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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

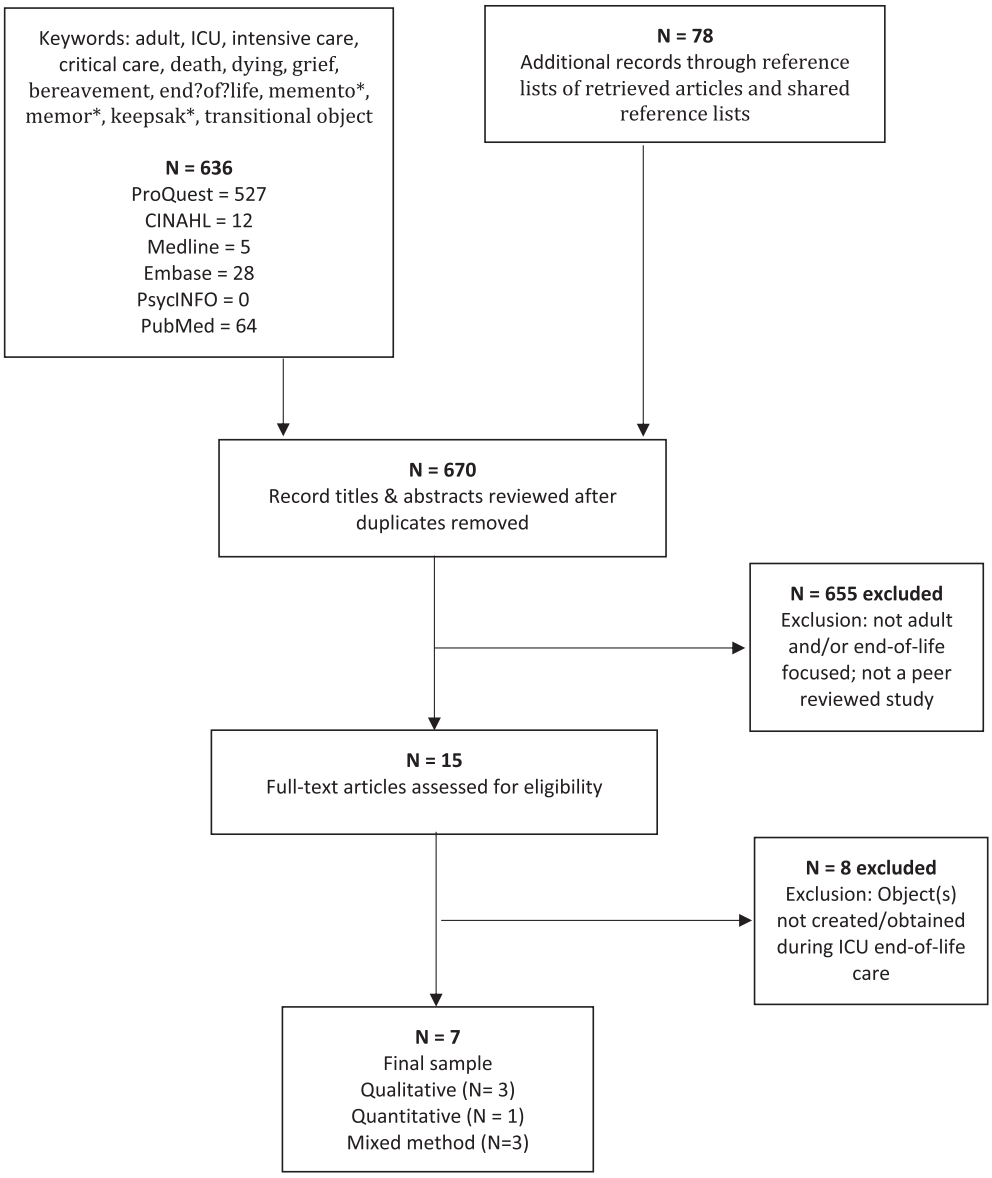

Fig. 1. Summary of literature search and selection.

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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