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**Memory-Making in Critical Care:
A Qualitative Thematic Synthesis**

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Submitted in fulfilment of the requirements for the degree of

Masters by Research

School of Medicine, Dentistry and Nursing

College of Medical, Veterinary and Life Sciences

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Abstract

Background: Caring for bereaved families is an important aspect of the nursing role in critical care, due to the significant number of deaths and the immediate and long-term effects on family members' individual grief. Memory-making practices are one way in which dying, death and bereavement can be acknowledged and supported within critical care. Memory-making was introduced into the care of babies who were stillborn and neonates who died to improve parents' experiences of bereavement, and has since become common practice in adult critical care settings. However, there is limited research to evaluate its impact on bereaved families and their grieving experience. This thesis is a qualitative thematic synthesis which aims to explore families' experiences of memory-making practices in critical care, with a view to gaining greater understanding of the ways in which memory-making impacts bereaved families and individuals, and the factors which affect their experience of memory-making.

Methods: A qualitative thematic synthesis was carried out to systematically identify and synthesise qualitative evidence to explore families' experiences of memory-making practices in both paediatric and adult critical care settings. A systematic search strategy was developed and five databases were searched (Medline, CINAHL, PsycINFO, Embase and ASSIA). Seven qualitative studies were included, exploring four adult and three paediatric critical care settings in which memory-making was initiated between 2014 and 2020. The memory-making practices included patient diaries, general keepsakes, word clouds and photography

Results: The qualitative thematic synthesis generated four main themes to describe families' experience of memory-making in critical care: connection, compassion, engagement and creation, and continuation. Connection was made through the shared experience of humanity and emotion, and helped to develop trusting relationships between families and nurses. Compassionate care supported and guided families during the end of a loved one's life. It welcomed families, and made them more comfortable in a highly technical environment. Engagement with memory-making led to the creation of memories and keepsakes, and was a therapeutic experience that supported the transition of saying goodbye. Families continued their relationship with their loved one and individual grieving process, after the death of their loved one.

Conclusions: Memory-making is a meaningful activity for families whose loved one has died in critical care; it brought focus and meaning during a devastating process in a highly technical environment. Families relied heavily on nursing staff for support and guidance, and perceived the offering of memory-making as compassionate care. The creation of keepsakes can foster deeper connections within families and staff, and has a positive impact on the bereavement experience. Families within this synthesis created their memories and keepsakes as a way to stay connected, and therefore continue their relationship with their loved one.

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This piece of work was about love and grief – there is beauty in knowing that we can be forever connected.

Author's declaration

I declare that, except where explicit reference is made to the contribution of others, this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Name: Doreen MacEachen

Signature:

Abbreviations

GP – General practitioner

ICU – Intensive care unit

HDU – High dependency unit

NOK – Next of kin

PPI – Patient and public involvement

PTSD – Post-traumatic stress disorder

QEUH – Queen Elizabeth University Hospital

How people die remains in the memory of those who live on.

(Dame Cicely Saunders, 1918–2005)

The loss of a loved person is one of the most intensely painful experiences any human being can suffer, and not only is it painful to experience, but also painful to witness, if only because we're so impotent to help.

(Bowlby, 1980)

Separation

*Your absence has gone through me
Like thread through a needle
Everything I do is stitched with its colour*

(W. S. Merwin, 1993)

Chapter 1: Death in critical care

1.1 Overview of thesis

Grief and bereavement are universal experiences; each of us will die and will experience the loss of a significant other. The manner of a loved one's death has significant implications for the grieving process and the experience of bereavement (Wimpenny et al., 2012, Stroebe et al., 2007). Death in critical care has its own particular challenges and impacts for the patient, for their loved ones and for the nursing staff, which in turn can impact the experiences of all those involved in dying, death, bereavement and grief (Pattison et al., 2020, Kentish-Barnes et al., 2015, Kentish-Barnes and Prigerson, 2015). Death in critical care often occurs suddenly, after a short period of acute illness, or shortly after an unexpected event or accident. This, therefore, leaves loved ones with much less time to prepare for death, which in turn has implications for grief and bereavement. The critical care environment is a highly technical one, with patients typically connected to machines and monitoring equipment. Patients are also often unconscious or otherwise unable to communicate with their families. For the family and friends of patients, this environment and situation is likely to be alien and unfamiliar, as well as potentially frightening and overwhelming, adding to their already significant levels of distress. They may feel unsure of how to behave in such an environment and may find it challenging to engage with their loved one and their care. Families are therefore reliant on staff to a great extent for information and support, as well as cues and models of how to interact with the patient.

Memory-making practices are one way in which dying, death and bereavement can be acknowledged and supported within critical care. This thesis aims to explore families' experiences of memory-making practices in critical care, with a view to gaining greater understanding of the ways in which memory-making impacts bereaved families and individuals, and the factors which affect their experience of memory-making.

The thesis consists of six chapters. In this first chapter, death, dying and bereavement within a critical care environment will be discussed. Chapter 2 is an overview of bereavement care and levels of bereavement support, theoretical approaches to grief and the theoretical underpinning of the study, policy, and service provision. It also discusses the origins of memory-making. Chapters 3 and 4 consider the research methodology and methods chosen for this study. Chapter 5 discusses the qualitative thematic synthesis and

the findings. Chapter 6 is the discussion, recommendations and conclusion. The thesis concludes with a personal reflection of the undertaking of this Masters by Research at the University of Glasgow (Appendix 1) and a proposed empirical study (Appendix 2), which has been designed following the results of this study to further develop our understanding of bereaved families' experiences of memory-making in critical care.

1.2 Death in critical care

Advances in healthcare and technology have increased life expectancy and people are living longer with chronic health conditions (Broden et al., 2020). One in five patients admitted to critical care will die during their hospital admission (Faculty of Intensive Care Medicine, 2019a). The onset of critical illness and death may often be sudden and unexpected and dying in critical care presents unique challenges for bereaved families¹ and staff (Pattison et al., 2020). Patients are often ventilated and sedated in critical care units. The level of individual patient consciousness can be impacted by the severity of their illness in critical care and there is often a delicate balance to be struck between providing life-prolonging interventions and allowing death to occur naturally (Broden et al., 2020). The most common cause of death is the withdrawal of life-sustaining treatment, at which point the focus then becomes comfort care. The withdrawal of active treatment is a skill which requires timely, clear communication within the multidisciplinary team, and between patient (if possible) and family.

It is therefore crucial that the patient's family and loved ones are engaged with and involved in their care, as they are the patient's voice and can represent and advocate for their wishes and preferences. This enables staff to connect with the patient and gain a deeper understanding of their needs.

Preparedness for death is a key factor in the psychological adjustment to bereavement (Buckley et al., 2015). However, this is not always possible since there will be situations and circumstances in which death is sudden with little prior warning (Worden, 1991). Bereaved families whose loved ones die suddenly have a different and often difficult experience whereby a lack of situational reality, feelings of guilt (often characterised by

¹ As used in this study, "family" refers to the people who matter most to the patients; this includes spouses, partners, children, siblings, relatives, friends, and anyone else who is important to the patient.

ruminating on alternative scenarios – a sense of “if only...” and feelings of helplessness may be encountered (Worden, 1991).

1.3 Critical care environment

Critical care is one of many specialised departments within a hospital where acutely ill patients are supported by a professional multidisciplinary team (Marshall et al., 2016). Critical care consists of intensive care units (ICU) providing level three care and high dependency units (HDU) providing level two care. Further classifications of care are demonstrated in Table 1.1, taken from the *Guidelines for the Provision of Intensive Care Services* (Faculty of Intensive Care Medicine, 2019a). Critical care is a highly technical environment, providing invasive care and continuous monitoring of patients’ vital functions such as heart rate and blood pressure via monitoring equipment. Patients admitted to critical care may have had routine complex surgery, a life-threatening illness or traumatic injury (NICE, 2009). It is estimated that, over time, demand for critical care beds will increase due to the growing and ageing population and advances in medical technology (King's Fund, 2020). One may suggest that advances in medical technology and innovative monitoring equipment create an intimidating experience for families in the critical care environment since it is typically dominated by such equipment.

The literature predominantly refers to intensive care or critical care; there are few articles which describe high dependency care. It is assumed that ICU is the umbrella term used to describe all levels of patients in critical care. Level two patients can be nursed in a level three bed, but a level three patient must be in an ICU (Table 1.1). The present study uses the term “critical care” to incorporate both ICU and HDU care, or will specify either ICU or HDU if necessary.

Table 1.1 Classifications of care

Level 0	Patients whose needs can be met through normal ward care in an acute hospital.
Level 1	Patients at risk of their condition deteriorating, or those recently relocated from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team.
Level 2	Patients requiring more detailed observation or intervention, including support for a single failing organ system or post-operative care or those “stepping down” from level three care.
Level 3	Patients requiring advanced respiratory support alone, or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure.

1.4 Bereavement in critical care

Caring for bereaved families is an important aspect of the nursing role. In certain areas of nursing practice including critical care this is especially important due to the significant number of deaths and the immediate and long-term effects on family members' individual grief (Harris et al., 2021). Therefore, the approach to care taken by healthcare professionals has potential to impact families' bereavement and well-being, in both the short term and longer term.

Experiencing the death of a loved one in critical care can be an extremely stressful event, and can lead to symptoms of stress, anxiety, depression, post-traumatic stress disorder (PTSD) and prolonged grief (Harris et al., 2021). Research literature describes interventions and strategies that are commonly used to support bereaved families; these include information leaflets, condolence letters, follow-up meetings, patient diaries and memory-making practices (Coombs et al., 2017, Kentish-Barnes et al., 2017, Johansson et al., 2018, Riegel et al., 2019, Thornton et al., 2019, Melby et al., 2020, Clarke and Connolly, 2021).

Memory-making interventions are used in paediatric end-of-life care to improve parents' experiences of bereavement (Thornton et al., 2019, Thornton et al., 2020, Thornton et al., 2021). In many healthcare systems memory-making practices originated in perinatal and neonatal settings as a process of creating keepsakes to support parents of stillborn babies (Gold et al., 2007, Thornton et al., 2019); these keepsakes most commonly took the form of photographs and hand/footprints (Koopmans et al., 2013, Clarke and Connolly, 2021). Memory-making continues to be strongly associated with this practice (Koopmans et al., 2013, Kenner et al., 2015, Thornton et al., 2019, Clarke and Connolly, 2021). However, in recent years memory-making has also begun to be used within adult critical care (Coombs et al., 2017, Efstathiou et al., 2019, Riegel et al., 2019), and the range of interventions used has expanded beyond the creation of keepsakes to include a wider range of memory-making practices, some of which may result in a tangible object, some of which may not.

This qualitative thematic synthesis of the literature will explore the use of memory-making in both paediatric and adult care settings. This study uses an expanded definition of memory-making, which encompasses the full range of practices used (including but not limited to the creation of keepsakes). As there are a limited number of primary studies

regarding memory-making in critical care, reviewing evidence from both adult and paediatric care settings will allow for exploration of a fuller range of memory-making practices. Additionally, since memory-making first emerged within paediatric care settings (as discussed in Chapter 2), studies from this area were felt to be crucial to a fuller understanding of families' experiences of memory-making. Also, this thematic synthesis offers an opportunity to review similarities and, or differences between adult and paediatric patients' and their families' experiences of memory-making in a critical care setting.

1.5 Clinical background of researcher

Most of my nursing career has been spent working in critical care in NHS Scotland, where I have developed a particular interest in providing end-of-life care and, more recently, bereavement care. It is a privilege and honour to provide a person their last acts of care. Despite 20 years of nursing experience and a passion for end-of-life care, each time I am involved with a patient and their family I find it challenging. Knowing how profoundly these experiences can affect the bereavement and grief of a patient's loved ones brings a feeling of urgency and responsibility. As nurses, these experiences can leave us wondering what we might have done differently, and if we might have done something better. We want to help our patients get better; with experience we realise that this it is not always possible. There are times when the best thing we can do for the patient is to provide a comfortable and dignified death. It is emotionally difficult watching others in pain as they experience the death of a loved one. It is also a reminder of the fragility of life and of my own and my family's vulnerability. These personal experiences have informed both the motivation to undertake the present research and some of the specific approaches to nursing, bereavement and grief used within this study. One particular illustrative experience is described in more detail in the next section.

1.5.1 Profound personal experience of memory-making in critical care

Matthew (pseudonym) was a 23-year-old man who was involved in a road traffic accident in the early hours of the morning. I met him several hours later at the start of my dayshift in the ICU. Immediately, it was suspected that Matthew had suffered a significant head injury and the medical team planned to carry out brain stem testing later that day. Unfortunately, the tests concluded that Matthew had sustained a brain stem injury and he was pronounced brain stem dead. This meant that he would no longer be able to breathe for

himself when removed from the ventilator. Matthew was pronounced dead at this point, despite his heart beating and the ventilator providing breathing.

Matthew's family consisted of his mum, two sisters and fiancée. They were shocked and devastated. They had to process a significant amount of information in a short space of time, while being sleep deprived from spending the night at the hospital. It was exceedingly difficult to witness this family's grief. Even as a healthcare professional, it was challenging and confounding to look at Matthew's healthy, young body in the bed and accept that he was dead.

Active treatment had to be withdrawn, as this artificially keeps the patient breathing when their body is unable to on its own. This had to be carefully and sensitively communicated to the family, as they needed to be prepared for what would happen next.

Before the ventilator was switched off, the cables which connected to the monitor were removed from Matthew's body; observations of vital signs were no longer necessary. Matthew's body was brought closer to the edge of the bed, allowing space for another person to get into bed beside him for a cuddle. In turn, I helped each one of his family get into the bed beside Matthew and made sure they were comfortable before leaving them alone, closing the door behind me. After each person had had their private time with Matthew, the ventilator was stopped. Matthew's family stayed with him until his breathing ceased. Matthew's fiancée had bought a teddy bear from the hospital shop; she did not want Matthew to be on his own and requested that the bear be always kept by his side.

This experience took place approximately 15 years ago and has had a profound effect on me. It remains to this day one of the most emotionally challenging and proudest moments of my nursing career. I could not change the fate of Matthew's death, but I could support his family to say goodbye. With certainty, I believe if another member of staff had looked after Matthew and his family that day, they would not have been given the opportunity to get into bed for a cuddle. Reflecting on this experience, I genuinely believe that Matthew's family would have appreciated, valued and been comforted by the process. I believe they would understand first-hand the value of the memory-making resources and bereavement support we now offer to families in critical care.

The experience of Matthew's death has influenced my nursing practice. It has inspired me to consider other ways to support bereaved families in critical care, which contributed to

the development of the Bereavement Support Team at the QEUH. It is a reminder of how vulnerable bereaved families are and the importance of good quality nursing care at such times.

1.5.2 Bereavement support services within critical care at Queen Elizabeth University Hospital, Glasgow

The Queen Elizabeth University Hospital (QEUH) in Glasgow opened in 2015 following a restructuring within NHS Greater Glasgow and Clyde health board. There was an amalgamation, which saw the closing of the Western Infirmary and the Victoria Infirmary and the relocation of the Royal Hospital for Sick Children to the new QEUH site. The QEUH is the largest health board in the UK and now one of the largest hospital campuses in Europe.

The state-of-the-art Critical Care Department at the QEUH consists of six units: three ICUs, two surgical high dependencies and one medical high dependency. In 2016 a small group of nursing staff working across the Critical Care Department created a working group to improve end-of-life care, and developed the Bereavement Support Service. The service includes offering memory-making resources at end of life, providing a condolence card and support documentation at time of death, posting a three-month follow-up letter and an invitation to attend a yearly remembrance service. It is a nurse-led service consisting of five nurses, with support provided by our medical team when families wish to return for a bereavement follow-up meeting. The follow-up meetings are attended by the family, a nurse from the Bereavement Support Team and a consultant from critical care. The hospital chaplain works with relatives who need further support by providing a talking service.

Memory-making is offered as part of bereavement support within critical care and includes taking handprints, family finger tree prints, tags for writing personalised messages, organza bags for hair locks/jewellery, and teddy bears. One teddy bear stays with the deceased, and the other(s) go home with the family, helping to create a continued bond (Klass et al., 1996, Klass, 2006). Here are four case examples of the support provided to the dying patient and their families at the QEUH.

Case 1: One of my nursing colleagues provided anecdotal evidence about memory-making resources with a 34-year-old man in ICU. The patient's wife expressed extreme gratitude for the teddy bears she received with her husband's finger prints on a tag, attached around

their necks. She felt the teddy bears would be a helpful way to try to explain to her three-year-old twins that their dad had died.

Case 2: During one Covid-19 lock down period, I offered the sister of a patient who had died the opportunity to take home a keepsake, as a physical reminder of her brother. As her brother had long hair and it was something he had been very proud of, she took away six locks of hair, some for his sons who could not be at their father's bedside when he died. The hospital visiting restrictions only allowed one person to visit when a patient was receiving end-of-life care.

Case 3: I had the pleasure of looking after Anne, an elderly lady in her eighties. Anne's chest infection made her short of breath and she required HDU care. Anne's grandson had power of attorney and together as a family they had conversations regarding Anne's wishes if she was to become unwell and was no longer able to make decisions for herself. After a few days of antibiotics and oxygen therapy, she improved and enjoyed a couple of good days in the company of her family, sharing lots of laughter, and even managed with the help of her grandson to do her last Christmas shopping online for her family.

Case 4: A couple wished to get married, but they did not think it was possible because of Covid-19 restrictions. However, due to a cancellation, the celebrant was able to marry the couple with only a day's notice. Despite the short notice, John's fiancée managed to organise wedding outfits, decorations and music, with the help of family and friends. The wedding took place in HDU, with John in bed. John was transferred to a hospice a couple of days later, with his new wife by his side

Families who have engaged with such memory-making opportunities report taking comfort from the keepsakes and appreciate them being offered. Anecdotal evidence therefore suggests this additional mechanism of support helps create a more compassionate culture, improve nurse-family relationships and encourage family involvement at end of life.

Aileen Labram (charge nurse) is another member of the Critical Care Bereavement Support Team at the QEUH. We have both been funded to undertake a Masters by Research at the University of Glasgow, as part of a service evaluation of the bereavement service currently offered to families whose loved ones die in the Critical Care Department at the QEUH. We discussed how to evaluate two different components of the service. Aileen's research is titled *Process Evaluation of a Bereavement Follow-Up Programme in Critical Care at the*

Queen Elizabeth University Hospital, Glasgow. I have chosen a purely qualitative piece of research exploring bereaved families' experiences of memory-making in critical care.

1.6 Covid-19 impact

The global pandemic of coronavirus disease (Covid-19) was first identified in China in December 2019 and reached the UK in late January 2020. The pandemic has caused an abrupt rise in mortality rates and four million deaths globally (Verdery et al., 2020), and is the leading cause of death among men and the second most common cause among women in England (Iacobucci, 2021).

As a result grief and bereavement care has been brought to the forefront of people's attention (Selman, 2021). Bereavement during a pandemic has additional challenges and burdens on families and communities, such as the isolation of terminally ill patients without the presence of loved ones, the occurrence of sudden and unexpected deaths, the restrictions on funerals and consequent further social isolation for bereaved families and individuals (Stroebe and Schut, 2021). Attendance at funerals was severely restricted, with a maximum of ten people allowed. There has been an impact on informal social support as people's freedom of movement and social interaction were restricted, which has prevented people from physically being together.

During the first wave of Covid-19 (March 2020) the Bereavement Support Service at the QEUH was immediately suspended, due to the overwhelming pressures and demands associated with unprecedented levels of Covid-19 infection and illness. The Bereavement Support Team feared they would be overwhelmed with demand but more importantly would be unable to offer sufficient support to bereaved families. Visiting restrictions were introduced across Greater Glasgow and Clyde hospitals with only one relative able to visit a patient if they were receiving end-of-life care. Both the lack of visitors and the increased pressure on critical care during the pandemic meant that families and staff were not engaging with memory-making in the same way, mainly due to infection control risks and lack of family presence. The pandemic has also had a significant impact on the emotional and physical well-being of front-line workers. Some of my nursing colleagues have shared stories of setting up video conferencing and holding the telephone to the patient's ear, in their final moments, in order for their loved one to say goodbye. "Clinicians experience extraordinary pressure multi-tasking care while holding mobile devices, listening to one-sided conversations" (Curley et al., 2020, p.1974). These are examples of embracing

technology to enable goodbyes, when families could not be physically together. Since the pandemic, delivery of bereavement care has changed, as telephone and video have become the primary mode of communication and support (Curley et al., 2020, Pearce et al., 2021). These new approaches to communication may not always be achievable, nor appropriate, as some families may find them too distressing (Fusi-Schmidhauser et al., 2020).

Covid-19 has affected this study, through both the increased physical and emotional demands at work and cancellation of all study leave. Despite feeling “heavy” at times, it is perhaps a pertinent time to conduct a study concerned with bereavement care. It provides an opportunity to hold open discussions and review bereavement policy and practice. The pandemic has therefore disrupted our usual experiences of grief, and has modified the ways in which we support grief (Wallace et al., 2020). The resulting impact on bereavement support services also reminds us that as human beings we are profoundly social and seek connection in difficult times, such as during a bereavement. What is clear is how deeply the absence of this connection has been felt by patients, healthcare professionals and communities.

1.7 Chapter summary

This introductory chapter has described the critical care environment and how families may experience the death of a loved one within this setting, including the particular challenges it poses, such as sudden and unexpected death in a highly technical environment. The researcher’s clinical background and first-hand experience of providing end-of-life care and bereavement support in critical care have been explored. These clinical experiences offer a fuller picture of how initial bereavement care is delivered to families at the bedside, and give context to how it may be experienced and what it might mean to bereaved families. The impact of Covid-19 on bereavement care has also been acknowledged. In the following chapter, bereavement and grief will be discussed in more detail, including bereavement care, policy and service provision in Western countries and cultures, and in particular in Scotland. Memory-making and bereavement care will be discussed in greater detail.

Chapter 2: Bereavement care

2.1 Introduction

Chapter 1 described death and dying in a critical care environment and the particular challenges this poses for bereaved families. This chapter focuses on bereavement as well as bereavement care, including how best to support bereaved individuals and families. In order to do this, the chapter begins with an overview of bereavement, grief and the grieving process, since this underpins the reaction to death and loss. This includes a brief review of traditional and contemporary grief theories, policies and practices and how these have influenced the bereavement experience over time. The chapter will then use this literature as a basis for discussion of a relevant theoretical framework to guide this thesis, and will conclude with a summary of current bereavement care in critical care.

2.2 Bereavement and grief

Bereavement is an unavoidable human experience, yet we do not all experience bereavement in the same way (Payne, 1999). Due to individual differences in cognitive and emotional processes, beliefs and values, our experience of bereavement will be a very personal one, further shaped by social norms and cultural values (Wimpenny et al., 2012).

Grief is the emotional and/or physical response to any kind of loss (e.g. death, relationship, health, job, finance, dreams, etc.) and therefore can be experienced multiple times during a person's lifetime (Payne, 1999, Wimpenny et al., 2012). Emotional symptoms of grief may include emotional numbness, yearning, anger, despair and acceptance (Arizmendi and O'Connor, 2015). Deeper psychological responses may include sadness, depression, high/sustained levels of anxiety and fear of uncertainty, thus potentially having an adverse effect on well-being. This can result in a physical response strong enough to result in fatigue, loss of sleep, changes in eating patterns and an increased vulnerability to infections and other diseases (Worden, 1991).

Bereaved individuals may experience any number of the symptoms of grief in no particular order and for no set duration as the intensity of individual experience varies (Arizmendi and O'Connor, 2015). The intense longing for the deceased individual is proposed to typically reduce over time as the bereaved individual comes to terms with the finality of their loss and integrates this acceptance into their daily life (Arizmendi and O'Connor, 2015). Others may even experience a positive outcome as a result of bereavement. It has

been estimated that a small proportion of bereaved individuals experience personal growth, an increase in resilience, and a heightened awareness and empathy for others (Gillies and Neimeyer, 2006, Jakoby, 2012). However, there are exceptions whereby, for some people, grief may never be over and they are unable to recover from it (Klass et al., 1996). This has been labelled as prolonged grief disorder (PGD), whereby emotional and/or physical dysfunction continues for very long periods of time following a significant loss (Prigerson et al., 2009, Lundorff et al., 2017). PGD is associated with up to 52 percent of individuals experiencing ICU bereavement (Selman et al., 2020). Risk factors for developing PGD include lack of preparation for death and family members not being able to say goodbye (Pattison et al., 2020).

2.3 Theoretical approaches to grief

Healthcare professionals need to understand grief and the grieving process in order to provide adequate and effective bereavement care and interventions. Classical or traditional grief theories/theorists centre on the resolution of grief and detachment from the deceased, and working through grief in discrete sequential phases, ending with a phase of resolution (Freud, 1957, Worden, 1991). Freud (1957) offered the first major grief theory: “grief work” is very prescriptive in nature, involving the process of breaking ties from the deceased. This theory profoundly shaped professional intervention in bereavement. The aim of Freud’s model was to help the person “move on” and return to a level of normal functioning as quickly as possible (Hall, 2014). However, many years later, following the death of his own daughter, Freud came to recognise the long-term nature of grief, most notable in his persisting strong sense of connection with her.

Contemporary theorists (Klass et al., 1996, Stroebe and Schut, 1999) focus on transforming relationships with the deceased, viewing bereavement as an active and dynamic process rather than the fixed structure and sequential process espoused in traditional grief theory (Payne, 1999). Attachment remains one of the most important aspects of contemporary approaches towards loss, bereavement and grief (Bowlby, 1980, Worden, 1991, Stephen et al., 2009). Despite grief being a normal response invoked by death or loss, it has been suggested that the intensity of grief experienced is dependent on the strength of the attachment with the deceased individual (Stephen et al., 2009). Outside of bereavement, attachment to other individuals helps us with basic needs such as security, love and safety. These attachments form from a very early age such as the attachment that develops between a mother and child. As with the negative impact when attachment is withdrawn or

broken between mother and child (Bowlby, 1980), the strength and nature of the attachment to the deceased and the attachment style of the survivor may have an equally profound effect on the individual's grief intensity (Hall, 2014). As previously stated, this can be compounded by circumstances of death, for example, where traumatic or violent death may pose more complex or intense challenges for the bereaved. In addition, the works of Worden (1991, 2009) have had a powerful influence worldwide, through his research and understanding of responses to life-threatening illness and behaviours in individuals who have a strong desire to willingly participate in and/or plan their own death. His recognition of individual differences, in terms of how death is perceived and the individual's response to it, led to his four tasks of mourning and six task mediators, including awareness of the importance of finding an enduring connection to the deceased while embarking on a new life without them (Worden, 2009). His resulting development of grief therapy has meaningful relevance to the concept of "memory-making" (Worden, 1991) in contemporary bereavement care, and with "meaning making" in contemporary grief counselling (Neimeyer, 2001), both driven by a need to create a sense of purpose or meaning.

The dual process model of coping (Figure 2.1) proposes that the grieving individual moves or will "oscillate" between loss and restoration, such that the period of restoration sees the grieving person switch focus onto other activities to provide a break/temporary relief from their grief (Stroebe and Schut, 1999). One can assume that in the short term this is part of typical adjustment and thus manageable. However, over the longer term it may be considered less normal since a person is stuck continually in this oscillation between two extremes, which has been reported as an exhausting struggle to overcome (Stroebe and Schut, 2010). Like Worden's grief model, the dual process model also considers the influence of other mediating factors on the bereavement process such as financial, employment or parenting concerns.



Figure 2.1 The dual process model of coping with bereavement
(Stroebe and Schut, 1999, p.213)

The development of attachment theory, individual differences and continuing bonds with the deceased in understanding bereavement has gradually emerged over time, from the traditional to contemporary theories and models of grief and bereavement. The current concept of the continuing bond or sense of inner relationship with the deceased individual (Klass et al., 1996, Klass, 2006) focuses on adjustment as opposed to detachment or oscillation. In contrast, this proposes the bereaved person slowly adjusts and redefines their relationship with the deceased (Klass et al., 1996), thus continuing their bond or keeping their relationship alive in a socially constructed sense (Valentine, 2008). This is achieved by reminiscing about the deceased and their life through the medium of storytelling, memory and keepsakes, internalising values or beliefs held by the deceased, to even holding imagined conversations, feeling their presence and performing activities in honour of them (Klass et al., 1996, Davies, 2004, Root and Exline, 2014). In the past, and according to early theories of grief, this would be considered a maladaptive response and a refusal of the bereaved person to accept the reality of the death (Root and Exline, 2014).

Furthermore, it is important to recognise that individual response can also be mediated by culture or other defined social constructs and their respective approaches to the acknowledgement of death and grieving. This is defined by Doka (1999) as a “disenfranchised grief” that is “not openly acknowledged, socially validated or publicly observed” (Doka, 2002). Examples of disenfranchised grief (Doka, 1999, Doka, 2002) can

be associated with relationships (divorce), loss (perinatal death and stillbirth), failure to see some individuals as capable of grieving (learning disabilities), stigmas (suicide, AIDS) and societal or cultural rules and rituals (open displays of grief or restricted/no display of grief).

However as both traditional and contemporary theorists suggest, knowing and remembering the person who has died continues throughout the remainder of the survivor's entire life to some degree or another (Klass et al., 1996). Therefore, one could argue that the social, behavioural and spiritual dimensions may best be accommodated in models which allow the bereaved person an active role in their grief. The continuing bonds model involves a non-linear, non-prescriptive approach that fosters long-lasting change but with potential for adjustment when necessary. Memory-making is a set of practices which links the processes of end-of-life care, death and dying, and bereavement and grief, and is founded on the idea of continued bonds with the deceased. Memory-making also links the three parties involved – the patient, the family and the nursing staff – and acknowledges each bereavement as a unique event involving a distinct set of familial and social relationships.

Grief theories have been discussed in order to understand the processes of bereavement and grief, and support services currently available to bereaved families. It is now important to consider a nursing model with which to successfully deliver bereavement care, and in particular memory-making in critical care. We now turn to a nursing model which might be most appropriate to bereavement care and the delivery of memory-making provision in critical care.

2.4 Humanistic nursing model

Nursing models incorporate fundamental concepts, values and beliefs about contemporary nursing. A theoretical framework provides a systematic and knowledgeable approach to nursing practice; it can therefore assist critical thinking when planning and providing nursing care (Masters, 2014). There are four central concepts of the nursing discipline: person (human being), environment, health and nursing (Masters, 2014). Many models or approaches to nursing look at the patient as a whole person rather than simply an illness or injury. These are considered holistic and humanistic approaches, addressing the patient's psychological and spiritual needs, as well as their physical needs.

A humanistic approach was chosen as an appropriate theoretical nursing model to underpin this research as it considers all humans: patient, family and healthcare professionals. There is no nursing experience that cannot be considered in terms of this theory (McCamant, 2006). For example, if patients are unresponsive (anesthetised, sedated or intubated), the nurse–patient relationship as experienced by the nurse, and in these circumstances the role of the nurse, expands to encompass significant others (McCamant, 2006). The humanistic nursing theory is therefore flexible and suitably applicable to end-of-life care. Paterson and Zderad (1976) described the universality of the act of nursing, making it a multicultural theory (McCamant, 2006). Therefore, the humanistic nursing theory offers “almost boundless diversity of human experience, and its breadth encompasses the full nature of nursing as a human interaction” (McCamant, 2006, p.335).

The humanistic model of nursing views the patient as an individual, and each situation as unique. Each patient is assessed and treated on a case-by-case basis. It is a holistic approach to nursing which stresses the importance of viewing – and treating – the patient as a whole person rather than an illness. Such an approach encourages and supports a gestalt view of the patient in relation to their personal, familial and social contexts (Paterson and Zderad, 1976). A holistic and humanistic approach to nursing is appropriate in critical care as end-of-life care, bereavement and grief are complex processes which involve – and profoundly affect – not just the patient and nursing staff but also the patient’s family and loved ones.

The humanistic nursing theory described by Josephine Paterson and Loretta Zderad (Figure 2.2) illuminates values and meanings central to nursing experiences and embraces the dynamics of being, becoming and change (Parker, 2005). It acknowledges that the nurse has become a nurse through choice and has made a commitment to help others with health-related needs. Nurses open themselves up to the unknown; they have the ability to relate to others, to wonder, to search and to imagine about others’ experiences (Parker, 2005).

Paterson and Zderad (1976) described five phases of nursing:

1. Preparation of the nurse coming to know: The nurse acts as an investigator, approaches with an open-mind and is willing to experience anything.
2. Nurse knowing the other intuitively: The nurse tries to understand the other.

3. Nurse knowing the other scientifically: The nurse is an observer and can analyse from the outside. The nurse goes from intuition to analysis.
4. Nurse complementarily synthesising known others: The nurse as a source of knowledge, to continually develop through education and increased understanding of their own experience.
5. Succession within the nurse from the many to the paradoxical one: The nurse works towards resolution.

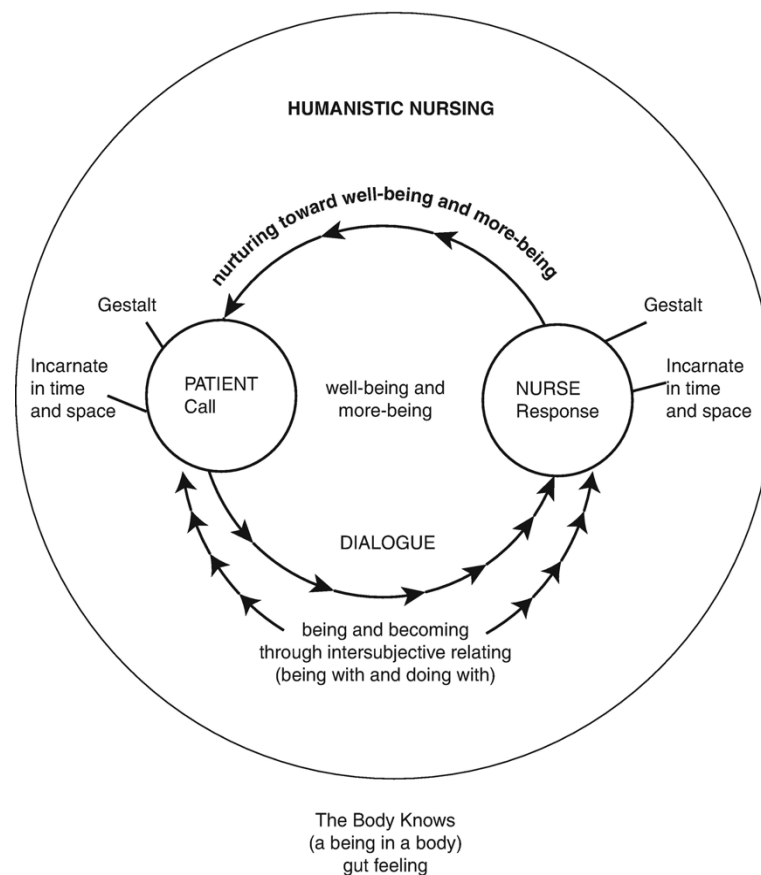


Figure 2.2 Humanistic nursing theory (Paterson and Zderad, 1976)

Humanistic nursing theory is multidimensional. It is a shared human response, as the nurse, patient and family members are seen as unique human beings with their own gestalt. Gestalt represents all that human beings are: past experiences, current being and hopes, dreams and fears for the future are experienced in one's own space–time dimension (Kleiman, 2010). In humanistic nursing, each person is perceived as existing “all at once” (Kleiman, 2010). It can therefore offer humanity in the highly technical critical care environment and encourages a continued focus on the patient as a whole individual, rather than a set of medical challenges. It supports the importance of caring and empathy as

patients receive end-of-life care and families receive bereavement care before, during and after the death of their loved one.

Such an approach, which considers the complex and unique set of links between nurse, patient and family, and acknowledges the time dimension of relationships, is appropriate for nursing in critical care, particularly in regard to end-of-life care and memory-making practices. Memory-making is a set of practices which explicitly works with the relationships between the patient and family and considers these relationships as having not only a past but also a future, which will continue beyond death. Memory-making practices also require that the nurse maintain close relationships with both the patient and the family and engage with them as unique individuals and a social group, with complex experiences and needs beyond the purely medical. The successful implementation of memory-making practices in critical care would therefore likely be greatly facilitated by a humanistic approach to nursing. The multidimensional nature of the humanistic approach to nursing is also felt to be appropriate to the models of grief and bereavement used in this research, which emphasise a non-prescriptive and non-linear approach to grief, and acknowledge the complex relationships between dying, death and grief, and the continuation of relationships and attachments beyond death.

Paterson and Zderad's (1976) humanistic nursing theory has been selected as the theoretical underpinning of this study, as it was considered to be appropriate for nursing in critical care, and also providing end-of-life and bereavement care. The theory emphasises a holistic approach, and values the caring, empathy and significance of a shared patient–nurse relationship (Wu and Volker, 2012). Each situation and circumstance is unique to the bereavement experience, as are the people involved. This suggests that when a nurse approaches bereavement and the bereaved individuals with an open, genuine attitude, this will benefit both the nurse and the bereaved individuals, helping to instil comfort. Recognising that life is finite, and we and those we love and care for will all face death eventually, ought to encourage the staff to provide their best efforts to ease the suffering of others experiencing distress and pain.

2.5 Memory-making

Historically, memorial objects such as mourning rings were common in Victorian times, as were jewellery pieces incorporating hair of the deceased person (Parkin, 1999, Renken, 2021)

Winnicott's seminal work *Transitional Objects and Transitional Phenomena* (1951) identified transitional objects as items which were selected by an infant for comfort, and to support the developmental stages of separating from their primary caregiver (Wakenshaw, 2020). For example, an infant may have a blanket or soft toy which provides comfort and safety when they are separated from their primary care giver (Goldstein et al., 2020, Wakenshaw, 2020). This concept links back to attachment theory. Grief has also been theorised as a manifestation of attachment (Bowlby, 1982, Shear and Shair, 2005). The use of keepsakes by bereaved individuals and transitional objects by infants can therefore be seen as rooted in similar fundamental processes: both act as ways to provide comfort in the separation from a person to whom we are significantly attached. As Gibson has commented, "Transitional objects are both a means of holding on and letting go" (Gibson, 2004, p.288).

Prior to the introduction of the concept and practice of memory-making in the 1970s, the remains of fetuses who died in utero or in the neonatal period were crudely disposed of since neither religion nor the health establishments provided them with a memorable identity (Payne, 1999, Hallam and Hockey, 2001, Carlson, 2012, Blood and Cacciatore, 2014), thus denying a proper burial or grieving experience as would occur in any other bereavement loss (Field et al., 1997, Brownlee and Oikonen, 2004). As a result, there was no birth certificate for stillborn babies, only a certificate of disposal of their remains, and even this documentation denied identity since there was no space on the form to record the baby's name given by the parents. Because of this "non-person" status, parents were prevented or discouraged from seeing or holding their dead baby as this was perceived to be in their best interest and to help them forget about their loss (Brownlee and Oikonen, 2004, Blood and Cacciatore, 2014). This approach neglected the physical and emotional responses of women and prevented them from receiving support (Brownlee and Oikonen, 2004).

To help achieve this, there was a "rugby-pass" approach in managing stillbirths whereby the stillborn baby was quickly "caught" after delivery and "back-passed" out of the delivery room to another catcher who would hide it out of sight (Lewis, 1979, p.305). As a result, Lewis (1979) campaigned for change, which led to recommendations for parents to have a more active role and allow them to make memories: for example, to meet and name their stillborn baby, spend time with them, dress them and have photographs, and be able to register the baby's birth. Five years on, however, Lovell (1983) reported that over half of bereaved mothers in his study never saw or held their stillborn child, in part because the

women trusted and relied on the healthcare professional to direct them, and when the mother wanted to see her baby it was implied it would be best not to, with one member of senior nursing staff commenting, “When it goes wrong, we prefer her to be on her own. Everyone finds it difficult to talk to her. Nobody knows what to say. What can one say? The staff feel that she is blaming them. We try to get them home as quickly as possible, into the community” (Lovell, 1983, p.757). This research highlighted how much depended upon the beliefs of staff on duty and their personal discomfort of being around bereaved families, which took precedence over their role of supporting the bereaved parents. However, it should be noted that there was little or no formal training and education in this transformational period.

Memory-making interventions were introduced in perinatal end-of-life care with the aim of improving parents’ experience of bereavement through providing “active physical contact and the creation of visible mementoes to aid and facilitate recovery from loss” (Elklit and Björk Gudmundsdottir, 2006, p.317). In 2008, one multinational study reported that the vast majority of mothers got to see (95 percent) and hold (90 percent) their stillborn child (Cacciatore et al., 2008).

A scoping review of memory-making in bereavement care for new born babies identified five recurrent themes across the 25 publications: contact with the new born, opportunities for caregiving, bereavement photography, collection and creation of mementos, and guidance in memory-making (Thornton et al., 2019). International perinatal and neonatal palliative care and bereavement guidelines recommend supporting parents to make memories with their babies in this way (Australian College of Neonatal Nurses, 2010, British Association of Perinatal Medicine, 2010, National Institute for Health Care Excellence, 2016, Perinatal Society of Australia and New Zealand, 2018).

The concept of memory-making has since been extended to other areas where patients are approaching the end of life such as adult critical care, with the aim of providing a tangible keepsake or memento for families following the death of a loved one (Riegel et al., 2019). Examples of tangible reminders are finger prints, items of clothing and locks of hair (Gibson, 2004). Keepsakes promote feelings of connectedness with the deceased in the same way they do for parents experiencing perinatal or neonatal deaths (Riegel et al., 2021). Such keepsakes can be displayed at home (as photos or handprints often are) or actively shared with family and friends, and may function as a prompt to storytelling and reminiscing (Riegel et al., 2019).

Memory-making also creates space and time, enabling families to spend meaningful time together before and after death: for example, by providing a private room in which the patient and family are afforded privacy for end-of-life care, and space for intimate closeness to cuddle, read poetry or prayers, play music, have intimate conversations, or even provide caring activities such as hair, mouth and eye care. Practical examples of memory-making practices can therefore include:

- Time spent with family and friends
- Shared activities
- Making, collecting and/or shared viewing of photographs and videos
- Creating hand and footprints in plaster or ink
- Keeping locks of hair
- Gathering comfort objects, such as special items of clothes and jewellery
- Carrying out rituals, such as the planting of a tree.

A recent service evaluation of ICU bereavement care in the UK identified nurses' pride and sense of achievement from providing individualised care at the end of a patient's life through such acts as bringing pets into the ICU, arranging weddings and taking a ventilated patient home for the day (Harris et al., 2021). Providing these memorable opportunities allows the patient and their families to spend meaningful time together and create positive memories at the end of the patient's life.

Anecdotal evidence suggests that families are appreciative, but there remains limited evidence-based research which has evaluated memory-making experiences for families in critical care. Memory-making may support bereaved families' continued bonds with their loved one. It promotes meaningful interaction between families and the creation and collection of physical reminders of the loved one in the form of tangible keepsakes. The keepsakes may play a significant role in coping with loss (Root and Exline, 2014), as the family feel connected to their loved one through the tangible keepsake. A recent scoping review of memory-making in adult ICUs identified seven publications describing four types of memory-making objects: word cloud images, electrocardiogram mementos, patient diaries and the use of photographs within the diaries (Riegel et al., 2019).

Keepsakes were recognised in bereavement guidelines following Covid-19 (Selman et al., 2020). Similarly, during the pandemic, NHS Greater Glasgow and Clyde health board incorporated memory-making into general end-of-life care. The "From the Heart"

campaign was launched in April 2020. A public appeal was launched to ask the community to knit pairs of hearts. A knitted heart was offered to bereaved families, and the matching heart was kept with their loved one. The knitted hearts were small tokens of comfort to help families feel more connected when they were unable to visit due to restrictions (Johnston and Blades, 2020).

Memory-making has featured in the bereavement literature within critical care. However, few studies identify memory-making interventions as their primary focus. As a result, the evidence underpinning memory-making in end-of-life care is scattered throughout the literature, impacting its availability to clinicians and policymakers. In addition, those studies that reported memory-making interventions provided limited detail. This has meant that evidence specific to memory-making practices has lacked the depth and quality required to guide clinicians and impact healthcare policy.

2.6 UK bereavement policy and service provision in Scotland

Grief, loss and bereavement are encountered frequently in hospitals and other healthcare facilities yet historically bereavement care has been mostly targeted to cancer care, palliative care and hospice settings (Stephen et al., 2009). Approximately 70 percent of all deaths occur in institutions, with 15 to 20 percent of deaths taking place in intensive care settings (Buckley et al., 2015). A Healthcare Commission report in 2007 found that bereavement care in acute hospitals was ad hoc and poorly performed (Stephen et al., 2009). This may have been because death is not a subject people have traditionally felt comfortable discussing openly. The introduction of hospices as a dedicated facility to care solely for the dying patient with cancer and other terminal conditions may have been the genesis of more open discussion. A British survey into social attitudes towards dying (2012) found that while 70 percent of people said they were comfortable talking about death, less than half (43 percent) discussed their wishes around dying, and only a tiny percentage (5 percent) had prepared advance care plans (NatCen, 2012). Reluctance to talk about death and dying make it more difficult to prepare relatives for death.

Strategic policy documents and policy papers such as *Shaping Bereavement Care* (2011) and *Living and Dying Well* (2008) directly acknowledged there was a need to increase acceptance of death and dying, and since then work has progressed to encourage and support discussions around death in our communities. For example, *Good Life, Good*

Death, Good Grief (Scottish Partnership for Palliative Care) and the Good Grief Trust² are UK support services run by the bereaved for the bereaved in the community. Their focus has been not just to support discussion but to actively support communities and individuals through death, dying and bereavement.

Fourteen specific recommendations and key principles were set out in the policy document *Shaping Bereavement Care: A Framework for Action* (Shaping Bereavement Care, 2011) to help guide nursing care for bereaved individuals. However, this policy is over ten years old and in that time many things have changed, such as the impact of the recent Covid-19 pandemic, and a rapid, drastic change in the needs of dying patients, bereaved families and entire communities. Three of the 14 most relevant recommendations in relation to critical care will be discussed below, from the researcher's perspective as a clinical nurse, whose role regularly supports death, dying and bereavement.

Recommendation 4: "Each board should develop a policy on care of those who have been bereaved" (Shaping Bereavement Care, 2011, p.3).

The policy seeks to recognise that people who have been newly bereaved may need to raise questions following a death and should be provided opportunities to do so. Bereavement follow-up is part of the Bereavement Support Service available in critical care at the QEUH. The service has been developed by a dedicated group of nursing staff, who have received limited formal support in terms of hours and protected time to deliver this service. A Danish study also highlighted that the provision of family bereavement follow-up care was driven by the goodwill of individual practitioners (Egerod et al., 2018). It has been extremely challenging during the pandemic to continue to run the service, on top of the additional requirements and adjustments needed to cope with Covid-19. The researcher is not aware of any other formalised bereavement service within the QEUH, one of the largest purpose-built hospitals in the UK.

Recommendation 7: "Each board should review its staff support structures to ensure that support is available for staff who are distressed by experience of death or trauma, and those who experience personal bereavement. Arrangements for debriefing should be reviewed in

² <https://www.thegoodgrieftrust.org>

critical care areas such as intensive care and accident and emergency” ((Shaping Bereavement Care, 2011, p.4).

The researcher has no experience of formalised debriefing sessions, and they are not available in critical care at the QEUH. Often when a patient dies, the bedspace is quickly occupied by another patient, and therefore the nurses’ focus changes from dealing with a death and bereavement to admitting another critically ill patient. Appropriate staff training is required to support debriefing sessions for healthcare professionals, or staff trained in debriefing should be brought in. Also, extra resources may be required for staff to attend debriefing sessions during their working hours.

Recommendation 10: “NHS Education for Scotland should explore the development of training and education resources to support health boards in the task of training staff across the workforce in bereavement awareness and bereavement care” (Shaping Bereavement Care, 2011, p.4).

Support Around Death³ is an online resource to support health and social care staff working with families before and after death. The website consists of short videos regarding specific tasks, for example, providing guidance on how to approach difficult conversations, such as breaking bad news or talking about a patient’s prognosis. Traditionally, these conversations are delivered by medical staff. None of the videos are specific to the nursing role or in particular how to provide end-of-life care to patients while caring for their family simultaneously. The videos may be a form of effective education but they cannot replace face-to-face teaching (human connection) and the opportunity this provides for discussion around such sensitive and highly emotive conversations and circumstances.

Work has been done to address these recommendations within the bereavement policy; however, there remain opportunities to improve the service provision. Scotland would benefit from an updated bereavement policy which considers the impact of Covid-19 in relation to healthcare delivery and the changing behaviour of the general public in terms of how they access healthcare (National framework for the delivery of bereavement care,

³ <https://www.sad.scot.nhs.uk/>

2021). This leads us now to consider levels of bereavement support individuals may require and the support services which are currently available.

2.7 Levels of bereavement support

It is important to note that not all bereaved individuals will require formal bereavement help and counselling (Stephen et al., 2009, Penny and Relf, 2017). Therefore, every death being a unique experience means bereavement care will be dependent upon the individual circumstances and reasons for death, and will require varying approaches to have meaningful and worthwhile emotional engagement with families and practical benefit (Wimpenny et al., 2012).

The public health model of bereavement support (Aoun et al., 2012, Aoun, 2020) advocates for the collaboration of formal and informal bereavement support (informal support, community support and professional support), to provide a three-tiered approach (Aoun, 2020). The public health model predicts around 40 percent of bereaved people require formalised support (community 30 percent, professional 10 percent). Many bereaved individuals likely have access to a range of supportive community interventions, such as family support, support groups, internet communities (such as Facebook groups) and telephone helplines (Harvey et al., 2008). Therefore, it is neither essential nor cost-effective to offer such support to everyone (Aoun et al., 2012), but better to focus on optimising the bereavement care experience for families, building resilience in communities, and achieving better levels of satisfaction with care provision. Thus, when planning bereavement support interventions, it is important to know about family and individual connectedness, continuing bonds and attachment (Stroebe and Schut, 2010).

The Faculty of Intensive Care Medicine (2019a) recommended family involvement in end-of-life care, to help prepare families for bereavement. Bereavement services were highlighted as being invaluable in order to support families' understanding of death within a critical care environment (Pattison et al., 2020). A UK national audit conducted in 2017 found that the majority of ICUs (96 percent) provided written bereavement information (Berry et al., 2017); however, 27 percent of ICUs failed to meet the Intensive Care Society's (1998) recommended guidelines for bereavement care. There have been many criticisms of bereavement care services in the UK: for example, a lack of reference to bereavement care in the Faculty of Intensive Care Medicine's 2019 *Guidelines for Provision of Intensive Care Services* (Berry et al., 2017, Harris et al., 2021), no focus given

to bereavement pathways or up-to-date recommendations in ICU (Harris et al., 2021), and the low priority afforded to bereavement care within healthcare policy and practice (Pearce et al., 2021). A recent rapid evidence assessment of bereavement support in the UK (Hewison et al., 2020) found that the provision of bereavement support was extremely varied and reported no conclusive evidence regarding the effectiveness of bereavement interventions.

Critical care bereavement support varies across the globe, and there is limited research into bereaved families' needs and how best to support families who have lost a loved one in critical care (Pattison et al., 2020). There is a further gap as despite the potential benefits of bereavement follow-up services there is currently no formalised critical care bereavement follow-up service anywhere in the UK (Pattison et al., 2020). Following up a bereaved individual in the same way as a patient is followed up in a clinical sense allows the newly bereaved to ask questions and understand the circumstances surrounding the death, share grief, and receive reassurance or referral for further support (Milberg et al., 2008).

A European survey into intensive care bereavement follow-up services (Egerod et al., 2019) found no standardised bereavement services, but identified some shared similarities across countries (viewing of the deceased's body in the intensive care unit; information on hospital-based support; viewing in the hospital mortuary; phone call from a nurse; condolence card or email; and general information on community-based support). In Sweden, most ICUs offer bereaved family members some kind of follow-up service although this varies, and there has been a general increase in the number of ICUs offering a bereavement follow-up conversation to families (Fridh and Åkerman, 2020). In contrast, an English survey found inconsistencies in bereavement care available within critical care, with 17 percent of units not offering any bereavement follow-up support (Berry et al., 2017).

An Australasia-wide ICU survey identified that bereavement services commonly offered memorial boxes, annual remembrance services and bereavement follow-up services (Coombs et al., 2017). However, research is yet to evaluate the effectiveness of bereavement follow-up in relation to family members' ability to cope with their bereavement (Milberg et al., 2008, Egerod et al., 2019).

A recent systematic review identified 14 papers evaluating nine bereavement support interventions globally (Efstathiou et al., 2019). Only Western countries were included

(Europe, Australia and New Zealand, United States); however, it is unknown if these interventions are transferable to non-Western culture. The most common support services offered are condolence cards or letters, meetings with medical staff and brochures on community/hospital bereavement services (Efstathiou et al., 2019). Other interventions include personal mementos, storytelling, research participation and use of a diary. However, the studies included in the review were small-scale studies that did not assess the effectiveness of any of the interventions.

2.8 Chapter summary

This chapter explored death, grief and bereavement. It discussed the impact of loss by death on individuals, and considered traditional and contemporary grief theories and how they help health professionals understand grief and how it may be experienced.

Highlighted were the limited evidence regarding how to best support bereaved people; the lack of a formal framework to deliver effective, evidence-based bereavement support; the lack of formal bereavement training/education; and the lack of clarity around who ought to provide it.

The impact of memory-making practices on families' long-term grief is unclear. Existing evidence indicates that bereaved families appreciate memory-making opportunities, whether that is through spending time with, and providing follow-on care for, family members, or creating/collecting keepsakes.

Contemporary grief theories focus on transforming relationships with the deceased and view bereavement as a dynamic and active process, which has significance for providing memory-making interventions for bereaved families. For example, families can be offered the opportunity to participate in creating memories and keepsakes during preparation for the final stages of their loved one's life in critical care. Understanding how families experience memory-making interventions is vital for providing appropriate support for bereaved families, and improves the quality of the beginning of their bereavement experience (Thornton, 2019). However, approaches to bereavement care often lack consistency as the support that bereaved people receive depends largely on the individual approach of the particular members of nursing staff.

Memory-making offers a potential way to approach bereavement support, but research into memory-making practices is limited. While there are recent scoping reviews of memory

making in critical care (Riegel et al., 2019, Thornton et al., 2019), these are overviews of the practices used, and do not explore families' experiences of them, or how they may impact grief and bereavement. The qualitative thematic synthesis presented here proposes an extended definition of memory-making, encompassing all forms of memory making practices, and aims to explore its impact on families' grief and bereavement through a thematic synthesis of existing primary research papers. As these studies are themselves qualitative studies, a qualitative thematic synthesis was felt to be an appropriate method through which to analyse them. It is hoped that this can offer a deeper understanding of the experience of memory making, and provide an evidence base from which to consider its development and more systematic use within critical care.

Chapter 3: Literature pertaining to the methods

3.1 Introduction

The research presented in this thesis was conducted to explore bereaved families' experiences of memory-making in critical care. This chapter presents the researcher's philosophical perspectives and the chosen methodology and research method for this study. The research utilised a qualitative evidence synthesis methodological approach, designed to answer the research question: *What are the experiences of bereaved families who engage with memory-making in critical care?* The thematic synthesis method and results are described in Chapters 4 and 5.

3.2 Philosophical assumptions

Paradigms are the way in which people view the world; they are composed of specific philosophical assumptions. Research requires a foundation for its inquiry, and this is provided in the form of worldviews and scientific paradigms (Gelo et al., 2008), which are lenses that help guide researchers to sharpen their focus on the phenomenon of interest (Polit and Beck, 2018). Paradigms represent the researcher's beliefs and values, and therefore they influence decisions made in the research process (Kamal, 2019). According to Lincoln and Guba (1985), paradigms consist of four elements: epistemology, ontology, methodology and axiology.

There are two broad paradigms which represent two world views: positivism and constructivism (also called the naturalistic paradigm). The positivist paradigm is dominant in quantitative research methods. Positivism is the study of society in a systematic and scientific way and involves inductive reasoning through observation, experiment, measurement, generalisation and finding patterns in the data (Ryan, 2018). Positivists believe that reality is the same for everyone. The researcher and those being researched are independent of each other when following a quantitative approach

The constructivist paradigm is dominant in qualitative research methods. In contrast to positivists, constructivists believe that knowledge is constructed from the interaction between individuals and their social world (Gelo et al., 2008), since these are not independent of each other. Consequently, this also means the existence of more than one single reality (Creswell, 2017). New knowledge is the product of the interaction between researcher and participants and thus requires closeness rather than distance from the people

or phenomenon under study (Holloway and Wheeler, 2010, Polit and Beck, 2018), and subjective rather objective observation. Interpretivism argues that truth and knowledge are subjective, whereas, realism believes in a world that exists outside the influence of the researcher (Ryan, 2018). Philosophical assumptions regarding the nature of this reality are therefore important in how the researcher makes meaning from the data (Kivunja and Kuyini, 2017). The researcher aligns herself with the constructivist paradigm, as she believes in multiple realities. For example, bereaved individuals will experience the death of a loved one and grieve in their own unique way. As discussed in Chapter 2, grief is also influenced by individuals' background and culture. There are many factors which influence dying, death and bereavement; therefore, there is no one reality as individuals and their circumstances are unique.

Ontological assumptions refer to beliefs about the nature of reality. This research is underpinned by relativism, as the researcher believes reality is socially constructed and multiple realities can exist (Braun and Clarke, 2013). Relativists believe that the world depends on how the individual views and experiences it (Ryan, 2018). Each patient and family will have their own perspective and experience of end-of-life care provided; this will also be influenced by their interactions with healthcare staff and previous experiences. This reflects the researcher's belief that there are multiple realities.

Epistemological assumptions are concerned with the nature of knowledge, and how we come to know the truth or reality (Kivunja and Kuyini, 2017). Epistemology influences the way researchers frame their research. From a positivist perspective, the researcher remains independent from the participants as the aim is to not influence the results. Researchers from a constructivist paradigm interact with the participants in the research and this interactive process is encouraged as it generates the data (Creswell, 2017). Researchers are inextricably part of the social reality being researched, i.e. they are not "detached" from the subject they are studying (Grix, 2018). The researcher believes that their role and the relationship between the researcher and the participant are essential to qualitative research. It is vital for the participant and researcher to connect and form a trusting relationship in order to draw out rich and in-depth data from the participants regarding their individual experiences.

Axiology is derived from the Greek *axios*, referring to value or worth. It refers to ethical issues that need to be considered within research studies (Kivunja and Kuyini, 2017).

Axiological assumptions reflect the researcher’s position and values within the study, which has an influence on the whole study.

Table 3.1 illustrates the researcher’s philosophical view for this study.

Table 3.1 The researcher’s philosophical view

Ontology	Relativism – reality is socially constructed and multiple realities can exist
Epistemology	Interpretivism – truth and knowledge are subjective
Paradigm	Constructivism – knowledge is constructed from the interaction between individuals and their social world
Theoretical underpinning	Humanistic nursing theory – views the patient as an individual and each situation as unique
Methodology	Qualitative – approaches seek to explore behaviour, feelings and experiences of people
Methods	Thematic synthesis – bringing together a body of research on a particular topic

3.3 Methodology choice and selection

Nursing research requires a wide range of methodological approaches to be able to fully investigate the diversity of service provision; three approaches to research are qualitative, quantitative and mixed methods (Creswell and Creswell, 2018). Quantitative research is formal and objective, requiring the reduction of a phenomenon to numerical values in order to carry out statistical analyses and test hypotheses (Grove et al., 2013). Quantitative researchers believe that there is one single reality, that all human behaviour is objective and measurable (Grove et al., 2013). As quantitative approaches are usually deductive and theory driven (Gelo et al., 2008), the researcher stays detached from their study as they try not to influence or potentially bias the findings (Grove et al., 2013). Since it is not possible to know a person’s values and influences during an encountered phenomenon, a quantitative approach would not be appropriate here.

Qualitative research on the other hand seeks to explore, describe and understand human experiences (Grove et al., 2013). According to Holloway et al. (2010, p.5), “The basis of qualitative research lies in the interpretive approach to social reality and in the description

of that lived experience.” Therefore, the researcher purposely selects specific participants in order to “collect the rich and in-depth data that can then become the basis for theorising” the phenomenon or experience involved (Holloway et al., 2010, p.4).

A mixed method approach involves the collection of both quantitative and qualitative data. Collection of different types of data by employing one or more methods provides a more detailed understanding of the research problem, as neither a quantitative nor qualitative approach alone will answer the research question (Creswell and Creswell, 2018). The research design does not have a particular set of philosophical assumptions, but selects the most relevant to answer the research question. Mixed methods research is often associated with a pragmatist paradigm. Pragmatists are open to any paradigm that best fits the research aims (Gelo et al., 2008).

A qualitative approach is considered best suited to explore bereaved families’ experiences of memory-making at the end of a loved one’s life in critical care. There are many diverse approaches for the collection and analysis of qualitative data and, although each one is based on a different philosophical position and/or comes from various disciplines, they do share some commonalities (Holloway et al., 2010). For example, each of them focuses upon human experience, and the researcher collects data and interprets the participants’ perspectives (Holloway et al., 2010).

3.4 Qualitative research

Qualitative approaches seek to explore behaviour, feelings and experiences of people (Holloway et al., 2010). They describes life experiences from the unique perspective of the person involved (Grove et al., 2013), and in doing so the significance of the human experience and the new insight which is the result of that can inform our nursing practice (Grove et al., 2013).

Qualitative researchers take a holistic approach, one which is flexible and observes the participants in their natural environment. Traditional qualitative methodologies such as phenomenology, grounded theory and ethnography are based upon a particular theoretical framework of procedures and techniques that inform qualitative research design (Thorne, 2016).

Phenomenology is concerned with understanding the “lived experience” of individuals (Speziale et al., 2011). Its roots are in philosophy and psychology, and it is an effective method for discovering a complex experience as lived by a person, and was considered a methodology which could be appropriate for this study.

Grounded theory was developed in the 1960s by two sociologists, Glaser and Strauss (Glaser et al., 1968). Their framework aims to develop explanations of phenomena by generating a theory supported by the data. Researchers start by collecting and analysing data without preconceived theories, since any preconceived ideas would prevent the development of new concepts emerging from the data; “The approach seeks to explain rather simply describe” (Holloway et al., 2010, p.175). Given that the purpose of this study was not to provide a new theory of how individuals engage with memory-making, but rather to offer an in-depth exploration of their experiences, grounded theory was rejected as a suitable methodology.

Ethnography’s traditions lie in anthropology and sociology, and it provides a framework to study patterns, lifestyles and experiences of a specific culture (Polit and Beck, 2017). It is concerned with understanding any number of people’s perspectives as well as interactions between the phenomenon, the individual and the environment in which it exists (Baillie, 1995). Ethnography researchers typically engage in extensive fieldwork, often participating in the life and culture under study (Polit and Beck, 2017). It is the researcher’s aim to explore bereaved families’ experiences of memory-making and not the cultural influence on the experience, so ethnography was not a suitable methodology for this study.

The traditional qualitative approaches are not always a suitable choice. Qualitative studies that do not have a formal name or methodological roots are referred to as descriptive qualitative studies (Polit and Beck, 2018). Descriptive qualitative research is less interpretive than phenomenological, ethnographic and grounded theory approaches and focuses on presenting the facts in an easy-to-understand way (Sandelowski, 2000). Researchers using qualitative description stay close to the data throughout the analytical process, to interpret the data and produce a rich description of an experience or event (Sandelowski, 2000, Neergaard et al., 2009).

A further form of qualitative research is qualitative research synthesis, which has “developed to become a valuable tool used alone or in conjunction with qualitative

synthesis for systematic reviews conducted in social and health disciplines” (Ludvigsen et al., 2016, p.320). A qualitative evidence synthesis is a methodological approach to developing new knowledge, based on the rigorous analysis of existing qualitative research (Polit and Beck, 2018).

3.5 Qualitative evidence synthesis

A qualitative synthesis is defined as “any methodology whereby study findings are systematically interpreted through a series of expert judgements to represent the meaning of the collected work” (Bearman and Dawson, 2013, p.253). Thematic synthesis is an inductive approach involving the systematic coding of data and the generation of descriptive and analytical/higher order themes.

Research synthesis and research evidence synthesis are general terms used to describe the “bringing together” of a body of research on a particular topic (Ring et al., 2011). These methods are often used in healthcare to evaluate the effectiveness of an intervention and therefore influence policy and practice (Majid and Vanstone, 2018). This type of synthesis can be beneficial since it draws together a large body of qualitative research (often small-scale studies) that collectively could result in new understanding, without the lengthy process of designing and conducting original research (Finlayson and Dixon, 2008).

Systematic reviews are the most rigorous type of synthesis, and are therefore the basis for most clinical practice guidelines (Gerrish and Lathlean, 2015, Polit and Beck, 2018). Such reviews of quantitative studies are called meta-analyses and those of qualitative studies are better known as meta-syntheses (Polit and Beck, 2018). Whereas a quantitative meta-analysis pools numerical results from individual quantitative studies and uses statistical analysis to determine the effect of an intervention or strengths of relationships, qualitative synthesis seeks to increase understanding of a phenomenon or patient experience (Grove et al., 2013).

As qualitative synthesis is a subjective process, it has often been criticised as having the potential for introducing bias (Bearman and Dawson, 2013). For example, two independent researchers reading the same text may likely come to different conclusions since they have different experiences, knowledge, values and experiences upon which to draw. Therefore, qualitative findings are by their nature unable to be generalised to the wider population and bias is acknowledged by those involved (Bearman and Dawson, 2013).

Although qualitative synthesis involves interpretive judgement, it begins with a structured and systematic review process (Hannes and Lockwood, 2011). Sandelowski and Barroso (2007) believe that qualitative synthesis prevents independent pieces of research being undervalued and underutilised. Thus, the collection of evidence from a collection of primary qualitative studies yields more powerful explanations and expands understanding of the phenomenon under investigation (Hannes and Lockwood, 2011). For this study, synthesis of evidence has the potential to provide a more in-depth understanding of bereaved families' experiences of memory-making in critical care.

There are several different ways to consider synthesis of qualitative studies; the method depends on the philosophical position of the reviewer and the research question. Methods broadly fall into "realist" or "idealist" epistemologies (Barnett-Page and Thomas, 2009). Two common healthcare methods for synthesising qualitative research were considered for answering the research question: meta-ethnography (Noblit et al., 1988) and thematic synthesis (Thomas and Harden, 2008). Both methods seek to go beyond the original data and find a fresh interpretation of the phenomenon under review (Barnett-Page and Thomas, 2009). However, both methods have different theoretical perspectives: meta-ethnography follows an objective idealism epistemology, and is based on the principle of collectively shared understandings (Barnett-Page and Thomas, 2009); thematic synthesis follows a critical realism epistemology, whereby our knowledge of reality is mediated by our perceptions and beliefs (Barnett-Page and Thomas, 2009).

The process of meta-ethnography typically involves seven steps and results in the production of a new "third order" interpretation by bringing together the findings from the individual studies. Meta-ethnography utilises the participant findings and author interpretations reported in the original studies (Ring et al., 2011). Atkins et al. (2008) argue that the process of synthesising research in meta-ethnography is not a clearly defined process.

Thematic synthesis identifies recurring themes in primary research studies, analyses the themes and draws conclusions across the studies. The resulting key themes are the combined understanding of the text in question and lead to fresh interpretations of the phenomenon under review. Thematic synthesis offers a clear, transparent and replicable method, which is a suitable choice for a novice researcher.

Thematic analysis was developed to address the need, appropriateness and acceptability of interventions. This method also aligns with the researcher's own philosophical beliefs, that there are multiply realities. As it takes into account people's views and experiences; it is for these reasons that thematic analysis was chosen as the method for the qualitative research synthesis. Chapter 5 discusses the thematic synthesis process and results.

In order to achieve new evidence on how bereaved families experience memory-making in critical care, a thematic synthesis was conducted in order to answer the research question: *What are the experiences of bereaved families who engage with memory-making in critical care?*

3.6 Data analysis

Thomas and Harden's (2008) method follows a three-step approach to analysing the data from the original primary studies. This approach is often used in healthcare to inform policy and practice as it facilitates analysis of the need, appropriateness and acceptability of the intervention involved, while taking into account the individual's views and experiences (Barnett-Page and Thomas, 2009):

1. Line-by-line coding of textual findings from primary studies
2. Organisation of free codes into "descriptive" themes
3. Generation of "analytical" themes – using the descriptive themes, reviewers produce a new interpretation which goes beyond the original studies.

During the development of the descriptive themes (step 2), the reviewer stays "close" to the primary studies – reading and re-reading transcripts and coded themes – and then "goes beyond" the primary studies when generating analytical themes, looking for similarities and differences, positive and negative coded data, and whether or not this fits with current interpretations from existing research literature. A synthesis approach brings together qualitative findings and re-interprets their meaning across multiple studies (Thomas and Harden, 2008). This draws on elements of grounded theory (taking an inductive approach using constant comparison) and meta-ethnography (using third order interpretations) (Barnett-Page and Thomas, 2009).

3.7 Trustworthiness of qualitative research

It is essential to all research approaches to demonstrate the quality of the research process. Qualitative research cannot be judged by the same criteria as the scientific paradigm (Bradshaw et al., 2017). Rigour for quantitative research involves discipline and strict adherence to a protocol. Validity and reliability are terms most often associated with quantitative research, and some qualitative researchers avoid the terms as they are associated with the positivist paradigm (Polit and Beck, 2020). The reliability and validity of qualitative research are described through methods to enhance the trustworthiness of the research (Lincoln and Guba, 1985, Holloway et al., 2010). Qualitative researchers assess the quality of qualitative research by how trustworthy it is.

Lincoln and Guba (1985) proposed a framework to establish the trustworthiness of qualitative research consisting of the following four criteria: credibility, dependability, confirmability and transferability. The authors later added a fifth criterion referred to as authenticity (Lincoln and Guba, 1985, Guba and Lincoln, 1994). See Table 3.2.

Table 3.2 Lincoln and Guba’s principles for evaluating trustworthiness in qualitative research

Qualitative research	Questions that underpin the principles of qualitative research
Credibility	How can we be confident about the “truth” of the findings?
Dependability	Would the findings be repeated if the inquiry were replicated with the same (or similar) subjects or similar context?
Confirmability	How can we be certain that the findings have been determined by the subjects and contexts of the inquiry, rather than the biases, motivations and perspectives of the investigator?
Transferability	Can we apply these findings to other contexts or other groups of people?
Authenticity	Have people been changed by the process? To what extent did the investigation prompt action?

Note: Table altered from (Johnson and Rasulova, 2017)

Credibility refers to belief and confidence in the interpretation of the data (Holloway et al., 2010). There are a few techniques that can enhance the credibility of a study, such as peer debriefing, member checking, data triangulation, audit and decision trail, thick description and reflexivity (Holloway et al., 2010, Polit and Beck, 2020). Not only do these strategies establish credibility, they also ensure confirmability. Confirmability refers to objectivity and reduces researcher bias, and involves two independent people being in agreement

about the accuracy of the data (Holloway et al., 2010). The researcher should act in good faith and not allow personal values to determine the research findings.

In order to ensure the findings of a study are dependable, they should be consistent and accurate (Holloway et al., 2010). Lincoln and Guba (1985) suggested keeping an audit trail, ensuring accurate records are kept of all the research processes. A peer review could establish how well research procedures have been followed (Bryman, 2016).

Transferability refers to the generalisability of the findings of the research. The researcher should provide an in-depth description of the study setting and participants, and a full discussion of the findings, so that others can consider the relevance of the work to other contexts (Holloway et al., 2010).

Authenticity refers to researchers fairly and faithfully showing a range of realities (Polit and Beck, 2012). Authenticity can be established through gaining full consent from participants and developing a trusting relationship with them. Transparency, sharing of information and description of the inquiry procedure are also ways of establishing authenticity (Amin et al., 2020).

3.8 Reflexivity

Reflexivity is the researcher's thoughtful awareness and acknowledgement of their views or position within the research. Researchers bring their own biases, values and personal backgrounds, and these can shape the interpretations formed during a study (Creswell and Creswell, 2018). Bias cannot be eliminated from research. The researcher's personal background, such as gender, culture and socioeconomic status, can also shape their interpretations during the study (Creswell and Creswell, 2018).

Qualitative researchers can enhance rigour, quality and trustworthiness of their research by being critically reflexive (Dodgson, 2019). Researchers are reflexive when they consciously reflect upon their role and involvement within the study (Holloway et al., 2010). A researcher's own beliefs and experiences can influence the way data is interpreted. Researchers do not come to a study naively; they have backgrounds in the topic of interest. Personal interests and experiences can be a source of strength for a qualitative study, but they must be accounted for. The researcher is part of the co-construction of knowledge, and with reflection and personal awareness, they may identify

deeper insights and thus provide a richer understanding of the human experience (Amin et al., 2020).

3.9 Conclusion

Different philosophical worldviews have been considered; the researcher aligns herself with a constructivist perspective.

In this chapter different qualitative methodological approaches have been considered as well as their relevance for use in this study. The researcher believes that the experience of the individual is unique and fundamental; this approach enables the researcher to collect rich data, which will increase the understanding of how bereaved families experience memory-making when a loved one dies in critical care.

A qualitative evidence synthesis was selected as the most appropriate methodology to (1) gain new knowledge and understanding and (2) answer the research question: *What are the experiences of bereaved families who engage with memory-making in critical care?* The following chapter will discuss the thematic synthesis method in more detail.

Chapter 4: Methods

4.1 Introduction

Research methods are defined as the steps, procedures and strategies undertaken for both the gathering and the analysis of the data needed within a study (Polit and Beck, 2012). The chosen research method(s) should be suitable to address the problem/topic being investigated.

Chapter 3 provided a justification for selecting Thomas and Harden's (2008) qualitative thematic synthesis framework. It was selected to analyse all qualitative data relating to bereaved families' experiences of memory-making when their loved one died in critical care. This chapter will discuss the methods used to conduct the qualitative thematic synthesis, including the systematic search strategy, data collection, relevant appraisal tools, and patient and public involvement. Chapter 5 discusses the findings of the thematic synthesis.

4.2 Search strategy

The aim of the search strategy was to identify all studies that had evaluated memory-making in critical care. The abstract and full text, if necessary, were then used to select studies which had evaluated bereaved families' experiences of engaging with memory-making in critical care. Studies from paediatrics and adult critical care settings were included. No time frame limits were applied since little is known on the topic in question and it was important to identify as many relevant articles as possible.

4.2.1 Inclusion criteria

Inclusion criteria for the search were:

- Family⁴ engagement with memory-making within critical care

⁴ Within the papers studied, 'family' includes parents, spouses or partners, children, siblings, grandparents and friends. This is in line with the researcher's own definition of 'family', as noted in Chapter 1.

- Studies using qualitative methods to elicit families' experiences of memory-making in a critical care environment
- Literature published in English language
- Published in peer-reviewed journals.

4.2.2 Search terms

In order to identify relevant literature a systematic search strategy was developed. The following health and social sciences databases were searched: CINAHL, Medline, Embase, PsycINFO and ASSIA. The search criteria were terms relating to (1) memory-making, (2) critical care and (3) bereavement (search strategy example can be found in Appendix 3).

An example of the search terms used in Embase included:

- intensive care unit* or critical care or high dependency unit* or coronary care unit* or ICU or CCU or HDU or PICU or NICU
- memory-making or memory box* or memento* or keepsake* or transitional object or tangible object or memoriali?ation or patient diar* or photo* or legacy or ritual*
- griev* or mourn* or reaction* or bereave* or grief*.

Due to the limited research available on memory-making in critical care, the sample included articles from both paediatric and adult settings. The Boolean operators “AND” and “OR” were used. When possible, the searches were managed using the Medical Subject Headings (MeSH) tool for information searches. All references in the identified papers were hand searched for further relevant articles of interest. Detailed hand searches were also carried out in three selected journals (*Death Studies*, *Nursing in Critical Care* and *BMJ Supportive and Palliative Care*) over the past ten years (January 2021 to January 2011). A ten-year period was chosen as this was considered to be a sufficient time frame to identify the vast majority of studies in this under-researched area. However, grey literature and thesis dissertations were excluded from the review due to time constraints.

4.2.3 Search results

A Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flowchart was used to track the inclusion/exclusion decisions of the identified articles (Figure 4.1).

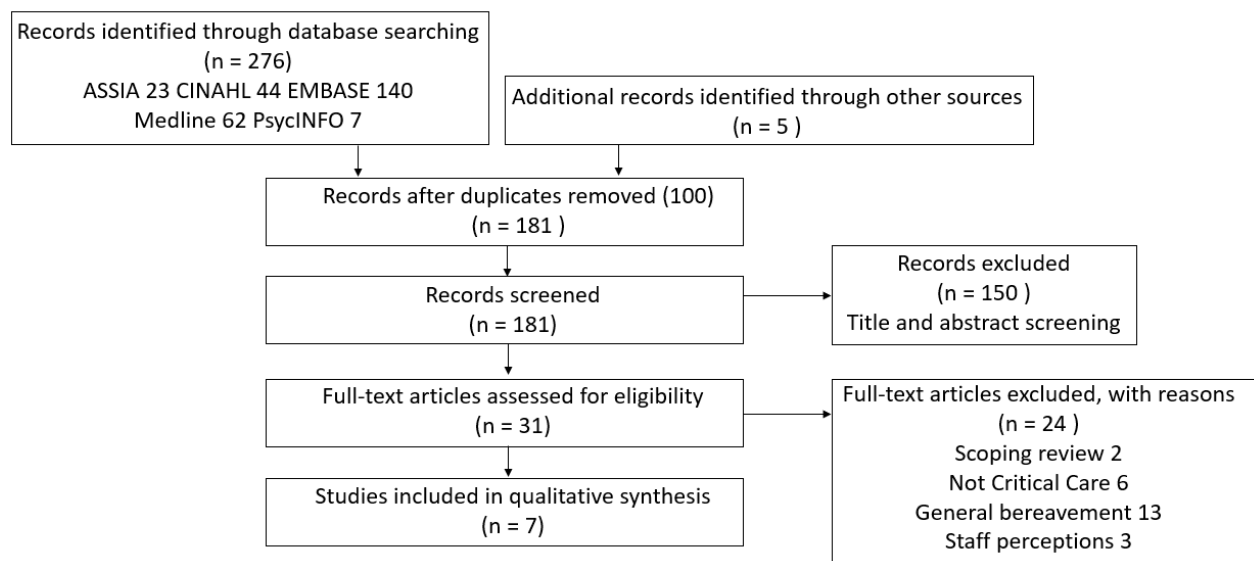


Figure 4.1 PRISMA flow diagram of search results

The electronic search was initially conducted in November 2020. This search yielded 276 results, with an additional five studies identified from hand searching. One further study was identified when the search was repeated in April 2021, but it was not included as it was a further analysis of a paper already identified, i.e. Thornton et al. (2020). Following the screening process, the final sample consisted of seven studies (Table 5.1, shown in Chapter 5). Six were primary studies (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Thornton et al., 2020) and one was a secondary analysis (Neville et al., 2020). This secondary analysis was included in this synthesis due to the paucity of qualitative studies on memory-making in critical care. Of these seven articles, four were from adult settings (Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Neville et al., 2020) and three from paediatric settings (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Thornton et al., 2020). Memory-making activities described in the adult literature included patient diaries (Johansson et al., 2018, Melby et al., 2020), word clouds (Vanstone et al., 2016) and keepsakes (Neville et al., 2020). The paediatric literature includes photography (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014) and general keepsakes (Thornton et al., 2020). The articles were published from 2014 to 2020.

4.3 Critical appraisal

The papers included in the thematic synthesis were evaluated using a guide for reading qualitative articles (Sandelowski and Barroso, 2007), a universal quality appraisal tool (Hawker et al., 2002) and a typology for classifying findings (Sandelowski and Barroso, 2007). All three appraisal tools were used to evaluate the congruency of the research aims and design, the ethics, analysis, findings and applicability of the research (Table 4.1). For the mixed methods articles, only the qualitative data was appraised. The Hawker tool calculates an overall score (ranging from 40 “good” to 10 “very poor”) to indicate the methodological rigour of each study. A typology for classifying findings (Sandelowski and Barroso, 2007) was used as the appraisal tool. The articles were scored independently by the researcher and her academic supervisors (DM and BMJ) and any differences in scores were discussed until a final rating was achieved. Due to the exploratory nature of this review, all seven articles were included regardless of their appraisal score, as it was felt they could still contain valuable interventions and would remain relevant for this thematic synthesis. All three appraisal tools were used to enhance rigour of the qualitative evidence.

Table 4.1 Summary of appraisal tools used in the thematic synthesis

Quality appraisal tool	Description
Reading guide by Sandelowski and Barroso (2007)	Comprises 14 separate domains: research problem, research purpose(s)/questions(s), literature review, orientation towards the target phenomenon, method, sampling strategy/techniques, sample size, data collection techniques/sources, data management and techniques, findings, discussion, validity, ethics and overall form
Typology for classifying findings in qualitative studies by Sandelowski and Barroso (2007)	The typology is presented in the form of a “continuum of data transformation”: (1) no finding, (2) topical survey, (3) thematic survey, (4) conceptual/thematic description, (5) interpretive explanation
Hawker et al. (2002) checklist	A validated scoring system that comprises ten questions, each one given a quality score ranging from 4 (good) to 1 (very poor), which generates a maximum score of 4 per question and maximum total score of 40

All the studies reported ethical approval; however, none of the studies discussed reflexivity of the authors. One reason for this could be the limited word count in qualitative articles and the researchers choosing not to discuss reflexivity to keep within the word count limit. Interestingly, the authors of the patient diary studies identified themselves as nurses who worked in the critical care unit (Johansson et al., 2018, Melby et al., 2020); Johansson et al. (2018) clarified that they did not interview families under their direct care. No further reflection was made regarding their position within the research or how it may have impacted it. Vanstone et al. (2016) and Neville et al. (2020) identified the number of authors and their contribution to the study, with no reflection of their personal impact. The three paediatric studies provided no information regarding the authors nor made any reference to reflective practice (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Thornton et al., 2020).

4.4 Data analysis

The researcher followed Thomas and Harden's (2008) three-step approach (as discussed in Chapter 3) to analyse the data within this thematic synthesis. Included data (direct quotes from participants, photographs and all text under the headings "results" or "findings") were extracted from the seven included primary studies, and were then coded in NVivo 12 software (QRS International, 2020).

The researcher stayed "close" to the primary studies by reading and re-reading the transcripts before coding data. Free codes were given to the data, line-by-line, which led to the generation of the descriptive themes. Analytical themes were then generated by grouping the coded data and placing them into a hierarchical order. This was an iterative process, where the researcher looked for similarities and differences, from data in the primary studies. Meanwhile focussing on answering the research question: *What are the experiences of bereaved families who engage with memory-making in critical care?*

4.5 Patient and public involvement

Patient and public involvement (PPI) is recognised as a key element in health and social care research (Brett et al., 2014). According to Brett et al. (2014), PPI contributes to the production of high-quality research. In accordance with the *UK Policy for Health and Social Care Research* (Authority, 2021), the needs of patients and service users should be not only considered but also included in the research design, and throughout the process

and dissemination of the results. This helps ensure improved standards of care for all and promotes patient-centred care (Brett et al., 2014).

Ms Highfield (name used with permission) has been the PPI representative for this research study. Ms Highfield has personal experience of memory-making before, during and after her mother's death, in the Critical Care Department at the QEUH. Ms Highfield has kept in touch with a member of the nursing team who cared for her mum, and expressed her wishes to support the Bereavement Support Team. Ms Highfield has been involved in this study from the beginning; she has been consulted on the results of the thematic synthesis and has provided a lay review of the proposed empirical study and the supporting study documents (discussed in Appendix 2).

4.6 Reflexivity

The researcher has been conscious of her position within this qualitative evidence synthesis and acknowledges her own personal experience of memory-making with families in an adult critical care department. The researcher has a long background of nursing in critical care, and has introduced and experienced memory-making with families when their loved one is receiving end-of-life care or has died. The researcher has a particular interest in end-of-life and bereavement care and is part of the Bereavement Support Team that has developed the bereavement support services available for families in critical care at the QEUH.

For this reason, and as recommended as good clinical research practice, a written reflexive account was kept throughout the data analysis and recorded in the form of a personal diary. This helped the researcher to consider her previous clinical experience of memory-making and to note any assumptions, elements of interest or potential biases which might impact her interaction with or analysis of the data. Having clinical experiences of memory-making and reflecting upon these deepened the researcher's thinking during analysis.

4.7 Chapter summary

This chapter discussed Thomas and Harden's (2008) method for qualitative thematic synthesis, including the systematic search strategy, data collection and relevant appraisal tools. The importance of PPI and reflexivity of the researcher were addressed. The following chapter will present the findings generated from the thematic synthesis.

Chapter 5: A qualitative thematic synthesis

5.1 Introduction

As discussed in Chapter 2, memory-making was introduced during the 1970's in the care of perinatal deaths, it has since become customary practice within adult critical care units when patients are approaching the end of their life, either before or after death (Riegel et al., 2019). Anecdotal evidence suggests that families are appreciative, but there is limited evidence-based research which has evaluated memory-making experiences for families in critical care. The aim of this qualitative synthesis is to systematically identify and synthesise the relevant qualitative evidence in order to better understand bereaved families' experiences of memory-making in critical care, answering the research question: *What are the experiences of bereaved families who engage with memory-making in critical care?*

5.2 Findings

The thematic synthesis consisted of seven papers (summaries of the main characteristics are presented in Table 5.1): six were primary research papers and one was a secondary analysis, i.e. (Neville et al., 2020). Two papers focused on evaluations of keepsakes offered as part of the Three Wishes Project (Vanstone et al., 2016, Neville et al., 2020), which was founded in the intensive care unit of St. Joseph's Healthcare in Hamilton, Canada (Cook et al., 2015). Both patient diary articles came from Scandinavia (Johansson et al., 2018, Melby et al., 2020). The other countries represented are Australia (Thornton et al., 2020) and the United States (Blood and Cacciatore, 2014, Neville et al., 2020). The methods used in these papers included grounded theory, interpretive phenomenology analysis, a secondary evaluation and mixed methods study. The qualitative components of the mixed methods study were extracted and included in the synthesis. The word cloud study interviewed families and clinicians, but only the family data was included in this synthesis (Vanstone et al., 2016).

The participants in all studies had close kinships to the deceased. Families described in this synthesis include parents, spouses or partners, children, siblings, grandparents and friends.

Text under "results" or "findings" and participants' direct quotes were coded line-by-line into NVivo version 12 (QRS International, 2020), qualitative data analysis software. The literature produced 228 free codes. The codes were organised into a hierarchical order, and this inductive method produced 17 descriptive themes. The final analysis generated four

analytical themes: connection, compassion, engagement and creation, and continuation (Figure 5.1). These four analytical themes describe how bereaved families experience memory-making in critical care and will be discussed in detail below (Table 5.2). The thematic synthesis will conclude with a discussion of the notable differences between paediatric and adult critical care settings.

Table 5.1 Articles included in thematic synthesis

Study/country	Aim	Methodology/methods	Study participants/time bereaved	Context	Main themes	Hawker's checklist and typology scores
Blood and Cacciatore (2014) America	Understanding best practice in perinatal bereavement photography	Qualitative descriptive methodology Recruited via bereavement organisations/social media Online survey Open/closed-ended questionnaire	Bereaved parents (104) 1958–2010 or later	Perinatal death, stillbirth and neonatal death 20 weeks gestation – 28 days after live birth Online bereavement organisations/social media	Obstacles to post-mortem photography Supporting parents' needs Creating quality mementos Obtaining consent Supporting both professional and family photography Variety and family participation in pictures Parents who were not asked if they wanted photos Broad appreciation expressed by parents	33; TS
Johansson et al. (2018) Sweden (three sites)	Explore families' experience of keeping an ICU diary when the patient does not survive	Qualitative study – Gadamerian hermeneutic approach Unstructured interviews	Bereaved relatives/friends (9) 3–11 months	ICU One university and two county hospitals Two-month follow-up call; if interested in study, contacted at a later date	The diary as a bridge connecting the past with the future 1. The diary promoted a rational understanding 2. The diary promoted an emotional understanding 3. The diary promoted social interactions	30; TD
Martel and Ives-Baine (2014) Canada	Parents' experience of end-of-life photography around the death of their new born in neonatal intensive care (NICU) and in their lives beyond the hospital	Interpretive phenomenological analysis Semi-structured interviews	Bereaved parents (10) Within 1–5 years of death Invited to bring photos to interviews	NICU – single site NICU bereavement newsletter from the hospital	Living relationships Parenting and knowing Nursing and support	28; TD

Study/country	Aim	Methodology/methods	Study participants/time bereaved	Context	Main themes	Hawker's checklist and typology scores
Melby et al. (2020) Norway	Increase knowledge of bereaved families' experience of receiving an ICU diary when a loved one does not survive	Descriptive phenomenology method In-depth interviews	Bereaved family members (5) Six to 18 months post-death	Across three ICUs in a Norway university hospital Written invitation to study (no follow-up)	Receiving the diary – a mixed blessing A long-awaited delivery Emotionally draining	28; ThS
Neville et al. (2020) Canada and America, four centres	To understand the value of keepsakes from perspectives of bereaved family members	Secondary analysis of Three Wishes Project and keepsakes value Mixed methods Semi-structured Conventional content analysis	Bereaved family members (60) 1–12 months post-death	ICU Four academic centres	Keepsakes are tangible items highly valued by families Creation of keepsakes with staff is a valuable experience and viewed as a compassionate gesture	24; ThS
Thornton et al. (2020) Australia	Explore significance of memory-making for bereaved parents and the impact of memory-making on parents' experience of neonatal loss	Grounded theory (Corbin and Strauss) Semi-structured interviews	Bereaved parents (18) No time constraints 1999–2016 On average 6 years (6 months–17 years)	Neonatal unit Online community-based bereavement services/social media	Affirmed parenthood Creating evidence Being a parent Being guided	34; CD
Vanstone et al. (2016) Canada	Describe how word clouds foster a narrative-medicine orientation Impact of word cloud from family perspective, clinician and project team	Qualitative content analysis Three stages of narrative medicine: attention, representation, affiliation Heuristic approach Mixed methods Semi-structured telephone interviews with family Semi-structured interviews with staff	Bereaved families (37) and clinicians (73) 1–6 months post-death (families) 1–2 weeks via email for clinicians	ICU	Narrative attention through word elicitation Narrative representation through word cloud creation Narrative affiliation through sharing word clouds	18; TS

Notes: Hawker et al. (2002) checklist score: 10 questions, quality score ranging from 4 (good) to 1 (very poor). Generates a maximum score of 40

Typology: CD = conceptual description; TD = thematic description; ThS = thematic survey; TS = topical survey

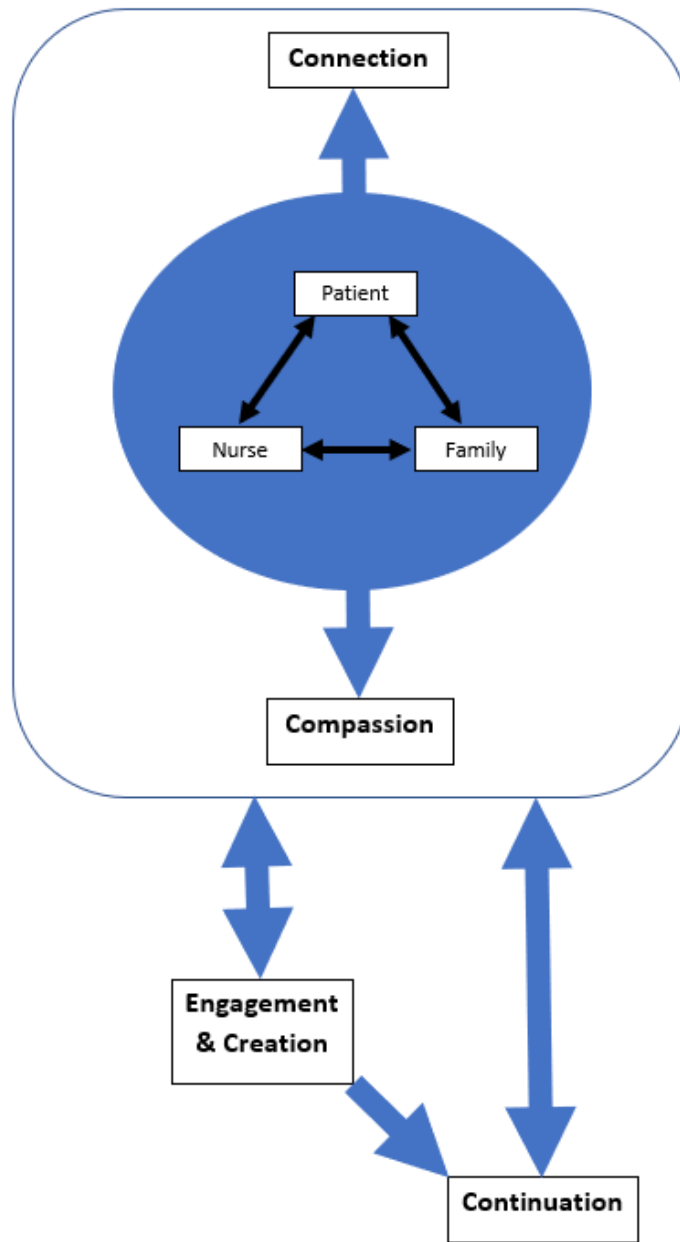


Figure 5.1 Conceptualisation of bereaved families' experiences of memory-making in critical care

Table 5.2 Description of analytical themes

Theme	Description	Examples
Connection	<p>Meaningful communication</p> <p>The exchange of emotions</p> <p>A shared sense of common humanity</p> <p>Bonding: parents developed a relationship with their baby and others reaffirmed their existing relationship with adult patients</p> <p>The establishment and/or development of trust</p>	<p>“The participants and their families communicated information about the patients so that the nursing staff could provide the best possible care” (Johansson et al., 2018)</p> <p>“Word clouds are a conversation piece, prompting reminiscence” (Vanstone et al., 2016)</p> <p>“The parents seemed to experience the photography as a way of forging connections and grounding meaningful relationships with their care providers, their newborn, and family and friends” (Martel and Ives-Baine, 2014)</p> <p>“The focus of their medical care and treatment was on our son. The focus of their human care, treatment and attention was on my wife and I...not in a medical sense but in a human sense” (Martel and Ives-Baine, 2014)</p>
Compassion	<p>Families received support and guidance from nursing staff</p> <p>Memory-making honoured the patient as an individual</p> <p>Memory-making process supported family-centred care</p> <p>Memory-making process supported decision making; parents decided how to spend time with their baby, what clothes to dress their baby in</p> <p>Gives permission to parental role</p> <p>Families and patient felt cared for</p>	<p>“To leave the photo taking to the parents is overwhelming...they are already dealing with so much. We were in no shape emotionally” (Blood and Cacciatore, 2014)</p> <p>“For many families, being invited to make and receive keepsakes was perceived as an invaluable demonstration of support from the clinical team” (Neville et al., 2020)</p> <p>“The bereavement photography organization and the hospital staff went out of their way to make incredible photos that we will cherish for a lifetime” (Blood and Cacciatore, 2014)</p> <p>“Let’s dress him a little bit and let you hold him” (Martel and Ives-Baine, 2014)</p> <p>“[Our nurse] showed us, through her openness, that...it was ok to do whatever I wanted” (Blood and Cacciatore, 2014)</p> <p>“I wish so much that someone had told me it was ok to take her pictures” (Blood and Cacciatore, 2014)</p>

Theme	Description	Examples
Engagement and creation	<p>Memory-making was a meaningful experience</p> <p>Active participation for families</p> <p>Therapeutic benefits</p> <p>Providing focus during a difficult time</p> <p>Supporting the transition to end-of-life care</p> <p>Physical evidence of the loved one's life/uniqueness</p>	<p>“The newborn's life story that could be told through photography” (Martel and Ives-Baine, 2014)</p> <p>“It's me reading to him” (Martel and Ives-Baine, 2014)</p> <p>“It was the process of...doing the hand mold and the fingerprints...it does kind of set in that you're saying goodbye...I think that for me, more than anything...was that it helped with the transition” (Neville et al., 2020)</p> <p>“Creating evidence through collecting mementos, taking photographs and involving others provided parents with crucially important affirmation of the baby's essential reality, and of the participants' status as parents” (Thornton et al., 2020)</p> <p>“They are the thing that I touch on a day-to-day basis the most. And they are definitely the most physical reminder... you can feel the little crevices in her footprints and the like” (Thornton et al., 2020)</p>
Continuation	<p>Interaction with keepsake at own pace at home</p> <p>Storytelling</p> <p>Rituals</p> <p>Grief/bereavement process</p> <p>Continuing/ongoing relationship with loved one</p>	<p>“I felt it was quite alright, really. Being able to open it and browse through on my own. Getting through it was hard going. It took an awfully long time” (Melby et al., 2020)</p> <p>“It is how I tell the story and how I communicate my loss, my pain, my love for my daughter” (Martel and Ives-Baine, 2014)</p> <p>“I talk to him in front of it every night. I light a candle. It is right under a picture of [Patient's Name]. I light the candle then I pray. Then I talk to him. I feel him around” (Vanstone et al., 2016)</p> <p>“But he does exist for me still” Thornton et al. 2020</p>

5.3 Connection

The overarching theme generated from the seven articles was connection, which was created through the exchange of shared humanity and emotion. This theme is fundamental to the other three themes that emerged (compassion, engagement and creation, and continuation) as to some extent they all depend on, and are built upon, connection. This may be connection between the patient and family members, connection among family

members, connection between patient and staff, connection between family members and staff, or any combination of these. From the literature, there are several key ideas which can define connection in the context of memory-making in critical care: meaningful communication, the exchange of emotions, a shared sense of common humanity, bonding, the established and/or development of trust, facilitation by staff, environmental factors, and social processes. These are illustrated in the following selected quotations, and will be further discussed below.

The participants and their families communicated information about the patients so that the nursing staff could provide the best possible care (Johansson et al., 2018, p.237).

Word clouds are a conversation piece, prompting reminiscence (Vanstone et al., 2016, p.4).

The parents seemed to experience the photography as a way of forging connections and grounding meaningful relationships with their care providers, their newborn, and family and friends (Martel and Ives-Baine, 2014, p.327).

The focus of their medical care and treatment was on our son. The focus of their human care, treatment and attention was on my wife and I...not in a medical sense but in a human sense (Martel and Ives-Baine, 2014, p.324).

The bereaved families did not experience the death of their loved one or memory-making alone, as they were supported and guided by nursing staff and other family members. Bereaved families, especially the parents whose baby died, depended heavily on the guidance and support from nursing staff, both during the dying process and while engaging in memory-making practices. Families may have been unaware of their own needs during this extremely challenging time, and would likely have been unaware of the memory-making resources available to them. Nursing staff therefore had to introduce elements of memory-making to families, such as photography and keepsakes. Nurses play a crucial role in introducing and facilitating memory-making practices (such as taking photographs), and communicating to families the range of memory-making practices that are possible in the hospital environment. As the quote from (Blood and Cacciatore, 2014) shows – “I wish so much that someone had told me it was ok to take her pictures” – if this is lacking, families can be left with profound regrets around actions not taken.

The importance of the facilitation role played by nursing staff is linked with the environment of critical care, and the ways in which this technical and (for the families) unfamiliar environment can create barriers to connection. Critical care was found to be chaotic and hectic for the families (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Thornton et al., 2020). Patients receive constant monitoring and observation when receiving active treatment. The technology and invasive monitoring are barriers to physical contact; families can be reluctant to touch their loved one for fear of doing something wrong and parents cannot hold their baby if they require an incubator. Devastatingly, some parents got to hold their baby for the first time when they were receiving end-of-life care, when their baby no longer required the incubator. Being in an unfamiliar environment, relying on the nurses to provide care for their baby, some parents needed guidance and reassurance, as they lacked experience and perhaps did not feel confident in holding their baby. Staff had been the main care providers up to this point. Nursing staff soften the critical care environment to create a calmer atmosphere by removing unnecessary machinery/monitoring from the patient and bedspace, thus removing barriers to physical contact. This allows families to be more intimate when the patient is receiving end-of-life care. One parent commented that their “favourite” photos were the ones that “didn’t have all the wires and tubes” (Martel and Ives-Baine, 2014, p.320).

The environmental barriers to connection were identified and reduced by compassionate care delivered by nursing staff. In this we can see the connections that are forged between staff, family and patient during memory-making, as well as the role that nursing staff play in facilitating the connections between the patient and their family. Personalised and humanistic nursing care recognised patients as unique individuals, provided dignity and honoured their life. This was acknowledged and appreciated by families, and it helped build and strengthen connections between family and staff. Nursing staff connected to convey empathy for patients and their families as they witnessed the intimate and devastating impact of death on the family.

When the families acknowledged that death was approaching, this brought focus to their own connection with their loved one. This connection was either new or established, depending on the age of the patient. Parents had to form bonds and connections with their baby in a short space of time. Regardless of how long the baby lived, their life was significant. It was important to the parents that their baby’s life was socially recognised (Blood and Cacciatore, 2014, Thornton et al., 2020, Thornton et al., 2021). When other

family members met the baby, this provided further “affirmation of the baby’s existence and of the participants’ parenthood” (Thornton et al., 2020, p.33). Families of the adult patients reaffirmed their relationship with their loved one. The creation of word clouds strengthened family connections as participants reminisced and shared stories about the patient, choosing words to represent their loved one (Vanstone et al., 2016). This brought the families’ focus to the patient’s life rather than their illness, while enabling them to support each other during a painful transition (Vanstone et al., 2016). In turn, this allowed staff to get to know more about the patient, enabling the provision of individualised care and strengthening connections with the patient and family.

Family participation in memory-making was a key component for staff getting to know more about the patient in the adult setting. Adult patients who require sedation and ventilatory support are unconscious and are therefore unable to communicate who they are and their wishes. To provide personalised care and to feel connected to the patient, staff rely on families sharing information about the patient’s identity and what matters to them. Patient diaries helped the family feel connected to the patient when they were unconscious, as they shared in words what had happened in their own lives; also, the diary recorded their presence at the bedside (Johansson et al., 2018).

Memory-making included family members who could not be at the bedside, and thus siblings and grandchildren were considered (Martel and Ives-Baine, 2014, Vanstone et al., 2016). A family friend expressed how keepsakes can serve as a substitute for moments that a family might have missed (Neville et al., 2020). For example, family members could contribute words to the word cloud, even if they could not be physically present at the bedside. One nurse took an electrocardiogram tracing of a patient’s heart for a family member who could not be at the bedside (Neville et al., 2020). Keepsakes were made to take home and share with others, or not, depending on the individual wishes of the family. The creation of these keepsakes respected, valued and included family participation, and gave consideration to those who could not be present at the bedside, and supported family-centred care.

5.4 Compassion

Compassion was the second theme generated within the thematic synthesis. It was fundamental to forming and developing connections, whether between patients and nursing staff or between nursing staff and family members. Connection and compassion together

facilitated and represented a shared sense of common humanity: the knowledge and understanding that, as humans, we will all experience death and grief. Nurses provided compassion through their empathy towards the families in the difficult and painful situation the families were experiencing; this was demonstrated through their reassuring and dependable presence, and their desire to provide comfort and care to the patient and their family. They welcomed family members, respected their role and made them feel more at ease in the unfamiliar critical care environment. Compassion was fundamental to the creation of memories and keepsakes, which subsequently were able to function as an aid to fostering continuing bonds/relationship with the deceased.

There are several key ideas which can define compassion in the context of memory-making in critical care: families received support and guidance from nursing staff; memory-making honoured the patient as an individual; the memory-making process supported family-centred care; the memory-making process supported decision making by giving families permission to make choices; and families and patients felt cared for. These are illustrated in the following selected quotations, and will be explained further below.

To leave the photo taking to the parents is overwhelming...they are already dealing with so much. We were in no shape emotionally (Blood and Cacciatore, 2014, p.5).

For many families, being invited to make and receive keepsakes was perceived as an invaluable demonstration of support from the clinical team (Neville et al., 2020, p.943).

The bereavement photography organization and the hospital staff went out of their way to make incredible photos that we will cherish for a lifetime (Blood and Cacciatore, 2014, p.7).

Let's dress him a little bit and let you hold him (Martel and Ives-Baine, 2014, p.321).

[Our nurse] showed us, through her openness, that...it was ok to do whatever I wanted (Blood and Cacciatore, 2014, p.5).

I wish so much that someone had told me it was ok to take her pictures (Blood and Cacciatore, 2014, p.5).

Families perceived the offering of keepsakes as a compassionate act (Vanstone et al.,

2016). It was a gesture which went beyond the clinical duties of the staff, “shifting focus away from the critical illness” (Martel and Ives-Baine, 2014, p.321). This built a level of trust and enriched interpersonal relationships in a short space of time between families and staff. When compassion was received by the families, it enhanced their memory-making experience. Compassion welcomed families and gave them permission to express themselves and their needs. For example, when the nurses normalised and promoted photography, parents felt more comfortable and confident to take their own photos of their baby (Martel and Ives-Baine, 2014). “I didn’t realize it was normal for people to take pictures of their dead children” (Blood and Cacciatore, 2014, p.5). Only half of the parents were at ease taking photographs initially; the other parents said photography “was the last thing on their mind” and “it didn’t seem relevant at the time” (Martel and Ives-Baine, 2014, p.321).

Bereaved families needed support and guidance. In particular, some parents described themselves as “confused”, “in a fog”, “numb” and “drugged” (Blood and Cacciatore, 2014, p.3). In an unfamiliar environment and facing the death of a loved one, families were in a state of shock and struggled to think clearly. A repeated theme from the paediatric literature was the importance of staff offering photography “more than once” as parents will likely change their mind and later live with regret (Blood and Cacciatore, 2014). Many parents acknowledged they initially felt “morbid” and uncomfortable taking photos of their dead baby; however, these photos later became their most “prized possessions” (Blood and Cacciatore, 2014). The nursing staff used their previous experiences and intuition to recognise that parents may not know what their needs are; they need time to think and process the information being given.

The careful way nurses and professional photographers worked around the family taking sensitive photographs of the baby, and the thoughtful consideration of the shots, are details the families appreciated later (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Thornton et al., 2020). The tactful introduction of photography before life support was withdrawn allowed for the (albeit limited) opportunity to take photographs of the baby alive, and before the physical changes of death had taken place in the baby’s body. Also, sensitive photography could hide any physical deformities the baby was born with. When the photos were not sensitively taken parents did not display them. One mother described her photos as “horrific” (Thornton et al., 2020). For the few families whose baby did not receive careful consideration while being photographed, this was an area of deep regret as there was no further opportunities to take more photographs. The most precious

photographs for parents were taken when their baby was alive, as the lens captured “living moments” and “parenting” (Martel and Ives-Baine, 2014).

As noted above in the context of connection, the physical environment in which a person receives care can negatively impact how families connect with the patient and staff. Compassionate care counteracted this by de-medicalising the environment; nursing staff removed the “wires” and “tubes” when the patient was approaching end of life as they were no longer required. This removed barriers to physical connection; parents could have physical contact with their baby and therefore take more natural photographs. “These were often the only moments participants had to perform the gestures of ‘parenting’ without the medical technology crowding the scene or distancing them from their babies” (Martel and Ives-Baine, 2014, p.320). Some of the babies required an incubator and were too vulnerable for the parents to hold. Even after the removal of these technical barriers, however, parents needed further support: when the parents were able to hold their baby for the first time, some needed reassurance that they would not “hurt” their baby (Martel and Ives-Baine, 2014). Parents felt more comfortable interacting with their baby and taking their own photographs once staff had given them permission to do so. It was important for staff to normalise these practices for parents to enable them to have meaningful interactions with their baby.

Compassionate care helped guide and care for families when their loved one was dying. It “orientated” and “grounded” families in the critical care environment (Martel and Ives-Baine, 2014). It respected the parental/family role and supported families to share precious time with their loved one, to create meaningful memories and keepsakes, which had a therapeutic effect on their bereavement. One parent commented that the staff “were looking after us too and helping us through and treating us...not in a medical sense but in a human sense” (Martel and Ives-Baine, 2014, p.324). Compassionate care was expressed by the nurses’ attitude and care towards the patient as a unique human being who is worthy of acknowledgement, love and mourning.

Family members appreciated and acknowledged the different ways in which they and their loved one received compassionate care, months after their death. One family member commented regarding the patient diary: “What they wrote, they wrote in such a way that they really cared for him as he lay there. Even when I wasn’t there” (Melby et al., 2020, p.5). A daughter commented on her experience of taking her father’s finger prints with the help of one of the nurses: “It’s just having somebody there, somebody from the staff that

could see a new side into our life with my dad or something personal about us, that it's not just another patient, it's not just a medical record number. I think that was very good for us" (Neville et al., 2020, p.944). This shared experience opened up a conversation about how the patient had previously broken his middle finger, which the daughter and nurse were able to laugh about together. Compassionate care strengthened the connections and bonds among family and nurses.

5.5 Engagement and creation

The third theme generated from the thematic synthesis was engagement and creation, which is used here to refer to both family engagement with the creation of physical keepsakes (such as photographs, diaries, hair locks, etc.) and the creation of lasting and emotionally significant memories through such processes as storytelling, reminiscing, and engagement in care. These are not necessarily separate; the taking of photographs, for example, was often just as significant for the process as for the end product, as will be seen below. Engagement and creation were the product of both connection and compassion. The compassionate care provided by staff created both the space and time for families to have the opportunity to create memories and/or keepsakes. This had a therapeutic effect on many of the families' bereavements and was seen across all of the seven included articles. The quality of the connection and the degree of compassion shown to each family had a profound impact on the quality of the final time spent with the loved one, potentially creating either fond memories or regrets.

From the literature, there are several key ideas which can define creation in the context of memory-making in critical care: memory-making was a meaningful experience; active participation for families; therapeutic benefits; providing focus during a difficult time; supporting the transition to end-of-life care; and physical evidence of the loved one's life/uniqueness. The following quotations have been selected to illustrate these.

The newborn's life story that could be told through photography (Martel and Ives-Baine, 2014, p.321).

It's me reading to him (Martel and Ives-Baine, 2014, p.321).

It was the process of...doing the hand mold and the fingerprints...it does kind of set in that you're saying goodbye...I think that for me, more than anything...was that it helped with the transition (Neville et al., 2020, p.946).

Creating evidence through collecting mementos, taking photographs and involving others provided parents with crucially important affirmation of the baby's essential reality, and of the participants' status as parents (Thornton et al., 2020, p.34).

They are the thing that I touch on a day-to-day basis the most. And they are definitely the most physical reminder...you can feel the little crevices in her footprints and the like (Thornton et al., 2020, p.33).

All of the keepsakes created evidence of the patient's life (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Thornton et al., 2020). Physical evidence of the patient was captured in hair locks, handprints and clothes worn. These were tangible keepsakes, representing the unique and physical identity of the patient. Photography was a visual reminder of a baby's appearance, and also captured profound grief, love and family bonding (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Thornton et al., 2020). Patient diaries documented the patient's journey, contained evidence of the care the patient received and gave families comfort in the knowledge that the patient had been given the best chance of survival (Johansson et al., 2018, Melby et al., 2020). The diary validated the families' grief: "The diary gave them confirmation of what they had been through and they found acceptance that grieving was still allowed" (Melby et al., 2020, p.12). Word clouds were created from family stories of the patient which then represented the patient's legacy (Vanstone et al., 2016). The keepsakes could be shared through storytelling and could be passed on to the next generation.

Parents bonded with their baby by spending time together during caregiving – holding, washing and dressing. The evidence of this bond and special moments together was captured through photographs (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Thornton et al., 2020). The lens could also capture raw emotion, love and heartbreak, which validated the parents' grief; it was also proof of the baby's existence (Thornton et al., 2020). Family members of the adult patients reaffirmed bonds with their loved one. Storytelling at the bedside and writing in the diary focused attention on the patient and away from the numbers on the monitors, making family members feel that they were part

of the team supporting the patient. For some family members, writing in the diary also helped make sense of their emotions (Johansson et al., 2018, Melby et al., 2020).

Participating in the creation of the keepsakes helped families prepare for the transition to end-of-life care (Neville et al., 2020). One family member expressed that “the process of creating the keepsake was equally as important as the final product of the keepsake itself” (Neville et al., 2020, p.944). This process further strengthened connection between family and staff: staff worked alongside the family to create the keepsakes, and some of the parents described the nursing staff as “friends”. Friendships were created among families and staff: four nurses were invited to be godparents at a baby’s baptism held in his room (Thornton et al., 2020). The families who returned for a follow-up meeting looked forward to meeting the staff again. Parents felt connected to their baby in the company of the nurses who knew their baby and had been a part of their precious family time.

Several studies related that the manner in which memory-making takes place has significant impacts on the family. The engagement and creation process is not necessarily an inherently positive experience; the manner in which it is carried out and the extent to which the family feels engaged with and listened to during this process are of paramount importance. Some parents commented the time spent with their baby was “rushed”, and they regretted not having more varied and detailed photos of their baby (Blood and Cacciatore, 2014, Thornton et al., 2020). Parents felt upset and angry when decisions were made without their consent (Blood and Cacciatore, 2014). Two parents described their anger at the photography company who deleted some of the poorer quality photos; all photos could have been meaningful to the families, and it was felt to be deeply inappropriate for another individual to decide on which photographs were “good enough” to keep (Blood and Cacciatore, 2014). One mother was distressed when the nurses took photos without her consent; it was against her Native American culture to take photos or keep items that touched the deceased (Blood and Cacciatore, 2014). Interestingly, the mother kept the photos despite feeling conflicted about them, but the fundamental point about consent and sensitivity remains valid: those photos could not be untaken, and this mother now had to respond to keepsakes she had not requested. Another parent commented that nursing staff should have asked her permission to allow another family member to take photos of her baby (Blood and Cacciatore, 2014). This highlights the importance of parental decisions and choices; they should be respected at all times.

5.6 Continuation

Continuation was the final theme generated from the thematic synthesis, and follows on from connection, compassion and creation. Connection and compassionate care facilitated the creation of family bonds, memories and keepsakes; these were, in turn, a means to facilitating the ongoing relationship between the family and the deceased. From the literature, there are several key ideas which can define continuation in the context of memory-making in critical care: interaction with keepsakes at one's own pace at home, storytelling, rituals, grief/bereavement processes, and the continuing relationship with a loved one.

I felt it was quite alright, really. Being able to open it and browse through on my own. Getting through it was hard going. It took an awfully long time (Melby et al., 2020, p.6).

It is how I tell the story and how I communicate my loss, my pain, my love for my daughter (Martel and Ives-Baine, 2014, p.322).

I talk to him in front of it every night. I light a candle. It is right under a picture of [Patient's Name]. I light the candle then I pray. Then I talk to him. I feel him around (Vanstone et al., 2016, p.6).

But he does exist for me still (Thornton et al., 2020, p.33).

The keepsakes described in all seven articles were treasured by the families as physical and tangible reminders of their loved one (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Vanstone et al., 2016, Johansson et al., 2018, Neville et al., 2020, Thornton et al., 2020). Memory-making, undertaken in a calm and compassionate way, may set the scene for the family going forward in their bereavement. Memory-making practices may also encourage other creative or meaningful ways for families to continue their bond with their loved one. Illustrated by one of the quotes above, a wife created a new ritual at home with her husband's word cloud, by lighting a candle and talking to him every night (Vanstone et al., 2016). Families could adapt and further personalise their keepsake. One father commented on a slide show he created: "The photographs are only part of it. The photographs give me the opportunity. Without those photographs, I can't have this, but photographs alone aren't enough. It is how I tell the story and how I communicate my loss,

my pain, my love for my daughter. It is so funny...it is like eight minutes that took me like 15 hours to create, but it was a labour of love” (Martel and Ives-Baine, 2014, p.322). This is an example of families living and continuing their bond with the deceased through the keepsakes, and how keepsakes can facilitate storytelling and reminiscing. The rituals constructed an inner representation of the deceased. Regardless of where they were in their individual grief, the families appreciated the keepsakes, and they were comforted by knowing that they were available, if and when they were ready to engage with them.

At home, family members could engage with the keepsakes at their own pace. Some parents publicly displayed photos of their dead baby, while others acknowledged that they were not ready to share their photos yet. Similarly, not all of the families had read the patient’s diary at home: all five of the participants from the Norwegian study had read the diary (Melby et al., 2020), compared with only four out of nine participants from the Swedish study (Johansson et al., 2018).

It was in the critical care environment that families began the transition of saying goodbye to the physical relationship with their loved one, and also began their grieving process. Compassionate care helped support the grieving families to create meaningful memories with their loved one; this included spending quality time together, allowing families the opportunity to express their love and create a keepsake which represented the physical uniqueness of the patient. Memory-making was a therapeutic experience, “enabling a journey of healing once they leave that environment” (Martel and Ives-Baine, 2014, p.327). Similarly, healing power was acknowledged in the creation of a word cloud. By remembering the whole person and focusing on their legacy, word clouds provide an alternative focus to time spent in critical care. “Word clouds offer a gentle entrance into grief and bereavement” (Vanstone et al., 2016, p.9). Having positive memories during this devastating time comforted families in their grieving process, months and years later.

The process of memory-making can perhaps be seen to serve as a crucial bridge between the stages of care, dying, death and bereavement: it encourages direct engagement with the difficult reality of a loved one’s approaching death; prior to the death, it encourages family to project forward to a time after death; and after death, the memories and tangible objects created can facilitate an ongoing relationship with the deceased.

5.7 Adult and paediatric critical care settings: notable differences

The thematic synthesis included families from both paediatric and adult critical care settings who had personal experience of memory-making when their loved one died. There were notable differences between the two groups. One significant difference was age of the patients at death: babies who lived from hours to 13 weeks compared to adult patients (ages were not discussed in the articles). The birth of the babies was quickly followed by their death; the oldest baby was 13 weeks old (Thornton et al., 2020). The parents had anticipated and prepared for the birth of their baby; their death had come as a “shock”. In such a brief period of time, parents had to get to know their baby and say goodbye, which had a devastating impact on parents. It was important for staff to support the parental role and acknowledge the unique identity of the baby. In contrast, the families of the adult patients may have had many years and memories together.

Regardless of the patients’ age at death, all the families were devastated by the death of their loved one and experienced the death in a highly technical critical care environment. Nursing staff were the main care providers who supported parents/families through this transition and helped them cope with the death of their loved one before and after time of death.

The age group of the patients influenced what keepsakes were offered. Photography was a significant component of memory-making in neonatal care as it helped parents retain the memory of their baby and provided evidence of parenthood (Blood and Cacciatore 2014; Martel and Ives-Baine, 2014; Thornton et al., 2020). The parents of children who lived longer had more opportunities to take photos of their baby alive and declined bereavement photography, preferring to remember their baby alive in happier times (Martel and Ives-Baine, 2014). Photography was not offered as a keepsake on its own in adult critical care, but was included in the patient diary studies (Johansson, et al., 2018; Melby, et al., 2020). One family member remarked that the photos had been carefully selected, as they did not find them distressing (Melby et al., 2020). Some of the family members within the studies were in the photographs, which they were extremely grateful for, as it was evidence of their relationship and presence at the bedside (Melby et al., 2020).

Patient diaries were not intended to be bereavement keepsakes; their intended purpose was to aid psychological recovery and prevent stress, depression and PTSD for patients who

survived an intensive care admission (Combe, 2005, Johansson et al., 2018, Melby et al., 2020). Therefore, it is assumed that the photos in the diaries were taken when the patient was receiving active treatment, as the studies did not describe the contents of the photographs (Johansson et al., 2018, Melby et al., 2020). In the Norwegian study, the photographs were a “surprise” to families, as this was the first contact they had with the diary (Melby et al., 2020). However, the photographs were “cherished” as the families did not take their own. All the families in the Swedish study had read or written in the diary during the patient’s stay; it had been always accessible to families to interact with (Johansson et al., 2018). In contrast, the first contact the Norwegian families had with the diary was when they received the diary by post. Receiving the diary in the post was “a long-awaited delivery” and “emotionally draining”; one family member waited three months as the diary had to be “quality assured” (Melby et al., 2020).

There was a noticeable difference in how the families received the diary emotionally: the families from the Norwegian study were unprepared for the contents of the diary and thus experienced more emotional shock when they received it: “Oh dear, there it was. My god, it was like an instant shock. Just had to sit down and breathe a little” (Melby et al., 2020, p.7). Both studies recognised patient diaries may cause potential harm to families if they did not get appropriate psychological support when receiving the diary (Johansson et al., 2018, Melby et al., 2020). This support was absent from the Norwegian study, and it was obvious from the families’ comments when they received it. The Swedish study followed up with a bereavement call within two months, yet it was not discussed how/when the families received the diary (Johansson et al., 2018).

5.8 Chapter summary

To the best of the researcher’s knowledge, this is the first qualitative synthesis of families’ experiences of memory-making which includes both paediatric and adult critical care settings. Despite some differences between the groups, this synthesis clearly demonstrates that there are shared experiences of memory-making in critical care, which can be summarised in the themes of connection, compassion, engagement and creation, and continuation. Memory-making is a meaningful activity for families, bringing focus and meaning during a devastating process in a highly technical and unfamiliar environment. Families relied heavily on nursing staff for support and guidance, and perceived the offering of memory-making as compassionate care. The creation of keepsakes can foster deeper connections within families and staff and has a positive impact on their

bereavement experience. The families within this synthesis created their keepsakes to stay connected and continue the relationship with their loved ones. The following chapter (Chapter 6) will discuss the significance and implications of the findings that were generated from the thematic synthesis, concluding with recommendations for future research and recommendations for practice and policy regarding memory-making in critical care.

Chapter 6: Discussion, recommendations and conclusion

6.1 Introduction

This chapter draws on the findings from the thematic synthesis reported in Chapter 5. The aim of the study was to explore bereaved families' experiences of memory-making in critical care and form part of a service evaluation of the Bereavement Support Service in the Critical Care Department at the QEUH. Thomas and Harden's (2008) thematic synthesis approach was selected to investigate the research question: *What are the experiences of bereaved families who engage with memory-making in critical care?* A thematic analysis of research articles from both paediatric and adult critical care settings identified four themes relating to bereaved families' experiences of memory-making: connection, compassion, engagement and creation, and continuation.

The principal finding to emerge from Chapter 5 is that memory-making can be a significant and impactful experience for bereaved families and individuals. The findings suggest that human connection is fundamental to families' experiences of memory-making. Compassion was found to enhance the connections between patient, families and nursing staff. Therefore, connection and compassion will have a significant effect on whether experiences are positive or negative, both of which may have a long-term impact on families' memories of the care they and their loved one received. Creation and engagement were found to be two further key concepts through which memory-making can produce positive outcomes for patients and their families; memory-making practices may lead to the creation of keepsakes and/or memories, and this process can foster a significant sense of engagement with a loved one and their care, with positive impacts for both patient and family. The objects and memories created may in turn facilitate a continuing bond between families and their deceased loved ones; continuation was thus found to be the fourth key concept through which memory-making can achieve positive impacts for families in critical care.

It is also evident that there are factors which can mediate experiences of memory-making and impact the extent to which memory-making can facilitate experiences of connection, compassion, engagement and creation, and continuation. This chapter will therefore discuss the key themes in memory-making and how these impact families; the manner in

which memory-making is introduced and supported; and, finally, the role of the nurse during memory-making.

6.2 Connection and compassion in memory-making

Connection was the overarching theme to bereaved families' experiences of memory-making in critical care. The key relationships of connection under discussion here are those between patient, family and staff. Brown (2021, p.170) defines connection as “the energy that exists between people when they feel seen, heard, and valued; when they can give and receive without judgement; and when they derive sustenance and strength from the relationship”. This definition helps illuminate key aspects of the nature of the communication between patient, staff and family during memory-making experiences in critical care. To feel seen, heard and valued is crucial to all three groups (Figure 6.1). Successful memory-making interventions are built on the principles of seeing, hearing and valuing what is important and meaningful for the patient and family, and the process of memory-making itself can further deepen this sense of being seen, heard and valued. Giving and receiving – and deriving sustenance from the relationship – applies bidirectionally, to the caring relationship between staff and patient, but also to that between the patient and family. Memory-making can act as a focus for giving and receiving between the patient and their loved ones, and can facilitate the deepening of bonds of connection. Communication is likely to be severely limited, as patients are often unconscious or otherwise unable to communicate. Memory-making offers opportunities for alternative ways for families to communicate with their loved ones; the collection of keepsakes promotes physical contact, for example, and playing the patient's favourite music may evoke memories and serve as a conversation prompt among the family or with staff. Staff and family can also develop very close connections, and can derive great sustenance from these relationships.

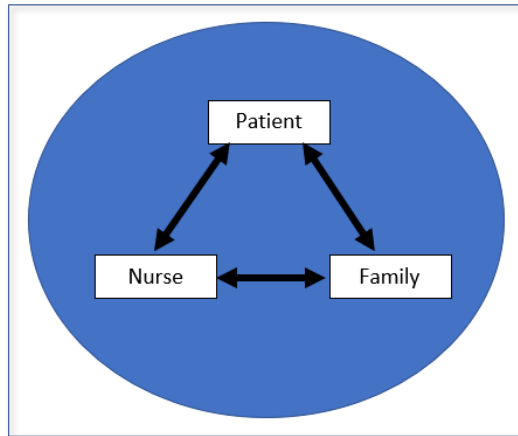


Figure 6.1 Connections in memory-making in critical care

It is perhaps not surprising that connection should emerge as the overarching theme of how families experience memory-making in critical care. Humans are wired to connect and connection is a fundamental human need, as it affects our physical and mental health and well-being (Martino et al., 2017, Saeri et al., 2018). People who have strong connections with others have been found to be happier, healthier and better able to cope with everyday stresses (Baumeister and Leary, 1995). Social support is one factor which influences how an individual will cope with loss, such as the death of a loved one (Jakoby, 2012). Limited social connectedness leads to poorer mental and physical health, including increased depression (Saeri et al., 2018). In the clinical context, human connection has been found to be a key element to patients' feeling of "being known" during their cancer treatment (Thorne et al., 2005). A sense of connectedness with others is crucial in determining the extent to which one's personhood feels dismissed or acknowledged (Thorne et al., 2005). That memory-making can facilitate connection between staff, patients and family would seem to be a fundamental mechanism through which it can benefit all three groups. Greater connection seems to both entail and stem from compassion. Both connection and compassion are fundamental to meaningful and successful engagement and creation with memory-making practices. The sense of continuation that memory-making can provide is a result of the creative process of memory-making, and is built on the foundations of connection and compassion (Figure 6.2).

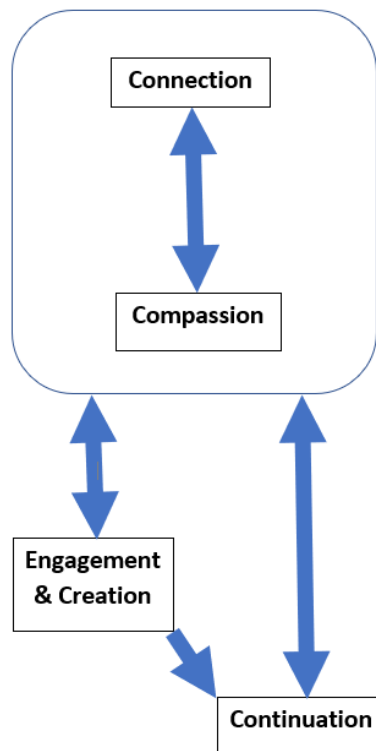


Figure 6.2 The interaction of four key processes in memory-making

The consequences of lack of human connection can be devastating, particularly at the end of life. This has been sharply and sadly demonstrated throughout the global Covid-19 pandemic (Kentish-Barnes et al., 2021a). Many families could not maintain connection due to the strict visiting restrictions. For many, there was no opportunity to provide personal care or hold a loved one’s hand, which is known to provide comfort and feelings of connectedness (Hanna et al., 2021). Lack of connection during the Covid-19 pandemic left some French families with a sense of “unreality”: visiting restrictions prevented them from being present during their loved one’s death, and they had no opportunity to view the body at a later date – or to confirm the death themselves – due to the closed coffin policy (Kentish-Barnes et al., 2021a). This was felt as a dehumanising experience, leaving many families with a profound sense of ambiguity (Kentish-Barnes et al., 2021a). A recent UK study into the experiences of relatives whose loved one died during the pandemic found that families desired and needed to maintain a connection to their loved one during their final days of life (Hanna et al., 2021). It is not surprising that a previous study found more than 90 percent of family members wished to have been present at the moment of death of their loved one (Otani et al., 2017). Dying alone is something that families find unacceptable (Kentish-Barnes et al., 2021a).

Visiting restrictions imposed during the pandemic have therefore reminded us of the central role of families in critical care and the importance of human connection (Ashana and Cox, 2021). In the absence of family members at the patient's bedside during the pandemic, it became the role of the healthcare professionals to try to enable some measure of connectedness. At times this was done by facilitating audio and video calls with family (Hanna et al., 2021, Kentish-Barnes et al., 2021a). However, in the absence of family, nurses often went further, and took on the responsibility of holding the patients hand while they died (Kentish-Barnes et al., 2021b). This practice is familiar to the researcher; she has held the hand of patients and witnessed her colleagues do the same in the absence of family at the patient's bedside.

Clinicians understand well the need for connection at such times, as well as the impacts of its absence. A lack of human connection and compassion can lead to unresolved grief for families, but can also have negative impacts on staff (Wallace et al., 2020). Human connection offers social support for patients but also prevents work-related stress (Soler-Gonzalez et al., 2017). Reduced feelings of compassion and social connection have been found to cause a deterioration in healthcare providers' own health (Seppala et al., 2014), and clinicians have reported experiencing moral distress in their role of enforcing visiting restrictions (Ashana and Cox, 2021).

Our findings suggest that compassion and connection work together, each strengthening the other, and play a crucial role in the success of memory-making in critical care. "Compassion has been defined as 'suffering with' or a deep awareness of the suffering of another, coupled with a wish to relieve it" (Sinclair et al., 2016, p.194). It is a core human value that is necessary in society (Shea and Lionis, 2017), is fundamental to healthcare (Ling et al., 2020), and has been identified as an indicator of quality of healthcare (Sinclair et al., 2016). Compassion unites people in challenging times and strengthens human relationships (Gilbert, 2009). The results of the present study support the idea that compassionate care and engagement with memory-making can be a framework to support families to cope with the death of a loved one in critical care (Bloomer et al., 2016).

Connection and compassion strengthen the relationships between patient, families and nurses, and this can facilitate more personalised care for the patient and their family. Our findings suggest that when care was personalised, it both honoured the patient's life and respected the role of the family. Memory-making allowed staff and families to work together to move through the transition to death, and saying goodbye. Nurses anticipated

the families' needs and helped prepare them for the death by creating a space for families to spend meaningful time together and supporting the families' emotions and wishes. In a recent study which sought to define a "good death" in a paediatric ICU, mutuality was found to be key to nurses and parents working together to develop an intimate understanding of the individual needs of parents (Broden et al., 2020). Mutuality ensured a shared goal in promoting the child's well-being, characterised by the relationships formed between the patient, family and nurse (Broden et al., 2020). It appears that mutuality is developed from the connection between the patient, family and nurse, and is further developed from the nurse's compassion, which supports the patient and family's clinical, situational, and emotional and/or spiritual needs (Broden et al., 2020). It is clear that each clinical environment and member of staff will have their own unique ways of providing individualised bereavement care; indeed, these are crucial to providing positive outcomes for families. The current research suggests that connection and compassion play a foundational role in bereavement care, and perhaps in healthcare more generally. Future research could further explore these concepts in terms of their implications for healthcare.

6.3 Engagement, creation and continuation in memory-making

Connection and compassion welcomed and included families in the critical care environment, and enabled them to feel part of the team providing care for the patient. This provided and created a space for families to engage with their loved one's care and share meaningful time together, leading to the creation of memories and/or keepsakes. Both the memories and keepsakes could facilitate a way of continuing the families' bond with the deceased and could later become a focal point for conversations after the death of the loved one. Engagement, creation and a sense of continuation were therefore fundamental in families' acceptance of death and dying.

The critical care environment (as noted below) can be an intimidating and challenging environment for families (Vanstone et al., 2016, Riegel et al., 2019, Schofield et al., 2021). Families enter this environment under the most stressful of circumstances, and, unless they have a medical or healthcare background, usually find themselves dependent on staff to explain and make sense of the situation (Blood and Cacciatore, 2014, Akard et al., 2018, Thornton et al., 2019, Thornton et al., 2021). The highly technical environment of the bedspace may be a further source of stress and anxiety, and may serve to create barriers, both physical and psychological, between the family and the patient receiving care. These

factors can therefore contribute to a sense of lack of agency on the part of families, as they may feel unable to (or unsure of how to) contribute to or participate in the care of their loved one (Thornton et al., 2019, Thornton et al., 2020, Blood and Cacciatore, 2014). This lack of agency and the associated sense of distance from the loved one that families may feel at this critical time has potentially negative consequences both for patient care and for the families' grief and bereavement. Memory-making has the potential to play a positive role in such situations (Martel and Ives-Baine, 2014, Vanstone et al., 2016, Beiermann et al., 2017, Akard et al., 2018, Riegel et al., 2019, Thornton et al., 2019). Taking part in memory-making practices can be a way for families to feel involved in the care of their loved one (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Thornton et al., 2020, Thornton et al., 2021). Since this process can foster closer connections between patient, family and staff, it also creates opportunities for greater communication between all three parties, to the benefit of all (Vanstone et al., 2016, Johansson et al., 2018). Memory-making can also involve – where possible – making the bedspace a more intimate, personal and welcoming environment. In this way, families can come to feel more comfortable in the critical care environment, and, crucially, more actively engaged in the care of their loved one, which can have positive impacts for their bereavement process to come.

The memory-making process may result in the creation of tangible objects or keepsakes, which can play an important role in bereavement (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Neville et al., 2020, Thornton et al., 2020). This process of creating these objects is highly meaningful in itself, but the objects' lasting nature can be a further significant aspect for families. As seen from the results of the thematic synthesis (Chapter 5), families interact with their keepsakes in different ways, with some publicly displaying photos/word clouds in their homes. As noted in Chapter 5, some families went on to further create/personalise/perform rituals with their keepsakes. In the researcher's own experience, some families whose loved one has died in critical care at the QEUH have reported having memorial tattoos of the hand print of their relative, or having the prints made into pieces of jewellery. Not only are these things visual reminders of a loved one, they also provide a prompt to conversations or storytelling about the loved one. Parents can experience disenfranchised grief due to the lack of social recognition of their baby (Doka, 1999); photographs and other physical keepsakes may be a way of introducing other people to the baby and facilitating a greater sense of social recognition (Thornton et al., 2020). These keepsakes are of course primarily mementos of a loved one, but the memories of the care

the families and their loved one received, and of the memory-making process itself, will be part of the picture, and part of the memory; as Dame Cicely Saunders has said, “How people die remains in the memory of those who live on” (cited in Hicks and Rees, 2008).

Grief and bereavement are universal experiences, and yet research recognises society’s reluctance to talk about death and dying (Bereavement Charter, 2020). People often struggle to have these difficult conversations, and may not feel adequately supported during a bereavement (Logan et al., 2018). If, as a society, we acknowledged and spoke more openly about the realities of these intensely painful experiences, people would be more familiar with them, better prepared for them and more open to being supported through their grief. A widening of the vocabulary used to discuss grief and bereavement might also help individuals become more familiar with and prepared for this inevitable human experience.

This has been recognised, and community organisations are trying to help society to become better at supporting people who are bereaved. The *Bereavement Charter for Children and Adults in Scotland* (Scottish Care, 2020) highlights that research has shown that, as a society, we have lost the cultural and societal ability to deal with dying and work through bereavement (Bereavement Charter, 2020). This makes it challenging for staff to know the best way to discuss it, on both a personal and professional account. Nurses can normalise grief by creating an open and supportive environment and a positive attitude to healthy grieving. This can facilitate the expression of emotion and encourage bereaved individuals to feel that it is socially acceptable to discuss grief. The current study demonstrates that memory-making can create a context in which difficult conversations can be broached and can take place, and can therefore foster communication with – and within – families during times of vulnerability. Such conversations can allow the family to better understand their loved one’s wishes and carry them out with greater awareness. This in turn may help the family approach bereavement and grief in a healthier way.

6.4 Significance of timing and approach to memory-making

It is clear that a patient’s death and the manner in which they were cared for can impact a family’s grieving experience, positively or negatively. Connection and engagement in the patient’s care leads to a sense of involvement, honours and respects the family’s role, and prevents the family from feeling powerless. Unfortunately, however, this is not always

possible. As discussed in Chapter 1, bereaved families whose loved one dies in critical care face specific challenges in this environment; for example, the death may be sudden and unexpected. Sudden deaths can be more difficult to grieve than other deaths, due to a lack of logistical, emotional and spiritual preparation (Broden et al., 2020). This results in a lack of reality about the loss, and exacerbates feelings of guilt and helplessness (Worden, 1991). Lack of preparedness for death has been highlighted as a factor in an individual's adjustment to grief, and also increases the risk of complicated bereavement outcomes (Sque et al., 2014). Preparedness was also an important factor in the process of memory-making. The manner in which memory-making is broached with families and the timing of memory-making practices can have significant impacts on families' and loved ones' experiences of memory-making.

The appropriate timing of a memory-making intervention, and whether it should be offered before or after death, will depend on the circumstances of each individual patient and their family. It will depend on the patient's clinical condition; the dying process may take a number of days or be rapid. A rapid death is common when life support is withdrawn, especially if the patient has required high levels of organ support. This affects the amount of time families have to engage with memory-making practices. There can therefore be no strict protocol on how and when memory-making should be introduced; it depends entirely on the individual patient and their family.

The findings of the present study show that, in addition to timing, the manner in which memory-making practices are introduced to families and loved ones is evidently highly significant. Receiving compassionate care created fond memories; these memories appeared to provide comfort to families, as they reflected on them during their participation in the research studies (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Neville et al., 2020, Thornton et al., 2020). Memories of what happened around the time of death can impact the bereaved for many years, to either support or hinder their adjustment to the death. A study into bereaved parents' experiences of a stillbirth found that "the quality of memories was the anchor point for a good or bad experience, with long-term and, often, unexpected consequences" (Downe et al., 2013, p.721). Each nurse will naturally have their own style and way of interacting with the patient and their family, and each family – even each individual family member – may have their own attitudes and responses to the idea of memory-making. It would be good practice to offer a range of memory-making interventions and opportunities, in order to accommodate personal choice and culture. The

researcher would suggest that the compassion and authenticity of the exchange in these moments, and an ability to respond to each situation as unique, is perhaps more significant than any prescribed approach or protocol. Authentic exchanges are a rich part of the memory-making experience. This brings us to the role of nursing staff in memory-making, and the education, training and support that nurses may require to enable them to provide authentic, compassionate care during the memory-making process.

6.5 Nurses' role in facilitating memory-making

As seen above, connection is one of the most significant aspects of memory-making – both the strengthening of connections between patients and their loved ones and the connections made between patients, loved ones and nursing staff in end-of-life care. Fundamental to these connections is the compassion of nursing staff: it is the compassionate care provided by staff that allows such connections to be made. Such compassionate care encourages and gives permission to loved ones to connect with the patient and, in practical terms, leads to the development of highly personalised care which recognises the unique situation of each patient. In this sense, compassion is deeply connected with the humanistic approach to nursing outlined in Chapter 2, and memory-making processes show the practical implications – and effectiveness – of such an approach.

Nurses were identified as the main care providers who introduced families to memory-making and supported their engagement with it (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Johansson et al., 2018, Melby et al., 2020, Neville et al., 2020, Thornton et al., 2020). They play an active role in guiding families through the process of memory-making during end-of-life care. In a recent study, critical care nurses identified introducing memory-making as their responsibility (Riegel et al., 2021). Nurses are in a unique position to support bereaved families; they work with patients to alleviate suffering and are a near constant presence at the patient's bedside in critical care. Identified within the humanistic nursing model, they have chosen a profession through which to help individuals with health-related problems (Paterson and Zderad, 1976). Nurses have a dual position: as healthcare professionals they provide good quality care, while as their own unique being/gestalt they can establish authentic relationships with patients and their families.

The nursing staff are compassionate strangers who use their clinical expertise and intuition to guide and support grieving families through an emotionally difficult transition. Nursing

staff have a duty to provide high-quality end-of-life care while recognising the needs of families during a highly emotional life experience. The nurses' compassion embraces the vulnerability of the grieving families and enables them to connect to and support the family. Nurses' own vulnerability will play a part in these interactions; witnessing individual grief may arouse emotions, or trigger personal memories of grief, or fears of future bereavement. Leong et al. (2004) suggest it is our shared vulnerability that enables us as nurses to provide the best care we can.

Constant observations and monitoring of the patient's condition are a necessary part of critical care nursing. This changes when a patient is receiving end-of-life care. The nurses' role and focus shift to providing more holistic family-centred care. Critical care is a highly specialised and technical environment; Erikson and McAdam (2020) describe it as a dehumanising environment. It takes time and training for staff to become comfortable working in this environment, so we can only assume how alien it may feel to families, with the added emotional distress of a loved one being critically ill. Patients and their families are visitors. A fundamental role of the nurse is to facilitate families and parents becoming active participants rather than passive observers in the care of their loved one. Therefore, it is crucial that nursing staff make patients and their families feel as welcome and comfortable as possible; this creates an open, non-judgemental environment. Nurses often remove the technology and reduce their own presence around the bedspace to minimise interruptions to the patient and family relationship during end-of-life care (Brodén et al., 2020). Therefore, nursing staff play a crucial role in removing technical barriers to physical connection, but also in mediating family members' sense of agency and comfort within that environment once those barriers are removed. Nurses can further humanise the bedspace by encouraging families to personalise the space with home comforts such as clothes, blankets, photographs or music. This creates an atmosphere and environment where if a relative wants to get into bed for a cuddle or help with caregiving, they feel comfortable doing so.

As previously discussed in Chapter 2, healthcare professionals' attitudes were found to heavily influence the mothers' decision whether to meet and/or hold their stillborn baby (Lewis, 1979, Lovell, 1983); the negative consequences of not meeting the baby were often significant feelings of regret. Some parents commented that, without encouragement, they would have lost a crucial opportunity to create keepsakes of their child (Blood and Cacciatore, 2014). Some parents needed reassurance that they were competent/capable in providing care for their new born. Therefore, it is good practice to return to families who

may be unsure or reluctant to engage in memory-making, to offer another opportunity to discuss the possibility of memory-making. This allows time for discussion and for the nurse to answer any questions or talk through concerns. It is important to note that the opportunity to participate in memory-making practices should be offered compassionately, and without pressure or judgement.

Families' experiences of memory-making are enhanced and enriched when staff are genuine and compassionate about their needs. The nursing staff are present in the family's pain; they do not avoid it, but rather brace it and support it. This offers validation of the family's grief. The families are not alone; their relationship and final time spent with their loved one is respected by the nursing staff. Authentic exchanges help to build the family's trust in the nursing staff, which further deepens their connection. Trust means the nurses are there to hold things together (Thirsk and Moules, 2013); compassionate care "holds" families together. This provides families with the strength required to engage with memory-making and the dying process of their loved one, particularly in the neonatal studies, where parents required support and guidance, to get to know and say goodbye to their baby in such a short space of time (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Thornton et al., 2020).

Maintaining a continued connection with the deceased may play an important role in coping with the loss (Root and Exline, 2014). Root and Exline (2014) acknowledged that social and cultural views have an impact on acceptable mourning practices, which can affect the bereaved's experiences of continuing bonds. Therefore, providing a kind and open-minded culture for bereaved families may have a longer-term effect on their bereavement.

End-of-life care encompasses the final acts of care and compassion the patient will receive. Although this can be emotionally challenging, it can be a deeply satisfying experience for nursing staff to know that they have provided good quality, holistic care to a patient and their family. To be potentially held fondly in the memory of a family who have a sense of peace from knowing that their loved one was well cared for creates feelings of personal and professional pride and increases job satisfaction for nurses.

The humanistic model of nursing views patients and nurses as unique individuals with their own gestalt (Paterson and Zderad, 1976). Nurses may have their own personal and professional experiences of bereavement and grief which can influence the care they

provide to families. They will draw on their own feelings and experiences when supporting others. It is important that these beliefs and experiences do not hinder the family's experience of memory-making. Good practice, such as self-awareness and reflection, is valuable in nursing care. This enables nurses to consider their own personal beliefs and experiences and how these might impact the care they provide.

6.6 Strengths and limitations of the study

A strength of the study was the qualitative thematic synthesis method, which was chosen as it has been used successfully to address questions relating to intervention need, appropriateness and acceptability (Thomas and Harden, 2008). To the researcher's best knowledge, this is the first thematic synthesis regarding memory-making in critical care, and offers a unique insight into families from both paediatric and adult settings.

Patient and public involvement (PPI) is now recognised as best practice and is an essential requirement to receive research funding (Gray-Burrows et al., 2018). Future research should ensure that families' views and experiences are integrated into the development of services to inform relevant good practice guidance. The PPI representative has been involved in this research process from the beginning. She has been consulted on the results from the thematic analysis and have reviewed the proposed empirical study design. Ms Highfield felt the four themes identified from the thematic analysis were a good description of her own personal experience of memory-making in critical care. Interestingly, the overarching theme for Ms Highfield was connection; she believed that without connection none of the other processes would have taken place. Ms Highfield describes her memory-making experience as lasting four days. Of the memory-making processes she experienced (providing personal care, listening to music, storytelling, creation of keepsakes, getting into bed for a cuddle), it is in fact her personal memories of that period that she cherishes the most. She has commented that she will never forget the care she and her mum received from the nursing staff, and recognises its long-lasting impact on her grieving experience. Ms Highfield acknowledged that she required guidance from the nursing staff – not just kind words but direction. The nursing staff encouraged and guided her to look after herself; they had an idea of what might be ahead and encouraged Ms Highfield to rest and prepare for the physical and emotional challenges of her mother's death. This PPI involvement was a strength of the study, as Ms Highfield validated the results of the thematic synthesis as a true reflection of her own personal experience of memory-making. It is good practice to include the views of families when developing and

driving bereavement healthcare services, as it adds to the robustness of the services and ensures they meet the needs of the families (Pattison et al., 2020).

The quality of any evidence synthesis depends on the quality of the identified primary research. The seven primary studies included in the thematic synthesis were quality appraised using Hawker's checklist (Hawker et al., 2002) and Sandelowski's typology of classifying findings of qualitative studies (Sandelowski and Barroso, 2007). The quality of the studies included in this thematic synthesis was variable. Only one study was appraised as a "conceptual description" (Thornton et al., 2020), and no study was classified as "interpretive explanation", indicating the highest quality. Appraising qualitative work is a subjective task, but it is nevertheless important to consider the quality of included studies as the synthesis findings may be compromised by the level of initial interpretation by the authors in the original studies.

The synthesis included articles published in English and only represented Western countries and cultures. Informative studies from wider international settings may have been missed, although the risk was minimised by the use of a systematic search strategy. Only one study included families who did not take part in bereavement photography (Blood and Cacciatore, 2014). The other six studies interviewed families who wanted to take part in memory-making. This could represent a biased position, as families who engaged in memory-making are more likely to have a positive view of it. This review has not considered the needs of families who declined, the reasons for their decision and potential barriers to family participation.

Legacy-making practices have been explored in adult and paediatric populations (Boles and Jones, 2021), but were not covered in the current study. Legacy-making has been reported as helpful for individuals with life-threatening conditions and their families (Foster et al., 2012). It is similar to memory-making as it is considered to strengthen human attachments, maintain connections with those who are deceased, and ensure the deceased will be remembered (Boles and Jones, 2021). However, legacy-making is primarily associated with end-of-life care rather than critical care. For instance, individuals and their family typically have time to prepare for death in other settings such as hospice care, whereas death in critical care is usually sudden and unexpected, posing unique challenges for patients and their families. Due to the different context within which legacy-making and memory-making typically take place, and given the focus on critical care in the present study, legacy-making was excluded from this thematic synthesis. Nonetheless,

legacy-making practices may share similar short- and long-term benefits to memory-making, and each set of practices could potentially inform and enrich the other. Future research could explore the different ways that memory-making and legacy-making support patients and families, and could expand our understandings of the similarities and differences between death, dying and bereavement in end-of-life care and critical care settings.

6.7 Recommendations

6.7.1 Education

The study highlighted the importance of connection and compassionate care during memory-making at end of life. Sensitivity and care are vital but are not enough; clinical education, training and an up-to-date theoretical understanding of the grieving process are essential to providing good end-of-life and bereavement care (Black et al., 2016).

Professional education ensures the provision of high-quality bereavement care (Stephen et al., 2009). A recent study reviewed healthcare professionals' knowledge, skills and role in offering memory-making, and recommended simulation-based communication teaching, reflective practice and observation of more experienced colleagues as ways to increase skill and confidence in providing end-of-life care and introducing memory-making (Riegel et al., 2021). Raising awareness of grief as a normal part of bereavement and understanding the process of bereavement are important (Stephen et al., 2009).

Manifestations of normal grief and prolonged grief reactions should be taught in healthcare courses, such as nursing and medicine (Kentish-Barnes et al., 2015). This would identify risk factors for families and focus on interventions which may help bereaved families (Kentish-Barnes et al., 2015).

It is vital that nurses are aware of the potential impact they can have and be conscious of how influential their role is in supporting end-of-life care for patients and their family's bereavement. The study has identified how crucial the nurse's role is in supporting families during the death of their loved one and the care they provide can have a long-term impact on the families' grief. The nurse-family relationship sets the tone of the critical care experience (Adams et al., 2017). Nursing staff need to know how to work with families under extreme stress and must have adequate communication skills to engage in difficult conversations. This is not something that can be easily taught; it requires a level of skill

and confidence. Staff can learn from each other, through role models and observation of experienced staff delivering good holistic practice (Macnab et al., 2003, Berry et al., 2017).

Ranse et al. (2012) highlighted the limited emotional and organisational support for nurses responsible for provision of end-of-life care. A recent study found limited evidence available regarding professional education and support to provide memory-making opportunities in adult critical care settings (Riegel et al., 2021). The same study identified barriers to nurses offering memory-making: a lack of knowledge, a belief that memory-making was unnecessary and the demand of a high clinical workload (Riegel et al., 2021). Some of the nursing staff considered that offering keepsakes to families was unnecessary, assuming families would have many existing keepsakes/mementos at home (Riegel et al., 2021). These factors have the potential to influence the quality of care provided to patients and their families. Nurses play a pivotal role in facilitating end-of-life experiences for patients and their families. Stephen et al. (2009) highlighted that staff often feel under-confident when dealing with death and bereavement as they receive no formal training.

Standardising protocols for bereavement interventions may be difficult as each patient's death and each family's needs are individual. However, evidence-based practice guidelines could improve implementation and appropriate care for all bereaved families as this supports staff to feel more equipped, by increasing confidence and competence in offering memory-making (Kochen et al., 2020).

Good quality end-of-life and bereavement care is critical to bereaved families, but can be emotionally draining for the staff involved. They face the challenge of ensuring the patient's comfort while simultaneously working towards meeting the needs of the family (Vanderspank-Wright et al., 2018). Staff awareness, personal reflection and the development of coping strategies are vital for the future care of patients and their families receiving high-quality, compassionate end-of-life care. The emotional burden for nurses of providing end-of-life care and caring for bereaved families cannot be overlooked. Staff are at risk of burnout and compassion fatigue (Coetzee and Klopper, 2010), which comes from the "cost of caring" and is developed from long-term exposure to suffering (Vanstone et al., 2020, p.1270). If staff are not supported emotionally, they will have less to give to patients and their families (Kenner et al., 2015).

6.7.2 Practice

Adult critical care departments are following their paediatric colleagues' practice in offering memory-making opportunities at end of life (Vanstone et al., 2016, Riegel et al., 2019, Neville et al., 2020). This is evident from the literature and the varied memory-making opportunities described (Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Neville et al., 2020). The thematic synthesis supports the view that memory-making is a meaningful and worthwhile practice for bereaved families whose loved one dies in critical care. However, it is important to recognise that not all families will participate in or appreciate what is offered. For example, as highlighted in the thematic synthesis in Chapter 5, one mother's cultural beliefs were disrespected when a member of staff took a photograph of her dead baby without her permission. Families should be given an opportunity to discuss their personal choices. The globalisation of society has led to multicultural populations with various perspectives and needs at end of life. This has resulted in communities speaking different languages and having diverse communication needs (Broden et al., 2020). Open, timely and appropriately tailored communication is essential to enable families to engage with memory-making opportunities, as time is precious.

There are a number of practical considerations when offering memory-making. In order to accommodate personal choice and culture, it is best to have a variety of memory-making materials available for families. A robust ordering system would ensure adequate stock levels and therefore availability. Dedicated staff would help ensure the smooth running of this service.

6.7.3 Future research

The memory-making practices offered in critical care varied, and each one was appreciated and brought comfort to families (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Neville et al., 2020, Thornton et al., 2020). Further research could explore whether certain keepsakes are more appreciated or valued by families than others or whether, as suggested by Neville et al. (2020) and Thornton et al. (2020), a mixture of keepsakes (such as hand/footprints, hair locks, poems) accommodates more family choice. There was no discussion within the seven papers of whether memory-making was offered while the patient was alive or after their death, nor the extent to which the timing of the memory-making intervention may have had an impact on individual bereavement.

Current evidence suggests that memory-making interventions are valued by bereaved families (Blood and Cacciatore, 2014, Martel and Ives-Baine, 2014, Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Thornton et al., 2020). Research into how families' perceptions and preconceptions of memory-making may affect their experience of grief remains limited, as does research into the factors which may influence preferences for particular memory-making practices (Thornton, 2019). There is limited evidence-based and formal evaluation of memory-making research around bereavement care. The adults in the studies included in this review had recently been bereaved (the time scale was less than six months) (Vanstone et al., 2016, Johansson et al., 2018, Melby et al., 2020, Neville et al., 2020). Longitudinal studies could explore the families' relationship with their keepsake later in their bereavement process: to what extent does the relationship with the keepsake change over time, becoming less or more significant as the family progresses through their bereavement?

Gaps in our knowledge and understanding of memory-making remain, therefore, and could be addressed in future studies. Do families show preferences for particular memory-making practices? What factors may influence such preferences? What factors impact a loved one rejecting or embracing memory-making? Within particular types of memory-making practice there are important questions to consider: for example, what impact do bereavement photos taken by families themselves have, compared to those taken by a professional photographer? Another key aspect to explore is the timing of memory-making interventions, and the impact this can have on families and loved ones. Further research could also explore the nontangible aspects of memory-making. Is the compassionate care provided by staff as important as a physical keepsake? To what extent do physical keepsakes function as a reminder of the loved one, or a more general reminder of the end-of-life process and the care provided?

Considering the gaps in our knowledge, and following on from the current study, the researcher has designed a proposed empirical study. The study aims to further explore bereaved families' experiences of memory-making in critical care, and in particular as a service evaluation of the current memory-making practices offered to bereaved families whose loved ones die in the Critical Care Department at the QEUH. The proposed empirical study will be presented and discussed in Appendix 2. The study would present an opportunity to potentially develop our understanding of grief and family connection following the Covid-19 pandemic. It also provides the researcher a further opportunity to extend her research experience by conducting a piece of primary research. Following the

completion of the present study, funding will be sought to carry out the empirical study in the Critical Care Department at the QEUH.

6.8 Conclusion

A thematic synthesis was completed to understand bereaved families' experiences of memory-making in paediatric and adult critical care settings. The synthesis identified an overall positive response; memory-making provided meaningful experiences for families who experienced the death of a loved one in critical care.

This study supports an expanded definition of memory-making as more than providing keepsakes: it also includes personal and nontangible experiences which are not recorded and may be difficult to express. Memory-making is a potentially enriching human-to-human experience, and was facilitated through – and further strengthened – compassionate connection. Families were not alone in facing the death of their loved one. Memory-making was a shared human experience for the families. Through the compassion and respect shown by staff, memory-making can strengthen the connection between families and nursing staff, and support families through an emotionally difficult experience.

Memory-making provides structure and purpose during an emotionally challenging time and allows loved ones to focus on a meaningful activity during a devastating time. It gives the family some purpose and choice in an environment and situation beyond their control. It guides the interactions between the patient, family and staff, and can strengthen the connection between families and nurses, while functioning as a communication tool which can facilitate conversations about patient and family wishes at end of life. Offering memory-making can open up discussions and create opportunities for families to engage with their loved one in a meaningful way. Professionals can support and guide families to achieve their wishes for their loved one. Memory-making is an effective intervention to support families and facilitate emotional adjustment following the death of a loved one in critical care. The benefits to families and staff could be shared with the wider hospital community outside of critical care.

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Appendix 1: Reflection of the Masters by Research process

Personal

The passion behind this piece of work comes from my own personal experience of grief. Grief is universal; it is something that we will all experience. So why are we so uncomfortable expressing and discussing our grief? I believe in order to support someone's grief, you have to connect with their pain, sit beside and tolerate it. This requires courage and vulnerability. My experiences of grief have taught and allowed me to be comfortable with other people's grief.

My grief does not come from a death but rather a mourning of an expected lifestyle. My son was diagnosed with cystic fibrosis at two weeks old. My world turned upside down and the world I knew changed forever. My grief was intense for the first two years following diagnosis. I grieved for the life I had anticipated, and hoped for, for my son. What surprised and disappointed me was people's inability to discuss and listen to my pain and fears for the future, and this included family, friends, colleagues and healthcare staff. I often felt isolated with my grief and quickly realised that people were uncomfortable and frightened of upsetting me.

Talking about your grief does not make it worse – you are already living with it. There are no right words to heal your grief, as the situation cannot be changed. I was not expecting someone to fix or heal me. Instead, I needed someone to sit with me, listen and give me time to talk, to allow me to validate my grief and process the changes. Individuals' personal discomfort often prevented them from supporting me. With others, I felt comforted by their compassion, consideration, curiosity and practical help, such as bringing lunch or entertaining the children so I could do some chores or have some quiet time. I appreciated and admired those who asked how I was feeling, as I realised that this took courage. My own personal experience of grief has had a profound effect on me and has influenced my approach to nursing and the care I provide. It has given me more confidence when providing end-of-life care and communicating with bereaved individuals. I believe that life experiences, especially painful ones, can help shape and enrich us as human beings.

The undertaking of the Masters by Research degree has been incredibly challenging, both personally and professionally. Now, approaching the end of the Masters, I am able to appreciate the process and thus understand how challenging it has been. I often wish I had started the course with the knowledge I have now; I spent too much time feeling intimidated by academia. As a nurse with 20 years of nursing experience and a passion for end-of-life and bereavement care, academic work was a daunting thought. However, I believe that bringing my clinical experiences adds value to the research. It has been a steep learning curve, with many new processes to learn. I am extremely grateful for this opportunity, and feel proud of this piece of research. I hope it makes a contribution to our knowledge of bereaved families' experiences of memory-making in critical care.

A highlight was attending a five-day qualitative research course in Oxford. It was the first time I had been away from my family for that length of time. I left for the train with a mixture of nerves and excitement. It was a fantastic course; the course leaders were particularly passionate about qualitative research and it was a great experience to be immersed in qualitative research for five days. I shared the course with a friendly and varied group of people from the UK and as far afield as Ghana. I will cherish my memories of my time in Oxford.

Professional

I have been nursing for 20 years and feel comfortable in my role as a critical care nurse. It has been challenging being a novice researcher, but also exciting learning new skills and seeing how different processes affect healthcare outside of my own speciality. I have more awareness and appreciation of the value of research in practice and policy.

The Bereavement Support Service at the QEUH was set up on years of nursing experience and intuition. I recognise how important these are, but also that they are not enough on their own. Healthcare services should be based on evidence rather than assumptions or received wisdom, and should have sound research at their heart. Carrying out this piece of research has enhanced my knowledge of bereavement and support services, making me a more knowledgeable practitioner. This has been a wonderful opportunity, and has stretched me beyond my capabilities. Completing this research feels like coming full circle: my particular passion for end-of-life care led naturally to my interest in bereavement care and the development of the Bereavement Support Service; this in turn led to the opportunity of carrying out a piece of research on bereavement. This invaluable experience means I now

have greater theoretical knowledge and understanding to inform my ongoing work in end-of-life care. I have come to understand the power of theory to back up nursing intuition and instinct, and appreciate that both aspects are crucial to good nursing care.

Throughout this Masters by Research, I have been supervised by two successful and motivated nurses – Professor Johnston and Dr McGuire. Both are passionate about the role and development of the nurse. Being a student at the University of Glasgow has been a privilege. Meeting students from different countries and learning about their nursing cultures has given me new insights. Being involved in research has made me much more aware of other research around me, and has given me the opportunity to engage in conversations regarding other research projects.

The global Covid-19 pandemic was unforeseen. Covid-19 has brought grief and bereavement to the forefront of our minds. More bereavement papers have been published, and society has been isolated with its grief. Covid-19 changed the way patients died in hospitals; more people died alone due to the visiting restrictions. Staff had to wear personal protective equipment, which restricted non-verbal communication. Healthcare clinicians worked hard to adapt. We already know that sudden and unexpected deaths increase an individual's risk of complicated grief and prolonged grief disorders. Funerals and social rituals of saying goodbye were severely curtailed. As healthcare professionals we appreciate the emotional burden this has placed on healthcare workers and the thousands of people bereaved. Hopefully, Covid-19 will now increase the priority of bereavement care and policy.

Having attended bereavement support meetings since the pandemic, it was clear to me that families struggled with lack of physical contact with their loved one before they died. Instead, families relied on talking to their loved one over the telephone or video calls. Some families did not have an opportunity to say goodbye to their loved ones, and others were permitted only one visit to say goodbye. Families communicated with healthcare professionals over the telephone, as an alternative to face-to-face communication. However, despite our best efforts in the pandemic, it is clear that the lack of human connectedness has had a negative effect on society, especially for bereaved individuals.

It has been challenging doing a piece of research on bereavement during the global Covid-19 pandemic. Death and grief have surrounded us at both the personal and social levels (not least through social media and news reports), bringing this painful human experience

into sharp focus. I often felt surrounded by grief both in my reading for this research and at work. It felt heavy at times, but it was also an opportunity to reflect upon the services we provide to bereaved families in the Critical Care Department, and was a reminder of their value. This research is timely: there could not be a better time to communicate the findings of this research to the wider community, or to remind my colleagues and policy makers of the importance of human connection in providing good quality bereavement care.

This piece of work has highlighted the impact of the art of nursing and the potential therapeutic contribution nurses can have on patients and their families. It has helped me reaffirm how proud I am to be a nurse. I think as nurses we undervalue ourselves and our contribution to patients and their families during a time of vulnerability. Nurses play a vital role in providing end-of-life care and bereavement care. This whole process has illuminated that death, grief and bereavement are part of being human. As humans we are wired for connection. That connection supports and guides us through our experiences of grief. Grief truly is the price we pay for love.

Appendix 2: Proposed empirical study

Introduction

Traditional and contemporary grief theories were discussed in Chapter 2 in order to understand how people may experience grief and how bereavement support, such as memory-making, may aid and support individuals throughout their bereavement. The thematic synthesis identified four common themes in how bereaved families experience memory-making: through connection, compassion, engagement and creation, and continuation. To further explore this area of interest, a proposed research study has been designed to examine bereaved families' experiences of memory-making at the QEUH. This proposed study, as with the current research, will be funded by the NHS. This appendix discusses the proposed study.

Nursing staff in the Critical Care Department at the QEUH offer families memory-making opportunities during end-of-life care or after the death of their loved one. Memory-making resources available in the Critical Care Department include taking handprints, family finger tree prints, tags for writing personal messages, organza bags for hair locks/jewellery, and teddy bears. One teddy bear stays with the deceased and the other(s) go home with the family. This is thought to create a continued bond (Klass et al., 1996, Klass, 2006) between the deceased and the family member(s), in that they both share the same item. The staff and families can use these resources in different and creative ways, depending on the needs, wishes or preferences of the family involved.

Rationale

Although there is no shortage of direct anecdotal evidence from families who have engaged with memory-making that the keepsakes provide comfort, there is a need to explore the range of outcomes arising from this service. Anecdotal evidence suggests that it creates a more compassionate culture, improves nurse–family relationships and encourages family involvement at end of life. As a consequence, such themes, and how they are perceived and experienced by families, and how these impact on their personal lives, ought to be explored in more depth. This will assist in improving the service we provide upon bereavement encountered in critical care and assist family members to have a positive bereavement and grieving experience.

Gaining insight into the “lived experience” will therefore help inform best practice in end-of-life and bereavement care. There is little documented about memory-making within the adult critical care environment; therefore, there is a need to further explore this area.

Qualitative research is widely used to describe the life experiences of individuals and give meaning to them (Grove et al., 2013). A qualitative approach will therefore be used for the purposes of this study, seeking to understand the families’ experiences of memory-making at the end of their loved one’s life. The results will have implications for improving the bereavement care experience in the Critical Care Department in the QEUH and beyond.

Exploring the bereaved families’ experiences will help inform best practice in end-of-life and bereavement care, and describe any wider benefit for families, the results of which will help us determine whether it is an intervention worthy of continuing on a permanent basis within the Critical Care Department.

Study aims and objectives

Aims

To explore the experience of memory-making of bereaved families in critical care.

Objectives

1. To understand what memory-making may mean to family members
2. To understand if memory-making supports family-centred care in the critical care setting.

Study design

The study will utilise an exploratory-descriptive qualitative design based on the frameworks described by (Stebbins, 2001) and (Sandelowski, 2000, Sandelowski, 2010). Exploratory-descriptive methodology is suitable to study areas within healthcare practice that have received little or no attention (Hunter et al., 2018). Therefore, this is used to both explore and describe the experiences of bereaved individuals who have recently lost a loved one within the Critical Care Department and the bereaved relatives’ experiences of memory-making.

At time of death nursing staff give the next of kin (NOK)/family a condolence card along with the information booklet *What to Do after a Death in Scotland*. The condolence card states that the Bereavement Support Service will contact them again after three months to offer further support.

The Bereavement Support Service routinely writes to the NOK at three months post-bereavement offering ongoing support, including the opportunity to come back and speak to members of staff if they have any unanswered questions. The last contact the Bereavement Support Service makes is to invite families to an annual Remembrance Service, which is held in November. Sending out information of the research study during the first year avoids cold calling, as the NOK has already been notified of contact being made at this time. Potential participants will be informed of the research project from three months post-bereavement by a letter of invitation (Appendix 4) from the Bereavement Support Team.

The letter of invitation contains an “opt in” expression of interest reply form (Appendix 5). If interested in finding out more about the study, individuals will be asked to complete this and return it to the researcher via mail, email or telephone. For those who return an expression of interest form, or contact the researcher to express an interest, the researcher will contact the potential participant to enable further discussion and address any questions they may have. A participant information sheet (Appendix 6) will then be posted/emailed (depending on individual preference) to the potential participant, providing more information regarding the study. If the individual is still interested in taking part, the researcher will arrange a suitable date/time for the participant to carry out a virtual interview. It will be made clear to participants they can withdraw from the study without giving reason at any time. Taking part in the study will involve one in-depth interview. It is thought that the interview will take on average one hour.

The researcher had planned to interview participants in their own homes or a quiet room in the QEUH. This plan had to be altered due to the Covid-19 pandemic and imposed restrictions such as social distancing. This means interviews would need to be conducted virtually as opposed to the traditional face-to-face method. Thus, interviews will be conducted using the Zoom video conferencing application. If the participant does not have access to an appropriate device to conduct a virtual interview, a telephone interview will be offered as an alternative.

Zoom video conferencing has an audio recording function, and with the participant's consent, the researcher will record the interview. The interview audio recordings will be transferred from the computer (once transferred they will be deleted from the computer) and stored in a secure network drive with restricted access on the University of Glasgow's dedicated web server. If telephone interviews are carried out, they will also be recorded with consent and transferred and stored as above as audio recordings. Access will be restricted by user identifiers and passwords. Only the researcher and her supervisors will have access to this data.

Study setting

The QEUH is one of the largest acute hospitals in the UK. It has major specialist services in renal medicine, transplantation, vascular surgery and state-of-the art critical care, theatre and diagnostic services. It has also recently become the major trauma centre for the West of Scotland.

This is a single-centre study in the Critical Care Department at the QEUH, Glasgow. There are six units within the critical care department: three intensive care units (27 beds), two surgical high dependency units (20 beds) and one medical high dependency unit (9 beds).

Sample and recruitment

Eligibility criteria

Participants will be identified by the nursing staff who have used memory-making with individual families. The following inclusion/exclusion criteria will be applied when recruiting participants.

Inclusion criteria

≥18 years old

>3 months bereaved

Can communicate effectively in English

Exclusion criteria

<18 years old

<3 months bereaved

Cannot communicate effectively in English

Sampling technique

Purposeful sampling and quota sampling will be carried out to ensure the inclusion criteria have been met, and both intensive care and HDU are represented in the study.

Sample size

Up to 15 participants or until data saturation is reached.

Recruitment

NOK details are recorded after the death of a patient by nursing and clerical staff. This system enables the Bereavement Support Team to contact families to offer support and invite them to the annual Remembrance Service. Nursing staff keep a record of families who have used memory-making within critical care. The researcher will collect this data and send out letters of invitation to a mixture of families from the six units within critical care.

Informed consent

Participants will be given two weeks to consider taking part in the study, after receiving the participant information sheet via post or email. Potential participants can correspond with the researcher for more information or express an interest. If they do decide to take part, a date and time will be set for the interview. The study will be explained again reading through the participant information sheet and an opportunity will be given to the participants to ask questions. Informed consent will be obtained from all the participants prior to the interview commencing. Written consent forms will be posted to the participant prior to the virtual interview (Appendix 7), which the researcher will ask the participants to send back in a pre-paid envelope. An option of either a virtual or telephone interview will be given. If the researcher has not received the written consent form prior to the interview,

they will seek verbal consent, which will be recorded on the audio recording of the interview. Participants will be notified that they can withdraw from the study at any time.

Data collection

Unstructured, in-depth interviews will be conducted virtually via Zoom. The interviews will be audio recorded and an interview schedule will be used to guide the interviewer (Appendix 8). The participant's demographic data and interview data will be anonymised, with a pseudonym given to each participant.

If the participant wishes for another supporting family member or friend to be present at the interview, this will be supported by the researcher. There is a possibility that the supporting member may contribute within the interview and this would be recorded in the transcription. The researcher will ask for their written/verbal consent prior to the interview; therefore, they must be 18 years or over and be able to communicate effectively in English. Quotes from the supporting member may be used but they will not be identified. A pseudonym will also be given to any supporting family member who contributes within an interview.

Participants will also be asked for their permission to take a photograph of their memory-making item(s) and informed consent will be obtained using a consent form (Appendix 7). The participant will be asked to send a photograph of their keepsake(s), if the researcher is unable to take a virtual photograph. The photographs will contain no identifiable information and will not include a picture of the participant. Previous families who have used memory-making have reported hanging handprints on their wall, having the handprint tattooed onto their body and a printing a family tree onto a large canvas. Photographs of the memory-making items could potentially provide rich data and provide more information of where they are kept and how the participant interacts with them, if at all. Permission and consent will be sought from the participant prior to the use of any of the photographs in a publication. Photographs will be stored along with the other study data, in a central file within a secure environment at the University of Glasgow for up to 10 years.

Pilot interview

A pilot interview gives the researcher an opportunity to test the interview on an individual similar to those included in the study. It gives the researcher an opportunity to identify

problems in the design of the interview schedule and the procedure for recording the participant's responses, including how to record on Zoom and where to make field notes. This practice interview allows the researcher to prepare for situations that might occur and develop strategies for dealing with them (Grove et al., 2013).

The patient and public involvement representative has agreed to take part in a pilot interview with the researcher; she wishes to share her personal experiences of engaging with memory-making when her loved one died in critical care. Although the data collected from a pilot interview cannot be included in the study, the value of it lies in allowing the researcher to practise using the interview schedule and make adaptations if necessary, and also helps the researcher reflect, prepare for future interviews and increase in confidence prior to the main study.

Data analysis

The audio recorded interviews will be transcribed using a University of Glasgow approved transcribing service, First Class Secretarial Services. The data will be subject to reflexive thematic analysis, following Braun and Clarke's (Braun and Clarke, 2006, Braun and Clarke, 2012) six-step framework as shown in Table A2.1.

Table A2.1 Braun and Clarke’s reflexive thematic analysis

Phase	Description of the process
1. Data familiarisation and writing familiarisation notes	Transcribing data, reading and re-reading the data, noting down initial ideas
2. Systematic data coding	Coding interesting features of the data in a systematic format across the entire data, collating data relevant to each code
3. Generating initial themes from coded and collated data	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Developing and reviewing themes	Checking if themes work in relation to the coded extracts and the entire data set, generating a thematic map of the analysis
5. Refining, defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
6. Writing the report	The final opportunity for analysis: selection of vivid, compelling extracts, final analysis of selected extracts, relating back to the research question and literature, producing a scholarly report of the analysis

Reflexive thematic analysis offers a flexible theoretical approach to analysing qualitative data, as it does not have a pre-existing theoretical framework (Braun and Clarke, 2006). It can answer broad or narrow research questions about people’s experiences, views or perceptions, and identifies, analyses and reports themes or patterns within the data. Themes are conceptualised based on the data, they express the meanings and representations of the participants. Braun and Clarke (2020) provide a six-phase approach for data engagement, coding and theme development (Table A2.1); the phases are guidelines and not rules. There is flexibility to fit around the research questions and data. Data analysis is not a linear process, but more a recursive process, where the researcher can move back and forth throughout the phases (Braun and Clarke, 2006).

Reflexive thematic analysis offers practical guidance for researchers new to qualitative research (Braun and Clarke, 2020).

Data analysis tools

NVivo 12.4 by QSR International (2020) is qualitative data analysis software, which will be used to code and manage the transcripts. NVivo basic training was included in the

Introduction to Qualitative Research Methods course the researcher attended at Oxford University. The University of Glasgow also provides courses in how to use NVivo and the researcher has attended an online seminar. Photographs will be taken on a digital camera, then will be uploaded onto an encrypted laptop. The photographs will be subsequently deleted from the camera's memory.

Confidentiality

All the study data will be held in accordance with the General Data Protection Regulation (2018).

Minimal demographic information (name, age, gender) will be collected from the participants before the interview starts. There will be no identifying features of any of the participants on the transcriptions. All participants will be given a pseudonym to represent them in the study, which will ensure that no individual can be identified. Participants' demographic details, consent forms and any other paper data will be stored in a locked filing cabinet in the Critical Care Department at the QEUH. Only the study co-ordinator will have access to the filing cabinet.

Electronic data, interview transcriptions and photographs will be stored in a central file store on a secure server, maintained in a secure environment at the University of Glasgow, with password-controlled access. Audio recordings from the interviews will be sent to a university-approved transcribing service. The audio data will be deleted once the study is completed. The University of Glasgow stores data for up to 10 years in a secure archiving facility. After that all of the data will be destroyed securely.

Ethical considerations

This study will be carried out in an ethical manner and will adhere to the principles in the Declaration of Helsinki (1964, p.1964).

Ethics and research development approval

NHS research ethics approval will be sought before commencement of this study. Approval will be sought as outlined in this protocol: study documentation, participant information sheets, consent forms and interview schedules will be provided to the

Research Ethics Committee (REC), and the project will be conducted as approved by the REC. In the event of any substantial amendments to the design, further approvals would be sought from the REC prior to the implementation of any change.

The clinical director and lead nurse from the Critical Care Department at the QEUH have reviewed and support this study.

Amendments

Should any substantial amendment be required to this protocol following a favourable opinion from the REC, the sponsor (NHS) will submit a notice of amendment to the REC which approved the study. The amendment would not be actioned until a favourable opinion was returned for the amendment. The clinical director and lead nurse from the Critical Care Department would be notified of any substantial amendments, as would the local research and development office. Non-substantial amendments would be communicated to NHS Research Scotland. The sponsor will be responsible for determining which amendments are substantial and non-substantial.

Assessment and management of risk

Risks to participant

Bereavement is a personal and sensitive subject. Asking participants to recall their experiences of memory-making at the end of a loved one's life may cause emotional distress, both during and after the interview. Equally, being given an opportunity to talk openly about their bereavement can be a therapeutic process (Sque et al., 2014). Death and bereavement are still considered taboo subjects in Western society (Valentine, 2008), often leaving people feeling isolated with their grief. Using an open/in-depth interview approach allows the participants freedom to share as much as they feel comfortable with (Valentine, 2008).

The participants' interviews will take place in a location they choose, keeping them in a safe and familiar environment. The researcher is an experienced nurse who is used to supporting bereaved relatives and has been part of the team that developed the Bereavement Support Service within the Critical Care Department at the QEUH. The

researcher has attended an advanced communication course, suicide awareness training and a qualitative research course which included interview training.

Safeguarding of the participants is a priority for the researcher. Participants will be reminded that they can stop the interview or withdraw from the study at any time, and their comfort will be monitored throughout the interview. If they become upset, the researcher will offer to stop the interview or take a break. The researcher will avoid leaving the participants in a distressed state and will aim to finish their interaction on a positive note.

The researcher will ask all of the participants if they wish their general practitioners (GPs) to be informed of their participation in the study. If so, the researcher will note the contact details of the participants' GPs and write to them to inform them that their patient has taken part in this research project (Appendix 9). The researcher will provide cards with support group contact details, if required. A handwritten thank you card will be posted to the participants to acknowledge their personal contribution to this research. If participants express an interest in the final findings, a summary will be sent to them at the end of the study.

Before the interview begins, the researcher will explain that they have a duty of care for the safety and well-being of others. If they believe the participant or any of their family members are at risk of harm, then the researcher will have to disclose this information to an appropriate agency. If the researcher is concerned about a participant being suicidal, it will be openly discussed, and the researcher will ask the participant's permission to contact their GP and any other supporting family member.

Risks to researcher

The researcher acknowledges their own emotional well-being throughout this study and the potential emotional burden of interviewing bereaved family members. Actions will be taken to reduce the risk to the researcher. The researcher will keep a fieldwork journal and reflect on events and monitor any impact on her. No more than one interview will be performed per day and the researcher aims to have rest periods between interviews. The researcher will have regular debriefings with her supervisors and has a good network of professional support, including colleagues and the hospital chaplain. The researcher is aware of more formal support agencies, if required.

The researcher has previously consulted the lone working policies for both NHS Greater Glasgow and Clyde and the University of Glasgow. These were consulted when the researcher had planned to carry out the interviews face to face in the participants' own homes. The researcher would have informed a colleague of the date, time and location of the face-to-face interviews and confirmed when the interview was finished. The researcher also attended a mandatory fieldwork safety course delivered by the University of Glasgow, which discussed health and safety issues when carrying out research.

Patient and public involvement

The researcher advocates for patient and public involvement in this research study. The role of the participant from this group is to ensure that the design and methods used are acceptable. A patient and public involvement representative for this study has provided a lay review of the draft protocol and will continue to be involved as the research progresses and will be consulted on the results.

Reflexivity/bias

Researchers are reflexive when they consciously reflect upon their role and involvement within the study (Holloway et al., 2010). The researcher has worked in critical care for 18 years and has a particular interest in end-of-life care and more recently has been involved in the design and development of the Bereavement Support Service within the QEUH. The researcher has introduced and supported families to engage with memory-making over the past five years, and has kept a reflexive diary throughout this Masters by Research course. Polit and Beck (2018) recognise that a reflexive journal is the most widely used strategy in maintaining reflexivity, and that its purpose is to make the researcher aware of their values, and social and professional identity – all of which can affect the research process. The researcher would continue writing in the diary when collecting data, as it would be beneficial to note any assumptions or beliefs that may bias the researcher prior to and during the interviews with the participants.

Summary

This proposed study would be a valuable piece of work to complete. The outcome of the study could potentially offer further insights into bereaved families' experiences of

memory-making in critical care, and further explore if memory-making can influence adjustment to loss.

Appendix 3: Search terms in Medline

S1 - AB (“intensive care unit*” or “critical care” or “high dependency unit*” OR “coronary care unit*” or ICU or CCU or HDU or PICU or NICU) OR TI (“intensive care unit*” or “critical care” or “high dependency unit*” OR “coronary care unit*” or ICU or CCU or HDU or PICU or NICU) **168,587**

S2 - (MH “Intensive Care Units”) OR (MH “Coronary Care Units”) OR (MH “Critical Care”) OR (MH “Critical Care Nursing”) **102,697**

S3 - AB (“memory making” OR “memory box*” OR memento* OR keepsake* OR “transitional object” OR “tangible object” OR memoriali?ation* OR “patient diar*” OR photo* OR legacy OR ritual*) OR TI (“memory making” OR “memory box*” OR memento* OR keepsake* OR “transitional object” OR “tangible object” OR memoriali?ation* OR “patient diar*” OR photo* OR legacy OR ritual*) 623,942 S4 (MH “Memory”) 66,633 S5 TI ((griev*OR mourn* OR reaction* OR bereave* OR grief*)) OR AB ((griev*OR mourn* OR reaction* OR bereave* OR grief*)) **1,205,912**

S6 - (MH “Bereavement”) OR (MH “Grief”) **13,236**

S7 - S1 OR S2 **205,804**

S8 - S3 OR S4 **689,990**

S9 - S5 OR S6 **1,211,734**

S10 - S7 AND S8 AND S9 **62**

Appendix 4: Letter of invitation



Bereavement Support Team
Critical Care Unit
Queen Elizabeth University Hospital
1345 Govan Road
Glasgow G51 4TF
Telephone 0141 452 3047
Email gg-uhb.bereavemen.qecc@nhs.net

Date

Dear (Name),

“An Exploration of Memory Making for Bereaved Families in Critical Care”

We are writing to you, to invite you to take part in a research project being carried out by one of the nurses in our Bereavement Support Team, from the Critical Care Department at the Queen Elizabeth Hospital. Doreen MacEachen is one of the Charge Nurses in the team and who also works in one of the Critical Care Units. Doreen is doing a Master's degree at the University of Glasgow and is currently undertaking a research project as part of her course.

We are writing to you because a relative or friend has died in the Critical Care Department. We believe that you took home a keepsake. This might have been a lock of hair, handprint or a teddy bear. Another name for it is 'memory-making'. As part of the research project, Doreen would like to interview people to find out about their experience of memory-making and what it meant to them. Finding out about peoples' experience will help us understand what is important to families/friends when a loved one is dying and help us potentially improve future practice.

We realise that this might be a very difficult and distressing time for you and that talking about this might be upsetting. You or someone else from your family can take part in the study.

You do not have to take part in this research study and you don't have to decide straight away. You have time to think it over and talk about it with family or friends. If you do decide that you would potentially like to take part or would like to know more about this research project, please get in touch and Doreen will contact you to discuss it further. Taking part would involve one virtual interview, the length of the interview depends on how much you want to say. We would suggest it might an hour of your time.

We have included a reply slip which you can post back to us in the stamped addressed envelope or contact us via our email address or leave a voice message on the telephone number.

Thank you for your time and consideration.

Kindest regards

The Bereavement Support Team

Version 1.2, July 2021

Appendix 5: Expression of interest form



Expression of Interest Form

“An exploration of memory making for bereaved families in Critical Care”

I am interested in finding out more about the above research project. I would be happy for the researcher, Doreen MacEachen, to contact me to discuss this further.

Name: _____

Address: _____

Please specify how you would like to be contacted.

Telephone number: _____

Email: _____

Thank you for your interest in this research project. I will be in touch soon.

Kind regards

Doreen MacEachen

Version 1.1, July 2021

Appendix 6: Participant information sheet



Critical Care Department
Queen Elizabeth University
1345 Govan Road
Glasgow G51 4TF

An Exploration of Memory Making for Bereaved Families in Critical Care

Participant Information Sheet

I would like to invite you to take part in a research study. Before making your decision, it's important to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask if there is anything that is not clear or if you would like more information. There is no pressure to take part in this study and you can change your mind at any time, without having to give a reason.

Who is conducting the research?

The research is being carried out by Doreen MacEachen, a MSc by Research student from the University of Glasgow. Doreen is also a Charge Nurse who works in the Critical Care Department at the Queen Elizabeth Hospital and is a member of the Bereavement Support Team. This research is being carried out as part of an educational qualification and aims to review the services offered at end of life for patients and their families within Critical Care

What is the purpose of the study?

The purpose of this study is to explore families' experiences of memory making at the end of a loved one's life in Critical Care, to find out in more detail the personal experiences for families and what it meant to them. This will enable us to review the services we offer to families in Critical Care and potentially make improvements if needed.

Why have I been invited?

You have been invited to take part in this study as you are the next of kin of a relative or friend who has died recently in Critical Care. The nursing staff offered memory making resources (keepsakes) e.g. a lock of hair, handprint or teddy bear. You were able to use some of the memory making resources with your relative or friend and took them home. The researcher would like to know about your experience of memory making and what your keepsake means to you now.

Do I have to take part?

No. It is up to you to decide. Read over the information sheet and take time to think it over and discuss with family or friends. If you or *another family member* who was involved in the memory making decides to take part in this study, you will be asked to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving reason. The researcher acknowledges that this may be a difficult time for you. It might be that you feel it is too soon to take part right now, but decide later that you have changed your mind or feel in a better place to participate. If this is the case for you, you can contact us anytime up to two weeks from the date of receiving this information.

What will happen if I take part?

If you decide you would like to know more about this research or potentially take part please get in touch, either by email, telephone or complete the reply slip and return it in the pre-paid envelope provided. The researcher will then contact you to arrange a virtual interview at a time that suits you.

The interview will be like a conversation; the researcher will help you talk about yourself in your own words. You will be asked some questions related to your experience of memory making at the end of life of your relative/friend. The interview will be recorded on tape to make an accurate record of what you say. Confidentiality will be maintained throughout, unless during the conversation you say something that suggests there is current risk of serious harm to you or someone else.

How long will the interview take?

There is no set time, it depends on how much you want to say. Some interviews might take 30 minutes and others over 1 hour. The researcher would suggest they would need at least an hour of your time. You can stop the interview at any time without giving any reason.

What are the possible advantages of taking part?

There is no direct benefit but it is hoped that by taking part in this research you will be providing valuable information regarding the support and care you received at the end of your loved one's/friend's life. You will have an opportunity to share your experience and potentially help shape future care for other patients and families.

What are the possible disadvantages/risks of taking part?

Talking about the death of a relative/friend can be difficult and might make you feel emotional. The researcher will make sure you feel at ease before starting the interview and if there are any areas

which you feel too sensitive to discuss, she can take note of this prior to the interview starting. If you do become upset you can take a break from the interview, or, if you prefer, postpone until a later date. While some people find it helpful to talk to others about their story to researchers this research is not the same thing as counselling. The researcher can provide a list of useful contacts which can be useful to access more help if you would like.

What happens to the information?

What you say will be recorded and anonymised (all personal identifying information removed), the recording will be sent to an authorised third party for transcription. Direct quotes from the interview may be used for academic papers conference and poster presentations, but these will not identify you. The information obtained for the purposes of the study will remain confidential and will be stored within a locked filing cabinet in a password protected room. The data is held in accordance with the Data Protection Act, 2018. This means that it is kept safely and cannot be revealed to other people, without your permission.

Researchers from the University of Glasgow collect, store and process all personal information in accordance with the General Data Protection Regulation (2018).

If possible, with your consent, the researcher would like a photograph of your memory making item. The researcher believes that the photograph may provide further rich data. These images should not contain any personal identifiable features, and will be destroyed upon completion of the research project. If you are happy to share a photograph of your keepsake, you will be asked to send the photograph to the researchers University email account. It will then be transferred to secure network drive with restricted access at the University of Glasgow. With your permission the photograph may be used in publications. After the study is finished, the transcript (typed up copy) will be stored at the University of Glasgow for 10 years, in line with [University](#) policy, and the recording will be destroyed.

What happens if I want to withdraw from study?

You can withdraw from the study at any point, without having to give a reason. If you chose to withdraw all data collected up to that point will be kept and analysed, direct quotes or photographs will not be used in any publication.

Who has reviewed the study?

This study has been reviewed by the University of Glasgow Research Ethics Committee.

If you have any further questions?

If you would like more information about the study and wish to ask questions, you can get in touch with the researcher here:



Doreen MacEachen

Tel number: 0141 452 3047 (voice box, leave a short message with your contact details)

Email address: 2507984M@student.gla.ac.uk

If you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher or Dr Lisa Kidd, who is not directly involved with the study. The normal NHS complaint mechanisms is also available to you.

Dr Lisa Kidd

Reader in Supported Self-Management

School of Medicine, Dentistry & Nursing

University of Glasgow

0141 330 6876

lisa.kidd@glasgow.gla.ac.uk

Thank you for reading this information sheet.

Kind regards

Doreen MacEachen

Appendix 7: Consent form



Participant Identification Number for this study:

CONSENT FORM

Title of Project: **An Exploration of Memory Making for Bereaved Families in Critical Care.**

Name of Researcher: Doreen MacEachen

Please initial box

1. I confirm that I have read the participant information sheet dated 19/08/2020 (version 1.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. Any data collected from you to this point will be included in the Study, direct quotes or photographs will not be used.
3. I agree to my interview to be audio recorded which will then be transcribed by a third party.
4. I agree to the use of my direct quotes being used in academic publications, conferences and poster presentations. The quotes will not identify me.
5. I agree to sending a photograph of my memory making item to the researcher via email.
6. I agree to the use of my photographs in academic publications, conferences and poster presentations. The photographs will not identify me.
7. I agree to my General Practitioner being informed of my participation in the study, including any necessary exchange of information about me between my GP and the research team.
8. I Confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.
9. I understand that all the data and information that I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of the researcher.

When completed: 1 for participant; 1 for researcher site file

Version 1.5, July 2021

10. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix 8: Interview schedule



Interview schedule

Name:

Gender:

Age:

Relationship to deceased:

Date of death:

Place of death: ICU SHDU MHDU

Cause of death:

Explanation of study given?

Are there any questions before we begin?

Confidentiality clause – if the participant is at risk of harm this information will have to be disclosed to an appropriate agency.

Consent signed?

Start time:

Finish time:

Version 1.1, July 2021

Questions

1. Can you start by telling me about your loved one (name)?
2. Can you tell me about your memory-making experience?

Probing questions

How and when was memory making introduced to you?

Was it something you thought of doing before it was offered to you?

What memory-making resources did you use?

Can you tell me about the keepsakes you created?

Did you take part in creating the keepsake?

Did you take photographs/videos of your loved one?

Where do you keep your keepsake? How often do you look at it?

Have you further personalised your keepsake, for example made into jewellery?

Have you found comfort in your memory-making experience?

What do your memories/keepsakes mean to you now, has their meaning changed with time?

Could you think of other items which would be good to offer families in the future?

Is there anything else you would like to discuss or add before the interview comes to a close?

Appendix 9: GP letter



Critical Care Department
Queen Elizabeth University Hospital
1345 Govan Road
Glasgow
G51 4TF
Tel: 0141 452 3061

Dear Dr

An exploration of memory-making for bereaved families in Critical Care

I am a Charge Nurse working in the Critical Care Department at the QUEH. I am carrying out an MSc at the University of Glasgow and as part of my studies I am conducting a research project. The purpose of my research project is to explore bereaved families' experiences of using memory-making once their loved ones have died.

(Name) has recently been bereaved, a close family member/friend has died in the Critical Care Department of the QUEH.

The Nursing Staff in Critical Care offer memory-making for families at the end of the life of their loved one. Memory-making facilitates families spending meaningful time together and enables the creation of keepsakes, such as hand prints and hair locks. Families appear to appreciate these keepsakes and memory-making experience. However, there is little literature in this area.

(Name of participant) has consented to being part of the above research study and has given their consent to inform you of their participation. This study consists of one, in-depth, qualitative interview with your patient. The University of Glasgow Research Ethics Committee have granted approval to conduct this study.

I have attached the participant information sheet for your information, if you would like to know anything more about this study please get in touch. I will inform you if I have any concerns for your patient's wellbeing.

Yours sincerely

Doreen MacEachen

Version 1, July 2021

