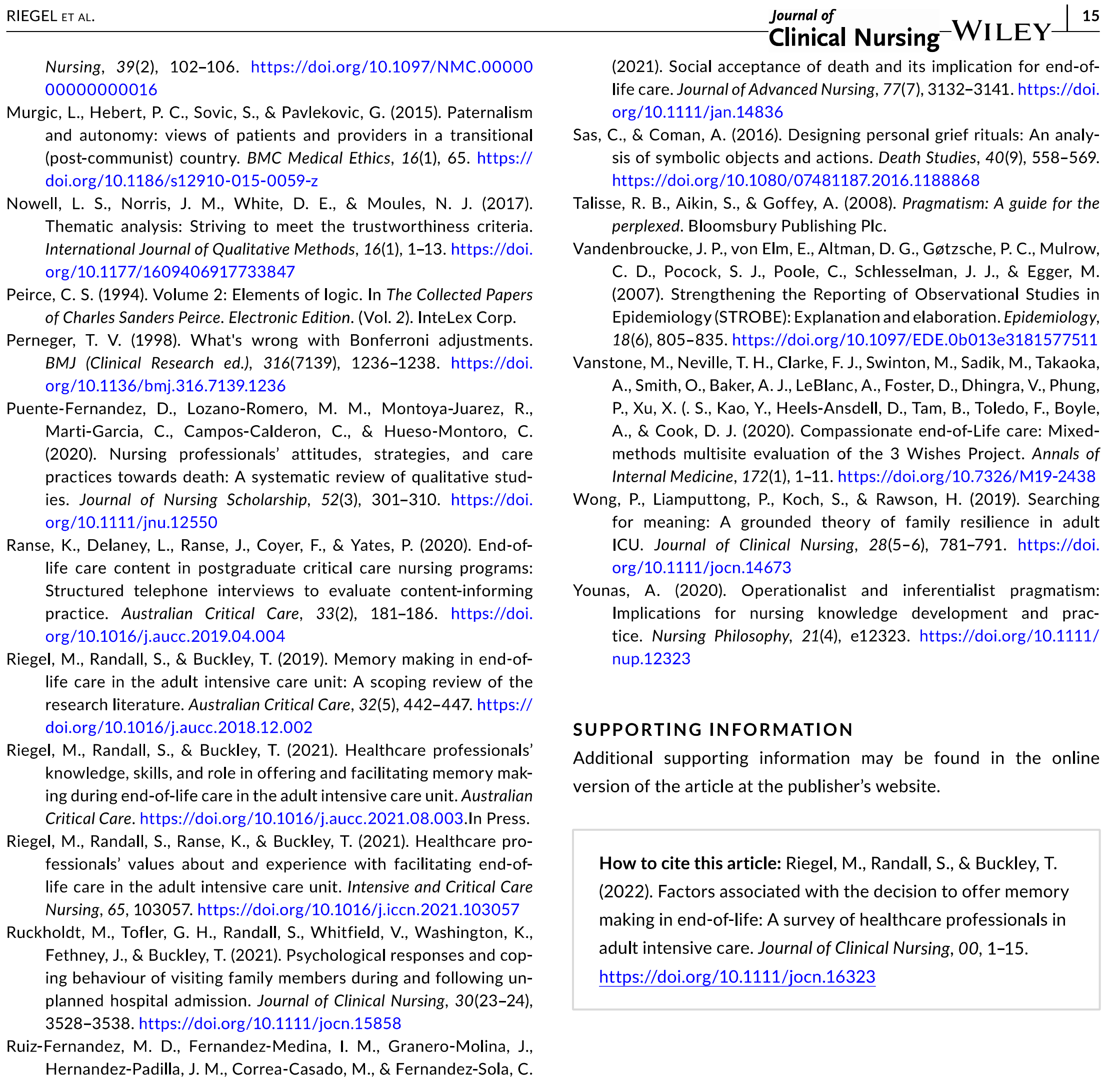

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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Key findings of elements needed to support the offering of memory making from the above peer-reviewed publication include role modelling, support to reduce negative emotions, workload assistance, and leadership/ organisational support (Riegel et al., 2022a).

5.2 BEREAVED FAMILY INTERVIEWS

The second study obtained data from family interviews to answer the question "What is the experience of relatives receiving memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?"

5.2.1 Family's experiences being offered memory making and its use in early bereavement

The second study reports the family's experience being offered memory making in the adult ICU and its use in early bereavement, and findings have been submitted for consideration in a peer-reviewed, international nursing journal. Data analysis from the family interviews generated three themes: guidance during end-of-life care that recognises the autonomy of the family; the objects being used as a trigger to accessing their memories; and the storage and preservation of the object by the recipient to be an indication of their sentimental value and use in early bereavement. The author of this thesis' personal diary was utilised in data analysis to reflect on the interviews to identify feelings and potential bias and to provide critical nonverbal content to the interview transcripts (Greene, 2014). See Tables A.1-A.3 at the end of this thesis for details of the 6-phase data analysis process undertaken for the themes generated.

Family's experience of memory making in adult intensive care and its use in early bereavement: A descriptive qualitative study.

Family's experience with memory making

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No conflict of interest has been declared by the authors.

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Keywords:

bereavement, end of life, family, grief, intensive care units, keepsake, memory making, nurses, terminal care, transitional object

Abstract

Aim: To explore the family's experience being offered memory making during end-of-life care in the adult intensive care unit and its use in early bereavement.

Design: Descriptive qualitative study utilizing inductive reflexive thematic analysis.

Methods: Interviews were conducted using a semi-structured format and occurred at the participants' location of choice.

Data Sources: Between May 2019-December 2020, a purposeful, convenience sample of 21 participants from a tertiary referral, adult intensive care unit in Australia.

Results: Three themes identified were: guidance during end-of-life by healthcare professionals that recognizes the autonomy of the family; object used as a trigger to access memories; and storage and preservation of the object as an indication of its sentimental value and use.

Conclusion: Memory making objects such as handprints, locks of hair, or toddy bears received in the adult intensive care unit were valued and utilized during early bereavement by most recipients.

Implications for the profession and/or patient care: Findings inform practice evidence gaps regarding the family's experiences of receiving memory making in the adult acute population.

Impact: Study addresses the challenge of providing person centered evidence-based care in end-of-life care demonstrating family members acceptability and desire to receive mementos in the adult intensive care.

Reporting Method: Reporting adheres to the COREQ checklist.

Patient or public contribution: Participants contributed through sharing their first-hand experiences of receiving memory making in the adult intensive care unit

What does this paper contribute to the wider global clinical community?

- Health professionals do not need to have an established relationship with the family member to offer the opportunity to create mementos, but timing of the offer can be important.
- Decisions about what objects to create should be given to the family members.
- Tangible objects appear to assist the recipient during their grief work in early bereavement.

Keywords: bereavement, end of life, family, grief, intensive care units, keepsake, memory making, nurses, terminal care, transitional object

Introduction

During end-of-life care in the intensive care unit (ICU), medical treatment transitions to comfort and dignity, and nursing care transitions to having an increased focus on the family (Bloomer, Poon, Runacres, & Hutchinson, 2022). Due to critical illness, there is frequently a shortened time from when end-of-life care for the patient begins and the subsequent death when family bereavement care starts. During this time, patient end-of-life care and family bereavement care is commonly concurrent and providing care to both the family and the dying patient is an essential part of ICU end-of-life care delivery (Bloomer et al., 2022). One potential end-of-life and bereavement care intervention for families is the act of memory making. Memory making is defined as *"an activity that provides a tangible object(s) that can help a bereaved individual create a connection with and provide meaningful memories about a deceased person"*, (Miller, Lindley, Mixer, Fornehed, & Niederhauser, 2014). Though information about memory making is predominately from neonatal literature, bereaved families in the adult population have also been reported to have positive reactions regarding the objects (Neville et al., 2020). Tangible objects created through memory making in the adult population have been reported to include handprints, footprints, locks of hair, teddy bears for children (sometimes referred to as huggy bears), patient diaries, word clouds, electrocardiogram images, and photographs (Riegel, Randall, & Buckley, 2019).

Background

Individuals whose loved one develops a critical illness and requires an emergency hospital admission are at risk of experiencing heightened emotional vulnerability and psychological responses including anxiety, depression, and anger symptoms. These heightened emotional responses can affect their ability to cope and to prepare for death if the critical condition is unable to be reversed (Lazarus, 2006). If the result of the acute care admission is death, loved ones who have low levels of preparedness for the death are at an increased risk of prolonged, heightened psychological responses and poorer bereavement experiences (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). For instance, one study reported rates of complicated grief for bereaved individuals after an ICU death to be five times higher compared to the general population (Kentish-Barnes et al., 2015). Another study reported 19% of next-of-kin at six months after an ICU death had symptoms of complicated grief (Downar et al., 2018).

The development of prolonged, heightened psychological responses for individuals during bereavement can severely affect their quality of life (Kentish-Barnes et al., 2015). A recent mixed method review and a rapid evidence assessment have reported limited, and at times, disputable, evidence on how to best support individuals during bereavement that is guided by their needs (Chen, Michaels, & Meeker, 2020; Hewison, Zafar, & Efstathiou, 2020). Rigorous qualitative research focusing on the family's experiences during end-of-life care has been proposed to assist in increasing knowledge of effective bereavement interventions (Chen et al., 2020).

Research focusing on the family's experience of memory making in the adult acute population is an under explored area of end-of-life and bereavement care interventions. According to the Dual Process Model of Coping with Bereavement (DPM), individuals adjust to bereavement by oscillating between confronting and avoiding stressors within loss- orientation and restoration-orientation (Stroebe & Schut, 2010). Loss- orientation refers to concentrating on, processing the experience, and possibly 'searching' for the dead. Restoration- orientation refers to restoring and reorienting oneself in a world without the deceased. The Dual Process Model theorizes that individuals who are able to perform the effective coping processes and oscillate between loss- orientation and restoration- orientation should experience a reduction in mental and physical complications from the bereavement (Stroebe & Schut, 2010). According to the Dual Process Model, grief work is incorporated in loss- orientation and includes engaging in memories of the deceased, learning to detach from the deceased, and confronting the events surrounding the death (Stroebe & Schut, 2010). Memory making objects received during end-of-life care have the potential to be used during grief work as an instrument to accessing memories of the deceased, as the dead can be embodied through the object (Cashell, 2007). Limited evidence is available concerning memory making objects as an intervention in the adult acute setting, including the experience of recipients receiving the object(s), whether they place value on the object(s), or how the object(s) is used during early bereavement.

Aim and objective

The aim of the study was to explore the family's experience of being offered memory making during end-of-life care in the adult intensive care unit and its use in early bereavement.

Methods

Design

This study used a descriptive qualitative design due to its ability to describe details of a phenomenon from those with experience in the phenomenon (Bradshaw, Atkinson, & Doody, 2017).

Theoretical framework

A pragmatist epistemology was adopted for this study.

Sampling and recruitment

The study site was a 17- bed tertiary referral, adult intensive care unit/ high-dependency unit located in Sydney, Australia. A purposeful, convenience sample of English-speaking spouse/

partner/ children/ parents over 18 years of age whose loved one received end-of-life care and where they participated in memory making activities as part of standard ICU care were invited to participate at the end of routine follow-up phone calls post ICU discharge. For participants who agreed to participate, a future time and location for the interview was arranged based on the participants' preferences. Potential memory making items included handprints, footprints, locks of hair, and teddy bears.

Sample size

After considerations for the quality of the data obtained during data collection and its applicability in addressing the research aim, it was determined that after 18 interviews with 21 participants that the data obtained provided adequate complexities and richness to generate meaningful knowledge (Braun & Clarke, 2019). No additional recruitment or repeat interviews were conducted.

Population and sample

Data were collected from 18 semi-structured interviews of 21 participants between May 2019-December 2020. Sixteen interviews were conducted face to face at the participant's location of choice, which was predominately at their home (*n*=12, 67%), four at other locations such as their place of employment (22%), and two over videoconferencing (11%). In three interviews, other family members also consented to study participation. In nine interviews, there was also the presence of non-participants, which were other family members who were present to support the interviewee or who lived in the home. Three eligible participants were invited to participate, but declined. One declined after being informed about the study at the end of the follow-up phone call as they did not wish to discuss their experiences, and two individuals declined participation after initially agreeing with no reasons stated. No participants chose to withdraw from the study after participation.

Inclusion and/or exclusion criteria

Initially, inclusion criteria included recipients who lived less than two hours driving time of the study site to allow the interviews to occur face-to-face. Because of public health measures related to the COVID-19 global pandemic, interviews from March 2020 were also conducted over videoconferencing. Exclusion criteria included if the death was more than six months prior to an arranged interview time.

Data sources/collection

A semi-structured interview guide was used to help stimulate the discussion (see Supplementary Material 1). All interviews were audio recorded on a digital voice recorder and transcribed verbatim by investigator XX. Transcripts were checked back against the original audio recordings for accuracy by investigator XX. The interviews occurred on average 55 days after the death (range 38 to 81 days). The average interview was conducted over 81 minutes, with the shortest interview conducted over 12 minutes and the longest at 246 minutes.

Data analysis

The entire interview data set were analyzed using inductive reflexive thematic analysis (Braun & Clarke, 2006, 2020). Inductive reflexive thematic analysis was chosen for its flexibility and ability to add value and insights to shared meanings in the data (Braun & Clarke, 2006). Data was organized with the aid of NVivo (QSR Internatinal Pty Ltd, 2020). Investigators XX and XX participating in regular meetings and followed the 6-phase process for reflexive thematic analysis, including data immersion and familiarization through listening to audio recordings, transcribing the data and re-reading transcripts; systematic data coding through reading transcripts line-by-line; initial theme generation by looking for larger patterns amongst the codes; review of the themes by all investigators in relation to the study aim and objective; further refining of the themes, and report writing (Braun & Clarke, 2020; Connelly, 2016). See Table 2 for a sample process of theme generation.

Ethical considerations

Ethics and site approval, as well as amendments in response to COVID-19 public health restrictions, was sought and obtained from the XXXX Human Research Ethics Committee to conduct the study (X/XX). It has been reported that individuals do appreciate participating in research following death of their loved one to share their experiences and can provide informed consent (Whitfield et al., 2015). Consequently, the predominate ethical consideration involved the interviews having the potential to cause participants to experience some degree of heightened emotions. The study investigator conducting the interviews was sensitive to participants' needs during the interview and planned to stop the interview should the participant express a wish to do so, or if the participant showed signs of distress beyond normal grief reactions. Interview location was chosen by the participants and predominately occurred at their home. Interviews conducted using videoconferencing were only audio recorded using the same devices had the interview been conducted in person. At the start of the videoconference, the participant consent form and demographic information sheet were distributed and returned using REDCap electronic database capture tools (Harris et al., 2019) hosted at XXX Institution.

Investigator XX conducted the interviews and maintained participant consent, privacy, and confidentiality by not providing direct patient care during the hospital admission to any of the patients or families interviewed, all interviews transcribed by investigator XX, transcripts checked for accuracy by investigator XX, and files stored on a password protected storage system. Additionally, participants' data were anonymized, given pseudonyms for identification, and the reported cause of death were categorized.

Rigor

For consistency, investigator XX conducted all interviews under the direction of XX who has expertise in qualitative research and XX who has expertise in bereavement and intensive care. XX is a highly experienced female registered nurse in intensive care with experience facilitating and a research interest in memory making. Following data interpretation using reflexive thematic analysis, the investigators' subjectivity is a source to assist in knowledge production within this study (Braun & Clarke, 2020). While investigator XX did not provide direct patient care during the hospital admission to any of the patients or families interviewed, she was recognized during the interview by one family member as having been in-charge of the intensive care unit during one nursing shift of their loved one's admission. Investigator XX did maintain a personal diary to document reflections of all interviews immediately after. All investigators participated in regular meetings to discuss and debrief about the interviews and maintained an audit trail in an electronic format (Greene, 2014; Lincoln & Guba, 1985).

Braun & Clarke's guide for assessment of thematic analysis research and the quality and the consolidated criteria for reporting qualitative research (COREQ) was utilized for reporting in this manuscript (Braun & Clarke, 2020; Tong, Sainsbury, & Craig, 2007). See Supplementary Material 2 for the COREQ checklist.

Findings

Participants

Participants' average age was 53.5 years old (range 25-89) and most identified as female (*n*=15, 71%). Most participants were born in Australia (*n*=16, 76.2%), and other countries of birth included New Zealand (*n*=2, 9.5%), Greece (*n*=1, 4.8%), Philippines (*n*=1, 4.8%), and the United Kingdom (*n*=1, 4.8%). The relationship to the deceased declared by the participants included spouse/ partner (*n*=11, 52.4%), child (*n*=7, 33.3%), sibling (*n*=2, 9.5%), and niece (*n*=1, 4.8%). Three of the interviews conducted included two participants in the same interview, where both referred to the same loved one who was deceased. The average age of death for the deceased was 66.1 years old (range 41-92), and many of the deceased were reported to have identified as male (*n*=11, 61.1%). Most participants reported the death to be sudden (*n*=18, 85.7%) and unexpected (*n*=15, 71.4%). See Table 1.

Table 1: Participant demographic data

Participant's pseudonym	Gender	Age	Participant's relationship to the deceased	Deceased's age	Cause of death as reported by the participant
Alice	F	50	Spouse/ partner	52	Septicemia
Barbara	F	73	Spouse/ partner	78	Respiratory disease/ pneumonia
Clare	F	63	Child	89	Septicemia
Daniel	M	45	Child	77	Respiratory disease/ pneumonia
Edward	M	63	Spouse/ partner	64	Cerebrovascular disease
Florence	F	62	Child	92	Other/ unknown
Gloria	F	89	Spouse/ partner	92	Other/ unknown
Hazel	F	67	Sibling	69	Septicemia

Irene	F	70	Sibling	71	Cerebrovascular disease
James	M	44	Spouse/ partner	41	Cerebrovascular disease
Kenneth	M	25	Child	67	Cardiovascular disease
Lillian	F	66	Spouse/ partner	67	Cardiovascular disease
Margaret	F	25	Child	58	Respiratory disease/ pneumonia
Norman	M	50	Child	85	Accident/ unintentional injury
Octavia	F	79	Spouse/ partner	85	Accident/ unintentional injury
Patricia	F	43	Spouse/ partner	44	Cerebrovascular diseases
Quinn	F	43	Spouse/ partner	52	Cerebrovascular diseases
Robert	M	40	Spouse/ partner	42	Other/ unknown
Shirley	F	32	Child	66	Respiratory disease/ pneumonia
Thelma	F	40	Niece	80	Cerebrovascular diseases
Uma	F	54	Spouse/ partner	63	Septicemia

Themes generated

Three major themes were generated through the process of exploring and analyzing the data on participants' experience of being offered memory making and its use in early bereavement:

- guidance during end-of-life by healthcare professionals that recognizes the autonomy of the family;
- object used as a trigger to access memories;
- storage and preservation of the object as an indication of its sentimental value and use in early bereavement.

See Table 2 for a sample process of theme generation.

Table 2: Sample process of theme generation following the 6-phase process for reflexive thematic analysis (Braun & Clarke, 2006, 2020)

Phase 5: Refining, defining, and naming themes	**Phase 4: Developing and reviewing themes**	**Phase 3: Generating initial themes from coded and collated data**	**Phase 2: Systematic data coding**			
Theme	**Theme**	**Theme**	**Codes- fourth iteration**	**Codes- third iteration**	**Codes- second iteration**	**Codes- first iteration**
Storage and preservation of the object as an indication of its sentimental value and use in early bereavement	Consideration and effort given to the storage and preservation of the objects provides an indication of its sentimental value, as well as how and when its used during bereavement	Storage and protection of object as an indication of its sentimental value and use in bereavement	Plans to keep the object.	Future plans	Location of object now	Location of object now
					Future location- keeping	Future location- keeping
					Future location- uncertain if keeping	Future location- uncertain if keeping
			Stored and utilized privately	Sacred but private	Initial location unchanged	initial location unchanged
					Location planned to change	location planned to change
					Preservation of object- initial	preservation of object- initial
			Stored in central location for everyone freer access, maintained the deceased part of the family unit, a component of a memorial/ shrine	Decorate in memories	Shrine made- central location	Shrine made- central location
			Object was created for another family member or used by others as a gift	Secondary creation of memories by making it into something special for others to utilize	Others using object as way of 'helping' and keeping busy	Maintained inspired by the deceased

Guidance during end-of-life by healthcare professionals that recognizes the autonomy of the family

One generated theme was *guidance during end-of-life by healthcare professionals that recognizes the autonomy of the family* when offering opportunities to create a memory making object (See Figure 1). Several participants reported the need for guidance in the death process due to being unaware of the potential to keep memento objects:

> *"She* [the social worker] *said, um, do you think the kids would like a trauma bear? …, I said, oh, I'm not sure. They're just about to turn 11. But, but they were very vulnerable and very upset at that time, and I said, why don't you bring them down and we'll see. … So, she brought them down, and just set them, and they looked at them, and the next thing they were grabbing them and hugging them. … I didn't really think about it at the time, but now you say it, it would have been nice* [to have been offered a handprint or lock of hair]. … *Oh, I think I'd go* [keep a] *lock of hair."* – Irene

Participants also reported the need for guidance due to feeling constrained by ICU 'rules', become emotionally overwhelmed with the death event, or knowing the practical implications of a death in the ICU setting:

> *"The girls participated in pretty much everything with it. They were hands on. The boys, I think they were more, um, sorrowing more than, um, then trying to, to do anything. They just, um, little. They were just upset to be able to do things like that. Whereas I'm, I'm guessing girls are a little bit stronger and able to do those things, but. Yeah, my sons were all very tender-hearted. They just. Every time they, they'd touch their father, they'd start crying so, yeah."* – Uma

Participants described having attractions, as well as disinclinations, to particular mementos offered:

> *"No, we didn't do the lock of hair. It just. I, I felt more of an association with the hand and the hand print. I didn't know what I would do with the hair lock. I didn't know if it was, like, necessarily, a weird thing to have?* (laugh) *Maybe I felt like a bit of an aversion to it, cause I don't know what I would do with that. Whereas a handprint, I was like, I can put it up and have it. Have a print of her. Not to say that other people may be comforted by that, but I felt more of a connection with like, the visual of her hand, and like, the whole, you're holding the hand. Your mothers hand.* (crying) *I just felt more of association with the symbol."* – Margaret

Many participants described not requiring a pre-established relationship with the healthcare professional before offering the memento objects:

> *"People make a decision, but it's the way it's presented to them."* – James

Participants talked about the timing of when to offer memory making and if it was to be offered before death, the healthcare professional should interpret family's acceptance of the impending death before making the offer:

> *"We were quite aware that he was going to die. You know. It wasn't like. As I say, other family that might be traumatic. They're still so desperately hoping the person will pull through and to be approached, like, well, looks like he's going to die. Do you want this? Like, go away. Hasn't died yet. You know, that could be a reaction. But in our case, we were quite accepting of that, um, you know. Reality pending."* – Florence

Figure 1: Reflexive thematic analysis' Phase 5 of the generated theme *Guidance during end-of-life by healthcare professionals that recognizes the autonomy of the family* with corresponding Phase 2 systematic data codes (Braun & Clarke, 2020).

Object used as a trigger to access memories

The next theme generated was that the *object was used as a trigger to access memories*. See Figure 2. Participants described the objects being an extension of the deceased where the deceased's values and preferences were important aspects of the object's creation:

> *"We didn't want any more hair being cut because he would have gotten really angry. So, we took four locks* [of hair and eight handprints]*"* –Uma

The object was also described to assist in the remembrance of the person and maintained a connection to them:

> *"So, when I put my hand on it* [the handprint]*, and I say, you know, I need you, I love you, and everything, and it just* (sigh) *sort of like, taking a deep breath, and you know. And it's just, yeah. You feel, I know it sounds a bit strange, but I feel like, it's her hand."*
> – Thelma

Some participants reported the activity of creating the objects as opportunities to talk about their loved ones' interests and preferences and form/ strengthen bonds with those assisting with the object creation:

> *"I was laughing with the nurse about, you know, oh, you know, he wouldn't like that color, or, you know, he'd be mortified if I did it in that color. You know, those types of things. And so, it became like, this, it sounds like such an awful thing to say, but it almost became like a fun activity on the day."* – Robert

Participants further assigned the object to specific memories, and at times, as a substitute for their deceased loved one:

> *"So the handprints, uh, to me, are sort of symbolic. More symbolic of our connection. The way we did it* [her hand next to her sibling's]. *The way I chose to have her hand connected to mine. And um, sort of a marking in time, of that, that time. Whereas the hair is more. It's her. You know. Her as an individual. And it doesn't remind me so much for our Sisterhood, but more who she was as a person. And um, you know, and because she really was very, um, fond of her hair* (laugh). *... So, her hair has a special meaning as*

> *well, you know, for her. And then for me. And it's much more her as a person rather than the two of us as sisters."* – Hazel

The quality and detail of the created object, as well as its presentation, were reported as being important aspects that contributed to the object being used in early bereavement as a person substitute for triggering memories:

> *"When you touch it* [lock of hair] *and you feel it, you feel warmth in your heart. Remember the beauty. And then you start remembering all the times that you were holding her hair, or helping her, or things she was saying to you at that point in time. Um. It helps. It, I mean, it. To bring back memories, yeah.* – James

Most participants reported taking pictures while in the ICU, though not being prompted or encouraged by healthcare professionals to do so. They described looking at the pictures due to their convenient location on personal cell phones when they were exploring their thoughts and feelings of the death:

> *"I just look. Yeah, all the photos. And see. Just to like, you know, sometimes if you think, ahh. You think that he's gone, or not. I don't think he's gone, but like, you know, I just look. Once in a while. Look. It helps you."* – Kenneth

During these intrusions of grief, some participants described the objects as being able to link their current emotional state to its cause:

> *"Yeah, I just think it* [the lock of hair] *makes everything final* (crying). *Yup. Yeah, its final."* – Clare

For some, the memory making objects received became attributed with feelings such as sadness. Despite this, the objects were not considered by participants as a burden:

> *"Burden to have my mum's stuff, not my dad's* [who died in ICU]. *My dad's I want to keep. My mum's, I feel obligated to. Very different."* – Shirley

Some participants reported not looking at the objects during the initial weeks of bereavement due to feeling emotionally overwhelmed as well as being too occupied with practical arrangements such as the funeral or required paperwork:

> *"It's still quite fresh and. It's hard to be reminded by the pain of that time. … But it's still so painful that it's hard to fuse, like, which part was comforting. Whether it was the object, was it the time we had, was it the activity* [of creating the handprints]*? I think it was probably combination of a few of those things."* – Margaret

A few participants described not feeling emotionally connected to the memory making objects received in ICU, but rather were more connected to objects received through the deceased's act of intentional inheritance received prior to their ICU admission and death:

> *"There'd be, like, lots of things that dads made, you know. Like there's just all the things that we've had, those things for ages. Like jewelry boxes, coffee tables. All the things that are around. Photo frames. All sorts of things he's, he's given us over the years. So they're still sort of around"* – Florence

Others discussed not having received intentional inheritances prior to death, so they utilized the memory making objects as meaningful keepsakes:

> ***"Because now I realize how very little of my dad there actually was left*** **(crying)*****.*** ***Sentimental things. I have nothing, virtually, but his tools, and his bed, and his chair, and his walker. Things that I can't keep. I can't reuse. I can't sentimentally have his bed on show, like. So, yeah"*** **– Shirley**

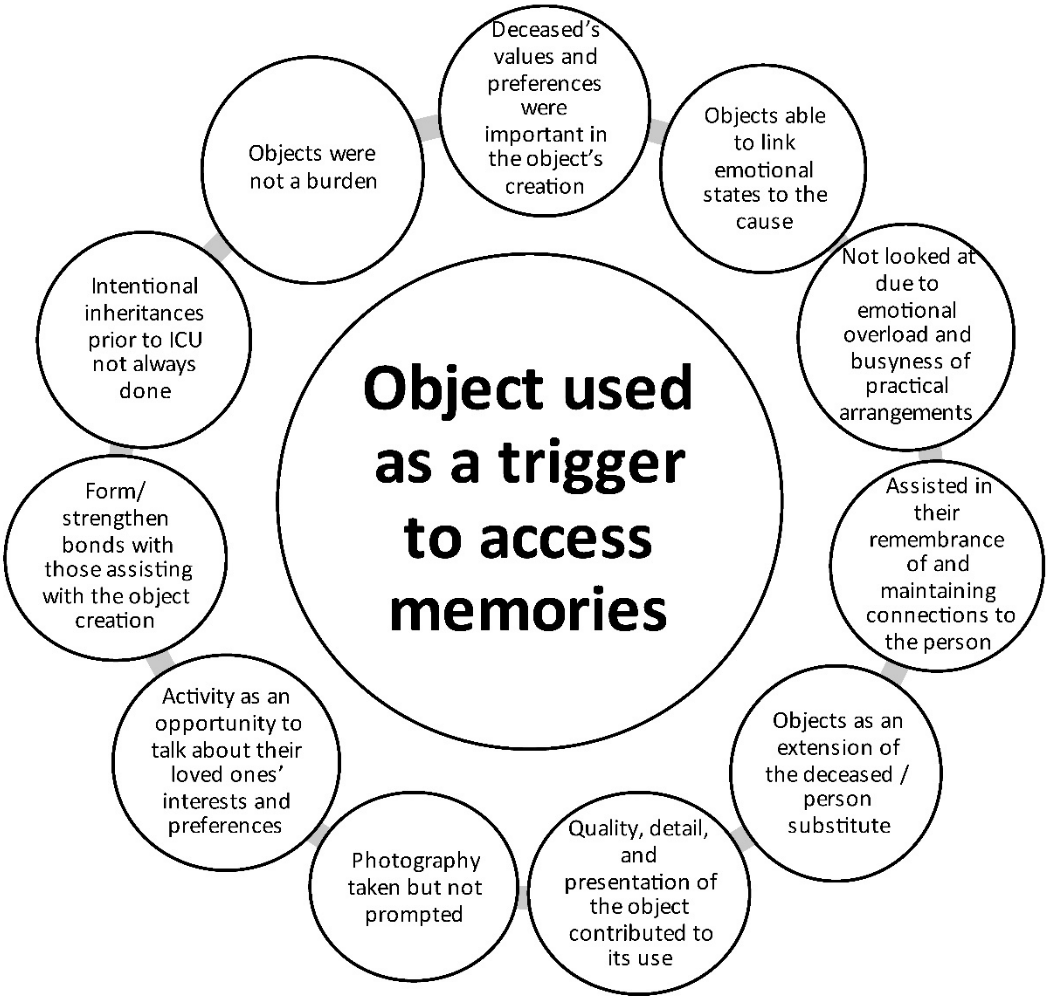

Figure 2: Reflexive thematic analysis' Phase 5 of the generated theme *Object used as a trigger to access memories* with corresponding Phase 2 systematic data codes (Braun & Clarke, 2020).

Storage and preservation of the object as an indication of its sentimental value and use in early bereavement

The final theme was that *storage and preservation of the object was an indication of its sentimental value and use in early bereavement*. See Figure 3. Some participants described the objects becoming secondary-type memories, where the object was primarily created for another family member, or it was used creatively and preserved by others as a gift, such as in a picture collage:

> *"I mean, my kids really do like having those things* [handprints, locks of hair, and teddy bears] *and they've been very useful. And yes, I think it is nice. ... Yes, it was very helpful for them. ... But, um, yes, they did really like them. ... I really liked to have those for the children, yup. ... I can't think of anything that I, that could have been offered to help me. Nothing was going to help me.* – Patricia

The location of the object was reported by some participants as being stored in a private space, such as their bedroom, where the object could be used primarily by them:

> *"She's got a special area in her cupboard in her walk-in robe, um, dedicated to her mum with a box with the hair lock and jewelry that I've given to her from her mum, and photos and, and, um, and the teddy bear."* – James

Whereas other participants preserved the objects in a central location within the family home by decorating their home with the memento objects. This was reported to allow family members freer access to it, maintained the deceased as part of the family unit, or was a component of a memorial/ shrine:

> *"We've got it* [handprint] *in, so as soon as you walk into our house, we've got our lounge room to the right, we've got um, it's like a buffet, a bench we've got there, and it's there. ... And then there's a photo of XXX in the middle. ... And then we've got some candles there. And then we've got his handprint next to it. Um, next to the photo.* – Alice

All participants reported plans to keep the object:

> *"I'll definitely keep it. I think it will. If* (sigh). *In a way, if it was to ever dispose of it* [handprint], *it would kind of feel like I was disposing of a part of him. Um. Strangely. So, no matter what, it would be something that I keep forever."* – Robert

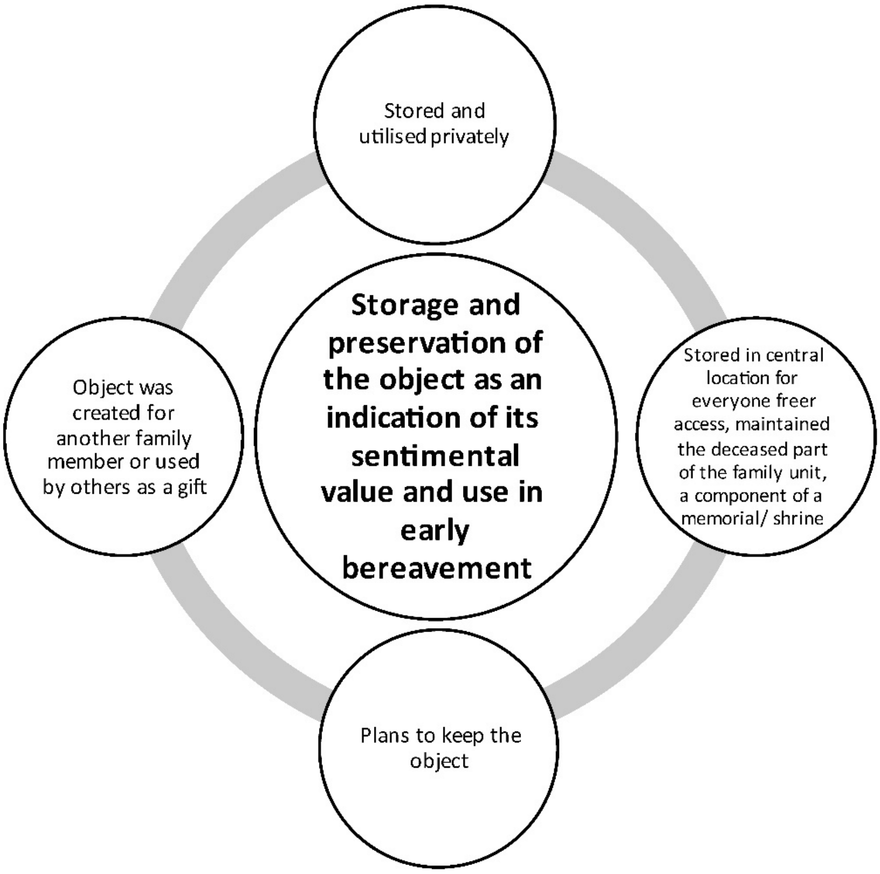

Figure 3: Reflexive thematic analysis' Phase 5 of the generated theme *Storage and preservation of the object as an indication of its sentimental value and use in early bereavement* with corresponding Phase 2 systematic data codes (Braun & Clarke, 2020).

Discussion

The aim of the study was to explore the family's experience of being offered memory making during end-of-life care in the adult ICU and its subsequent use in early bereavement. The themes generated were: guidance is required during end-of-life by healthcare professionals that recognizes the autonomy of the family; the object was used as a trigger to access memories; and storage and preservation of the object is an indication of its sentimental value and use in early bereavement.

Participants described appreciation for the guidance given by healthcare professionals, predominately by the registered nurses, during end-of-life care and valued being able to make final decisions for themselves. In our study, some participants were highly involved in the creation of the mementos and others expressed satisfaction in their decision to have the registered nurses make final decisions and create the objects on their behalf. Additionally, the relationship to the deceased in our study varied and included spouses, children, and a niece, indicating that a variety of loved ones have the potential to desire a memory making object when given the opportunity.

Many participants also described the deceased's preferences being important when choosing and creating the objects, such as the quantity of hair cut or the color of paint used. They further described the continuation of the deceased's values and preferences being important because the memory making objects were an extension of the deceased. During end-of-life care, without engaging the family in the decision-making and allowing for autonomy in choice, these important pieces of information are unlikely to be known by the healthcare professional. Consequentially, objects created without considerations of the deceased's values and preferences risks the memory making recipient considering the object as unimportant or attaching negative reactions to the object and creating a potential harm.

However, participants who decided to create the objects, but later did not consider them to have high value, did not describe the objects as negative or a burden to have. End-of-life care interventions are reported to commonly lack the ability for families to make decisions for themselves, despite the family's desire to make their own decisions (Chen et al., 2020). How an individual grieves is dependent on variables such as gender and culture (Stroebe & Schut, 2010), and other studies with bereavement interventions in the adult population, including memento objects, have reported the intervention not appealing to everyone (Beiermann, Kalowes, Dyo, & Mondor, 2017). It has also been reported that evidence for effective bereavement supports is limited and varied, though it is uncertain how much of this is attributed to the family not being able to make decisions for themselves.

Participants described timing to be important for accepting the offer of memory making as both pre and post death offerings were made by healthcare professionals and accepted by families. Therefore, the healthcare professional's ability to interpret the family's acceptance and deciding to offer before or after the death could affect the individual's decision to receive objects. The ability to interpret nonverbal body language and facial expressions that might indicate anxiety, confusion, distress, or worry and then responding with probing questions or reassurance has been reported by families as a form of supportive communication (Wong, Liamputtong, Koch, & Rawson, 2015). Supportive communication skills can be enhanced through education using approaches such as the SPIKES (Setting up interviews, assessing Perception, obtaining Invitation, giving Knowledge, addressing Emotions, and strategy and Summary) model for how to delivery bad news, reflection, and practice using simulation (Shaw, Davidson, Smilde, Sondoozi, & Agan, 2014). Communication and information sharing with families is reported to often involve the registered nurse due to their ease of access for the family and their demeanor (Wong et al., 2015). Additionally, registered nurses have been reported to consider themselves having the time to spend with the family to provide for the family member's needs compared to medical practitioners (Riegel, Randall, Ranse, & Buckley, 2021) and perceive a professional responsibility for memory making (Riegel, Randall, & Buckley, 2022b). The inclusion of registered nurses in patient information updates and providing registered nurses with increased communication skills training could assist with assessing the timing of when to offer memory making.

Most participants in our study did not describe strong preferences in requiring a pre-established relationship with the healthcare professional to accept guidance during end-of-life and the offering of memory making. This suggests any healthcare professional has the potential to engage with loved ones about memory making regardless of the length of time admitted in ICU or the establishment of a rapport. Alternatively, registered nurses are reported to prefer having providing prior care to a person before being involvement in the withdraw of medical treatment (Vanderspank-Wright, Efstathiou, & Vandyk, 2018), and healthcare professionals have reported that having an established relationship with the family is an enabler for them to offer memory making (Riegel, Randall, & Buckley, 2022a). It is possible that some families might have declined to receive a memory making object due to poor timing of the offer or not knowing the healthcare professional making the offer, which would not be captured in this study. Additional research is needed to include families that declined memory making to determine their preferences and reasons for declining the offer.

Participants described objects as something they could go to when they desired reminiscing, to trigger and connect with their memories of the deceased in early bereavement. Some participants reported not engaging with the object(s) during the initial weeks and explained this was because they were preoccupied with other bereavement stressors such as funeral arrangements or hosting families and friends. They described actively avoiding the object during this time knowing the object would cause an additional stressor due to its ability to evoke memories of their loved one. According to the Dual Process Model of Coping with Bereavement, not viewing the memory making objects during the initial weeks does not indicate maladaptation to the bereavement (Stroebe & Schut, 2010). Experiencing grief work is often described as exhausting and difficult, so avoidance and oscillating towards restoration-orientation is reported to be beneficial in bereavement (Stroebe & Schut, 2010), and appears to be what these participants were experiencing. Additionally, these participants still stated intents to look at and keep the objects in the future and had preserved the objects in private, special/ sacred spaces. Some participants also acknowledged their expectations that the memories evoked and the prevalence of the object in their daily life to change over time, but still had no intention of disposing of the object in the future. According to the Dual Process Model, it is anticipated that with further time away from the death event, participants' use of the object to trigger memories for use during their loss-orientation phase should reduce (Stroebe & Schut, 2010).

Participants described the objects as extensions of their deceased loved one, and these sentimental objects having the ability to provide a source for the grief emotions they were experiencing. Feeling connected to the objects/ mementos and the memories triggered by the object will be individualistic, since the contexts, feelings, and experiences generated by the object will vary with each person. For many participants, the objects were described as an extension of the deceased where color preferences, the ability to visualize smaller details such as ridges in the prints, touching/ comparing hands, or the texture of the hair were important when they used the objects to trigger their memories during grief work. Outside of the healthcare setting, others have reported objects used as instruments to assist with the recollection of memories (Cashell, 2007), and in our study, recipients of the memory making objects report a similar utility. Additionally, characteristics of the memory making object, such as its size, allowed it to be hidden away and actively avoided when times of avoidance were described during early bereavement (Stroebe & Schut, 2010). Others in the adult ICU setting have reported that the object produced to be equally valuable to recipients as the gesture of its offering (Neville et al., 2020), but our generated findings did not support this, as participants described the object triggering detailed memories of the deceased person and not the experience of the hospitalization.

Often times, terminally ill or advanced aging individuals are reported to spend a substantial amount of time and emotional energy selecting the right person to inherit and keep their possessions/ objects before they anticipate their own death to occur (Finch & Mason, 2000). The object's recipient does not just inherit the object; they utilize the object in their bereavement as a way to keep memories of the person alive (Finch & Mason, 2000). In this study, most participants considered the death to be sudden and unexpected, and it is possible that these inheritance rituals did not have the opportunity to occur prior to hospitalization. Additionally, the function and purpose of those intentional inheritance objects is similar to how the ICU memory making objects was utilized by recipients, as generated in this study's findings. Having a potential lack of intentional inheritance objects could have contributed to the memory making objects being regarded as meaningful keepsakes by the recipients.

During bereavement, some recipients in this study discovered a lack of sentimental objects to connect to and remember their loved one with after the death, despite inheriting their loved one's possessions. It was not until after death that they realized very few objects contained sentimental value that allowed them a connection to and remembrance of their loved one. It has been reported that healthcare professionals in adult acute care can believe the family to have enough mementos at home, and it being inappropriate to offering memory making during adult end-of-life care (Riegel et al., 2022a), but findings generated from this study highlight the need to allow individuals to make their own decisions in what they want to use in bereavement. It also raises the possibility to actively encourage, rather than just offer, these time sensitive mementos in the event individuals during bereavement discover a lack of sentimental objects for use in their bereavement and grief work. Future research is needed to explore if family members who declined memory making later regret this decision.

During study recruitment, the COVID-19 global pandemic emerged worldwide, and some end-of-life care and participants' bereavement were affected by public health restrictions such as ICU visitation restrictions, travel restrictions, and density caps on gatherings such as funerals. Although no study participants provided the diagnosis of COVID-19 as the cause of death, it has been reported that during the COVID-19 global pandemic, place of death, expectedness of the death, and relationship to the deceased were associated with additional challenges in early bereavement compared to pre-pandemic (Selman et al., 2022). Findings generated in our study included the need for guidance that recognizes the individual's autonomy, the objects having sentimental value to the recipients, and being used to trigger memories of and connections to the deceased. Our findings did not indicate the objects triggered predominate memories of the ICU, hospitalization, or the patient's diagnoses. This suggest that the findings generated in this study could be generalized through transferability (Smith, 2017), and memory making's utility as a bereavement intervention not be limited by the cause or location of the death.

Strengths and limitations

Strengths of this study includes successful recruitment of bereaved family members to explore their experience in end-of-life care and early bereavement. Recruitment for this study was conducted in a site where memory making had already been established as a standard end-of-life care intervention for greater than three years. This study explores an under researched area of adult bereavement interventions and addresses evidence gaps regarding the family's experience being offered memory making and its use in early bereavement. Findings from this qualitative study have included contextual details about the participants and the deceased, as well as evidence using quotations. These rich descriptions should facilitate readers' reflections for this study's applicability into other experiences, situations, and settings and assist in achieving potential generalizability of the results using naturalistic and transferability, which is a distinctive strength of qualitative research (Braun & Clarke, 2020; Smith, 2017; Tracy, 2010).

A potential limitation to this study is that it interviewed participants within six months after the death and therefore does not capture participants longer term use of the mementos, which might change over time. Additionally, the experiences of those who declined memory making and the reasons they declined the offer is not captured in this study. This study recruited from a single-site in Australia, so findings might not be transferability to other adult intensive care units or to adult acute care areas.

Recommendations for further research

In this study, participants were interviewed less than six months after the death, so memory making's long-term effects on bereavement requires further exploration. Additionally, investigations into the experiences of those declining memory making is needed to determine factors related to their decision and their preferences for bereavement interventions.

Conclusions

This new empirical evidence contributes to the knowledge of the family's experiences being offered memory making and its subsequent use in early bereavement, which is an under reported area in the adult acute population. Based on the experiences of participants in this study, memory making objects as a bereavement intervention provided in the adult intensive care unit are accepted, wanted, valued, and utilized during early bereavement. Future research is needed to explore long term effects on the psychological stress experienced during bereavement, and the experiences of those declining memory making to determine factors related to their decision and their preferences for bereavement interventions.

Relevance to clinical practice

In summary, findings generated from this study included that the timing of offering memory making could be done pre-death but requires the healthcare professional to consider the family's receptiveness of the impending death. Additionally, developing a relationship with the healthcare professional prior to the offer of memory making is not required for the loved ones to accept the offer. The offer of memory making should not be limited to individuals based on the relationship to the deceased as a variety of loved ones have the potential to accept and utilize memory making objects during early bereavement. Further, the loved ones should be given the opportunity to make decisions for themselves. Ultimately, the memento objects appear to be the most useful portion of this bereavement intervention and could assist the recipient trigger memories during grief work.

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Supporting Information 1: Semi-structured interview guide

- Tell me about your loved one.
- How did you find the ICU staff/environment during this time?
- What made you decide to receive a memory making object?
- What did you initially think about the object/staff when you were approached about it?
- When were you approached about the object?
- How did they approach you?
- Tell me about the object.
- What makes that object special?
- How did you treat/react to the object in the first few weeks?
- How do you treat/react to the object now?
- Where is the object kept?
- What do you think you'll do with the object in a year/2/5 years from now?
- Is there anything else you'd like to add that I haven't already asked you about?

Supporting Information 2: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	**Item**	**Guide questions/description**	**Page No**
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	10
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	10
3.	Occupation	What was their occupation at the time of the study?	10
4.	Gender	Was the researcher male or female?	10
5.	Experience and training	What experience or training did the researcher have?	10
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	11
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	10
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	10-11
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	6
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	6-7
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	7

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12.	Sample size	How many participants were in the study?	7
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	8
Setting			
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*	7
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	7-8
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	12-13
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	8
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	7
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	8
20.	Field notes	Were field notes made during and/or after the interview or focus group?	11
21.	Duration	What was the duration of the interviews or focus group?	9
22.	Data saturation	Was data saturation discussed?	7
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	10
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	10
25.	Description of the coding tree	Did authors provide a description of the coding tree?	13-14
26.	Derivation of themes	Were themes identified in advance or derived from the data?	9
27.	Software	What software, if applicable, was used to manage the data?	9
28.	Participant checking	Did participants provide feedback on the findings?	11
Reporting			

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29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*	15-27
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	15-27
31.	Clarity of major themes	Were major themes clearly presented in the findings?	13
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	15-27

5.3 CHAPTER SUMMARY

In this chapter, the results presented from the first study to answer the question "What is the experience of healthcare professionals offering memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?" included participants considering memory making to include creating tangible objects as well as nontangible activities. Participants also largely believed families value memory making and the offer being beneficial for the families. Having organisational supports and good interpersonal relationships with families enabled the healthcare professional participants to provide the offer of memory making to families. High workloads, inexperience offering or facilitating memory making, and being afraid were barriers to offering.

Participants with experience offering memory making had higher confidence and comfort in this end-of-life care interventions compared to those without experience. Experienced participants were also more likely to be able to spend time supporting the family, were less likely to be limited by family's behaviours, or consider themselves being time limited to provide the offer.

Compared to registered nurses, medical practitioners considered themselves having less emotional and instrumental support after a death including colleagues asking if OK, lower availability of counselling services, perceived insufficient time to spend with the family, less in-service education for end-of-life topics and symptom management. Whereas registered nurses were more likely to consider themselves uncertain what to say to family members during end-of-life care compared to medical practitioners.

The results generated from the second study to answer the question “What is the experience of relatives receiving memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?” included three themes: guidance during end of life by healthcare professionals that recognises the autonomy of the family; object used as a trigger to access memories; and storage and preservation of the object as an indication of its sentimental value and use in early bereavement.

Chapter 6: Discussion

This chapter discusses the interpretation of the results from Chapter 5 related to the thesis aim to *explore the experience of memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU) from the healthcare professionals offering and the family receiving the intervention*. To do this, two research questions were answered:

1) What is the experience of healthcare professionals offering memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?

2) What is the experience of relatives receiving memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?

Section 6.1 summarises the significant key findings from the study of the healthcare professionals and the study of the bereaved families. Section 6.2 integrates and discusses the thesis findings. Section 6.3 includes the strengths to this thesis, and section 6.4 acknowledges the limitations.

6.1 SUMMARY OF SIGNIFICANT KEY FINDINGS

The key findings from the first study to answer the question “What is the experience of healthcare professionals offering memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?” are:

- Participants mostly agreed that end-of-life care is as important as curative care and responses suggest shared values concerning end-of-life care and patient and family preferences.
- Differences were observed between registered nurses and medical practitioners in relation to organisational culture and aspects of emotional support, education, and time availability. These differences can be summarised as registered nurses being more likely to report end-of-life care as a nursing-led practice, have emotion supports available after a death, have greater access to ongoing end-of-life care education, and have greater perceived time to spend with families.
- Almost 70% of participants reported experience offering memory making opportunities to family members.
- Participants reported memory making to include the creation of tangible keepsakes as well as nontangible activities.
- Registered nurse participants were more likely to report initiating memory making to be their professional responsibility.
- Participants reported not offer memory making due to a lack of procedural knowledge and were less likely to offer it without having received prior

education. Participants without experience offering memory making were less likely to have received education related to memory making.

- Participants also reported not offering memory making if they believed the family already having enough mementos at home or believing the patient's friends would not be interested.
- Most participants reported they have the necessary skills to offer family members the opportunity to create memory making objects and that they knew the benefits of memory making. Most participants did not consider it difficult to offer to family.
- Having positive experiences with the family's response to memory making was described by some participants to be a motivating factor for them to make future offerings of memory making to a family.
- Witnessing memory making being offered appears an important enabler since participants with experience in memory making were more likely to have observed colleagues offering/ facilitating memory making compared with those without the experience.
- Those with experience offering memory making reported greater confidence, comfortable, and pride in their ability to offer family the opportunity to create mementos. Those without experience were more likely to report being afraid to offer memory making opportunities to family.
- Meeting the family for a short period was not reported to be a barrier to offering memory making but having a rapport with the family was described to assist the healthcare professional approach family members with the offer of memory making.

- Participants reported that the decision to offer memory making was influenced by environmental and supply resources that were available.
- Participants reported their decision to offer memory making was also influenced by their workloads and other patient care priorities.

The key findings from the second study to answer the question “What is the experience of relatives receiving memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU)?” are:

- Family member participants who had experience receiving memory making objects described the timing of offering memory making could be done pre-death but requires the healthcare professional to consider the family’s receptiveness of the impending death.
- Family member participants described not requiring a preestablished relationship with the healthcare professional prior to the offer of memory making for them to accept the offer.
- Family participants had diverse relationships to the deceased, therefore a variety of people have the potential to accept and utilise memory making objects during early bereavement, and the offer should not be limited by the relationship.
- Family participants described appreciating guidance by healthcare professionals during end-of-life care but valued being able to make final decisions for themselves.

- Family participants who decided to create the objects, but later did not consider them to have high value, did not describe the objects as negative or a burden to have.
- The memory making objects were described by family participants as an extension of the deceased, so the quality of the object, such as the ability to visualise smaller details like ridges in the handprints, and the deceased's values and preferences, such as favourite colours for the paint, were important when choosing and creating the objects.
- Many family member participants considered the objects something they could go to when they desired reminiscing of their loved one.
- The objects did not appear to trigger predominate memories of the ICU, hospitalisation, or the patient's diagnoses for the family participants.
- Memory making object recipients had no intention of disposing of the object in the future.
- The objects appear to be the most useful portion of the end-of-life and bereavement intervention.

6.2 INTEGRATION AND DISCUSSION OF THESIS FINDINGS

Healthcare professionals' and family members' experiences with memory making had an overarching theme of 'time' as well as inherent desires to do what they perceive to be the right thing. Integration and discussion of thesis findings include:

1. The perception of having time to spend with the family after a death was greater for registered nurses than medical practitioners, and participants experienced in memory making were more likely to have the time to offer memory making.
2. Organisational supports of time affect the experience and ability to offer memory making.
3. Healthcare professionals' inherent desires to do what they perceive to be the right thing to facilitate a good death can include memory making interventions.
4. Timing of when to approach the family is important in the experience of offering and accepting.
5. Timing of when family members use memory making can be contingent on their personal grief journey.
6. Recruitment and inclusion of family members in the early months of bereaved appears acceptable and feasible in research studies.

6.2.1 Key findings 1: Perception of having time to spend with the family and to provide memory making

Registered nurses were more likely than medical practitioners to perceive having time to spend with family after a death (Riegel et al., 2021), and participants experienced in memory making were more likely to believe they had the time to offer memory making (Riegel et al., 2022a). Healthcare professionals offered memory making because they anticipated it would assist family members grieve and provide them with positive recollections of their time in ICU. They also anticipated receiving positive family reactions to the offer (Riegel et al., 2022a).

According to the philosophy of pragmatism, our knowledge of what we believe to be true informs the future actions we take (Biesta & Burbules, 2003), which can help to explain the motivations that contributed to 69.8% of surveyed healthcare professionals reporting experience offering memory making (Riegel et al., 2022b). Since memory making had been offered for nearly two years at the study site prior to this study being conducted, participants' knowledge gained from their past experiences would have affected their future offerings. Had the experiences of healthcare professionals been reported to include more negative outcomes from families, their overall viewpoints of memory making would be expected to have been more closely aligned with negative associations. This would have affected their future actions in offering memory making and would have generated greater overall negative results in the study data. This finding of healthcare professionals having overall positive experiences with offering memory making has been similarly reported in other studies in the adult acute population (Beiermann et al., 2017; Cook et al., 2015). In the study by Cook et al. (2015), their end-of-life care project included providing mementos such as framed word clouds and reported the project to strengthen team bonds and assist with humanising the care provided. Beiermann et al. (2017) similarly reported all study participants, who were nurses, indicated the Electrocardiogram (ECG) Memento provided to family during end-of-life care being very well received.

It is likely that having positive experiences with offering memory making contributed to healthcare professionals making time during end-of-life and bereavement care rather than potentially procrastinating or considering themselves not to have time to offer it. According to the Temporal Motivation Theory (Steel & König, 2006), deterrents from procrastinating tasks include a person having high self-efficacy, beliefs of being capable to achieving a task, and experiencing rewards during the task (Steel, 2007). From this thesis findings, healthcare professionals with self-reported experience offering memory making were less likely to forget to offer memory making opportunities to family, to believe they didn't have time to offer, or to consider it to be too time consuming (Riegel et al., 2022a). They also had greater self-efficacy with higher confidence and comfort offering compared to those with no experience (Riegel et al., 2022a). Other studies have reported individuals sometimes use procrastination as a form of emotional mood regulation for perceived negative tasks (Sirois & Pychyl, 2013), and individuals who have higher emotional intelligence are less likely to procrastinate (Hen & Goroshit, 2014; Zohar et al., 2019). Emotional intelligence is the capacity to reason about emotions, and of emotions to enhance thinking and includes the ability to perceive, use, understand, and manage emotions (Salovey & Grewal, 2005; Salovey & Sluyter, 1997). Although procrastination has not been discussed in other adult memory making studies, procrastination has been reported to be used by physicians in order to self-manage the emotional weight experienced when needing to communicate to family members regarding impending patient deaths (Cipolletta & Oprandi, 2014).

To offer memory making to the family during end-of-life and bereavement care, the ability to interact with the family was considered a necessary skill and personal attribute for the offering (Riegel et al., 2022b). It is likely that healthcare professionals with higher emotional intelligence and a greater ability to use, understand, and manage the heightened emotions both of themselves and of the family during end-of-life care would be less likely to procrastinate offering memory making or consider time to be a constraint. Others have also reported the healthcare professionals' ability to interpret nonverbal cues and verbal messages to be important when offering memory making objects (Beiermann et al., 2017). Opportunities to enhance emotional intelligence, including the ability to participate in difficult conversations, might be useful to improve the healthcare professional's capabilities in offering memory making as part of end-of-life care (Riegel et al., 2022a). However, others have suggested more research is needed to determine the effect emotional intelligence has on healthcare professionals' ability to deliver care in heightened emotional situations (LeBlanc et al., 2015). As such, further research is needed to determine the effects emotional intelligence has on offering memory making.

Some health professionals considered barriers to offering memory making to included believing it was unnecessary to offer this opportunity to the family (Riegel et al., 2022b), and those without experience were more likely to be afraid to offer memory making (Riegel et al., 2022a). According to the philosophy of pragmatism, our knowledge of what we believe to be true informs our future actions (Biesta & Burbules, 2003), so if a task is considered unpleasant or of low value to an individual, one will be more likely to procrastinate performing or completing the task, if at all (Sirois & Pychyl, 2013; Steel, 2007). Although study participants overall agreed to having emotional supports when facilitating end-of-life care (Riegel et al., 2021), if healthcare professionals are afraid to offer memory making or do not consider memory making of high value, they will likely use time as an excuse and believe to lack time to offer it or forget to offer it to the family. Other studies have reported healthcare professionals who experience fear or insecurity when delivering end-of-life care are likely to employ avoidance with both the patient and family to self-manage the emotional burden experienced with this type of care delivery (Puente-Fernandez et al., 2020), and this study extends those findings. To foster positive experiences with memory making, strategies to emotionally support healthcare professionals is necessary.

6.2.2 Key findings 2: Organisational support allowing for time affects the experience and ability to offer

Healthcare professionals reported increased workloads as a barrier for them to offer memory making, and conversely reported organisation supports of time and supportive co-workers as enablers (Riegel et al., 2022a, 2022b). Workplace teams have been described to need coordinated efforts to achieve common goals by resolving and adapting to task demands (Kozlowski & Ilgen, 2006), and others have reported the importance of successful ICU team performance for patient care delivery (Ervin et al., 2018). Team performance is reported to be measurable based on the team’s ability to define and agree on goals and care priorities, which can include the quality of death and dying and tending to the needs of the family (Ervin et al., 2018).

Organisational support to allow for time to deliver end-of-life care, promote teamwork, and develop a culture of shared goals is necessary to enable offering memory making and will affect the experience for healthcare professionals and families. While routinely creating a memory making object without involving the family could reduce healthcare professional’s workload by eliminating the communication element with the family, it may not align with the family’s preferences. Additionally, healthcare professionals specified that providing the family a choice to receive memory making objects was an important factor in their decision to offer it, so routinely providing an object would go against these motivation and goals (Riegel et al., 2022a). According to the philosophy of pragmatism, individuals and organisations across all levels coevolve through recursiveness, or a looping process of stimulus, responses, and action. Organisational structures provide the means, routine, and cultural rules that individuals can leverage in order to revise and adapt to meet new conditions and to make changes to the workplace structure (Farjoun et al., 2015). By organisations providing supports to enable the offering of memory making, individuals can leverage these supports to revise and adapt their end-of-life care delivery to include memory making. Others have also reported that facilitating memory making objects as part of end-of-life care required organisational supports, including education to assist with appropriate timing to approach the family, as well as fostering a culture of shared goals within the healthcare team and outside stakeholders, such as hospital foundations (Beiermann et al., 2017; Reeve et al., 2021).

Overall, survey participants had similar core values relating to palliative concepts, including concepts such as *end-of-life care is as important as curative care in the critical care environment* (Riegel et al., 2021). Additionally, healthcare professionals believed families valued and benefited from being offered memory making (Riegel et al., 2022a). This suggests interdisciplinary ICU team cohesiveness and shared values, goals, and objectives for end-of-life care delivery, which has been reported to be an essential component of teamwork (Salas et al., 1992). High performing teams are reported to be composed of team members that are capable of dynamic resource allocating in response to fluctuating contexts and demands in order to accomplish goals (Kozlowski & Ilgen, 2006). In this thesis study, medical practitioners reported they had insufficient time to spend with the family after a patient dies compared to the registered nurses (Riegel et al., 2021), and registered nurses felt a greater professional responsibility for initiating memory making compared to other healthcare professionals (Riegel et al., 2022b). While others have also reported memory making being predominately a nurse driven intervention (Reeve et al., 2021), registered nurses taking the lead in offering memory making could indicate effective teamwork at the study site by leveraging nurses' proximity to the family, time, and knowledge to accomplish the memory making taskwork to achieve ICU team's overall goals of care delivery.

6.2.3 Key findings 3: Healthcare professionals' inherent desires to do what they perceive to be the right thing to facilitate a good death can include memory making interventions

Healthcare professionals considered the act of memory making to involve non-tangible activities such as allowing the family to spend time with the patient after death, preparing the body for viewing, assisting the family to reminiscence about the patient, and assisting in positive ICU memories such as personalising the room (Riegel et al., 2022b). Others have reported concepts of a "good death" to also include pain and symptom control, being prepared, feeling closure, and clear decision making (Krikorian et al., 2020), and for patients with a preference, the majority expressed a desire to die at home (Ali et al., 2019). As previously described in this thesis, the healthcare professionals at the study site had similar core values related to palliative concepts, suggesting greater holistic care provided to the patient. Having similar core values amongst the ICU team could assist in minimising instances of moral distress when they desire to do the right thing and facilitate aspects of a "good death", but feel constrained from doing so (Lamiani et al., 2017). The healthcare professionals' responses to include multiple aspects of care delivery as 'memory making' suggest a desire to meet their professional and moral obligations in end-of-life care by providing 'soft skills' to accommodating concepts of a good death experience for the patient and family.

6.2.4 Key findings 4: Timing of when to approach the family is important in the experience of offering and accepting

Most family member participants reported the death to be sudden (86%) and unexpected (71%). This is higher than other ICU memento studies reporting only

50% of deaths being unexpected by family participants (Beiermann et al., 2017), but is similar to other ICU bereaved studies where 76% of participants were reported to considering the death unexpected (Buckley et al., 2009). Therefore, families, and possibly patients, would have been unlikely to be prepared for death prior to the emergency hospitalisation. Findings from the bereaved family interviews included the need for guidance during end-of-life care that acknowledged their autonomy in decision-making. This is similar to others reporting families have a desire to regain a sense of control and participate in end-of-life care decision making, while still requiring and valuing guidance during the end-of-life care experience (Chen et al., 2020; Wilson et al., 2018).

To provide guidance to the family, the offering of memory making requires the healthcare professional to determine appropriate and dedicated time to approach the family, as well as time to assist in creating the objects, if desired, by the family. This study's healthcare professional participants believed interacting with and developing connections to the family were enablers and skills that assisted them offering memory making (Riegel et al., 2022a, 2022b), although family members did not require an established relationship prior to acceptance. Following the philosophy of pragmatism, when the healthcare professional is confronted with unfamiliar end-of-life care contexts to offer memory making, they will use reflexivity in order to reflect on their knowledge of previous situations and actions in order to adapt to the new situation (Younas, 2020). Similarly, family who experience a death in the ICU environment also utilise their past knowledge and experiences to manage the death

(Ansell, 2011; Biesta & Burbules, 2003), so limited experiences with an ICU death or memory making would contribute to their desires for guidance in these processes.

The timing of the memory making offer was described by families as important since they desired a degree acceptance of the situation before receiving the offer, which has been similarly reported in other memory making studies (Beiermann et al., 2017). In this thesis, registered nurses were more likely to have sufficient time to spend with the family after a patient dies (Riegel et al., 2021), which would contribute to the registered nurses ability to appropriately determine the timing of the offer compared to other ICU healthcare professionals. Others have reported nurses consider their physical presence as a professional obligation in delivering end-of-life care (Vanderspank-Wright et al., 2018), and this thesis expands those findings for registered nurses becoming the predominant offeror of memory making in end-of-life care.

6.2.5 Key findings 5: Timing of when family members use memory making can be contingent on their grief and bereavement journey

Most bereaved family participants described using the object(s) as a trigger to access their memories during times they were reminiscing about the deceased. They also described the objects being an extension of the deceased and a form of a physical substitute for the deceased. Others have reported memento objects from the adult ICU to be as equally valuable to the family as the healthcare professional's gesture of offering (Neville et al., 2020), and in the paediatric setting, family have been reported to consider the mementos to be a caring gesture from the healthcare professionals (Brooten et al., 2013). Alternatively, this thesis findings suggests the object is the most important portion of the intervention and not the experience of receiving it during the hospitalisation, which is consistent with the philosophy of pragmatism's theory that memories are a source of knowledge, and that signs or objects can serve as instruments to accessing these memories (Cashell, 2007; Dewey, 2003; Hookway, 2000; Peirce, 1994).

After a death of a loved one, the surviving person's self-image, societal role, and relationships to others drastically alters (Jakoby, 2012). Their bereavement experiences will be based on their culture and is further affected by their adaptions to new social structures caused by the permanent absence of the deceased (Hobbs, 2011). According to the Dual Process Model of Coping with Bereavement, individuals adjust to bereavement by oscillating between confronting and avoiding stressors within the categorical phases of loss- orientation and restoration-orientation. During the loss- orientation phase, the individual performs 'grief work', where they engage in memories of their deceased loved one, including memories of the end-of-life care and subsequent death (Stroebe & Schut, 1999, 2010). As the individual adapts to the death, less time is expected to be spent in the loss-orientation phase and grief work, therefore less times should be required using the memory making object as a trigger to accessing memories for their bereavement adaptation.

Some family participants had not engaged with the memory making objects within the average interview time of 55 day (range 38 to 81 days) after their creation due to feeling emotionally overwhelmed, and others described spending greater amounts of time in the restoration- orientation phase of bereavement with practical arrangements such as the funeral. Loss- orientation’s grief work is described as difficult and exhausting (Stroebe & Schut, 2010). Since individuals require a degree of mental preparation and capacity to perform grief work, deliberately avoiding objects that could triggers memories of the deceased is likely to be a form of self-regulation of their mood. For those that had not yet engaged with the object to trigger memories, they described future plans to preserve and engage with the objects in the future. Future research is needed to evaluate how memory making object are utilised in the longer term in bereavement.

6.2.6 Key findings 6: Recruitment and inclusion of family members who are bereaved is acceptable and feasible in research studies

The recruitment of individuals into studies containing sensitive or heightened emotional context, such as bereavement, are categorised as high-risk ethical applications within New South Wales, Australia. Recruitment of family members in this thesis included an introduction letter informing them of the study after they were able to freely decide to receive a memory making object as part of standard ICU care. At the conclusion of a routine follow-up phone call around week five after ICU discharge, family members who met inclusion criteria were offered to participate in the study, and a future time and location for the interview was arranged based on their preferences. In total, 21 participants participated an average of 55 days after the death, where the average interview length was 81 minutes. Three eligible participants were invited to participate but declined. One declined after being informed about the study at the end of the follow-up phone call for reasons including not desiring to talk about it, and two individuals declined participation after reading the full participant information sheet with no reasons stated. No participants chose to withdraw from the study after participation.

Most interviews were conducted in the participant's home, and often, the author of this thesis was offered a beverage such as a cup of tea to welcome her into the home. To gain an understanding of the deceased and to foster a rapport with the interviewee, initial questions focused on the deceased and their interests and relationships. Often participants displayed normal grief emotions such as crying, but never asked to stop the interview or appeared to become overwhelmed. Emotional displays of grief during bereavement research has also been reported by others in bereaved studies and has been described to be a cathartic experience for the family rather than a harm endured (Butler et al., 2019). Some participants at the end of the interview offered to meet again if necessary, and others expressed feelings of relief to have the opportunity to talk openly and in-depth about their experiences, reaffirming that the grief displayed by participants was cathartic rather than harmful. Findings from this thesis supports others who have reported that bereaved individuals find study participation acceptable and feasible during early bereavement (Whitfield et al., 2015).

6.3 THESIS STRENGTHS

This thesis explores an under researched area of adult end-of-life and bereavement care interventions and addresses the evidence gaps regarding the healthcare professionals’ and family members’ experiences with memory making. The studies took place in an environment where memory making had been integrated into routine practice, and care provided during this stage of a person’s life is commonly managed within the adult ICU.

The study of healthcare professionals achieved a high survey response rate (78%), which allowed for the results to be reflective of memory makings’ use in clinical practice at the study site. Recruitment for this study was conducted in a site where memory making had already been established as a standard end-of-life care intervention for nearly two years. The healthcare professional’s survey instrument was composed of a prior validated survey for provisions of end-of-life care, and questions specific to memory making were created guided by the Theoretical Domains Framework.

Findings from bereaved family interviews demonstrated successful recruitment of bereaved family members to explore their experience in ICU end-of-life care and early bereavement. This qualitative study explored an under researched area of adult bereavement interventions and addressed evidence gaps regarding the family’s experience being offered memory making and its use in early bereavement. These rich descriptions from participants should facilitate reflections for applicability into other experiences, situations, and settings and assist in achieving potential generalisability of the results using naturalistic and transferability. This is reported to be a distinctive strength of qualitative research including reflexive thematic analysis, and purposefully different than quantitative research’s use of statistics to inform generalisability (Braun & Clarke, 2020; Smith, 2017; Tracy, 2010).

6.4 THESIS LIMITATIONS

The study of healthcare professionals’ memory making experiences reported in this thesis represents a self-selected sample. Results provided a snapshot of participant's perceptions at one point in time from a single-centre ICU in Australia and are only applicable to those who participated, so may not represent perspectives of those who did not participate. Additionally, results were self-reported, which may contribute to a level of bias in the results (Rosenman et al., 2011). Statistical analysis was limited due to the sample size of medical practitioners and social workers. The comparison of participants with experience versus no experience is based on their response to a single, subjective question, though the definition of memory making was provided within the survey. Some of the responses provided by participants under the skills category represent personal attributes rather than skills that can be obtained. Nonetheless, responses from each healthcare professional group were representative of the proportion of professionals within the study ICU, and for transparency, results are reported as the participants have provided them.

Limitations to the bereaved family study reported in this thesis includes knowledge of memory making’s long-term effects on bereavement since inclusion criteria included the interview being conducted within six months of the death. Consequently, participants longer-term use of the memento objects and potential changes over time is not captured. Additionally, the experiences of family who declined memory making, the factors related to their decision, and their preferences for end-of-life and bereavement care interventions was not captured in this study. Although this study included contextual details about the participants and the deceased, information might not be transferable to other adult intensive care units or other adult acute care areas.

Chapter 7: Conclusion and recommendations

Section 7.1 of this chapter provides a brief summary and conclusions of the thesis aim to *explore the experience of memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU) from the healthcare professionals offering and the family receiving the intervention*. Section 7.2 provides final recommendations for future practice. Finally, section 7.3 provides concluding comments.

7.1 CONCLUSIONS

This thesis reports findings of healthcare professionals' and family members' experiences offering, receiving, and using memory making from the adult intensive care unit as an end-of-life and bereavement intervention. The purpose of this research was to discover whether memory making would be an appropriate end-of-life and bereavement intervention provided in the adult ICU. The thesis began in Chapter 1 by provided a historical background for memory making, including some of its first documented use in sixteenth century with deceased's hair being used to create jewellery posthumously (Hallam & Hockey, 2001; Pointon, 1999). And more recently, its utility in the perinatal bereavement to support parents' time with their stillborn child (Butler et al., 2015; Carlson, 2012).

In Chapter 2, the original and an updated scoping review was presented, which reported an increase in reports of memory making research over the last four years in the adult ICU. The types of objects reported to be offered in the adult ICU setting include word cloud images, electrocardiogram mementos, patient diaries, photographs, crochet hearts, locks of hair, fingerprint keychains, and hand moulds. Despite the increase in identified research studies in the adult ICU setting, there remains limited empirical evidence for the utility of memory making from bereaved loved ones, and its use during their bereavement. Additionally, there is a paucity of information concerning the healthcare professionals' experience with and factors required to provide memory making.

In Chapter 3, the methodology was detailed within the philosophy of pragmatism, which emphasises the importance of the problem and is not limited to a single method to understand the problem (Creswell, 2003; McCready, 2010). As described by Peirce, signs, objects, or keepsakes may serve as instruments of our memories, thoughts, and knowledge, as the deceased are represented to the bereaved loved ones through the keepsakes (Cashell, 2007; Hookway, 2000; Peirce, 1994). Other theoretical perspectives for this thesis were presented, including the Theoretical Domains Framework, which was utilised as the framework for the third section in survey instrument for the healthcare professional's study. In the study of the bereaved families, the Dual Process Model of Coping with Bereavement was utilised to provide contextual understanding to the family's bereavement experience.

Chapter 4 provided the methods used to conduct the two study arms of this thesis. The first study was a survey design administered to adult ICU healthcare professionals. The survey utilised Likert scales and open-ended questions where section two explored factors influencing the provision of end-of-life care in the ICU, and section three explored the participants' experiences facilitating memory making as part of end-of-life/bereavement care in the adult ICU. The second study was a descriptive qualitative study utilising inductive reflexive thematic analysis from semi-structured interviews from a purposeful, convenience sample of consenting surviving spouse/ partner/ children / parents whose loved one died while in the adult ICU and who did participate in memory making. Potential memory making activities included handprints, footprints, locks of hair, or teddy bears.

In Chapter 5, the results of the two studies were presented in the form of peer-reviewed, international nursing journal publications. The first results publication from the survey instrument concerned the healthcare professionals end-of-life care values and experiences. It concluded healthcare professionals reported similar palliative care values, but compared to registered nurses, medical practitioners reported lower emotional and instrumental supports after a death. However, registered nurses reported lower scores of knowing what to say to family in end-of-life care scenarios (Riegel et al., 2021).

The second results publication reported the healthcare professionals' knowledge, skills, and role in offering and facilitating memory making. It concluded that participants had positive experiences with offering memory making in the adult ICU, and that registered nurses perceive a professional responsibility for offering memory making. To support healthcare professionals with the offer, education should include conceptual and procedural knowledge and communication techniques. Additionally, the organisation should facilitate supports to accommodate the time requirements for the intervention (Riegel et al., 2022b).

The third and final publication from the survey instrument reported factors associated with the decision to offer memory making in end-of-life care. Results included participants believing families value memory making, and the offer of memory making being beneficial. Enablers to offer memory making included organisational supports and good interpersonal relationships. Barriers were identified as the ICU environment, workload, being afraid to offer, inexperience offering, having a lack of resources, and legality concerns. Those with experience offering memory making were more likely to find pride in their ability to offer, were able to spend time with the family, and observed colleagues offering. Experienced participants were also less likely to be afraid or report the family's behaviours limiting their ability to offer (Riegel et al., 2022a).

The findings from the study of bereaved family have been submitted for consideration in a peer-reviewed, international nursing journal and reports the family's experience being offered memory making in the adult ICU and its use in their early bereavement. Findings from this study generated the themes of guidance during end-of-life care that recognises the autonomy of the family; the objects being used as a trigger to accessing their memories; and the storage and preservation of the object by the recipient to be an indication of their sentimental value and use in early bereavement. This study concluded that memory making objects received in the adult ICU can be accepted, wanted, valued, and utilised during early bereavement by a variety of recipients.

The results of the two thesis studies were then integrated and discussed in Chapter 6 with six key findings based on the thesis aim to *explore the experience of memory making interventions during end-of-life/bereavement care in the adult intensive care unit (ICU) from the healthcare professionals offering and the family receiving the intervention*. Overall, healthcare professionals offering and relatives receiving memory making in the adult ICU appear to be associated with positive experiences, with a high proportion of healthcare practitioners reporting to offer memory making as part of standard practice. Much of the healthcare professionals' experiences can be associated with time, including the perceptions of having time to offer it based on their comfort and confidence with the intervention, the organisational supports to allow time to offer it, and the timing of when to approach the family. The experiences of healthcare professionals offering memory making is also associated with the perceived contribution to providing a 'good death' for patients and a less burdensome bereavement experience for the family. Family's experiences with memory making are additionally influenced by the timing of when they are approached with the offer, the guidance and time provided to allow for consideration and creation of the object(s), and the timing of when they use the objects in early bereavement as a remembrance instrument. Additionally, based on the family interview experience, bereaved families are willing and capable of consenting to participating in research studies.

7.2 RECOMMENDATIONS FOR FUTURE PRACTICE

Healthcare professionals offering and relatives receiving memory making in the adult ICU do appear to be largely associated with positive experiences and have utility and acceptability as a bereavement intervention in the adult ICU. Although the experiences were largely positive in both studies, some healthcare professionals reported being afraid to offer memory making and barriers to offering included workload, and inexperience offering and facilitating. To support healthcare professionals offering memory making as an adult ICU end-of-life care practice, supports should include role modelling the practice, workload assistance, and continuing education opportunities incorporating communication skills training and practice creating the objects. Providing these additional supports can increase healthcare professionals' self-efficacy to determine when and how to approach the family with the offer of memory making, as well as allowing the dedicated time to approach the family and assist in creating the objects. Future research is needed to determine the effects emotional intelligence has on offering memory making for healthcare professionals, as well as the need for multi-site studies to provide a larger and more diverse sample of participants.

Family participants were interviewed less than six months after the death of their family member, so this thesis' findings raise the need to explore the family's long-term effects of psychological stress during bereavement and the role memory making objects have on their bereavement experience. Motivations for family members declining a memory making object should be explored to discover factors related to their decision, religion or cultural influences, if they later regret this decision, and if alternative bereavement interventions would be preferred. Additionally, the use of patient diaries as a memory making items is an under reported area and requires further exploration to determine its feasibility and acceptability as a memory making bereavement intervention.

7.3 CONCLUDING COMMENTS

In conclusion, findings presented in this thesis provide new insights into memory making's use as an end-of-life and bereavement care intervention in the adult intensive care environment. Overall, healthcare professionals reported positive experiences offering this intervention and appear motivated to offer it to the family when supports are available to facilitate their offer. Most family members who chose to obtain a memory making object(s) described valuing and utilising the object to trigger memories of their loved one. Although a few family members described not being emotionally connected to the memory making object or had described being too emotionally overwhelmed to perform the remembrances in grief work according to the Dual Process Model of Coping with Bereavement during their early bereavement. The significance of these findings supports the implementation of routinely offering memory making within the adult intensive care to the family as an early bereavement intervention, and this thesis provides recommendations for supports, education, and future research for memory making in the adult ICU.

In closing this thesis, the author was moved by the words from one family member on their experience of being offered the opportunity to make a memento as part of the end-of-life care:

> *“they* [the healthcare professionals] *were so busy monitoring and trying to, um, keep him alive … and doing their job … adding something extra on to their task ... I was so grateful when they asked if we could* [sic] *keep a lock of his hair, or, um, have a handprint. Some of my children were just so thrilled with being able to get a token of their dad.” -Uma*

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Appendices

Appendix A: Healthcare professionals' end-of-life care practices survey instrument

SECTION 2: End-of-life care practices

- This section is about your own personal practices and experiences in end-of-life care within your current adult intensive care unit (ICU).

Definition:

- **End-of-life care (EOLC)** is the care that is provided after a decision has been made to withhold or withdraw treatment, with death of the patient the expected outcome.

TICK [✓] ONLY ONE BOX PER QUESTION. If you are unsure about your answer, please tick the box that most closely represents your practice/opinion:

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**
My supervisors/managers ensure staff caring for patients at the end-of-life are supported						
My supervisors/managers provide guidance that assists me to provide end-of-life care						
After caring for a patient at the end-of-life, my colleagues will ask me if I am OK						
I feel supported when caring for a patient at the end-of-life						
My colleagues appreciate the stressors associated with caring for patients at the end-of-life						

	Completely disagree	Mostly disagree	Slightly disagree	Slightly Agree	Mostly agree	Completely agree
When a patient dies in ICU, counseling is available if I need it						
End-of-life care is as important as curative care in the critical care environment						
I can influence the patient and family's experience of end-of-life care						
End-of-life care should include care of the patient's family						
It is a privilege to care for a patient at the end-of-life and their family						
My own personal experiences of death have influenced the care I provide to patients at the end-of-life and their family						
Analgesia should be titrated to keep the patient comfortable even if this hastens death						
Pressure area care should continue to be provided for a patient at the end-of-life						
In ICU, families are given adequate time to consider decisions to withhold/withdraw treatment for the patient						

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**
In ICU, family meetings with the healthcare team are held to resolve differing views about a patient's treatment						
In ICU, the patient's preferences (or their likely preference according to family) for end-of-life care are considered						
In ICU, families are involved in decisions about the dying patient						
In ICU, withdrawal of treatment is delayed whilst waiting for relatives of the patient to arrive						
When a patient dies in ICU, families have sufficient time to spend with the patient						
The physical environment of ICU is ideal for providing end-of-life care						
ICU is adequately equipped to support the comfort needs of the family during end-of-life care						
Private rooms are available to care for the patient at the end-of-life						

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**
ICU is adequately staffed for providing the needs of dying patients and their families						
When a patient dies in ICU, healthcare staff have sufficient time to spend with the family						
After a decision is made to withdraw treatment, less time is spent with the patient by the critical care medical team						
After a decision is made to withdraw treatment, nurses are left to manage the care of the patient						
In ICU, end-of-life care is mostly allocated to junior healthcare staff						
After a decision is made to withdraw treatment, I spend less time with the patient						
The medical staff support end-of-life care for dying patients in ICU						
In ICU, when a diagnosis with a likely poor outcome is made, families are informed of end-of-life care options						

	Completely disagree	Mostly disagree	Slightly disagree	Slightly Agree	Mostly agree	Completely agree
In ICU, the team expresses its opinions, values and beliefs about providing care to dying patients						
All members of the healthcare team in ICU agree with and support end-of-life care when it is implemented						
In ICU, a plan of care for the patient is clearly documented by the medical team						
In ICU, the critical care team and the patient's primary medical or surgical team agree on a plan of care						
I have received in-service education that assists me to support and communicate with families of dying patients						
I have received in-service education that assists me to provide care and manage patient symptoms at the end-of-life						
I draw on evidence from the literature to provide end-of-life care to patients and their families						

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**
My postgraduate education included end-of-life care content relevant to the critical care context						
Patients at the end-of-life require little nursing care						
I feel adequately prepared to care for patients at the end-of-life						
I don't know what to say to the family of a patient at the end-of-life						
I have limited knowledge of symptom management for patient's at the end-of-life						

Please continue to the next section…

Appendix B: Healthcare professionals’ family bereavement support with memory making survey instrument

SECTION 3: Family bereavement support with memory making

- This section is about your personal beliefs about family bereavement supportive practices in an adult intensive care unit, in particular the process of supporting “memory making”.

- If you are not sure about your answer, then please tick the box that most closely represents your practice or opinion.

The act of memory making involves the following:

PLEASE ANSWER EACH QUESTIONS WITH ONE TICK BOX [✓]

	Yes	**No**
Asking the family questions about the person (patient) to learn more about them		
Allowing the family to keep a lock of hair of the person		
Giving the family written information about bereavement care		
Allowing the family to spend time with the person after death		
Allowing the family to create hand or foot prints of the person		
Preparing the body for the family’s viewing		
Being present at the time of death		
Talking to the family or patient about his or her prognosis		

Other: ____

For the questions to the remainder of the survey, please refer to the following definition of memory making:

- ***Memory making*** is an activity that provides a tangible object(s) that can help a bereaved individual create a connection with and provide meaningful memories about a deceased person. For this survey, tangible objects include handprints, footprints, and/or locks of hair.

PLEASE ANSWER EACH QUESTION WITH ONE TICK BOX [✓]

	Yes	No
I have received education related to memory making for families		
I have read literature/published information about memory making		

If so, where did you read about it? Please select all that apply:

☐ Medical/nursing textbook
☐ Medical/nursing journal
☐ Website
☐ Other (please specify) ______________________________
☐ Social media
☐ Blog

PLEASE ANSWER EACH QUESTION WITH ONE TICK BOX [✓]

	Yes	No
I have offered memory making to families in intensive care		

If no, what has prevented you from doing so?

____

____

____

	Yes	**No**
I have observed my colleagues offering/facilitating memory making to families		

If so, please give an example of what you observed:

____

____

<u>TICK [✓] ONLY ONE BOX PER QUESTION.</u> If you are unsure about your answer, please tick the box that most closely represents your practice/opinion:

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**
I know the benefits of memory making for the family						
I believe families value memory making after a death						
Initiating memory making is the responsibility of the nurse						
Initiating memory making is the responsibility of the social worker						
Initiating memory making is the responsibility of the medical practitioner						
I believe offering memory making is beneficial for the families.						

The outcome(s) I anticipate from families being offered and/or doing memory making include(s):

____

____

____

	Completely disagree	Mostly disagree	Slightly disagree	Slightly Agree	Mostly agree	Completely agree
I am committed to offering memory making as part of my practice.						

I offer memory making to families because:

____

____

	Completely disagree	Mostly disagree	Slightly disagree	Slightly Agree	Mostly agree	Completely agree
I have the necessary skills to offer families the opportunity to create memories after a death						

The skills most needed to offer families the opportunity to create memories after a death are:

____

____

The skill(s) I think I need to improvement on to provide memory making is(are):

____

____

	Completely disagree	Mostly disagree	Slightly disagree	Slightly Agree	Mostly agree	Completely agree
It is not always appropriate to offer memory making to families after a death						

I feel it is NOT appropriate to offer memory making to families if:

____

____

____

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**
The intensive care environment is a barrier to offering memory making						
I am afraid to offer memory making						

I am afraid to offer memory making when/because:

____

____

____

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**
After a death, I am able to spend time with the family if they need support with memory making						

What enables you to provide memory making for families?

____

____

____

What barriers prevent you from offering memory making to families?

____

____

____

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**
It is routine for me to provide memory making for the families						
Providing the family with memory making is something I plan to do in the future						
There is a lack of resources for me to offer memory making for the families						

TICK [✓] ONLY ONE BOX PER QUESTION. If you are unsure about your answer, please tick the box that most closely represents your practice/opinion:

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**	**Not applicable to me**
The memory making opportunities I provide have been influenced by my nursing colleagues							
The memory making opportunities I provide have been influenced by my medical colleagues							
The memory making opportunities I provide have been influenced by my social work colleagues							
I often forget to offer memory making after a death							
I need to have developed a rapport with the families before I offer memory making							
Being involved in family meetings about end-of-life care influences my decision to offer memory making to families							

	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**	**Not applicable to me**
I feel confident offering memory making to families I have just met							
I find it difficult to offer families the opportunity to create memories after a death							
The family's behaviors can limit my ability to offer memory making to them							
In my past experience(s), I have been comfortable offering the family the ability to create memories after the patient has died							
I find it emotionally satisfying to provide memory making							
I find pride in my ability to allow families to create memory making after a death							
I frequently do not have time to offer memory making after a death							

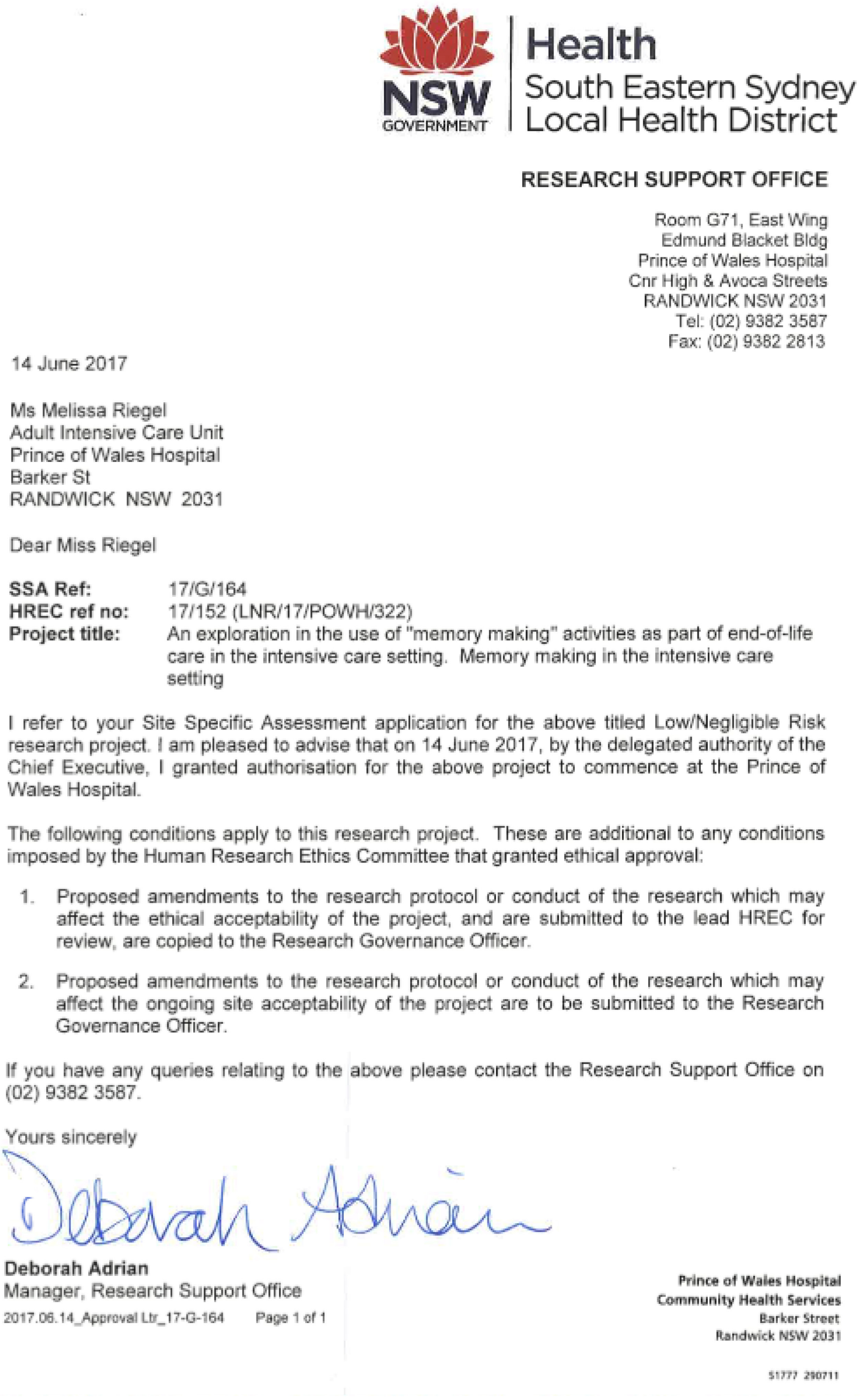
	Completely disagree	**Mostly disagree**	**Slightly disagree**	**Slightly Agree**	**Mostly agree**	**Completely agree**	**Not applicable to me**
I find it personally upsetting to provide memory making at end-of-life							
It is too time consuming for me to offer memory making to the families after a death							

Other comments I wish to share in relation to memory making:

Thank you very much for taking the time to participate!

Please return the completed questionnaire in the sealed box in the AICU Tea Room

Appendix C: Ethics site approval for survey of intensive care healthcare professionals



NSW GOVERNMENT
Health
South Eastern Sydney
Local Health District

RESEARCH SUPPORT OFFICE

Room G71, East Wing
Edmund Blacket Bldg
Prince of Wales Hospital
Cnr High & Avoca Streets
RANDWICK NSW 2031
Tel: (02) 9382 3587
Fax: (02) 9382 2813

14 June 2017

Ms Melissa Riegel
Adult Intensive Care Unit
Prince of Wales Hospital
Barker St
RANDWICK NSW 2031

Dear Miss Riegel

SSA Ref:	17/G/164
HREC ref no:	17/152 (LNR/17/POWH/322)
Project title:	An exploration in the use of "memory making" activities as part of end-of-life care in the intensive care setting. Memory making in the intensive care setting

I refer to your Site Specific Assessment application for the above titled Low/Negligible Risk research project. I am pleased to advise that on 14 June 2017, by the delegated authority of the Chief Executive, I granted authorisation for the above project to commence at the Prince of Wales Hospital.

The following conditions apply to this research project. These are additional to any conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.

If you have any queries relating to the above please contact the Research Support Office on (02) 9382 3587.

Yours sincerely

Deborah Adrian

Deborah Adrian
Manager, Research Support Office
2017.06.14_Approval Ltr_17-G-164 Page 1 of 1

Prince of Wales Hospital
Community Health Services
Barker Street
Randwick NSW 2031

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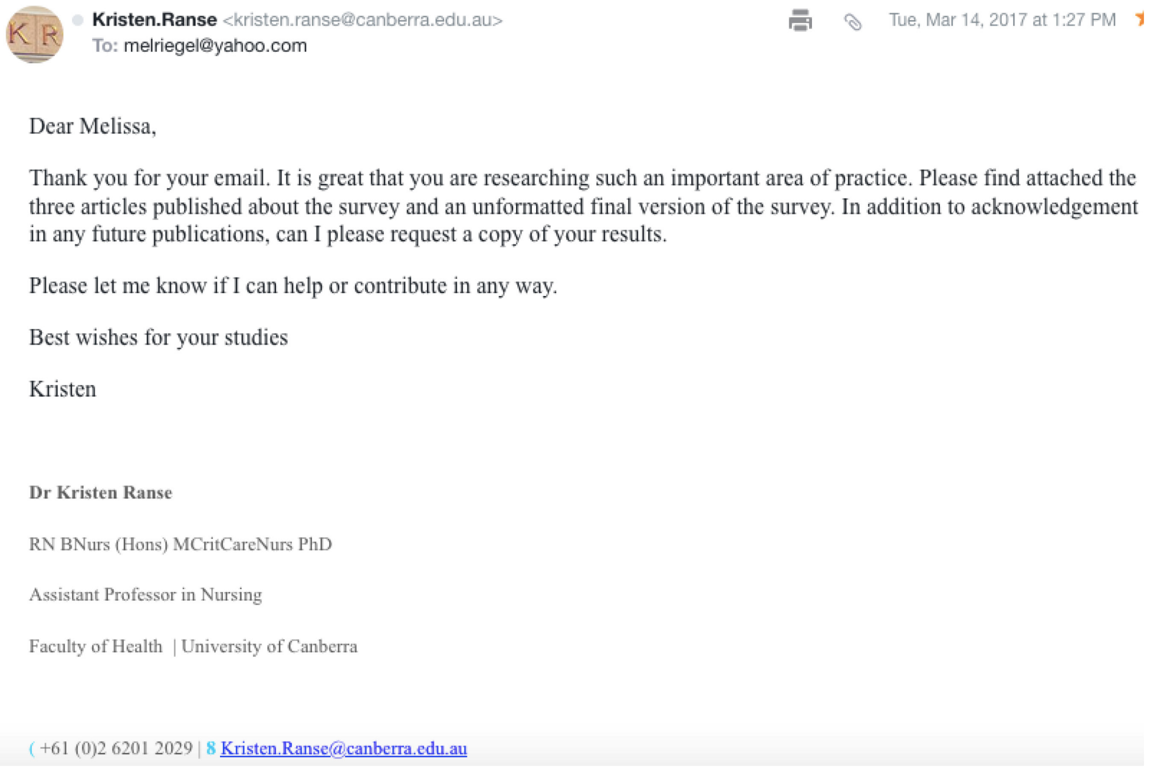
Appendix D: Permission to use provisions of end-of-life care survey



Kristen.Ranse <kristen.ranse@canberra.edu.au>
To: melriegel@yahoo.com

Tue, Mar 14, 2017 at 1:27 PM

Dear Melissa,

Thank you for your email. It is great that you are researching such an important area of practice. Please find attached the three articles published about the survey and an unformatted final version of the survey. In addition to acknowledgement in any future publications, can I please request a copy of your results.

Please let me know if I can help or contribute in any way.

Best wishes for your studies

Kristen

Dr Kristen Ranse

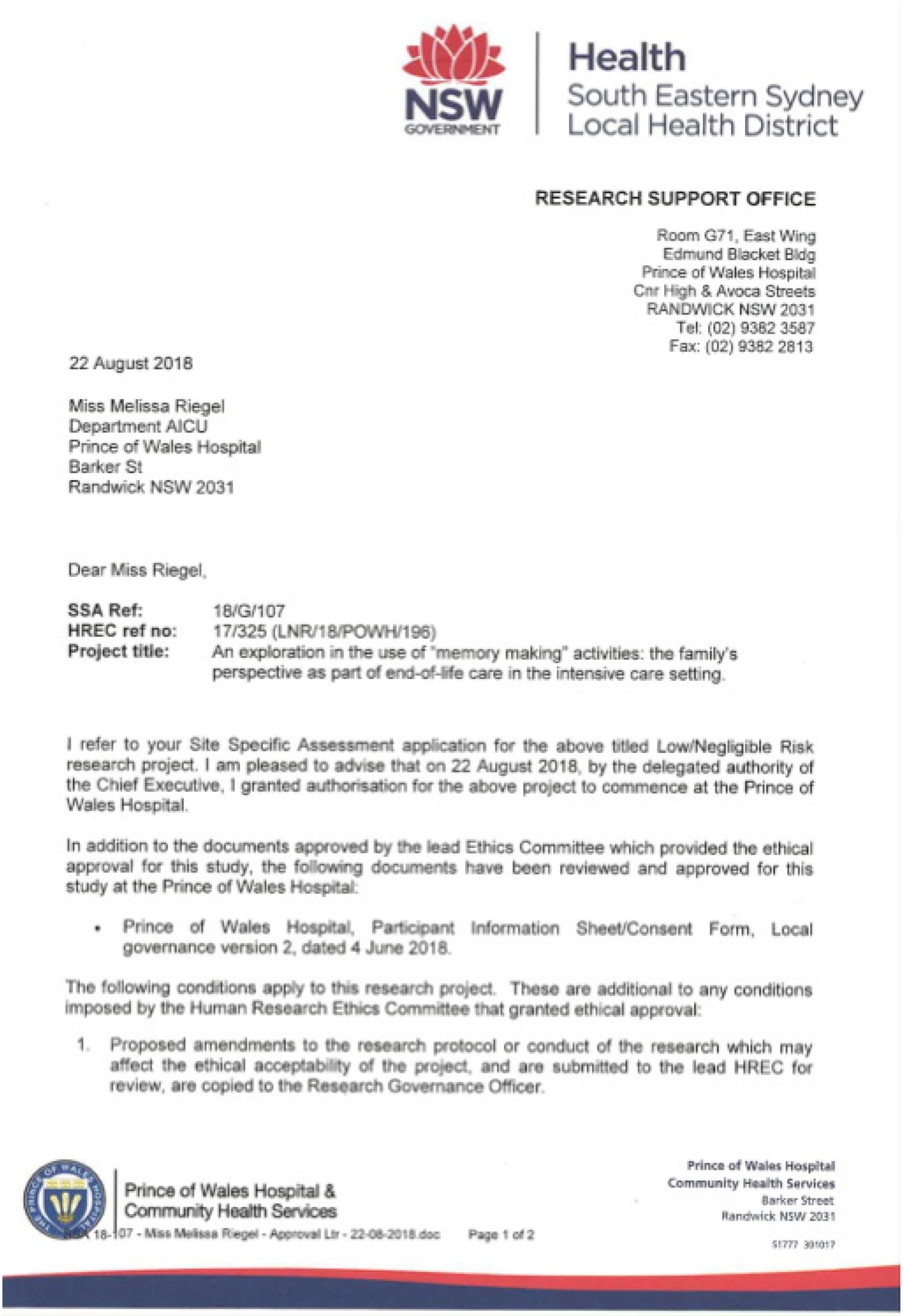
RN BNurs (Hons) MCritCareNurs PhD

Assistant Professor in Nursing

Faculty of Health | University of Canberra

(+61 (0)2 6201 2029 | 8 Kristen.Ranse@canberra.edu.au

Appendix E: Ethics site approval for bereaved family interviews



NSW GOVERNMENT
Health
South Eastern Sydney
Local Health District

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RANDWICK NSW 2031
Tel: (02) 9382 3587
Fax: (02) 9382 2813

22 August 2018

Miss Melissa Riegel
Department AICU
Prince of Wales Hospital
Barker St
Randwick NSW 2031

Dear Miss Riegel,

SSA Ref:	18/G/107
HREC ref no:	17/325 (LNR/18/POWH/196)
Project title:	An exploration in the use of "memory making" activities: the family's perspective as part of end-of-life care in the intensive care setting.

I refer to your Site Specific Assessment application for the above titled Low/Negligible Risk research project. I am pleased to advise that on 22 August 2018, by the delegated authority of the Chief Executive, I granted authorisation for the above project to commence at the Prince of Wales Hospital.

In addition to the documents approved by the lead Ethics Committee which provided the ethical approval for this study, the following documents have been reviewed and approved for this study at the Prince of Wales Hospital:

- Prince of Wales Hospital, Participant Information Sheet/Consent Form, Local governance version 2, dated 4 June 2018.

The following conditions apply to this research project. These are additional to any conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.

2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.

If you have any queries relating to the above please contact the Research Support Office on (02) 9382 3587.

Yours sincerely

Asatina Viviani-Tukutama
Research Governance Officer

SSA 18-107 - Miss Melissa Riegel - Approval Ltr - 22-08-2018.doc Page 2 of 2

Figures

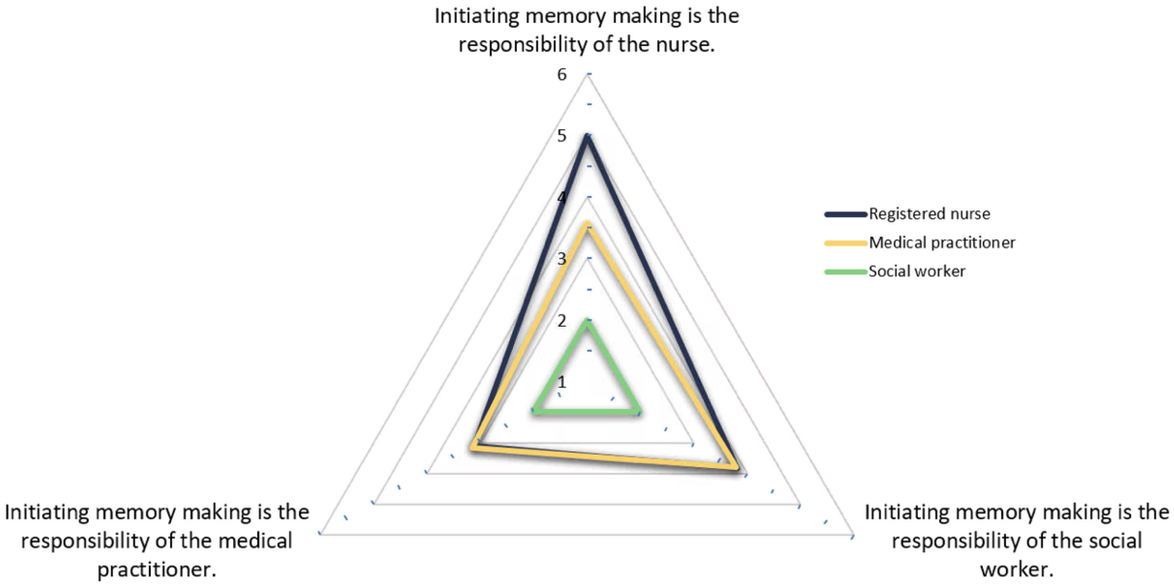
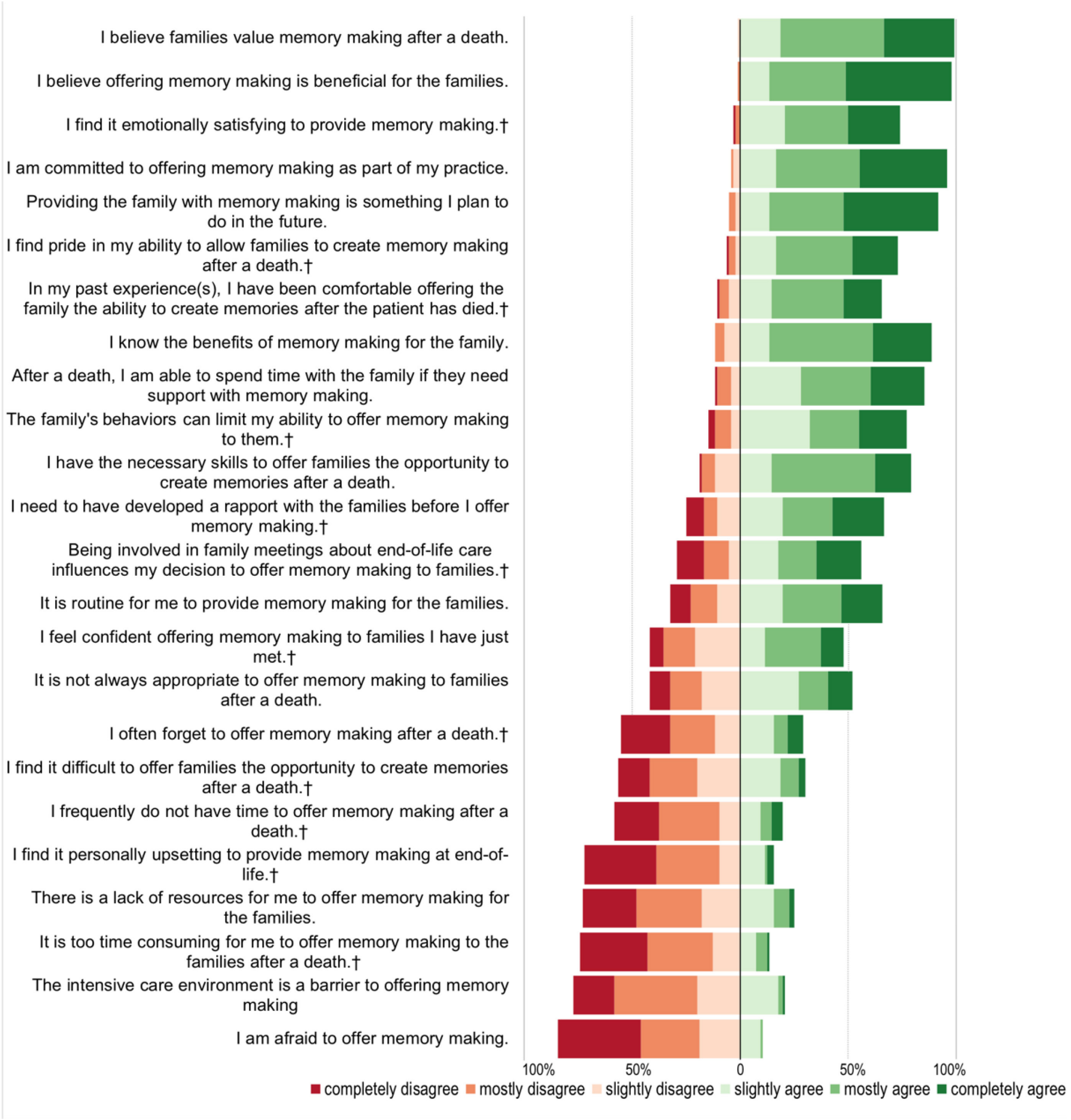


Figure A.3: Comparison of participant mean rates of agreement by profession for three questions related to responsibility for initiating memory making, where the axes are based on the 6-point Likert scale: 6 = completely agree; 1 = completely disagree (Riegel et al., 2022b).



†Question utilised the option of 7 = not applicable to me

Figure A.4: Likert scale responses for overall participants in descending order of scores of agreements as represented in percentages (Riegel et al., 2022a)

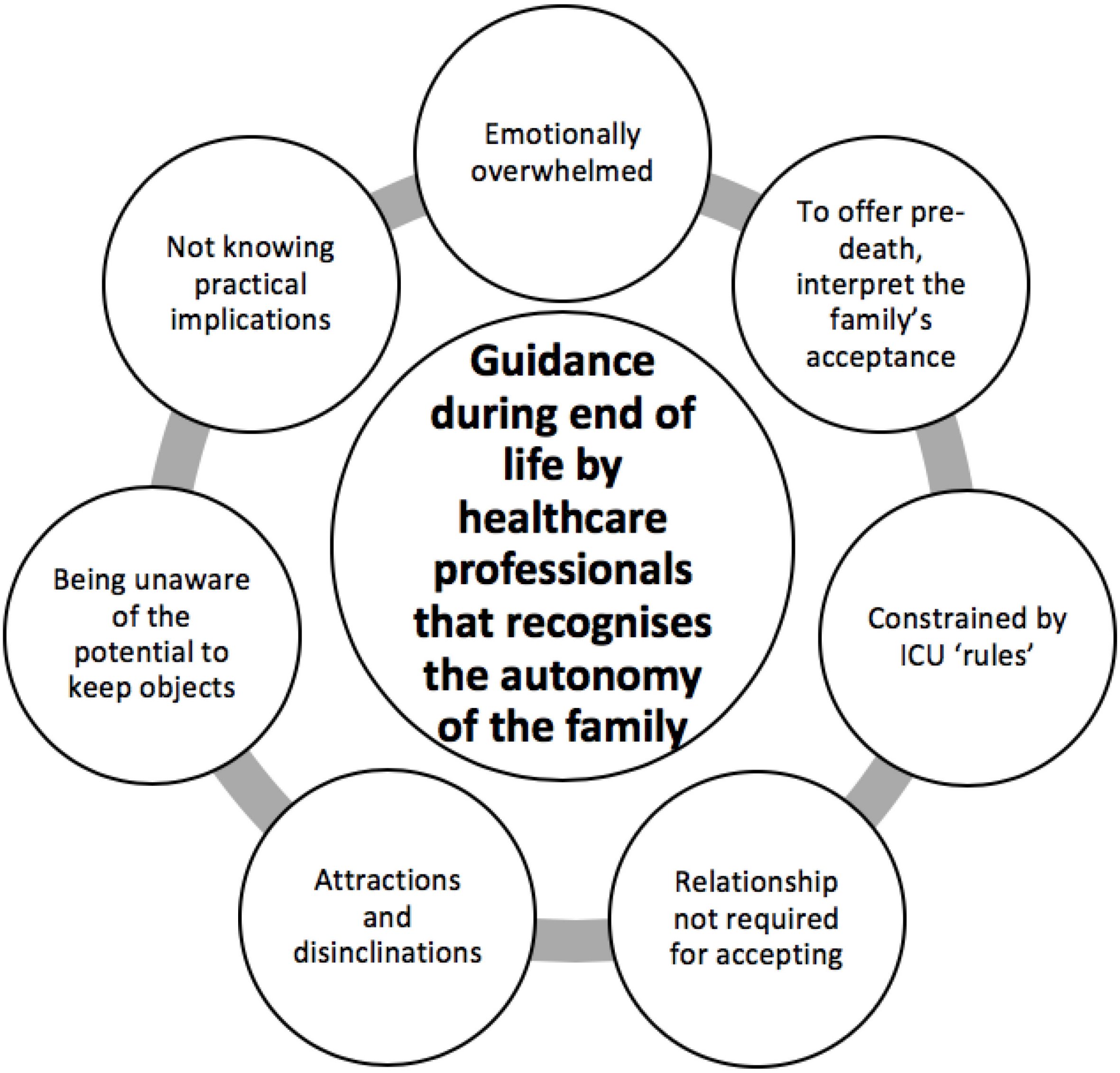


Figure A.5: Reflexive thematic analysis' Phase 5 of the generated theme *Guidance during end of life by healthcare professionals that recognises the autonomy of the family* with corresponding Phase 2 systematic data codes (Braun & Clarke, 2020).

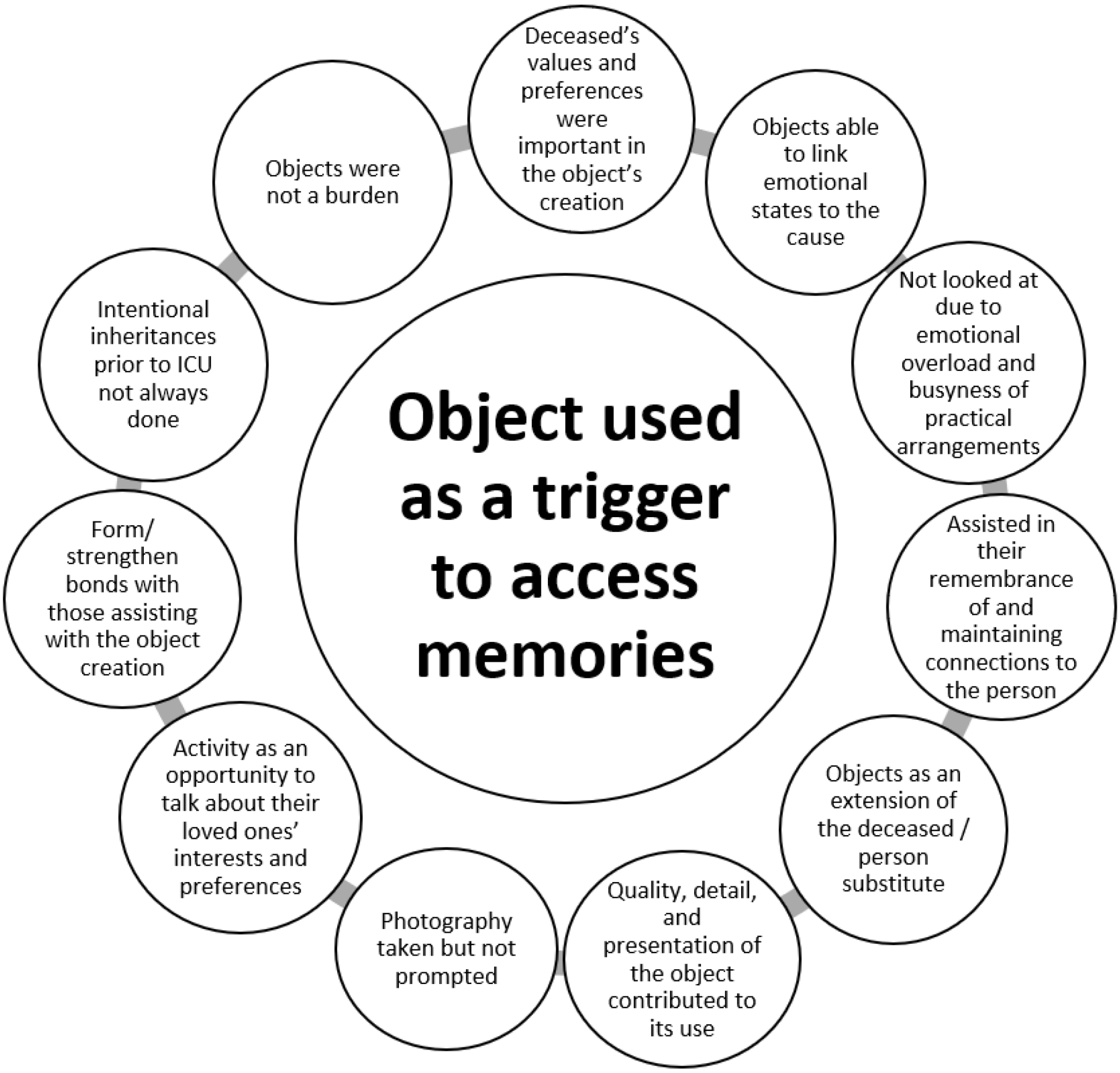


Figure A.6: Reflexive thematic analysis' Phase 5 of the generated theme *Object used as a trigger to access memories* with corresponding Phase 2 systematic data codes (Braun & Clarke, 2020).

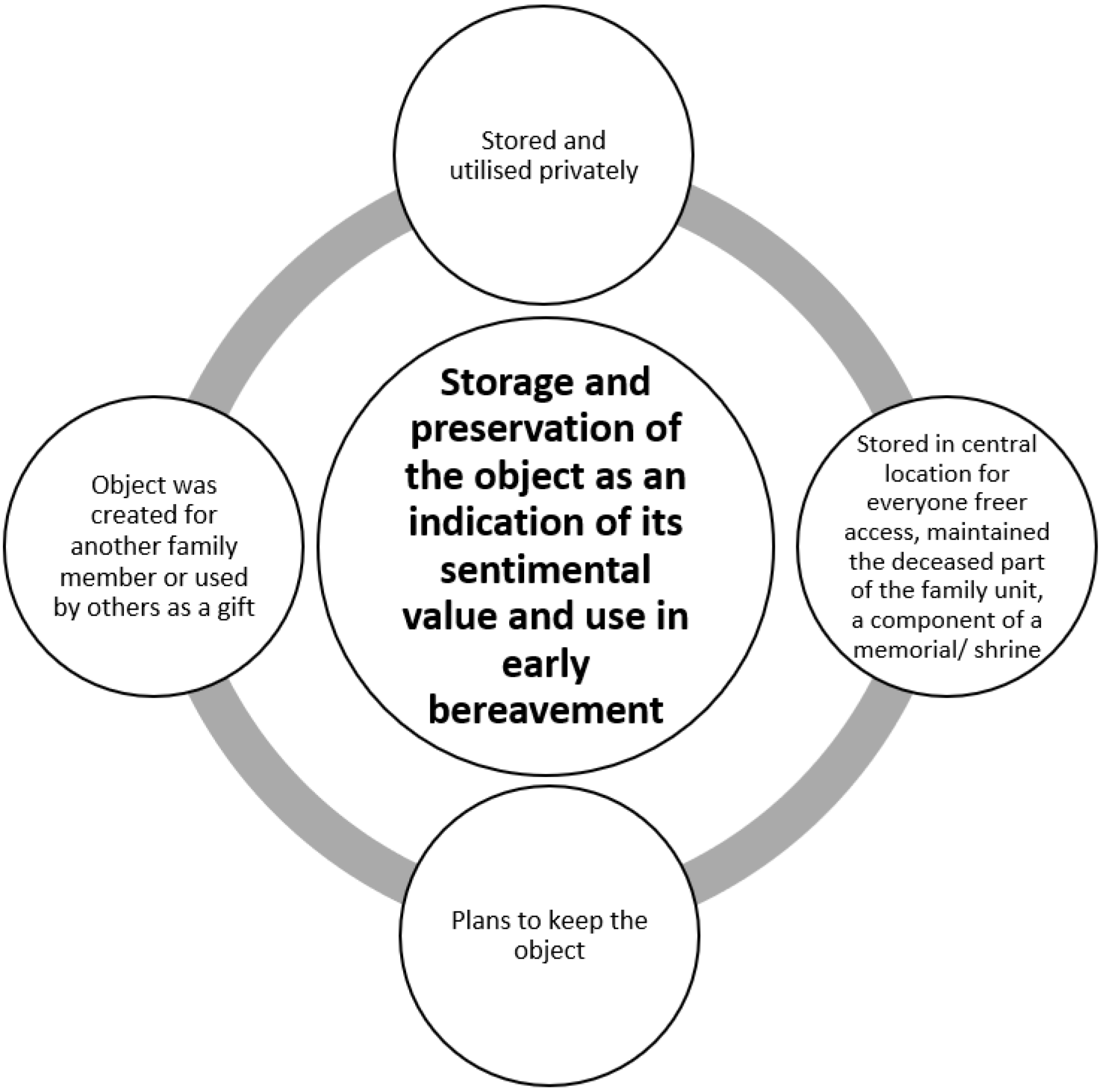


Figure A.7: Reflexive thematic analysis' Phase 5 of the generated theme *Storage and preservation of the object as an indication of its sentimental value and use in early bereavement* with corresponding Phase 2 systematic data codes (Braun & Clarke, 2020).

Tables

Table A.1: Process of theme generation from family interview data following the 6-phase process for inductive reflexive thematic analysis (Braun & Clarke, 2006, 2020)

Phase 5: Refining, defining, and naming themes	**Phase 4: Developing and reviewing themes**	**Phase 3: Generating initial themes from coded and collated data**	**Phase 2: Systematic data coding**			
Themes: third iteration	**Themes: second iteration**	**Themes: first iteration**	**Codes: fourth iteration**	**Codes: third iteration**	**Codes: second iteration**	**Codes: first iteration**
Guidance during end-of-life by healthcare professionals that recognises the autonomy of the family	Guidance by healthcare professionals that recognises the autonomy of the family when offering them opportunities to create a memory making object	Guidance and autonomy are simultaneously necessary	Attractions and disinclinations to mementos	Avoiding paternalism & decision making for the family.	Communication: general	Communication: general
					Experience receiving:	COVID-19
					Diary writings	Culture
			Being unaware of the potential to keep objects	ICU rules and regulations	Death reaction	Death reaction
					Offering of object	Diary writings
			Emotionally overwhelmed	Assist overwhelmed families	Pre-death background heightened emotions	Environment
					Regrets on reflection	Environment: neutral
					Person helping to choose object	Environment: personalise
			Relationship not required for accepting	Acceptance of object not reliant on knowing the offer-er	Staff guiding family in process	Environment: short ICU time
					Staff: negative	Family processing of

						information at death
			Constrained by ICU ‘rules’		Staff: positive	Instigator of MM
					When approached	Person helping to choose object
					After death	Preconceptions about ICU staffing
			To offer pre-death, interpret family’s acceptance	Offering predeath requires offer-er’s ability to interpret the situation	Before death	Pre ICU incident reaction
						Staff guiding family in process
			Not knowing practical implications			Staff: negative
						Staff: positive
						Staffing, different each shift: positive
						Staffing, different each shift: negative
						When approached
						After death
						Before death
					Uncertainty of best time to approach	Uncertainty of best time to approach
					Who received object	Who received object
					Who should receive it	Who should receive it
						Object created by
					Family created object	Family created object
					Nurse performed MM not family	Nurse performed MM not family
						Object creation as distraction in ICU
						Object creation preventing goodbyes
						Organ donation

Table A.2: Process of theme generation from family interview data following the 6-phase process for inductive reflexive thematic analysis (Braun & Clarke, 2006, 2020)

Phase 5: Refining, defining, and naming themes	**Phase 4: Developing and reviewing themes**	**Phase 3: Generating initial themes from coded and collated data**	**Phase 2: Systematic data coding**			
Themes: third iteration	**Themes: second iteration**	**Themes: first iteration**	**Codes: fourth iteration**	**Codes: third iteration**	**Codes: second iteration**	**Codes: first iteration**
Object used as a trigger to access memories	Objects were utilised in bereavement as a catalyst for memories	Object used as an emotional memory placeholder	Activity as an opportunity to talk about their loved one	Bonding / story telling	Alternative objects: clothing, diary	Other objects wished from ICU
			Form/ strengthen bonds with those assisting with the object creation	Not typically done in the past / Normalisation of death mementos	Feelings elicited by object	Object chosen
			Quality, detail, and presentation of the object contributed to its use	Quality of object created and its presentation to the family is important	Ease of object availability to interact with	Other objects of value
			Objects able to link emotional states to the cause	Linkage of feelings to the source of the feelings	Memory placeholder, record	Object as memory
			assisted in their remembrance of and maintaining connections to the person		Object chosen	Improvement suggestions
					Colour choice	Colour choice
			deceased's values and preferences were		Other objects of value	

			important in the object’s creation			
					Other objects wished from ICU	
			Photography taken but not prompted	Photography	Photo preferences	Photo preferences
					Delay in interacting with object	
					Object to hold onto	Convenience for viewing
					Perception of the act of caring	
					Convenience for viewing	
					Why they took pictures	
					Why interacting with object	
					Why they wanted object	Object reactions
					Object reactions	Continued reaction to object
			Not looked at due to emotional overload and busyness of practical arrangements	Not looked at during initial weeks due to emotional overload and busyness of practical arrangements	Continued reaction to object	Initial reaction: neutral, uncertain
					Initial reaction: neutral, uncertain	Interactions with object
					Interactions with object	Object as comfort item
					Object as comfort item	Object initial reaction: positive
					Object initial reaction: positive	Object initial reaction: strange
			objects were not a burden	Mementos aren’t a burden to have	Object initial reaction: strange	Object quality suggestions

					Object quality suggestions	Object viewed as
					Object viewed as	Object able to be communication starter
					Object able to be communication starter	Object as finale
					Object as finale	Object as memory
					Object as memory	Object as person substitute
			Objects as an extension of the deceased / person substitute.		Object as person substitute	Sign, meant to be
					Sign, meant to be	Symbol of comfort, caring
					Symbol of comfort, caring	Post ICU continued memories
			Intentional inheritances prior to ICU not always done; instead, objects provide meaningful keepsakes	Intentional inheritances received prior to ICU	Objects collected in the past	Objects collected in the past

Table A.3: Sample process of theme generation from family interview data following the 6-phase process for reflexive thematic analysis (Braun & Clarke, 2006, 2020)

Phase 5: Refining, defining, and naming themes	**Phase 4: Developing and reviewing themes**	**Phase 3: Generating initial themes from coded and collated data**	**Phase 2: Systematic data coding**			
Themes: third iteration	**Themes: second iteration**	**Themes: first iteration**	**Codes: fourth iteration**	**Codes: third iteration**	**Codes: second iteration**	**Codes: first iteration**
Storage and preservation of the object as an indication of its sentimental value and use in early bereavement	Consideration and effort given to the storage and preservation of the objects provides an indication of its sentimental value, as well as how and when it's used during bereavement	Storage and protection of object as an indication of its sentimental value and use in bereavement	Plans to keep the object.	Future plans	Location of object now	Location of object now
					Future location: keeping	Future location: keeping
					Future location: uncertain if keeping	Future location: uncertain if keeping
			Stored and utilised privately	Sacred but private	Initial location: unchanged	initial location: unchanged
					location planned to change	location planned to change
					preservation of object: initial	preservation of object: initial
			Stored in central location for everyone freer access, maintained	Decorate in memories	Shrine made central location	Shrine made central location

			the deceased part of the family unit, a component of a memorial/ shrine			
			Object was created for another family member or used by others as a gift	Secondary creation of memories by making it into something special for others to utilise	Others using object as way of 'helping' and keeping busy	Maintained inspired by the deceased